Stacy Orloff Oral History.

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Biography

Dr. Stacy Orloff, Ed, D, LCSW, is the current Vice President of Innovation and Community Health at Empath Health. Prior to her current appointment, she served in management and executive roles for Empath Health’s children’s program. She has been employed at Empath Health, as of this interview, for 29 years.

Dr. Orloff has dedicated her life’s work to developing some of the first U.S. children’s hospice and palliative care programming, including bereavement support programming and development of continuum of care planning. Dr. Orloff co-chaired the National Hospice and Palliative Care Organization’s ChiPPS committee for ten years, and sat on numerous executive steering committees. She has also authored and co-authored over 40 peer reviewed publications and books covering topics of ethics, community programs, psychosocial needs, infants, children, and adolescents, bereavement, patient psychosocial health, and interdisciplinary training with practitioners.

Interview Abstract

Dr. Stacy Orloff begins the interview describing her experience after completing her MSW degree and one pivotal serendipitous event: she looked at the classified ads in the newspaper for the first time and found a job opening for a children’s program in her local hospice. After she took that position, she found that all her training in life led up to being a children’s advocate in the hospice setting. Dr. Orloff reflects on the beginning of the community-based hospice movement that now seems to provide fewer services than it was once able to due to the regulatory policies. She also describes some of the early challenges she faced with bridging the training gap to equip adult palliative and hospice clinicians with the necessary tools to care for children, even if they might only care for children a few times a year.

Dr. Orloff then recounts several stories of early palliative and hospice care practices that depict the early need for services designed and dedicated to children. Dr. Orloff also describes her experience finding and working with other interdisciplinary practitioners in creating global programming.

Dr. Orloff concludes with her goals of creating streamlined hospice and palliative services for families that also provide other practical services such as economic assistance and respite care. She envisions a time where all providers on the continuum of care can come to the table together to provide the best quality care for children without the barriers of practice “turfs.”
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Today is June 27, 2019. I am Bryan Sisk, and I am in St. Louis, Missouri interviewing Dr. Stacy Orloff over the telephone for the pediatric palliative care oral history project. Dr. Orloff is in Clearwater, Florida. So, thank you Dr. Orloff for joining me. To get us started, could you tell me when your mind turned toward pediatric hospice and palliative care as a career focus?

I actually began my career in pediatric hospice and palliative care in 1990. When the idea first sparked for me, I would say was in the early 1980s when I was working on my master's degree in social work. I did some research in pediatric oncology and was very interested in that field. When I graduated with my master's degree, I started working at a family service agency. So, my focus wasn't specifically on health care, although it was always something that intrigued me. I think that it came from some early experiences I had growing up with death—that of a family member or close family members that were not children who died, they were adults. But I found that the serious illness and death didn't frighten me. I actually will say I grew up in a family that was probably not unlike many other people's families, that was somewhat death phobic; that just felt really awkward to me. Like, "Okay, why can't we talk about this? Why are we maintaining distance from the person who is ill?" I always felt like, "this is isn't the way it should be, this doesn't feel right to me," either as the family member or as the close friend of the person who is ill.

When I was working at a different social service agency, before I went into my private practice, I had the opportunity to be involved as a family therapist with a family, and the mother worked at the local hospice agency. So I learned something about it and thought that it was intriguing. Then, I was also a field instructor for the MSW Program that I had graduated from. I was supervising a student, who after graduation started working at the local hospice. So, I had two connections of people I liked and respected a lot, who were there, and for really the only time in my life, and back in the day when newspapers actually ran classifieds of open positions, I looked in the paper one day and there was an ad, for a part-time position with the local hospice in the children's program which I felt was perfect for me. I interviewed and accepted the position and so started there in 1990, and that's been my life's work ever since.

Was there something that you have envisioned before that or was it just a culmination of all these chance opportunities falling at the same time?

I think it was probably mostly chance, although I'd like to think that I might have sought it out in some point in time if it didn't come to me quickly as it did in my professional life. I think that it comes back to a really strong
sense of advocacy that I feel for children in particular. I was aware of it too even as I became a mother in understanding how little power and control children have of their lives. As an anecdotal example, I can think of a time I went to the grocery store with my children when they were young and asking, "May I have a pack of gum," you know, "May I take my shoes off." Whatever it might be, just about anything in their lives, kids have to ask for the "O.K." from a grown up. That has always just been a part of who I am. So working somewhere where I could be a voice for children, that's pretty much been my true north since I was a teenager. So I'm not at all surprised this is where I landed, but it was really kismet, whatever you want to call it, the one time that I looked in the newspaper, there was that one ad. So that's what really brought me to this work as early as it did because there was not much happening in our field at that time.

Bryan Sisk: So, what was the state of pediatric hospice care when you were starting out?

Stacy Orloff: Well I can speak from the community hospice perspective because again our local children's hospitals didn’t have a formal program, at least in the community setting we did— I can't really speak as much for how it might have been in the hospital. Although I worked with a lot of my hospital colleagues. I think in the early days of hospice care—so this is going back almost 30 years now— that we as an industry, we always had regulations, but different than they are now. So let's talk about the 6 month life expectancy for hospice care. That has been the admission criteria since the demonstration programs, before Medicare made hospice a benefit, and then other payers followed suit. However, there was a lot more flexibility in being able to keep patients on your census for a longer period of time, just in terms of regulatory scrutiny.

And I'm not saying any of us did anything that wasn't legal or right or incorrect in any way, but the regulatory requirement the type of data evidence that we needed to show disease projection, or the questioning by federal audits that are happening now of patients who are on census, child or adult, for greater than 6 months—there just wasn't that kind of scrutiny. I think early on, we had children in our hospice program far greater than 6 months and we were really able to meet the child and family's needs because we really had time to get to know the family, and they us, to develop trust and rapport so that we could be of greater assistance; listening to the family with their decision making process, unlike what often happens now where you have a much shorter period of time because patients of all ages are referred much later. As always, though, our documentation supported a gradual physical decline. I would say as a community based program, and I know that probably many folks that you are talking to are
hospital-based, it was easier for us to do all of that because we were the only ones doing it in a community program, especially hospice providers, were really doing—not all, but the majority of hospice care of what we would call now hospice and palliative care. Later it started to take hold in hospitals, which isn't a bad thing, I'm not being critical of that, but it did change the landscape. I feel it took something away from the community and I think our services are much more fractured than they were back in the day.

[00:10:46]

**Bryan Sisk:** Now prior to the 90s, I've talked with people who talked about how challenging it was early on, as late as the 70s and the 80s, to get adult hospices to care for children at the end of life. What was the state of hospice in 1990?

**Stacy Orloff:** Well, I would agree. There were just a handful of us that were willing to take children, by us I mean hospice providers. So we all kind of knew each other and we had this great fellowship and collegial relationship in terms of how we helped each other with resources, with questions—it was a really exciting time to be a part of this movement because we were really creating something and doing a lot of teaching and training. So that was pretty cool, to feel like we were doing something of service for children and their families. So from the hospice perspective early on, we got very involved with NHPCO [National Hospice and Palliative Care Organization], which was NHO at the time the National Hospice Organization, when we were starting out, and trying to develop resources and ways to support the adult hospice providers to care for children and how to develop relationships and collaborations with their local children's hospitals. Or even if they didn't have a children's hospital in their area, a hospital that admitted pediatric patients, and how they could do this. So those were pretty exciting kind of heady days to work on this, but there was a lot of concern and fear because caring for a child is very different, obviously, than caring for an adult. So if you're only going to care for a couple of children each a year, then how do you train your adult staff to feel comfortable in caring for children? So here I can say we created a lot of educational materials and did a lot of training of our staff, as an example, the different ways to calculate dosing of pediatric medications, how to assess—you know maybe if you have a child who is a little agitated, start small and simple look and in her ears; maybe she just has an ear infection versus thinking this is a terminal event. So we had a lot of national support from NHO and early on developed our pediatric work group which went by the name ChiPPS [Children’s International Project on Palliative/Hospice Services], to really create some resources and really encourage the community based hospices to admit children.
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You mentioned the comfort and training aspect of why some of these adult hospices weren’t regularly taking children. Were there licensure and regulatory issues or was it just primarily that "we can't we can't keep staff appropriately comfortable and trained for the small number that's coming."

The latter. So there aren't any different regulatory or compliance issues. Hospice regulations are the same for all, regardless of age. There's not a distinction and really never was until the Affordable Care Act was passed which allowed us to offer concurrent care to children who have Medicaid as their payer source, but obviously that was not that long ago in the scheme of things. So no, there were no regulatory differences in caring for children, but it really was a practice issue. We actually, with all the work we did here—I was very proud of us as a hospice because, even before I stated in 1990, there was history of us admitting a child as needed. But when I started in 1990 and then when I stepped into a leadership role at Suncoast Hospice/Empath Health in '93 with the children's program, is when I was really able to start creating a more formalized program. I hired our first pediatric nurse, because before, we had provided training to nurses on our home teams who cared for adults to teach them to care for kids. Which, if you're only taking care of one or two children a year, that's fine. But not if you're really trying to create a program. So even for us—I'll share an example of what I think most hospices went through.

We would regularly admit children to our hospice houses if they met the criteria. I can't tell you the exact date but it was in the early 1990s, we had a young child admitted in one of our hospice houses and she was a toddler. At the time of admission, she was being kept alive by artificial nutrition and hydration. Her parents ultimately made the decision to stop all artificial nutrition and hydration. We were supportive of that decision. I also want to clarify that we didn’t have any concerns about admitting a child with all of those interventions, which was also very different, not all hospices would do that. Frankly there are still hospices in this country, even on the adult side, that won't admit an adult patient who's ventilated. This child was at our very small hospice house—we had six patients. We had some staff who had been caring for this young child for the entire time she had been there which had been several months at that point. They were very unhappy and very uncomfortable with the decision that the parents made.

So what we did, because it was important to us to support the family who had the right to make that decision and to keep this young child where she was with us, as well as to support our staff who were struggling emotionally and spiritually. We temporarily moved these staff to one of our other hospice care centers and they worked there until after our patient
died. We were respectful of the employees who were struggling emotionally and spiritually and didn't necessarily agree with the family's decision, however our role was to support the family because they had the right to make that decision. [It was a balancing act to find a way to support the family, our patient, and our staff. I think we did a great job.] (Added by Dr. Orloff upon review) We met with the staff and respected their feelings that they could support the family, but they just couldn't be there, it was just too hard for them. We had the means to do that, so I think things like that happened and still happen. You'll have hospice staff who'll say "I came to work at hospice to take care of adults; I didn't sign on to take care of an ill child." I think for anybody who's in the pediatric field, whether it's end of life care or not, people choose to go into the specialty because we have an affinity or desire to serve a child and his or her family. Unless you are a hospice that only cares for children, then you're always going to have some kind of rub like this. I think we spent a lot of time, we both meaning the small "we" within my organization, and then the national "we" in trying to break down some of those barriers.

[B00:20:52]

**Bryan Sisk:**

I'm trying to get an understanding of the scope of the challenges of taking care of kids that were nearing end of life when you were started. Thinking nationwide, what proportion of hospices, whether it's in an actual hospice or home care, what proportion of them were open to children, were you an exclusion, was it 50/50 what would you say?

**Stacy Orloff:**

There were not very many of us. I'd say probably not facetiously at all, you could probably count us on less than two hands. One of the early surveys we did—and I don't have access to it right this moment but if you have an interest I'm sure I could it pull up. Back in the 90s, when we started with NHO doing some surveys of hospices, there were very few hospices that would say that they would not take of a child. However, the reality is how many of them did? There were not a lot and for some again, it was a training issue, not feeling like they could invest financially in having pediatric trained staff while knowing that the volume would be so small. From a financial resource it, for some, didn't feel like a good investment a good business decision in that way. I think also from a business point of view, the cost of care would always be greater than the per diem that we would get for proving the care — which is still the case. It is often the case for adults also, but caring for kids can be quite expensive. So hospices who really were committed to caring for children and creating a pediatric program understood that they were taking on a huge financial commitment and needed to have the financial reserves in order to cover the cost of that care, because reimbursement wouldn't come close to covering the cost.
I'll give you another example. We had a child that we were caring for; he was probably about five or six when he became our patient. And we live in Florida, so we have lot of water. So this young boy became our patient after he drowned in a friend’s pool and was revived. His parents very much wanted “everything to be done,” and so this young boy had a lot of external support to keep him alive. We admitted him. We didn't know what the parents’ goals of care would be over time and if that would change—he, most certainly, met criteria for hospice care. The family had private insurance—the father worked in law enforcement, mom also had an outside job, and there was an older sibling. We ended up negotiating with his commercial insurer for a reduced monthly per diem if they would approve for us to keep this young boy on our census; and they did. [The per diem we negotiated did not come close to covering all of this young boy’s cost but it was the right thing to do. It allowed us to provide care without having to continually request approval from the family’s insurance provider.] (Added by Dr. Orloff during review) There were times where he had like a little mini ICU in his bedroom at home. But I am incredibly proud beyond words that we chose as a hospice provider to do that. We cared for him for probably three or four years. The parents got divorced, the older sibling had a lot of difficulties, and ultimately the family made the decision to stop all artificial means of life support and he died very peacefully in our program. The thing too I'm incredibly proud of is his mom became very politically active—this was an incident in a family swimming pool. And so she advocated at our state capitol and got a law passed regarding restrictions on pools, including ensuring pools are covered, and regulations for any new in-ground swimming pool and the bill was named in this little boy's honor. We did it; we committed as a hospice provider because it was the right thing to do for this family. Again, it was much easier to do it back then than now. Now with the increased scrutiny we wouldn't have been able to care for him in a hospice program for that length of time. We're also licensed as a home health agency, so I'd like to think that if that were to happen now we would have admitted him to home health and had him in our home health program, or one of our other palliative care programs. We wouldn't be able to do now what we did then, as far as keeping him in hospice for as long as we did. Those were the kind of kids that needed us too. Back in the early days, also one other things I thought of Bryan when you were talking about the nature of children we cared for, early on we didn't have as many oncology patients as we do now. Although we still don't—we probably have more in palliative care than we do in hospice care. But we had a lot genetic anomalies, neuro compromised children, because those were the kids kind of fell in the cracks and were slowly dying. So back, then those were a lot of kids we cared for, again "we" here and "we" nationally.
Around this time and a little bit before this time, there were pediatric focused hospices there were developing, certainly in the U.K. [United Kingdom], and then there were a couple in the states, but they seemed to more so focused on offering the end of life care, but also offering respite care. Was that something that was unique to those institutions or was that something that most hospices did?

No, those were pretty unique to those institutions because there really wasn't much of reimbursement stream for that. Way back when in the 90s—in fact I still have all the articles I had shared with our CEO [Chief Executive Officer] at the time about all the different pediatric hospice houses in the U.K. I said to Mary at the time "We're going do this. One day we're going do this." And she nodded her head "Okay Stacy, we'll see about doing that." Ultimately we found other ways to provide inpatient hospice care. We do have our own hospice care centers and we've always admitted children into them, and I think made things as child friendly as we could. Also looking on the healthy kids side, having playrooms and place for children who have either ill brothers or sisters or parents, grandparents et cetera, at the care center. We created a place where they could go and hang out. So we ended up taking that track. I did apply and got an assessment grant probably in 90s also, to do a needs assessment for a pediatric hospice house and surveyed a five county area contiguous to see if we could support a need. I worked with our local children's hospital. But yeah, it's costly and there is not much reimbursement. There was an article in a recent New York Times Magazine—did you see it was May 19th. ¹ So there's a nice article, I've got it right here on my desk. It's called the Goodbye Home and so it's highlighting the George Mark house and two other homes in the U.S., but they all struggle financially. So we don't really have a good model in this country with our health care system and our payer system like they do in the U.K. and other European countries for that. In that regard, to do something, like say respite, you have to follow the hospice COPS, the conditions of participation. And that's limited to five days and the reimbursement is adequate, but not great.

For a lot of these families whose kids didn't have a hospice to go to and they didn't necessarily have home hospice care that they could do, were they staying in the hospital? Or where were these kids dying?

Stacy Orloff: A lot of them, the burden of care was on the family and there were some agencies that would provide what we would call now shift care nursing. Traditional home health doesn't provide shift care—you'll get a skilled nurse to come in to attend to your medical needs but not stay for hours. At least in the state of Florida, with certain payers, we've been able to use the home health benefit, and been reimbursed for extensive shift care up to 24 hours a day if that's what the physician ordered.

Although it's getting harder and harder to do that because that's typically only been a Medicaid reimbursement. You lose a lot of money doing that. In some regards, it's not much better than it was, although there were some what I'll describe as more social service agencies that would provide some assistance. But the families—as we're talking, I just had these images, thank you so much for this—the families that we cared for so long ago. It was so difficult for them because they pretty much had 24/7 responsibility for their very sick kid. If the parents worked outside the home, they may have gotten some care during the day from a community-based hospice. If their child got sick, then they would go into the hospital and may have been in the hospital for great periods of time or discharged home, back into the hospital, discharged home, and ultimately in the hospital to die.

It was very humbling walking into a home and really witnessing, and I don't use these words lightly because the families would say it too with of course great love for their kids, but the burden of responsibility was 24/7. Parents frequently felt they couldn’t even close their eyes. Trying to take a shower some days was impossible because you had a really medically compromised child and you may not have a nurse in your house other than you and you're not a nurse. It was a difficult time.

Bryan Sisk: What I'm wondering about now, when you were starting out, how did you find a community similar minds?

Stacy Orloff: It's a good question how did we find each other? Well I think at least through the hospice world, we were connected to larger hospices, more progressive hospices, and nationally active hospices. We would meet each other at conferences because our CEOs were very involved through the national organization and were encouraging our staff coming to conferences. We met like minded people at these conferences. I'll share one example. I met this long distance colleague shortly after we both started working in the field. She's a nurse and she was at a hospice in Buffalo at the time. We connected and started doing a lot of training and teaching together, some professional writing together. Many of us were involved in the ChiPPS group at the time, and so that kept us connected too. This one person I met, we are very dear friends now. The work brings you together
too. But I think because there weren't many of us, we just connected. At the time, I was probably the only person in Florida leading any pediatric efforts, there was my colleague in Buffalo New York, there were a couple of people in California, somebody in Minneapolis, Texas, Philadelphia, Pennsylvania area. At the time that we (ChiPPS) started we were international so there were a couple of people in Canada that we were connected with and that was about it.

Also too, I think for me, I still feel this way to some extent, there weren't a lot of social workers that were leaders in the field. I'm not trying to say that to toot my own horn, but it was sometimes a little lonely. Many of the leaders were either physicians or nurse leaders. I felt very accepted by everybody, but I think the lonely part is that often times I'd be saying, "Hey, let's not forget there are psychosocial needs, there are spiritual needs." These amazing wonderful people whom are close colleagues of mine were attentive to the holistic nature of [pediatric end of life care, but their primary focus was on the medical needs. I often felt I was one of the few trying to ensure we kept our focus on an interdisciplinary approach.]

(Added by Dr. Orloff during review) Representing these voices early on was a little lonely because as we were coming together as a movement. I can really just think of one other person that I would consider to be a leader in the field who I would consider to be a social worker. Everybody else like I said would be doctors or nurses.

Bryan Sisk: Do you feel like that holistic view you were talking about of not only pain and symptoms, but also psychological, spiritual, but also family distress, do you think that view that was initially held by a minority of people involved in this movement or most people how would you characterize that?

Stacy Orloff: I think that everybody early on understood that and paid some attention to it. I think that as we were really trying to this as quickly as possible, and do it right, and we knew we had so much to do—I think often people feel comfortable in their own silos. When we were together that was kind of, like, what I call like putting the glue together like, "Okay you've got this piece, this piece, but we got all of these pieces together." Some of the early leaders, I mean they definitely got it, they were not excluding that, but it wasn't what they were the most comfortable with, that wasn't their professional training.

Bryan Sisk: What were your biggest challenges from, I guess thinking about maybe 1993 on when you starting take more of a leadership and executive role, what were the biggest challenges in providing the care of these kids needed?
Stacy Orloff: Three things come in my mind and in no particular order. I think one was fear, whether it was on the provider level, people who were afraid to care for children. It wasn't just because they have the professional training, but they saw that child and it made them think of their own children, or their grandchildren, or their neighbor’s children or someone else. In terms of having good professional boundaries or ability to have that level of self-awareness, that was very hard. I think to some extent this is still an issue in some spots. That's one thing I think we all struggled with.

Two, was the financial reimbursement and financial burden. I'll come back to that, because the other thought is somewhat tied into that. It really was just getting the commitment to do it, because ultimately who is best to do this work? I say, "it's the right thing to do." Who is better able to care for a terminally ill child than a hospice provider? How can we say no? How can we not do this? So if you could get over that hurdle, someone who could say, "This is the right thing to do, or absolutely, yes you're right, we're going to figure out a way to do this." Just like I'll say that as a hospice provider in our area, more than 30 years ago, we were one of the first health care organizations to care for an HIV [Human immunodeficiency virus] client before we really understood what HIV was. We have a very large affiliate organization that's an AIDS [Acquired immunodeficiency syndrome] service organization that has grown tremendously. We've always been a hospice but said yes, we're always going to get to "yes," we just have to figure out how. But that was it, if we could get a hospice to say, "Okay, yes you're right, we need to do this," then we can provide the education, the training or the mentorship, the coaching or whatever, but then there's the financial hurdle. So we get the hospice leadership to say "yes" to caring for the child. Now we say you're going to commit to doing this but it's going to cost you, you're going to lose money on caring for these children. Can you do that, do you have foundation funds? Can you fundraise? What are you going to do? And just the fear, the abject fear of some folks who would say, "I didn't sign on for this." Because most people again, just thinking about us societally as being somewhat death-phobic, you came to work at a hospice because you thought you were going to take care of dying cancer patients who are 85 years old.

Bryan Sisk: I did want to check in, how are you on time, do you have a hard stop in five minutes?

Stacy Orloff: No, I can go—actually I meet with somebody at 11:00, but I can wiggle. I can go a little bit longer.

Bryan Sisk: From your perspective, what do you think was the spark that really drove the development of pediatric palliative and hospice care as specialty?
Stacy Orloff: I would say—are you asking from a national perspective, what do I think was the spark?

[00:46:58]

Bryan Sisk: Yeah, looking globally at very little awareness of this is the 60s, 70s, 80s to where it is now, what do you think started all of that?

Stacy Orloff: I think it's very personal. I think that if you witnessed in some fashion, whether your own eyes and ears or hearing the stories from somebody else, but knowing that you have a child and a family who struggled and who didn't die the way in which they wanted, or you know they could have, is what sparked all of us to be that voice and to be that advocate. Kind of to say, "Shame on us, we have to do this better." I think in some regard, no different how the hospice movement began in general. I'd give you the same answer if asked me that question about hospice in general. I think on top of that you overlay that, the folks who had the pediatric focus and said, "Okay, but we have a child here in a back room of a hospital who's dying and nobody's talking to the parents." I think it kind of has to break your heart for you to say, "I can do something about this. I can make a difference."

[00:48:56]

Bryan Sisk: And thinking about the adult hospice movement, how much do you think the adult hospice movement affected the development of pediatric palliative care and hospice care?

Stacy Orloff: I think actually it goes both ways. I think early on it helped to open the door for caring for children, because I think again, you add these progressives who understood why that 70 year old adult in the last room on the hospital ward, that nurses aren't going to see as often, that there is a better way of dying. You had Dame Cicely Saunders, I mean you had all of that going on and people who said, "People should not be dying like this in this country. We can do this." So you had those progressive folks who were able to expand their hearts and minds to say "Well yeah this is for everybody. This isn't just for grownups." I think in that regard the adult movement help in the pediatric world. I think now since we've been able to do concurrent care for pediatric patients since the Affordable Care Act, which is something that I have been very involved in, I think we're helping the adult providers because there are a lot of new models of hospice care through the CMS [Centers for Medicare and Medicaid Service] Innovation Center there are going to be tested. Those of us who have been doing concurrent care for peds can be helpful to say "this is how you can do it. This is how we can function, that it works financially, and we're meeting all of our other outcome goals," and things like that. I think in that regard, the adult world has looked to us a little bit. There's been a great expansion of palliative care programs in the hospitals for children. I think that has
helped to grow adult palliative care programs in the hospital—not as much perhaps in community-based programs. I think that there's more paediatric palliative care in hospitals than there is in community-based programs. I think I would say the same thing about adults.

[00:51:54]

**Bryan Sisk:** Over your career looking back, I guess about 20 to 30 years now.

**Stacy Orloff:** Yeah, almost 30.

[00:52:03]

**Bryan Sisk:** What are the biggest changes in the care provided to suffering and dying from serious illness?

**Stacy Orloff:** I think from an access point of view that there's greater access. I think that in working with our children’s hospitals, other physician partners, and colleagues, that we're much more collaborative and often times helpful to the physician practices to help them engage in some of those difficult conversations about goals of care and treatment options so that families are getting more access to more accurate information about their child's prognosis then they've had in the past. I think that we've done that well. Oh, I just lost my train of thought ask me that question again.

[00:53:27]

**Bryan Sisk:** What have been the biggest changes in care you are able to provide?

**Stacy Orloff:** I'd say the proliferation of palliative care in general as a specialty has been helpful and certainly on the pediatric side that's helpful. The fact that more children have access to palliative care programs in the hospital is a good thing. I think bridging that connection back to the community partners is still something to work on, but that's been wonderful. Especially having the name, being able to call it something—there's something more than hospice care, because palliative care in its truest sense is different than traditional hospice care. And so it’s going to help increase access because it’s increasing communication. We’re talking more about different treatment options and family schools of care.

[00:54:49]

**Bryan Sisk:** Where do think the field is in more need of for growth?

**Stacy Orloff:** I think we need to do a better job of bridging hospital and community programs; understanding and recognizing what our areas of expertise are. I think especially in communities where a hospital has access to community partners who can extend their work as far as palliative care to hospice care, instead of trying to reinvent the wheel and do that on their own in the community, that we're better served by bridging and working with other community partners to do that, because that's our area of expertise. I worry a little bit that hospitals may be expanding. I understand the footprint of population health and all of that, I mean that's something as a fairly
progressive hospice that we're focused on too. We're much more than a hospice provider. But I think we all have natural expertise in things and so we're better serving the families that we serve jointly by knowing when to hand off and refer, and so I worry a little bit about that.

Bryan Sisk: I have two quick questions left. The first is, looking back over your career what is your favorite contribution you've made to this field?

Stacy Orloff: You said quick huh? [laughs] What is my favorite? I think the privilege of meeting all the families I have and being able to speak, to be a voice for them in the greater community.

Bryan Sisk: That was pretty quick. [laughs] That's wonderful. Lastly I'd ask you to dream aloud for me, so if budget, politics, reimbursement, turf, and things we've talked about were no obstacle, what would be the ideal care for these children in another 10 years?

Stacy Orloff: I want it to be totally seamless. I'd want there to be hospice houses, I'd want there to be respite, and I'd want where we would be members on each other's team; so that when a child was in a hospital, the home-based hospice or the home-based palliative care teams would be part of rounding and in team meetings and vice versa. To me, we do our job well when it seems to be seamless to the family and they don't have to repeat information to all the different teams caring for them because we're hearing directly because we're in the same meetings with them. We're all together in service to the ill child and his or her family. And families have access to everything that they need; so that they have a respite home where their child can be well taken care of and happy so that they can go off and do things with their other healthy kids, or whatever they want we can do; that they have access to food if they're struggling economically. I guess if I could wave my magic wand they (the families) would get what they need and we'd all come together. You used a really important word, Bryan, and that's turf, so there is no turf, it's just as all of us together.

Bryan Sisk: Well this has been phenomenal. Is there any part of history that I haven't touched on did you think that I should know about?

Stacy Orloff: I don't know, I'm just having fun just kind of going back and thinking. No, I think you did a pretty good job. I'm sure you're going to hear some of the things I haven't talked about from other people. There was a lot of work in the early days, including writing and publication, kind of being a maverick too, in order for people to pay attention. Like I said, trying to be the voice for the child and family. It was great it, it was a great time because we were all committed around a singular goal and I think we achieved a lot.
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