

Pediatric Medical Complexity: Shared Insights

In this World Shared Practice Forum Podcast, co-authors Dr. Barry Markovitz and Ms. Ann Schrooten discuss their book, *Shared Struggles: Stories from Parents and Pediatricians Caring for Children with Serious Illness*. They share personal experiences and narratives from families and clinicians to explore the unique partnership between families and healthcare providers caring for children with serious illness and medical complexity. Lastly, they highlight the importance of communication, empathy, trust, and humility in building meaningful relationships that support children and their families throughout their care journey.

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Sarah Marcley 00:04

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Jeff Burns 00:18

Welcome to OPENPediatrics World Shared Practice Forum. I'm Jeff Burns from Boston Children's Hospital. Today we have a very special interview. These podcasts have been going on for at least 15 years, and frankly, I think I'm chagrined to say we've never had a parent on the podcast, and today we do. Today we're going to be speaking with the authors of a book that was published in 2021 entitled "Shared Struggles: Stories from Parents and Pediatricians Caring for Children with Serious Illness," and with us today are the authors Ann Schrooten, the parent of a child born with a complex condition, who has more than 15 years experience interacting with pediatrics subspecialists and other healthcare professionals who cared for her son. Ann welcome to OPENPediatrics.

Ann Schrooten 01:11

Thank you, Dr. Burns. Happy to be here.

Jeff Burns 01:13

And also with us is her co-author, Dr. Barry Markovitz. Dr. Markovitz is well known to the audience of OPENPediatrics, for his many contributions. Dr. Markovitz is the professor of pediatrics at the Division of Pediatric Critical Care, University of Utah School of Medicine, and at the Intermountain Primary Children's Hospital. Barry, welcome.

Barry Markovitz 01:37

Thank you very much. Honored to be here.

Jeff Burns 01:39

Well, I guess my first question is, is really, how did this come about? I think we could all perhaps imagine it, but what is your story? How did this book come to be, and why is it important for pediatricians and parents of children with medical complexity?

Ann Schrooten 01:59

In talking about how the book came to be, the first thing I'd like to share is a little bit about how Barry and I know each other. I met Barry in 1999 when he was one of the intensivists who was caring for my son Jack, who was two months old at the time and was admitted into the pediatric intensive care unit at St. Louis Children's Hospital. And after a long and complicated course, Jack was discharged from the PICU with a trach and on a ventilator. And Barry took on the role of managing Jack's home vent after discharge. At the time, Jack didn't have a diagnosis, so the hope was that the ventilator was just a

temporary intervention. And after a couple years, when Jack was three, our family moved from St. Louis to Phoenix, but despite the break in the doctor-patient relationship, Barry and I kept in touch throughout Jack's life. I often reached out to Barry for his advice and reason when it came to Jack's care. And Barry always listened and helped in any way that he could. Jack was eventually diagnosed with a rare congenital muscular dystrophy, and in January of 2014 at the age of 15, Jack died from complications of his disease. And it was, it was shortly after Jack died that Barry and I partnered to write this book together. And what we recognize is that the connection we had and what we'd learned from each other needed to be shared. But we wanted to expand the conversation to include other parents and other physicians. So we reached out to our respective networks of parents and colleagues asking for stories about an interaction or a relationship that they'd had with a family or a physician that had a significant impact on them. And the response we received was overwhelmingly positive, and as a result, 46 of those stories became the book *Shared Struggles*.

Barry Markovitz 03:57

When you had on OPENPediatrics recently, Doctors Mema and Morrison, talking about the power of narrative medicine, it struck me that it is stories that really tug at your heartstrings that make you pay attention. It's what newspapers do when they report about a tragedy. They dive into great detail about one family or one child, and it means so much more to us as humans to hear these stories and read them than just reading about numbers in a randomized controlled trial. I think it takes too long for these lessons to make their way through into a pediatrician's mindset. It's just not taught, and so hopefully reading stories will, and listening to this podcast, for example, will open pediatricians' eyes and hearts to some of these issues that we've uncovered.

Jeff Burns 04:45

Well, Ann in all of our communication prior to the podcast, I did not realize that your son had died. And so first, you know my condolences. And for all of us who care for children, we love what we do, and it's because of working with people like you, but we also understand from all that experience that there's more, no more devastating event in the life of a human being than the loss of a child. So our condolences on that, and I must also share with you that I had a nephew who died of Duchenne muscular dystrophy, and saw what that was like for my sister and our family as well. So, our condolences to you.

Ann Schrooten 06:02

Thank you.

Jeff Burns 06:02

But you, you turned this into a positive, and you know what you described about my colleague Barry didn't surprise me, even though you had moved to Phoenix, you and he continued to have that relationship, you know. You can go on Amazon, and I read a sample from the book, and you can see all these stories emerge. And one of the recurring themes is about communication. Tell us about communication. What should we know about how pediatricians and parents with children with a chronic complex condition experience that?

Barry Markovitz 06:09

So I think the punchline is for pediatricians to learn to see the children through their parents' eyes. We have a quote in one of our presentations from Thoreau that says, "could a greater miracle take place

than for us to look through each other's eyes for an instant." There's a story in the book that we, that I read when we gave presentations about this by Elisha Waldman. He's trained in oncology and palliative care, remarkably articulate and thoughtful human being. He talks about real quickly, he was moonlighting in the PICU as a palliative care fellow. This young woman was admitted, multiple complex medical conditions, cerebral palsy, virtually immobile, certainly not communicative. And at some point, the mother says, "You know, my girl's hungry. Can you start feeding?" And he, he looks at her like she's got two heads, like your daughter didn't do anything. How could you know she's hungry? And then you know one thing led to another. He goes, then as a palliative care physician, he goes to on a home visit to their house, and he thinks he sees the girl lying in bed on her side, like she was before, staring into space, and he walks around to look at her face, and she smiles at him. Sorry, it never ceases to tug at my heartstrings, this story, but because we've all been there, we've all looked at these children and said, how do you communicate with them? They can't possibly communicate, and they do, and Ann will tell more, but it's really important to use the parents as interpreters for these children. Just because they're not verbal doesn't mean they can't communicate. And you know, there's a quote from one of the physicians, "even if you don't believe what the parents believe, believe in the parents."

Jeff Burns 08:05

That's a, that's a beautiful anecdote, and a beautiful quote. Believe in the parents. Ann—communication.

Ann Schrooten 08:15

Well, I think the message of seeing the child through the parent's eyes, obviously, is especially important when you're dealing with a nonverbal child. My son was nonverbal, but there's often an assumption that a nonverbal child can't communicate, and that's just simply not true. They communicate with their eyes, their facial expressions, their body language, and just like a parent can begin, you know, with their newborn baby, eventually understands what that child wants through observation, and we've been caring for our children, some of us, me for 15 years, some people longer, but you learn, you learn what their nonverbal cues mean, you know that their gestures, their facial expressions, their nuances, we learn what they're telling us, and I think the important thing is that it takes patience and it takes powers of observation to connect with and communicate with a nonverbal child, but most importantly, it takes a desire to want to communicate with them, and I'll just share, my son had this t-shirt with these words on it that I think sums up the important message perfectly. It's just because I can't talk doesn't mean I have nothing to say.

Jeff Burns 09:34

That's terrific. Another theme in your book, and again, the book is entitled "Shared Struggles: Stories from Parents and Pediatricians Caring for Children with Serious Illness." Another recurring theme is physician caring and empathy, and when I saw that as one of the themes, I thought to myself, you know, I wonder what, if you could roll a video of how I might appear on rounds, and you know, some days rounds are, you know, we're busy, we're, you know, we've got 12, 15, patients, and they're coming, they're going, and so you're, you're trying to be efficient, you're moving through rounds, but I also wonder, like, what are we conveying to the parents as we go through the daily grind of rounds, in particular, what are we conveying in terms of our empathy and our caring. Ann, can I ask you first, caring and empathy, what did you have to say in the book, what should we know?

Ann Schrooten 10:38

Well, I think when it comes to caring and empathy, I mean, we saw a lot of that in the book, and I think that's the message here, is that courses through many of the stories, and one that resonates with me is gratitude. I mean, we notice the doctors that listen to us that want to hear what we have to say. I mean, our children introduce us to the most remarkable people who take care of them, to become, become part of our team. It's very much a team effort, and we spend a lot of time around our children's doctor, so we can't help but form a deep bond with those people that are part of our child's care team. And so, when your child's in the hospital, there's nothing more comforting than seeing the familiar face of your child's doctor that knows you and knows your child and greets you with a smile and a hug, I mean that means the world to us. And then also we need advocates, we advocate all the time, but knowing that this doctor knows you and then becomes and helps you and becomes your frontline advocate, so advocates on your behalf, so you have to do a lot less advocating. It releases a lot of that burden of advocacy, and then also for those of us who, when our child reached this point in their life where there's nothing more that medically can be done for our child, it means the world when doctors stay with us, and they show that they care, and they show that our child's life mattered, and I don't think Barry will mind me sharing this, that he came from out of state to attend my son's funeral, and he spoke at my son's funeral, and to say that that meant the world to me is an understatement. If I can, I would like to read a quote from the book that talks about this, a short quote. "The same holds true for Joey's pulmonologist, his humility, compassion, and ability to embrace our pain, as well as his own helplessness, opened our eyes to the importance of connection. By this point, we had long ruled out a miracle and any potential solution to the unfixable problem that a fatal diagnosis is. Instead, connection and the presence of others became the most vital and valuable gift to us. Connection takes us deeper than job descriptions and formalities, but it needs to take its own shape and can never be forced or fabricated, it cannot be achieved through a formula or a prescribed set of best practices. It can be as simple and profound as a pediatric pulmonologist in civilian clothing sitting on a couch with his dying patient gently cradled in his arms."

Barry Markovitz 13:17

I think you've really hit the nail on the head, there. I'm not the first one to say this. Parents don't care about how much you know until they know about how much you care. And Jeff, you asked about rounds. It's hard to do on rounds, but you can take five or 10 minutes, go into the family's room, sit down, be at eye level, don't tower above them, standing when they're sitting. Listen to them, you know. I've, I don't know, who said this first. You have two ears and one mouth, and you should use them in that proportion. These families want to be heard. They know you don't have all the answers, but making sure that they know that you care is, is that that is 90% of the therapeutic bonding and relationship.

Jeff Burns 14:05

Oh boy, you both are just so articulate. And by the way, Barry, you just quoted one of my favorite, Zeno of Citium, that we're born with two ears and one mouth, and yes, we should listen twice as much as we speak. Another theme that's in your book is quality of life, and I have to share with you when I was, I think I was a fellow in medical ethics at Harvard Medical School, and someone explained to me the concept of a comparative versus a non-comparative assessment of quality of life, and it stayed with me forever, and I've tried to teach it, and that is, I think, most human beings probably make comparative assessments of quality of life, you know, they, they look at some individual, and then they compare that individual's quality of life, they presume, to everyone else around them. Whereas, as I was taught many years ago, no, your job is to make a non-comparative assessment of quality of life. That is, it's referenced only to that individual, what was their quality of life before this operation, or before that

event, and that was such a crystallizing distinction for me, and I've used it ever since, as I mentioned. But what do you all have to say about quality of life?

Barry Markovitz 15:31

Well, I think that's a great segue, Jeff, because it is very dangerous for us to impose our values on these children and these families, our values are our values, and we should not be imposing them. The corollary to that is my opinion. You should never say what you would do if this were your child. You have no idea what you would do if we're your child, because you're not in the shoes of that family, you know. And it's been demonstrated that by my colleague here at University of Utah, Stefanie Ames has done several really, I think, landmark studies. Children with medical complexity in their families are discriminated against by their providers. Usually it's covert, it's not intentional, but they feel discriminated against because we don't, we don't see these children as having the same value that a healthy child does, and Ann can comment further, but it's not disability, and it's not what they can't do, it's what the value they bring to their lives and to their family lives, and that's not for us to decide.

Ann Schrooten 16:38

Well, as you can imagine, quality of life is a very sensitive subject for parents of children with severe disabilities, and it hurts when, it stings when we hear doctors think that our child has a low quality of life, but I mean, honestly, if in 1999 I struggled with whether a child who would never walk, talk, eat by mouth, breathe without a machine, could have a good quality of life, but then we brought Jack home, and for 15 years he showed me what a good life really means, and as, as Barry said, quality of life, it goes beyond our child's medical needs and their, what they, their diagnosis, it's the relationship we have with our child that gives our child's life value, not what they can or cannot do, and I also think quality of life should not be based on what you see in a hospital, because that's just a snapshot in time, and without question, being in a hospital is not a good quality of life for the patient or the family, so there's just so much about our child that's not seen when they're in the hospital and when they're sick, it's not seen, you know, that our child is happy, they have a sense of humor, they mean the world to their family, their siblings, and the people who love them, so quality of life really should only be determined by us, because we experience the whole picture, and so it's important to let the family decide for themselves and their child what quality of life means.

Barry Markovitz 18:16

Someone just to follow up, someone taught us to ask a family, show me a picture of your child on a good day at home, or a video, and the differences are striking from what they, how they behave when they're in the hospital. So that's a great, it's also another great way to form empathy and create that trusting bond with a family by asking.

Jeff Burns 18:39

Again, I'm just sitting here absorbing the words from you both, or they're just so illuminating, you know. Barry, to your last point, you know, it's always really helpful to me when the families post pictures of their child at home, you know, wherever they want in the room, and yeah, I will confess, it's a, it is an eye opener, because you know, we're only seeing the child as they are in the hospitalized context, but to see the child at home is so helpful, you know, another theme here is hope. Hope, what did you write about hope? What should we know about hope?

Barry Markovitz 19:31

So, if I may read a quote from a very wonderful physician that I know very well, "it is a strange mind space to know what is likely to happen, and to simultaneously wholeheartedly hope and strive for something different. Parents of children with life-limiting medical conditions are forced to inhabit this space. They knew too well the oscillation between optimism and despair, visualizing the dream and being confronted by the reality. Being a physician for these children and their parents requires sensitivity to that experience, and I believe a willingness to genuinely align oneself with the parents. Only by doing so does one earn the right to speak the painful truth, to gently help them prepare for the loss to come. It is I am discovering the greatest art of palliative care, or of good medicine in general." I feel like hope could be its own podcast, because it's so layered, but what - what I'll say is that it's important. A parent who has hope is not a parent who does not accept the reality of their child's disease or prognosis. Hope is literally how we survive. It's what gives us the strength to get up each day, put one foot in front of the other, and be the best caregiver, advocate, and voice for our child that we can be. And our hopes are also not fixed in time, they change over time as our child's condition changes, as we become aware and accept our child's condition or prognosis, I mean, when my son first came home from the hospital without a diagnosis, my hope was that this was all temporary, it was going to go away, and when that didn't happen, then my hopes shifted to I hope he's happy, I hope he wakes up every morning knowing he's loved and feels safe, I hope he has a good day without pain. I mean, there's always something to hope for. So, it's important to be mindful to never extinguish hope, because I think there's a worse thing than false hope, and that's no hope.

Jeff Burns 21:36

Yet another theme, if I could ask you about, is humility.

Barry Markovitz 21:41

Yeah, humility is a rare but vital characteristic for physicians caring for such children. Humility says, I don't have the answer, let's find it together. Humility in a physician is decidedly not a sign of weakness, but rather the brave, the sign of strength. And so, for him, humility.. I'm going to read an excerpt from a parent's story. "What has always stood out about Dr. B is his humanness. Is he the most knowledgeable pulmonary doctor on staff? Probably not. The most experienced, not even close. Neither is he some idyllic Patch Adams, but he connects with his patients and their families. When Addison was first discharged from Children's as a baby, and we were assigned to the least experienced pulmonologist in the group, we, Addison's parents and her doctor, were all rookies at caring for a medically fragile and complex child. We listened to each other, we learned together, and we came to trust each other. Dr. B understands and acknowledges that our lived experience in managing Addison's medical needs over the years carries equal weight with what was learned in medical school. His willingness to be vulnerable to admit when he was wrong, and his taking time to know us, not just as parents of a patient, but as people with common interest, displays a rare humanity that is often missing in the doctor-patient relationship. This humanity stands out. This humanity is instrumental in creating a trusting relationship, and a trusting relationship with your child's doctor is imperative when you have a child with a chronic complex condition that will require a lifetime of medical care."

Jeff Burns 23:17

These quotes that you're choosing are just so poignant, instructive gems, absolute gems. There's so much here, but I'm curious, you know, if you had to summarize, what are the overarching takeaways that you want to leave us with today? What would you say?

Barry Markovitz 23:40

I want to emphasize that there's not one parent in this book that ever praised their physicians based on their medical knowledge or technical skills. No one said that was the slickest bronchoscopy I've ever seen. They all commented about those features, or lack thereof, like empathy, listening, emotional intelligence, compassion, being trustworthy, these so-called soft skills are what really make a great physician, especially children with medical complexity and their parents. I cannot emphasize that enough.

Ann Schrooten 24:12

Well, our book is called Shared Struggles, and I recently heard the relationship between the physician caregiver and the parent caregiver referred to as a shared enterprise, and I really like that, but the key word is shared, and the fact is we need each other. The parents' experience, expertise, and input carries just as much weight as the physician's education expertise and experiences and while we certainly don't walk the same path, we share many of the same challenges of uncertainty, difficult decision making, holding on to hope when it seems impossible, and it's through working together, respecting each other. And recognizing our shared humanity that we can give our children the most best moments and the best possible life for however long that will be.

Jeff Burns 25:14

Well, you both have been founts of wisdom here today on OPENPediatrics (25:19). Let me ask you this, and Barry, forgive me if, if I didn't check this on PubMed to see if you've already done it (25:27), but may I suggest now you've written a book, you don't have to write anything more, and so this is quite something for me to suggest that you should do some more writing (25:38), but what I'm wondering is, if it wouldn't be invaluable for you to do a review narrative piece, a review article, thoughts, a narrative piece, I guess it would be for Pediatric Critical Care Medicine. Critical care medicine really distilling what you've got in the book, but you know you both have even more time to have thought about these issues and experienced them in terms of talking with others who've gone through these experiences, and I think distilling these into a narrative piece would be invaluable for colleagues around the world right now to reflect on what you both have learned from others. These are not just your stories, there are other stories from parents and pediatricians in the care of children with serious illness (26:37). Now I'm putting that out there in a way that now you have to answer. You don't have to answer.

Barry Markovitz 26:44

No. Well, it's funny that you started with this. Perhaps you should have done PubMed search. We did write a narrative piece in PCCM called Just Because I Can't Speak Doesn't Mean I Don't Have Anything to Say. So, just from Jack's T-shirt, so we did, we did that, and then Ann has, cannot be stopped. She's an, you know, immovable force. She's created a documentary interviewing three parents, and three sets of parents, and three pediatricians, all you know, all of whom, who wrote stories in the book, and we're figuring out how to get that, you know, disseminated, so we are continuing, especially Ann, to get to try to get this message out in whatever format and whatever venue that we could reach the most people.

Jeff Burns 27:33

Well, Barry, I should have, I should have done the PubMed, and worse still, I should have remembered it, and I didn't. I didn't see it, but the citation for that piece, which is entitled 'Just Because I Can't Talk Doesn't Mean I Have Nothing to Say,' was published in Pediatric Critical Care Medicine in June of 2025

and again the authors are Ann Schrooten and Barry Markovitz, and so we will have that citation in the links to this podcast, along with your book, and again, our deep thanks for both of you being with us today. We've been speaking with the authors of the book entitled Shared Struggles: Stories from Parents and Pediatricians Caring for Children with Serious Illness. The co-authors, Ann Schrooten and Dr. Barry Markovitz. Thanks so much for being with us on OPENPediatrics.

Barry Markovitz 28:37

Thank you very much.

Ann Schrooten 28:38

Thank you.

Sarah Marcley 28:40

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Referenced:

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