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Stacy Remke Oral History.

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Biography
Ms. Stacy Remke, LICSW, is Senior Clinical Teaching Lecturer and pediatric palliative care social worker who has aided the development of palliative care best practices for over 40 years. In her career, Ms. Remke has had an international presence in developing pediatric palliative programming models. Additionally, she has contributed to developing educational and academic texts on children’s psychosocial pain experience, children’s medical fragility, palliative home care, interdisciplinary team models, and secondary provider trauma.

Interview Abstract
Ms. Stacy Remke begins the interview by describing her initial career path in social work around aging and how she came to develop her interest in care planning for pediatric end of life needs. Ms. Remke then describes her observation that both providers and parents would not have meaningful discussions about the realities and practicalities of children who were seriously ill or dying. She also noticed that providers were resistant to utilizing hospice services for seriously ill pediatric patients and that they expressed sentiments like ‘you’ll take care of my patients over my dead body.’

Ms. Remke then describes the early practices of communication and miscommunication around pediatric end of life. She also describes branding and attracting physician interest in her agency’s pediatric hospice programming as a constant task the agency struggled with initially. Ms. Remke recalls some of the successes and challenges of the early years she was working with her small multidisciplinary team, including defining how social work could work to compliment nurses and other providers.

Ms. Remke concludes the interview by describing her goal to see more children and families with the full spectrum of supportive care that they need. She also describes one of her favorite contributions to pediatric palliative care being her model of multidisciplinary health care planning, now the preferred model in palliative care programs. Finally, Ms. Remke suggests that the field could benefit from equally compensating services and increasing access to professional development resources for disciplines that provide a holistic experience, such as social work, chaplaincy, and child life specialists.
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<td>Cystic Fibrosis</td>
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<td>EPEC</td>
<td>Education in Palliative and End of life Care</td>
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<td>ICU</td>
<td>Intensive Care Unit</td>
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<td>MSW</td>
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<td>NHPCO</td>
<td>National Hospice and Palliative Care Organization</td>
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Today is December 10, 2019. I am Bryan Sisk and I am in St. Louis, Missouri interviewing Stacy Remke over the telephone for the Pediatric Palliative Care Oral History Project. Ms. Remke is in Minneapolis, Minnesota this morning. Thank you so much for joining me today. To get us started, could you just tell me when did your mind turn toward pediatric palliative care as a career?

Well, I think my backstory is that when I was in graduate school in the mid-80s; 1980s, early 1980s, I wound up taking what was kind of, a volunteer course that was actually like the dying role play of being a dying person. I did that because I had thought it sounded really great, and since I was in graduate school and I knew that I was not that scared of it I should probably explore it. And it was really, quite a transformative experience in terms of sensitizing these issues of death and dying in general. And when I reflect back on it that was really quite early in the evolution of hospice care in the United States which I didn't really appreciate at the time. Probably, I don't know within 10 years within the first evolution of hospice in the states.

Anyways, fast forward, graduated with my MSW [Master of Social Work] degree, worked for a while in aging and mental health, and then took a job at Children's Hospital And Clinics of Minnesota; that was part halftime in the hospital and half-time in the home care program which at that time focused on children who we're medically fragile, cared for in the home with a lot of high tech and extended hours of nursing needs. And that was a significant population that I worked with at that time. And then also our hospice program was housed in the home care department and it was started by a nurse Becky Bedore, who was the graduate assistant of Ida Martinson who did the first home based study that demonstrated in 70s, that you could take child home to die anywhere if you have one committed nurse to support the family.

And so Becky has been recruited to the Children's Hospital in the later 70s to start a hospice program there and met a lot of opposition, because as the lead oncologist said at the time is basically, "You'll take care of my patients over my dead body," and it tells you little bit about the attitudes that were prevalent at the time.
But anyways, the home care program took care of sometimes five to ten children a year who wanted to go home and die. As the social worker in that program, I took care of those children with my nurse colleagues and whoever their physician was. And then I think just because of the sensitivity that I had developed earlier as I was doing social work in the hospital, I just started seeing issues like why is no one talking about the fact that this child is dying, why isn't anybody bringing that up to the family so they can make choices, and things like that. And then because I had one foot in our hospice program and the home care, it was really quite an opportunity to follow families between the hospital and home, and back and forth overtime. I think that just helped crystalize my understanding of how valuable that is, that model of providing care oversight and over time. Then our hospice program in the 1990s—probably around 95-ish, got a small grant to sort of beef up the program and we were able to hire a nurse coordinator and also a chaplain part time. Our census grew at that time and that's when we hit 14 patients and got quite overwhelmed. [laughs] Which, I laugh at that now, but anyway at the time it was quite significant. But no, we encountered that issue as everyone does, that families are so—they spoke for their children, that they're not willing to define an endpoint. Like hospice care is a very hard sell in pediatrics. And we experimented with should we say children are eligible if they're likely to die inside five years or two years, and basically discovered that no time frame was acceptable to families. And I remember very vividly in 1999, one of my nurse colleagues said, "What we really need around here is the palliative care program," and I remember saying, "What's that?" and then from there we shifted our focus and that was much more successful.

[00:05:36]

Bryan Sisk:
How did you develop interest in caring for kids and not adults? How did that come about?

Stacy Remke:
You can say a lot of things, but I actually think it was destiny. I used to drive by Children's Hospital on my way to work at my old job and I thought, "I think the next time I see a job there I think I'll apply for it." In hindsight I think, it's just seeing how these things happened. I had a few friends who worked at Children's Hospital in the neonatal area. I think I was actually quite interested in the experience of children, the lives of children. Although I really didn't have that as a focus per se in my graduate training or anything. As I look back, I think I've always had sensitivity to kids in that way. It's kind of random.

[00:06:50]
Sometimes the best things in life are. You were talking about after Ida Martinson's work. Can you give me the name of her research assistant of the nurse who started the hospice? What was her name?

Becky Bedore, Becky, B-E-C-K-Y, Bedore, B-E-D-O-R-E.

You were talking about how at that time there was a lot of resistance from the pediatric oncologists, or was that oncologists in general?

I think it was the medical establishment in general. I think we saw the same things that you hear about nowadays, which is oncologists don't like to give up on their patients. And then there are other issues in the areas of neonatology where children were considered too fragile to go home to die, some of them, which is sort of an ironic message. Then what I noticed too is there were lot of children with what we might call chronic complex conditions who were very fragile and people just weren't noticing when they were deteriorating, but the families were.

The families were noticing but they weren't able to get that across to the medical team or what do you think was going on?

I think it wasn't framed in terms of the patient, the child is dying. I think it was framed their needs are changing and they need more intervention. And then as you talk to them and you give reflective feedback like, "it sounds like your child has been changing since this point in time. As you tried more things, it really hasn't fixed it. What do you think that might mean," those kinds of conversations. That exploration often helped families reveal their darker fears, that of course, their child wasn't going to get better and underlying panic of trouble beneath the surface. I think in a way, things are not the different now than they were then in the sense that families often focus on discreet symptoms, discreet problems, "you miss the forest for the trees" kind of. And then they present to medical clinicians who are responding to their questions and see the same thing and so, it's very easy to go down this path of intervention I think.

As a social worker, were aware of many other social workers there were involved early on as palliative care came to be?

There were none—or very few. I could count on one hand the social workers that were working in this field. I remember the early days—when we hit 14 patients we said, 'There's gotta' be somebody who know more
about this than us." And, "let's go to some conferences and find them." We would go and we would have had more experience than most anybody there. I think our program grew up simultaneously with Boston, Buffalo and maybe Akron. They all developed around the same time. The Buffalo program and our program were more nurse/social worker home-based programs. I think there were a few people, I mean definitely Stacy Orloff was active, Marsha Joselow in Boston. I remember meeting somebody from Kentucky whose name escapes me right now. There were a lot of programs that had social workers that would come and go, that didn't make it their focus or their career for a while. I meant it took probably—I don't know. I would say it's only in the last 10 years or so that you see a lot of social workers actually choosing to work in the field and in a program to actually engage workforce development, so that's a relatively recent phenomenon.

Bear in mind, there were no physicians really interested in our work. We had a pulmonologist, a critical care guy who was our medical director of our homecare program. Actually, he was the medical director over our hospice program, and he's actually pursued hospice and started a physician certification that was available at the time, prior to the subspecialty certification. For a long time we were doing a lot of work to try to encourage physicians to work with us and refer patients, so it was a really different era.

Was your role as a social worker different as part of this growing palliative care team than it would have been if you were a social worker for a pulmonology team or a cardiology team?

Those teams don't have social workers typically, they might use hospital based social workers when their patients are in patients, but they typically don't have social workers in clinics except for maybe, like CF [Cystic fibrosis], specialty programs like that, at least in my experience. Cardiology is maybe beginning to think about it now. But, yes, I mean I think I had the luxury at the time, because our hospital was small, it was very family focused, someone that finds the needs in terms of what families needed and wanted. We were given a lot of latitude to do what was necessary. I think that was like a golden opportunity for us to develop a service that matched what families were asking for.
The social work role, I feel that good social work is good palliative care and vice versa. It is person-centered, it goes over time, it addresses all the domains of personhood. It kind of amuses me [laughs] when I hear physicians using terminology that's from social work school. Anyway, I think I was given a lot of room to develop the role. I didn't really have a good idea of what I was doing at the time. [laughs] I think I was just responding to patients needs as they presented, and was actually able to do a lot of things. More recently when the program I worked for grew, some of those interventions and stuff got delegated to other people. For example, I did a lot of clinical hypnosis early on and I was the only one doing it and sought out those skill sets myself and then at some point that relegated to an integrated medicine program. Then those folks were able to bill for it, so they're the ones who did that. So in some ways the role got compressed. I don't know what the word is you want—more limited which I think is really a shame because I think for patients and families, it's really more user-friendly if multiple skills set exist within a smaller group of people and they don't have to have as many people that they're interfacing with, overtime anyway.

**Bryan Sisk:**

Pediatric palliative care is an interesting field in how it was initially developed largely by nurses and non-physicians and has really maintained, at least for the most part, this interdisciplinary and multidisciplinary team based approach. Early on, how did you and the team figure out what roles you guys could share, what roles were unique for you to each figure out your place on the team?

**Stacy Remke:**

I was the only social worker, so I decided what I was going to do and how I was going to do it. I do remember Becky our manager saying at one point, "the nurses don't know what social workers should do, so you need to tell them." And I was like, "Oh! Okay." And so, now I do teach interprofessional education and one the competencies is understanding the training, the roles, and the responsibilities of each other. And that was my first glimpse into how important that is, it's like, yeah, they don't know, and we just have to tell them. I did develop guidelines, like these are the kinds of situations I would like to hear about and basically, any child that's in a life limiting or life threatening condition, I want to hear about because as a social worker because I wanted to meet them, provide an assessment, and plan with them for their needs. And then the nurses I think certainly, referred crisis situations. We just developed it as we worked together. I think it was are really rich experience when I collaborated with my nurse...
colleagues who were insanely skillful in pain and symptom management, family counseling, and collaborative factors, and they worked fairly independent as they had to, being primarily out in the community. We were a scrappy bunch. And we kind of worked it out. We had to communicate a lot, we had to talk a lot, and that was probably the biggest challenge.

Who did you learn from?

I think I was extrapolating from other things I had learned about. There were no models at the time, certainly, when we started going to meetings. I remember going to an NHPCO [National Hospice and Palliative Care Organization] meeting in New Orleans in probably the early 90s. It was very eye opening to attend the first Montreal conference that we went to, which I think was the second year they did a pediatric day and there were 40 people there. And that was like, "We found our tribe." That was really helpful. I did this sort of work for 27 years clinically. I think over that time, we were able to hone our practice skills, because there weren't models out there, and that's one of things I'm committed to now is providing models and guidance for the next generation of practice, so they don't have to learn the painful lessons we learned along the way.

You talked about finding your tribe when you went to a conference, and suddenly there was a whole room of people that were interested in the very things you were interested in. What did that mean for you? What did that do for you?

There were 40 people, it wasn't that big of a room. [laughs] I mean it was very affirming and validating and relieving. It's like there were people we could talk to about these challenges who understood what we were doing. I mean in social work we talked about parallel process, in some ways we were in the same position as these families, that we were kind of the only ones we knew doing it quite this way and it was isolating and it did feel risky at times. I think in hindsight, I did not appreciate what I now refer to as vicarious trauma that we were all coping with. And this, I think, is a huge issue the field, so it's just now beginning to be talked about. I think that was part of the tribal nature of it, these were people who saw the same things we did, understood what was necessary. We were able to creatively problem solve to get there, give us a network that we could call on before the internet really. Overtime I think the pediatric palliative care team has been particularly good at that, creating a friendly network so you could ask
questions and call upon each other. I think that started because I think it was so small, the group doing this work, and developed really warm relationships with one another, and then I think, has modeled that going forward.

[B00:21:40]

**Bryan Sisk:** Taking a step back and looking at the overall adult hospice movement, how much do you think that adult movement development affected the development of pediatric palliative care?

**Stacy Remke:** I think in some sense they kind of laid some groundwork, in the sense of defining the model and especially of hospice, and finding a specialty practice for sure. And I know I learned a lot of things; the hospice philosophy of preventing pain, not just treating it but actually trying to anticipate it and get ahead of it; how you schedule meds and all that kind of stuff, and comfort things you know, like comfort and existential distress. And so, those kinds of concepts that came out of the adult world definitely informed my pediatric practice for sure. And again I credit and leaders in that area to helping to sensitize me early so that I could bring that into my pediatric work. I know one my nurse colleagues who wound up doing a lot with—I mean her focus is pediatric palliative care, Jody, she was a hospice nurse and also very interested in children. And so, she literally straddled both of those worlds and I know learned a lot from adult practice, pain and symptom management kind of stuff. I think that there is definitely there was a lot of resources to draw on and it's very different. You know you just deal with families—well, little children of course, and their diseases and the way their bodies work, and metabolize and all of that stuff and then also their families and the stage of life and this inherent and that's having a child that might die or will die.

We wound up doing a lot of consulting with adult hospices that we were engaged to care of children and coaxing them, it's not so painful as they imagined, or it might be, but they can do a lot of good. I would have to say more what’s needed in the adult world is helping them feel empowered to take care of children.

[B00:24:34]

**Bryan Sisk:** Was that a big problem?

**Stacy Remke:** Yes, I remember going to an NHPCO conference probably around the mid-90s maybe, and there was starting to be a focus on pediatrics, and there was a plenary about pediatrics. I remember sitting next to some nurses saying, "Oh, we could never do that." And then a couple of years later in a
similar experience, and the nurses were saying, "Maybe we should try and
do this, it seems really important," And I thought, "Wow, in a couple of
years look how that's changed." Which is cool.

Bryan Sisk: Were there any ways that adult hospice or adult palliative care created any
barriers or impediments for the development of pediatric palliative care?

Stacy Remke: I was working in a children's hospital, so things like Medicare guidelines
and hospice finance insurance benefits really did not apply. So, in that way
no. We really did not have much to do at all with the adult hospice world
except when we were trying to make referral to maybe a more rural area
for example; a kid wanted to go home to a community that didn't have
pediatric hospice in which we would provide support and coaching to
them. But really that was kind of the extent of our involvement. I think
sometimes there would be a perception, because there wasn't a hospice
benefit that is this child could draw on, that maybe hospice wasn't
available to them, but we were able to work that out in most cases. But no,
I didn't see that as a big issue.

Bryan Sisk: When you were beginning your work and caring for a lot of these families
who had a child suffering and dying from these serious illnesses, in what
way was that care most lacking at that time? What were the biggest
problem in that care that you observed?

Stacy Remke: That's a good question. I mean always there were maybe a couple of kids a
year where we could not get on top of their pain and that was always
excruciating for the team. And things got somewhat better when we had
medical expertise that was built in that, although not a ton better. I mean
again, I think the nurses I worked with did a phenomenal job with that
stuff and they were very creative in their problem solving strategies. I
think that the attitudes of a lot of the referring physicians—I remember one
little baby who went home from the NICU [Neonatal intensive care unit]
to die and the physician didn't want to make a homecare referral for
hospice because he thought that either the service of the home visit was too
expensive to the family, even though they had insurance. I just thought that
was really crazy because they just spent a couple hundred thousand dollars
in the NICU, and now to send the family home alone essentially to have
that death occur seemed really barbaric to me. We were able to work that
out. The way we worked it out is we explained to the physician that if the
family didn't have home care providing services, they would be subject to
a police investigation when the child died at home. So that persuaded him and maybe the $90.00 was well spent. I mean just stuff like that, that was really strange actually. I can't explain his thinking here. But there were a lot of attitudes; it would be too much for families, it would be burdensome. I don't know, some of those things we still with that palliative care everyday of course, to some degree.

I guess the other things that were hard were—I remember we took one child home to die and we were disconnecting ventilatory support at home, and stated he would die within moments to hours. And after about 6 hours he wasn't dying and we were running out of morphine, and then we needed another shift of nurses to come. So, those kinds of logistical things, which were challenging in the home environment, but again people usually pulled it off. So just, the work force was small. There were family support needs that I think could have been better addressed. I still think the ancillary services that families need; social work, chaplaincy, child life, music therapy, are poorly reimbursed, but they really enhance the quality of life. And it is disheartening to me to see the focus on billable services. Either those other services should be billable or, as happened in our program, there were philanthropic dollars that covered a lot of it, but those were the things that mattered. Death and dying is a human problem, it's not a medical problem. And there are medical aspects of course, that you manage well, but I get concerned with what I see now which seems to be a high medicalization of things.

I did have a younger physician say to me once that they thought having goals of care conversations was a medical responsibility. And as we talked about it, I said to her, "Are you saying that you don't think I'm qualified to have a goals of care conversation," and she just kept reiterating it was medical responsibility. I was like, "Well I've been basically doing that for 20 years. I'm not sure how you can say that to me." Anyway, I think that's something that's under-appreciated as how much processing families need to come to these plans. I think that we need a robust team of people to hold those conversations; that they happen overtime. People have found out there have been different ideas with different people as they sort of explore their priorities and needs. I don't think we appreciate that. It's framed as, "we'll sit down and have a goals of care conversation, and it'll be a done deal." And at least in my experience it was more nuanced and gradual. I guess it can be done if you're in the ICU [Intensive care unit] and you need to get it done. But I think for families that are dealing with these issues
Thinking about interdisciplinary and multidisciplinarity, when you talked about that anecdote with that younger physician, it made me wonder how has that shifted overtime as more physicians have become engaged in palliative care?

Well the medical subspecialty really changed things. On the one hand we needed more physicians engaged as champions for palliative care and develop that medical expertise that's needed. And then also what happened from my perspective is, it started to overshadow the way the interdisciplinary team could function as. I think a lot of that has to do with how big the team is and how the practice gets set up in each individual place. I mean they talk about if you've seen one pediatric palliative care program, you've seen one pediatric palliative care program, which is kind of true, but I've talked with social workers who express concern that their role on the team has gotten kind of marginalized, that it's hard for them to figure out how to use their social worker skills well. I think that part of that is that we have a number of people trying have these similar conversations with their families. It's been defined as the core component of the medical practice to have meaningful conversations, which I think it is and families want to have those physicians. But just yesterday I was participating in a simulation exercise with pediatric fellows learning how to deliver end of life care, basically have difficult conversations. And what was so striking to me is the level of responsibility that they feel for those conversations to go well, which tends to put a lot of pressure on them. I just keep thinking, "bring a buddy with you, bring a social worker with you or a chaplain who can help you have that conversation well." Instead of it resting on the shoulders of single discipline, let's bring our different skill sets an enhance that conversation. I don't think I appreciated it for a long time how each discipline does something very different with information that they get, and that's the richness of the team. We all get the same assessment information perhaps, but then what we do with that information, and the sort of the natural direction we will take it given our perspective, tends to round out the picture and creates a bigger safety net for the family. I think that's important for us to think about as we design teams and services and explain it to insurers, which is a whole other issue.
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**Bryan Sisk:** Following up on that, you had talked about using some philanthropy dollars to achieve some of the clinical goals. From your perspective, what has been the role of funders and philanthropists in driving this development of pediatric palliative care?

**Stacy Remke:** The classic formula has been like, the CAPC talks about, a third of program support comes from billables, a third from operational support from the institution, and a third from philanthropy. And definitely our program relied very heavily on philanthropy. When Stefan Friedrichsdorf was our physician leader, came, he was very good at working with the foundation of our hospital and securing support. We had had a number of grants before that, specifically to expand regional and then national education around pediatric palliative care. So that helped us to engage more partners and just kind of spread the mission you could say, about pediatric palliative care. I would say that actually philanthropy has really been quite key in helping to scale-up services and to demonstrate palliative care is a good option for children and their families before the payers would take it on. And now I think we see that happening with palliative care benefits, concurrent care, that kind of thing. People are seeing the value of it and building it more into insurance coverage, which is important.

[00:38:32]  
**Bryan Sisk:** From your perspective, looking back on this history, what do you think was the real spark that drove this push for pediatric palliative care? What was it that got this all started?

**Stacy Remke:** What a good question. I think like, again we're like 10 or 20 years behind the adult movement in our development. We saw that model there, or some of us did. I think with the advances in technology where that line between living and dying got a lot blurrier for a lot of children, and the advances of medicine were such that we had to face questions like, well we can do a lot of things, but should we do those things? And looking at the benefits and burdens of therapies for each individual child and the complex decision making that families had to wade into—I think that all became the background that pushed the development of the special skill sets that were best equipped to respond to those needs and that ultimately palliative care I think. It kind of grew back out of hospice maybe.

It's interesting, I've had conversations with friends who are adult hospice nurses. And one—I remember him bemoaning the fact that palliative care
was on the rise because in hospice they used to know what they were doing and how to do it, and now it's gotten all muddy. What was striking to me was, I think palliative care wades into those places where the decisions haven't been made yet and the options haven't been chosen yet—other people haven't chosen from the available options. So it's that process of choosing and weighing that is very pivotal to palliative care. In a way, hospice benefits by those choices that were already made by people who opt for hospice, which I think is part of the complexity of it and sort of the raggedy nature of it.

I do want to say that in 2007 when we had a little bit of money leftover from an education grant—it was simultaneous with fair amount of growth and programs, and there were a lot of people defining what pediatric palliative care was who are not doing pediatric palliative care. And we were very concerned about that in our program and with our colleagues that we were networked with around the country. And so we used a little bit of money that we had leftover and hosted a meeting of people that we knew at that point [laughs] who were doing pediatric palliative care. We kind of knew everybody that was doing it, and I think we got about 40 people in the room ultimately, which was most people. And the meeting was called the Forum for Pediatric Palliative Care—it was here in Minneapolis. And out of that meeting, we came up with the working definition of pediatric palliative care, a commitment to use common language to describe what we were talking about, established a research network, the Pediatric Palliative Care Research Network--the familiar name for the research group is “Peppercorn.”

Bryan Sisk: Oh, that's where that came from.

Stacy Remke: The name came a little bit later, but that's where the idea of research network bloomed from. There's something else, sort of coordination of educational initiatives and kind of a commitment to share information. And it was identified that the meeting of the profession would happen at the academy meeting, that we would designate that as the meeting place. I thought that meeting was really important. I kept meaning to write up an article about that, but I kept getting waylaid. To me that was pivotal moment. There were three fellowships in pediatric palliative care at the time. The one at Children's Hospital was about to be the fourth. So that gives you a little snapshot of where things were at that time. And then you look at now 10 or 12 years later, it's just mushroomed—it's just great
because kids and families need that. So I am very proud of that, that we were able to pull together and create some scaffolding for the growth of the profession that I think has carried forward very well.

[Bryan Sisk: 00:44:00] When you look over your career, what have been the biggest changes in the care we provide to these kids that are suffering or dying from these serious illnesses?

[Stacy Remke: 00:44:00] I think it's very positive that we can name that, the children who die. And we've become a virtual network of affirmation and validation for these families that have often thought like, the fact the we're a specialty means to families that there are others that have been walking down this path before them. And even they never meet them, they can benefit from that knowledge and what we've learned from those prior families. To me that huge that we've crafted some kind of a safety net around this very painful experience. To me I think that's important. What was your question again?

[Bryan Sisk: 00:45:09] What were the biggest changes you've seen in the care that these kids receive?

[Stacy Remke: 00:45:09] I think the fact that now palliative care is kind of seen as an essential service if you're calling yourself a pediatric hospital you have to have a palliative care, I think that's huge and positive.

[Bryan Sisk: 00:45:35] And this is always an uncomfortable question for people, but think of all the work you have contributed, what's your favorite contribution to this field?

[Stacy Remke: 00:45:35] My favorite, well it's funny because I always think of myself as a clinician first, clinical social worker. And yet, I'm seen as someone who's done a lot of program development stuff which is true because I wound up a part of the leadership team that grew a substantial program. I mean at some point we were one of the large ones in the country, those early days. And I told you how I freaked out when we hit 14 patients. When I left my job at Children's and started teaching full-time, I think we had about 80 patients at a time in our current census—that was how much we've grown. But I think my favorite part was problem solving, essentially terminal anxiety, as part of Children's and being able to pull together all the elements of my knowledge and skills that help relieve that. I think I feel most proud of that and I think also that's something that I have not seen scale up and I would like to see that happen, so I haven't given up on that,
but talking more about how to do that more creatively. And then I think that forum and that early stuff I think was really fun and exciting. I do feel like I've watched this whole field grown from literally like a handful of people who are commonly sensitive to this issue, to these very effective programs and knowledge base.

I've done a lot of work with EPEC [Education in Palliative and End of life Care] Pediatrics and was the co-investigator on that with Joanne Wolfe, and Stefan Friedrichsdorf—that has been—we had no idea when we started it how important that would be and literally traveling around the world and sharing what we knew about pediatric palliative care, and then also being challenged to think about what that looks like in resource poor countries or places where the culture is so different. I mean is really just been different and fantastic.

[00:48:28]

*Bryan Sisk:* What do you think has been the biggest challenges that face the field currently?

*Stacy Remke:* I think I would really like to see—talk more frankly about effective interprofessional care and what that looks like, putting the medical model aside and thinking about how do we address this in a more holistic way in the current system that we have. I think that's important to do. And again, I think it's wonderful that there is a number of physician leaders who have stepped up and are pushing the envelope. I remember talking to Joanne Wolfe once about, "Won't we be working ourselves out of a job? At some point it's medical care, so once we change the world, [laughs] we won't need palliative care anymore." And she said, "Well, there's always going to be new therapies that will create new side effects and new challenges." And she talked about that very effectively, about how the specialty of palliative care works at that frontier and problem solves there. And then sort of the primary palliative care is what we want everyone to understand about the needs of these kid and their families at the bedside. So there's a lot of work to do for sure. I think the education piece and embedding that more effectively into the care of children will be important. And I think that's starting to happen all over the place, but it's just going to be a lot of work to do for that.

[00:50:32]

*Bryan Sisk:* Lastly I would love for you to just dream aloud and think about if budget, and politics, and interdisciplinary strife, if none of these things were an
obstacle what would you ideally want care for these children to look like another 10 years?

**Stacy Remke:**

It's been kind of ironic for me to see to me to see now that's the preferred model of care is the one that we did back in the day, which is, we had a team with people that were hospital based who could move out into the community, had a clinic, so the same team of people could follow the child and family wherever they were. There were specialists, but we also collaborated very closely with their primary team, whoever that was, and I think that worked really well. And I think it created some financial challenges just in the way that billing and stuff works, but as we say, we removed a barrier. I think that's the model that families would like, that practitioners can find satisfying. So it lends itself well in an interprofessional collaborative practice where you are actively talking about who's going to do what, and who's got the skillset that’s needed today.

Then I think just kind of an appreciation for how practitioners can learn and evolve within their own practice, through active engagement with each other, having time and space for growth and skills development, and also restoration; that we need time for people to rest and recover from their exposure to secondary trauma. So that also I would like to see built in. Vacation time, education money for all of the disciplines, not just doctors and nurse practitioners. That's something in the literature that demonstrates support for resilience, is being able to go and move your brain in different ways and learn.

People also get personal support, professional support by attending socially at those meetings. At Children's Hospital we were very fortunate that as social workers we were considered part of the professional staff that we actually got pretty good time off and money for conferences, but I know that was rare and for most social workers they don't get that, chaplains don't get that, child life specialists don't get that. If you're not a nurse practitioner, it's very hard to get that as a nurse. I think those are the big things. I'd like to see more babies be more comfortable and their families more supported.

[00:53:56]

**Bryan Sisk:**

This is been phenomenal. Those are all of my questions. I guess in the last couple of minutes, is there anything but you think that I missed in this history that I should dig more deeply into?
Stacy Remke: Oh probably, but I can't think of anything right now. [laughs] No, a lot's happened and I think it's great that you trying to capture it, and I think it's also very gratifying to me that it is now impossible to count all the individuals. In my career, there was one point where I literally knew everybody that was doing this work and I can't say that anymore and that's interesting and a good thing. Now I'm looking at the end of my career I'm thinking about my personal legacy. I also feel like there are some things that I still want to say before I go west into the sunset. I think it's been incredibly gratifying to be able to be a part of this group of people that manifested this thing.

[End of Audio]