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From Crisis to Connection: Matching Families with Home Nursing Support in Complex Care

In this Complex Care Journal Club podcast episode, Ms. Kathryn Knight and Dr. Brian Jordan discuss a national survey of families of children with medical complexity on access to home health nursing. They describe the impact of the nursing shortage on families, a nonprofit resource to facilitate connections between families and home nursing, and next steps from this work.

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Emily Goodwin 00:04

Hello and welcome to the Complex Care Journal Club Podcast. My name is Emily Goodwin. I'm a pediatrician in complex care at the Beacon Program at Children's Mercy Kansas City, 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 am delighted to have both Ms. Kathryn Knight and Dr. Brian Jordan joining me today. Ms. Knight is a medical mom and the co-founder and executive director of the 501 c3 national nonprofit, Hello Nurze. Dr. Brian Jordan is an Associate Professor of Pediatrics at Oregon Health and Science University and a neonatologist at Doernbecher Hospital and board member of Hello Nurze. They are the lead and senior authors of the article, The Impact of Lack of Access to Home Health Nursing on Families of Children with Medical Complexity in the United States, published online in the July/August issue of Home Health Care Now. Thank you so much for being here.

Brian Jordan 01:00

Thanks for inviting us. It's a pleasure to be here.

Kathryn Knight 01:03

Thank you for having us.

Emily Goodwin 01:05

We'd like to ask you to share a little bit about your study, starting with the gap you identified and your research aims?

Brian Jordan 01:12

When we started this project, it was in part to try to figure out where we would put the limited resources of Hello Nurze. One of the things we discovered was that, while there was a lot of research done on the pediatric nursing shortage side of things, focused on the workforce supply side, we saw that there was very little out there on the demand side. What families navigating life at home with children with medical complexity, what they're actually navigating. Even when home health care has been prescribed and approved, there just wasn't much information on what the family experience was like. So we set out to do a study to try to fill that knowledge gap and get more than just anecdotal stories. So we surveyed families across the United States. There were 242 responses from across the country, from families across the continuum of care. Some of their respondents to our study were currently inpatient, some had been recently discharged, and some were, like years and years into their home health care journey. It was a really sobering experience to get the results back on this study. What we found was a really shocking difference in what families experience after they go home. We found that one in three families of kids with medical complexity, are going home without any home health nursing care at all. I'm talking about kids here who have tracheostomies, home ventilators, G tubes, supplemental oxygen, very intensive healthcare needs. And our study showed that one in three families were going home and doing it completely by themselves, with no home health nursing. We did find a small fortunate few, about 14% of families, had the full complement of nursing care that they were trying to secure, but it was a lot of families going home without enough support.

Kathryn Knight 03:32

Something that I definitely want to highlight is the importance of having that broad national reach. It was so essential for the research that we did. Because, as Dr. Jordan has alluded to, you know, pediatric home health is administered so differently across states. Medicaid and insurance reimbursement rates vary drastically. Access to

nursing care itself is deeply affected by geography and so many other factors that are out of control of these families. And as Dr. Jordan noted, you know, just because a family has approved coverage does not necessarily mean that that's the coverage that they're going to receive. Our research showed us that nearly 87% of families said that they had nursing coverage approved by insurance, and as Dr Jordan noted, only 14% had all of their hours filled. 29% had zero nursing hours covered, despite the approval, and 38% of families said that their child's hospital discharge was actually delayed specifically due to a lack of nursing.

Brian Jordan 04:23

As a clinician, you know, particularly as an ICU physician, I really didn't understand the gap between, you know, care that I knew was needed, care that I prescribed for home and understanding that it was covered by insurance. In my mind, those two things were like, okay, this is going to be handled. It's sort of like, you know, I'm sending out a prescription, I expect the pharmacy will fill it. But in this case, that was not at all what was going on. And this was a major blind spot, at least for me, and I think other ICU pediatricians out there probably can relate to this. What we do in inpatient care is great. It's well resourced, but what we prescribe is not necessarily what is all happening out there. And when that gap in care exists, it is completely upon the shoulders of the families to cover that that difference. And so if one in three families is going home without any home health nursing support that I thought they were getting, it is just a massive difference in what the family's experience is going to be, and also what I thought, you know, their ongoing care would look like.

Kathryn Knight 05:34

And I think to add on, Dr. Jordan, it's so important to understand the trickle down impact on families as a result of that lack of coverage. So within our survey, you know, it was reported that 88% of families had to make major employment changes due to unmet nursing coverage. And I think really notably especially for myself, since this impacted me, those changes were not shared equally between parents. It affected mothers more than it affected fathers, and 42% of families reported losing over \$50,000 in annual income as a result of the employment changes caused by unfilled nursing. So it is so much more than just these kids don't have the necessary medical care that they're being prescribed. These families, as Dr. Jordan mentioned, are carrying the weight of that, and it's impacting all aspects of their life.

Emily Goodwin 06:34

Yeah, this certainly spoke to me as a outpatient pediatrician of children with medical complexity. Families are often telling me we have approved nursing hours, but we don't have a nurse to fill all of those hours, and the child still needs the care. So how do families fill that gap?

Kathryn Knight 06:54

I am kind of well versed in this space. I am a medical mom. I had my daughter at 27 weeks. She spent the first nine months of her life in the hospital, came home trach vent, G tube, oxygen dependent. And we were given the opportunity to finally bring her home at nine months old because she was medically ready to be there, or keep her in the hospital until we found nursing care. We were literally one of the families that we have surveyed. We decided to take our daughter home. Nine months in the hospital is a really long time. We also have an older kiddo, and we really wanted our family to be together. But as a result of the unfilled nursing hours, the massive nursing shortage that's impacting families like mine, my husband and I were literally sleeping in shifts. Like we've said before, the families are carrying the burden of the care that the system cannot deliver. You know, we would change at 2am my husband would go in the room and be with my daughter, suctioning, doing emergency trach changes, providing G Tube feeds, ensuring that the oxygen is secured appropriately. This is something that is an unbelievable amount of work, and really very high medical acuity, and unfortunately as a parent, you have a child, and you don't actually expect to be responsible for this level of care. I don't have a medical background. My hospital luckily discharged us with really great training, but families are literally filling the shoes of nurses who go to nursing school for years, years to do the work that that families are doing, a lot of times without any kind of compensation for the coverage that they're, care they're giving.

Emily Goodwin 08:56

Ms. Knight, you pointed out, taking shifts with your husband, the impacts are far reaching, not just with foregone family employment, but also sleep. And we don't ask our physicians and caretakers in the hospital to work non-stop without a break, they have shifts right? And so what you're really highlighting is there's significant impacts of the home health nursing shortage, on families that even with all the training they're doing this care and work, but they need that support. And how do we help them find that support that the children need and deserve to stay at home and in their community? So I wondered if you could talk a little bit more about the Hello Nurze platform?

Kathryn Knight 09:40

Hello Nurze's founding program, the Connection Hub, is a free digital platform designed to make finding nursing care easier for medically complex families throughout the United States. The Hub doesn't replace third-party nursing agencies; instead, it empowers families and nurses by serving as a first step—bringing greater transparency and expanded search reach to the matching process, and helps to ensure a better fit for everyone. We are a very small nonprofit, and we often approach projects in kind of a scrappy manner. But I think the reason that we decided to go the digital and social media route is because, as a medical mom, my own experience showed us that that's where these families were. There is such an incredible community of medically complex families that find each other within Facebook groups or on Instagram or, you know, other platforms. And they're there because this is such a unique life to live, and they're able to find each other, connect, support one another, provide advice, celebrate the small wins in a way that only another medically complex family can really, truly understand. And so we wanted to make sure that we were reaching families where they already lived, where they were already sharing this advice, where they were already frankly, like complaining about the nursing shortage. It just, it was a very seamless place for us to reach out to them and say, hey we want your voice. We want to hear what you have to say. Because we are looking to actually fully assess what's happening in this landscape and utilize the data that we're going to gather to help drive change.

Brian Jordan 11:43

The other thing I would add is that, we had some open ended questions. There were common themes, but one of them that really stuck with me was how grateful the families were to even be asked, to even be reached out to for the purpose of research and trying to understand what their lives are like, so that, if for no other reason, more people understand what they're going through. Obviously, solutions are better than just awareness, but even just awareness, I feel like was a goal for a lot of families, just "thanks for seeing us" kind of thing.

Emily Goodwin 12:15

Yeah that speaks to the tremendous need, and I am grateful to both of you for amplifying the voices of those people and bringing this forward, to bring attention to it. I wonder if you could talk about what do you think are the implications for clinical practice? What do you recommend for members of the interprofessional care team for children with medical complexity based on your findings?

Brian Jordan 12:38

Yeah, thanks for that question. One of the biggest implications of all of this, the findings of the study are how much variation there was in the relationship between identifying a child who has medical complexity, who needs home health nursing, but the different rules about what that means about the timing of discharge. So it's kind of, in my mind, it's a little bit of a double edged sword here. On the one side of things, I really want to make sure that all of the home health nursing needs are met. On the other hand, if we make that a demand, you know, and we delay discharge, that's bad. The flip side is we can send kids home early, when they're ready, get them out of the hospital, get them out of this environment, but it is often in an under-resourced situation. So this finding that we have in a study about delay and discharge kind of points to both problems, both that there's inadequate care, and also that the solution to that causes, you know, longer stays, neither of which is a great situation.

Kathryn Knight 13:38

But that's really where Hello Nurze tries to step in as a nonprofit. We are not replacing agencies or clinical teams, but what we're trying to do is create tools to fill in the missing supports within that system that Dr. Jordan just explained. For instance, we've created our connection hub on HelloNurze.com and it allows families and nurses to connect directly with one another. My daughter's pulmonologist likes to call it the eHarmony for medically complex families and nurses. It helps to expand the nursing search reach for families, it adds transparency for nurses, which helps with nurse-family fit. It even allows nurses who actually aren't even in the home health field yet to see what being in the home health field might look like for them. Families are also empowered to share more information, not only details about say, like clinical needs schedule, but it actually allows them to share the really important things and showcase details about their kid. Showcase their personality, sharing pictures, enabling potential nurses to see that that child is so much more than just a medical diagnosis or a case number, which from where we live in the Hello Nurze world, really helps encourage more nurses to consider pediatric home health because it is such a potentially scary place to be for a nurse. You're the only medical team member in the home. But what we've tried to do is add transparency that says, you know, if a nurse isn't here, obviously the families are the ones that are caring for these kids. And the families can share how hands-on they are within these profiles, can share that they are fully trained by their hospital to provide the necessary care and make those nurses feel comfortable being the "only medical team member", but they have this incredible support of the families who, again, in a lot of cases, are really well trained.

Emily Goodwin 15:53

I wonder if you could elaborate, what do you think the messages are for patients and families from this work?

Brian Jordan 16:01

One of the main messages is, we see you. Early on in our work, Kathryn pointed out to me that she really viewed this problem that their family faced as a hidden crisis, because nobody else knew about it. Nobody else who didn't have the same, you know, life experience, other families that they met in the NICU, or other families that they met, you know, online through these support groups. That is a main message, but that doesn't actually help anyone. That's good, that we that we see that, that we see you and we hear you, and they hear these stories. But it is that advocacy and research in this space is the way to move the needle on this. So, you know, right now, the system is very variable across the country, and every state does things differently, and every hospital does things differently. There is some work being done to standardize that. So one, for example, Dr. Chris Baker, who's a pulmonologist at Children's Colorado. He, through his affiliation with the American Thoracic Society, has put guidelines forth, national guidelines for standardizing of the transition of care for kids with tracheostomies and home ventilators from inpatient to a training process and going home. And while I'm talking about that, just for anyone out there who's listening this, in my mind, is a model that really could be the national standard, the one that they have adopted at Children's Colorado. Kathryn can speak to this because she actually went, went through it. But they've got a system for kids who have trachs and ventilators who are heading home, of 27 individual steps.

Kathryn Knight 17:37

It's a roadmap.

Brian Jordan 17:37

And then this is something that every family has to go through before they can achieve, you know, the further readiness for going home. Now this is to say nothing of home health nursing, but this is just family readiness, and that includes things like hands on simulations for parents and actually, you know, for the pediatricians out there, their sims that they're doing there, it basically looks exactly like NRP [Neonatal Resuscitation Program] or PALS [Pediatric Advanced Life Support] recertification. You know, they get a scenario, something's going sideways with your kid, and then they have to jump in and intervene. And then afterwards, you know, it's filmed, there's a debrief. And when you go through something that rigorous, families really feel confident in providing the care

that's needed. Again, we're talking about families providing this care, rather than home health nurses providing this care. But in the current system as it exists, this is a really nice, elegant solution to this problem, and in my mind, it could be adopted as a national standard. I can say that at my hospital, we are trying to do that right now.

Kathryn Knight 18:39

And I think it's so important until there isn't a nursing shortage, and until every family can go home with the full amount of nursing hours covered, that families are trained the same way that Children's Colorado is training myself and other families, because all of the responsibility is falling on these parents, and it makes a huge difference when you are going home for the very first time, having that confidence when you have your first, you know, medical emergency, because they happen. Having the SIM lab, having all of those steps of training, is literally life or death for these kids and for these families.

Emily Goodwin 19:26

I certainly agree that it's so important to have families feeling confident and comfortable in the skills that we're asking them to do, especially in the context of the home health nursing shortage. You've talked about a few things, but I wonder if there's other important next steps from this work, or lessons learned to share with other researchers in this field?

Kathryn Knight 19:46

You know, Dr. Jordan mentioned the nursing pipeline side of things. And through our research and an additional survey that we actually executed at Hello Nurze, our Nurse Pulse survey, we found that only 18% of nurses reported ever learning about pediatric home health in school. That is a huge missed opportunity for nurses who could potentially help this incredible high acuity pediatric population at home, and because it's not being talked about, it's really no wonder that there's a nursing shortage. Nurses don't even know that the opportunity exists. That statistic actually led us at Hello Nurze to work on a brand new program called the FACES project, and FACES stands for Families Advocating for Care, Education and Support. It's a short form video-based curriculum that we're putting together that can be utilized by nursing schools to introduce nursing students to real medically complex families and open up the doors of consideration for the world of pediatric home health. We need to include pediatric home health in more nursing school curricula and medical schools.

Emily Goodwin 21:03

I would love to learn more about that, or feel free to share more information about that curriculum, or how our listeners may learn more about it.

Brian Jordan 21:10

That aim is trying to introduce the idea to more nurses, to get more nurses in the available pool of folks who could be providing home health care to address this gap. So that's that is one important aspect of things that we can do. But one of the reasons that there aren't enough home health nurses is lack of awareness, but another is the fact that the compensation for home health nursing is not adequate. That is not compensated to the same level as folks providing basically the same care in a hospital setting. And that's a, you know, that needs a policy solution. So there are, you know, there are a few areas like that where more money needs to be allocated to these kinds of things, at the national level and at the state level, to really encourage people to come into the workforce by offering them the compensation that they deserve for the care. A handful of states will compensate families for providing this kind of care. There are some differences at how this goes state by state. So we are at Hello Nurze, are trying to characterize these differences to provide families a resource for how they can approach this. And again, in my mind, this is a little bit of a double edged sword. I think families should be compensated for providing this kind of care. We're talking about providing ICU level care in your home, 24/7 in shifts with your spouse and these things. In my opinion, that should be compensated so long as compensating families for this doesn't become the model of care. I think they should be compensated for that, but that is to deal with the current

problem, not the long term solution, which really involves public policy changes, more nurses, better compensation for nurses, that kind of thing.

Emily Goodwin 23:03

Well, clearly, there's a lot of future directions and advocacy that folks can learn from your work and continue to build upon this. Is there anything else that you would like to share that I didn't ask you about today?

Kathryn Knight 23:17

So the FACES project is a brand new program that Hello Nurze is working on, a direct result from our understanding that only 18% of nursing students learn about pediatric home health care while they were in school. And like I mentioned before, it's a project where we share real stories of medically complex families in video, short form video format, with nursing schools so that they can easily incorporate it into their curriculum. We know that by introducing home health nursing, pediatric home health nursing, to nursing students, it is kind of a long term play of, you know, increasing the amount of nurses who consider this part of the healthcare field.

Brian Jordan 24:09

And if anybody out there is interested, if hearing us talk about Hello Nurze, and the solutions is trying to provide is it gets you excited, please feel free to reach out to us and join we're always looking for additional excited people who can put their energies into trying to help us solve this problem. We're looking for people at all levels. If you're interested in doing research in this area, if you're interested in joining the board of Hello Nurze, please reach out to us.

Kathryn Knight 24:35

We're a tiny team doing big things.

Brian Jordan 24:39

To summarize the things that we have been talking about today, there's a huge problem out there of families who have children with medical complexity and the inadequacy of home health nursing. We've talked about a lot of, you know, figures and things, but in our study, one in five folks face delays in their discharge of longer than a month. And we talked about the reasons why, but either way, they're stuck in the hospital for a long time. And one in three families, when they were going home didn't have any home health nursing support at all. These are really big numbers, and when those things are happening, it's families that pick up the slack. We talked about how sometimes they're compensated for that, but often not. And it doesn't have to be this way. So you know, if we can get more home health nurses, if we can get more support for them, if we can get inpatient teams to, to not look at the discharge process as a wrap up, as an ending for their care, but rather as an important transition, and really get the inpatient teams to understand the implications of the care that they're asking families to do, I think those would all be really important steps in moving this forward, and taking this from a hidden crisis to at least one that everybody can see.

Emily Goodwin 25:52

Well thank you both so much for your time, and thank you to you and your team for advancing the field of complex care. Thank you for listening to the Complex Care Journal Club podcast. We aim to highlight research that has the potential to be practice-changing, values patient and family engagement, and 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 on the OPENPediatrics YouTube channel. Thank you for joining us.

Journal Club Article

Knight K, Knight G, Jordan BK. The Impact of the Lack of Access to Home Health Nursing on Families of Children with Medical Complexity in the United States. Home Healthc Now. 2025 Jul-Aug 01;43(4):213-220. doi: 10.1097/NHH.0000000000001356. Epub 2025 Jul 7. PMID: 40619624.

Other References

Baker CD, Martin S, Thrasher J, Moore HM, Baker J, Abman SH, Gien J. A Standardized Discharge Process Decreases Length of Stay for Ventilator-Dependent Children. Pediatrics. 2016 Apr;137(4):e20150637. doi: 10.1542/peds.2015-0637. Epub 2016 Mar 10. PMID: 26966133; PMCID: PMC4811306.

Foster CC, Agrawal RK, Davis MM. Home Health Care For Children With Medical Complexity: Workforce Gaps, Policy, And Future Directions. Health Aff (Millwood). 2019 Jun;38(6):987-993. doi: 10.1377/hlthaff.2018.05531. PMID: 31158008.

Hello Nurze. Connecting families and in-home nurses. Accessed August 27, 2025.
<https://www.hellonurze.com>

Hello Nurze. The F.A.C.E.S. Project. Accessed September 5, 2025.
<https://www.hellonurze.com/p/faces-project>

Moore PE, Boyer D, O'Connor MG, Baker CD, Rettig JS, Sterni L, Halbower A, Wilson KC, Thomson CC. Pediatric Chronic Home Invasive Ventilation. Ann Am Thorac Soc. 2016 Jul;13(7):1170-2. doi: 10.1513/AnnalsATS.201603-196CME. PMID: 27388405; PMCID: PMC5462000.