Pamela Hinds Oral History.
Biography
Dr. Pamela Hinds PhD, RN, FAAN, is the Executive Director of the Department of Nursing Science, Professional Practice, and Quality, and Professor of Pediatrics at the George Washington University. She is currently serving on the National Academies of Sciences, Engineering and Medicine (NASEM) Roundtable on Quality Care for People with Serious Illness and the NASEM Committee on Childhood Cancers and Disability. Her expansive research career has focused on the pediatric cancer experience and quality of life. Dr. Hinds has authored and edited over 400 journal articles and book chapters and continues to advance the field of pediatric palliative care.

Interview Abstract
Dr. Pamela Hinds begins by identifying some early experiences in her nursing career that led her towards a career in pediatric palliative care. She recalls some of the challenges of funding research and reframing some of the discipline’s stigma around child-death from “physician failure” to a patient and family-informed process of the bio-psycho-social changes that were happening to the child. Dr. Hinds goes on to describe some of the successes in pediatric palliative care being the cultivation of the multi-disciplinary then interdisciplinary team approach as well as the changes in the relationship between providers and families. Dr Hinds describes the on-going challenges in pediatric palliative care being credibility, funding, and policy, but she relays her excitement to continue to help develop this specialty into a vision of patient-first advocacy and patient choice.

Glossary of Acronyms

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Bryan Sisk: Today is April 19, 2019. I am Bryan Sisk, and I am in St. Louis, Missouri interviewing Dr. Pamela Hinds over the telephone for the Pediatric Palliative Care Oral History Project. Dr. Hinds is in Washington DC. Thank you, Dr. Hinds, for joining me today. To get started, could you just tell me when did your mind turn toward pediatric palliative care as a potential career focus?

Pamela Hinds: My first exposure was when I was a nursing student and I was working with a little boy who had leukemia. At that time, it was a fatal illness. This was in the 60s and 70s. It was a sobering experience for me as a very young woman, new to the profession, to be caring so much about a little one who was not going to survive. In particular one day, I had missed him. I'd been off the unit and away from patient care for a couple of days and when I came back it was very clear to me he had lost ground. He reached out to me wanting me to hold him and I stepped right into holding him, but the way I picked him up hurt him.

The thought that I could cause a child pain, oh, was really horrendous for me. That made me think about dedicating time and effort towards relieving pain and other symptoms that a child might have when so, so ill. That got me started and at that time the philosophy was that you really needed to have experience in palliative care, and so I did begin. I had time in an emergency room, nursing time in critical care and then my graduate program I wanted to focus on how to create an environment of care that would be gentle for children. Then went on to my doctoral study some years later, many years later, because I really wanted to look at hope and how it was that we as clinicians, particularly nurses, might be able to foster hope in children and adolescents who were quite, quite ill. That's how I got started.

Bryan Sisk: When you were starting out, did you find a community of similar minds on the subject?

Pamela Hinds: No, we really didn't. In fact, people often thought it was hard enough to be a clinician dealing with children who did not feel well, but quite hard to be with a child who might not get better. That was the sense that people had at the time was yeah, but this child might never get better. No, we didn't find many likeminded people, and I have to say it made me self-conscious about what I was choosing to do and what I was looking at. I had to really question myself about that.

Bryan Sisk: Did other people externally question you?
Pamela Hinds: Yes. Family members, friends, professionals all suggested it would be very likely more worthwhile if I focused my career on children who were going to recover, children who could become well again. I think people honestly felt protective of a young person in a new career that focusing on something so sad might turn the career in a direction that would be sad too. I think it was a protective effort based on the real belief that children did not get better.

Bryan Sisk: What was it like to be essentially alone in the early steps?

Pamela Hinds: I think as a young professional, I was doing multiple things at the same time that all were related to palliative care, but they were not as—now they would fit the definition of palliative care, but at that time palliative care was very much defined as end-of-life only. I'm sure that it would've looked to other people as if I was doing a blend of activities that were not necessarily moving in the same direction. Using today's definition, they would have all been seen as palliative care. We've just developed a broader definition these days.

Bryan Sisk: Along this journey, when did you first start to find others who cared about the same work and the same issues?

Pamela Hinds: I think it was in the 1980s and it was very exciting. That became more pronounced, most definitely in the late 1990s, and then we really had a widening circle. For me, I had been educated on the undergraduate and at the graduate level, to really believe in interprofessional care. For me, I honestly believed, still do, that the best care is given by a team of diverse disciplines and for me the best research is that way, then the best—sorry, the best care is that way then the best research should be that way as well. That helped me to really seek out interprofessional opportunities and colleagues. I really think that is the way to live. I think professionally it's so exciting to live that way.

Bryan Sisk: Who did you learn from or how did you learn when there weren't a lot of people doing this in the late 60s and early 70s?

Pamela Hinds: I think we learned from people in specialties where there was a high death rate. For me that was critical care. That was the emergency room and it was pediatric oncology. You sought colleagues and we had quite a discussion about taking care of the suffering child, taking care of yourself very quietly. How would we do that?
Then when I finished my doctoral studies in 1985 and then went to St. Jude Children's Research Hospital where I spent the next two decades and found a whole host of kindred spirits. That was part of the excellence of that time period and certainly of those individuals. I remember creating different studies and always having a translation piece to that: a piece that would go to the parents, the piece that would go to our children, and the piece that would go to clinicians. These were incredibly well received, but we also did experiential offerings and one was about the meaning of being a pediatric oncology specialist. One was about having hope in serious situations and one was about mistake making. I'd have to say those are examples.

We did grief workshops and other kinds of things, but I would honestly say to you probably the best attended was mistake making. I honestly believe that we all feel quite badly about making a mistake—I just think we're all very conscientious people. It's horrifying enough to make a mistake - period, but it's particularly horrifying if it's with a child whose life is ending soon. You want so badly to do well by that child, and it may be your last chance to do well by that child. I think that makes it incredibly more complicated frankly, yeah.

Speaking of St. Jude, or really any tertiary academic medical center, a lot of times parents are coming for a cure. St. Jude is the patron saint of lost causes or last chances. What was your experience coming into a situation where people might have viewed death as a failure as opposed to a natural end?

I think I experienced that commonly, even amongst individuals who were seasoned. I think it was very difficult for a number of my physician colleagues to see it as anything but a failure. Concerningly for me, they honestly thought that those of us around them thought that, too, about them. Truthfully, we never did. It was very hard to convince physician colleagues that no one saw them as having failed that child and I can remember having very direct, very honest conversation with senior physicians at St. Jude Children's Research Hospital about why we did not see it that way. How comforting that was for them because they honestly believed we must have thought less of them.

Have you seen that change over time or has that stayed the same?

I have seen that change over time, but I would say to you quite honestly, there are still physician colleagues who suffer from that, and I do mean suffer. Yeah. I know that when for example I had
done end-of-life studies, palliative care studies, most times we've had a three-step process confirming eligibility of the family before we ever approach the family. The first step is to check in with the attending to make sure that the family could at this point fully understand that this is a research study that I'm approaching them about, that they have the right to refuse and that it wouldn't be too emotionally burdensome for them. Almost always my physician colleagues have said, "Yes, you could approach this family. They would meet those criteria."

Also, almost always there would be a gentle smile and the physician would say, "I know you said you're only studying the family, but aren't you really studying me, how I do palliative care?" Truthfully Bryan, we've never done that. That's never been a part of our studies. I think that even when our physician colleagues don't say that they suffer from that, they likely do, or they may. I guess it's at least a risk. Yeah.

**Bryan Sisk:** Thinking back to when you were starting out, how do you think clinicians at that time understood a child suffering?

**Pamela Hinds:** In my early days of being a nurse, those were the days when you still had a written medical order that said, "Do not tell the child the diagnosis. If the child speaks of being worried, comfort the child and that things are going to get better." We were one of the earliest, probably, groups that benefitted from the research and done by Glaser, Strauss and Benoliel about awareness of dying.¹ These pioneers were DRs. Barney Glaser, Anselm Strauss, and Jeanne Quint Benoliel.

They studied settings where the patients knew that they were seriously ill, but they did not want it to be spoken of, because they worried that by speaking of their deteriorating condition, they would make their families uncomfortable, and they didn't want to do that. We then benefitted from this research finding in terms of having the honesty within ourselves and beginning, likely stumbling at first to have more honesty with our patients and families, at least when they asked us to do so. That was a real indication for us to do our best to communicate.

**Bryan Sisk:** In the *Awareness of Dying*, I've heard that book come up from a couple of people. Is that a book that you think broadly impacted pediatric palliative care?

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**Interviewer:**  *Bryan Sisk*  
**Interviewee:**  Pamela Hinds  

**Pamela Hinds:** You know it's interesting. It's a great question. I'm not sure that I know that it broadly affected care, but I know that it trickled down to my community hospital and then later my academic medical centers where I worked, because we did change care and care policies. I guess I can honestly say to you, I don’t know how broadly that affected care in that decade, but it certainly did affect the care settings that I practiced in.

**Bryan Sisk:** Do you think that the clinicians, when they were tending or not tending to the child suffering, do you think there was a focus on individual symptoms, or do you think there was a holistic view of suffering or do you think there is just agnosticism about all of it?

**Pamela Hinds:** I think that initially we really went after pain. I think we recognized that children were having pain. One of the early turning points for us was the work by Jo Eland and she was a real force. She was a nurse and she studied pain and believed that—in fact published in the area of the myths about pediatric pain. That helped to really turn things around, at least in nursing practice, but she really also worked closely with physician colleagues to say "children are having pain. It's unbearable and we are under treating them and you've got to change it." It became a real mantra in the 70s, "We've got to treat child pain."

That was coming from nurses and physicians and it did lead to new policies, changes in intrusive procedures, and then to the belief that pain was measurable. In the 1980s we started measuring pain by child reports and it became, I'm sure as you know, a standard and now is a JCHO [Joint Commission on Accreditation of Healthcare Organizations] standard, but if you're not measuring pain, you are not practicing—you don’t have a best practice. They can give you a formal recommendation that counts against you with surveys and in-between surveys. I think it's incredibly exciting to look back and see where we've come. At the time it seemed very slow, but definitely coming.

**Bryan Sisk:** When you were beginning your work, finishing nursing school and going through emergency department and ICUs [intensive care units], what were the biggest challenges for caring for these suffering children with these serious illnesses?

**Pamela Hinds:** We had so few tools to make it better. You had to witness the suffering because we could not give them relief. That meant, not only did you witness the child suffering; you witnessed the family suffering. You could do all that you had within you and there are many things that you can do to try to make a suffering child
comfortable. Certainly, pharmacologically was a primary effort, but we also tried to change, oh, my gosh, position, temperature, lighting, distraction, I mean everything we could think of from a non-pharmacologic stance to make a child comfortable or to get reprieve.

Oh, boy, inducing sleep was just such a relief for all of us because it was so awful to witness the suffering that you just couldn't quiet. It just didn't stop. I think there was a lot of urgency. You know, "It's got to be better," was really a mantra. "It's got to be better."

[00:18:05]

**Bryan Sisk:**

Obviously nurses are, at least today, are by the bedside much more frequently than physicians and I assume back several decades ago, physicians were probably less tied to computers that didn't exist and more with patients. But was there a difference between the awareness of the pain and suffering from the nurse's perspective and the doctor's perspective?

**Pamela Hinds:**

Yes, and I think it led to some tension, but some suffering was so overt, no one could miss it and we should always speak to any level of suffering. I feel that's part of what nursing contributes to a team through our presence and being able to give firsthand accounts of what we're seeing. Our other colleagues cannot be there. That's our job. And so we should be able to give detailed accounts of what we're seeing that's so believable, that we can make care better for that child. I think physicians and nurses will openly talk about and certainly we've documented that we are not always in synchrony.

I don't think that's unusual and I don't think there's anything abnormal or wrong with that. I think it's how a team should function in keeping each other informed enough so that ultimately we get very close to being at the same place at the same time. What teams will often report to me is that it is the nurse who gets to a certain awareness first. It may be because the parent has said something to the nurse. It may be because of observations, and it is the nurse then who will say, "Have we had the conversation with this family yet?"

It is the nurse who keeps bringing that very difficult point up, and physicians will explain to me that they are not ready at the same time that a nurse is, and they will say, "No, no, we still have other things – other treatments - that we are doing, and we really want to do these other things." I think that creates a tension and I've often wondered if that tension has a purpose. Instead of us ignoring it— because it's hard – and certainly it is hard to deal with the tension –
speaking to it as part of being a team. It's like a tension in a family, it's hard. But instead of trying to work around it, we should address it because maybe there are clues about that child's status that are embedded in that tension, quite frankly.

Bryan Sisk: Was there a hesitance of using opioids or stronger medications for pain in kids back when you were starting out?

Pamela Hinds: Definitely. There was a clear sense that we only had data from adults that we were taking a huge risk in dosing children with what was deemed to be an adult drug. There was always the fear that we would kill the child through the medication because it was an adult drug and we didn't really know pediatric dosing. We had such fears about that, and I mean all of us – not at all limited to a single discipline but a fear shared by all of us. That made it urgent to try to address some of the very overt suffering that we were witnessing, and the parent was witnessing, too. We did try dosing that was previously untried. With adults even we were using incredibly high doses.

Bryan Sisk: When did that start to change?

Pamela Hinds: I would say the mid-90s was when I recognized that we had really turned the corner. Before then it was anecdotally unique cases, but I think by the mid-90s we were routinely using certain drugs because we did not have the adverse effects that we had feared. We didn't always get efficacy to the extent that we had wished either, but we didn't have the adverse outcomes that we had feared.

Bryan Sisk: What was used for pain when there is concern about, I'm assuming, concern about morphine and things like that?

Pamela Hinds: There was a concern about morphine, and it was a pronounced concern, but we did use it. We used it in relatively small doses at that time. Yeah.

Bryan Sisk: It was mainly the dosing that was smaller?

Pamela Hinds: Very much so. Yeah. Of course, now we recognize that children can tolerate high doses. But we started out at miniscule doses. I think the disease, like leukemia was so aggressive because our treatments then were still being refined. We were making definite progress, protocol by protocol, but I think about the hesitancy that we had. We had such an aggressive form of disease and such overt pain, but we were really iteratively finding our way.
Bryan Sisk: Was there similar concern or hesitation with the toxic chemotherapies they were given?

Pamela Hinds: No. I think that's a really interesting question. We recognized that that was all protocol-driven in pediatric oncology. We felt like we had a roadmap and having a roadmap really makes a difference, I believe, in our thinking. What really pleases me is tracking what we thought we saw as side effects of these new drugs that we were using in chemotherapy. It led to really great discussions amongst all members of the team. We nurses would bring forward our information from infusions as we were the ones who were giving the infusions in the rooms and we had made the careful observations. It was a great collaboration between nursing and medicine. It was really terrific.

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Bryan Sisk: What about psychological and social needs? How were those viewed for the patients and the families back in let's say the early 70s?

Pamela Hinds: I think children were dying fairly quickly then, to be honest with you, and so we needed to have psychology involved at an earlier point than typically happened. That really did change with some of the work by Spinetta, about coping and the advantages of having a psychologist as a member of the care team. I would say by the 80s that was considered routine care. They really had to be embedded. At that time point children were surviving, and it was a very different prognostic situation.

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Bryan Sisk: In terms of the psychological and social, was that something that—did it seem like most doctors were on board and advocating for that or more so that most doctors allowed the nurses and psychologists to pursue that? What was your sense of their view about that?

Pamela Hinds: I really saw my physician colleagues welcoming that. I didn't—sometimes you would have another member of the team, like a nurse, make the suggestion, but I never saw—well, I rarely saw an attending refuse or say something that was negative. Very rarely.

[00:26:45]

Bryan Sisk: Then for these children, were they involved in their own care at that time?

Pamela Hinds: Yes. Now this varied. [laughs] Quite frankly, it varied. Increasingly children were asking us questions, the nurses around the bedside, and increasingly waiting until their parent left the room to have a discussion. Yes, I would say to you that children were getting very involved and it really thrilled us as nurses about
that. I think there was also a societal shift of recognizing the importance of the child’s voice. Children were being invited into other kinds of conversations too.

They were being recognized as more articulate and in research we were inviting children to rate symptoms, and to talk to us about their quality of life in the 1980s. If they could articulate about those topics, our reasoning was they could also articulate about end-of-life decision-making. A lot of that was really tied to our comfort in pursuing palliative and end-of-life research by seeking the child voice, became more possible because we had previously included them in symptom studies.

[00:28:21]

Bryan Sisk: Do you think that societal shift was around the 80s at the same time or when do you think that occurred?

Pamela Hinds: I do think it was around there. I do. I think the 80s and 90s were really quite significant family structure shifts and family inclusiveness and children had voices that they had not had before.

[00:28:46]

Bryan Sisk: When in your career did you understand that the things you were interested in were being called pediatric palliative care or pediatric—when did that phrasing and that kind of conceptualization of the things you were doing come to your mind?

Pamela Hinds: Boy, it's a good question. Do I know? [laughs] Certainly, in the 70s it was being used, but primarily for end of life. I went to St. Jude in ’85 and was very involved in palliative and end of life care from the beginning. But it was in the 2000s when I approached hospital leadership about creating a palliative care service and defined it using the academy's definition ‘from the point of diagnosis of a very serious or life threatening illness’. This was not the first time that someone had approached the hospital leadership about creating this kind of service, but I think our timing was better because we had done research in the area and that was the dominant culture there.

If you could get external funding for an area of science, must be it was worth doing! We had had some very good luck in getting that funding. Then I got appointed to the Institute of Medicine's committee on Children Dying in America and that really—and I had a very supportive physician colleague, Dr. Joe Mirro who was the chief medical officer at St. Jude and I will always credit him with having supported my participation in that committee work. I said to him, "You know, if I accept this invitation, I'm going to
have to indicate to them that we do not have a palliative care service." He said, "Oh, but do it anyhow." That experience plus others really helped us to create that service and to begin research in this area, and that included end-of-life decision-making from the child's perspective, including from the child that was dying. It was really very exciting; exciting days.

Bryan Sisk: In thinking back to end of life, another question I had about your earlier experiences, what was the presence of the clinical team members around the end of life? Were there people around or where they avoidant? Can you tell me a little more about that?

Pamela Hinds: I think initially it wasn't so much avoidance, it was trying to be thoughtful of the family. The assumption was that we should leave them as much to themselves as we could and many of these children, many, died in the hospital. This followed of course, Ida Martinson's groundbreaking work\(^2\) where she clearly taught us that children could die at home, that it was very acceptable to families, physicians and nurses involved in that model. Others since then, building on that work have taught us about the cost of that care. I would say initially it was probably just uncomfortableness, but primarily wanting to do what the families might want us to do. We often did that without asking the family. It was an assumption and it was only later that we really started asking, "What would you like? How can we best do this for you?" I think it took us a while to find our way. I think instead of talking about something, we primarily thought, "How would my family want this done?" We got very careful, truthful.

Bryan Sisk: Have you seen that change over time, or has it changed in some pockets and not in others?

Pamela Hinds: I think it's definitely changed. We talk much more openly with each other as a team and we will ask families, how would you like this to be? I think it's very different.

Bryan Sisk: As you were getting your experience in critical care and emergency medicine to try to get the skills you needed to do this career, what were the biggest challenges you faced as you tried to build this palliative care career?

Pamela Hinds: Credibility amongst other services, soothing fears that a palliative care service would step in and interfere with their relationship long established with a child in a family. I think we underestimate that

anxiety in our good colleagues. That continues to be a real anxiety. Are we going to sever, replace, someone who's really had a very important relationship with the family already? I think then for me additionally was the challenge of finding research funding for this kind of work because we knew that we didn't know what we needed to know and that we needed to do research to learn firsthand from these children and their parents and each other about what we could do.

I think professional courage is part of this story for all of us finding our way. Being confident that if in fact we erred, and you'll always hear us talk about not wanting to do harm. If we erred, that we had the skills and the relationship to correct what we might've done and start again.

[00:35:20]
Bryan Sisk: How do you think these developing palliative care teams, how do you think they were initially viewed by the pediatric patients themselves?

Pamela Hinds: With caution. I think they liked the people on the team, but it was another team. It was clear it was a different focused team. I think, and I mean that from the family perspective primarily, just cautious like, "What is this?" But I have seen stellar relationships evolve between a palliative care team and another specialty care team and between the palliative care team, the family, including all members. It has been an evolution and a lot of it is being able to self-describe what we do, answering to uneasiness to others, and being very mindful about what our presence does to the presence of others.

[00:36:30]
Bryan Sisk: You had mentioned research funding which is I guess for everyone is an ongoing challenge, but probably was a lot worse back then.

Pamela Hinds: [laughs] It was. There was no strong interest at NIH [National Institute of Health] initially in this kind of research. Our early funding was from oh, gosh, The Project on Death in America. Quite a name, and this philanthropist really did get several of us started, Joanne Hilden, Joanne Wolf and I were all funded through this mechanism. From there I went on to NIH for funding, but I credit that philanthropist in getting us all started.

[00:37:21]
Bryan Sisk: When did NIH start to develop an appetite for this type of research?

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Pamela Hinds: I guess it again depends upon how we define palliative care, because certainly there was pain research funded by NIH for decades. Very notably in the previous decade NIH took note of the importance of palliative care in the broadest sense and including end-of-life care and that they should be involved in funding research. The mandate went out for this kind of research to be funded. The home for that was of course the National Institute of Nursing Research and the office is there, but other institute can co-fund this kind of research. What's good about having an office within an institute is that funding mechanisms are coming forth as well visionary thinking and planning. They've had new ones this year, several in 2018, 2017, 2016, further back. It's really significant for us that the NIH has this office. Now it frustrates people because the overall funding of something that is overtly labeled "palliative" and "end-of-life research," is a very small percentage of the overall budget. That's factual. But if you look at the broader definition of palliative care, a fair amount more would be noted. It's not by any means anywhere near the amount of dollars being put into cure-oriented research, but it does have a foothold and it has very passionate and dedicated individuals who are leading that office.

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Bryan Sisk: From your perspective, what drove the development of pediatric palliative care as its own specialty?

Pamela Hinds: Need. I think there was clearly a need that was recognized, had its own body of knowledge and it had passionate and committed people who wanted to make that their career. I would say I think need was really the driving force.

Bryan Sisk: Who do you think was recognizing that need?

Pamela Hinds: Families initially, and so I think part of the reason that Jo Eland was so successful in the 70s, and Ida Martinson in the 70s and 80s, was that they aligned with parents, parents whose children had suffered and died. They were determined not to have this happen again. It isn't just those two individuals, but what was so significant of course was that they aligned so well with a care recipient or consumer. I would say I believe that when a health care professional aligns well with families, they're unbeatable. They're absolutely unbeatable. Both of them took these models internationally and that also influenced how far we could go with this work.

[00:40:55]
Then along that path, what do you think were the biggest challenges as it was developing into a specialty?

I would go back again to credibility and the fear of severing or interfering with relationships with others, building that body of knowledge. Publishing original research took a while. When we first did the Institute of Medicine's 2003 report, so we started that in 2001, there was very little research and we were citing what's considered classic and older work. A lot of that book was anecdotal, experiential report, national statistics on children, the causes of death, but not much research on symptom management and the actual dying.

Then fast forward to that 2015 report, as we were bringing in evidence, two of the leaders for that working committee said "You probably want to have a special section called "Other" and have all the pediatric data there." I said, "No, no, we are way beyond that. We have enough data now for every section to reflect pediatrics." That was a huge step forward for us to be able to say that. My hope is that we will have another report in another seven to ten years and it will be so substantial. It may be a freestanding pediatric report based on evidence.

Wow, that would be a dream.

It would be, yes. It really would be. You said something really significant today in our previous conversation about discourse, needing to have discourse. I would support you in that statement, but what I would say to you is what we know is that as palliative care specialists, we are not as skilled with public discourse as people such as a Sarah Palin, who really grabbed the public attention so thoroughly, so incorrectly, that the Affordable Care Act had to drop the sections related to hospice and palliative care. She did it by using that phrase, "death panel." She was absolutely wrong. It was declared the greatest lie of the year, but very effectively destroyed that part of the bill.

We in turn were not effective in countering her approach. We've got to learn to do that. We've got to have public discourse about dying, about suffering and we've got to be able to do it in a way

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that our voice can be heard above a politician's voice or any other person's voice that is frankly, blatantly incorrect and alarmist. We have not yet mastered that.

*Bryan Sisk:* I agree. That's a pervasive problem for really all of science.

*Pamela Hinds:* I would agree with you absolutely.

[B00:44:39]

*Bryan Sisk:* How much do you think the adult hospice and palliative movement affected the development of pediatric palliative care?

*Pamela Hinds:* Oh, I think we owe them a lot. *laughs* I'm very grateful to them. In fact, I often think that we ought not to try to distinguish ourselves too, too much and we always say a child's not a little adult. Of course, that's true, but I also think we can learn much from our adult follies and given that we have such a much-reduced population. We would possibility prevent ourselves from learning something if we didn't join forces with them in some ways. Better for us to really test what's different and what's the same in children adults than just a claim that there's no similarity, I think.

[B00:45:34]

*Bryan Sisk:* Were there any negative influences? I guess any problems or barriers that were created from the adult hospice movement on the development of pediatric palliative care.

*Pamela Hinds:* Really none that I know of, but I would say they were more advanced than we were. They had a head start and so we do have to compete funding wise when I think about NIH. Yeah, so it's fair I guess to say that there is that to be said. I've never sensed interference or competition.

[B00:46:17]

*Bryan Sisk:* When you look over your career, what do you think have been the biggest changes in the care that we provide for these suffering children?

*Pamela Hinds:* Oh, gosh. I'm thinking of it in several categories. We really do see it as family centered care and so all family members are much more intricately involved with the care than ever before, so that's a real advance. We really have advanced through technology with care intervention. I know I mentioned terminal sedation to you in a comment earlier today. That's clearly an act out of desperation, but it wasn't an option.

There was no such option to really go after what is eluding us, and I don't think that's the greatest example of technology, believe me, but there are repeated examples of where we now recognize and
intervene with symptoms broadly stated. It isn't just pain. We're going after something that we would've said decades ago was unimportant, that's fatigue. What can we do to help a child who's overwhelmingly experiencing fatigue and can no longer achieve developmental milestones? We think about that now and I don't think—I know we didn’t think about that years ago. We were not thinking like that.

I think the other category where we are very different is communication. No longer do we have those orders written, "Do not tell the diagnosis, do not speak." We know that we wouldn't do that. That we would be responsive and listen well and honor the child's voice, so I think it's quite different over the decades.

[00:48:19]

**Bryan Sisk:** You have a voluminous body of work, so how do you think your work contributed to these changes?

**Pamela Hinds:** Oh, now that I'm probably not going to be so good about. I really don't know. I'm not sure Bryan. It's a fair question, probably one that I don't reflect on because I think instead of how much we have left to do. I'm excited about all that we have left to do. We have quite a bit. It's good that you make us look backwards and I often say that here. We should look back because if we don't, we won't see how far we've come. Looking back sometimes gives you clarity on what you've got to do next. I guess I should think about that a little bit more than I have.

[00:49:15]

**Bryan Sisk:** What do you think, looking at the field where it sits now, what do you think are the biggest challenges that we face right now?

**Pamela Hinds:** I think credibility remains a challenge. Building the field both with knowledge and numbers is essential. Research funding you will always hear us say is so, so needed. It is, but I feel as a young field, we have more going for us than many other fields and part of that is the interprofessional approach. It's well-established in this specialty and there are older specialties where it is not, and I wish it could be because it makes such a difference.

[00:50:27]

**Bryan Sisk:** What do you think the field really needs to grow?

**Pamela Hinds:** I think technology will always remain a need for us. I think the work with communication is essential. I feel very good about the focus made on both. I think policy is gonna be essential for us and though not a ‘first thought’ for us, if we're going to have public discourse about what is needed, we've got to be better at public
discourse. That means being well prepped for it and seeking opportunities to engage the public in these kinds of discussions.

Bryan Sisk: What do you think are the strongest areas of the field currently?

Pamela Hinds: I do think collaboration across settings is very strong. I do think the relationship between the clinical investigators and the Office of End of Life Research is very strong and waiting to be built more. We have such champions there and they really just need our support in order to do that. I think I would go with policy as where I'm sure we've got more work to do.

Bryan Sisk: Lastly, I just want you to dream aloud for me. If budget and politics and Sarah Palin's, and all these other things were no obstacle, what would you want care for these children to look like in another ten years?

Pamela Hinds: I would want for these children to be able to choose the location of their care and that we could fully meet their choice. They know where they thrive, and there are some children who choose hospital care. I would like that to be a choice. I would like our care to be so present, so effective that our families will not feel alone. I would like our care to be so effective, for the time that we have them with us that they never forget that, that they know that we believe in them, that they were good parents, and that they did something really remarkable for that child.

Bryan Sisk: Beautiful. Well, that's the end of my questions. Is there anything else about this history that you wanna tell me about or you think that I might have missed over?

Pamela Hinds: You know, the only thing that I might mention is that along the way, different disciplines, including nursing, created position papers, standards of practice, scope of practice, all related to palliative and end of life. I think that's so excellent that the disciplines formalize their support in ways that are meant to guide practice. It's the official sanctioning and so I think that's important to note and some of those position papers were very much about managing pain and the ethics of intervention. Certainly, for nursing, we began those in the 2000s, early 2000s. I don't know the start date for similar kinds of things in medicine, but I think the American Academy of Pediatrics has something very similar as I go over their position statements. I think that's worth mentioning.

Bryan Sisk: Anything else?
Pamela Hinds: That's perfect and I so appreciate you going after this. Keep right on going Bryan. You're doing important work.

[End of Audio]