Stephen Connor Oral History.

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Biography

Dr. Stephen Connor, PhD is a clinical psychologist, researcher, palliative care consultant, and currently the Executive Director of Worldwide Hospice Palliative Care Alliance (WHPCA), where he develops palliative care programs in Sub-Saharan Africa, Eastern Europe, Asia, and Latin America. Dr. Connor has 44 years of experience as a leader in developing and implementing hospice and palliative care programs domestically in the U.S., and internationally. He has served in numerous leadership roles in this field, including service as the CEO of several of the first U.S. hospice programs, chairing the International Work Group on Death, Dying, & Bereavement, eleven years as Vice-President for Research and Development at the National Hospice & Palliative Care Organization, and serving as a member of the Editorial Board of the Journal of Pain and Symptom Management. Dr. Connor has published over 125 journal articles, books, book chapters, and reviews. He is currently studying bereavement and health, denial in the terminally ill, outcome & global measurement in palliative care, and evidence-based care for the dying.

Interview Abstract

Dr. Stephen Connor begins by describing some of his early professional experiences and mentors who supported him as he developed his interest in death and dying. Dr. Connor explains that after several “epiphany moments” and observing some of the death and dying practices abroad, he and several other like-minded professionals said: “You know, really, we should just start a hospice.” Dr. Connor then describes his early professional experiences of co-founding some of the earliest hospice programs in the United States, which drove his career from local hospice programming to national programming and finally into the international programming, research, publications, and evidence-based practices for the new fledgling field of children’s palliative care. Dr. Connor shares stories of pivotal moments from his career journey, which spans from the beginning of the pediatric palliative field, through the HIV/AIDS pandemic, all the way to the present. He explores multiple topics such as pain management, policy, program design as they relate to palliative care across the lifespan and from domestic to global socio-economic and techno-political differences. Dr. Connor explains the many ways children’s palliative care has changed since the field developed, as well as some of the barriers and successes he’s seen. Dr. Connor concludes with his goals for the future of pediatric palliative care to be accessible, policy protected, and serving the need for bereavement services.
### Glossary of Acronyms

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Bryan Sisk: Today is May 3, 2019. I am Bryan Sisk and I'm in St. Louis, Missouri. I'm interviewing Dr. Stephen Connor over the telephone for the Pediatric Palliative Care Oral History Project. Dr. Connor is in Fairfax Station, Virginia. First, thank you, Dr. Connor, for joining me today. To get us started, could you just tell me what turned your mind toward hospice and palliative care as a career focus?

Stephen Connor: Oh, well that's interesting. Actually, very early in my career, I'd started working in heroin addiction treatment and was at a conference in Naropa Institute in Boulder, Colorado. This was in 1974. I took a course there. This was a Buddhist Institute and at the time, I was quite interested in Eastern religions. Just for extra information, I took a summer course on the Yogas of the Bhagavad Gita, which was taught by a former Harvard professor, Richard Alpert, also known as Baba Ram Dass later on. One of these lectures was on death and dying and he had showed pictures of Buddhist monks meditating in front of corpses as well as pictures and footage of California Highway Patrol car accidents, motorcycle accidents, and things with mangled bodies and such.

Basically, he was saying to us, "Why do us Westerners have such a hard time with death and dying? Why are we so allergic to it and unwilling to deal with it?" During that lecture, it's like almost a light bulb went off in my head. I thought to myself, "Wow, I really should be working with cancer patients and not heroin addicts." It was really kind of an epiphany moment. I went back to where I lived at the time, which was Monterey, California, and started actually doing some volunteer work at the hospital. I connected with an oncologist there by the name of Dr. Jerry Rubin—not the famous Jerry Rubin, but I guess famous in his own right. Jerry and his nurse Becky and I started working together.

Jerry was running a project he called the Cancer Recovery Project, which was basically a cancer support group for his patients. I said, "Well, let me help you run the group, Jerry," and so we both co-led the group for about a year and learned a lot from cancer patients about what they needed. We were doing guided imagery; we were doing body work. They were taking their chemotherapy and radiation therapy and we were trying to use visualization to help augment their immune response and all. They all kept dying, of course, or almost all of them.

One day we had a coming together after we'd just heard about hospice in the U.K. [United Kingdom] and we thought, "You
know, really, we should just start a hospice." And so we started one of the first 10 in the United States which was the second one in California, in Monterey, and started to link this in terms of pediatrics. In all of the hospices that I worked in—I worked in four different hospices in the U.S. before going to a national organization—we always took care of kids. It never occurred to us not to take care of children if they needed that hospice care. That's my origin story.

**Bryan Sisk:** What proportion of the patients that you took care of in hospice do you think were kids? Was it pretty small or mixed in?

**Stephen Connor:** It was mixed in, but it was always a fairly small number. Back in the beginning days—and we can step through that—everything was all volunteer. We had maybe 20, 30 patients on census. We had maybe a hundred volunteers. We had professional as well as lay volunteers. Eventually, we started raising money in the community and we could afford to pay for some of the staff time, but it was usually always—out of 20 or 30 patients, usually there were one or two kids in the early days.

I left there to go work in Hospice of San Francisco and start that program. We had the same kind of—it was basically around 30, 35 patient census. We helped get the HIV/AIDS [Human immunodeficiency virus / Acquired immunodeficiency syndrome] hospice going called Coming Home Hospice in San Francisco. That was right at the epicenter of the AIDS pandemic or beginning of it. Then there were lots of young people. This was not pediatric palliative care, but a lot of the gay men particularly that we were seeing were in their late teens, early 20s. We think about pediatric palliative care as extending into early 20s nowadays, at least, but these were not illnesses, obviously childhood illnesses that someone grew up with and then died of at a later point. It was just always part of the hospice.

I was at a hospice for 10 years at Kaiser Permanente in the Bay area and then went out to Kentucky for six years to help run a program in central Kentucky, in Louisville. From there, I went to the National Hospice and Palliative Care Organization in 1998 as the vice president for research and professional development. When I arrived there, there was a project just about to happen called ChiPPS, the Children's International Project on Pediatric Hospice Services. The guy whose post I took, Galen Miller, as vice president, he had been approached by the pediatric palliative care experts, really all over the world, and they said they needed a professional home to work on developing the field. We said sure,
and we held the first conclave of pediatric palliative care experts in Dallas, Texas in 1998. Literally, people from Australia, from Germany, from Poland, from South Africa, from everywhere, pretty much, came together.

We got funding for that project, brought everyone together. They formed a whole bunch of workgroups to work on significant issues. Our first publication was the *Compendium of Pediatric Palliative Care*¹, which was just an opportunity to bring together what anybody knew about pediatric palliative care at that point. Then there were a number of other publications that came out of it. The working group just needed some sort of professional home, at least as a transitional object, if you will. ChiPPS is continuing to operate as a regular newsletter, which is exceptionally well-written. The person who pulls all that together is a fellow named Chuck Corr, who's a professor, who'd written quite a bit on children's palliative care and on death education in general. If you're not familiar with it, I'd suggest you take a look at it. It's on the NHPCO [National Hospice and Palliative Care Organization] website.

I've read through a couple of those articles or a couple of the issues that came out. Especially, there's one that was looking back on the founding of the field and that was really informational.

Right. I know the issue. I've always felt strongly that palliative care had to include children. There's two different schools of thought about that, which is that in the U.K., the folks developed very much a strong, independent pediatric or children's palliative care focus separate from the adults. And in other places, it's been adult providers developing a capacity to deliver children's palliative care. I eventually joined the board of the International Children's Palliative Care Network. We have tended to use the preferred term "children's palliative care" rather than "pediatric palliative care" just to make it a little less clinical, with the definition of children including neonates, infants, children, adolescents, and even young adults.

As the field was taking shape—we talked about in the mid-70s was when you started one of the first hospices and that was, I think, in Yale. That was only in what, '73 or '74 when the first one started, so that was within the first year or two.

Have you noticed a difference where initially hospices were taking in kids, has that changed over time as the pediatric discipline of palliative and hospice medicine has arisen. Has that changed or do a lot of these community hospices still have a small number of kids that are on their census?

The situation in the United States is that—I'll look up the number while we're talking because it's changed over time—but the last I looked at it, I think it was at least two thirds or more of general hospice certified programs in the U.S. admit children and have a special program for children. Let me just check on that. Just a minute.

There aren't that many programs that have shared pediatric staff. It depends on the size of the program. The program I work with here in the Washington D.C. area, Capital Caring, has a dedicated pediatric team and they work closely with children's hospitals in the area. But you have to be pretty large in order to afford or to be able to have enough children on census to be able to establish a specialized team and hire people with pediatric training. If you're a small hospice, you'll work with the pediatricians locally. The nurses may have some pediatric experience, but usually they're not dedicated pediatric nurses.

Do all kids generally have a fatal illness that they're imminently dying in hospice similar to adults? Or is this more of a respite care similar to the U.K. model? What do you usually see for these kids?

We know because we've done the Global Atlas of Palliative Care at the End of Life and we've done the Lancet Commission that globally, the number one diagnostic need for children's palliative care are congenital anomalies. Cancer's actually fairly far down the list; it's only about five percent of the need. But the difference is that in high income countries children don't die very often of cancer and there's a much lower perinatal mortality.

But in the rest of the world and particularly lower income countries, we have a very different profile of diagnoses, where you've got—protein-energy malnutrition is a pretty big cause of childhood deaths. HIV is huge in Africa still. You have a lot of perinatal mortality and people—even children who get meningitis, where we consider that to be just—it's obviously potentially

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reversible, but there's a high burden of suffering, a high mortality rate outside of high-income countries. The typical hospice patient in the United States for children's hospice would be—a lot of it is cancer; a lot of trisomy 18 and other trisomies—general anomalies and other major childhood illnesses.

There is a component, obviously, where parents don't want to think about palliative care for their child—they want to continue to seek cure. Those children sometimes will end up coming to us very close to the end of life. Most of the kids live longer. On average, I think children being in a hospice have longer length of stay than adults. They're very unpredictable. They're very resilient.

When you think back about starting out in the late 70s, from my review of the literature and from talking with some other people that were clinicians inside of actual children's hospitals, there was a lot of hesitance that people mentioned about being aggressive in treating pain, with just concerns about not knowing doses, side effects, or toxicities for kids that led to a lot of withholding medications. Was there that same uncertainty inside of the hospices for these kids?

From my early days, we never hesitated to treat pain fairly aggressively in children. We do have pretty good guidelines now for persisting pain in children with medical illness. Opioid use disorder is really a psychological problem and it's not that common in children, interestingly. If we have a child that had to undergo some serious pain and their condition improves and they don't need opioids, when we withdraw the opioids, they're not usually having any problem with any psychological craving or anything like that.

We don't really see much problem with opiate use disorder in the palliative care population anyway. These are people with real pain, generally. Pain's the perfect antidote for morphine and you're not getting the psychoactive effects as you would—Facts and Figures—as you would with adults and even adolescents. Have you seen NHPCO's Facts and Figures for 2015?

Okay. It's on the website. It's the most recent summary we have of children's palliative care or pediatric palliative care in the United States. It gives a profile of the kinds of illnesses that children have. We all like the framework used by Together for Short Lives in the

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UK, which looks at infants and children and adults—children with what we call "complex chronic conditions," whether it's cardiovascular, congenital or genetic respiratory or neuromuscular. By the way, there was a change in the law in the United States that allows children to get what we call "concurrent care." So that curative treatment restriction that exists in the Medicare Hospice Benefit—the states can waive that requirement, really, for the Medicaid population. So kids can continue to get aggressive treatment for their underlying condition, attempting to cure the kid. Not all conditions are treatable, but any that certainly can, have continued treatment.

We've also, through the work we've done with the Lancet Commission, made sure that we have broadened out. We didn't initially count injury as a potential for palliative care, but when a child—or adult, for that matter—has a very serious injury and may or may not survive, they certainly need palliative care. We also have the whole issue about perinatal hospice care, which is that you have children that have—. This is more often in high income countries that have diagnostic capacity to determine a child's likely going to be born with severe deformity or illness or unlikely to survive because of genetic disorders and what have you. In those children, it's an interesting thing because people sometimes accused palliative care programs of kind of a passive euthanasia—which we do not do, by the way.

The people who are—the abortion-rights folks really love seeing these perinatal hospice programs because it's a way for a parent with a child that's not likely to survive to go and continue their pregnancy and give birth to the child, rather than abort the child and then have that child for maybe one day or whatever. That's quite meaningful to parents, to have an opportunity—even if the child is severely ill and born with congenital malformations, deformations or chromosomal abnormalities, to be able to have at least some experience that that was your child and not just have it be an abortive procedure. But there are also huge bereavement issues here for parents, whether or not the child—our programs get involved with SIDS [Sudden Infant Death Syndrome] and kids who die from drowning or suicide, even accidents, assault. Anyway, it's a very different territory in terms of the kind of diagnoses and progression of illness than adults. It's a very different story.

[00:20:44]

Bryan Sisk: How long was the lag between the uptake of adult hospice and palliative care versus children's palliative care really taking off and getting a foothold?
Stephen Connor: You mean in the U.S. or globally?

Bryan Sisk: In the U.S. and then thinking about globally after that.

Stephen Connor: Well, I think there was a reluctance. Marsha Lattanzi and I did some surveys of this back in the 80s and we tried to encourage hospice programs to accept children. A lot of them just felt uncomfortable. Over time, it grew as programs grew and they developed more sophistication. In the early days of hospice, it was pretty much all oncology and maybe some motor neuron disease. That was 90 plus percent cancer in the 70s, 80s, mostly. That has gradually shifted and now admissions to hospice programs for cancer are down below 40 percent. So that it's reflecting the nature of what people die of in the United States.

That's something we're starting to see happening in other parts of the world with limited resources. When you're prioritizing based on amount and degree of suffering, it's easy to just focus on the cancer patients. But then over time and when resources are available, you expand out from there. We're seeing a big growth in adult dementia or Alzheimer's disease and the old-old, 85 plus population is growing. The children's population has stayed pretty much stable within hospices. As hospice has grown, the proportion of hospice patients that are children has stayed about the same, but the numbers have grown a bit.

The problem we've always had with children is that they're spread out all over the country. Going back to the 80s, even before, we've had what we call "islands of excellence" in children's palliative care. This basically meant that those places where there were well-developed children's hospitals, they became a magnet for development of palliative care for children in the U.S. The further you got geographically away from the hospital, the fewer services were available. We actually tried to create a model at Children's Hospital in Minnesota. It was a hub and spoke model; we got some funding from Congress to do this actually, where we created a center in Minnesota that was a magnet for five states surrounding Minnesota.

People from those five states came in. The hospice people came in and were trained in pediatric palliative care. They went back out, but the center maintained a consultation service so that, as they admitted children into their hospice programs—if they had a difficult—a problem with a case, they could call in consult with the children's hospice in Minneapolis. That model worked actually,
and I think it's still working, to some extent. The other side of the coin is Project—the name I can't think of at the moment, but it was run by Millie Solomon. You've got pediatric professionals who don't know about palliative care and you've got palliative care professionals who don't know about pediatrics. So, our effort with that project was to create a model for how to get hospice professionals that didn't have pediatric background comfortable with the idea of taking care of children.

On the other side of it, you had lots of people in pediatrics who knew nothing about palliative care. There was another very, very large project—I can look up the name of that for you if you need—where they were training people working in pediatric settings in how to do palliative care. Between those two efforts, I think that was an effort to try to see if we could really improve access to palliative care for children. It doesn't mean that you necessarily have to go into a hospice program if you're a child that has palliative care needs. It could be as effective if you have your current care providers who are pediatric-based becoming better at palliative care and then delivering it directly to you as part of standard care.

How have the definitions in—considering children, how have the definitions of palliative care and hospice changed over time? Have they come closer to being one entity or have they really isolated into separate silos? What's your view on that?

Well, in the U.K., the whole system from the beginning was designed as a separate service from adult services, so that pretty much continues in that way in the U.K. Some other countries, like South Africa, have emulated that model. Even in places like Belarus, there's a children's hospice pretty much really focusing on the needs for children. In the U.S., we have a couple of centers—George Mark House out in California, for example—that is a dedicated children's palliative care service. But for the most part, it has just been part of a hospice or palliative care service because people don't all have that—there're so few of those facilities. We have been less separate in the United States—it’s been more integrated. But in lots of other places it hasn't been. I think there are pros and cons to either approach, really. The consensus within the pediatric palliative care community is it's better to have specialized children's services, ideally. That's not always possible.

What have been some of the pros of having more of a less distinct separation between childhood and adult in the U.S.?
Stephen Connor: Well, just simply access to services because the kids are so spread out. If they're going to go home and if they are able to be cared for at home, you're going to have to have people who are nearby that can care for them. Generally, in every case—at least in the United States—you've got competent pediatric professionals caring for the child and the question is how does the hospice or palliative care service add value to that, if at all, and provide additional services? I think one of the main arguments for that is that, we're not just taking care of a child; we're taking care of the whole family.

When I had young people, whether they were the patients or they were young children in the home, we paid a lot more psychosocial attention to the family. We have a pretty serious problem with siblings being neglected, if you will, when a child is being cared for at home. All the attention goes to the sick child and not to the other siblings, so you have to counterbalance that and make sure that those kids aren't left out and not neglected, if you will. A lot of art therapy work is done and we always had an art therapist that we used for the children to be able to draw and to express their feelings. That's quite important on neuro-play therapy: whatever works with the child, whether it's the child who's the patient or the siblings.

I think it just integrates it into the existing—in a hospice program in the U.S., for the most part we don't take over the medical management of the child. We encourage the primary care physicians to maintain their primary care relationship and then we support them. They write the orders. We're providing recommendations on treatment. A lot of people think that when you go to a hospice, you just go to some building, leaving the hospice physicians and staff to take over everything. That's not actually how it works for the most part unless the primary care physician really doesn't want to participate. We look at it as a teaching opportunity for the primary care folks, whether they're pediatric or adult.

Has the growth in the focus on children’s palliative care and that becoming a research-based discipline, has that had any impact going the other direction on adult hospice and palliative care?

Stephen Connor: Well, I think one of the interesting things that has happened with this concurrent care is that when the Medicare Hospice Benefit was created in the early 1980s, it was the only Medicare benefit that was added during the Reagan administration and it was a bipartisan bill sponsored by Leon Panetta in the House and Bob Dole in the Senate. The only problem was that everyone was trying to figure
out how to make this work. There was a demonstration project done, but David Stockman, who was Ronald Reagan's budget director, basically said in effect, "You can't have your cake and eat it, too. If you're gonna get palliative care, you have to give up curative treatment." That was a huge mistake in the beginning.

We went along with it because we needed a payment stream of some kind. We had a hard time arguing against it because we didn't have evidence. It's quite clear that what that caused was for people coming into hospice programs to be the vast majority of people admitted at the brink of death because they don't want to give up curative treatment until it's painfully obvious to everybody that the person's not going to respond or survive treatment. If we had not had that restriction or had some flexibility in that area, then we could've gotten people in a lot sooner. This is true for adults and children. What happens is when you're introduced to palliative care principles earlier in the course of an illness, you tend to make better decisions about treatment. You don't tend to use as much futile treatment. Clinically, the outcomes are better.

We've seen that in studies where we're comparing early introduction of palliative care against current care or the usual care. We've even had some studies—including one I did—that didn't prove, but at least gave some indication that it was possible that some of the patients actually lived longer if they got palliative care than if they got aggressive standard care, cancer patients, anyway. With kids, it was especially difficult because, for a parent to forgo curative treatment is so difficult. In the early days, the kids really were all pretty much near the end, either very close to death or there was no treatment. Because they're different than adults and they're more resilient and they respond better to treatments than elderly people, generally, we found that there was an emotional as well as a practical argument for allowing them to continue treatments, so that's when this—there was a demonstration project, several of them.

Some of them were funded by Open Society Foundation, Robert Wood Johnson Foundation. What we did to begin, we did develop some evidence that maybe the curative treatment restriction wasn't such a good idea, particularly for children. We've learned from children in that regard that it's a bad idea to restrict access to appropriate treatments. In fact, the first definition we wrote back in 1979 for the National Hospice Organization at the time, we wrote that palliative care was a combination of palliative and curative therapies that diminished over time, based on the condition of the patient. That's how we did things before that restriction came in.
People would continue their treatments. They would make thoughtful decisions about when to discontinue those treatments.

**Bryan Sisk:** From your perspective, thinking about again, children's palliative care as a specialty or a discipline, what was it that really drove that development?

**Stephen Connor:** Of children's palliative care? Well, I think that what drove it was one thing we do know, Bryan, is that we—that children are less likely to get palliative care than adults and that's true everywhere in the world. Part of it was a feeling this is immoral. This is wrong. It shouldn't be happening. Children should not be disadvantaged in terms of access to palliative care against adults. We also had a pretty passionate group of leaders in pediatric palliative care all around the world who felt very strongly that this was a huge unmet need that needed to be further developed. Was that what you need?

**Bryan Sisk:** Do you think it was something that was driven from inside medicine or do you think it was something that was demanded by society and medicine responded?

**Stephen Connor:** In my experience, it was driven more inside medicine by demand because parents didn't know what they didn't know. They didn't know what palliative care could do for their child. If anything, they were suspicious of it [laughs] and it was really the health professionals who started. When you look back on the hospice movement—of course that was started in the U.K. by health professionals. In the United States in the 70s, the hospice movement was a consumer movement. It was driven by people who wanted to take back both birth and death from the healthcare system that had badly managed it.

You had all kinds of birth aid, Lamaze, and all kinds of consumer movements going on, food co-ops. Everything was people taking control because at that point, back in the 60s and early 70s, healthcare was wholly interested in prolonging life; had no interest in death. It was Kübler-Ross who opened that door in society in 1969 with *On Death and Dying* that allowed the conversation to change and to say, "Well, wait a minute. We should be able to die better than this, not just be institutionalized."

**Bryan Sisk:** It sounds like in adult hospice, it was following a greater cultural and societal wave of autonomy, taking control of your own, and then the rise of bioethics—all of the things that were culminating. It seems like pediatric palliative care didn't necessarily have that same wave, since it lagged behind a little bit. Do you think that's
why it was really driven by the clinicians, as opposed to pulled out from society?

*Stephen Connor:* Yeah. There were some things that—when you look back on Elisabeth's work, there were lots of—in the early days of the HIV pandemic, a lot of kids were dying of AIDS, little kids. They'd gotten it from mother to child transmission. That really actually was something that brought attention to the need for children to get palliative care because at that time, there was no treatment for HIV. Kids were dying—babies, young children—through no fault of their own. The whole idea of children dying is just such a difficult topic for society even today to think about and deal with that it had to be driven more by the professionals, just because people couldn't deal with it. They could deal with old people dying and we need to do better not—death is not the enemy. Trying to redefine that whole social paradigm.

[00:39:51]

*Bryan Sisk:* I guess tagging onto that, what do you think have been the biggest barriers or challenges as the field and pediatrics have been trying to develop?

*Stephen Connor:* Well, I think our barriers continue to be all of the same ones. Psychologically, just acknowledging your children dying is a big barrier, the idea. We should do more to cure childhood conditions and illnesses. We ran into that with the HIV, but why invest money in palliative care? We should just do everything we can to try to cure people, period. That remains stubbornly stuck at a hundred percent. It's great to cure people. We're all in favor of it, but the reality is still the same: that people are dying. With a child, of course, it's particularly difficult because it's not timely. They're not supposed to die. The psychological barriers, I think, continue to be the main barriers.

We've overcome some of the regulatory barriers with changing and eliminating some of the restrictions on concurrent treatment. Even the six-month prognosis, which was the other big barrier for adults, that was another one that came in under the hospice Medicare benefit—nobody in the world but us have these weird rules, by the way. In other countries, they don't have six months requirements or curative treatment restrictions. It's only in the U.S.

The other problem is just geography. Children are just spread out and they don't cluster in particular big groups, except in some large cities, obviously, where you have enough children. It's difficult to really develop the service delivery side as its own independent thing. When you look at the U.K., it's much more compact, so it's...
easier to reach children and create a service delivery model that is specialized, but when you are in a big country and very spread out, it's just harder to develop specialized services that can reach people.

Looking more worldwide, looking at developing countries and less-developed countries, what are the biggest barriers and challenges there?

Money. Well, money's a big part of it because 95 percent, I think, of the need for children's palliative care is in low and middle-income countries.

Wow.

The high income countries—we moan about our problems with geography and psychological barriers, but we're really pretty good at keeping kids or curing kids and preventing them from developing conditions that end up in needing palliative care. But the need for children's palliative care—the unmet need is in low and middle income countries and this is what—why ICPCN was formed, International Children's Palliative Care Network—and WHPCA, for that matter, my organization—to address the unmet need. We documented it in the *Global Atlas* and the *Lancet Commission report*. The big lion's share of it is there. You've got an 80/20 problem. You've got 80 percent of the existing palliative care services in high income countries, where 20 percent of the overall need for palliative care exists and you've got less than 20 percent of the capacity in low and middle income countries where 80 percent of the need is.

For children, it's even more of a disparity because it's 95 percent, not 80 percent. Developing palliative care in one of the resource settings is quite difficult. It requires that the community come together to support these families and in many parts of the world—actually, you see a pretty good response in Africa, let's say, compared to the former Soviet republics, ironically, though we have one of the most premier—these are stereotypes or over-generalizations because the best children's hospice—one of the best children's hospices in the world is in Minsk, in Belarus. How that developed was because of the passion of a particular woman who wanted children's palliative care and raised the money and twisted enough arms to get it to happen. Belarus is not—it's a high middle income country, having somewhat more resources. There's great palliative care for children in Romania and then Kyrgyzstan, for instance, they have a palliative care center for children there.
It can be done, it's just—it requires leadership, championship, and community support. The problem in the former Soviet countries is that there's no legacy or history of volunteerism and community ownership of caring. The state took care of everything during Soviet journey, so people just aren't used to it and they are quite poor. But in Africa, you've got a sort of tribal culture where the community really does care for itself or for—people care for each other, even when they're poor. We see, interestingly, in some communities a lot more charity than we see in high income communities many times, just because people are all suffering and they're all in it together and they recognize that. They're not so divorced from it. It's not separated from them and kept from them. It's right in their faces, if that makes sense.

**Bryan Sisk:** You've had a career that spanned about what, 40 years or so?

**Stephen Connor:** Heading into my 44th year.

**Bryan Sisk:** Forty-fourth year. Over your career, what do you think have been the biggest changes in the care provided to these kids that are suffering and dying?

**Stephen Connor:** Well, we have actually improved a huge amount in terms of the body of knowledge of palliative care and knowing how to relieve suffering for children and adults. You can't relieve all suffering, obviously, but we can manage symptoms; we provide that extra layer of support for families. Families can be unleashed to do great things for their loved ones if they're trained. We train family members to essentially be nurses and then support them—you have to support them 24 hours a day and that's one of the secrets, I think, with palliative care has been a capacity to respond around the clock, 24/7. Without that, you can get into some really nasty situations and people end up in emergency rooms and people end up suffering. There's just still so much work to do. There're so many people who have no access to even healthcare, let alone palliative care, in the world.

Many countries in Africa, 50 percent of the population who live and die without ever seeing a health professional, so there's huge amounts of work to do. One of the things that recently has shifted our paradigm a bit is we used to think about palliative care as for people who are gonna die, who have life-threatening, life limiting or terminal illnesses. Now, we don't really care so much about that. We think more about, "Is this person experiencing serious health-related suffering?" If they are, then they probably need palliative
care. Forget about the prognosis. Forget about the particular type of illness a person has. If anybody is experiencing what we call "serious health-related suffering," the vast majority of those people are probably going end up dying of their illness prematurely anyway. If they don't, then good. Hospices get punished for admitting patients that don't die on time in the United States.

You said that was a recent paradigm shift. When did that transition of you—from focusing on death or threatening life to just serious health-related suffering—when did that transition start?

Well, it's really been over the past five years or so as people have begun to come to terms with the staggering number of people who need palliative care worldwide and the fact that we're not very good at predicting or prognosticating. The health profession is not really very good at it as some might pretend we are. What's staring us in the face is people who are in great pain or great distress and what are we going do about it? A lot of people just feel like the paradigm around dying turns off the public anyway. Anytime you bring up death, people's brains shut down. That's the research on it.

There was some research done at Center to Advance Palliative Care by Diane Meier and her group around—they did some very interesting research asking people how they felt and what they thought words meant. When you start to talk to people about death and dying, what words make you uncomfortable? What words can you resonate with? "Serious illness" was actually the easiest term for people to wrap their heads around. Life-threatening. Those are all abstract terms that people don't quite understand. They understand what serious illness is and they understand that we need to do something about that. People need help when they have serious illness.

We have a definition of palliative care from the World Health Organization that we've had for many, many years and that's being rethought, but it would—revolved around—we all hated the term "terminal illness," so we got rid of that a long time ago. We prefer terms like life-threatening, but those are sort of the inside baseball terms in the field of palliative care. People scratch their head when you say things like that.

In the last couple of minutes here, I would really love to just have you dream aloud for me. If the budget and politics and all those things that we've been talking about were not an obstacle, what
would you want care for these kids to look like in another 10 years? Let's start in the U.S. and then think about worldwide.

Stephen Connor: Well, the interesting thing is that we're not talking about that many people. I did the research on the need for palliative care for children globally. In the first one we did, in the *Global Atlas*², it was 2 million kids. The Lancet Commission results we got were 5 million kids. That's all based on mortality—I'm going say this as a prelude to answer your question. When we look at the need for our care, we're always looking at mortality statistics and that's a mistake. We knew it would be better if we used prevalence data. We identified the conditions that people need children's palliative care for and then we look at how prevalent that is in the population.

Unlike adults, a child might need palliative care for a day or for 20 years, and so the prevalence is much higher for children than it is for adults because people get a severe illness or serious illness and they die within 24 months at most. Usually, it's six months or less. With children, it's very different and there's a very different complex of different conditions. We took a real hard look at that. We got data from countries that represented almost 60 percent of the world population. We took out all the sequela that were not—where you'd need palliative care and we ended up estimating the total need as about 21 million children and of those, 8 million in any given year would need more specialized services, but the others had some palliative care needs.

They had some suffering that could be addressed, but it wasn't a real severe situation where you'd need specialized services. We got it up to 8 million anyway. Just to think about that: if you've got 5 to 8 million children in the world, in a given year, who need pediatric palliative care, couldn't we figure out a way to do that? How much is it going to cost—the cost of an aircraft carrier? [laughs] We did, in the Lancet Commission, some estimates about that and even just to get medication for children was really pretty cheap. You could raise the money without too much difficulty. We shouldn't really just expect low income countries to be able to find the money—we have a problem with distribution of resources anyway—but I think the world needs to come together.

In the U.N.'s [United Nations] Sustainable Development Goal framework, if you're familiar with it, there's one goal for health. It's called Good Health and Well-Being. It's the third goal. Within the third goal, under 3.8, universal health coverage. I just came back from meetings at the U.N. in New York this past week, where
we've been trying to figure out how do we get to universal health coverage by 2030. There's going to be a high-level meeting on that in New York in September, but it really is the lever we have right now to say—because actually, universal health coverage has been defined as promotion, prevention, treatment, rehabilitation, and palliation. That's the continuum of universal health coverage care. That's what every country should be able to provide to its citizens without impoverishing them. No one should be left behind.

We're doing a crap job on that at the moment in the United States, unfortunately. But there are a lot of countries that are taking this seriously and they're really trying to figure this out. How do you design systems that can deliver all of these elements of health care to a population? Our dream is that we get to a point where palliative care is embedded in universal health coverage in every country in the world and that includes adult and children's palliative care.

Even if we did just the children, it's 61 million people a year. That is a conservative estimate by the Lancet Commission. If you've got, say 5 to 8 million children a year that need palliative care, let's cost that out. We did an essential package of palliative care: what does it cost per day to deliver palliative care to a population? It's not that much money. Each country, we can come up with an estimate for it. We spend about $18 billion a year on hospice care in the United States right now. That's quite a lot of money. It doesn't need to cost that much. We need to embed it—about two thirds of people who need palliative care can likely be managed fine by their primary care providers if they have some basic—at least basic training in palliative care.

Children are a little more complicated, but we still think it would be best if every pediatrician who graduates has a basic competence in palliative care and every nurse that is trained in pediatrics should have a competence in palliative care, basic competence. There should be some specialists to teach and do research and other things. Anyway, my answer to your question is, it's part of the larger framework in our world. People have a right to health care—it's a human right and we should be getting on with it. It should be a priority over other things and we should include palliative care in all of it for adults and children.

[B00:58:16]

Bryan Sisk: Great. Well, anything else that you think I should know about this history and trajectory of palliative care for children that we haven't talked about?
Stephen Connor: Oh, boy. Well, just that we can't neglect the bereavement aspects of children's palliative care, because when a child dies, it has a ripple effect on the family and the community that affects society. It causes a lot of grief, divorces, suicides, lost work, depression. We tend to sweep that under the rug sometimes as a society. Need to be doing much more around the impact that bereavement has. We know that children who get palliative care, that actually for families, grief is easier than those who witnessed the child suffering and never get—and don't get the support from palliative care. There's more post-traumatic stress, then, as a result of that.

Another reason why we need to make sure palliative care is included, because bereavement support is part of the whole as we know palliative care and as we write the standards for palliative care, every palliative care service is obligated to continue to provide support to families after the death of a child. On that note, I guess we can wrap it up for now, but I'm happy to answer any questions in the future.

[End of Audio]