Balancing a Child's Interest With the Interests of Other Family Members

Professor Groll proposes four models for thinking about how to balance the interests of parents, families, and a sick child.

Featured Speaker:
Daniel Groll, PhD
Daniel Groll, PhD is an Associate Professor of Philosophy, Carleton College.

Transcription:

Welcome to the Peds Ethics podcast, where we talk to leaders in pediatric bioethics about a hot topic or a current controversy. Here's your host, John Lantos from the Children's Mercy Bioethics Center in Kansas City.

John Lantos, MD (Host): Hi everybody. Welcome back to the Pediatrics Ethics Podcast coming to you from Children's Mercy Hospital Bioethics Center in Kansas City, Missouri, home to the soon to be National Football League Champion Kansas City Chiefs. I am thrilled to be here with Professor Daniel Groll, a Philosophy Professor at Carlton College in Northfield, Minnesota, also an accomplished rock musician and a bioethicist. Welcome Professor Groll. We're going to talk about the article you wrote and published in Pediatrics in October of 2014, called Four Models of Family Interest. This is an article that challenges some received wisdom in pediatrics, particularly that guiding principle is that we should always focus on what is best for the child who is our patient. You paper addresses the idea that sometimes we also need to consider what is best for other family members or even for the family unit as a whole. And then you talk about a couple different models for how we might think about family interests. So, Dan, can you briefly describe those four models of family interests that you developed in the paper?

Daniel Groll, PhD (Guest): Yeah, absolutely. Maybe I can just take a step back to start. I mean the question in the background is how should we think about the place of nonpatient interests and I mean it's obvious that the patient's interests matter a lot and they're typically thought of as the primary focus and you could think that other family members interests don't matter at all. But that seems like a really, really strong view. And when you think about it, it seems like not a view worth taking seriously, particularly if you put yourself in the mind on the decision maker, typical decision maker in a pediatric context which is the parents.

So, if you imagine the parents now have other children, it just seems right away it seems ridiculous to say the only thing that matters are the interests of the child who happens to be the patient. So, if you start with the presumption that family interests matter; the question then becomes how do they matter. And how does their mattering intersect or interact with the patient's interests mattering? How should we sort of think of how all those interests interact if we throw them into the hopper?

And so the paper outlines four different ways of thinking about how to answer that question. So, here's

one thing you might think. You might think the interests of other family members matter only in so far as paying attention to them is going to help serve the interests of the patient. And I call this the oxygen mask model. And it gets its name from the instructions that they give you when you get on an airplane which is that if you know these masks descend because of depressurization of the cabin, attend to yourself before helping your child. And the advice there is not heh parents, you are number one, think of yourself because you matter more. It's like actually, you'll be more effective at serving your child's interests if you first get your own mask on.

Host: In this model, they only matter because they are good for the child. So, it's really –

Daniel: Correct. Right, so they are instrumentally valuable or they're a tool for promoting the interests of the child. So, that would be one way of thinking about why the interests of other family members matter at all. But another way of thinking about it would be to say well hold on, there's not really this sharp divide between the interests involved and this is again I think really clear if you think about the alignment of interests between a sick child and the parents. The child has an interest in getting better and the parents have a serious interest, one of their own interests in their child getting better. So, there's not a sharp divide between the parents' interest and the child's interests. And so you might have this thought that in serving the child, we are also at the very same time, serving the parents' interests. I think there is really something to that. So, I think most parents have as one of their fundamental interests, that their child does well. So, you might think we're not ignoring the interests of the family members when we attend to the child, we're actually taking them into account because they are already kind of built in as it were.

The third model, which I call the family interest model says well, in addition to whatever interests the patient might have and the parents might have, and the other siblings might have; there's a set of family interests. And these interests can't just be reduced to the interests of the individual members. And so you might think that in addition to asking what's good for the child and maybe what's good for the siblings, what's good for the parents; you need to ask this question. What's good for the family? What will serve the family's interests?

And then third, there is what I call the direct model. And the thought here is just that the patient has interests, the parents also have interests, certainly those interests can align in many, many cases; but I don't think that they always align. I think that doing what's good for one member of a family, can cut against the interests of other members of the family and so according to this model; you just need to acknowledge that there are people in the family whose interests might not be served if we do this rather than that. And suggest that we take that into consideration. It doesn't say how much we should take them into consideration but to say they are there and so; sacrifices are on the table for someone in the family and that matters. That should be part of the calculation in deciding what to do.

Host: And none of these models say who should be deciding which model is appropriate, right? There are considerations that whose ever in charge ought to take into account.

Daniel: Yeah. I mean so I think the question is right, which one seems like a good way of thinking about the place of family interests. And my own view is that definitely the oxygen mask model is highly relevant. I mean I think it's really good advice to say as a caretaker you want to take care of yourself so that you can be a more effective caretaker. That seems like an important thing to think about. And I

think it's really true to think seriously about the fact that parental interests and children's interests can sort of can be very difficult to disentangle those two so that you are serving parents' interests and serving a child's interests. And I think it's also right that in some cases parental interests or sibling interests can be harmed or not served by acting in the best interest of the patient. I think all of that is right and all that needs to be considered.

The one that I'm most skeptical of is the family interest model. I personally have more of a hard time understanding what it would mean for the family to have interests that are different from the interests of the individual family members. But one way you might think about that is a family might have fealty to certain ideals, certain goals, certain commitments that matter to them, that they are respected or promoted. That isn't a matter then of serving the individual interests of family members. So, yeah, I think they probably all have a place.

Host: So, you start the paper with a case and the case goes sort of like this. You imagine a 10 year old who has a serious brain tumor and he can get treatment in his hometown or there's a treatment that's maybe better available at a center that's 500 miles away. And you ask the question, do the parents have the obligation to go get the treatment that might be better even though it would impose a terrible burden on the family? They have two other children. Now certainly it would be permissible is the family says yeah, we want to do this to pack up their family and travel 500 miles. Nobody would say they're bad people. But the tension comes up if they say nope, that's just too great a burden. That's too disruptive of our family life. We're going to take the treatment that might not be quite as good, might not be the best thing for our 10 year old with the brain tumor because other interests matter. Would there be a difference in your four models about how that decision should be made?

Daniel: Yeah, that's a really good question. I mean I think it's true that you could tell a story using any of the models that could get you to the conclusion that actually it's permissible to stay where you are, right? So, the oxygen mask model you could tell the story that it appears like it's in the patient's best interest to go these 500 miles but actually if you think about the long term impacts on the family and maybe their ability to keep working and to provide – do they have access to support services and the like; maybe it's actually not in the best interest to so thoroughly dislocate – it's not in the best interest of the patient to so thoroughly dislocate the family. And so I think you could use – I don't think any of the models will very clearly point one way or the other. And so, depending on your frame of mind, you might be like well, what's the – why are we making great hay then of these four models given that any of them could be used to sort of generate any answer.

And I have some sympathy with that. But I'm a philosophy professor and so one thing that we like to do is kind of figure out what's going on under the hood. So, it's not enough for us that like a car drives, two cars might perform the same when you are watching them from the road, but we want to know well what's – like what's driving them. What's in fact generating the conclusions that we are arriving at. So, I think there's theoretical interests to try and figure out what kind of story we would tell to explain why, and I'm incline to think that it would be permissible to decide not to move away.

Host: Yup. And I can imagine cases where the models would lead you in different directions. Imagine a pregnant woman whose fetus is in distress and the only recommended treatment is a C-section; she might be sacrificing her own interests, not putting on her oxygen mask for the sake of the baby but maybe also for the sake of the family and the ideals of what a family member should do for another

family member. That is, be willing to take some risks for great benefit.

Daniel: That's right. I guess what I would say there is I actually don't think that's inconsistent with the oxygen mask model, because the oxygen mask model says you should attend to your own interests if doing so will serve the interests of the patient. And in this case, it looks like it wouldn't so it would be the equivalent of normally you should put your mask on first, but if there's a case where if you or your kid gets a mask, there's one mask. Let's say there's only one mask comes down. Put it on your kid. And the oxygen mask model doesn't say otherwise. It just says if it would in fact be in the interests of the patient for you to attend to your own interests first then you should do that. So, even there, it's not clear to me that it points in a different direction.

I think one thing it does do is – I mean this may be something that you can talk about. I'm not a medical doctor. And I have not spent a huge amount of time in hospitals, certainly not compared to you. But it seems like there's a kind of pressure given the dominant narrative that we should act in the patient's best interests that if we're going to accommodate the fact that this would be a – have a really profound impact on family members; that the story of why that matters is going to have to go through why in fact it's best for the patient if we attend to those family interests. And I guess I feel like that that leads people to maybe contort themselves into explaining how family members' interests matter instead of I think the more honest route is saying like look, the mere fact that someone is a patient doesn't mean that no one else in the family matters. I think this is like especially clear if you're dealing with siblings.

And outside of a medical context I think we are all super comfortable with this idea that it might be best for me to send – it might be best for my child if they go to this extremely select school in another city, let's say, maybe that's really best for them. But look, I've got three other kids and it would be absurd to ignore their interests. I don't see what it is about the medical context that would change that. So, I think there's something – yeah go ahead.

Host: It almost seems like you're suggesting that a family should be a utilitarian universe where the goal is not to prioritize any one individual but to maximize overall wellbeing or happiness.

Daniel: I don't think I would say that. I do think I think this. That like interests should be treated alike. And in a case of like of someone who is very, very sick; it's usually true that that person has interests that are not – no one else has interests quite like that. So, we're comparing an interest in maybe basic health or survival against an interest let's say in not changing schools if we're talking about a sibling who has to move. You'd say well, look that's a significant interest, but it's not nearly as serious as an interest in surviving. But I think that's consistent with thinking that we should treat like interests alike.

I don't think the task then is just to maximize interest satisfaction. So, I do think – well what do I think? I'm not exactly sure what I would say at this point. Except I'm willing to not say it's about maximizing interests satisfaction. I think there's sort of some maybe basic goods, maybe some basic rights that take priority over certain other interests and it doesn't matter how much you aggregate those other interests, they'll never outweigh some of these more basic fundamental goods that are at stake.

Host: And maybe it's in situations where the need is particularly great that is a life threatening illness where if resources aren't provided, if people don't make sacrifices, a child is going to die. That people

say, that's when the interests of the sickest child should take precedence over most other considerations. Maybe not all.

Daniel: That's right and I'm super sympathetic with that. I think what I want to highlight is that there's a difference between saying the patient's interests are the only thing that matter and saying the patient's in this case are so weighty or so significant that the interests of the other people involved; it's not that they don't matter, but they don't matter enough to change what we ought to do in this case.

Host: So, towards the end of the paper, you suggest that parents may be too willing to ignore their own interests in order to do what's best for their children. Do you think that's true?

Daniel: Well, I don't know if it's true in a medical context and we are dealing with a child who is extremely ill, and issues of life and death are on the line or basic functioning or the possibility of flourishing. Because in that case, I am inclined to think, especially as a parent, - so a qualification to my claim that like interests should be treated alike. I actually think that's not true when it comes to parents and kids. So, I think parents' interests should be discounted in relation to their children's interests. Because I think that's just in the nature of parental obligations. So, if a child and the parent have the same interests, the parents in my view counts for less than their child's but when it comes to your –

Host: That's the one oxygen mask.

Daniel: That's right. Yeah, exactly, that's the one oxygen mask. That's right. If there's multiple children, then I think like interests should be treated alike. So, in the case of like an acutely ill child; I don't think parents are too willing to sacrifice their own interests. Here's what I think. I think it should be acceptable for parents to think for themselves but also to vocalize the fact that in doing what they are almost certainly going to do by way to help their child; they themselves are sacrificing something. Even if they have a profound – which they do – a profound interest in their child living and flourishing, nonetheless, I think it needs to be acceptable for them to acknowledge like look this is a significant sacrifice for me. I'm giving up this other thing that really, really matters to me. And I'm in some sense totally happy to do it and willing to do it and I would do anything else; but let's at least note that there's something on the other side of the ledger. I think that's important because I think parents are people too.

I think outside of the medical context, I think it actually is true that we live in a culture where parents are encouraged to subjugate their own interests with respect to their kids, I think to maybe too great an extent and I think that's often very gendered. So, I think it's when mothers and women – I think – there's this picture of the ideal like mother saint who doesn't care for herself at all, acceptance so far as she's able to serve her children. And it's seen as unseemly for someone to say like look this might not be great, it might not be best for my kids, but this is what I need and not so I can take better care of my kids, but this is what I need, I'm also a person in this relationship. And so I do think there's like a cultural narrative that's worth pushing against that says parents have interests, they don't always align with their kids and we should acknowledge that.

Host: I think that does sometimes come up in the clinical context where we will see parents who are driving themselves insane, they're exhausted, and they just need to go home and get a good night's sleep. And we need to give them permission to do that.

Daniel: Right and that's like a really nice example where you could very easily say and the reason you need to go home and get sleep is so that you can come back tomorrow and be a better parent for your kid and that's true but I think it's also worth acknowledging you, yourself continue to be a person with dignity and this is good for you and we don't need to say anything else. Go home. Do this thing for you.

Host: Well this is a great paper. And I know it's gotten a lot of attention. I've seen it widely quoted and widely cited so for our listeners the paper is called Four Models of Family Interests, came out in the Journal Pediatrics in October of 2014. The author, our guest today is Professor Daniel Groll from Carlton College in Minnesota. He's a philosopher and a bioethicist whose pushing boundaries and challenging some conventional wisdom in pediatric bioethics. And thanks for listening. I'm John Lantos, host of the Pediatric Ethics Podcast that comes to your from the Children's Mercy Hospital Bioethics Center in Kansas City, Missouri. Dan, thanks for being with us.

Daniel: Thanks so much for having me. This was a lot of fun.

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