Dr. Lynn McPherson:

This is Dr. Lynn McPherson, and welcome to Palliative Care Chat, the podcast series brought to you by the online master of science, PhD and graduate certificate program in palliative care at the University of Maryland. I am delighted to welcome you to our podcast series titled, Founders, Leaders, and Futurists In Palliative Care, a series I have recorded with Connie Dahlin to support coursework and the PhD in Palliative Care offered by the University of Maryland Baltimore.

Dr. Lynn McPherson:

This is Dr. Lynn McPherson. I am the program director of graduate studies in palliative care at the University of Maryland Baltimore, including our Graduate Certificate Master of Science, and our brand spanking new Doctor of Philosophy PhD in Palliative Care. And I'm very excited to be with my colleague Connie Dahlin, who will be introducing our guest speaker today, who works in a field that makes me tachycardic when we have a need for someone like her. So Connie, take it away.

Connie Dahlin:

Hello everyone. Again, Connie Dahlin here, part of the faculty for the PhD program. And I am so honored to be introducing Dr. Pamela Hinds, who has really been a leader in nursing and a leader in pediatric palliative care. She's right now, the executive director of the department of nursing science, professional practice and quality, at the children's national health system in Washington, DC. But she's been involved in palliative care for a long time, was involved in the Institute of Medicine, Dying In America report. She's represented hospice and palliative nurses across the way, in addition to distinguish research.

Connie Dahlin:

So Dr. Hinds, we are so excited to have you and to give us the importance of this pediatric perspective, which pediatric I hope you will define for us what you think the ages are, because we know there's perinatal, neonatal, children, adolescents, young adults, depending on where you work. So just sort of talking to us about your thoughts about what's important and what you think some of the trends are, and just where you think sort of this interface, even between adult and pediatric care can kind of merge.

Dr. Pamela Hinds:

Well, thank you so much for this opportunity to reflect with both of you. I am so excited about this program that you were creating, and actually very grateful for the attention that you giving to pediatrics. The fact that you are giving this attention to pediatrics, already helps to place in perspective the historic advantage that we are now finding ourselves in with pediatrics. Even though pediatric palliative care is centuries old, it really did not come into its own federally state-wise and even locally, until our current decades. So I really am very grateful for your attention.

Dr. Pamela Hinds:

I'm going to go back to your important mention of the IOM report, Connie, and I'm going to really speak to the significance of this report. At the time, I was at a research institute, and it was very heavily dependent upon public donations. And cure was clearly the message that we were giving at that time. And rightfully so, as that was the mission of that institution. When I was asked by the Institute of Medicine to represent pediatrics and nursing on this first report, I went immediately to my hospital leadership to explain it that I felt I should say yes, but I also felt that this would be an embarrassment to my institution, because we did not have a formal palliative care program. My leadership needed to give thoughtful consideration of that request and decided it was important enough to risk public embarrassment. And so there began my relationship then with the Institute of Medicine, now, of course the National Institutes, National Association of the Sciences and Engineering and Medicine.

Dr. Pamela Hinds:

That report, which came out in 2003 was a landmark. In essence, what we learned in was course the sorrow and suffering that aligns with children who have a fatal or life-threatening illness and who are unlikely to survive. We had however, very little data for that report in terms of empirically-based. We had experientially based data. We had important historic work that had been done by a real pioneer, Dr. Ida Martinson, who actually created one of the first home studies in America, where nurses would have beepers 24 hours a day, to be on call for families who chose to take their child home, when it was quite clear that the child would not live much longer. And her findings were persuasive about the comfort that this program gave, the likelihood of parents using it. And there began then a research initiative for all of us across many disciplines.

Dr. Pamela Hinds:

To continue that story about coming from a research institution, I then came back from the IoM experience, and began very carefully planning for a palliative care initiative in our facility. And to do that, I, each year brought forward the offer to our leadership, to conduct a culture analysis, to see where we should do certain strategies to promote palliative care in pediatrics, and where we might want to be careful. And for seven years, we later wrote about this experience and labeled it, the Zigzag Experience of Creating Palliative Care Programming In a Hospital Setting. I was told by leadership, "Not this year, why don't you do a little more of this and a little more of that, so you can hear the zigzag." And in particular, knowing the culture of my setting, I knew I needed to get independent funding for palliative care research. And indeed we did.

Dr. Pamela Hinds:

And the more we did that, the more persuasive it became, and more in alignment with our institutional values and goals. And one night I got a phone call saying, "All right, tomorrow have on my desk, your business proposal for this program." I said, "Absolutely." And did. And as good luck would have it, our CEO made an appointment to meet with me about this culture analysis and the business plan. A bit of an anecdote on that day, I was welcoming 60 new employees. And in my enthusiasm in describing the benefit of research for children with a life-threatening illness, my skirt fell off to the ground. And as it so happened, that was the evening that I was to meet with the CEO, to ask him to champion pediatric palliative care in our cure-directed facility. And I went of course, to his office for this evening appointment. And I said to his stalwart assistant, "Mary, how has his day been?" And she went, "Oh," and turned away and could not even look upon me. And I thought, "Oh my goodness." So as I walked into his office, he said, "You'd best closed the door." And I sat down and he said, "Today of all days, it's been a horrible day. And you're asking me for all this money to start a palliative care program. Are you sure that you want to go through with this?"

Dr. Pamela Hinds:

I said, "Indeed, I do." And he said, "I've read all your documents." And then at this very sober somber man, began to fight a smile. And of course I said, "Art, what is this?" And he said, "I heard about the skirt." And I thought, "Oh no, I've lost all my negotiating edge". But in fact, he said to me, "I'm going to champion this with a board." And he did. And I would like you to believe, of course, that the culture analysis, the business plan were the persuasive elements, they were helpful. But he was also experiencing his own palliative care needs with a very ill family member. And I think sometimes circumstances help us to bring forward the fact that children do suffer, children do die. And if they do, everyone around them does too.

Dr. Pamela Hinds:

So that IOM report had a profound effect on funding for pediatric palliative care research. And it was funding that we needed and the NIH stepped forward with good courage, and in particular, the National Institute of Nursing Research was designated to be the point place for funding for this kind of research. And there began a whole new decade of a focus on children's symptoms, measurement, interventions, management, and how to bring research into clinical care of suffering children.

Dr. Pamela Hinds:

And we adopted, in response to your important question about age, the NIH definition, which at that time was zero, birth, to age 21. As you know, that definition has been expanded by other associations up to the age of 36. So it's a very wide age then, at this point in time, and that's attributed to now children who would have died at birth or very young, are surviving and they're surviving into adulthood. They are not necessarily surviving fully cured or without troubling functional impairments, but they are surviving. And we in pediatrics feel responsible for following them, and doing all that we can to make their lives as positive as possible.

Dr. Pamela Hinds:

So then the second report that came out from the IOM, Dying In America, was a blend of adult and pediatric palliative care experts. And again, I had the privilege of serving on that panel. And as often happens with pediatrics, I was told you can write a small piece that will be called other, and the rest of the texts will be about adults. And I said, "Do you know at one time that might've been very fitting because we, at that time, did not have much data, but this is different now. We have data. We know about children's symptoms, functional impact, suffering, and I can write something for every chapter." And indeed, those of us who represented pediatrics on that panel, in particular, Dr. Phil Pizo and me, wrote something for every chapter. And that became another landmark indicating how far pediatric palliative care had come. And as you know, we now have a third of working group. It's a round table, also sponsored by the national academies. And pediatrics is very actively involved in that particular round table. And we are producing regularly workshop summaries in paperback form, documents that I think will be very helpful for your students, your learners, for sure.

Dr. Pamela Hinds:

So where are we going then with pediatric palliative care? And where is the interface between adult and pediatric care? What we recognize in pediatrics is that children continue to suffer and they continue to die. And we recognize that increasingly children are dying in their home settings. So it used to be at one time that in the high nineties, the percentages than was for children dying in the hospital. And that has decreased every decade for the past three decades. And it's now much more likely that 60 to 62% of children are dying in the hospital many times after the stay in a critical care unit, and only then has palliative care begun. But then at least then a much higher percentage of children who were dying in the home. And this is where the interface begins between pediatrics and adult care.

Dr. Pamela Hinds:

It's very hard to find prepared pediatric healthcare providers in hospice settings, even though it feels in our specialty that far too many children suffer, far too many children die, it is still the rarity. And so it's more likely then that the greater numbers are in adults who are suffering and dying. And therefore, understandably hospices are geared to that patient population and their families are still geared towards taking care of the ill child, the ill child's family and the ill child's home care providers, professionally and family. That means we're developing curriculum to offer to what are typically the providers of adult healthcare, to prepare for providing care for children. And in particular, I'd like to mention people like Dr. Debbie LaFond, Dr. Deb Fischer, Dr. Kathy Perko who have created home curriculum to help prepare the adult provider to take care of the very ill child, as well as the ill child's family and their adult home-based professional caregivers.

Dr. Pamela Hinds:

We have taken full advantage of tele-health in this regard. So the curriculum is often offered by tele-health. But now when families indicate they would prefer to take their child home from the hospital, we are doing an official handoff so that we can still be present to an extent for the child who's going home, who knows us. And this work has been published by Dr. Meagan Weaver, and she's done a terrific job of documenting what happens when you do that handoff from the hospital-based pediatric team to the adult based provider, family and the child. And in her work, she's been able to document that the children are delighted that they're not forgotten by the hospital-based team. So here we are on the screen in their homes, and they think this is pretty terrific.

Dr. Pamela Hinds:

What we think is also pretty terrific is that we are no longer just talking to one family caregiver who's at the hospital. We are talking to sometimes a room full of people who are taking care of this child. So it's the family that lives with the child, it's the extended family who's going to be involved in the care, it's the neighbors. And they are all very eager to learn what they can do, but they shouldn't do. And then there are the home hospice providers, the home visiting nurse, et cetera, in the room who are learning from us as well. It's an incredibly positive experience to be able to do what we consider to be somewhat of a handoff, doing it live and doing it more than once. And that's what telehealth is allowing us to do in that interface. So the interface now has a formal curriculum, and also has a pediatric presence in the room during care. And that has seemed to be a very comfortable place that we have achieved at this point in time.

Dr. Pamela Hinds:

Now, let me be sure I stop there so you can ask me questions.

Connie Dahlin:

Well, I think that's been lovely of sort of thinking about that because I think, Dr. Hinds the interesting part for me of recognition and sort of this highlight, as you know, I edited the NCP guidelines, and we're very deliberate starting in 2009 to kind of start adding that pediatric content, and it moving from the hospital now to kind of the community, I also think about the interesting part that I've been having this discussion, at least within nursing and sort of in medicine is that, the care that we approach is really the same. We in adults have a lot to learn from pediatrics in this family centered care, because pediatrics has done it so well. I think the challenge that I've been sort of saying is, so we think about the assessment process, it's the same. But then how do we apply it? Because I think in pediatrics, when we think about applying it to children, that's a special population. Applying it to geriatrics as a special population.

Connie Dahlin:

And it's been interesting, these discussions that I've had of saying, oh, but we're different. I'm like, "Well, but we're all healthcare providers. So we're all coming from the same learning part." And so sometimes I think that there's a lot of work of us trying to show our commonalities instead of always highlighting our differences. And I'd just be curious what some of your thoughts are about if you agree with that or not, or if there's other ways we need to look at it and kind of keep moving things forward.

Dr. Pamela Hinds:

Well, I appreciate your words a lot, Connie. And I certainly can remember the effort that pediatrics gave to making the distinction between children and adults. Because at one time it didn't appear in care that we made much of a distinction; same rules, same approach, medicines not particularly tested for use in children, but based upon use in adults and so on. So there has been a concerted effort to say children have important differences, and therefore the government, product companies, the FDA, need to make special requirements to protect the wellbeing of ill children. And so we think that all of that effort gone into labeling, et cetera, was greatly needed. I think there are also advantages to working together across the age spectrum, across the diagnosis spectrum, across the illness spectrum.

Dr. Pamela Hinds:

What we now experience in pediatrics is for us remarkable in that the children quite sincerely who died within usually 48 hours of birth are living, and into adulthood in some instances. We need to be working together to treat together. I do think that there is much to be gained by that kind of collaborative approach. I would share that at this point there remains, and I recently did another presentation to really treasured colleagues at the FDA, about children's patient reported outcomes. And as you know, this work is built upon decades of instrumentation, where we have carefully assessed psychometric properties, carefully looked at how these instruments perform within active clinical settings. And at the end of the presentation, a very remarkable individual said, "But as you know, we really can't trust children to be able to tell us what they're experiencing."

Dr. Pamela Hinds:

So even though there's such strong evidence, such strong scientific foundation to dispute that, it is important for us to know that it's a belief out there still, and even amongst the most well-informed individuals in science. So we still need to anticipate that children will be treated differently, and how we might involve adults in their own care. Children are clear when they want to be involved and when they don't want to be involved. And they are quite able to tell us yes, no, and why. And so it's important to give them the opportunity to give us those responses, to guide our care, to be the best that we can be.

Connie Dahlin:

I'm sort of still thinking in of what you just said, that children can't be trusted. And yet I keep thinking there is very well, there's also sometimes such an honesty because they haven't been taught to kind of have this filter. And so, in fact, they're probably more honest than anybody, in different time periods. Certainly you can imagine adolescents what's going on or whatever. But that is just fascinating. As you think about the future, are there particular areas... I mean, it sounds like we still need to do some work about understanding children's decision-making almost. But are there other future areas that you think are going to be very important on the horizon?

Dr. Pamela Hinds:

I think coming to us on the horizon is a different way of analyzing symptom data and a different way of analysts and function data, so that we can literally much more quickly, much more succinctly know if this child is in a high suffering profile, a medium, or a low suffering profile, and treat accordingly. And that is going to propel our assessments and our interventions forward in a much more rapid manner, because it's going to be simplified and much more useful than giving a clinician scores. From four to 11 different instruments or items, we will be giving one score. And I'm pretty excited about that advance that is coming from research. And that will be with us very soon and readiness for trialing in clinical care.

Connie Dahlin:

Wonderful.

Dr. Pamela Hinds:

Yeah, I agree with you. I am so happy about that, Dr. Peterson, it's just a real advance for us. So that's definitely coming. Definitely coming now and in place already is inserting the child voice into cancer clinical trials. And in years past, that was a separate research study, not embedded. Now, under current cooperative group leadership, particularly the chair, Dr. Doug Hawkins, these are moving into embedded-ness, and that's a second real advance for the child voice during serious illness.

Connie Dahlin:

Lynn, do you want to ask the last question?

Dr. Lynn McPherson:

I do. In like one minute or less, what advice would you give our PhD students as they're moving forward into their new career? And most of them are not pediatric specialists. What advice would you give them?

Dr. Pamela Hinds:

I really believe in teams. And that means if the best care is given by a team, and I believe it is, then to be part of a team. And I believe if the best care was given by a team, the best science is done by a team, and it should be in kinship with each other. So that means looking for your partners who share your values, your ideas, respect what you bring to the table, and are all about supporting where you want to go with your own ideas and your own career, and where you can be a part of supporting the career and ideas of others. So team in many ways, is what I would recommend.

Dr. Lynn McPherson:

You're such a kind and gentle and obviously brilliant person. I want to kidnap you and make you come live in my house. There's a treat, right?

Dr. Pamela Hinds:

I'm glad Lynn did that false impression.

Dr. Lynn McPherson:

Thank you so much, Dr. Hinds. And Connie, thank you for being our lovely host today. And we look forward to hearing about more research from your institution. Thank you so much.

Dr. Pamela Hinds:

Happy to share in the future. Thank you for what you're leading.

Dr. Lynn McPherson:

Thank you.

Dr. Pamela Hinds:

Take good care now.

Dr. Lynn McPherson:

Yeah. I'd like to thank our guest today and Connie Dahlin, for the continuing journey in our podcast series titled, Founders, Leaders, and Futurists In Palliative Care. I'd also like to thank you for listening to the Palliative Care Chat podcast. This is Dr. Lynn McPherson, and this cut presentation is copyright 2021 University of Maryland. For more information on our completely online Master of Science, PhD, and Graduate Certificate program in palliative care, or for permission requests regarding this podcast, please visit graduate.UMaryland.edu/palliative. Thank you.