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Focus on Abilities: Parent-Identified Outcomes of Preterm Infants

In this Complex Care Journal Club podcast episode, Ms. Pearce and Dr. Synnes discuss a series of patient-oriented research studies aimed to partner with parents in reimagining meaningful outcomes for premature infants. They describe the inclusion of parents on the study team, recruitment of parent participants, lessons and challenges while conducting the study, messages for other researchers and parents, and next steps from this work.

SPEAKERS:

Rebecca Pearce, B.Ed., M.Sc.

Vice Principal, Villa Maria High School

Parent Partner

CHU Sainte-Justine and Canadian Premature Babies Foundation

Anne Synnes, MDCM, MHSc

Clinical Professor, Neonatologist

University of British Columbia, British Columbia's Women's Hospital

and British Columbia's Children's Hospital Research Institute

Kilby Mann, MD

Assistant Professor

Pediatric Rehabilitation Medicine

Children's Hospital Colorado

Initial publication:

February 10, 2025

Kilby Mann *00:03*
Hello and welcome to the Complex Care Journal Club Podcast. My name is Kilby Mann. I'm a pediatric podiatrist at Children's Hospital Colorado, and your host for this episode. In this podcast series, we seek to discuss emerging evidence in the care of children with medical complexity and its implications for practice. I am delighted to have Rebecca Pearce from the Canadian Premature Babies Foundation, and Anne Synnes, a clinical professor at the University of British Columbia, staff at British Columbia Women's Hospital and investigator at British Columbia Children's Hospital Research Institute, joining me today. Rebecca and Anne are lead authors for the article, "Partnering with Parents to Change Measurement and Reporting of Preterm Birth Outcomes" published in Pediatrics in November of 2024. Rebecca and Anne, thank you so much for being here. We'd like to ask you to share a bit about your studies, starting with the gap you identified in your research aims. And Rebecca, would you like to start?

Rebecca Pearce *00:55*
There's a long tradition in evaluating outcomes, particularly neuro developmental outcomes, in children that are born extremely preterm. So generally, depending on the hospital, these extremely preterm children are assessed in neonatal follow up programs, usually when they're around 18 to 24 months of age. And this is done for several reasons. It's done for clinical care, and it's also to help refer children to early intervention if necessary. For example, speech language therapy or physiotherapy. It's also done for data collection, for benchmarking, for quality improvement, and also information for management and family counseling. Up until now, the choice of what information to collect and to report during these neonatal follow up has been based on feasibility, validity, availability, cost, and also what doctors and scientists decided what they thought was important. And the issue here is that no one has really asked parents what outcomes that they felt were important to look at in follow up. So in order to address this lack of family input, we sought to engage families in rethinking what outcomes were meaningful after the birth of an extremely premature baby. So in our paper, we presented our research experience, integrating parents, clinicians and also researchers in a series of studies to identify meaningful outcomes after preterm birth, how we shared the knowledge gained and changed and are still attempting to change practices. So we conducted a series of studies that we called the Parents Voice Project. And there were several goals behind this project. We wanted to capture the voices of many diverse parents. We hoped to examine the perspectives of parents in more detail, and we wanted to involve parents in all aspects of research. So this includes methodologies, recruiting participants, analyzing transcripts from qualitative interviews, interpreting results, revising manuscripts, and also presenting results for knowledge translation. So for example, we asked more than 1000 parents attending a neonatal follow up clinic visit, a single question about how they perceived their child's health development before the child's assessment. So we learned that there were important differences between parents perceptions and the clinician and researchers classifications of the presence and severity of developmental problems in the child. So the agreement between how clinicians assess the development of preterm children and how parents viewed their own children's development was very low. Parents were more likely to see their child as normal or less severely impaired than clinicians were. We also use clinical scenarios sent to over 800 stakeholders to describe and compare the severity of different types of neurodevelopmental impairments, and these include cerebral palsy, hearing problems, vision problems, developmental delays and also combinations of these conditions. So we learned that the term severe is interpreted very differently by parents. In that conditions that the medical system thinks are severe, are not often considered severe by parents. In two other studies, 447 parents were asked more in-depth questions about the impact that their child's pre term birth had on their lives, and this includes their well-being, their health, any

informational needs they may have had, as well as outcomes that they considered important, and what information they thought doctors should be communicating to parents. Parents identified that things like their child's feeding, sleeping, respiratory, health and behavior were very important to them. And this is significant because these outcomes are not systematically studied in preterm children. Parents also wanted a more optimistic approach in their doctors, as well as a more balanced perspective. They didn't always want bad news or to hear about the negative from their doctors. They wanted more practical advice and information about the future if their children had a disability or impairment, not just a medical diagnosis.

Kilby Mann *04:45*
As I was delving more into this article, two things that really stuck out to me this concept of deficit-based research and moving away from that. And then I think I also was just very impressed with the numbers of parents and responses you got. So I think that's such an incredible piece of your methods and how you did things. And I think there's a lot of movement now to make sure parent voices or caregiver voices are included. And so I just think this is a great example of how to do that. Anne, do you have anything to add thinking about just kind of this research project in general?

Anne Synnes *05:17*
Based on the findings of the Parents Voice Project, the parent partners on our research team emphasized that our research results really needed to lead to real change in the ways that doctors collect and communicate the outcomes of prematurity. Parents were integral in disseminating our results to not only the medical community, but also to families and other stakeholders. So in this paper, we described how we used two video teleconferences and surveys, first to identify themes where actionable items and consensus statements could emerge, and secondly, to identify the best way to measure the seven outcomes identified as important or meaningful in our studies. These outcomes included child well-being, quality of life and function, socio emotional and behavioral outcomes, respiratory, feeding, sleeping and caregiver well-being and mental health. Fourteen actionable consensus statements were identified. 10 have been or are in the process of being implemented throughout Canada, and five consensus statements, which we thought were stretch goals turned out to be implemented or have become the focus of research grant applications. In summary, our collaboration between parents, clinicians and researchers, was finally successful, whereas the researchers would previously have counted success, whereas six publications in well recognized journals, all parents view the changes in practice occurring in Canada and abroad, a success. We have been actively disseminating our findings in a variety of media, and are pleased to be able to participate in this podcast.

Kilby Mann *07:05*
I wonder if there are any other opportunities or challenges or lessons learned about this work that you've done and where to take it next?

Anne Synnes *07:14*
We see a number of opportunities. We were lucky in Canada that the Canadian Institutes for Health Research, CIHR, provided research funding for patient-oriented research. And that stimulated us to think about new research questions and the research question we then identified was actually proposed by a parent. Our community of parents, clinicians and researchers provided a variety of perspectives, resources, solutions and positive energy. We're very lucky that our Canadian neonatal follow up network involves all the follow up programs of Canada, and so we have a network where engaging site investigators as researchers, but at the same time they are also the recipients of the knowledge. So it's very close between the users and the people we're disseminating to. We were able to leverage the data from Parents Voice Project to publish other papers related to general health outcomes, and, for example, about breathing-related outcomes that parents think are important. Parental perspectives of extreme prematurity and outcomes like in preterm birth and decisional regrets that parents of preterm children have. The challenges are that time to develop, cost them to develop the relationships that became so important for this work. And whereas researchers are mostly salaried, and we have

dedicated time to work on research projects. Parents have various backgrounds and skills. They have, obviously, a family to care for and other commitments, and we have to figure out, how do we allow parents to participate to the degree that they are able, they want to? The group of studies requiring different commitments, therefore, work very well for us. And over time, we also discovered the exceptional abilities and commitment of a small group of parents like Rebecca who were able to take leadership, speak at conferences and write manuscripts. Certainly, the COVID pandemic was a challenge for us. We had to adapt our methodology, how we communicate, get comfortable with Zoom, And for example, and the clinics closed, and we were using our clinics to recruit participants to recruit patients and then our parent groups were able to recruit via their social media. So that helped us solve that problem. For researchers; choose your research outcomes carefully, so that the results will provide information that your patients and the stakeholders need. And unless you look at outcomes that are important to families or patients, you can't find interventions to improve outcomes. Change can be hard; Working collaboratively with strong representation from parents and a parent advocacy group, clinicians and a network of researchers made it possible to implement change and go beyond just writing manuscripts. We also feel that the process we used is generalizable to other countries and other patient populations.

Kilby Mann *11:16*
Rebecca, do you have anything to add about the challenges or lessons learned, especially from a parent perspective?

Rebecca Pearce *11:23*
I mean, as Anne said, I think social media is incredibly helpful in using, harnessing organizations like Préma-Québec,which is the organization in the province of Quebec that's kind of the main go to for the parents or families of pre term babies. And also the Canadian Premature Babies Foundation, which is the Canadian wide organization that's similar. They have a lot of resources available. I'm not sure if there's something similar in the US organizations, but you can always reach out to them. I would say, for parents, don't hesitate to get involved. You know, you can reach out to researchers, for example. And see if there's anything that you can do. And I would also ask, you know, doctors and clinicians as well, like the reason that I got involved with this is because a neonatologist who took care of my daughter when she was in the hospital back in 2009, she sort of recognized, I guess, kind of a kindred spirit in me. She was a neonatologist who had also had an extremely premature baby who was quite sick, and so it was she that reached out to me, you know, a year or two after my daughter was born, to say, 'Would you be interested in being involved in, looking, for example, at consent forms? You know, we have this consent form here. It's really, really long. We have like a parental perspective about whether the language is correct, whether we can shorten it, things like that. And that's kind of where my involvement my involvement took off. So I would say to doctors out there, you get to know parents pretty well. So if you do speak to parents that you think would be interested in doing this kind of work, don't hesitate to reach out to see if they would be interested.

Kilby Mann *12:55*
Yeah, that's great. I think we've talked a little bit about how this can be applied to other situations, or really how you built this work about the implications for clinical practice. I wonder what you recommend for members of an interprofessional care team, for children with medical complexity, based on your findings?

Rebecca Pearce *13:13*
Again, my message to clinicians would be, first of all, it's a very general message to try to be open to change and also to implementing new ideas in your practice and follow up. Specific again to neonatology, I don't think it's super common again, for a lot of doctors to collect information, for example, about, you know, how a child is functioning, , or feeding, sleeping behavior. And so I think it's important to be open to these changes. When communicating with parents and patients, clinicians should try to use objective terms and phrases. So just as an example, your child may need a hearing aid, rather than objective words, like, your child has a severe neurodevelopmental impairment or a severe impairment. Just as a personal example, when I was in the hospital,

a doctor who came to speak with us about what would happen after I gave birth, and I asked him straight up, you know, what problems might my children have. Extreme prematurity was not on my radar, and so I asked, what, you know, what are some of the issues that might arise? I still remember 15 years later, him saying, well, they might have trouble with math. And this is based on research. So preterm children often have specific difficulties in math, in particular in school. And he could have very easily said, you know, your child might have a mild to moderate NDI (neurodevelopmental impairment) or your child's going to have a learning disability, and that would have been really scary for us, and it wouldn't have told us a lot about anything really, but the fact that he put it in the sort of functional term, I was kind of like, okay, okay, we can handle that, that's not, you know, it's not a big deal. And so this communication with parents should really be based on research, and it should be much more concrete and clear than, you know, neuro developmental impairment or learning disability or things like that. Don't be deficit-based. So what we mean by that is try not to focus on all of the things that a child can't do, or all of the things that a child won't be able to do, but rather try to turn the focus on their abilities and what they are and what they'll be capable of doing and are capable of doing. Again, try to discuss what outcomes matter to parents or patients. So in our research, we found that most parents were far more interested in understanding how their child's condition will affect their functioning. If a child is diagnosed, for example with cerebral palsy. You know that tells, it says something, but it's really not a lot of clear information. So what does that mean for that child? Will they need to be in a wheelchair? Will they be non-ambulatory?, There's a huge range of functionality for children with cerebral palsy. So what does it mean for that specific child? So just like in the research that I read when my daughter was little, a diagnosis, for example, of a moderate neurodevelopmental impairment or something like bronchopulmonary dysplasia, which is a lung disease that's common in babies that are born preterm, doesn't give parents much information about what that means for a child's day to day functioning, for their abilities, and what kind of life or difficulties that they may face. What is important to parents is often very specific to that family. So it's really important to try to get to know your families, who they are, what's important to them. Some families want the big picture. Some families want a lot of detail, and I think that's something that you'll only know about if you actually ask these individuals what's important for them to know and what information they want. And finally, as I previously mentioned, try to support and identify parents and patients to get them involved in research that will help answer the questions that are important to them.

Kilby Mann *16:43*
Yeah, I think, I think about how important our language is and how we say things and what terms we use. So one of the last questions is, what sort of messages you have for patients or families from your study? I know you talked earlier about just how you got so many families involved, and I was wondering a little bit about kind of the demographics of the parents you got?

Rebecca Pearce *17:01*
So the first thing that I would say to patients and parents are areas that they can absolutely get involved in research and making important contributions, but I would really encourage parents to do this whenever possible, to really take these opportunities, because it's incredibly rewarding for many reasons. I was lucky, like I said, that I had one of my daughter's doctors who recognized that I was someone that could be interested in being involved in research. And I know it's very powerful for medical professionals to hear from parents and patients and to understand their lived experiences and what's important to them. And again, there's nothing that's special about me. You know, truly, any parent can do this, and if there are certain skills that parents need to develop, they can easily learn those skills, like public speaking, for example. In our studies, we found that parents and patients definitely have a variety of opinions, and this is, again, why we had a study where we made participation super easy by just asking the simple question, how do you feel about your child's development? Are they developing, you know, normally, or do you think that they have some sort of impairment? We were able to capture the voice, again, of more than 1000 parents, which is about 80% of all eligible parents. With respect to the parents who participated in the studies, and the parents that we had were broadly representative of the population of Montreal. So as far as educational levels, for example, ethnic backgrounds. So we were really able to capture a real cross section we did find in our research that ethnicity and education in particular did affect parental responses. And this

is again, why it's important to sample a broad range of stakeholders. And for parents, I would say, just from my personal opinion, that not to get frustrated when change takes time. So Anne discussed some of the recommendations that we made based on this research, and I remember this was done quite a while ago, I think more and more clinicians are becoming open to these ideas and putting some of them in place, but it still takes a long time. And so sometimes it can be frustrating when you know you're like, are we still talking about this? Like, do we still need to convince people that this is a good idea? And it takes a while sometimes for research to be disseminated and also to be assimilated into practice. So be patient. If you're a parent of a premature baby and you're going to a follow up clinic, for example, I would say don't hesitate to ask questions if the information that you're receiving is unclear. So that's the role of a clinician is to give you the information that you think is important for you. And also, don't hesitate to share information with doctors about any concerns you could have about your child, again, even if you're not asked about them. So you don't just have to answer the questions that you're being asked. Make sure to share all of your concerns with your clinician.

Anne Synnes *19:38*
When we were planning this study, we certainly anticipated in the one study, we said, we're going to make it as easy as possible. We're not going to get a lot of information, but we'll at least be able to catch everybody's voice and when we wanted to look more in depth about parents views on you know, what information should be provided and what should doctors be telling parents, that took a lot more time. So we didn't have as broad, but it was reassuring to see that there were consistent messages. So we feel pretty comfortable that results reflect most parent's views. There are a few groups that are hard to capture. For example, children in foster care. We do wish that we could get more representation from First Nations families. They tend to be underrepresented. Now that we know that, working with the CanadianPpremature Babies Foundation, they're actively looking at how, how can we get those groups involved in research and participation? So I'm feeling optimistic that it just going to get better over time.

Rebecca Pearce *21:12*
Yeah, another group that's a bit underrepresented sometimes, is dads. So men, it's often, at least from the like, the side of the research, of being involved with the research team and stuff, there are definitely more women. When I think about some of the projects that I've been involved with where there's, like a parent advisory committee, for example, or parents who are conducting interviews. I think it's still a challenge sometimes to get to dads.

Kilby Mann *21:37*
What do you think are some of the important next steps from your work?

Anne Synnes *21:42*
As I mentioned before, we came up with consensus statements that we wanted to work on. And so from a practical perspective, the Canadian Neonatal Follow Up Network is working on implementing those in Canada, which is relatively easy for us, but we are making more connections with people in the United States, so we're trying to go internationally as well. And we identified that there were some topics that we needed more resources to implement or make changes, and I was very happy to see that we've put in grant applications based on these consensus statements in our previous work. So that with that grant funding, we are now working on how to improve communication with parents of children born extremely preterm, to include more optimism, more practical information and a more interactive form of communication. Now we are working to provide guidelines for health conditions with evidence-based management, such as cerebral palsy, with the International recommendations, but putting it into practice doesn't happen by itself. Using implementation science and having a plan and support systems on how to do that was one of our goals.

Kilby Mann *23:32*

I think it's a good thought process for us with whatever outcome measures we're using. Is it important? Is there a parent voice? Rebecca, did you have any thoughts about next steps with this work?

Rebecca Pearce *23:44*
I mean, I would just say, continue. Continue on. Continue sharing the information, I think, as much as possible. I know for the Parents Voice Project over the years, we've done a lot of knowledge translation or dissemination as much as possible at different conferences or at grand rounds for different hospitals, for example. Just so that it's something that people have and even if they haven't read any of our research it's just an idea that people have in the back of their head when they're interacting with families, not just again, of premature babies, but I guess of any family of a child with lots of complicated medical issues, to really think about what's important to parents and to try to figure that out as well. Another thought here again, is if we don't know what's important to parents and to patients, what outcomes are important to them, then it's very hard to find ways to actually design studies to try to improve those outcomes.

Kilby Mann *24:35*
That's great. I just want to open it up. If there's any other important pieces of information related to this work that you wanted to mention?

Rebecca Pearce *24:44*
I mean, something that I think that Anne kind of just touched on there, that I think is also important. Thinking back to one of the slides that we sometimes use in our presentation, and that's the outcomes it's the 2020 Canadian Neonatal follow up network, results of the NDI the neurodevelopmental outcomes of babies born between 23 and 28 weeks gestational age, at I think it's 18 to 24 months, but also I think it's seven years. And the thing that strikes me, the lower the gestational age, the higher the risk of an NDI, or a severe NDI. But this is kind of fluid these diagnoses. And what I mean by that is, if you look at the same group of kids when they're older, the percentage of children that are, mild to moderate or severe NDI is actually different. That's why it's so important for clinicians to remember that these diagnoses that are done at this follow up should not be used for prognostication. They shouldn't be used to try to tell parents, this is the future for your child. Because clearly, that's not the case. These should be used to refer children for early intervention if necessary, and to give an idea of how that child is doing at that moment and whether they need more help developing, for example, language or movement.They definitely shouldn't be used to tell parents how what their kids are going to be, you know, in the future. And I remember after my daughter was born, when I read, because that's the first thing that I did every time something horrible happened in the NICU. The first thing I did was go to the research and be like, what does this mean? And reading about NDI, I mean, it was really terrifying, because, again, it didn't give me any perspective about what a serious or moderate NDI means. Like, what does that actually mean for a child, for their functioning? And is that something that means they're gonna, you know, have a moderate NDI for their whole life? It was really unclear to me. So I think it's important to remember that for clinicians, to keep that in mind as well when they're communicating and giving information to parents.

Kilby Mann*: 26:36*
Thank you so much. Thank you so much for your time Rebecca and Anne, and thank you to you and your team for advancing the field of complex care. Thanks for listening to the Complex Care Journal Club Podcast. We aim to highlight research that has the potential to be practice-changing, that values patient family engagement, is relevant across disciplines and diagnoses, and uses high quality or novel research methods. We invite you to join the conversation by suggesting an article that you would like to see discussed in this podcast using the form provided on the OPENPediatrics YouTube channel. Thank you for joining us.

Journal Club Article

Pearce R, Synnes A, Lam MM, Richter LL, Bacchini F, Jones M, Luu TM, Janvier A; PARENTS' VOICE NETWORK. Partnering With Parents to Change Measurement and Reporting of Preterm Birth Outcomes. Pediatrics. 2024 Nov 1;154(5):e2024067093. doi: 10.1542/peds.2024-067093. PMID: 39354888.

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