Dr. Lynn McPherson:

This is Dr. Lynn McPherson Welcome to Palliative Care Chat, the podcast series brought to you by the Online Master of Science, PhD, and graduate certificate program in Palliative Care at the University of Maryland.

I am delighted to welcome you to our podcast series titled, Founders, Leaders, and Futurists in Palliative Care, a series I have recorded with Connie Dahlin to support coursework in the PhD in Palliative Care offered by the University of Maryland, Baltimore.

Connie Dahlin:

Welcome, everyone. This is Connie Dahlin, one of the faculty with the University of Maryland, PhD, and this is one of our podcast series. I am joined, as usual, with Dr. Lynn McPherson, who is the director of the Palliative Care Program at the University of Maryland, and we are really honored today to be talking with Dr. Stephen Connor, who many of you may not know, but he has really been a formidable presence in hospice and palliative care since the beginning, even before the Hospice Medicare Benefit.

So, Dr. Connor has worked continuously in hospice and palliative care as a researcher, as a licensed clinical health psychologist... which, we haven't heard that many from some, so this will be good for you to sort of hear another discipline. He's been a consultant, he's been an author, educator, and an executive. He worked at the National Hospice and Palliative Care Organization as the Vice President for Research and International Development, and now he has really shifted his focus more to international development, and he is leading the global alliance of national, and regional, and other hospice and palliative care organizations of 86 countries. So, that's only a small part, so, Dr. Connor, I'm going to let you give a little bit more about yourself, and who you are, and where you've been.

Dr. Stephen Connor:

Great, Connie. Nice to be with everybody, and really thrilled that we're seeing a new sort of generation of leaders come and emerge in hospice and palliative care. You're needed. We're happy to have your contributions to take the field to even better places than we've been. Certainly, we have plenty of challenges. So, Connie mentioned I'm the Chief Executive for the Worldwide Hospice Palliative Care Alliance. It's an alliance of over 350 organization in 102 countries, presently. These are the palliative care associations, the regional associations, the national associations, and lots of, some providers, but the academic institutions.

Anyone who's really interested in hospice and palliative care, and seeing if we succeed all over the world. But, I did, as Connie said, start out in the United States, in Monterey, at the... what was it that time? Hospice of Monterey Peninsula, now Hospice of the Central Coast. And it was an interesting journey, getting there. I've been working, just initially in my career with heroin addiction treatment, and kind of got a little burned out on that, just kind of because it was these, basically, people who were trying to get... who had been arrested for possession of heroin, or some other illegal drugs, and were sent in urgent to see someone to work on their addiction problem, but most of them didn't really want to be there anyway.

So, I went to the first session with Europa Institute in Boulder, Colorado... this was in 1974.... and had a kind of epiphany, which was, I was at that time studying a lot of Eastern religions and kind of into that whole thing, and felt like I should be working with cancer patients instead of heroin addicts. There was so much suffering involved, and that we had just heard about hospice in the UK, in the United Kingdom, at St. Christopher's.

Anyway, so I went back to Monterey, spent some time working with an oncologist named Jerry Rubin... a different Jerry Rubin... but Jerry, who had died recently of cancer, which was quite sad, was running what he called a cancer recovery project, which was a support group for the patients he was caring for, and I offered to help lead the group with him, and so we kind of formed a partnership, and after... all the patients kept dying. We would try to get them to use, visualize their cancer, their treatment, and how they would participate and improve their wellness and health, but they all kept dying.

So, most of them wanted to talk about what their hopes and fear were, and things that were, that they couldn't talk to their families about, usually. So, we did a lot of work with some and learned from them. They taught us what people need when they're facing the knowledge of impending death. And so, we decided we'd start a hospice. It was '75, so we started that hospice, just all volunteer. When we began we just built it from the ground up based on some of these principles we'd learned. We trained ourselves, kind of self-learned how to do palliative care.

At that time the term palliative care wasn't really in use. Balfour Mount, who was a physician in Canada had coined that term because in Ontario, in French Canada, in French the word hospice is associated with a poorhouse, and so he coined that term instead of hospice. He used palliative care, which is the cloaking and the covering up of symptoms, and making people comfortable. So, this is is long before the Hospice Medicare Benefit came along, so we were scrimping, and getting money from the community, and just trying to put together some services. Started out with home care, bought a house in Carmel Valley, refurbished it.

Well, that was a nightmare because of the lack of any regulations covering what we were doing, and certificate need in California was very tough. But we managed to finally, finally open it. We had support from our local congressman, Leon Panetta, who went on to be the house main sponsor of this Medicare benefit. And then, I was brought up to San Francisco to start a hospice in San Francisco, just before AIDS hit in 1979, and I was there, in that program, for about three and a half year. During the start of the HIV epidemic we helped get the Coming Home Hospice going for men who had sex with men, and I basically... there was not enough money to run it. We were doing a kind of coalition hospice with money from San Francisco Foundation. I just said to the board, "I don't think this is going to work."

So, I went off... anyway, I ended up helping start hospices in the Kaiser community system for 10 years. I was there on the front lines, some of my most rewarding years as far as clinically being there every day with patients, helping them process the fact that they were facing a life of needles. And we set up a program in Martinez, but at that point I was married and my wife had three little children. We were married in California and we thought we needed to move somewhere less expensive to live, and just to get out of the way, because the schools were sort of crumbling at that point because of the lack of property tax that we did to support the schools.

So we moved to Kentucky, I took a job running the hospice of central Kentucky, which then became the Alliance of Community Hospices. We formed together with a hospice in [inaudible 00:08:36]. I was co-Chief Executive of that. I had a chance to do private practice for five years, for... and we were there for six years. And I got the call, I was elected to the NHPC award... NH Award at that time... and then was tapped to become vice president for... at that time it was research and professional development.

So, we did the conferences, I helped build the organization, and then I got, sort of around the year 2000... This was in '98, when I went, to around 2000 to start working on international development, started in Romania, and was a project to help them write national standards. I had been Chair of Standards and Accreditation Committee for NHPC for quite a few years before I came up there.

And so, anyway, I got bit by the international bug, was kind of done with being worried about things in the US. I thought I could see so much needed to be done abroad, and it turns out that we have a kind of 80-20 problem. We've got 80% of the needle most for palliative care in low and middle-income countries, but 80% of the actual palliative care service delivery's in high-income countries. So, it's really been a journey to sort of reverse that trends somewhat by building models, indigenous models of palliative care to make it more in settings with limited resources, and I think we've learned a lot, all of the things we take for granted about hospice.

Cicely Saunders once said to me, "You don't need to do it the same way." I used to ask her, "What do you think we should be doing in the US about these problems with conflict between palliative care, and hospice, and all this?" And she says, "I don't know. You guys have to work that out. But there's nothing set in stone: you could do what makes sense for the people who need the care where you are. There are different models." Anyway, but it's to start us off.

Connie Dahlin:

So, when you think about... I mean, it's kind of amazing, what you've seen, and that's kind of amazing legacy. But when you think about, like you started off in this volunteer part, and the the hospice benefit was kind of being formulated, I mean, what were your thoughts and-

Dr. Stephen Connor:

Oh, yes. Well, the Hospice Medicare Benefit, well, in some respects was a kind of deal with the devil. So, the backstory about this is that when we wrote the first standards for hospice care in the United States, the very first standard in 1979 that was written was about palliative care and what is palliative care, and it was defined in that standard as a combination of curative and palliative therapies that maximized patients... So, in other words, using curative treatment to help a person live a bit longer, or manage their symptoms better, was fine with everybody. But this, during the Ronald Regan administration, the budget director, David Stockland, sort of said, "Well, you can't have your cake and eat it too. If you want to get a Medicare payment model we kind of have to give us... you can't have curative treatment and hospice at the same time, and you've got to have some sort of cutoff as how long people should live."

Both of those were terrible [inaudible 00:12:37]. That's a financial person. We were so desperate to get any payment stream that we just said, "And we'll throw in bereavement for free with the followup." So, he got his way, we got the benefit, but we've had to live with that ever since. The curative treatment restriction, unfortunately, it's what causes us to have such a bimodal distribution of lots of people for a short period of time, a small number of for a long period of time. Not so much in the middle, which is what we really want, people to be getting palliative care for two or three months so we have enough time to prevent the problems that results in people going to the hospital. We don't need to create a therapeutic relationship with patients, and families, and head off all the problems we know that they're going to encounter.

Connie Dahlin:

Do you think in hindsight, seeing that, I mean, that's what we want the students to understand. This was about negotiation, if you will, right? And kind of reading a timeline and thinking you want something and you're going to have to compromise. When you think back... I guess there are two parts of my question. Are there other parts you wish you maybe had compromised less on, and you push for something more; and then the second part is, in hindsight, which is always 20/20, do you feel like, that the hospice benefit was the right way to go or not?

Dr. Stephen Connor:

Well, it was a two-edged sword, in a way. I mean, the Medicare Hospice Benefit has been remarkable in the fact that the majority of people who die in the United States get some palliative care. There's no other country in the world like that. I mean, the UK doesn't even come close to that, and they're supposed to be the number-one sort of leader. But, they're not getting it for enough time. Used to be the big criticism of hospice was, "Yeah, great, but nobody knows about it and nobody gets it," and it was that way for many, many years.

I think part of what happened when the for-profit sector realized that they could actually make a profit off of hospice care, it started to grow like wildfire because the smaller nonprofits weren't that interested in growing that much. So, we had a curve that went kind of like this, gradually up, and in the 90s all of a sudden it started to go like this, and in the 2000s it's the fastest-growing benefit in the Medicare program, and there's still lots of people who don't get it.

And the bigger problem is they get it, but they only get it the week before they die, so 35% of patients are seven days or less, and [inaudible 00:15:38] is three weeks. So, it's brink-of-death care, more than it is the kind of quality palliative care that we'd like to see it be, and that is a result of those restrictions, because if physicians have to make a six-month prognosis and sign a paper, and then the patient can't get curative treatment, then you've got incentives to wait til the last minute to refer someone to palliative care.

Connie Dahlin:

Do you think it was worth it, Dr. Connor, to say, "We'll make sure the patients give up curative therapy in order to get hospice," or do you wish you had stood firm on that?

Dr. Stephen Connor:

We didn't have the evidence at that time to counter that argument, and we've sort of had... there's some degree of face validities that, yeah, well... But our philosophy before that, I mean, was codified. I mean, we have the original standard that we wrote back then, and it is very clear. It came from, actually, the International Work Group on Death, Dying, and Bereavements Assumptions and Principles about care done on patients, because it was, in reality... I mean, we didn't get in the way of those sort of decisions about whether some insurance company paid for treatment or whatever.

It was just part of the thing, and we would... you were more likely to make better decisions about continuation of aggressive treatments if you have someone walking along with you who can help you sort of think through where are your goals of care, what's important to you right now, do you want to reach some milestone or do you just want to focus on comfort or... And we have had some, we've had a few reports. I did one of them, research reports, that showed evidence for some patients surviving longer with palliative care than those who don't.

We're not entirely sure, yet, because of palliative care, because we can't randomize people, but it is, certainly from a clinical standpoint, I mean, we've seen so many of these patients who come, little train wrecks at our door, and we get them sorted out and they get better [inaudible 00:18:04], better care. Then we talk to their families, we make sure to get them their medications. It's certainly reasonable that they might live a few months longer than they would have otherwise if they were over treated and constantly given loads of chemotherapy that knock them down, or other treatments.

But, to answer your question, I don't think we should give up on the idea of getting ride of the cure treatment restriction. I think it's something we need to... we now have more evidence. I mean, Ira Byock tried to do that in promoting Excellence Program through the Robert Wood Johnson Foundation.

They put together a pretty good body of evidence. The problem was they [inaudible 00:18:51], under, I forget, a dozen sites or so, and nobody used the same instruments to measure what they were doing, anyway.

But we've seen that with children, certainly. We've gotten rid of the treatment cures restriction for children, and I think you could make an argument for adults. I think we need... a lot of this is in the context of the evolving payment structures that are going to be coming in the next decade, which are going to change everything, and likely end up changing to where we are focused more on people with serious illness, and serious [inaudible 00:19:36] suffering, and not prognostic-based eligibility systems, but severity of symptoms and severity of disability... which makes more sense, which we had in the beginning.

Connie Dahlin:

Interesting. So, you mentioned in that the International Work Group on Death and Dying. So, that's sort of like, you were involved in that, and I'm sure that also played into you getting involved in some of this international thought. You want to talk a little bit about that group, because I think many people don't know about that group, and that it still exists, and what it does.

Dr. Stephen Connor:

It's a secret society. It was founded in 1974. Cicely Saunders and Elisabeth Kubler-Ross were two of the 10 or so people who founded the international work, and it was an organization that brought together leaders in the field of death, dying, and bereavement to come together in an egalitarian way, to just sort of push the envelope, to think about the field, how to develop it. We had a model of writing papers that were called Assumptions and Principles. And so, the assumptions are things that are universally true about something that came... I mean, we've done lots of different... I did the ones psychological-psychosocial care for dying patients and their families, and we tried to come up with some real fundamental, basic ideas, and then guidance for people on how in the world you take out certain universal principle [inaudible 00:21:17] out.

The organization does still exist. It's going fine, I'm on the board, but we meet every 18 months. The pandemic has kind of thrown a monkey wrench at things. We were supposed to be in Zimbabwe last year and had to cancel that trip, and then Oslo, is being postponed til next year. It rotates in different parts of the world, so it's... we try to only have one out of every three meetings in North America. But, it's still a pretty fertile kind of underground of bringing people together, and it's more about supporting leaders in the field. I mean, IWG is, the organization is not as important as its function, which is to help build and develop leaders in the field, and to get to be a member you have to be invited, and have to be a member, a leader already, pretty much. So it's sort of we're enhancing leadership.

Connie Dahlin:

That's why you said it's a secret society.

Dr. Stephen Connor:

[inaudible 00:22:25].

Connie Dahlin:

So, tell us a little bit more, then, about... you did all this interesting stuff. You were there with the Hospice Benefit, you were there with NHPCO, and then you make this launch into really focusing on international.

Dr. Stephen Connor:

Well, we realized that there was no voice for palliative care in the arena, and where health policy is being made is the global level, at the UN, at the Commission on Narcotic Drugs, it's the World Health Organization, World Health Assembly. And, it was just nobody saying, "Hold on, you forgot palliative care." So, we had the International Association for Hospice and Palliative Care... formed by Jo Magno way back in the 80s... and they were focused primarily... they were an individual membership organization for professionals, working kind of like an American academy versus an IHBC; whereas we didn't, the providers didn't have their own sort of voice and therefore [inaudible 00:23:30] was self-perpetuating.

It's a great organization, but we needed to have a structure where the regional and national organizations could have a voice, and IHBC, at that time, wasn't really interested in doing advocacy work. They're now partners, we're all together. We were together with WH this morning on a conference call about WH's plan with work for palliative care. We succeeded in getting a resolution on palliative care passed in 2014, which was a huge thing for us, because it gave us everything we want, but of course, these are not enforceable. They're aspirational. Member states unanimously said, "We need to strengthen palliative care through the life course within our countries," but we still have only about 12% of the need being met globally.

And, palliative care is associated with dying, still, even though we do our best to try to say no to that. People with serious illness and extra layer of support they need and all that, but as far as the worldwide Hospice Palliative Care Alliance formed for that purpose, and then when the resolution passed, we sort of realized, "Well, who's going to do the work? Who's going to actually help get out there and help support local leaders, build up local leaders?" I also, for seven years, worked as the palliative care consultant for the Open Society Foundations International Health Care Initiative, run by Kathy Foley and Mary Callaway.

After I left at HBCO I was the lone executive to help get WHPCH started, but in order to pay the bills I had to work, so I got paid by Open Society Foundation as a consultant. Then I was working in dozens of countries around the world to help develop leaders in the countries: people who had stood up and said, "Yeah, I wanted palliative care." There had to be a champion, somebody who wanted to build palliative care in their own country for this to work. We had the wonderful fellowship program at St. [inaudible 00:26:10] Hospice that Frank and Charles... Frank Ferris and Charles developed... but that just sort of put a dent in the problem, it didn't resolve, that it was significant.

And then they were shut down by the US government. It's a Greek tragedy, of sorts, which we won't need to go into right now, but that... So, we lost that and then we ended up trying to do the equivalent of getting someone through a fellowship training in palliative care from afar, over a three-year period. Anyway, there's just so much work to do.

Connie Dahlin:

Well, it seems also like when you're the international party... and I only have a very small perspective of, it, just having taught in different countries and traveled... I mean, I think, in my mind, you have some countries like Vietnam or parts of Africa where they're looking at hospice and palliative care because of

HIV still, and we don't have that understanding, and you still have some places that really look at hospice and palliative care as cancer care.

And, in the United States, we're really trying to move beyond just cancer patients, but, I mean, you're much more eloquent about this, of understanding that the context of the health of that country is what are the diseases and what are their access to medications. I mean, I could just speak to my experience of... I delivered care in Guatemala six times, and this is a population that doesn't have access to healthcare. We really focused on indigenous populations, but that means that they're walking 6-10 miles to see us. In terms of medications, we can bring some stuff, but as you know from the US government, you have to be very careful about that, and then try to figure out the followup.

And then, doing my work in Honduras, I mean, it wasn't just... you had a lot of people who are interested, but then there's a whole safety issue, right? Even for us as visitors, saying, "You can't go out at night, it's not safe for us to go out." So, when you're trying to even travel... I mean, so there's just so many interesting parts because of the social structure. I'm just sort of curious, what are some of the things that you think about? Because I know you have much more depth of things than that. But then, when we think about international palliative care, that we in the United States, we want our students to understand because if they're only US-centric that's a problem.

Dr. Stephen Connor:

Yeah. Well, so we use the public health model to try to build palliative care in these countries. For WHO, it's the triangle. We actually turned it into a house, which is a much better model. But, the basic model is: policy, education, medicine, implementation. And so, you need bottom-up and top-down at the same time. So, you need somebody there who's starting the program, you need to support them. We were able to do that through the international, through Open Society Foundation because we gave grants to start home care teams, mainly in these countries.

The care is quite different because it's more driven by what we call community health workers, and this is a lesson for us, because we have all these sort of... I call them guild issues, because people don't want a half shift. The nurses won't let the aides do things that they can do just fine. We don't use volunteers adequately enough. Fortunately, we do get, I think, palliative nurses... hospice nurses do get a good... I mean, they are really managing the patients. They have to give the orders, and now we have a lot of nurse practitioners working in the field, and that's, I think, been a real boon, and even PAs.

But, it is remarkable how much... we have a project in Bangladesh that we've been running for five years, which is a laboratory for how to figure out how to provide care in [inaudible 00:30:31] resource settings. It's in one of the informal settlement communities of Korail, and the care is delivered by what was call palliative care assistants, who are trained by us, basically as nurses' aides, with backup from [inaudible 00:30:52] University in Dhaka physicians, and others come out from there to see the patients when they're having problems.

And, once of the problems with these community health worker programs is that they throw them out there without backup, and you get into a lot of difficult stuff with that. We do have to ensure access to medicine. That is a huge problem right now, everywhere outside North America, Australia, and Western Europe. We have 83% of the population of the world unable to access strong opioids for pain relief, period. I mean, either they're not available at all, or they're so highly restricted that you might get an injection once a day for 10 mg, and it just makes-

Dr. Lynn McPherson:

Why is this situation?

Dr. Stephen Connor:

Well, it's a bit complicated. People... and this was true in the United States. When I started working in palliative care everybody got a few shots of Demerol for pain control. That was it. So we had to train our physicians on how to use oral morphine to control pain and other more sophisticated things, but the basic principle has not changed in 50 years.

It's oral morphine around the clock, by the mouth, by the clock, to the person's needs, and what I hear from the government... well, the governments are afraid, and clinicians are afraid. They're taught in medical school that morphine is a terrible medicine, that it should only be used as a last resort, in the most extreme circumstances. They're terrified of causing shortness of breath after someone has... The only risk of shortness of breath is an opioid-naïve patient taking a large dose, as you know, Lynn, better than anybody.

And methadone's a risk, but by and large it's a very safe drug, and for even treating shortness of breath, of course, with morphine, which if you tell them that they go, "You're kidding. For shortness of breath? That'll stop them from breathing." They don't realize the legwork. But the other problem is the governments. There's a lot of countries that have a lot of illegal medicines. I mean, when I was working in Kirghistan, Tajikistan, those countries where you've got the order of drugs coming in from Afghanistan, the Golden Triangle, albeit through Europe, and they're... You can buy heroin in Bishkek for about the same price as beer.

Dr. Lynn McPherson:

Wow.

Dr. Stephen Connor:

They're draconian about it, but they don't quite understand the difference between illegal and illicit medicines and illicit use of controlled substances, so we try to educate them and try to overcome some of the fears and myths. But, and a lot of these countries are small. They don't have volume. It's really hard to make... the drug companies don't make any money. That's a huge part of the problem, because there's no financial incentive for them. They're awash in fentanyl at the moment, but they don't have any oral morphine.

Connie Dahlin:

yeah, which is also interesting to me because I know... and some of these countries... and I'm sure you get involved in this, of like, okay, so you're trying to do palliative care, you're trying to bring in medications, but then you're bringing in these medications that we shouldn't be using as first line: fentanyl patches, pricey... and methadone... I wouldn't want just anybody to be using that. But yet, you also don't want these people to suffer, so how do you help some of these situations?

Dr. Stephen Connor:

So, we had in 1961 a single convention on narcotic drugs pass. That was the first big global treaty to control psychoactive substances, control medicines, and that treaty put equal weight on availability for medical and scientific use and prevention of misuse. In the decades since, 1% has focused on [inaudible 00:35:55] been focused on access for medical and scientific use, 95% of the drug control has been around prevention of issues, and it's [inaudible 00:36:05], because the medical-grade morphine is not a problem.

People don't generally... they're using illicit drugs and making tighter restrictions on access to medical analgesics doesn't have any effect on the illicit market, and it doesn't... we don't really see problems that'll get use disorder in palliative care patients. I mean, we have some patients with a history of opioid use disorder, and we have to treat those patients a bit carefully, but usually... they have pain, too, so it's not necessarily a problem if you put in place some boundaries.

But we have a true opioid crisis. I mean, we've got serious problems because what happened in the 90s is we opened the door to treating chronic pain with opioids and made it okay if pain's a fifth-level sign, all of it... we all were part of that. I mean, we were pushing access to opioids for medical use, but we weren't... and Kathy and I used to argue about this... Kathy Foley... because I said, "Well, let's focus on palliative population. Let's not be advocates for everybody who has every kind of pain."

She and lots of other people didn't agree with that, and I think... I mean, it was an issue of rights, it was... there were studies done in the early 90s that showed very low incidence of opioid use disorder when people are taking medical prescribed opioids. But we were wrong about that, and it's because we didn't understand things that Charlie Cleveland taught a long time ago about self-medication. I mean, people using medications to sort of deal with their emotional issues and other problems.

We also have all the problems with polymorphism of the central nervous system, which is that we all react very differently to opioids. Some people, and I think this is where the 1% or 2% rule came. We have people hyper-metabolize some opioids, who just, first time they take an opioid it's like they light up like a Christmas tree. I mean, it's... being involved in opioid/heroin addiction treatment, I've seen this happen. One injection and they're [inaudible 00:38:47]. But that's because of their physiology, and then you've got all these people who are depressed or having emotional problems, self-medicating with medicine.

So, we didn't take all that into account, so it ended up being 20-some percent of people who were at risk. I mean, the majority of people don't develop opioid uses, or if they get Oxycontin for toothache or whatever.

Connie Dahlin:

All right, and I'm going to switch a little bit. And so, I was thinking of, you are in international work. What are some of the biggest challenges? I mean, you've sort of mentioned that there's really inequity in terms of access of medications, who can receive services. But what are some of the other challenges that you think are important that our students need to be aware of as they're becoming leaders?

Dr. Stephen Connor:

Well, a lot of it comes down to political will, and I mean, every country... especially these countries where there are limited resources, where people are paying a lot of the costs out of pocket, you have a two-tiered healthcare system. People with money are getting, paying to go to private clinics and get whatever care they want. That's good care. Everybody else has to wait in line in a public hospital, maybe get something if they haven't spent all the money for that month's chemotherapy budget.

And it's a really, I mean, a two-tiered system in so much of the world. That's a big problem, and palliative care is viewed as a kind of added extra, where we help them understand that really a lot of it is about training people to do care differently. I mean, education is a huge part of this, because if we can at least get everybody who graduates from medical school or nursing colleges to have a basic understanding of palliative care, we think probably more than half, probably as many as two-thirds of the people who have palliative care needs could be managed by their primary care providers, if they had training. [inaudible 00:41:02] training.

Specialist kind of care is needed for people with more severe symptom problems, real difficult to manage tauopathies, and things like that. And for teaching, all those people who are doing... But really, palliative care should be part of primary care. It is the best model of care for non-communicable disease. We spend 80% of our money on acute care, but 80% of the people have chronic conditions they are being treated for.

That's another 80-20 problem. We should be reducing the overemphasis on acute care by doing the preventative work of working with people with complex chronic conditions, and getting them palliative care as early as possible, and that prevents them from going unnecessarily to the hospital, which saves the system money. I mean, the whole argument for palliative care and hospice care is you prevent unnecessary hospitalizations, period. That's the whole argument. And there's very good evidence that we do: even in low and middle-income countries we're now seeing some evidence, limited amounts. Most of it is for high-income countries.

But, we have to get in there early enough to do it. A lot of time what we see with this brink-of-death care is that the referral comes when they're on their way home from the last hospitalization, whereas if we were in there two months prior they wouldn't have gone to that last hospitalization, and that's for health planners. I mean, we just argue constantly, having to pick that argument.

Connie Dahlin:

Well, I think you bring up, I mean, and that's something we think about, also, in the United States: kind of rethinking... we moved everything to the hospital. Is it time for us to move things back from the hospital into the community, and palliative care can do that. And, sort of thinking about what does it mean... I'm just thinking about the World Health Organization. They have the two reports, one on integrating palliative care as part of primary care, and then the other on building pediatric palliative care, which I know for somewhat developing countries children don't live as long just because the diseases that we take for granted-

Dr. Stephen Connor:

Oh, yeah.

Connie Dahlin:

Yeah.

Dr. Stephen Connor:

Kids, for mortality, 20% in the United States, 80% or more in low to middle-income countries.

Connie Dahlin:

Wow. 80%.

Dr. Stephen Connor:

Yeah.

Connie Dahlin:

Wow.

Dr. Stephen Connor:

That part of the challenging kids initiative, and are partners at the International Children's Palliative Care Network. Julia Downing and I are.

Dr. Lynn McPherson:

Can I ask, do you hold out any hope for improvement on the international front?

Dr. Stephen Connor:

So, yeah. I mean, we published this little ditty, which is... I added... it's got the World Health Organization logo up here in the corner, which took Herculean efforts to get. But, this is an advocacy publication. It's a little book that basically tracks how we're doing in palliative care, paints a picture of palliative care globally, and we were able to... This is the second edition. So, we also have several parallel research projects that we're doing. One of them is on mapping levels of palliative care development.

So we had, in 2011, we published in 2014 with data from 2011, that we estimated that there were 16,000 palliative care services globally, and caring for about three million patients. And, in 2017, when we redid the, six years later, we're up to 25,000 providers, programs, services, and seven million patients getting palliative care. So, we are making progress. It's slow, and of course the need for palliative care is ramping up. It's going to almost double by 2060.

We had the Lancet Commission Report, which I think has been a great tool for us to use in reframing palliative care to be around serious health-related suffering, not about dying and prognosis approaches to these things. It's a package, minimum package of palliative care in that report that Felicia Knaul, with Eric Krakauer, did a lot of the work on this. But that package is what we're using to try to get palliative care embedded into universal health coverage benefit packages in countries.

The world, I mean, the sustainable development goal number three, is good health and wellbeing, and in that, through point six, is universal health coverage by 2030. We're not going to make it, but we're making progress and we're working with those countries that have made a commitment to universal health coverage. The United States is not one of them, but we do have a kind of universal coverage because the safety net.

We also just finished a project with our friends in Spain on coming up with an agreed set of indicators at the country level for palliative care, measuring palliative care progress. The 18 indicators, 10 core indicators. We're pushing for one of the core ones to be the measure for universal health coverage by countries. We have one for NCDs, but these measures, it's like you'll say a measure didn't happen.

We have to have valid, reliable indicators and measures with publicly available data so it isn't a Herculean effort for a country to measure something, like just simply the thing of how many services are there per million population in a country. Is there a national action plan or strategy for palliative care in the country? Are they budgeting anything for palliative care? Is there an office at the ministry of health? Do they measure quality? They're also going to be releasing the results of the quality of death and dying index that comes from the Lien Center. It's been done.

So we have several tools to sort of measure and prod countries into improving palliative care, and I think we have a good case for support as to why palliative care should be part of every healthcare system. We were successful in getting it included in the continuum of services that defines universal health coverage: promotion, prevention, treatment, rehabilitation, and palliative care.

Dr. Lynn McPherson:

Great.

Dr. Stephen Connor:

That's something I'm proud that WHPCA accomplished in getting the UN to include us, because they didn't. They are always focusing on prevention treatment and neglecting the rest of the good stuff.

Connie Dahlin:

I'd just say they are also, in the sense of even though they have a definition, they forget that all of us are going to die at some time, right?

Dr. Stephen Connor:

Yeah.

Dr. Lynn McPherson:

I'm not. I've decided I'm not.

Dr. Stephen Connor:

The death rate is stubbornly stuck at 100%.

Connie Dahlin:

So, Stephen, there's a lot, and it seems like you've persevered and you've pivoted from starting hospice to then thinking about the research part on US spaces, to then the global part. Are there things that you're worried about at this point?

Dr. Stephen Connor:

Well, corruption is still a big issue, sucking away resources that should be used for the public good. That's happening in more of the world than we'd like to think. That's tough to fight against. We are staunchly non... we don't take bribes, we don't bribe people to get what we want.

Connie Dahlin:

Right.

Dr. Stephen Connor:

We had a nice story from our friends at Casa Hospice Esperante in Brasov, Romania, had, with funding from a UK charity, built and developed an absolutely first-rate inpatient hospice with daycare and all kinds of bells and whistles, and the government, the office in Bucharest that granted your license to open was demanding a bribe from them, and they wouldn't do it, and it just went on and on. So, they finally decided they would contact the major newspaper in Bucharest, and on the front page of the newspaper was a headline that said, Ministry of Pain, and the problem with not letting them open... they were open within a week.

Connie Dahlin:

Wow.

Dr. Stephen Connor:

So, you've got to be a bit careful about naming and shaming. Sometimes that can backfire on you. But that time it worked quite well and they moved ahead. But, it is a problem, and again, it goes back to clinical will. I mean, the prime ministers and presidents of both countries, and the ministries, have a lot of health problems to deal with, and palliative care's not at the top of their list.

And so, we're just getting it to where this willingness... Sometimes it takes people in power to have a relative die of cancer or something else, or those things to happen, and some of it is really about leadership. I mean, you take a woman like Odontuya Davaasuren, who's the mother of palliative care in Mongolia. Mongolia, we have a six-level mapping levels of palliative care scheme, and about 20 countries are at the highest level or top level. Mongolia's one of them because of her absolute determination, and twisting a lot of arms, and training a lot of people, and having the strength to just never to give up, to just persevere and to convince people and be passionate and inspirational. She was a graduate of the San Diego Fellowship Group.

Connie Dahlin:

Oh, wow.

Dr. Lynn McPherson:

And India has made some good strides, right, with Palliative India and Dr. Raj?

Dr. Stephen Connor:

Dr. Raj is a saint.

Dr. Lynn McPherson:

A force of nature.

Dr. Stephen Connor:

He's wonderful, yeah, and Suresh Kumar, who runs the Neighborhood Network, a project in Kerala. Kerala has sort of been the incubator for palliative care in India. They also have been the original model that everyone's adapted to do home-based care using community health workers and volunteers they trained, and they have thousands of volunteers in Kerala at work with patients, along with the aides, and the nurses and physicians.

So, there is a lack of mental health support within palliative care globally. We talk about how important it is. Our hallmark is whole person [inaudible 00:52:55] total pain managing physical, psychological, social, spiritual domains and dimensions of human experience, but yet we don't have very many people around with skillset of actually being able to help people with significant problems with grief or with depression, anxiety, with all kinds of problems we frequently see. Now, nurses and physicians, we can train them to do a lot of good interventions. They can be quite effective. But, we don't have enough mental health support, and honestly, that's true in the United States, too.

Connie Dahlin:

Yeah, I would agree. I mean, if you think about it, I mean, I think with hospice it's required, right? But for the palliative care programs, the people that they don't usually hire are the social workers or the chaplains, and so I think that's something to-

Dr. Stephen Connor:

Turned out with the pandemic that chaplains in particular were in great demand in the ICUs, and interestingly... this has been a bit of a two-edged sword with the pandemic. I mean, it has highlighted the importance of palliative care and healthcare systems, even while they've been shutting down other programs around the world and taking the beds for COVID patients, and seconding people. Sean and Diane... Sean works in New York... said they're the most requested specialty consultant in ICU at [inaudible 00:54:27], it was palliative care.

Connie Dahlin:

So, I think about for our students, you've had this long career, you've gone in different places. What would you say to them in terms of thinking about the future and stepping in?

Dr. Stephen Connor:

Well, I think... It's funny, when I hear people use the term "classic hospice". It's sort of like Classic Coke. They're talking about the Medicare Hospice Benefit, and they didn't realize that before the Medicare benefit, I mean, hospice was just doing things, whatever it took. People were volunteering time, everybody was bending over backwards to do what people needed. It was on a, not a high-volume scale. But, I guess if you're coming in the field now, be prepared for changes in the way things work and the way people get paid, because they're not going to keep paying us this much money for hospice benefits in the future. The carve-out is going to go away eventually, the Medicare Advantage carve-out.

So, we're going to see more health systems sort of picking up the torch, to some extent, in having to deliver some kind of palliative care to the patients they care for. I think we need to think more broadly, and we need to be much earlier with patients. I mean, getting them... the skills of palliative care need to be brought to bear much earlier. That's been demonstrated over and over again, that early introduction of palliative care. Make it part of oncology practice, make it part of cardiology practice. Make it part of respiratory therapy practice that palliative care should be initiated early on, when patients are sort of midway in their journey of increasing chronic illness and comorbidities.

And, we don't have to be so wedded an insurance benefit, and hopefully we just get more resources, as we said, shifted from all that money in acute care into community-based care. We need the communities to be involved here. I mean, I think... we lost a fair amount of that. We did preserve the requirement that hospices use 5% of their patient care delivered by volunteers, but we have close to half a million volunteers working at hospices in the US. We have about 1.4 million, I think, globally. Volunteerism is a huge thing.

We had, when we developed the family evaluation of hospice care post-death tool that we used in HPCO for years and years... it's now been replaced with hospice compare measures kind of hospice items that the... we were looking at what are the things that predict the highest scores of excellence for a hospice in the results of surveys, and we didn't believe it at first. We had to go back a couple times. Jo [inaudible 00:57:59] and I reanalyzed it. But, it was the percentage of volunteerism that was directed toward the patients in that hospice that actually made... which resulted in more what we call top-box scores: the fives out of five and ten out of ten scales, the absolute best score you could get.

The only thing that we could really see in that analysis that really made a difference was the intensity of the use of volunteers, and because people perceived that differently than they do... and no matter how good the nurses are... they are paid professions... this was the community supporting, and that meant something very different to the people

Connie Dahlin:

Well, and I think that that's something... I talk a lot to palliative care programs to say, "Just because you're a palliative care program doesn't mean you shouldn't be thinking about that. I mean, in this day and age there's so many high school students, so many college students who have to do community service, and you and I both know the volunteer role has changed. So, it may not be patient care, but it may be dropping off meds, it may be dropping off supplies, it may be taking... I mean, so as we use the younger generation.

But, a lot of palliative care programs haven't thought about the fact that volunteerism is still there, and I often wonder, it's because palliative care kind of coming out of an academic medical center, at least where I used to work, the volunteers were wives of physicians who wore these salmon-pink jackets, didn't want to get their hands dirty. Well, the role of the volunteer has evolved, right?

Dr. Stephen Connor:

Oh yes.

Connie Dahlin:

Yeah. So, anything else that you would say when you... we have these students that we're so excited, and they are going to be our next leaders. Any other sage advice that you would like to leave them with?

Dr. Stephen Connor:

Well, you're entering a field which is going to just increasingly be in demand as time goes on. Like they say, death and taxes. We're going to see... the demographers call it the Pig and the Python. That's the [inaudible 01:00:17] generation. We're moving through the age pyramid, and so we're going to see just a big increase in the number of people who need palliative care and hospice care. And, there's plenty of challenges. If any of you are interested in going, working internationally, I get a lot of people contacting me and saying, "Well, I want to go over and help start hospices in other countries. I want to do that." And, not that easy.

I tell them, "Well, pick a country, first of all, that you feel like you have a connection to and you have passion about. Go contact the people there, offer your services free or make yourself useful." I had a friend who used to run the National Center for Death Education, psychologist nurse, who just decided that she wanted to go to Zimbabwe... Karen Walgren. She's been working there for years, and she lives there now, and just doing tremendous teaching, training, helping out.

Eric Krakauer picked Vietnam as his main focus. He's worked in lots of countries, like I know, but he has been sort of single-handedly the one who helped Vietnam get going. There's lots of opportunities, but you have to sort of create your own opportunity. We all create our own realities. So, if that's the reality you want, you'd have to create it.

Connie Dahlin:

Okay.

Dr. Lynn McPherson:

Thank you so much, this was wonderful.

Connie Dahlin:

Yeah. This has been great. I think, Stephen, in terms of-

Dr. Stephen Connor:

Thank you.

Connie Dahlin:

... thinking about the breadth that you have, and your lens of being in the beginning and that whole part of also just as a leader, going from your community out to your state, out to national, to international, I mean, that's also another sense of leadership. So, thank you very much for your time and your thoughts. I think for our students-

Dr. Stephen Connor:

No problem.

Connie Dahlin:

... we've just offered you a whole different perspective of a little bit of difference from United States, and in comparison. And so, to understand some of the things to think about that we have as issues in the United States, and then thinking broader, and sometimes also having some gratitude for the things that we have. So, thank you very much.

Dr. Stephen Connor:

I think it's our responsibility, particularly as we kind of get out there in our careers, to help nurture, and mentor, and support people coming into the field. There will be plenty of challenges. I won't see the promised land of everybody getting palliative care.

Connie Dahlin:

No.

Dr. Stephen Connor:

It'll be long after I'm gone, but at least we can make a dent in it. Anyway, it's been fun being with you both.

Dr. Lynn McPherson:

Thank you so much.

Connie Dahlin:

Thank you.

Dr. Stephen Connor:

For the programming, it's really needed, and we have a handful of them that work. And, if there's anything more I can do to help, let me know.

Dr. Lynn McPherson:

Certainly will. Thank you. I'd like to thank our guest today, and Connie Dahlin, for the continuing journey in our podcast series titled, Founders, Leaders, and Futurists in Palliative Care. I'd also like to thank you for listening to the Palliative Care Chat Podcast. This is Dr. Lynn McPherson, and this presentation is copyright 2001, University of Maryland. For more information on our completely online Master of Science, PhD, and graduate certificate program in palliative care, or for permission requests regarding this podcast, please visit graduate.umaryland.edu/palliative. Thank you.