Transcript: SickKids VS Parent Stress (Part 1)

Introduction

Hannah Bank Parenthood doesn't always go as planned, just ask Julie Rose about the birth of her son Owen.

Julie Rose The day Owen was born was incredibly exciting because we got to meet our new little guy. But it was also terrifying because I had been in the hospital a little bit earlier with some complications, and he was born very premature, so we didn't exactly know what his health would look like at that point.

Hannah Julie spent her first days with Owen in a neonatal intensive care unit.

Julie We had no experience ever seeing a child with all these tubes and lines hooked up to them. He was completely dependent on everything to just survive. We were pretty naive to what was coming and our life ahead with him.

Hannah Once Owen gained enough weight, he was discharged and went home for the first time. But soon after, the little guy became seriously ill. Julie rushed him to SickKids. It turned out Owen had serious intestinal bleeding. Doctors later discovered Owen's gut couldn't absorb enough nutrients. They inserted a line into his body to give him the nutrients to keep him alive. Owen still needs one today. He's almost six now.

Julie We call it his lifeline. It is completely responsible for all of his nutrition, all of his medications, his antibiotics. And that line is critical to his life. He's hooked up to a pump every single day. He's hooked up to his nutrition every single night. We're managing that all, and we are doing all of his care. All of that is a day to day process. This isn't stuff just as needed. This is his life and this is our life, and this is our commitment to our kid and keeping him going and keeping him healthy.

Hannah But as Julie discovered, supporting a kid with complex medical needs can take a toll on families.

Julie It's incredibly overwhelming. You're so hyper focused on that day, that moment what's happening, symptoms and so you get overly consumed with just trying to manage hour to hour in a lot of situations.

Hannah Children with complex medical needs often have life-limiting conditions that impact multiple parts of their body and require different medications. Many also need technologies to survive, like tubes for feeding or breathing, and they tend to get admitted to the hospital repeatedly. It's no wonder research has shown parents and caregivers of chronically sick kids are at a greater risk of feeling stress, anxiety and depression, or even developing post-traumatic stress disorder.

Julie There's a ton of guilt. There is a ton of grief for different reasons. You feel a sense of loss for almost everything going on in your life. You didn't experience the childbirth you wanted to. You didn't experience the first holding of the baby that you wanted to, and you feel this sense of loss all the time. And it just gets compounded day after day after day when you're living and breathing this with so many other families down the hall. I think it's really important to recognize that there are so many families in the absolute darkest place of their lives when they're going through anything with medical complexity. And it is very, very hard to get yourselves out of that.

Hannah The reality is hospitals are only starting to recognize the extent of caregiver stress, fatigue, and burnout. At SickKids, one particular doctor you're about to hear from noticed how much pressure Julie was under and, together, they decided to do something about it—both to help Julie but also other caregivers across the country. You're listening to SickKids VS, where we take you to the frontlines in the fight for child health. I'm Hannah Bank, and this is SickKids VS Parent Stress (Part 1).

Act 1

Hannah Welcome to the Complex Care Program at SickKids. The staff here supports more than 570 kids across the province of Ontario. They also assemble a personalized care team for each child on top of any specialists that need to be seen at the hospital. Each of these personalized care teams normally consists of a physician, a social worker and an information coordinator to help juggle medical appointments. Think of them as lifejackets or rafts for families who feel like they're drowning.

Dr. Julia Orkin We attempt to make the care streamlined, clear, supportive with really communication and the family's goals of care in the center.

Hannah That's Dr. Julia Orkin. She joined the complex care program more than a decade ago as a trainee. Now she's Medical Director. I know it may get confusing to keep Julia straight with Owen's mom, Julie, so I'll refer to Julia as Dr. Orkin—even though she prefers chatting on a first-name basis.

Dr. Orkin We often take the first few months to get to know the family, to understand where are there gaps, and we often ask the question, where do you hope that your care would be improved or where do you think things aren't working, where are you struggling? And then we work together to say, OK, let's figure out what are our goals and objectives are, where your medical needs are. Let's proactively plan around whatever it might be and take our time.

Hannah Dr. Orkin had a similar conversation with Julie when Owen first became a patient, roughly five years ago.

Dr. Orkin When they came in the room that very first time, she had like an agenda, and I remember being like, OK. And then she had a list and she had hard questions and I thought, Oh my goodness, look at what she's done. Like she has out of nowhere grappled with really complex things, including, like, how is my child going to eat and survive? She had ensured that he was getting the utmost care, and I remember just saying, like, we're going to do this. All of that guard went down. She was like, OK, I'm safe and Owen's safe. We're going to figure this out. We may not figure it out today, but we're going to figure this out.

Hannah Julie also remembers their first encounter.

Julie It's a roller coaster for families in general living in the hospital, and you're meeting so many faces, so many different physicians. I remember very clearly when Dr. Orkin became part of our care team. She came in and had a huge conversation about us with a reality check for me of he's sick, and he's going to need a lot of ongoing care and he's dependent on technology to live, and you're going to need the support, and your husband's going to need the support and you have another child at home. And she just put it in perspective in a way that I was like, wow, OK. So it shifted gears on how we were treated as a family as well as how Owen was then going to be treated as part of our family and the ongoing support we all needed.

Hannah Over time, though, the pressure weighed on Julie and the stress became relentless.

Julie I was crying every single day, and I was having some really depressing times living in the hospital, and our family was divided, and I wasn't seeing our daughter, and my husband's work had to happen because I couldn't work. And all these things were happening and compounded in that first year of his life. And we also had a really sick kid laying in a bed and we didn't know what was going to happen to him. As a mom and as a family living in the hospital, the last thing you want to do is leave the hospital to go help yourself. You just, you would simply rather suffer inside and be with your child than go get your own help.

Hannah That sinking feeling is all too familiar to Dr. Orkin. She's seen other parents struggle with guilt as well, but it became clear to her that Julie could benefit from additional support, so she gently suggested as much.

Julie Julia was a huge integral part of me actually getting therapy, and so she was somebody that I did trust, I did listen to. And she would come in all the time to check on Owen, but she was really checking on me as well. So she was able to set me up with somebody right across the street once a week that I could at least go to and and know that Owen was OK and he was taken care of by the team inside the hospital—and I was going to be better by doing this.

Hannah Those interactions with Julie, plus similar check-ins with other caregivers inspired Dr. Orkin to think differently about how her team helped families. They started exploring ways to better support parental well-being by noticing issues both big and small.

Dr. Orkin We noticed maybe the parent is crying a lot in an appointment. It's not our role to say that that parent has a diagnosis of depression. The role is to actually say, OK, could we provide more in-home nursing? Could we actually advocate for respite? Could we change the feeding schedule with the medications so the family could actually get a four-hour chunk of sleep? Is there things that we could do as a medical team? At the same time, we are trained to recognize where there's a challenge and then link with the right people—so the right social worker or the right psychiatrist—who understand that this is different. There's a, you know, there's a complex medical child in the play, but this parent needs help. And that's really where we're shifting and focusing on as a care team is that parent support. So that if the child’s not doing well, the parent’s not doing well. If the parent’s not doing well, the child's not doing well. And it cannot be in isolation.

Hannah For Dr. Orkin, that shift to providing more parental support coincided with a curiosity about studying what might make the most impact. She and her team then met with Julie and other caregivers at the SickKids Family Advisory Network who volunteer to improve the hospital experience.

Julie Julia is highly aware of the need to have families involved in everything, and it's a huge plus for all of us, because it means that real families living and breathing this are actually providing the feedback and the understanding of what's truly going on and what mentally is going on, what physically is going on and the needs associated. And if we could go back in time, and I wish this was available for us, what would make an impact for you?

Hannah Dr. Orkin listened closely. Then she and her team developed a study focused on supporting families with high-risk babies in the neonatal intensive care unit, meaning infants who are born quite premature, face complications and often undergo multiple surgeries.

Dr. Orkin The concept of this research study is not just to provide care to the baby—that goes without saying that the baby requires medical care and medical needs. It's actually to provide parents readiness, support and education in order to go home with everything that they may need from their own personal tool belt of skills.

Hannah It turned out complex care and medical teams across the country were also interested in the study. SickKids became the lead site for the research, while other hospitals in Toronto, Ottawa, Montreal and Vancouver joined the effort as well.

Act Two

Hannah Before the study could get going, Dr. Orkin had to think about who would deliver the actual assistance and coaching to parents. Nurse navigators seemed especially well-suited for the role. If you're like me, you might be wondering exactly what a nurse navigator does.

Dr. Orkin You are like Jell-O. You're moldable to whatever the family needs in that moment, so if they need education—done. If they need support—done. If they need help making an appointment with a clinician—done. It doesn't matter what their needs are, the nurse navigator’s there to anticipate and support in any way, shape or form, and their role is to be really lockstep with that family. At SickKids, we have an incredible nurse navigator named Kim, who has a very long-standing history and experience providing care for children with complex needs, and we were able to secure her as a core team member for this project.

Hannah Meet Kim Colapinto. She has worked at SickKids for more than two decades and supports a lot of worried parents. She's also been one herself.

Kim I've had my own personal experience with childhood disability and helping a family member who needed to access the system as well. Not having someone that I could consistently talk to or consistently ask questions of, I found really challenging. And even though I had the skills, because I am a pediatric nurse practitioner, actually going to a lot of these things yourself is very different. And I think it informed my practice so much as a nurse. I can understand a little bit better how you can leave an appointment feeling very overwhelmed by the information that was given, and I always try to think, how would I have preferred things to be said to me?

Hannah Kim and other nurse navigators who are supporting Dr. Orkin’s study have been providing parents with three specific supports. The first is education—to help parents anticipate their child's care needs once they're all back home.

Dr. Orkin So readying the family with what to expect: What could you do in these scenarios? How would you encounter this? Really supporting them with their baby with prematurity or medical needs.

Hannah The second way Kim offers support is by teaching mindfulness and flexibility through a technique based on acceptance and commitment therapy.

Kim It's really about trying to be mindful, trying to be present in these moments in your life and to also do meaningful action. So, basically, it's having families think about what's important to them and how do they want to show up in their life knowing that there's going to be thoughts, feelings, past experiences that will maybe interfere with your ability to live some of those values. And then the question is, what action do you take? So there's nothing that's right or wrong, good or bad. It's really what we call just noticing. So you're noticing how it makes you feel.

Hannah Dr. Orkin describes acceptance and commitment training this way.

Dr. Orkin These thoughts are really challenging. I could park myself in this negative thought around my child or my current state or my reality, but instead, I'm going to acknowledge them and I'm going to go back to a place of what my values are. I'm acknowledging that today is a horrible day. But what did I want to get out of today? I wanted to be present and be a good parent or be present for my other child or whatever it is.

Hannah The third way Kim supports families who participated in the study is by helping parents manage multiple hospital appointments across different specialties and by guiding them on exactly where they need to go. She also shares a handy resource binder that parents help fill with tips on caring for their kid, like notes on using certain medical technology or giving different medications. It may not sound like much, but Julie actually inspired the idea after feeling overwhelmed when she brought Owen home from the hospital. Back then, she saved Owen's nutritional information, discharge papers and receipts for his medical supplies. She also added a photo of Owen with his sister, Zoe.

Dr. Orkin This is where Julie really helped us. She showed us how incredibly organized she was beyond like anyone's imagination in terms of how she organized Owen's care and his needs.

Julie On our binder, I have our key team members on the front with their business cards. So I don't have to dig through anything to find a name and a number of who I need to call in an emergency or in a stressful situation. And it's a way for us to just own our child's life and the areas that we have no experience in and be able to feel confident. It's also a place where as a parent, you can feel a sense of control over what's going on with your child and you're not reaching out to their care team over and over and over again to ask them questions.

Kim It's just a good place to keep everything, right, like that you need to remember to do or things to think about when you go to appointments because it can be very overwhelming. You go to the doctor and then you forget everything, right?

Hannah Kim and Dr. Orkin hope their three areas of support prevent some of the additional stressors parents might otherwise feel when caring for kids with complex medical needs.

Dr. Orkin The concept that we always say is give them a boat and a lifejacket if we know that this first year is going to be hard—and they may not need it. We don't necessarily know that every single family may need every single thing. They may, but it's not reactive. You put some supports in place, so it doesn't become a crisis.

Hannah The team is now analyzing their study's results, and I'll turn to some of their findings in a moment. But, first, I want to acknowledge that SickKids breakthroughs are only made possible with the incredible support of our donors. That's why we're proud to recognize CIBC as the premier partner of the SickKids VS podcast. The bank and its team members care about making a difference. CIBC has championed SickKids for over 30 years and is the largest corporate supporter of the SickKids Cancer Sequencing Program. CIBC also generously supports SickKids through CIBC Miracle Day and an active employee giving and volunteer program.

Act Three

Hannah Across the country, more hospital staff are starting to acknowledge the immense impact of medical complexity on families like Julie's. They've seen firsthand how parental mental health can be critical to supporting the outcomes of a child. Here at SickKids, Dr. Orkin and her team are examining the experience, stress and health of families who participated in their study. They're trying to determine which support systems increase emotional well-being, and some of their early observations are promising, including gratitude for nurse navigators like Kim.

Kim I got some very positive feedback from the families when we would do some mindfulness together. And it was really just try to pull them into the present moment, try not to think too much about the past, try not to think too far ahead, but really just try to to be present now.

Hannah Here's what one parent said about acceptance and commitment training. The strategy really helps me to step back and just take it a day at a time and just focus on now and get out of that real anxiety. All of which made me wonder what would success look like for Dr. Orkin beyond this one study?

Dr. Orkin The first is a recognition that change can happen. We can be flexible. We can change how we provide care to meet the needs of patients and families in whatever way that is. And as a system, we can do that. I look forward to the next 10 or 15 years to see how much further we can come.

Hannah For parents like Julie, benefits are already being felt both in the hospital and back at home.

Julie We're starting in a place where parents and caregivers are actually being looked at as the whole unit because you really can't survive without everyone working together in the family unit. We are just so, so lucky that we have a team who embrace the family and embrace us as a whole and support us entirely in order to move forward and forge ahead every single day, whether it's good or bad.

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