

Dr. Lynn McPherson:

This is Dr. Lynn McPherson and 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.

Hello everyone. This is Dr. Lynn McPherson, the program director of the graduate certificate master of science and PhD in palliative care. And as you know, this is our ongoing series of founders, leaders and futurists in palliative care. Our podcast series and these are being used in our educational programs. I'm delighted to be joined by Connie Dahlin who's one of the faculty members in both the master's and the PhD, and our guest today, Dr. Kathleen Foley. Connie, why don't you take it from here?

Connie Dahlin:

I'm so excited to have Dr. Foley. And I just don't even know, Dr. Foley, if you know you have a Wikipedia page?

Dr. Kathleen Foley:

I do?

Connie Dahlin:

Yes, you do. So in terms of introducing everyone, Dr. Foley has been in pain and palliative care and cancer care for a number of years. She was an attending neurologist at Memorial Sloan-Kettering in New York city. She's done a lot of work, which she'll talk about from working with the World Health Organization to working with the Open Society Institute's project on death in America. She has helped really support the research of a lot of people. There is a Kathleen Foley Retreat that's held every year to help new researchers think about how they're going to plan their future careers. And she's been involved in so many other pieces.

So without further ado, I'm going to let Dr. Foley talk a little bit about how she got into this work, and what was that in the time? So you are just telling us a little bit about how things started in the 80s.

Dr. Kathleen Foley:

I want to thank you, Lynn and Connie, and thank you for helping to further educate everyone in the world about palliative care. Because I think there's an enormous need for graduate level courses and for programs, and so I'm totally supportive of this. I think it's spectacular, and the world will benefit from it, so thank you.

Having said that, there's a long history and whoever tells the story tells it their way. So in part, this is my way or my perspective. My perspective is a neuro-oncologist placed in a cancer center, asked to develop a pain research program, and being confronted with, first in the early 70s, with large numbers of cancer patients who predominantly were receiving intramuscular pain medicine on a PRN basis, and sometimes we were given placebos. That was the 70s, that was the mid 70s.

I trained in one of the best neurology programs in the world. I trained in the best medical program in the world, you'd say, and never had I even written [inaudible 00:03:09] or an opioid for a patient as a neurologist, so that's like pretty extraordinary. So here I was placed into the circumstance to develop a research program when I didn't know a lot about pain.

Fast forward from that, it became clear that pain, we decided was a neurological complication of cancer, and was a pillar of the development of the field of neuro-oncology. And luckily I had an extraordinary chairman of that department, Dr. Posner, who felt that pain was critically important, and he convinced me to come to Memorial. So I was there with Dr. Ray Houde and with Ada Rogers, a wonderful, extraordinary analgesic nurse observer. And so I learned how to assess pain from Ada Rogers, from a nurse. I went on rounds with her, and I learned how to talk to patients, and I learned how to assess them, and I learned the methodology of doing clinical analgesic trials from Ray Houde and from Ada Rogers.

And so part of our research program was then to figure out who had pain and cancer. And the numbers that we found then are the numbers that still seem to pretty much exist, that a third of cancer patients in active therapy and two thirds with advanced disease had pain. And this is the same for children. Although in children, it was not typically advanced disease, but rather procedures that was the cause to a high occurrence of pain. And this was at a point in time that there was little expertise on many of these, now what are the standard components of care.

The hospice movement was burgeoning and I played an important role in the sense of being able to provide the evidence base for how to use drugs in pain with patients with cancer. We studied heroin and demonstrated that the Brompton cocktail, although widely useful for those in England, was not really necessarily going to be effective for Americans. One, because heroin is a highly charged illegal substance in the United States. And so the study that we did was, we were able, with support from the National Institute on Drug Abuse, to obtain confiscated heroin to give it in varying doses to patients compared to morphine. And to demonstrate that heroin was a great, good analgesic, but it didn't look any better than heroin, and patients didn't really seem to prefer it any differently. There were a small number of patients who seem to do better on heroin. And fast forward, they became a group of patients who we now think probably have different split variants of their morphine receptor.

So moving forward, we developed this program in pain. We argued for what the best guidelines and treatment should be of the cancer pain patient. And we argued that the opioids were the mainstay of therapy. And that the WHO at the same time, with colleagues in Italy, Vittorio Ventafridda and with John Bonica, who was at that point the President of the International Association for the Study of Pain, with Mark Swerdlow, who was a British anesthesiologist. We met together and said, "We need to do something that the WHO could take forward." And Jan Stjernsward was the then head of the cancer unit at WHO. And he was a great advocate for a WHO public health model for a cancer care of which palliative care was a critical point.

And so in 1982, we met in Italy and we had a meeting, from which in 1986, we published the first guidelines for WHO. They were field tested by Vittorio Ventafridda. There's a lot of controversy about how they were tested, et cetera. But again, they demonstrated that the majority of patients would require a strong opioid at the end of their life. And that led to the mandate of the WHO to have morphine as a central medicine.

So that was happening internationally, but back at Memorial where most of the work was done, our focus was on trying to improve the care of cancer patients with pain, yet, the majority of our patients died. And so we were really lacking in how we were going to provide really good end of life care. So we had good symptom management. We got that down, but we didn't have a process of care.

And through the 80s, we worked hard. We created the Supportive Care Program. We worked with WHO. We were developing, really, I think much of our efforts were focusing, my efforts were focused on improving pain for patients with cancer. And in that framework, we moved to begin to advocate much more broadly for a system of care that would allow patients to receive continuous supportive palliative care at home without requiring them to have to give up their active treatments.

So fast-forward in 1993, a woman, Patricia Prem, a social worker, and a friend of George Soros called me up and asked me if I would meet with her to discuss George Soros' interest in improving the care of the dying in the United States. And so we met and this eventually led to a program of which I became the director called The Project on Death in America. And I've sent Connie, I'm sorry, Lynn, I did not send you a copy. I only have a copy, but I sent a copy of this book that David Clark has written on The Project on Death in America. It's probably a little tedious, but there are elements in it that you might find helpful or useful. And David Clark, from the beginning as a sociologist and I would say a social historian, a medical historian, we contracted with him to write the history. And so he had access to all of the meetings and notes and publications that we had out of that project.

So fast forward, The Project on Death in America, which Susan Block became a co-director of the scholars program, was focused on improving the care of the dying in the United States. And from 1994 to, for nine years, we had \$45 million to improve the care of the dying. And although at the beginning, we thought this was an enormous amount of money, we rapidly saw that it was not anything about what we needed to do.

But luckily, the Robert Wood Johnson Foundation with the leadership of the program officer Rosemary Gibson, also had in this extraordinary \$250 million effort to improve the care of the dying in the United States. So we were lucky to be able to collaborate and partner with them and to learn from them and to work with them. And so what happened in the 90s was that there was this extraordinary attention to who dies? Where do people die? And how did they die? And so I went to Institute of Medicine meeting where it became apparent that we really knew nothing about how people died in the United States.

And so this fast-forward led to the report called Approaching Death, which was supported by the Institute of Medicine, which our Project on Death in America supported, to be able to look very critically at how we care for people in the United States. And then in 2001, a second publication was focusing on the care of children who were dying in the United States.

And so both of those, I think are landmark publications that anyone who wants to read the history of, at least the US history, should probably read. For those at an international level, probably they should read some of the early chapters in the Oxford Textbook of Palliative Care that were published in that same period of time, in the early 90s. Because they would give another tip of scope of what was happening internationally.

Our project on death in America was to support scholars, and we eventually had 87 scholars in various disciplines, predominantly physicians. We then developed a nursing leadership program that Betty Ferrel helped direct, and we had developed a social work program. And each one of those has been enormously successful because the current leaders in the field: the physicians, the nurses, the social workers, are the leaders. They're the people who, in my mind, have taken over the world and moved and sustain the field. And so the social work program continues to exist. It continues to advocate and has been closely allied with the American Academy of Hospice and Palliative Medicine, although remains a separate group. And the nursing program, clearly the program evolved into HPNA, where there are extraordinary leadership programs. And many of the scholars are now out, 20 years, 45 years, and they're the editors of the journals, they're the chairs of the department, they're extraordinary leaders.

So that project had a very elite strategy. And I think this is important because what we saw in 1993, and what we saw in the beginning, and what we saw throughout the period of time, was that everyone knew there was a problem. Everyone knew that people who were dying were not receiving appropriate care. The majority of people were dying in hospitals. The incredible support study, so I think this is another study that everyone should have to read and think about and probably have Joanne Lynn

talk about it, because it was the game changer. It was a tipping point of where we moved to realize that how we care for the people, how we provided end-of-life care in the United States was profoundly limited.

And so in that setting, we focused on the idea that we needed a very sort of elite strategy. And our elite strategy was that to change medicine, we needed to do so from within. So we created our Trojan horses. So our Trojan horses were these positions who were assistant professor level. Most of them have not tenured who we supported their salaries for three years to be able to, and we supported part of their salaries. I think it was \$75,000 a year, maybe it was less, but not a huge amount of money. But allowed them to have time to cultivate and develop their research expertise or their academic components in educational research or advocacy at their institutions. And so those groups have now subsequently become the leaders, both in the US and we included Canada. So there were a series of Canadian experts. And so out of that group came Harvey Chochinov in Canada, Joanne Wolfe in the US, Jim Tulsy, and I could go on, and Bob Arnold, let me go on and on and on. So they're extraordinary. And out of the nursing leadership, again, extraordinary leadership that Betty led.

But the idea was that if we didn't have a health care, a cadre of healthcare leaders, that we were not going to ever change medicine. And there were wonderful reports. So it's fun if you go back and look. If you looked at the textbooks, Joanne Lynn did a survey textbooks and showed that in the textbook chapters in cardiac disease and congestive heart failure, when the algorithm got to congestive heart failure with every treatment, it then went back to other supportive approaches. It never said the patients died, yet, that was one of the leading causes of death in 2000.

So over this period of time, in developing The Project on Death in America, our focus predominantly was on this medicine piece. We did a whole variety of programs in the humanities. We did a series of programs in arts. We gave universities the opportunity to change their history or social science courses to talk about death and dying and do some kinds of meetings. And all of those I think were helpful in raising the public awareness. But with \$45 million, we didn't have money to do public awareness. And really, I think to the credit, and I think anyone who's tried to change a field has to decide what their narrow focus is or how they're going to get focused, and how they would benefit from it.

So Robert Wood Johnson did a much more public engagement. We did some great videos, one you would definitely want people to see. It's a video about developing hospice programs in prison, which was, it's a 20-minute film and it's spectacular. So coming out of that, and I'm being faster about but I will, and you can ask me specific questions, but coming out of that, at Soros, we were US programs, and they felt that we should exit it, the field. That we've been pretty successful and they weren't really totally willing to give us more money to do this. But at the same time, the Soros in Central and Eastern Europe and in Africa have foundations, and those foundations were taken up with The Project of Death in America, and they wanted us to help them internationally improve the care of the dying.

So fast forward, in around 2003, when we exited The Project on Death in America, we had started an international effort in 1997 in working with colleagues in South Africa, and then we began to expand that. And so then we had that project that went from about 2003, which is now exiting. So it's existed till 2021. The best way to know everything about that program is to read a series of papers that we published at the JPSM in about 2014 or 2015. And there's a story for each one of those papers. But basically the framework of that was, in 1999, at the European Association of Palliative Care meeting in Geneva, we brought together the staff of these foundations and asked them what they needed in their countries to be able to improve the care of the dying.

So these are program officers working in a foundation, and they're, again, extraordinary people. And they came with saying, "Listen, we need education, we need every type of training and we need policy. And if we're going to do policy, we need to have the WHO being the policy maker for us because

our governments will listen to policy." And so at that point in time, we developed and created this WHO model for palliative care and began working in that framework.

And again, each of these foundations took up this mandate, and they'd put \$30,000 or \$50,000 in their budgets. And we would match that from New York and help them to develop these programs in their countries. But we knew that they couldn't move forward unless they knew how to do needs assessments. So Steven Connor was a great help to us because he was a consultant and worked in many of these countries, helping them put together, bring together the stakeholders in the countries, bring them together and begin to focus on what was needed to develop a palliative care initiative.

And from the beginning, we only use the word palliative care, from the beginning, many of these countries had just small starts and volunteer hospice programs. Many of them had had the exposure to Robert Twycross or Cicely Saunders or to the English movement. So they were clearly well-versed in the understanding of what hospice was. But we were moving the envelope by saying, "This is palliative care. This is for the seriously ill, probably in the last years of life. And it's not just about end of life, but it's taking care of patients with serious illness." All of those papers exist and they are the models of some of the programs we did, so we created a roadmap of what a country has to do to develop a policy. And then some of the countries have reported how they did their roadmaps.

And then we provided support to develop essential medicines programs. And so working with WHO and working with the International Narcotics Control Board, and working with experts like David Johnson at the time, or subsequently James Cleary, and with Liliana De Lima creating a model of essential drug policy. And so that was critically important because the major problem, so drug policy is a critically an important piece of this, because even now, the greatest public health inequity in the world, this is by the public experts, is the lack of availability of strong opioids in middle and low-income countries. And so the WHO was very much on our side with the mandate that, and the focus was heavily initially on the cancer population, but then has in probably the last 10 years, so from 2005 on, expanded to include a much broader, more geriatric program, elderly population. And at the same time, the growth of pediatric palliative care has happened.

And so, again, as resources, Julia Downing recently gave a talk to us on a webinar for OSF as part of our exit strategy, about the developments of what's happened in international children's palliative care. And so I think it's a great talk and I'm sure she'd be willing to give it to you or be available to you. So reach out to her and she's obviously a PhD nurse. And so our efforts then from the Soros piece was that we had all these foundations, and we had people in the foundations who wanted to work on it, and we had countries that want it to work on this. So we were the arbiter of providing and networking these individuals to be able to get the expertise they needed to create a national needs assessment, to create a national strategy, to figure out how to advocate with their representatives, so from the leadership skills, and how to do appropriate drug policy.

And the stories for each country are extraordinary. So in Georgia, for you to get a prescription, you would have to go into the local police station and walk all the way to the back to a room where somebody sat at the desk and gave that prescriptions. In Ukraine, the most amount of medication you could ever receive, it would be 50 milligrams of morphine a day. This is regulated by the government and a nurse would come to your house to provide it. So there were just extraordinary examples of what we consider it to be really human rights abuses.

So concurrently with creating this network and these foundations, and trying to argue that there was a moral imperative to do this, we learned that people didn't really care about the moral imperative, and we needed more a club to teach them that they needed to do this better. And so we then began to coordinate with, first with Human Rights Watch, and then specifically with Diederik Lohman, who again, would be a great person to talk about how we could frame this within a human rights perspective. And

at the Open Society Foundations, Jonathan Cohen and Tamar Ezer were two leaders that were interested in helping human rights. And so they were great, again, helpful.

And so we created a campaign called Torture in healthcare, and we used Ukraine as the example. And again, this is extraordinary video pointing out the difficulties of an individual with far advanced cancer trying to receive appropriate pain medicine. He's a very compelling guy. His mother does everything possible. His friends do everything. The hospice is taken care of, try to help the best, but it's not enough because he doesn't get appropriate pain management. So we eventually use that advocacy in this campaign on torture to accuse the Ukrainian government of torture and healthcare. And they did change the laws profoundly. And what has happened in Ukraine is a great model of how palliative care, even though it's still fledgling and still moving forward, was able to change policy by understanding what the issues were and what the human rights framework was. So we moved from a health framework to a health and human rights framework.

And at the same time along, even though there's so many elements, so I'm hitting the highlights here just to keep it short. So what has come before is that these individual countries have created at, so we see the building palliative care at a country level requires enormous understanding of the environment and the local issues, at the same time is networking those individuals within international network. And so the International Association for Hospice and Palliative Care whom we supported and the Worldwide Hospice and Palliative Care Association that we also supported. We were supporting them through this foundation monies to be able to help network these individuals and train them and educate them.

And then as we move forward, we decided we really needed an international leadership program. And Frank first ran that, and that was a program that there were approximately about 22 fellows. It was a highly intense program. They each had a mentor. They each had some monies that they could use. There wasn't lots of monies, but monies that they clearly had at their discretion to use to be able to advance palliative care. And they came from Kenya, Zippy. So another person that would be great to have speak, is Zippy, who runs the Hospice and Palliative Care Association in Kenya. And she herself, obtained a PhD during this whole process, from I think a British University. And Zippy has been a great advocate and leader, but began as a Gracia's Hospice leader in Kenya. And Kenya has been a great model of how they change government policy, how they were able to train and educate physicians and how they were able to expand community workers.

So all of this is occurring during the Aids epidemic. And so we supported the whole movement of community workers, and these are typically 10 or 20 community workers with one nurse assigned. And I've been out on rounds with them in South Africa, and they're extraordinary. And they go from hut to hut and place to place, village to village providing care and providing medications, and on in Ziploc bags, morphine in these little Ziploc bags, pretty extraordinary, and being able to create a community of effort through these community workers who were incredibly well, were volunteers for the most part, but were well-resourced in understanding what their role was and how they could provide supportive care to patients at home with a nurse supervisor. So those were great community workers.

Fast forward from that, the leadership program, as I said, that Frank created, and then there 10 million other programs within all of that. That's the big picture piece. So we first did PDIA and then we did this international effort, and we were basically their advocates. But at every point there was a challenge, at every attempt to do anything, there were people telling you, you couldn't do it, and you shouldn't do it, and why would you do it?

And one of the criticisms of our program was that we never were able to create a civil society that rose up and fought for the care of the guy. So I think in defense of that, we didn't have enough money to do that, because any attempt to make change in what one's theory of changes, to do a change

of public attitudes requires extraordinary amounts of money because it requires the whole engagement of social media and a whole other dilemma. So we didn't do that. So we were always more of this elitist, we're going to make the medical system work for these people so that when the demand is there, it will be a system in place with people trained up to do this. And you see the groups that are just extraordinary.

Connie Dahlin:

Well, Dr. Foley, it's so interesting though, because I also wonder, and here we are, and you took us through, and I was thinking, also with some of the other countries I know, like in Vietnam, that focus for palliative care was on Aids care, because that's what it was the focus. So you also had to look at what diseases were there. But I think for the United States, in particular, and I'd be curious, it feels like we are the one country that is still so death denying. And even in spite of COVID, we're still death denying. So in terms of how you had to focus like the bang for your buck for your money, that is such a big change, right? To try to help people understand not only care for the dying, but like you are going to die. We're all going to die.

Dr. Kathleen Foley:

And the great line was that, for Americans, give me liberty or give me death, and death is always a second choice, so that's it. Definitely, the American perspective.

Connie Dahlin:

And I think, again, you've shown for our students who are listening to this, there has been this very coordinated strategy that you couldn't have people just off doing things by themselves because that wouldn't have been affected, but that you were strategizing and starting off with the pain with the WHO within the PDIA, but then at the same time you're working with the national groups in the United States in consistency and Europe. So this whole part about, also thinking about, you have this much money, that's always a big decision of how do you take that money and think about what's the best way to spend it? In hindsight, it's always 2020, but that you were trying to think about that and knowing, "Okay, well you have Robert Wood Johnson, where do you figure out your expertise of where you interlink, but where can you also be more effective by spreading out?"

Dr. Kathleen Foley:

Yes.

Dr. Lynn McPherson:

Well, I have two observations to make. You did a half an hour straight without inhaling, number one. And number two, you are a mover shaker, trouble maker, girl. Wow, I never realized. That's amazing.

Dr. Kathleen Foley:

I literally don't take credit because there are so many different people. And Mary Callaway, who, again, would be great for you to talk with, Mary was the associate director of the Project on Death in America. And she became the director of the International Palliative Care Initiative. She was the force that was even more extraordinary, I'm telling you. What an amazing woman. And everyone that we engaged with did what they were supposed to do. And it was incredibly collegial.

And I think the good news for us from the Soros side was that we didn't need to take credit for anything, because we had a funder, we had the money and we didn't need to raise money. So we didn't have to prove to anybody else that this was the best. The other important piece for us was that George Soros said that if you didn't have failures, you weren't funding the right people. So we had this extraordinary opportunity to fail. All right?

Dr. Lynn McPherson:

All right.

Dr. Kathleen Foley:

And at least in PDIA, the board was made up of people like Bob Butler who had been the head of the National Institute of Aging, and David Rothman, who was this extraordinary social historian, and [inaudible 00:31:48] who was a constitutional lawyer. So we had these great advisors who were very involved in the day-by-day activities of the Project on Death in America. They really bought into it. And so that was also quite extraordinary. It was just an extraordinary time of great people and a lot of convergence. And I think, it's still sad to say that in the world, 50% of the people in the world have no access to palliative care and the other 50% have it in varying stages. And the more high-income the country is the better access we have to palliative care. And if you look at the number for pediatric palliative care, we have 20 million kids who could benefit from palliative care.

So I think that the element, the big picture, this very big picture, is we're not going to have palliative care anywhere unless we have policy, unless we have the economics on our side, and unless we have the healthcare professionals. So anything anybody does has to focus on that. And some will focus on policy and become the best policy wonks. So anywhere you could have PhD people who know about the economics of healthcare and you can put them off into that and have them work on that. And anywhere that people that want to do policy and help them think about what policies you need to have and what are the model policies and how did they work?

In each country, Rwanda has taken on palliative care to the credit of Eric Krakauer and the group in Harvard, in partners in health, and has put in a national policy, and has made drug available, and has figured out some of the economics of it. There's an example that we think that Rwanda would do that. And Vietnam that you mentioned, Connie, one of the sad stories of Vietnam, from Eric was that they did not have much access to opioids initially. Eric worked hard in making that happen and there was a foundation there Atlantic philanthropies did support in Vietnam, and they helped co-fund some of the activities there, as well as Eric being able to get some US government monies. However, in one of the hospices, they basically had screaming room, because when it had no opioids, they moved the patient into the screening rooms, because they had no opioids.

Dr. Lynn McPherson:

That's just awful.

Dr. Kathleen Foley:

Well, but it was the reality. And you have to know, having been there, having been through South Africa and witnessing, South Africa was so much better than some other countries, because, at least in South Africa, we eventually were able to get morphine because they had a really rich, Liz Gwyther was the head of the hospice association there. So if we look at country models, Liz Gwyther is a great model for having to talk about South Africa. And it might be useful if you, 10 minutes of South Africa, and 10



minutes of Kenya, and what Anne Merriman did. So Anne Merriman, you have to talk to because she's Uganda.

And the wonderful thing that happened when we began our international palliative care initiative from Soros, was that Joe O'Neill became head of the PEPFAR program. And Joe was a friend and had clearly a positive perspective about how to move palliative care forward. And so he helped support the development of the African Palliative Care Association. But we were a major supporter of that, because we needed to know that we needed associations on the ground, made up of the people on the ground to be able to develop what they needed for palliative care, not what we wanted them to do. And every country is different. Every society is different.

So coming back to your question about this, Americans are not wishing to die, I'm coming to recognize that nobody ever wants to die. So I think, but when they catch onto the fact that they're dying, then they want to die well. So we need to somehow rather frame it as, "If you are going to die, this is how you should die. And that if you don't get palliative care, then you've missed out on the best thing that could ever happen to you."

So my perspective is, "What do you mean you died and you didn't have palliative care? Well, then you had crappy medical care, that's it." So we need some way or other to say, "What do you mean you didn't have palliative care?" And I think the work that Diane has done in setting up CAPSI, and again, Soros was a major supporter of CAPSI. He probably, this is post-PDIA, it was a grant that was made that didn't go directly to CAPSI, but eventually it came to CAPSI of over eight million dollars over a period of time to CAPSI. They had to match the monies, they had to do all sorts of other hoops that they had to jump through, but they eventually did. So Soros was also a supporter of CAPSI, and in trying to move that forward in the US.

So I think this issue of public attitudes is that various strategies do work, and there are people who teach you how to do campaigns and run campaigns, and we learned a lot from them. So some campaigns, we were out to go against the people. So we did, coming out of the human rights efforts, so I think, again, maybe you might get some human rights person who wants to [inaudible 00:37:15] PhD, and that person, we've published a whole series of papers, not me, but individuals in our groups, what are the human rights of palliative care? And what is the right to health? And then what is it for children's palliative care? What are the specific rights for adults? And now for geriatrics? And there's a whole move continuing forward. And COVID clearly was, showed where it failed, is how we took care of the elderly and what the rights of the elderly are to receive good end of life care.

So I think there's another whole dimension that you might have a talk on, on what are the human rights issues? And I think I have a lot of these slide sets that when I can find the access where they are, I could send you some, which I'm happy to give you. But I think it would be good for them to understand the whole human rights dimension.

So we started with the human rights dimension back with the International Association for the Study of Pain, where we said, "Pain relief is a human right." The WHO agreed with it, everybody agreed with it and it became a mantra. We then moved forward with the idea that palliative care was a human right, and created the background materials that you need to have to decide what makes something a human right? And then we went to the special repertoire on torture and pleaded before that body, that people not receiving adequate pain relief were being tortured, because they were receiving unreasonable care, and it was inhuman, and it met all the criteria.

And then what we did fast forward is when the Human Rights Council would meet, we would bring different countries to the human rights council and say that they had accused them of human rights abuses because they didn't have access to morphine available. I think that our human rights work

was probably more powerful than anything we ever said about moral imperatives or do the right thing or anything else, because there is a human rights framework that countries have to listen to. And by putting it into that framework, it was a powerful lens to advance palliative care. Because then we had a whole group of lawyers on our side who were brave advocates advocating for human rights. And we were educating another group of people.

And the second group who I think are so critically important, are the economist. So years ago, I had written a chapter for Dean Jamison in his burden of disease books. And he became a wonderful friend and advocate of making morphine available for patients with pain and cancer. And so, he just couldn't understand why it couldn't happen or why we didn't do it and all of the above.

And so fast forward from that, and this is, and I think it would be good, again, one could talk with Felicia Knaul to hear this story, we were able to develop a Lancet commission on pain and palliative care. And that report was published in 2018. And that Lancet commission report basically is written by economist. Felicia Knaul is an economist. It's written by a public health expert, her husband, who is Julio Frenk, who had been the head of the School of Public Health at Harvard is now the president of the University of Miami. We had Paul Farmer who, again, was really an enemy to palliative care at the beginning, who now was totally converted to palliative care. And Eric Krakauer was a major writer on that, an organizer on that piece.

And what they came up with was what we all needed, was the concept of health-related suffering. So health-related suffering was going to be the indicator or the measure by which we would evaluate populations to decide how much the government would then have to put out to cover the needs of the concerns of health-related suffering in patients. I would like you to know that the word suffering was never published in the New England Journal of Medicine. In fact, there's a paper about how they never wanted to use the word suffering. And yet we got this, [inaudible 00:41:23] body of Dean Jamison, and Felicia Knaul, and all these big international global economists to agree that palliative care was a human right, that it was a public health issue, and that health-related suffering was the way we should talk about it. And that governments needed to assess the degree to which their population suffered from health-related suffering. So there's a whole angle on that.

Connie Dahlin:

It's fascinating. I think what you're getting at is exactly what we're trying to think about with some of the people coming in from PhD, is that it's not just about clinical, there's so much broader to this writeup of: the policy, the social justice, the economics, the business, the public perception, all of it. And I think you're right, in these days, what people saw over the past year of COVID, I'll be very curious to see if that even sticks for them or if it fades, because they did see death in a very different way. I wouldn't say it was the way we wanted them to see it, although it was just the reality of what the pandemic has been and continues to be. But I think also this part of, I think what you're seeing, Dr. Foley, is, in one sense, we focus, people get so focused on just the clinical because that's right in front of them, but there's-

Dr. Kathleen Foley:

Yeah, that's not going to get us anywhere.

Connie Dahlin:

Right.

Dr. Kathleen Foley:

We need to have the best clinicians in the world. So everything we need to do is train them up, but it's going to be, the policymakers, it's going to be the economist, it's going to be the politicians, it's going to be those that make a difference. And I think, use CAPSI as a model, is an example where really it was a brilliant strategy, which I give enormous credit to Rosemary Gibson and to Diane Meyer and everyone who's worked on it, to be able to make it possible for healthcare systems to know how to cost account for palliative care. Because if we don't pay for it, we're not going to have it. The volunteerism is over. So anybody who thinks that this is going to be nice sweet care that we're going to provide, it's not going to happen. It's only-

Connie Dahlin:

Go ahead. [crosstalk 00:43:40]

Dr. Kathleen Foley:

I was thinking the financial people are so essential too. And I've come to grow to love them because they've helped so much. And that's why I think that Lancet article and [inaudible 00:43:51] that's out there, and then there's a newer one by Katherine Sleeman who looked at 12 more countries, is so important.

Connie Dahlin:

And when you think about where we've come in 40 years, I have two parts to this question. One, is this where you thought we would be? And two, what are you worried about for the future?

Dr. Kathleen Foley:

Well, as you can see, I'm an optimist. I've been in this field for a very, very long time, and I think it's come a long way. And I think it's come a long way at each of the levels where I think it's important. At the clinical side, we now have an evidence-based. So we were thought to be just these nice compassionate people, and now we've been evidence-based. And that evidence-based is growing day by day, by day, with extraordinary research coming out of nurses, physicians, economists, social historian, it's extraordinary.

We have a policy agenda. I'm going to put the world first because I have that interest, and then I'll come back to the US. So at a world level, by passing the WHO resolution in 2014, every country is supposed to develop palliative care efforts, and these countries signed on to it. So that WHO resolution was the stick that we needed to hammer over the heads of the politicians, and just say, "What do you mean you don't have a policy? You signed on and said you'd do it." And does that matter? It does, if you keep doing it. It does if you keep reminding people. It does if you do report cards. It does if it makes them not look so good on the international scene.

So for the example in Ukraine, when the minister of health was told by colleagues at another meeting, that there was torture in Ukraine because they didn't have available morphine, he was really embarrassed. And he said, "I got to do something about it." And that was moving him forward to do that. So there is a shame, blame component to how policies make a difference. But the WHO resolution was important. All of the work, and I haven't spent time on this, is all of the work that has been done to create a concept of a balanced drug policy, and what that concept of the balanced drug policy is. And understanding that what are the risks for availability of opioids and what are the benefits?

I'm optimistic that all of these stepping stones are there. And now I think they're moving out and becoming assimilated into systems without necessarily being called palliative care. They're going to

be called supportive care. I want to call this palliative care forever. Eduardo Bruera to succeed at MD Anderson called it supportive care. Every policy we've written has called it palliative care at an international level, so I wouldn't like to have to change that language back. Okay.

My optimism also comes from the point that other groups have signed on. So there are three different, I think that maybe there are two different documents, or maybe three, that a group in Italy did where the religions of the world signed on to palliative care. And so there are these three big declarations signed by the religions of the world saying, "Palliative care is essential." And it was Muslim. It was just a broad, broad group, but that was another group coming together, though we didn't necessarily know that they wouldn't. And then at the same time, the Vatican, and Pope Francis has his own definition of palliative care, which is very much like the WHO one. And basically the Vatican signed on to palliative care, with the idea that palliative care should be widely available throughout all their institutions and be fully supported. And there are group people like Carlos Centeno and a variety of people that have published on what the Pontifical Academy of Life, now it's called PAL-LIFE in their whole programs, so that's like another group that has come forth.

And these keep popping up in different places, new other groups. So my enthusiasm is that people are slowly catching on. Coming back to the US, I think because of the work of CAPSI, and really the work of the American Academy of Hospice and Palliative Medicine and HPNA, and a variety of the national hospice and palliative care organizations, all of whom seem to be on the same page pretty much with idea of how they're getting care paid for and how to get it paid for. I think that coming together is moving the care system forward better.

So I'm quite optimistic that it's going to still be bumpy, that nobody's going to race to thinking you want to have a palliative care doctor, but when you need it, you're going to want it, and you're going to have it. And I'm seeing more and more people who would not even mention palliative care to me, I'm here in the middle of Idaho and I met a local doctor here, and he said, "Palliative care really has changed what we do." And I sit on Cuniff-Dixon Award Foundation, and reviewing these hundreds of applications, maybe there's a 1,000 points of great doctors in these communities. It's a physician award, that are doing amazing things with whatever resources they can do.

So I'm optimistic because I think we're coming to become a more mature country that understands why we need palliative care. So we just got to fix the policy, we've got to fix the monies, and we need people like a Diane and many more like her who know how to do this. So, if you could train a whole group of Harvard MBAs in palliative care, that would be great. I'm using these as examples, but this is who we need on our side to do this. That's my optimism.

And probably what I think have been the things that we didn't do well, is we haven't created this large, huge, civil society of people who are out there marching in the streets, like the AIDS group. And it's because we're not a disease. And because anybody who has a disease, be it cancer, be it AIDS, be it LS, everybody wants a cure. So we, palliative care people, have to be on the side of cure. Okay? We just have to be on the side of care. So when, in 2001, we published with the National Cancer Policy Board report, improving palliative care for cancer, in every deficit, you can imagine. Do you know that at that point in time, the National Cancer Institute never used the word death. They only use language like mortality figures. When patients were sick and dying, they never talked about hospice or palliative care, except maybe in one line.

We had a student that went through every document. And the only people that talked about death were the military in their Department of Defense breast cancer programs, where when you go to those meetings, they have a picture of every dead woman who was in the military who died of breast cancer. Because the military memorializes the dead, the National Cancer Institute berries the dead. So we have to understand that this is our culture. Now, has NCI gotten better? Yes. Has the American

Cancer Society gotten better? Yes. But let me tell you, it took a long time for both of them to be on the page to talk about dying.

The American Cancer Society told me if we talked about dying, that nobody would want to get treated, they'd be so frightened. So I said, "Well, could we just listen to every one of your little groups and let's hear what the patients are saying on those groups?" And you get on a bladder cancer group, or you get in a breast cancer group, and you're just listening to the conversations. And their first thing is, "I thought it was going to die." Well, if it's their first line, we can help them. Because if you're going to die, we know how to die well. So how do we ... Both of you know this, so I'm just making the point, that you've been through it, you know all of these pieces, but it was so real at that time. It was constantly in our face.

When the National Cancer director, at the time, when we wrote this report, it was supposed to be presented to the board of overseers. It happened to be the day that the Twin Towers fell. I am in Washington, standing, waiting to get my presentation, and watching the Twin Towers fall, the meeting gets canceled, and it was like front death in that one, so that was the end of that. But then the NCI did move forward, and did do a lot of great programs, and did create a palliative care program at NIH, which to its credit, and did create a funding strategy for palliative care. But is it enough? No. Was it enough? No. One could go through a list of bad things that happened and negative things, but I'm not there.

And last thing on the opioid epidemic, as you know, and so this is it, as a major advocate of improving pain management for patient, clearly the large number of patients who are receiving palliative care, who had non-cancer pain, were individuals that we advocated for. And these were people who were dying, and as the support study show, that two thirds of the dying had significant pain. The nursing home patients had no access to pain relievers. This is in the US in the 1990s and 2000s, the work of Joan Teno and many other people, Sean Morrison. So, how do we separate the palliative care people from the other groups of patients with chronic nonmalignant pain? And then the debacle that happened in the opioid epidemic.

And so, I think that's been a terrible, terrible problem. And I think, I'm hoping that the pendulum will switch, will start swinging back appropriately. But in the process, a lot of science has been misrepresented, a lot of people have been accused of things that are not true, myself included, and both the pain patient with cancer or with serious medical illness is being undertreated for their pain. So that's a very big issue. So you should also have your people read the books about the pain issue if they're interested in that piece.

Connie Dahlin:

Yeah, I worry that too, of where we are in the pendulum and the politics. And I think though, the other thing that you went back to, Dr. Foley, is even just talking about, if you look at equity, the amount of opioids that United States has compared to the rest of the world to begin with. And then, I don't know, and both of you probably know much better in terms of the opioid crisis in the United States, how do we compare to other countries, even with any [crosstalk 00:55:25]

Dr. Kathleen Foley:

Well, they've used Germany as the example. Lukas Radbruch could talk to this. Germany has as much opioid per population, and they didn't have an opioid epidemic, because they have a care system. Those patients, they care. They see a doctor. They have an assigned physician. They have assigned physical therapy. They have assigned other approaches. It's pretty extraordinary. So this is an American problem

and an American disease created by a group of Americans in which everyone who plays should take some pieces of blame.

But the sad part of it coming out of this, is that the deep pockets of the pharmaceutical companies will go to hopefully help treat addiction, which I totally think is the most important thing that could happen, but it's not to do anything related to pain. It's not going to help with pain patient. It's not going to make drugs available. And the CDC guidelines have had really a significant impact on access to medications here.

So what I've worked on, I'm making this concept that opioids were a mainstay of therapy for cancer pain, and the WHO still says that, it's just not possible to get them in these country. And they're using the opioid epidemic in the US as an excuse. It's pretty extraordinary.

Connie Dahlin:

Is there anything that you feel like, you've offered so many places for our students to think about and all the resources, is there any other place that you feel like, as palliative care has evolved here, that we haven't focused on that maybe is, that's a place we just didn't go to or we didn't get to?

Dr. Kathleen Foley:

Yeah, I don't think that we probably did as well as we might've done, inside of closed systems like prisons, we moved it, there are hospices in prisons, but I think that's the issue. So I think this angle of prison film is really pretty amazing, and maybe you've seen it, it's 20 minutes but it's mind changing. They're [inaudible 00:57:39] through the walls and the doors of the prison, and the volunteers of a hospice are inmates, some of whom said, "The last time I saw a patient die was the person I killed." So pretty powerful. And creating rituals and support for those individuals.

I think pediatric palliative care too is so extraordinary, and that field is just blossoming forth incredibly well. And luckily, there were 43,000 kids in the US who die each year, at least. We should do this well. This is a no brainer, so these are areas we could do this really well. And there are such great physicians and nurses and psychologists and social workers doing this, so what a field? They're just extraordinary, extraordinary. I'm humbled by everyone who does this work because they're so extraordinary.

Connie Dahlin:

[crosstalk 00:58:40] Yeah?

Dr. Kathleen Foley:

I don't know, I think the question is will people who get this PhD be able to use it? And I think, yes, because I think every system is going to need to have individuals with this level of expertise. And clearly at an international level, so I'm really a fan of this, have you talked at all with Irene Higginson and the group with Cicely Saunders? Because Irene, obviously they do a PhD program and they've done one that, again, we supported through our International Palliative Care Initiative to encourage international PhD students. So they've had great students in Africa as an example.

But Irene now is in another position where she headed not only the ... Look, she's head of the, what is it? The Florence Nightingale School of Nursing plus something else, she has another component. So I think they would be great to talk with, because I think they're an extraordinarily great research group at an international level. So, if there's a way to work with them. And I think Irene would be good

because you're going to get an over the water view of this over the phone. And she's tougher on the field. I'm kinder to it. I think-

Dr. Lynn McPherson:

I've spoken to the people that run her PhD program and it's a very impressive program.

Dr. Kathleen Foley:

Oh, it's extraordinary. They're great. They're totally good.

Dr. Lynn McPherson:

Yes. There were three in the UK, Liverpool, King's College and Lancaster.

Dr. Kathleen Foley:

Yes, and Lancaster, right.

Dr. Lynn McPherson:

Yes.

Dr. Kathleen Foley:

And who is that? Sheila Payne is in Lancaster or? I'm not sure who it is.

Dr. Lynn McPherson:

No, it's a gentleman. I've forgotten the name, but-

Dr. Kathleen Foley:

But I think, again, the best is that if all of us can ... So what I found, if there's a way that no one feels in competition and in collaboration, creating that.

Dr. Lynn McPherson:

Oh my gosh, I talked to King's and to Lancaster and they were incredibly gracious. [crosstalk 01:00:48] insights and they wished us nothing but the best in launching our program. So I agree. I think we could use 10 more programs just like any of these to get the-

Dr. Kathleen Foley:

And I don't to know what you guys think is the future. What do you think the big challenges are out there?

Dr. Lynn McPherson:

Oh boy, that's a loaded question, right Connie?

Dr. Kathleen Foley:

Who's going to pay for this PhD then? How much does it cost to do?

Dr. Lynn McPherson:

It's not going to be bad, actually. It's going to a three-year program. If you apply yourself, you can get it done in three years. And tuition is not terribly high, all things considered. This is not one of those ... Most PhD programs, you bring the young person into your college, and they live in a basement for five years, and they get a stipend to be a graduate assistant. This is not like that. This is adult learners, it's completely online, it's asynchronous, they pay their tuition, they do their work, they're not a graduate student, and they have a full dissertation committee like everyone else. So we value a very, very, very practical applied process and education. So they're getting all the appropriate coursework. And I'm a little greedy. I don't want them to just be researchers, although they will be good researchers, I want visionaries who are amazing educators, who are advocates, both in their community, within the profession and worldwide.

Dr. Kathleen Foley:

Yeah, that's great.

Connie Dahlin:

I think also the other thing, Dr. Foley, is that, when we created the course, what I was saying is we have made it very clear. And you've gone that way, of saying, we need people who are policy people. We need people who are creating new technologies to think about this. We need people who are thinking about the quality of metrics so that when we're saying it's good, it's good. We need still people to think about what is this interprofessional work. Because I think where people mostly focus, and you mentioned this, is that, this part about heart, having the heart, and if we're good at clinician, everything will change. And I think that was lovely but the naivety that we've moved beyond that, and that reimbursement is important, and if people don't understand that reimbursement has to support a practice, they're going to fail.

And so really trying to give people this broader context to really show the evolution of the field, but also just the evolution of the world. And so, I think some of the people, you mentioned a little bit about policy and if we bring it to the United States, it's been 10 years since we've been talking about Pachita, and my question is, so if we need to move on from Pachita, then-

Dr. Kathleen Foley:

Well, tell me what happened. Did it pass or what?

Connie Dahlin:

No, it was about to be passed last year, but then it got pushed off the last minute because of the pandemic. But I just think in my mind, I'm-

Dr. Kathleen Foley:

And I think we started that in 1995 or six ... So this is a very long-

Connie Dahlin:

So it just was at some point of us learning with palliative care that one pain medicine isn't right, you got to think about this, started to, do you put all your eggs in one basket or do you start thinking of a multi-pronged approach? And what you were talking about of-



Dr. Kathleen Foley:

I'm sort of, let a 1,000 flowers grow, because you don't know what they're going to grow to.

Dr. Lynn McPherson:

Yeah.

Connie Dahlin:

Yeah. So I think that's what we're trying to think about. And I think you've given people so much thought about all the different pieces and that the history has been this knitting together of this fabric in so many different ways, of being woven together, and what we have now people would have no idea of so much history is behind it. And really, I think we have evolved. With all of the struggles, if you think about it from where you were saying, we had Brompton's cocktail and now we have all these different opioids, whether people can afford them or not by their insurance, that's beside the point, we at least have them. So we're trying to figure that out.

But then also, what you said of knowing which patients we should be using, what medications, and I'm thinking about all of these other pieces. I think that we are becoming more sophisticated. And I still worry myself about, if I think about program development, people want the recipe, and it's like, "No, no, there might be some ingredients, but you're going to use different amounts of everything." One program is one program. And you've already said this, it really depends on the context and the environment, even in the United States. What happens in a rural area in Idaho might be really different from New York city.

And so how do you learn, like what you said, a needs assessment, to take all that in and figure out the players? I do feel like the one place in the United States that we have a great amount to learn from other countries, is really this community health worker model [crosstalk 01:05:39]

Dr. Kathleen Foley:

Yes.

Connie Dahlin:

... so resistant to it because it's not medical. And yet, if you think about communities and having that broker, if you will, who knows the community, who can translate that, who knows the resources, maybe if we start integrating that more, and then we shift from a fee-for-service model, maybe that's where our hope is. And so that's where I think about this work in the community, that that's where we're going to look at Africa, looking at-

Dr. Kathleen Foley:

And India had this extraordinary community.

Connie Dahlin:

Right.

Dr. Kathleen Foley:

Well, that wasn't really extraordinary model. Although in the beginning, when I was in Missoula, I think the Mayor of Missoula, Montana, who also was an academic, was a believer in communitarian theories.

And so he, part of Irene's project there was all about the community. I have to go back and look at that, but I think he did a lot of work on community work using Missoula, Montana. And he was funded by RWJ. But I do think in looking at clearly middle and low income patients, that this issue of community workers tied to ...

So there's a group, do you know this group called, I think it's called City Health or City Health Advocates or something, I don't know if you know about them? But what they've done is they've contracted with Medicaid to get patients, keep people out of the ERs and keep them going to regular doctors on a regular basis. And so I recently was talking with someone who works for them, and they are, this is a master's level, has a master's in public health, who was doing this kind of work, where she's acting as the community health worker and getting them to the right doctors, getting their diabetes under control, that sort of thing, and is this mediator. So he has a skill for ...

I think that's a great kind of model. I gathered this group. I can send you the ... And I'll look up their name. But I'm quite impressed with that. It would be a great model for the palliative care piece of this. Because it's the population as well who often doesn't receive adequate care and then ends up wanting, or whether they want or not, getting the Cadillac of care that they don't need, and also not necessarily respecting their choices for how they would like to die. So I think that's another kind of a great model that would be possible.

I think there are lots of different smart opportunities. But I think my concern is, is that we're just not going to have enough great doctor leaders to do this because everything has gotten so hard to do [crosstalk 01:08:22] because everything has gotten hard to do. And everything in medicine is transactional and not person centered.

Connie Dahlin:

Right. I think the only other place that I think also we can learn internationally is when you also look at health disparities and some of the structural racism that also includes palliative care. And so how are we going to break through some of that? So if I think of what you've done in other countries, we probably also have a lot to learn in those areas as well.

Dr. Kathleen Foley:

Oh yeah. The people are just extraordinary in what they've done. But that I can only tell you across the board. As much as they say, "Well, people in Africa are more accepting of dying," I don't think India is accepting of dying. [crosstalk 01:09:07] No, I think, but there are cultural aspects of what happens and then how they do this.

Dr. Lynn McPherson:

Well, Dr. Foley, This has been magnificent, truly magnificent. You are, I admire you so much, and your lifetime of work, it almost moves me to tears, truly.

Connie Dahlin:

Yeah, it was great work, so lots of good supporters. Okay, so thank you for what you're doing.

Dr. Lynn McPherson:

Thank you very much. Connie, any last words for you as we wrap up?

Connie Dahlin:

This transcript was exported on Aug 17, 2021 - view latest version [here](#).

No, thank you again for what you've done and thank you for all your wisdom for this [crosstalk 01:09:37]

Dr. Kathleen Foley:

Let me know how you're doing. Okay?

Connie Dahlin:

Well, we're going to make this a required recording for our students because you have offered so much for them, and so we're grateful for that.

Dr. Lynn McPherson:

Yes. Thank you.

Dr. Kathleen Foley:

Bye. Take care.

Connie Dahlin:

Bye.

Dr. Lynn McPherson:

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 2021, 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](http://graduate.umaryland.edu/palliative). Thank you.