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Families Face Ethical Challenges More Often Than They Change a G Tube: Rethinking Our Care

In this Complex Care Journal Club podcast episode, Dr. Miriam Shapiro, Ms. Kate Detwiler, and Dr. Vanessa Madrigal discuss a survey of families with children with chronic conditions about ethical challenges they have experienced in their child's care and sources of support. They describe the residual distress reported by families, implications for clinical practice, and next steps from this work.

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Katie Huth *00:04*
Hello and welcome to the Complex Care Journal Club Podcast. My name is Kathleen Huth I am a pediatrician at Boston Children's Hospital, and your host for this episode. In this podcast series, we seek to discuss emerging evidence in the care of children with medical complexity and its implications for practice, I'm delighted to have Dr. Miriam Shapiro from the University of Minnesota, Ms. Kate Detwiler from Children's National, and Dr. Vanessa Madrigal from Children's National. They're joining me today as first, second and last authors, respectively, of the article, Ethical Challenges in Pediatric Medical Complexity: A Survey of Parents published online in the Journal of Pediatrics in January 2025. Miriam, Kate and Vanessa. Thank you so much for being here.

Kate Detwiler *00:48*
Thank you for having us.

Katie Huth *00:50*
You guys are a unique research team, and I know you've collaborated in the past, so I'd love if you could just speak to how you came together as a team and put this particular paper in context?

Miriam Shapiro *01:03*
To start identifying how we came together as a team, we need to credit Dr. Renee Boss at Johns Hopkins School of Medicine and Berman Institute of Bioethics, who was my mentor in fellowship and has been a collaborator and gatherer of people interested in chronic critical illness and kind of touching on ethics and palliative care. And I think it is through Renee that I met both Kate and Vanessa.

Kate Detwiler *01:33*
Renee brought us all together through a research collaborative that she leads for the CCI [Chronically Critically Ill] population and children with medical complexity. And through that group, there are clinicians from across the nation who specialize in a myriad of clinical specialties. I'm a hospital administrator for the complex care program at Children's National, and the former administrator of our Palliative Care Program at Children's National, but I'm also the parent of a child with a rare disease and who is a child with medical complexity. And so she was gracious enough to allow me to participate and become a parent researcher within the group.

Vanessa Madrigal *02:18*

I'll just add to that, I started working with Renee when she first started that CCI group, the Chronically Critically Ill group. I think Miriam, you and I, that's when we probably first met too. We became a subset of that working group that then decided to look at these questions of ethics consultation and ethics definitions in this population, expanding it ever so slightly from kind of that more narrow, chronically critically ill group to children with medical complexity. And Kate and I have a special relationship because we've known each other for many, many years now. And and she serves, I'm the director and chair of our pediatric clinical ethics committee at Children's, and she has served on that committee at various times. And I've learned a great deal from both of my colleagues.

Katie Huth *03:10*
Thank you for sharing that background and your personal and professional connections to this work. I'd love to hear how this particular study came to be. Can you talk about the gap that you identified and what your aims were?

Kate Detwiler *03:23*
I identified the gap a couple years ago. I had a friend who had a serious illness come to kind of a pivot point, and we had some serious ethical challenges to work through. And I realized through that experience that I had no tools at my disposal. As a parent, as somebody that has worked in the healthcare space. And I was really, I was really upset about that. That how could I have been caring for a child with medical complexity for all these years, and been around all these amazing, intelligent, caring, thoughtful providers, and I didn't have any resources or framework to kind of help me prepare to deal with this, although adult situation, but not uncommon situation that you know most of us find ourselves in at some point in our life. And so the group was looking for a new project. Renee asked the group, were there any interesting ideas that we could pursue? And I shared that I had this personal experience, and it was really distressing to me that I didn't have any tools. And how could parents not have any tools? And are there tools out there and I missed them? And she said, it's funny that you ask because another family asked me this very same question a couple months ago, who was in the NICU, and I she had done an rather extensive literature review and found very little. There's very, very little for parents from a resource, education framework perspective. And so that led us to this broader question of, what do parents use for their ethical questions, their ethical concerns or ethical challenges? What resources have they identified? How do they define medical ethics? And from this very personal experience, we are now, I think, three years into this research project.

Miriam Shapiro *05:40*
It's so great that Kate brought this to us as a group. We had some really rich discussions as a team, as we were trying to put together the study and how we wanted to do it. For this paper in particular, we were trying to answer the question, what are the unique ethical dilemmas that are faced by parents of children with medical complexity? With the goal that if we understand that better, we can develop more inclusive and supportive healthcare practices and ethical resources that are available and accessible to these parents and families, so that when questions specifically ethical questions arise, they have access to resources that might help them navigate them.

Katie Huth *06:24*
Can you talk about the methods that you chose and some of your key findings from the study?

Vanessa Madrigal *06:29*
We decided to do a mixed method study. And we ended up devising a survey that we wanted to distribute to families or to parents. And so we found a couple of groups that agreed to post these surveys for us, both in listserv, and one of them agreed to do it online as well. And then embedded into the survey, they could show interest in being interviewed, and we were able to then reach out to them afterwards and interview that subset of patients that wanted to share a little bit more and be asked questions. So this collaborative group came up with the survey questions and then the questions for the subsequent interview. The key findings was the challenges that are most frequently identified do have some significant overlap with those most commonly addressed in the

ethics literature or looked at in the ethics literature. And by ethics consultants related to children with medical complexity, such as disagreement or conflict among medical team members. And it also extends, as we expected, to some extent beyond the topics that we commonly address or we commonly see in both literature and in consults. For example, the most frequently identified challenge was in deciding about letting a child participate in school sports or social activities.

Katie Huth *08:02*
It's interesting that you, as an interprofessional group, including parents, came up with this survey, which included these 15 case examples or types of ethical issues, and I was curious, for that one in particular, how that emerged as one of the potential ethical conflicts that may have arisen?

Miriam Shapiro *08:20*
That's a great question. We had as a starting point a study that a team of researchers at the NIH [The National Institutes of Health] had done interviewing adult patients and families about ethical issues that had arisen in healthcare, but we brought that, kind of what they found to this group and said, how do we drill this down? How do we make this applicable to children with medical complexity? I recall a lot of input coming from the parents saying, we need to ask about this.

Katie Huth *08:52*
And it seems like you hit the mark. I was quite impressed just reading through you got over 200 families who participated. And I noted it was one in four had to face a challenging decision just in the last month, and that all of the 15 scenarios that you had included in the survey, people sort of attested that they had experienced them, or at least some families had. So that I think was an important finding just in and of itself, just how common that families might be experiencing these, but also the concept of the residual distress that they're experiencing. I was just curious to hear your reflections on the data, and any surprises?

Miriam Shapiro *09:30*
I'm glad you brought up that issue of residual distress. We were quite surprised at the proportion of parents that reported residual distress. So for each of the 15 ethical challenges that you mentioned already that we asked about, we asked respondents to indicate how distressing the challenge was and we gave them three options. This was very distressing at the time, and I still have questions about it. This was upsetting at the time, but no longer bothers me, or I did not worry too much about this. And for 6 of the 15 challenges, more than 50% of the parents chose the first option. And generally those, the issues that rose to the top, there are ones that we tend to think of as ethically challenging, like conflict with the medical team, or difficulty with decisions around limiting care or things like that. But it was a surprising finding.

Katie Huth *10:31*
What are the implications for clinical practice for these findings? Specifically, what do you recommend for members of the interprofessional care team for children with medical complexity based on these findings?

Miriam Shapiro *10:41*
I think that this issue of residual distress is really important, right? That we as clinicians need to be attuned to the fact that residual distress exists, that it's there and that families are bringing into any current encounters, potentially things that happened before. And that this may have impacts for ongoing care, for ongoing conversations about care, for future decisions. Another key point is that we need to be aware of the fact that there are ethical dimensions to challenging situations for families that may exist kind of outside of our typical clinical realm, and that families may not have the same language or frameworks to explore these situations that we use in our kind of in the clinical environment. Which may mean that we don't perceive the challenges there to be specifically ethical in nature. And so we need to kind of be more open minded, I think about how we think about

what's going on for families, and how we engage them in questions about the challenging decisions that they are facing in the care and life with their child.

Vanessa Madrigal *12:08*
To add to kind of this question of residual concerns. I mean, I think this population is one that comes in frequently to the hospital, engages multiple times with with medical providers. And so to realize that this is happening in the background, it really speaks to a lot of the questions of trust that we know exist. And so if there, I think that what we're starting to try to understand is if these ethical dilemmas or ethical tensions that parents are experiencing are related to if those tensions have not been addressed or spoken about or discussed with clinicians, might there be an opportunity to do so? And in so doing, perhaps start to address or start to consider why there might be certain trust issues. I know that we found those very striking as well. We anticipated some of that residual distress, but I think really were impacted by how much of it there was.

Kate Detwiler *13:21*
When we think of interdisciplinary teams, we often think of, you know, the provider, the pharmacist, the social worker, but we should maybe consider broadening that group to include clinical ethicists. To Vanessa's point, that for children with medical complexity, they have much more frequent interaction with the healthcare system. They're much more clinically vulnerable, and because this distress is residual we should be addressing it in a longitudinal fashion, rather than an episodic one.

Katie Huth *13:59*
I think you all raised some interesting comments on what could be considered in the discussion of the paper around you know, in the outpatient setting, whether there's opportunity for longitudinal engagement of someone with an ethics background. And I also really thought the suggestion of having access to ethics training for family caregivers was an interesting one as well. And Kate, you had mentioned that this whole study, the genesis of it was around not having the resources or knowledge as a parent to turn to. And I'm just curious if you can share a little bit more about some of those ideas.

Kate Detwiler *14:33*
Well, I think you know often for parents, at least in my experience, I'll speak for myself, we ponder these ethical challenges in the middle of the night. You know, two o'clock in the morning, you know the hallway is dark, maybe you have a bedside nurse that, you know, has time to chat with you and break down some of your concerns. So I think for what we're looking for in the long term, ideally, is to secure some funding to identify and create some validated resources. So that's what we're kind of looking for, I think in the long term. Because right now, parents reported in the study that they're using Dr. Google, they're using their friends, they're using their family members, they're talking to their spiritual advisors, but none of this is validated in an evidence based sort of way. So that everybody's using the same language and starting at the same point of reference. And that goes a long way. You know, as a parent of a childhood medical complexity who works in healthcare, I share a lot of the same language, and that breaks down a lot of barriers for me much faster than for other folks. And so if we can get, we can incorporate some training for parents that they can access on their phone in the middle of the night, some videos in the middle of the night, some very simple, accessible tools, hopefully families would, would experience less residual distress.

Vanessa Madrigal *16:06*
We work really hard from kind of our ethics program lens to help clinicians across the hospital and cross hospital settings have the same language when we talk about ethical challenges or kind of aspects of decision making with an ethical lens. And it's it's very helpful for people to be able to share those frameworks and share those languages in conversation with each other, and it really, we receive a lot of feedback that it's it can be very helpful for the clinicians. And so I think what Kate is suggesting, and kind of what we've learned through this process, is, wouldn't it be helpful for parents and caregivers to have similar frameworks, or being able to kind of teach them

similar language? And then the other piece is, this was also Kate's idea, there is a lot of kind of preparatory guidance that occurs before a child with medical complexity gets discharged from the hospital. So for example, from sometimes with the palliative care lens and Kate fill this in too, but from the palliative care lens, or from technologies that are going to be used at home, there's a lot of kind of training and teaching that happens and and there may be an opportunity there to learn from those disciplines of how to prep parents when they go home, if they are also experiencing some of these tensions or questions at home.

Kate Detwiler *17:38*
I mean, definitely, you know, you're trained, when you go home with a G Tube [gastrostomy tube], how to change that G Tube. And at most, you're probably changing a G Tube every quarter to, you know, maybe semi annually. And these families are telling us that they're experiencing ethical challenges more frequently than they're changing G tubes. So I think that's really telling about where, where we should put some effort and resources into providing families with training and frameworks and education.

Miriam Shapiro *18:10*
I think one of the other things to highlight is that, you know, literature supports that ethics consults in general are underutilized, and some of that's related to it being not necessarily a resource that's available, especially with a pediatric lens, everywhere that kids are taken care of, but this is perhaps evidence to support more utilization of ethics consults, earlier utilization of ethics consults. It often ends up seeming like a last ditch end of the road, oh, things have gotten really bad. We should call in ethics because everything's swirling and nobody's happy and nobody knows what to do, and there's all of this conflict, but maybe that's us using ethics consult services and ethics teams and ethics committees, wrong.

Katie Huth *19:01*
You've highlighted, even just with the nature of your survey itself, that ethical challenges go far beyond kind of the goals of care conversations to other aspects, like the one that you had mentioned around participation in school and other activities, so that, in and of itself, I think, was a source of advocacy for how we think about ethics in complex care. What are the messages for patients and families from your study?

Kate Detwiler *19:26*
We've touched on a couple of them already, like while there are resources that families currently are using, like Dr. Google, friends, family and spiritual advisors, most parents aren't accessing the limited ethical tools that we do have, like ethics consults. And that's probably because they don't know that they're available. And we kind of talk about that in our next paper, but we also explore in our next paper that ethics consults really aren't available to families in a very accessible sort of way, and that we probably have some work as a community to change the perception of ethics consults. And kind of work very similarly, in parallel to palliative medicine, to kind of change that narrative to one of punitive to one of helpful, resource-oriented, collaboration. And then I think for families, it's really important to know that ethics consultants, they're really there to help. They're not there to be punitive. They're there to draw on their resources and their frameworks and their training and philosophy to help parents figure out what they really want, or how to choose between two really bad options, which is often the case in this very complex world that we're living in. And with very few exceptions, the ethics consults advocate for the family and the child, and that they're your friend, and that parents of children with medical complexity should make themselves aware of how to get an ethics consult, either through talking to their pediatrician or talking to their specialty medical home provider.

Katie Huth *21:25*
Thank you. You've all sort of touched on this a little bit, but is there anything else that you want to comment on in terms of important next steps from this work?

Miriam Shapiro *21:35*

The first one is to finish analyzing and writing up and publishing the remainder of the study, which includes qualitative data, so really people more in depth and more nuanced responses to to these issues. Because as qualitative data always does, it adds dimensions to what we could only ask about in a limited way in a survey. As Kate mentioned, we want to develop family specific resources. So using the data that we've generated here to guide that process is an important next step. And then we've thought about, how do we reach out to the clinical ethics community? Right, and say, hey we have a bigger job to do than how we've been thinking about it. Can we frame shift our approach to ethical challenges for children with medical complexity? And to that end, Vanessa and I have submitted an abstract to the American Society for Bioethics and Humanities addressing these issues, and so we'll hopefully be given an opportunity to bring this directly to the bioethics community in that way.

Katie Huth *22:55*
Our listeners really find it valuable to hear a bit from behind the scenes. You know, as studies are performed, if there's any particular opportunities or challenges that arose while you were developing and conducting the study?

Miriam Shapiro *23:12*
So many. I think one of the biggest things that we spent a ton of time on on the front end was how to, because one of our questions was, what do families understand about ethics? How do they define ethics? We didn't really want to prime the pump or bias families by stating outright, hey, we're interested in ethics, right? Um, partly because ethics does sometimes carry a weight as a term that people are familiar with and wary of, right? Often because it's, it's the team that's involved when there are times of conflict or when there are times of disagreement. So how do we ask about the ethical dimensions of challenging situations? Right, you can have challenging situations that are hard in all sorts of ways in addition to the ethical dimensions. But like how do we decide how to balance benefit and burden? How do we decide right and wrong? How do we decide what aligns with our values as a family? These specific dimensions of a challenging decision is what we were after, but we didn't want to say ethics. And so trying to figure out how to word our questions that we could have the best chance of getting at those points without using the word ethics was a big challenge. I think, as always, our way to find parents to answer these questions, we had to find organizations that had families with them, or that were parent, family focused organizations. They had to agree to distribute our survey and then people had to respond to that. So I think you already have a bias about who is answering the questions are people who are involved and engaged. Because they're people who are looking at Listservs, who are engaged with family organizations, and then we found that the people who responded were more educated, more resourced, mostly mothers. So we're missing perspectives here, but you know, it is what we got.

Katie Huth *25:30*
Any other things that you wanted to share?

Miriam Shapiro *25:33*
I just want to shout out the diversity of our research team, again, as a real strength of the success of this project. I think that we were able to develop a survey and interview questions that spoke to families, and that generated helpful data for us to continue to work with, because we had so many perspectives on the front end, in thinking about the issues, in thinking about how to frame them, what to ask. You mentioned early on that we had asked about these 15 scenarios, and some of them were already a little bit outside the box when you think about ethics. And people said yes to all of them. It makes me wonder, what else should we have asked about, right, that people might have also said yes to? So we wouldn't have even gotten to those 15 without the breadth of our the kind of professional and social background of our research team.

Katie Huth *26:36*
I think you certainly have a wonderful model for engaging multiple stakeholders in your research together and certainly benefiting from the expertise and the lens that's provided from your family partners. So thank you for sharing this model for us in this episode. Miriam, Kate, Vanessa, thank you to you and your team for advancing

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

Journal Club Article

Shapiro MC, Detwiler K, Shepard J, Bernhard T, Li X, Boss RD, Madrigal VN. Ethical Challenges in Pediatric Medical Complexity: A Survey of Parents. J Pediatr. 2025 Apr;279:114478. doi: 10.1016/j.jpeds.2025.114478. Epub 2025 Jan 27. PMID: 39864504; PMCID: PMC12013584.

Other References

Cho HL, Grady C, Tarzian A, Povar G, Mangal J, Danis M. Patient and Family Descriptions of Ethical Concerns. Am J Bioeth. 2020 Jun;20(6):52-64. doi: 10.1080/15265161.2020.1754500. PMID: 32441594; PMCID: PMC7673656.

Pang J, Batson L, Detwiler K, Miller ME, Thorndike D, Boss RD, Shapiro MC. Where do families turn? Ethical dilemmas in the care of chronically critically Ill children. Monash Bioeth Rev. 2024 Jul 8. doi: 10.1007/s40592-024-00201-6. Epub ahead of print. PMID: 38976209.