Parenting is Hard

Part 3

You can watch the video of this podcast at: youtu.be/rxP73iY4HjA

[00:00:02] **Krissy Dilger:** Welcome to the SRNA "Ask the Expert" podcast series research edition. I'm Krissy Dilger with the Siegel Rare Neuroimmune Association. This is the third episode of "Parenting is Hard," a mini-series exploring an often overlooked but deeply important topic, the experiences of parents raising a child with a rare neuroimmune disorder, and how this impacts their other children.

[00:00:27] Joining us for this special series is Barbara Babcock, a family therapist with the UK's National Health Service. Barbara has conducted insightful research into how parents navigate the needs of their non-diagnosed children, alongside those of a child with a rare neuroimmune condition. Through this series, she'll share her findings and offer guidance for families facing these unique challenges.

[00:00:52] Barbara holds a Master of Science in Family Therapy from King's College London, and a Master of Arts in Coaching Psychology/Psychological Coaching. You can find her full bio in the podcast description. SRNA is a nonprofit focused on support, education, and research of rare neuroimmune disorders. You can learn more about us on our website at wearesrna.org.

[00:01:16] This episode was made possible in part by the generous support of Amgen; Alexion, AstraZeneca Rare Disease; Genentech; and UCB.

[00:01:27] Thank you so much for joining me today, Barbara. I'm excited to get into more of your research today on the podcast and I learn from you. So, to start us off today, we can begin by talking about your first theme that your research brought about and that is “beliefs around being a parent have to change”. Can you introduce this theme, please? What is meant by that?

[00:01:59] **Barbara Babcock:** First of all, thank you for having me back. It's great to be back and, getting into the nitty gritty, what were the results of the research? And that first theme in this research, because it was a reflexive thematic analysis, we have the theme, which is also supported by sub themes and something known as code labels.

[00:02:21] I'll share that. top level theme you just mentioned and what else is going on underneath it that's supporting it. So it was that beliefs around being fair as a parent have to change and there were three, like sub themes or code labels supporting it. One was defining what balancing or being fair means.

[00:02:46] The second one, the family's context prompts a redefinition of fairness, and balancing your attention on all your children is not possible. So that is, so this is very much around parents who wish to be fair towards their children, yet how they conceptualize and practice. Just that will differ among families, but regardless of how they practice it, it is challenged in the context of having a child with a condition. And so, one's relationship to this parenting norm of being fair, starts to undergo change within the family.

[00:03:27] **Krissy Dilger:** I can imagine how that would be a natural dynamic shift. So, your research identifies, like you mentioned, balancing and being fair. As important to parents, how do parents' definitions of these concepts change or evolve after the diagnosis of their child?

[00:03:50] **Barbara Babcock:** I noticed that, I came, I noticed that my parents were using the word balance a lot. I just want to balance my time and attention on all my children. And I was really curious about, okay, what's this about? And maybe I was curious because I'm not a parent and I haven't had that experience. And so, this is really important that my position as not being a parent influences the questions I ask.

[00:04:22] Hence, I'm like what do you mean by balance? What does balance mean? And they said, oh you just want to be even and fair. And I'm like, really? They're like yeah. I'm like why, how do you come to that? And one family said we just all automatically think that. And I was like, even more curious.

[00:04:47] I'm like, all? automatically? And another family said it comes naturally. And I was like thinking, wow, it's like you become a parent and then all of a sudden you automatically think, I need to treat all my children and give them all the same amount of time and attention. This is interesting.

[00:05:09] And then. But another family, they talked about actually, no, I don't make sure I give them the same number of play dates or the same number of gifts, or the same number of hours spent with a child. I attend to their needs there and then. And they gave the example of, my child needed bedsheets.

[00:05:36] And so the other child said what about me? Why don't I get new bedsheets? And the mother said because you don't need them right now. Your sister does. But you might need something else at a point in time that your sister doesn't need. So, this parent had a different approach. Rather than making sure the same number of this, the same number of that, it was more needs based. So how parents conceptualized fairness, it could depend on their definition. Is it the same amount of something or is it more needs based?

[00:06:15] **Krissy Dilger:** It's so interesting how you, I don't think many people feel the need to challenge that, that automatic, as you said, need to feel balanced or equal, which is just an interesting thing to really think about because why do we think that way? And, it is kind of ingrained, I guess, in, in all of us, at least, it might be a westernized or American thing, or I think your families that you spoke to were mostly in Great Britain, right?

[00:06:55] **Barbara Babcock:** Yes, they were all living in England, and they were white British or white other, meaning they weren't white, but not originally from Britain. And so that's an important consideration. This was a white population and how they experienced the world and what is important, maybe different from, say, someone, a person of color who may have to deal with structural racism, for example, or someone from another country. South Asian, for example, or maybe from East Asia. What would be their definitions of fairness? It might be quite different if you're from a different country, for example.

[00:07:46] **Krissy Dilger:** Yeah. Going, leading off from that, how does context or societal or historical expectations affect parents' beliefs in, how they need to balance their parental roles?

[00:08:07] **Barbara Babcock:** I think that is so important and almost not known about in our society. So, because the parents are saying we automatically think that this comes naturally. I think, okay, it might have been learned from one’s, having been parented oneself. It might have been read about in parenting books or on a governmental website like I've seen in this country.

[00:08:37] But, you give all your children equal amounts of time. But you have to think about society. So, if you think of the American Constitution. All men are created equal. So, fairness is embedded in the political system. It's embedded in education, make sure everybody gets a turn. And so, when you start looking around that society and the different aspects of society and culture, particularly Western industrialized cultures, like America, Canada, the UK, Australia, it's this real thing around fairness that comes through in the culture.

[00:09:21] Linked to that are parenting norms. I'm going to use some jargon. “Societal parenting discourses." That means, as a society, what do we think is normal and right around parenting? You can also use the phrase parenting norms. What's in the literature is, as a parent, you're expected to treat all your children equally.

[00:09:54] That is good parenting. But also, what you start to see, particularly from the nine, the mid nineties onward, is something around intensive mothering ideology, where mothers are expected to know their children really well, know all their needs, be the best caregiver, oh, and their needs come last. And when you start to think of when an illness comes into the family, how that challenges the parents.

[00:10:33] So that context, that sociocultural context, be a good parent, treat all your children equally. But then you have a child with additional needs that might be under the care of ten different specialists. You're sourcing their supplies from five different locations. In America, you have the insurance, the health insurance component, which takes a lot of time and energy and can be a very difficult process to deal with.

[00:11:08] So it starts to be very difficult to spend, give all your children equal time and attention. When you have one child requiring so much, particularly in the earliest phase of the illness where the child's in hospital and you have, and a parent who has to be with them in hospital and that hospital, what if it's located an hour and a half away from the family home or five hours away from the family home? A parent is removed out of the family home for a period of time and that can create its own challenges.

[00:11:44] **Krissy Dilger:** Yeah. It is so true how the mother role is, it puts so much pressure, I think, on women in our society, and it's It garners its own conversation even outside of the context of your research, but yeah, within the context of your research, it is interesting how it affects this particular family dynamic. How do parents perceive their own ability to divide attention between their children?

[00:12:27] **Barbara Babcock:** Interestingly enough, when I think about how the research topic came about, when I had this online chat with 16 mothers, this was the most often mentioned concern. How do I balance my attention on all my children?

[00:12:41] So it seems like there's a high proportion of people out there who struggle with it. They struggle with saying, like this, what I, this example I'm giving comes from a quote in the research, “sibling, you take yourself off the football”, because sometimes a mother was saying, sometimes a child who has the most needs is the priority and it's really difficult.

[00:13:11] It's really hard. They don't like it. They don't like doing it. But it's like, I kind of don't have a choice, I need to do it. And so, it's and we'll get, we'll talk in a future episode about how parents then subsequently deal with this. But it's a real struggle. And I noticed it was a struggle even for the family that operates on a needs-based approach to fairness.

[00:13:38] They still struggled with not being able to give the sibling as much time and attention as they would like. Because with some of these conditions, like ADEM, for example the child affected by ADEM can develop ADHD-like symptoms, really, really difficult behaviors that can be a parent's experience is really challenging. And so if a child is in a meltdown, and you have to attend to their needs, keep them safe, maybe keep yourself safe, keep the other children safe. You're spending all that time trying to calm the child down, support them, you have other children. It's how they're viewing it, but you can't split yourself.

[00:14:30] Because if you're the only parent at home, you do have to deal with that meltdown. And it's a real challenge. It's like there isn't a right way necessarily. It's almost understanding, yeah, sometimes you will be giving the child with the neuroimmune disorder more time and intention, because it will be absolutely necessary to do that.

[00:14:57] **Krissy Dilger:** Yeah. So, another factor that can play into this theme of how beliefs around being a parent have to change is possible new caregiving responsibilities that parents take on for their children. How are parents' beliefs affected by these new responsibilities?

[00:15:25] **Barbara Babcock:** What I noticed in the research was the language parents were using.

[00:15:32] So their beliefs around recovery. First, the child with the condition has the greater needs. Understandable. Also, the recovery process, it's got to be consuming. We threw everything at recovery. And so, you think of, yeah, you're throwing everything at recovery. And I think. Any parent would do this if a child, if you could do something to help your child recover, yeah, you're going to do it.

[00:16:06] And of course, that will increase time spent on caring responsibilities and hence that phrase, parental differential treatment, which means you're giving one child more time, attention, support, whatever, than another child. And yet it can be warranted in cases like recovery. So, you could see how the recovery process can foster it because parents are doing anything that they can.

[00:16:36] But there's also a parenting norm when your child is unwell in this way, you do everything for them. And it's, I'm not saying that's a bad thing at all. But that's an expectation that we have, you do everything for them, and when a parent doesn't do everything for them, sometimes they can experience judgments around that, but also.

[00:17:02] Like I said that parental differential treatment, giving that child more time and attention, can be absolutely necessary. We learn from the charities, from the physiotherapists, for example, the physical therapists, that physical therapy, physiotherapy is so important because it can prevent worsening of symptoms and poor health outcomes.

[00:17:28] Of course, you're going to make sure your child has physiotherapy every day. And if the health care system can't give it to your child every day, the parents often learn this skill so they can give their child physiotherapy every day. But also, sometimes you find that advice from medical and health care clinicians.

[00:17:50] They may think, “Okay, a good parent throws everything at the child who has the illness. You need to do everything.” And that too can foster that parental differential treatment. And one of the key things coming out of this for me is, when is it okay, medically safe to ease off on therapies so parents have more time to attend to all family members' needs?

[00:18:19] And I think that's an important consideration that parents can legitimately ask, you know, the doctors, the physiotherapist, when is it okay, medically safe to ease off? Particularly if another child has, maybe will have mental health needs and needs more attention or another child is having a transition to high school or secondary school.

[00:18:46] They might need some more attention for a time. So, to start addressing other needs is thinking about when is it medically safe to reduce it and there might be other times you might want to increase it because you get an opportunity Say have a week stay at a rehabilitation center where you can get lots of really useful Expert input and so yes, you will do that at that point in time

[00:19:16] **Krissy Dilger:** All very interesting considerations that you know, I myself wouldn't have thought of as someone who isn't a parent myself. But it's interesting the themes that have come out of your discussions with these families. Yeah, it does lend new perspective. Going off of what you were just talking about, this is related, but so obviously parents who now, whose child is diagnosed with a rare neuroimmune disorder, these parents will have to learn new skills.

[00:19:54] Can you talk about this learning curve for the parents? And you can touch on possibly; you discussed it a little bit. When answering my previous question, but how the expectations from statutory bodies or healthcare professionals can play into this and expectations for illness management can be a learning curve in itself.

[00:20:19] **Barbara Babcock:** Yeah. You think about your child, may have to permanently use a wheelchair or have a tracheostomy or a feeding tube. And when you think after the initial acute phase, illness management and recovery rehabilitation occurs in the home. So, it's very much down to the parents to learn all the skills they will need to keep their child safe and well and alive.

[00:20:57] So it's immense. They become a nurse without getting the degree and they become an expert in the condition and how it affects the child and what the child needs from a medical and health care perspective. So, there are so many new roles that they have to take on and the skills to develop.

[00:21:19] So if a parent hasn't been used for advocating for the child's needs with health care insurance professionals, that's going to be a key skill, particularly in America from the, I'm thinking of the insurance and getting things paid for. Now in our system here in the United Kingdom with the National Health Service, we don't.

[00:21:42] We might not struggle to get things paid for, but it's about getting timely health care, because here we have waitlists and sometimes depending on the need, the waitlist can be longer than we have. So, there's that issue, all those different roles and skills they're learning. But when you think about it, you have a child with this rare neuroimmune disorder.

[00:22:10] As a parent, you have a lot more contact with statutory bodies, medical and healthcare professionals. Social care might become involved, the benefit system, health insurance companies, all these external bodies are now, eyes on you, the family, the parents, and so parental competence can be subject to scrutiny.

[00:22:39] Is the parent doing a good job at managing the illness at home? And all of these external professionals, they'll be looking at this through the lens of what they think makes a good parent and what they think makes a good parent in this context. And they may not fully appreciate they're doing that.

[00:23:04] Are they realizing that? As a doctor with the degrees, they have and the social cash that gives a doctor and potentially a good salary and their cultural background. And then how the parents perceive the doctor, their relationship to help. It can be a very interesting dynamic.

[00:23:35] And so you find that parents are, their competence in managing this situation that they're learning in is much more subject to scrutiny than say a parent who doesn't have a child with a disability. Oftentimes, it's more mothers, have traditionally been the ones bringing the child to the doctor.

[00:23:57] Not always. That is changing. Fathers are getting much more involved in the raising of children, the emotional caregiving, the practical caregiving of parenting. However, fathers can still be rewarded. Oh, you're doing that for your children. Well done. And whereas women, it's yeah, you just get on and do it.

[00:24:21] And I'm not saying that's the case for everyone. I'm not saying this is a blanket truth. What I mention here is what I found in the research literature. So, we still have that gendered theme around caring coming through slightly. So that's where, as a medical healthcare professional, it's being really aware of, what's my view of what a good parent does.

[00:24:48] And a good parent does generally, but also in the context of having a child with a disability, with a chronic illness. Just to check your biases and are they ever coming through in an unhelpful way? I think there's a lot of medical health care professionals can do to ask the parents, this is a tough situation you're in and your parenting is changing.

[00:25:13] How, what do you think is good enough for right now and what you're doing? And being really mindful of that as the professionals working with the families.

[00:25:24] **Krissy Dilger:** That's a really great point. That's a very good point. So, I think that was the end of my official questions for you, but I wanted to open the floor in case there were any aspects of this theme that we didn't touch on or that you wanted to explore before we wrap up.

[00:25:48] **Barbara Babcock:** Let me see. Was there anything I could add? It's just like the parents because they have a child who has additional needs, their definition of what does it mean to be a good parent has to undergo a whole redefinition process. It has to change because how they might have done it in the past may not suit the current situation.

[00:26:21] And sometimes what ends up happening is parents still try to parent according to these societal parenting norms. You must treat all your children equally, give them all the same amount of time and attention. And it can become an impossible task. And so, they have to find a different way of parenting and attending to all their children's needs.

[00:26:47] And actually, change, what does it mean to be a good enough parent? What does it mean to be a family when we're dealing with these ongoing challenges that are very real?

[00:27:04] **Krissy Dilger:** Great. Thank you so much for going through that, that all that important information that you found in your research and the time you took to, to really delve into those topics. And I am sure that there are many listeners right now who can empathize with a lot of things we talked about today and really see themselves. represented, which I think is important.

[00:27:34] **Barbara Babcock:** Yeah.

[00:27:35] **Krissy Dilger:** Yeah. Thank you. Great.

[00:27:40] **Barbara Babcock:** Thank you. You're welcome.

[00:27:43] **Krissy Dilger:** At the end of this mini-series, we will host a Q and A episode where Barbara will answer questions from the community. To submit your question, please visit srna.ngo/submit . You can also find this link in the podcast description. Thank you to our "Ask the Expert" sponsors, Amgen; Alexion, AstraZeneca Rare Disease; Genentech; and UCB. Amgen is focused on the discovery, development, and commercialization of medicines that address critical needs for people impacted by rare, autoimmune, and severe inflammatory diseases. They apply scientific expertise and courage to bring clinically meaningful therapies to patients. Amgen believes science and compassion must work together to transform lives.

[00:28:36] Alexion, AstraZeneca Rare Disease is a global biopharmaceutical company focused on serving patients with severe and rare disorders. Through the innovation, development, and commercialization of life transforming therapeutic products, their goal is to deliver medical breakthroughs where none currently exist. They're committed to ensuring that patient perspective and community engagement are always at the forefront of their work.

[00:29:00] Founded more than 40 years ago, Genentech is a leading biotechnology company that discovers, develops manufacturers, and commercializes medicines to treat patients with serious and life-threatening medical conditions. The company, a member of the Roche Group has headquarters in South San Francisco, California. For additional information about the company, please visit www.gene.com.

[00:29:47] UCB Innovates and delivers solutions that make real improvements for people living with severe diseases they partner with. And listen to patients, caregivers, and stakeholders across the healthcare system to identify promising innovations that create valuable health solutions.