Biography
Dr. Sarah Friebert is the Director of the Pediatric Palliative Care Division at Akron Children’s Hospital, the Inaugural Chair Holder for the M.D. Leadership Chair in Pediatric Palliative Care at Akron Children’s Hospital, and Professor in the Department of Pediatrics at Northeast Ohio Medical University. Dr. Friebert developed one of the earliest programs in pediatric palliative care in the United States, and she has held many leadership positions over her career in the fields of pediatric palliative and pediatric hospice care. Also, she has made many important contributions to the literature on palliative care for neonates, infants, children, and adolescents. She serves on numerous boards, committees, and organizations locally and nationally. She has also published and coauthored over 50 journal article and texts and is an international presence on pediatric palliative and hospice care.

Interview Abstract
Dr. Sarah Friebert begins the interview by describing how she constructed her own academic path during her time as a hematology/oncology fellow and navigated barriers, including her mentor discouraging her and her work in palliative care during her time as a medical trainee.

Dr. Friebert then goes on to describe her early career experiences in hospice care and the positive results she had after reaching out to others in the palliative field for inspiration as she developed her own palliative care service model. She also expresses one of the early barriers to delivering palliative care services was a profession-wide focus on curative care, which was “potentially at the cost of quality of life and family wholeness.” Additionally, she noted the early disregard of palliative care as “glorified social work.” Other barriers she described were territoriality from other physicians, as well as the misconception that hospice and palliative care are the same entity.

Dr. Friebert concludes the interview by describing her vision for the future of pediatric palliative care, including the provision of choices of services for families, and a seamless continuum of care. She also hopes that pediatric palliative care will become more fully integrated into health care systems and that palliative services will be accessible both in cost and geographic reach.
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# Interview Roadmap

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Bryan Sisk: It is August 26, 2019. I am Bryan Sisk and I'm in St. Louis, Missouri interviewing Dr. Sarah Friebert over the telephone for the Pediatric Palliative Care Oral History Project. Dr. Friebert is in Akron, Ohio. Thank you Dr. Friebert for joining me today. To get us started, could you just tell me when your mind turned toward pediatric palliative care as a career focus?

Sarah Friebert: Well that's not a simple question. I actually came to it gradually throughout medical residency training by virtue of the experiences that I was having. At the time that I was going through training, there wasn't something called pediatric palliative care. So I didn't even know it was a career choice.

I have some personal experiences that led me to be interested in bettering care for people at end of life. Then during my residency training, I was exposed to a lot of very high technology, high acuity care and was very excited about that but was also dismayed to find what we were doing to families along the way. So, I began exploring a little bit and apprenticing myself with some of the early pioneers who were doing what at the time was called supportive care. And that's how I began to learn about the field.

As a career choice, it became clear to me during my pediatric hematology oncology training that I wanted a combination career in palliative medicine and in hematology/oncology.

Bryan Sisk: And you said there were some personal experiences. Were they any that you wanted to talk about?

Sarah Friebert: Not particularly.

Bryan Sisk: Okay. And you had also mentioned that you had mentors or people that were doing what was called supportive care. Who were some of those people that you were learning from?

Sarah Friebert: When I was at the Children's Hospital of Philadelphia doing my residency, Dr. Jean Belasco, who was a neuro-oncologist there, was doing a lot of actually clandestine supportive care, even home visits, with a nurse that she worked with, Pat Dann. She had started a kind of a children's home care program basically for children with brain tumors, primarily, but who were struggling with oncology issues at their homes. And Dr. Belasco would make home visits and would really coordinate their plans of care. And I spent some time with her in an "elective," which gave me a whole other view of what could be done in end of life care. That was really the earliest exposure I had to a clinician in my own field who was doing something like that.
Outside of Dr. Belasco, were there other people of a similar mind as you were coming into this awareness?

Not when I was in my residency training. There were not a lot people doing any of that sort of work, or people like me, until I was in fellowship and really began volunteering at a local hospice agency. Again, from my personal experience, I guess I'll just briefly say it had to do with my grandparents dying.

But when I started working there, I very quickly had my eyes open to this other area of care that I hadn't known much about prior to doing that. And I mostly did it to escape from the labwork I was being forced to do for my pediatric hematology/oncology fellowship training. I shouldn't say forced. It was more, that it was obviously a requirement of my fellowship, but it was not where my heart was. And when I started working in hospice, and putting together those early experiences, it really began to form for me a picture of, in fact, why I had gone to medical school, and what I was hoping to do in medicine as a career.

So, as you were volunteering in hospice and as you were getting these experiences around the end of life, what steps did you take to start to form that into a career because, like you were saying, there really wasn't a career path at that point?

I was working at the hospice initially as a volunteer and trying to learn all the different ways and all the positions and types of jobs that occurred at hospice. And about four months after I began working there in that capacity, the medical director of this large community hospice agency actually left; he resigned and left. There was an associate medical director there whom I also knew, obviously. So, it was her as the one paid physician, and me as a volunteer physician. After this happened, the leadership of the hospice came to me and said, "Hey, how would you like to work for us?" and I said, "Well, I'd love to work for you except I don't know what I'm doing and I also want to focus on pediatrics."

So, over the course of a relatively short period of time, we crafted this employment agreement wherein, I worked for them during the bulk of my last two years of peds heme/onc [Hematology/Oncology] fellowship as a paid employee, as an associate medical director. During that time I crafted my own fellowship, if you will, where I apprenticed myself to various people, both within the organization as well as outside, to gain some experiences. And I also worked on a pediatric program expansion and business plan and putting together a pediatric-specific hospice and palliative care team to begin serving pediatric programs around or serve our patients rather.
So, it was really a fellowship within a fellowship that I created myself out of an interest and also being on the ground there, working there, and feeling like I needed more training to understand what I was doing. So, seeing adult patients, obviously, but also peds patients. They didn't have a large pediatric census at the time, but my goal was to grow their peds program, which I did over the ensuing few years.

[00:05:56]

Bryan Sisk: So, as you were developing this fellowship within your fellowship, how did your heme/onc fellowship directors and divisions directors, how did they view all of this?

Sarah Friebert: Well, it was positive for them in the sense that—so normally the expectation at the time was that if you were in an academic fellowship like heme/onc you were supposed to essentially secure funding for yourself for years two and three of your fellowship. So, the expectation was you would get grant money, or you would get foundation money or something to fund your research project that would offset the cost of your fellowship training.

So, instead of doing that, I did work in the lab. I had actually, I did what I needed to do. I had a successful lab experience in the sense that I learned quite a bit in the lab. I don't want it to make it sound like it was, you know, something that I hated. I published a couple of papers as a fellow, which were the requirements for finishing my fellowship. I was fortunate to work in a very high-level productive lab. But at the same time, I was working in hospice kind of on my own time, but I rearranged for the hospice salary that I was receiving to be paid to the fellowship as my kind of income.

So, I was allowed to do that. However, the attitude toward it was not the most positive thing in the world. I think my fellowship director, who had been in a lab, expected me to have the academic career that she herself had not had – she hadn’t quite risen to the levels which, I think, she was hoping. I think she was hoping, she was looking to me to sort of live that dream out. So, she was discouraging of this and felt that I was wasting an opportunity.

And so it was a little difficult to navigate but because I was still meeting the expectations of the fellowship through the classic pathway, she really didn't have any ground to stand on. My other fellowship faculty mentors were fairly supportive of what I was doing.

When I finished, though, I had had a job lined up to work where I had been doing my fellowship, but that job was taken away from me at the last minute for a variety of reasons that I won't go into. I had every intention of having a combined career in palliative care and in pediatric
hematology/oncology. So I found positions that allowed me to do both of those half time. I said I won't talk about that.

But as I was leaving, my fellowship director's words to me were that I was throwing away my academic career and that she was sorry that she had wasted an academic fellowship slot on someone like me.


Yep. Yeah, you are laughing but it wasn't funny. It's devastating to have your fellowship director and your mentor say that to you, especially because she was one of the people, one of the reasons that I got into medicine in the first place was because of her, but that changed. Anyway, I made the best of it. [laughs]

Sarah Friebert: I essentially found a position where I could work. The places that were available to me geographically to work in heme/onc and close to my home were only interested in having a full-time hematology/oncology physician. They did not want a part time person. So, I found a position about two hours away and I worked there 10 days a month and then I would go home 20 days a month and continue to work in hospice. So, it was a split career for about a year and a half until the position became available at my current institution, at Akron Children's Hospital for hematology oncology. I interviewed here and moved the half of my practice that was heme/onc down here; and continued to work for the large hospice at the same time.

And after several months of doing that here, the administration and my oncology division director wanted to know more about what I was doing with the other half of my time. They said well, you know, is there any possibility that you'd want to do what you're doing up there, down here? So, that's when we began to talk about creating a program to deliver hospice and palliative care to patients out of Akron Children's. Then eventually I transitioned full-time to Akron Children's doing halftime palliative and halftime oncology.

Bryan Sisk: Have you maintained that half time or have you become full-time palliative care?

Sarah Friebert: Full-time palliative care. I gradually pared down over the ensuing 15 years. About four years ago, I stopped doing heme/onc entirely.

Bryan Sisk: Well as you were developing this program, this must have been the early 2000s?
Sarah Friebert: Yes.

Bryan Sisk: So, this was before it was a board certified specialty; there were only a very few programs in the U.S. like this. So how did you go about developing it?

Sarah Friebert: Well, when I was at the hospice agency and developing their pediatric program, I did a lot of research about program development and I contacted some of the early leaders in the field, not necessarily people that would have run programs, but who were doing field work in palliative medicine. I interviewed them and asked them a lot about what they were doing, and I got articles from them.

I'll never forget Kate Faulkner who was an early pioneer in pediatric palliative care. She still practices, although she does primarily adult palliative medicine now. But this was back in the days before the Internet, recall. So, I wrote her a letter and told her what I was doing and that I was really interested in the field. She sent me a huge box of xeroxed articles about home care, palliative care, and pediatric palliative care. It was probably, I don't know, 50 pounds worth of these journal articles and papers. It was just amazing that she took the time to do that.

So, I just sought people out and tried to connect with people of all sorts, not just people in the field but people who had started community-based programs, grassroots programs, and kind of learned on the ground. Then as I began to develop the program here, I worked closely with our home care agency here and some other folks who were doing similar community-based work though not necessarily in palliative care; and just tried to, again, learn as much as I could.

I went to early conferences from CAPC, the Center to Advance Palliative Care, NHPCO [National Hospice and Palliative Care Organization], and from other groups and just tried to steal/copy as much as I could and made it up as I went along.

Bryan Sisk: So, as you went through and you were working as administration at a hospice from fellowship on and then developing these new programs, how did you approach the business aspects of this? Because that's not something that a lot of physicians get training in.

Sarah Friebert: Well, CAPC helped with that, as I mentioned, the Center to Advance Palliative Care, and kind of gave me a little bit of business fundamentals. One of my early mentors, when I was at hospice and trying to create the program there, was a woman who essentially created a grassroots community-based program for families of patients with cancer. So, she
started this organization from the ground up and built this foundation. And I learned a lot from her. She shared her business plans with me and just sort of her thought process and how she went through this. So I learned a lot about that. I also really did spend time, especially when I came to Akron Children's, learning about the finances of healthcare in general and also, then, as I mentioned, through the professional organizations and their conferences; really did try to pay attention to that aspect of things.

So, it was a combination of learning from things that were not exactly like this, from home care to this other community organization, but then, also, within the organization from the folks that were "on the other side," meaning the business or finance side. And really taking it upon myself to realize that nobody knew, nobody was going to know what to make of this program unless I could advocate for it and I could make a case for it. And so I felt like it was part of my job, literally, to be able to understand the nuts and bolts of how to run a successful program.

You had mentioned that as you were working split time between Akron and the hospice, that at some point the leadership came to you and was interested in bringing your hospice skills and palliative care skills back to Akron. What do you think it was that kind of triggered their interest?

A couple of things. One, we have, we had, until very recently had a very progressive CEO [Chief Executive Officer] who was very community-oriented and was very connected with most of the major organizations in the community, even though we are a freestanding children's hospital—or maybe because we are a freestanding children's hospital, we have close relationships with the adult facilities in town and many of the other organizations. There was a robust program, the beginning of a robust program in hospice and palliative medicine at one of the adult hospitals here. And so, I think that began to inform what we could be doing over here.

Also, concomitantly, the year 2000 was the year that there was a community discussion about end of life care in response to the Robert Wood Johnson push for having these sorts of conversations in your community about ethical issues and end of life care. And so, as a result of that, one of the takeaways from meeting was that we needed community and hospital-based options for patients of all of ages to be able to get end of life care services.

So, Children's took that very seriously and they actually—the ethics committee, decided to create a policy on end of life care in response to that. And as part of that, I think they began to think about, "well how are we actually delivering end of life care?" Obviously, today, and even well
before today, palliative care does not equal end of life care, but that is where it started.

So, with all of those pieces and parts, they also, I think, saw in me somebody that was a young dynamic, if I can say so myself, but as someone with leadership potential—and I was told this—that they felt like my leadership energies and my vision about what could happen might as well be channeled for this organization [laughs] rather than kind of spreading it out in places where I wasn't devoting it to Akron Children's. I think they also wanted to sort of see what the possibilities were. So it was multi-factorial.

I also pushed a little. In addition to being pulled, I pushed a little to say, "Now, this is what we are doing up Cleveland," and I think this is true for any competitive market. There's a little bit of, "Well, if they are doing that, maybe we should be doing this," and wanting to keep up with the Joneses. So I played that to the best of the advantage of the local kids that I could.

Well thinking back around med school residency fellowship, what were the biggest challenges that you saw in the care for these kids that were suffering and dying from serious illnesses?

Well, yeah, part of the reason I came to this is that I had, and during my residency, a couple of really just very salient transformative experiences where I went through myself or saw a family go through things that I thought, 'there just has to be a better way.' There was just no—everything was about pushing for the frontier of medicine and saving lives and expanding cures and really kind of pushing the envelope. And that's all great. I mean I did my residency at the Children's Hospital of Philadelphia, it's a fantastic place. There's a lot of extremely cutting-edge stuff going on there, and we were always pushing the envelope.

But there was something lost in translation, and what that was, was just the price of constantly pushing for survival over, potentially at the cost of quality of life and family wholeness, and basically holistic attention to the people that were going through the journey. I saw that again and again, and I heard that again and again from patients and families. And it was disheartening to try to balance what we were doing to kids and not really feeling like we were doing a lot for them.

So, as I mentioned, as a resident there I was personally involved in or witnessed several situations that made it clear to me that there wasn't a lot of training for this type of care; there weren't a lot of systems in place to help, and people were very frustrated by that probably, and in some cases took their frustrations out on people who weren't able to really defend themselves. That sounds more nefarious than I mean it, but what I mean is
that sometimes when you are pushing for the finish line, you don't realize how you are leaving bodies on the side of the road as you go. I just kept thinking, "there has to be a better way, there has to be a better way." And I never—I wasn't critical of what was going on around me as much as just thinking, "you know there’s something missing here. What else can we be doing while we are doing all this really great, fantastic high-tech stuff?"

So, what I saw was an education deficit. I saw multiple barriers to just even getting people to think about the fact that there was something other than the cure, the cure, the cure, or the latest, greatest technology. And that patients, and families weren't really being given options or informed consent or a real true voice in their healthcare. And that bothered me. I'm not sure if that answered your question.

Bryan Sisk: Did you hear many people back at that time talking about or thinking about suffering and what suffering might have been?

Sarah Friebert: Not at all.

Bryan Sisk: Because this is around about the time Cassell\(^1\) started writing more and more about that.

Sarah Friebert: Not at all at our level, no. I mean I read his book very early on. There were probably a couple people, like I said, when Dr. Belasco and I would talk about it, it was almost like we were having a secret society-based meeting. [laughs] We could say these things out loud because it was almost anathema to consider that, "this might not be the best thing to do for people. Just because we have the technology doesn't mean we have to use it." But that was not the prevailing wisdom. And this is not an indictment of CHOP [Children's Hospital of Philadelphia] -- it was just how things were then.

I'm a big fan of that. I'm an oncologist for goodness sake. We have gotten where we've gotten in pediatric oncology because we've pushed really, really hard. But I think that pushing has come somewhat at the expense of some of the other domains of humanity that contribute to suffering. I wasn't hearing a lot about it at my level, that's for sure.

Bryan Sisk: So aside from the end of your fellowship where you told me about your mentor really tearing into your career decisions, what were some of the other big challenges you faced as you forged this new career?

Sarah Friebert: People not feeling that this was truly a medical discipline. I've had many people tell me along the way that, "You are just being a glorified social

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worker, why did you go to medical school," that this type of care, "this is not how we have ever done things before." I've heard that a lot as I've had to break down barriers and set up new service paradigms and bring things to light. I've heard, "Well, we've never done it this way before."

So, a lot of it was change management, changing attitudes of people, changing just the culture around even talking about the fact that not all things end in cure, and we have such an aversive relationship with death and dying in this country, which still persists. There were a lot of those very practical barriers.

There were also barriers around how do you structure this kind of care to bill to get it paid for. A lot of what we are doing in the fee for service environment is not reimbursed, costs a lot of money. What's the return on investment? How do you measure the impact that you are having? Just on and on and on, all those sorts of questions, that I still get, because this was not the latest, greatest, shiny MRI machine or a new cool cardiac surgery technology that we have to offer that's going to save lives and bring in money through the way that healthcare is currently reimbursed. So, a lot of reimbursement challenges, funding challenges. Just people feeling like this branch of medicine wasn't a real branch of medicine and, "all you want to do is take my patients away and tell me what a bad job I'm doing and step on my toes." There were a lot of fears about territoriality, about hidden agendas, about people feeling like they had already been doing this, so they didn't need any help, thank you very much. Just every barrier that you've ever read about palliative care I've encountered in spades. And just tried to serve systematically – like Chinese water torture, keep dripping, pushing my way through challenges by burying them one by one just by persistence, by showing up, by trying to be collegial and conciliatory and trying to push, but not push so hard that you break things along the way.

A lot of those barriers still exist. Some of them are better. Some of them are gone. There are some new ones. But whenever you build building something new—it was also very helpful to have, you know, there were emerging colleagues. There were other programs that started to crop up. We developed a little bit of a support network. I remember some of the earliest meetings with pediatric palliative care practitioners or people at meetings, and there would be three of us in a room, and now there's hundreds. And so, you gradually build that community, and you come to realize that you are not alone and there are other people going through this, and you use each other for support. And you—it began to create just a wave of change that builds on itself. It can be really, really exciting.

I think that one of the biggest blessings of this is to be able to come in at the beginning of something and witness, and even maybe be a part of architecting something that's a creation of a transformational way of
delivering healthcare that wasn't there before. Being part of that is really exciting. And you're going to get bumped and bruised along the way when you build something new, but the payoff is more than worth it.

**Bryan Sisk:** So from your perspective, what do you think was the spark that led to this eventual development of a new field of pediatric palliative care?

**Sarah Friebert:** Well some of it, I think, was what I've already said, though I might need to think about that answer a little bit more. But I think partly it was beginning to have informed consumers who began to ask more questions, as the pendulum began to swing away from paternalism in medicine where we just tell you what we are going to do; people started asking questions. I think, I don't know if it's a sociological phenomenon of the Baby Boomers who became more informed and asked more questions and were less likely to just take on surface value what anybody was telling them. Or if it was really a realization that the costs, both financial as well as otherwise, physical and emotional, were starting to just show up as bigger players in the healthcare agenda, and whether that started to inform people's consciousness about the price that we pay for the type of care that we provide.

I also think there's been way more of a shift in the country as a whole, well in the world, about sort of whole-person care in general; wellness and a lot more sort of attention to that domain in general, which in some ways, has filtered into heath care. Perhaps in some ways it's been driven by healthcare, but it's also filtered into all of the things that we do now in the self-help industry and the promotion of wellness. I think that has helped, and I think that we've also seen that as we've pushed back the envelope of death, in other words, we are extending people's lives, as Ira Byock said, "We've invented chronic illness." So, we are creating chronically ill people from patients who used to die. And these people are living longer with more and more complexities and more and more needs. I think we've realized that we are not capable of managing that. We haven't planned for it. We haven't staffed for it. We haven't figured out the right systems for it, and we are stuck with this growing population of people. While the death rate is going down, the population of people with chronic complex conditions is increasing. People are demanding more complete care, and we don't have the systems to deal with it. And I think that's contributed to the rise of the need for services that can really take the whole family into account and try to help plug those holes. That's the off-the-cuff answer to your question.

**Bryan Sisk:** So as these pediatric palliative care teams were cropping up across the country, we talked about this a little bit, but how were you guys viewed by the clinical teams that you were engaging with?
Sarah Friebert: Initially, with a lot of suspicion and territoriality and, "No thanks, we are doing that already," and "We don't need you," and "This isn't real medicine." Some people were earlier adopters and those people were very helpful in terms of bashing down some of the stereotypes around what palliative care was and wasn't. But there was a lot of suspicion and a lot of feeling that this was something that was going to showcase what other people weren't doing.

In other words, if you really look at what pediatric palliative care does and is, it's not something that is really was outside of the realm of a well-trained, well-intentioned physician, right? I cannot do brain surgery, but if I have sufficient—well I could if I had sufficient training—but I should be able to facilitate goal-directed decision making and manage basic symptoms of my patients and have conversations about what matters to them and facilitate coordinated care for them.

So, when you look at sort of the core tenets of what is involved in pediatric palliative care, a lot of people just looked at this and said, "Well, that's what I do. That's what being a doctor is. How is that special? Why is that a board certification? Why do you need a whole team of people to do that?" Carving out what's special about that has been more difficult, than I think, in some specialty fields where people recognized that they're never going be as good at heart care as the cardiologist, or as good at the brain as a neurologist. So, I think, that's contributed to it too.

Bryan Sisk: Another thing, looking through this history that I learned about is, there's palliative medicine and pediatric palliative medicine, as a specialty for physicians. Then there's palliative care in the hospice and the community. So as this medical profession was developing, was that readily welcomed into the broader hospice and palliative community or were there any divisions at the beginning of that?

Sarah Friebert: I think there's been division within the field between hospice and palliative care. I think that people that were staunch hospice early advocates felt and still feel that palliative care diluted the message of hospice and was a way of pushing under the rug what hospice was doing.

There's a saying that, "All hospice is palliative care, but not all palliative care is hospice." Hospice is a part of palliative care, it's a time-limited tail-end part, or however you want to describe it. I think people in the hospice world were, and some still are, threatened by this idea that there's this watered-down version that's really not very different from hospice. But it kind of dilutes the power and the impact of a true hospice interdisciplinary team model.
Yeah, there was division even within, you know, the National Hospice and Palliative Care Organization which used to be the National Hospice Organization. And when NHO [National Hospice Organization] became NHPCO, there were a lot of people that were not happy about that. And so that, I think, contributed. Because when you have people within, and people without that are highly critical, that can make it tough.

I know that the board certification fight was a tough one. Most people feel that this is a very valuable aspect of medicine that should be trained for and showcased as a specialty. But I think there was a lot of fear about the people that had been doing this for a long time. What did that mean for them? What does that mean for workforce if we are going to start making this into a board-certified medical specialty that undercuts the value of the whole interdisciplinary team?

Hospice was a nurse-led initiative initially. I think there was some suspicion that physicians wanted to come in and take this over and make it all about medicine, and it's not. It's about a team, and it's about good holistic interdisciplinary care. There's a risk if you make it too medical, that it could lose the power of all the other people on the team who are just as important.

So, I think there was a threat from that, and a threat from a lot of angles, and there still is to some degree. I mean, there are still some people that confuse hospice and palliative care, and some people that feel that palliative care just shouldn't exist. But, you know, there are always naysayers.

What about the patients and families themselves in pediatrics, how did they respond to these teams as they were developing?

Well, it depended, and it still does on who is messaging it and how it's being messaged. So I think we've had many, many, many families over the years that have said, "Well, who wouldn't want this kind of care?" once they found out what it meant. But a lot of people equate palliative care with hospice and they are afraid of it, and that's true at the provider level too.

I think there is a difference between the way pediatric palliative care and adult palliative care are focused and run. I think that distance is getting smaller. But I think for a long time, palliative care in the adult world really was just a little further upstream from hospice. So, whereas hospice would have been the six month prognosis and less, palliative care would be more like a year or less.
On our side of the fence, we have kids in our program who are here for a decade, right? So, there's not a tie to a prognosis, there's not a tie to a timeframe. But it takes a long time for the public not to think that way or not to see that when they look on the internet and look up palliative care, and get very defensive or blown away by what they think that means.

Many providers still think of it as giving up. If those providers are the ones introducing the concept to the families, the families are already going to get a jaded picture of what the service is about. I've had a lot of people—and there are a lot of programs in this country, as you know, that are not called palliative-care programs. They are called supportive care, they are called advanced care teams, and all those sorts of things, and that's partly for marketing reasons.

There are plenty of people out there who say, "Just don't call it palliative care, call it something else, and we'll call you." Well, to me that's just a moving target. Our job is to educate people as to what palliative care is and isn't, and not just change the name, because that's just a shell game. So, there's still a lot of public misperception, but it's getting better. I think just continuing to educate, educate, educate, and show folks that it's about a well-rounded holistic interdisciplinary care that addresses suffering, will eventually break down those last barriers.

Sarah Friebert: We successfully market our service as away from end of life, to focus on care coordination for children with medical complexity. And to really try to be that beacon of light for families so that they have one-stop shopping. So what was helpful to other teams or other specialties was, 'we are not going do what you do, but if the family reaches out to us, and we are available 24/7 and they call us at 3:00 in the morning, we can troubleshoot for them and get them to the right people and the right providers and make that process easier for families.'

So, when we started talking about that, we started talking about—this was also in the days before hospitalist medicine was as big as it is. So, kids would get admitted to the hospital on someone's different sub-specialty service week by week, depending on what was wrong with them. You know the same kid would come in, they'd be on neuro one week because it was a seizure issue, and the next week they'd come back and they'd be on a GI service, and then they'd come back and they'd be on the pulmonary service, and so on. There was no conversation or continuity and it was before the electronic health record. There was a lot of disjointed fragmented care, and that's what families started complaining about. So,
we marketed ourselves towards, 'we are going to be that care coordination group where we are going to listen to the family, we are going to carry their goals forward, we are going to help across transitions, and we are going to be the message people.' That was a big step toward people not seeing us as end of life, and that was very successful for us.

Another piece was really just family support. Yes, we do goals of care. Yes, we do pain management, but really family support when they are going through something horrible. PICU picks up the phone and calls us when a kid comes in who was previously healthy and has a near drowning, because they know we are going to support family. Whether that kid's going to do fine or not, we don't necessarily know initially, but we know their family's rocked and they need some continuity and some support.

Then we started working backwards and say, "Okay. Now you get us. Now you are calling us for everything. 'Well, you know, there's others who can help. " But once they let us in the door, then it was easier to start using our resources more appropriately once they got over the fear factor.

[00:39:14]

*Bryan Sisk:*

Another thing that I've picked up in my other conversations is an ongoing debate about who should be, in terms of patients, who should be included in palliative care? You had mentioned the idea of complex care, and I've heard a wide range of, 'it should be closer to end of life or serious life-threatening illnesses or life altering illnesses.' So how has that debate played out in the recent decades?

*Sarah Friebert:*

Well, I think it's still playing out. However, it is resource based. If you are in a place—for example, when I started the program here there, was not a medical complexity service. So many places have one of those where they have a complex care service or a medical complex children service, either inpatient or outpatient or both. If you have that, then maybe your palliative care service might look a little different because it's really about, what are the gaps in your system and what can palliative care help fill? That's not to say that the field should be defining itself by the environment it's in. In other words, we shouldn't be 90 different things to 90 different people.

But I think there is a huge overlap between medical complexity and palliative care. The way I see it is, if you look at sort of acuity as being a pyramid, a layered thing where its bottom biggest part of the pyramid is kids who are mostly well. Then there are kids with one chronic illness or two chronic illnesses, but they are not necessarily severe. They could have obesity and ADHD [Attention deficit hyperactivity disorder] or diabetes and hypertension or something like that. They are more complex, there's a million different definitions of complexity.
But what we are talking about is really the top of the pyramid, the kids with the most complexity, who are involved with the most specialists, who are medically fragile, who have the highest risk of dying or being seriously ill and having their lives significantly altered by medical technology. That's the group that you can call them "complex medical conditions." You can call them "extremely complex medical conditions." You can call them "life altering," "life threatening," life whatever you want. But it's really kind of, if you look at a spectrum and you think, where should we be deploying resources, like a scarce resource, like a pediatric palliative care team, you don't want them spread thin all across chronically ill kids. You want to focus them on the high utilizers and the kids the palliative care team has the biggest chance of impacting. So, it is very gray, and different places do it different ways.

I happen to believe that kids who have chronic complex medical conditions are medically fragile. They could die at any minute. They are far less likely to make it out of childhood. And those are the kids that need enhanced support. If you wait until someone that has a prognosis in months, or people think they are at end of life—first of all, we are terrible at that. We get it wrong all the time. Secondly, you miss the opportunity to get in with these families and work with them over months and years and get to know them. And really, if you want, any hope of bending the trajectory of their care, you need to be in with them. They need to trust you, and you need know them and you need to help them make the decisions that may not pay off next year in terms of what they do or don't do to their kid, but will eventually if you are hanging in there with them. So, if you wait till the last minute, it's too late.

All those conversations have occurred or not occurred, most likely not occurred, and people are making crisis-based decisions that are very expensive, that'll end up being out of line with what their goals would have been had they done it in the light of day when things were calm. So that requires time and hanging in there with them during ups and downs. So, yeah, maybe you discharge the patient. Maybe they are stable, and they do really well, and they can move on. But if you just are seeing the very end of life, you are missing tremendous opportunities to me.

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

**Sarah Friebert:** Well, I don't think we would have one without the other. I'm not sure I really understand that question.

**Bryan Sisk:** Meaning there's sparks in adult hospices and in palliative care movements from Cicely Saunders in the late-60s early-70s on, and then 20, 25 years later pediatric palliative care developed. Do you think that it was more of
creating a field in which it could grow, or did it, has it actively played a role in pediatric palliative care as it's developed over time?

*Sarah Friebert*: I think both. I think it's actively played a role in the sense the adult hospice folks are the first folks to start saying, "You know, we don't know what we're doing with younger kids. We need models and we need ways to care for the patients." I think there was a little bit of that that came from it, and certainly creating the space for a field and a way of thinking and words and payment structures and all that certainly laid the groundwork.

Do I think we might have gotten the pediatric palliative care without that? Yeah. But would it have taken a lot longer? Yeah. I think we would have gotten there eventually because of all the things I was talking about earlier about creating medical complexity and looking at kids. In pediatrics we are very focused on the family and we always have been. And pediatrics is really where the patient-centered medical home started, and those initiatives focused on more than just the disease in front of you. Would we have evolved with the model that was similar? Possibly. But the adult movement and the starting there gave us a framework—instead of building something new, we could remodel and adjust and tweak it to be more appropriate for our patient population.

[00:45:14]

*Bryan Sisk*: Were there any barriers that the presence of the adult hospice movement and all of what that entailed, did that prevent or create barriers for pediatric palliative care in anyway?

*Sarah Friebert*: Yeah, I think, yeah, the focus on death and dying and end of life, even though hospice will tell you that's not what they're about, they have a, I think, a harder road to hoe there with proving that. So that's a barrier. I think the barrier, although the Medicare hospice benefit was a fantastic thing, it's actually proven to be a barrier because it was what everything needed to fit into cost-wise for a very long time.

And that was the model for how this kind of care should go. And that's based on adult cancer patients who relapsed, and then they progressively get worse, and then they die within a prescribed period of time. It's not based on our population of kids who play until they die, who have very unpredictable courses, who are just all over the map. I think somehow, in some ways, that model getting literally institutionalized through Medicare and through the way the payment was based through Medicaid and even the private insurers, created a very specific template for how this kind of care should go, which has been difficult for us to break out of.

The whole six month prognosis came from that, for example, and we are still fighting that. So, as opposed to thinking about a model of care that extends across a child's lifespan, however long that is, we still have to
fight people thinking about 'there has to be a certain prognosis', or 'they have to have a do not resuscitate or an allow natural death order,' in order to qualify for these services. So, yes, I think there have been barriers introduced by that.

Bryan Sisk: Just a couple more questions. What do you think are the biggest challenges facing pediatric palliative care as a field right now?

Sarah Friebert: Money and workforce. We have to find a way to fund this sustainably. The models that we have now depend very heavily on—it's a perfect model for value-based care, and we are living in largely still a fee for service world. Most of the care that we provide is not reimbursed. We are very heavily dependent upon philanthropy and grants and other sources of income, and it really shouldn't be that way. It's emerging as standard of care for a certain population of kids, and it needs to be reimbursed the way that it is being delivered. I think that’s one of those challenges.

Then the other challenge is that as more and more of these kids that need more and more of these services and more programs are developing, we don't have enough people to do this work. That's true of hospice and palliative care across the spectrum, not just peds, but it's a workforce issue.

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

Sarah Friebert: I think that the community that we've created as a group of like-minded people trying to do something progressive and wonderful is a strength. I think the intellectual and socially responsible curiosity of most of the people who do this kind of work is a strength and can be parlayed into really solid evidence-based practice and sharing of knowledge and information. I think the fact that it fits perfectly with value-based care and aligns with the kind of care that most people would say they wanted if they could design how they wanted to be cared for. It's a strength if we can get to the point where that's how our system rewards or sustains things that are worthwhile. It's a strength and I think that a history of building this field over time carefully, not just kind of all of a sudden we have a thousand big box stores as everybody wants to compete with everybody else, but really being thoughtful about where the need is and what we need to do to develop these appropriate networks and services has been a strength.

Bryan Sisk: Then the last question is, I'd just love for you to dream aloud. If budget and politics and turf and all the other things we talked about weren't an obstacle, what would you ideally want care for these kids to look like in 10 years?
Sarah Friebert: Every child who has or needs palliative care needs to have access to a high quality, truly interdisciplinary team-based palliative care program that could join with the family at the time of diagnosis or before, and walk with that family for as long as takes and as long as the family needs our services. And that those services would be everything from every domain of suffering that a family could choose to take advantage of.

I mean, we call our service a palette of care for a reason. There's a palette of services that the family can have access to. And each of the colors on that palette represents a different discipline or a person or strength or skillset, and we allow families to pick what they want off that palette to create a picture of quality of life for their family. It's a corny analogy of the family painting their own picture, but that's, I think, what we want. At the same time, to guide them appropriately and help them make decisions that they can live with through the rest of their lives, and help kids live the very best life that they can. And so somehow, we have to spread the availability and the quality of these programs to encompass, not just kids that live near a freestanding children's hospital or near a major medical center, but children living out in the middle of nowhere with significant illness so they can have access to the same level of high-quality service.

Bryan Sisk: Absolutely. Those are all my questions. Is there any big gaping hole in the history we've talked about that I should really dig into in the future?

Sarah Friebert: I don't think so. I mean, I hope that you are—I don't know who you are talking for your project. I certainly hope it's a lot of leaders from a lot of the other disciplines, not just medicine, but people that have laid the groundwork in social work and psychology, and all the other fields that have contributed to this movement, child life, et cetera. Because I think everybody's got an equal share in this, whatever it is that we are doing. [laughs].

Bryan Sisk: I am, absolutely.

Sarah Friebert: But no, I mean, if I think of anything else, I'll let you know, but not off the top of my head.

Bryan Sisk: Okay. Well, thank you again for your time, I really appreciate it.

Sarah Friebert: You're welcome. Good luck with the project and I'm excited to hear of what happens.

[End of Audio]