

## Considering the Ethical Roles We Play as Clinicians and Parents

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In this episode, Dr. Bryanna Moore and Dr. DeeJo Miller lead an interactive discussion focusing on Bryanna Moore's recent published article, "Exploring the Ethics of the Parental Role in Parent-Clinician Conflict"



Featured Speaker:

**Bryanna Moore, PhD | DeeJo Miller**

Bryanna Moore, PhD, is an Assistant Professor in the Department of Bioethics and Health Humanities at the University of Texas Medical Branch in Galveston, Texas, where she also serves as a clinical ethicist. She received her PhD in Philosophy from Monash University in Melbourne, Australia, and completed postdoctoral fellowships at the Children's Mercy Bioethics Center and Center for Medical Ethics and Health Policy at Baylor College of Medicine. Her interests span pediatric ethics, clinical ethics and medical decision-making, virtue ethics and death studies.

DeeJo Miller's life changed in 2004 when her 13-year-old daughter was diagnosed with Burkitt's non-Hodgkin's lymphoma. Over the next 18 months she spent over 300 days inpatient with her daughter who eventually received a stem cell transplant. DeeJo was hired by Children's Mercy as a "parent on staff" in February 2008 to utilize her experiences in the healthcare setting and collaborate with staff by serving as a voice of the families.

Through her role as Director of Patient and Family Engagement, she provides leadership to the organization to advance patient- and family-centered care principles, concepts and culture. She offers direction and expertise in planning, decision making, and organizational change related to patient and family engagement. Additionally, she leads the Patient and Family Engagement Team who oversees 20 Patient Family Advisory Councils to inspire a PFCC culture and influence the quality, safety and experience of care at Children's Mercy.

Transcription:

Host: Hello, and welcome to another edition of the Pediatric Ethics Podcast sponsored by the Children's Mercy Bioethics Center. My name is Jeremy Garrett and I'll be your host. Today, we'll be considering the ethical roles we play as clinicians and parents, and I'm thrilled to be joined by two terrific guests that bring different perspectives to this topic.

Dr. Bryanna Moore is an Assistant Professor of Bioethics and Health Humanities at the University of Texas Medical Branch in Galveston. She's originally from Australia, a philosopher by training, and she spent some time in Kansas City with us as a Pediatric Ethics Fellow, and then went on to also have a fellowship at the Baylor College of Medicine in Houston.

She's recently published a paper entitled, Exploring the Ethics of the Parental Role in Parent Clinician Conflict with her co-author, Rosalyn McDougal. That's going to be the basis of our talk today. However, we're also joined by a second, DeeJo Miller, who brings two important perspectives to the discussion of what it means to be a good parent.

She is herself, a parent who underwent a long and arduous medical journey when her daughter Hannah, was diagnosed with cancer, and she also has more than a decade of experience as the Director of Patient and Family Engagement here at Children's Mercy, Kansas City. We'll start with Dr. Moore, though and Dr. Moore most listeners of the Pediatric Ethics Podcast are going to be familiar with concepts like the best interest standard, the harm principle, parental authority, and the zone of parental discretion. These concepts, of course, figure prominently in the academic literature of pediatric bioethics and in the clinical setting of ethics consultation in pediatrics. But in this paper you co-authored with Rosalyn McDougal, you're encouraging us to consider the ethical value of another and more underexplored concept, namely this idea of a parental role and the way that that's informed by our concepts of what it means to be a good parent. Can you tell us more about what got you interested in that concept and why you think it's been underexplored, and also why you think it's crucial for ethicists and clinicians to begin paying much more attention to it?

Guest 1: Absolutely Jeremy, thank you for that question and I'm really happy to be joining you and DeeJo today. What got us interested in that concept, so appeals to roles and role-based ethics are something that we hear a lot like on the unit in the hospital, we often hear doctors say things like, as a doctor it's my job to do X or, as a nurse, I can't in good faith do Y for my patient. So I think roles are all around us. In a space like a hospital where there's this division of labor and everyone's sort of working together in these different roles to provide care to patients and families and what got us interested in the parental roles, the fact that we often hear explicit appeals to professional roles in healthcare, but we don't always hear explicit appeals to the parental role, but sometimes we do as well.

So sometimes parents will say something like, I'm her mom and that means I know her best or as her dad, I feel like I have to do this. So I guess some of the moral architecture that underpins roles, and what sort of ethical work we allow role-based appeals to do when trying to justify decisions about a child's care.

And it's really funny that you asked about why we think it's been underexplored, it's almost so obvious to say, the parental role matters ethically. Right. Yeah, of course it does. But we were interested in the idea that some of those traditional concepts in pediatric ethics that you mentioned, hadn't talked about the ethics of the parental role as explicitly as you might expect. So we thought, okay, let's take a closer look at this and see what comes out of it.

Host: Yeah, it's really interesting to think that when a parent makes that claim that you just mentioned, as a parent or as her mother; they're clearly signaling a unique type of moral claim or reason, right? You wouldn't need to make that claim if you were simply making a claim about what's in the patient's best interest. You could just state, this is what I think is in their best interest. But when you add that as her mother, as a parent, you seem to be signaling something important and it is strange that that hasn't been picked up too much in the pediatric bioethics literature before your article.

Guest 1: Right. And one of the things that sort of motivated this paper was that the pediatric ethics literature sort of says like, parents' reasons don't necessarily matter to whether a treatment decision is justified or not. It's the effect of that decision on the child that should really be guiding us ethically and I don't know if I want to go so far as to say that we're skeptical about that, but we let clinicians, as I said, appeal to role-based reasons. And that's like widely accepted idea in bioethics, you know, that's where a lot of our ethical principles come from, is the idea, like, as a clinician, you have these kinds of, you occupy this role and it generates these kinds of obligations towards your patient.

And so we were just really interested in whether parents could make similar appeals on ethical grounds, and if so, what that would mean for pediatric ethics. Right? Kind of pushing on some of those core concepts like the harm principle and best interests.

Host: Well in the paper you described some fascinating work that is informing our idea of what it means to be a good parent, and you're drawing it from both the conceptual and normative domains, as well as empirical studies. Could you briefly describe some of the main conclusions about the parental role that seemed to be emerging from this work?

Guest 1: Sure. It's a growing and really rich area and I'm a little worried that I won't do it justice by trying to summarize it really quickly. But the take home message is really parents have a strong role-based ethic that they speak to when we do studies and we do qualitative work with parents. This comes across very, very clearly that parents have a range of good parent beliefs, but that the idea of good parent beliefs is action guiding.

So being a good parent means different things to different parents, looks different in different families, but most parents feel constrained by their role and the obligations that they feel it produces. Whatever they think those obligations are. There is some, sort of consistent themes and threads in at least the empirical work on good parent beliefs and the parental role.

So many parents mentioned things like feeling that loving and comforting their child, providing a sense of security and privacy, retaining responsibility for decisions and what happens to their child. Things like the need to actively do something, problem solving, emotion focused coping strategies, feeling informed about their child, what's going on with them, especially medically. Things like providing, protecting, preserving the child's sense of self and interest. These are consistent themes in the literature. Parents speak to these when asked how they understand their role as a parent and that when a child becomes ill, there's a lot of parents really have to kind of step to it and navigate new relationships, new spaces, new rules and norms. Provide comfort and participate in caregiving, in really new and challenging ways, and pivot into this new space and maintain their role in the face of what are often really challenging situations.

Host: One of the more interesting words that emerged here was this idea of piloting and all of the trepidation that comes with piloting in the real world with aircraft, of course. You can imagine thinking of your child in a similar way, and that there's a destination they need to get to eventually.

And there's this journey along the way and you've got all this complex stuff that has to happen. And how do you safely land the plane, in the basic vicinity of where you intended to, is a big challenge. I think it is interesting to reflect on the ways that a role-based ethical lens, focused around our ideals of what it means to be a good parent, could change ethical analysis of pediatric decision making as opposed to a lens that focuses primarily on things like duties or consequences or principles. What are some of the main changes that you see in the way that our analysis would look with this role-based approach? And what do you see as some of the primary strengths and limitations of that approach?

Guest 1: So what we think a role-based lens can help with is to really help us recognize the stakes of conflicts with care teams for parents, and that sometimes when we're pushing parents a little bit or trying to convince them to make different decisions, it can feel like we're asking them to be a bad parent or to kind of revise their, their identity or think about what a good parent means differently.

And that's really challenging. And as an ethicist or as a physician or a nurse, if someone asked us to make a decision that we felt was directly in conflict with doing our job well or performing our role well, we would really struggle with that too. So we think that really attending to roles allows us to reframe conflicts in a way that more accurately reflects the nature of the disagreement. That can help us clarify the stakes of the conflict, particularly with intention to the stakes of the conflict for parents and sort of how difficult it is to go directly against what you feel like is your role-based ethic and just help us promote empathy and understanding that, as you were saying earlier, Jeremy, piloting in this really new environment is incredibly challenging. It's you know, the parents who are in the clinician's world and trying to figure out how to parent in that new space. And that requires flexibility and sort of a lot of validation on the care team's part.

Host: That certainly seems to be much more threatening to a parent's identity, if their idea of what it means to be a good parent is violated versus some abstract ethical principle. I think we can all agree on that. Before I turn over to, uh, DeeJo Miller, I want to just have you address the case that you use in the paper. This case of Baby J, who's a young girl in the NICU with an extremely poor prognosis, that leads to conflicting views about her care between her parents and the clinical team. You use this case to sort of illustrate both how the traditional toolbox of pediatric ethics might approach this case, and also how a shift to considering how baby J's parents understand their role and the way that might change how we understand the ethical issues and questions at stake in this case. Could you briefly summarize that case for our audience and how you see the role-based approach impacting and ideally improving the consultation process as well as the relationships and the clinical care at the heart of the case?

Guest 1: Sure. So the case that we present is a story of an infant who was born at 26 weeks gestational age, so very premature, who's now at 50 weeks of life and has remained in the neonatal intensive care unit for continuous cardio respiratory monitoring, the provision of respiratory support. She's receiving tube feedings, artificial nutrition and hydration.

She has had numerous respiratory infections. She has BPD, Bronchopulmonary dysplasia, really common for premature infants. And she's been experiencing episodes of bowel dilation and distension of unknown origins. So it's been really tricky to feed her and then get her kind of growing. Her parents were at bedside regularly earlier in her hospitalization. They've since had to go back to work. This is a really common situation in NICU. You know, parents can't be there 24/7, right? They do visit her on the weekends. They sometimes come by on the weeknight. They receive phone updates from the team most days. In the story that we tell Baby J, the patient has developed another respiratory infection and experienced multiple episodes of desaturation where her oxygen levels have dropped sharply and to a dangerous level requiring her to be bagged and for oxygen to be provided. Sometimes the ethicist will get called into these situations. We'll hear something like, the Neonatal ICU team, the NICU team are debriefing and it turns out that the care team feel that continuing to treat baby J have a really low chance of any improvement in her condition.

They'll consult us because they're worried and will hear things like, you know, these parents just aren't getting it. All of this is going nowhere. We're just hurting the patient at this point. We're not helping her with all of this anymore. And as ethicists, we'll often speak to two parents as well, and in the case that we present at least, we write that the parents insist that baby J's overcome every setback so far and they still believe they'll be able to take her home with a little bit more time.

And that as parents, those two words are really important. As parents, they can't imagine giving up on her. Cases like this are not, or situations like this are not uncommon. And it's not uncommon for an ethicist to get called just to help everyone move through things and see if we can get to a point that everyone feels comfortable with.

And what we think a role-based lens can really add is just really paying attention to those two little words that I said before as parents. So figuring out how parents understanding of their role and the obligations that it produces, how that is driving their decisions, and what sorts of choices they feel are even on the table or imaginable. And so when we apply a role-based lens and really think about what is constraining parents ethically in their mind?

We think that it can shift the care team's mindset away from these parents don't get it, they're hurting their child, this family's difficult to work with, to really recognizing that these are just parents trying to be good parents. And that they as parents and we as clinicians have different kinds of commitments and a different kind of relationship to the child or patient in this situation. For the team, things like protecting baby J from physical pain associated with interventions. That might seem really obvious that that should be given a lot of ethical weight, but we can imagine that her parents are valuing patience and keeping a steady routine in

place, maybe a little bit more than protecting her from some of those interventions at this point in time. As these are qualities that have helped them survive as parents.

And just reframing conflicts in the way has the potential to shift the dynamics between parents and the team, sort of out of, out of this adversarial mindset, out of battle mode or so, at least we argue in the paper and into a more flexible approach. And that could be something as simple as the ethicist, helping everyone recognize there's no one right way to parent as a child or be a parent, during a child illness and death. Value judgements in this space are really complicated cuz there are often no good options for parents. And whatever we can do to validate their role, is important to partner with them in working through the decisions to be made in these sorts of situations.

Host: Thanks. I want to bring in our second guest now DeeJo Miller and DeeJo, you bring a, an important perspective to this discussion. You are a mother and you gained firsthand experience with how the concept of a good parent can factor into tough and complex pediatric decisions, when your daughter, Hannah, was diagnosed with non-Hodgkin's lymphoma at age 13. Could you tell us a little more about Hannah and her medical journey and the ways that this may have highlighted and challenged, and maybe even changed your understanding of what it meant for you to be a good parent?

Guest 2: Sure. Thank you. And I feel like I'm going to just reiterate a lot of things that Dr. Moore talked about because I was nodding my head a lot, which nobody can see. But that, was happening. So, with my entry into the medical field, it occurred suddenly. So we had a very healthy 13 year old daughter and she had a 15 year old brother.

We were very engaged in competitive Olympic style weightlifting, and she wasn't feeling well. I kind of, she'd never been really sick, so kind of pushing and knowing that something wasn't right, but I didn't know what wasn't right. Just something wasn't right. And the multiple trips to her pediatrician to get finally that diagnosis and what that meant and that change in an instant from a world we knew to a world we didn't know. And our role as parent in protecting our child in this world that we didn't know anything about, carried a lot of fear. And that moment, in time when we learned, then that next moment when we had to walk into her room and deliver that news to her, knowing that her life was going to change too. And this sudden feeling of as her parent, we weren't in control. We did not have the same control we'd had 15 minutes ago. And from there it just snowballed. And she had a really aggressive cancer. So, her treatment was very aggressive. We spent over 300 days inpatient during the next 18 months.

She had 10 months of chemo and then her cancer came back and, so went down an experimental clinical trial route and complications and being dropped from the trial and multiple surgeries and compassionate use exemption and, just really trying anything. And, I can remember when the cancer came back and we were handed the paperwork to enroll her in this clinical trial, the one clinical trial she qualified for.

And I saw on the bottom of page three that said that my child was eligible because she wasn't expected to survive three months. And I just signed the paper and handed it back to the doctor because my husband, who's six foot two, couldn't stop crying. And I couldn't handle him. And my daughter was just, we were planning a vacation and all of this was changing.

So, you know, we're talking through that and we just had to keep moving forward. And I can remember thinking she's going to die trying to survive. Like, that's how hard we're gonna try because I wasn't in it for the short term. I was in it for the long haul. Like, I want her be alive down the road.

And I was willing to help her get there, whatever that looked like. Because I knew that if we gave up, that was permanent. And if we kept trying, we had the potential. And so in the midst of all of that, Hannah was 13 and we had a regular teenage daughter mother relationship, and now we're doing this in public. I always felt like, suddenly you're thrust up on a stage and you have to live your life on this public stage, and people are walking by and looking at you.

Some people are coming up on this stage with you. And there's a lot of people milling around in the background, and you have to sleep up there and you get a, a small door to take a shower behind. And all of those things are in public. And, trying to figure out just how to parent in public and manage these societal expectations of what we had thought was a good parent, before the diagnosis, and then what does that look like in healthcare in this world we didn't know anything about? And how do we navigate that? And continually at the same time, there's good news coming in, there's bad news coming in. People are coming in with no news. That, just the uncertainty of how doing that, and really for us, for me it was that tunneling my vision down to what I considered the bullseye, and that was Hannah. What were her needs and what could I do in this? There was a lot of things I couldn't do. I could be present. She didn't have to emotionally go through this alone. We were fortunate to have the ability for me to be present, and to be able to navigate that.

And so, for me it was about, what could I live with? What would I be able to go on with? And that also carries with it what can I live with in the community that which I live. So with my family and my friends and, you know, I had to be able to defend all of our actions because everybody has questions and has ideas for what you're, you're doing.

And, that's from my community. And then on the other side of the stage is all of the medical professionals, that are also looking at me, and I have to be able to defend what I do and doing all of that in the midst of being present with my child and being that support for her as she physically went through all of that experience.

Host: That's a powerful, you put a lot of powerful insights, I think, into this concept there, in the way that it is multifaceted. You're not just occupying this role of a good parent, for the clinical team and you're not just putting it out for your own family or for your wider family and circle of friends and, outer community but all of those at the same time.

And you're constantly moving back and forth, I suppose, in what that looks like. And I really appreciate you bringing that point up. I, it never really quite occurred to me exactly what you're saying. Now that you've said it, it's incredibly, compelling and reminds us to be very gracious with people that they're in a very unique position where they're having to live out their role-based, views and ideals in front of everybody, in a way that isn't normal, in everyday life. You also bring another unique perspective though, to this discussion, and I want to explore that briefly before we conclude. And that's your professional role at Children's Mercy, Kansas City that you've had for more than a decade now.

Following Hannah's battle with Cancer, you were asked to become one of two parents on staff with a job description of basically trying to empower parents and families and make sure their needs and interests and perspectives are kept at the center of the care that we offer here at Children's Mercy.

In your roles as family-centered care coordinator and director of patient and family engagement, what have you learned from other parents and families about what's most important to them when their child is a pediatric patient? And how do we empower them to live out their ideal of being a good parent in this very difficult situation? What have you learned from these, parents and families you've worked with?

Guest 2: Hmm. It's been amazing to be opened and my eyes opened to this concept. Everyone comes with so many different backgrounds, I knew that. But when we were going through our experience, I knew mine, I knew mine really well. I met other families in the midst of it. And now being able to work at the hospital to really impact the system and how do we create the environment that promotes really patient and family centered care concepts of that information sharing and dignity and respect and working together? What does that look like? And working with families who are served as advisors and who I meet on the floors. There's so many things that we have in common because I can talk about my experience and the things that I just shared and other families, oh yes, they totally get that. And yet our lives prior to stepping into the hospital are completely different. I always thought it was really amazing that the friends that I made, because the rest of our lives didn't even come into play when we were walking our kids through their medical experiences.

And so now I, I meet all of these other families and I learn their stories and, what they're carrying up to that moment when they're placed up on the stage and it's very different. We can even look the same. We can even speak the same language, but their backgrounds are very different.

And so I'm, so hyper aware of the fact that we all come to this place very differently, but then we have so much in common. And it's that love for our child. It's that fear for our child. It's that struggle to learn how to best navigate in this world, this medical world that we're suddenly thrust into and it's being never on our best day.

You know, the hospital does not create better personalities. We're sleep deprived, we're scared. We don't know who's coming into the room, if they have good information, bad information, no information. So we all have these streams of things in common and that love and that fear and that doing this in public. And yet we also come. What prepares us to be able to do that is, is our history and it's all so very different and so through my work here then, it's really how can I help create the this system so that families, regardless of their background, staff, clinicians, providers can step in front of them and give them space. To be present with who they come with, their history, what they bring to this situation, and acknowledge that how difficult it is, how hard it is to just do all of this present, unprepared, without rules. Society doesn't have a clue. You know, there aren't any reality shows that, that teach you this. And so, being accepted into that environment, is I think where we have that opportunity.

Host: Yeah, it's, it's hard enough to be a good parent when everything in the world is going right for you and so much more difficult to be a good parent in public, navigating a complex medical system. We're really lucky to have you here at Children's Mercy helping our parents and families navigate those challenges.



I'd like to conclude though, by asking each of you, you've listened to each other, you've listened to the different perspectives that each has brought to this topic, the philosopher and clinical ethicist, and the, on the one hand, and the parent and the family-centered care professional on the other. What do you think we can learn about the parental role and its ethical significance from combining these theoretical, professional, practical, and these highly personal insights. DeeJo, I'd like to start with you since you, you said you were nodding along as Bry was speaking, you said you were nodding along as Dr. Moore was speaking and, and addressing the questions that I was asking her. What do you learn from the work that she and Rosalyn McDougal are doing here?

Guest 2: Mostly, I just love the fact of bringing this to the attention, you know, that we can't train the world's population so they're prepared for their child to have a devastating medical experience and how to do that. But we can provide that guidance for those who are patient facing, parent facing, to help these patients and families feel acknowledged for this unusual situation, environment that they are suddenly put into and acknowledge who they are. They are the permanent role in their child's life. If their child lives or doesn't survive, that child is going to live with that parent in their heart, in their memory forever. And Hannah survived and there were people that gave me some of that support along the way that acknowledged how difficult that was, how I seemed to be doing a good job, and that encouraged me more and more each time so that I could be a stronger advocate for Hannah. I could be her voice, knowing the history and background that we have. And, this paper I love how that acknowledges that, because it feels undervalued. You know, we don't walk around with a badge with letters after our name, but I knew Hannah before anybody. I went home with Hannah. Nobody else did.

And so to be given that outright value for who you are, I think will build better relationships between clinicians and families so that there can be mutual learning and then reaching those best outcomes and helping, patients and families reach whatever those are, we don't, don't know, but oftentimes we end up defending our stance because we're feeling pressured to blindly follow this medical advice.

But I know that if I hold on two weeks and they change who the attending is, I might get different advice. Why would I give up now? And so building those relationships, I think this provides that opportunity so that clinicians also have a better experience then, and it doesn't feel this tension of trying to convince somebody of what they should do, but instead, mutually guide each other through this experience for the best outcomes, whatever that looks like for that child and, for that family that loves that child.

Host: Dr. Moore, I'd love to hear what you take away from listening to DeeJo's story and her experience drawn from more than a decade of working with parents and families faced with difficult decisions.

Guest 1: Yeah, a couple of things. I mean DeeJo, you said something really important before you said, what could I live with? And that for us was an idea that we came back to again and again as we worked on this paper, and when I say like what we think a role-based lens helps do is clarify the stakes of a conflict.

That's what we mean. Like the stakes for parents are often literally like, what can I live with? Sometimes, what can I live with after my child's death? And their stakes are so high. I think the stakes are higher for parents, not always, but typically, than they perhaps are for the clinicians caring for the child, although they're also high for clinicians.

But hearing you say that, that was the sticking point for you and that it is for many other parents is what we were trying to get at with this paper. So it's, encouraging to hear you say that and to hear you say that parenting looks really different for different families.

There's no one right way to parent well, and that you've worked with parents of all different shapes and sizes, families of all different shapes and sizes, but that there are some consistent things like this kind of fierce love for the child and this fear that you feel when your child becomes sick and that no one teaches you how to navigate that, how to pilot it. But hearing that there's this identification between parents where it's like you get it, right. If you are a parent, you get it. And that what I'm hearing is, and this is kind of where we ended up in the paper, is that the parental role, it helps to explain what parents are experiencing, their moral psychology, why they might prioritize or deprioritize certain things, but also it's a source of courage and love and other morally valuable things and just, yeah, exactly what you said. What we wanted to do with this paper is just really pull the importance of the parental role into the center of the stage and just try and encourage us to honor it when we work with families when their child is sick.

Host: Seems like a great place to wrap up. Again, the paper that has been discussed today, by Dr. Bryanna Moore and Rosalyn McDougale is entitled Exploring the Ethics of the Parental Role In Parent Clinician Conflict, and it appeared in the November December, 2022 issue of the Hastings Center Report. I want to thank both of our guests today, Dr. Bryanna Moore and DeeJo

Miller for joining us and sharing these valuable perspectives on this important concept, and encourage all of you to subscribe to the Pediatric Ethics Podcast on your favorite podcast platforms and apps. Again, this has been the Pediatric Ethics Podcast sponsored by the Children's Mercy Bioethics Center in Kansas City, Missouri.

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