

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.

Connie Dahlin:

Hello everyone. My name's Connie Dahlin and I am one of the faculty with the University of Maryland Master's Program in Palliative Care. And I am joined as usual by Dr. Lynn McPherson, who is the Director of the School of Pharmacy and Graduate Program with a master's in palliative care and this PhD in palliative care. We are really thrilled and honored to have really one of our best supporters for palliative care, Rosemary Gibson. Rosemary has been in the palliative care movement for a long time and a little different from just being clinical and on the ground. In fact, she's been more formative for us because she had particular place in terms of being in Robert Wood Johnson and being in other places to kind of think about why palliative care was necessary and some of the issues about it.

Currently, she is a fellow at The Hasting center, another important organization for you as our students to know about that really sets the culture of care. But she has such a rich background in terms of being an author and a writer and a grant writer, and really understanding this whole part of health care reform. And she's done a lot of work with the American Hospital Association and really helped foster and support some of the work that you heard from some of our other speakers, from Ira Byock to [Jeannie Twitch 00:01:57], to Betty Farrell, to [inaudible 00:21:42]. All of these people have had an interaction with Rosemary. So we are really thrilled for you to join us.

In terms of starting, I guess I've kind of given a background for why I think it's important. I would love for you to kind of talk, Rosemary, about your kind of entry into, what we call palliative care might not have been called that at the time, what sort of intrigued you and what sort of made you feel like, okay, I'm going to be part of this because I have a passion and I can see change needs to be made.

Rosemary Gibson:

Well, Connie, first of all, thanks to you and Lynn for your leadership over the years and for what you're doing now to cultivate future leaders. Hello, everyone. I hope you have a very fruitful and truly satisfying enriching career in palliative care, both for your professional life and meaningful to you personally. I was at the Robert Wood Johnson Foundation in the mid 1990s. I had just come there. RWJ is the largest healthcare philanthropy. And there was a major study that the foundation had funded. It was a randomized trial about patients in the ICU.

And long story short, the results were published in JAMA in 1995. And they reported that even with a tried intervention to improve people's experience with serious illness and toward the end of life, even with that intervention, it didn't work. That people still died alone, in pain, their preferences not known, let alone honored, their symptoms were not managed. And I'll never forget watching on the television news, ABC News that night when Peter Jennings, who we know later died of cancer and had palliative care, he reported on this study and it was all over the evening news that how we cared for people at the end of life was basically terrible.

So the foundation had funded this study and there were some, folks at the American Medical Association were not very happy about it, because it showed that we were not doing well by patients. And so I thought, well, maybe I can do something about this. I was still young, green at a philanthropy.

At that time being in a philanthropy, you had a lot of flexibility and freedom. We were called social entrepreneurs back then. So I would say, well, maybe we could do something. And the response I got was Oh, no, you can't do that. It won't work. The academic centers are just too tough to take on.

But then there was something that was happening that changed everything. So Connie and Lynn you remember the name of a person that had 90% household recognition name, And that was Dr. Jack Kevorkian.

Dr. Lynn McPherson:

Oh, gosh.

Rosemary Gibson:

If you want to know what prompted palliative care, it wasn't studies, studies help. They provided the data, but you had a physician out there and you'd see him on headline news even on 60 Minutes, he was helping people with serious illness end their lives with physician assisted suicide. And I'll never forget watching a 60 Minutes segment with Dr. Jack Kevorkian, a physician from Michigan. And he helped on live TV, a gentleman who wanted to end his life. And that caused such a, my term mortification, among leaders in medicine, the American Medical Association. It takes a lot to rattle the AMA. And so what that did was it created the will and the realization and openness that we needed to do something. And that's what we needed. And this is a great lesson. If you want to make social change, you need something that lights up everybody. It's not a political, it was across the board that we have failed. And that gave an opening for physicians, for nurses, for others to say, you know what, we're not really good at this.

And the first grant that I worked on is with the American Medical Association to create a 101 course in palliative medicine. And it was exquisite. And it was done by Dr. Charles von Gunten, who was the lead author of EPEC, Educating Physicians on End-of-life Care with Dr. Linda Emmanuel, who was at the AMA. And the response to that was absolutely extraordinary. There was a physician from the Marshfield clinic who said, "This is like feeding manna to hungry people." We have to remember that at that time, there were maybe one or two hospitals that had something called palliative care. It was Kathy Foley at Sloan Kettering, but it was small. It basically didn't exist except for a few people who were doing it individually.

So I went to some of the EPEC trainings, and I just saw the reaction of physicians. They were never taught how to do this. And as I said earlier, before we got started, if you picked up a medical or nursing textbook, you would never know anybody ever died. And so we started to change, well, I'll get to that in a minute. So I went to some of the EPEC trainings, and they use the best of pedagogical methods for teaching, and there was role playing. And I saw that physicians felt comfortable. One woman stood up and said, "I'm an ICU physician. And I just learned today that the way I then extubating patients has been wrong all my entire life and I've been teaching generations of students wrong way. I have been causing unnecessary suffering to my patients." This is what was coming out.

And I'll never forget Charles von Gunten, who was then at Northwestern, he said, "I remember as a resident, there was a patient who was in great distress. And he walked in the room, said something [inaudible 00:08:44] and walked out. And he said, he did that because he didn't know what else to do." So there was this opening. And EPEC took off. It's been gone around the world from what I understand. And it was a trainer-trainer model, not centralized, but bottom up. And I said, well, we need something for nursing. And I remember Dr. Betty Farrell calling up, she had an idea for a project. And I said, Betty, we need an EPEC for nursing. And Betty Farrell just took that and ran with it and created a 101 course in palliative nursing and did it for all different levels of nursing. And that too has gone around the world,

translated in multiple languages. I call ELNEC the story of the loaves and fishes. And I felt terrible when the money was running out, but Betty and her team just kept going and going because it was the right thing to do.

And once again, I'll never forget the evaluations. What people wrote about their EPEC training. The nurses was, absolutely stunning. This was meaningful to people personally and professionally. This was not what we see so much in healthcare today, top-down, you better do this. This was a true grassroots movement of people who knew either through their family life, people they've seen in their own families or what they saw in a clinical care setting that said, this is terrible. And that was a huge force coupled with a societal factor of Jack Kevorkian out there doing what he was doing saying, we got to do better. That just lit this bonfire. And the first thing we had to do was help people know how to take care of people with serious illness.

There was a lot of end of life focus back then for palliative care because of what Kevorkian was doing, but now it's migrated to, this is just good care of people with serious illness. So that's how it got started. And that was the beginning of a \$250 million investment by the Robert Wood Johnson Foundation. And I had the privilege of being the architect of the programmatic side over that for about 10, 12 years.

Dr. Lynn McPherson:

Wow.

Connie Dahlin:

Wow.

Rosemary Gibson:

And we can go into the sequence. The first one was, I can keep talking, but please interrupt me-

Connie Dahlin:

[crosstalk 00:11:14] No, no, no, please. I think this is really important because I think, Rosemary, one thing that you have done that nobody else had really mentioned is I think this embarrassment of palliative care. We've talked about Kubler-Ross, we've talked about Florence Wald, we've talked about [Sicity Center 00:11:27]. We didn't kind of talk about this person Jack Kevorkian in the United States of how much that effect. So I think it's important for our students to kind of remember that while we sometimes think of this as a kumbaya moment, that there's been some social pieces that have happened and continue to happen. If you think about the whole Death With Dignity movement, and so I think this is really important. So please go on because you're bringing up things because you are so in the middle from a very different perspective, and that's exactly what we need these leaders to hear, that there's a clinical perspective, there's a historical perspective, there's a philanthropy perspective.

Rosemary Gibson:

And all these wonderful clinical and other people I met are just extraordinary people. And I saw my job as a philanthropy is simply putting gas in them, giving them money for gas for their cars so they can go and do what was their passion and what they were really smart at doing. But there's a, you reminded me of something like Connie, that hospice was out there, but it was out there and it was viewed as something separate. That's what they do in hospice there. And for many years, the great people in hospice were toiling out there. And we need to bring that type of care into the settings where still back

then and probably today, most people die. And in hospital settings, they die terrible deaths because they're surrounded by machines. Sometimes you can't even see them. And we forget that there's a real person there.

So the first part of our platform, and I would say this palliative care work was the first time that RWJ, I developed a strategy and we had strategic objectives and we had measurement, that had never been done in philanthropy. So first it was educating the physicians and nurses. We started there. And I relate a part of putting content out there. I said, okay, so what will motivate people to want to learn this content? So I went to the licensing exams, the US Medical Licensing Exam and the NCLEX, the folks that do the NCLEX exam at National Council State Boards of Nursing. And I said, would you like to put this content on your exam? And given what was going on in the whole society they said, absolutely it's time.

And so we funded an effort to have a great clinical people, physicians work with the National Board of Medical Examiners and for nursing leaders. I think Betty was very involved in that to work with the NCSPN. So put it on the test because this is important enough in our profession that we need to know this. And then the American Board of Internal Medicine, they did a two-part series that just flew off the shelves. It was a 101 ABM for internal medicine. And then they had what was terrific volume two, a set of one page case stories written by physicians about their experience of caring for people with serious illness, some good, some not so good. And that gave the motive, this is personal as well as professional. And we brought the two together. And I think this is why this palliative care field has moved very quickly and has been pretty successful in growing.

We have a long way to go, but it was because it engaged people emotionally at a visceral level, as well as being part of our profession, that we need to know the science. We need to know the clinical application in the care of patients to achieve better outcomes.

So that was the first platform of providing educational opportunities for physicians and nurses. And we stuck with that because it was great to see in EPEC, you had social workers and lawyers and ministers. Again, that umbrella extended very broadly and that happened on its own. So that was a part one. And then what was happening was we were getting calls from people that wanted to know, how do I do this? How do I set up something called this palliative care program? Because, Connie, you mentioned you were at Mass General with Dr. Andy Billings, and you guys were one of the first. And Charles had his program at Northwestern. And I remember talking with Andy and Charles, and they said that, we're getting all these calls from people. And that said to me, now that people were becoming knowledgeable about the science and the practice of palliative care, they wanted to know what can I do when I go back home to my organization? Where do I begin to actually put this into action?

So the conversations with Andy and Charles and others, we said, well, we need something to help people set up a palliative care program and to learn from those who have started doing it. And that's where I came up with the idea of a center where people can, it can be a hub for this knowledge development exchange and acceleration. So I went up to a visit with a Dr. Diane Meyer and Dr. Christine Castle at Mount Sinai Hospital in New York. And they had a palliative care program at their hospital as well.

And I went to them for a variety of reasons in part, because Chris was, Dr. Castle was well-known to the medical community, had been at American Board of Internal Medicine, knew leaders in medicine like the American Hospital Association. So she could make great connections. And Diane was a truly committed clinician. And I think she says this publicly. She said I've been thinking of leaving medicine and just going to open a bookstore or something. Because there's many of your people listening to this right now, understand there are some real challenges. And there were challenges back then. And this was back in 1998 or 1999. So it was happening very quickly.

1995, the study was reported in JAMA. Jack Kevorkian was out doing what he's doing, helping people end their lives. We started EPEC and ELNEC the next year or two. So in 1999, went up to Mount Sinai and I said, would you submit a proposal to the foundation to start a center? I came up with the name of the Center to Advance Palliative Care, and they did that. And in 1999, CAPC was launched. I got some pushback from a lot of people saying, well, why are you going to Mount Sinai? It's not exactly a great place that exemplifies what's going on. And I had a number of reasons for that. And it turned out to be quite successful.

Here we are. CAPC just, because what we needed was an... This was a model that the foundation had used called National Program Offices for different initiatives. We would set up something called a National Program Office that would take a national leadership role in taking an idea, a concept, putting it into practice and working with people around the country. And so CAPC took off, it just celebrated its 20th anniversary about a year or so ago. And they've successfully evolved into a membership model. They got off philanthropy. And so what we needed was not just good clinical knowledge, but business sense. We need someone who can create and sustain an organization. And we had to use different tools like social marketing, because the message for palliative care, this is an important lesson that I learned for being at RWJ, you need social marketing to, how do you message, how you message a physician is different than, and how you message an oncologist versus a trauma physician or a family physician is very different from the message that you'll give to a surgeon, for example. And then it's a totally different message for nurses, and yet a totally different message for hospital CEOs. How do you get hospital CEOs on board to support establishment of a palliative care program?

We had to bring in finance people. We have to render to Caesar what is Caesar's. So how do you make the financial case for palliative care? And that's not because we wanted it to be monetized, but that's just the reality of the organizations we live in. And I'll never forget a story that was published in The Wall Street Journal below the fold, when it was people read physical papers about how palliative care can actually add value to hospitals. And you can bet that that was read by hospitals CEOs.

And I'll tell a quick story. You mentioned you had Patrick Coyne on as one of your participants in this series. At the time Pat was at Virginia Commonwealth University Hospital and they were having some people to come in and help the hospital be more financially viable. And they were worried that they were going to be cut. And back then MCV Hospital was a public institution. And so I put them in touch with a great capability that was developed at CAPC and their financial algorithms about how you can show that you're making a contribution to the organization, not just for patient care, but you also know how to talk to your financial people in ways that they'll understand. That was absolutely critical. And when you had that capability, financial people would say, oh, well, this makes a lot of sense now, you're talking my language.

Again it's, in a good sense, social-marketing thing to help them understand what this is and how do you help them make it work for their institution. And so the folks that VCU hospital, they took advantage of CAPC's toolkit. And after the consultants left and gave their report to the board, they were so excited that the report that they gave to the board was palliative care should be integral to this hospital. So we needed to develop all these different tools if palliative care was going to live and thrive in the real world. But now we have the challenges of how do we remain faithful to it. And I'll get to that in just a minute.

So I think one of your questions, Connie was, was there a turning point? When did you know that this was going to happen? And here was the moment. So one of the things we did when CAPC was set up, we had funded Bill Moyers who came to us. He was from PBS, did documentaries on a whole range of subjects, highly respected as a journalist. He came to us and he said, "I watched as my mother

has gone from aging to dying", and he wanted to do a documentary on this. And after a lot of work and hours and hours of filming many of the leaders in palliative care, you probably remember that Connie. A four, I think it was four and a half hour, four, maybe six hour documentary over four nights was aired on PBS. And what we did to ensure that hospitals knew about it, because what they did was they showed what care could be like, how it could be better for people with serious illness. And it was hospice hospitals, and it was absolutely stunning.

After the fourth day, after six hours, I didn't want it to end. It was so good. And it gave a platform to so many people in the field. So when that program aired and a letter had gone out to every hospital CEO saying, by the way, this is going to be on, we hope you'll watch it. And here's what we had very quickly, CAPC had been only open about nine months and sent out information on palliative care. After that aired, foundation had been contacted by 25% of US hospitals saying we want to do what we saw on that program.

And that's when I, I'm still getting chills. That is when I knew that we were there and CAPC had arrived at exactly the right time. And the confluence of communications, clinical, in clinical side of an organizational side. And now the communication side to communicate broadly to the public. And so I remember talking to our board of trustees, I had to get approval for all of this from our board. And they were generally very, very supportive and they said, okay, so how many hospitals will have palliative care programs by X? And I absolutely had no idea, but I pulled a rabbit out of the hat and I said, we'll have 1000. And there are about 5,000 hospitals at that time, 4,800. And that's the exact number, about the exact percentage, 25% of US hospitals that contacted us. And there's more, but I'll just stop there.

Connie Dahlin:

Wow. Amazing of just you were kind of thinking of all these things. So you had started ELNEC and EPEC because of the support study, which the students, you will have to read the support study, that's part of your required reading. But also of thinking. So when you had ELNEC and you also had CAPC, talk to us a little bit about, because we had Ira on what made you think about this promoting excellence [inaudible 00:27:18]?

Rosemary Gibson:

Yeah. Promoting excellence was the first thing we did right around the same time of EPEC. Because frankly, we didn't really know what to do, but we put out a call for proposals. And I still have that call for proposals up in my files. And it was called Promoting Excellence in End-of-life Care. And it was simply to say that this is an incredibly important issue, we need to fix it. And we want to hear from you the field, from community-based, hospital-based, how can we promote excellence in end-of-life care? So that was the first national program. And so, announced that we were going to be in the space.

And you've heard from Ira and Jeannie who did a magnificent job with promoting excellence. And I'll never forget there was, they were a grantee and they said, when we got this call for proposals and we were all in the meeting room thinking about how to respond to it, people just applauded. That was something whose time had finally come. And we got so many proposals. We couldn't fund everything, but there needed to be a focal point of national leadership to say, this is important for our country, for our health, obviously for patients and their families. And you've heard about the whole variety of projects and how they morphed into some great work in communities across the country.

What was especially extraordinary was the national advisory committee that we brought together for promoting excellence and end-of life care. I give tremendous credit to Ira and to Jeannie for cultivating that advisory committee. These were leaders in their medicine and nursing and other

professions. [inaudible 00:29:31] Raphael from the Visiting Nurses Service in New York City, an icon in the field. Rich Payne, an African-American pain and palliative care physician who was, what was it, Sloan Kettering, and then went to Duke. Rich Delapena from Kaiser Permanente, that inspired him and he led the palliative care development at Kaiser Permanente system.

And I'll never forget that after maybe seven, eight years, the program was coming to an end. Nobody wanted it to end, but we had to end it. And nobody wanted to leave this advisory committee because it formed so beautifully. Again, because of people's personal, as well as professional commitment. And this experience of, we call it social change, it addresses the head and the heart. It's not something that comes Massive, from Medicare or CMS, but this is truly grassroots. And if you look back at the history of hospice, hospice was grassroots because something was terribly wrong, and palliative care had that same grassroots and that's what helped it grow. And then we have the challenge now of when the grassroots meets reality of this big system that has its own purpose and operates too often for its own benefit and not the benefit of patients. And we should talk about that.

Dr. Lynn McPherson:

No, I think that would be great. Given what you know and what you see now what, what keeps you awake? What are you worried about and what are some of the directions that you want to tell our students as leaders of where they need to move to or help go to the next level?

Rosemary Gibson:

Well, I remember giving a talk at the American Academy of Hospice and Palliative Medicine, which they invited the nurses that year. And now they've merged, they've come to, Connie, you know about that, right? And I said, how do we remain true to what we've started? How do we ensure fidelity to the principles of patient and family focused-driven palliative care as we grow up as a field, because we basically built a field. If I had to think of a contribution that we were able to do at RWJ, we built this field because it didn't exist. We had hospice, which was an incredible contribution, but we were able to build this field.

I'll tell you an ending story before we leave, remind me to do that, but it's out there. And I remember having an email exchange with Dr. Steve Schroeder, who was then president of the Robert Wood Johnson Foundation and he was internal medicine position at UCSF. And I give him tremendous credit that he let us run with it. He allowed us to lead and he was always there to guide the ship, make sure we were going in the right direction. And I said to him, "Steve, I'm very grateful for your leadership because that's what made this possible." And this is a lesson that today is really tough to do, that organizations often don't give people the room to lead.

So I have to give credit where credit is due, that Steve's leadership allowed people, allowed me to lead, be a servant leader, really, to the people who wanted to do better. And all this time, Connie and Lynn, I'd be on the phone with people, leaders in the field and say, how do we do this? I remember talking with Dr. Susan Block about how can we get into this, the medical licensing role, get in there to put this on the exam. And she was brilliant because what did I know? But just like in palliative care, you have to listen. You have to ask and just sometimes just sit and listen. And people will tell you what to do. They'll tell you how to do it. It's not that we had any knowledge at the foundation. I didn't have any knowledge. I knew nothing of this, but knew enough that we had to just listen and then make judgements.

Dr. Lynn McPherson:

Well, if I could say one thing, when we were doing this, Connie said, "We've got to talk to Rosemary Gibson." And shame on me. I said, I'm sorry. I don't know who that is. And she explained to me who you were. I was like, oh, okay. Oh my gosh, you must be so tremendously proud of your legacy. The things that you started 20, 25 years ago are still leading the field today. You must be laying in bed at night and say, dang, we did a good job. It's amazing.

Rosemary Gibson:

Well, Lynn, let me tell you, this is also, I'll tell you now, this is an incredible story. And it's why we do what we do. So a couple of years ago, my sister, my older sister called and said she had been diagnosed with cancer. And she had gone through some treatment. And then nine months later she needed a major surgery. And so I went up, this was at Brigham and Women's Hospital in Boston. I would have to see her after the surgery and she was on the oncology floor. And I was in the room. I was actually very impressed with the care that she was receiving. And I've written books on medical mistakes and overtreatment, so I'm a pretty tough customer. You know?

And so she went out for a test or something. So I'm sitting there in her room and a beautiful young social worker comes in and she sits down. And she said, I want to thank you. I said, well for what? I had never been there at this hospital for, I didn't know her. And she said, well, your sister's oncologist from Dana-Farber had told your sister, Julie, that the care she was getting was because of what I had done. And I had no idea how they knew anything. And that was the first time that I realized that she was in the palliative care unit on the oncology floor at Brigham and Women's Hospital.

Dr. Lynn McPherson:

Wow.

Rosemary Gibson:

It gets better. The bedside nurse had done the ELNEC course because I was chatting with them about how they got into palliative nursing. The nurse manager on the floor had done the 18 month course at Harvard Medical School interprofessional for mid-career people. They'd come in for a couple of days, several times a year.

Dr. Lynn McPherson:

I did the program too.

Rosemary Gibson:

You did? I had provided seed funding to Andy and Susan to start that program.

Dr. Lynn McPherson:

Of course, you did.

Rosemary Gibson:

These were the people taking care of my sister.

Dr. Lynn McPherson:

Wow. A small world.

Rosemary Gibson:

And that was my last visit with my sister.

Connie Dahlin:

Well, you know what, it's sort of interesting, Rosemary, as I actually started my nursing career on the surgical oncology floor at the Brigham. And so it was very interesting for me because at that time going way back, the Farber used to have their own floor and the Brigham had their floor. And so patients would come over and go over. And it was very interesting of this concept of palliative care and hospice care and these conversations. And just thinking about how far we've come. But I think what you really remind us is there's this interesting social context, this philanthropy, this social change that happens that has to be a partnership and collaboration between people like you, who are visionary to understand something is not right and we need to figure out a strategy, to clinicians who want to do it, to the CEOs who need to fund it, to this other architecture behind that kind of is the structure upon which we have healthcare. There's so many different parts.

And so I think that the part for us is helping our students who are going to be leaders saying that there is a social change and there's so many constructs from a messaging to providing a care, to thinking about the financial picture. And you've been such a part of that, which probably when you started out and thinking about some of the ethics and the medical errors and things like that of quality to then palliative care, that was also just an interesting transition as well.

Rosemary Gibson:

That's a number of great points there, Connie. Just two things I want to share with you from being with my sister for that period of time. This is school of pharmacy, right?

Connie Dahlin:

Mm-hmm (affirmative).

Rosemary Gibson:

The quality of the pain management that she had was extraordinary.

Dr. Lynn McPherson:

Good drugs that are living through chemistry and better dying through chemistry too, right?

Rosemary Gibson:

Yeah. And the second thing is the importance of listening to the patient and family. I remember my sister telling the story of what it was like to go from where she was in Massachusetts by ambulance to the hospital. And she described feeling every bump, how painful that was. So I'm sitting in her room and she was out. And I heard the nurses and the doctor talking, they weren't talking to me, but they were talking among themselves. And the doctor said, well, how about hospice? And the nurses said, the family doesn't want that, meaning me. And here was the reason why, for her to be physically moved, it would be so painful. And thank heavens for the nurses who understood that. And that taught me so much about, we think we know, but we don't really know until we ask and engage.

And one of the best questions, and I think this is something for everybody, was taking care of patients. And Connie, you probably, both of you know this. It was first taught to me by a physician up in

Wisconsin. He said, his favorite question to patients is not what treatment do you want or this, or do you want hospice or the clinical trial. He said the most important question is, what's important to you right now? People can answer that question and they will tell you, and what was important for me was my sister was getting great care and I didn't want that disrupted nor to have her suffer just for the sake of being moved because, well, it's a different payment thing. And I couldn't have asked for anything better than what happened.

The other thing that was really wonderful, and I've learned this from the social worker, I thanked her, she also said, thank you for my career in palliative social work. The other thing I learned is the importance of telling people when they've done something, to let them know. That's an incredible gift you give to them. And the other bigger picture is, the good work that you've done, Connie, Lynn, this will come back to us, the people that we love and we make the world a better place. And that's what I say to future leaders who are listening. You have the opportunity to figure out how to make it better and it's not easy, but when you do, it's extraordinary.

And you know how I knew we were right on track? It's not what I thought. You can't have ego in this. It's when we would get letters from the Robert Johnson Foundation, someplace up in New Jersey, we got letters from family members.

Dr. Lynn McPherson:

Wow.

Connie Dahlin:

Wow.

Rosemary Gibson:

Somehow they found us out and they got to us. And I remember a letter from a woman whose husband died in a palliative care program in Ohio that I think was involved in the palliative care leadership centers. And she just thanked us. And she said she saw that we're going to be giving more support to help more hospitals do this. And she said, I just want to thank you for what you've done for my family, for my husband and my family.

And when you get that kind of feedback, that's when you know, it's not the performance reviews at the hospital or the metrics. This is where the real conflict is for people working in these complex systems. You have your duty to Caesar, your boss and the organization and all its metrics. And then you have the duty to the patient and their family. And too often that conflicts that creates a lot of angst. And I just hope that palliative care, back then I called it, here's what I called palliative care and what I observed. We were rescuing people, physicians, nurses, others from the rising waters of the Medical Industrial Complex and putting it there. We're getting in lifeboats to get out of those rising waters and create something different.

Connie Dahlin:

Wow.

Rosemary Gibson:

And those rising waters are still there, and even more than what they were. And it's a huge challenge. How do you take good care of people in these systems? And I've watched how palliative care people were interacting with, because I still go out to palliative care programs, and I see the frustration how

many palliative care patients they have to see in a day. Well, this is not your eight minute primary care visit, which also is not right. That's why I say, how do we remain true to this in the environment in which we're working. And it's not easy. And I think having conversations about that would be really important.

Dr. Lynn McPherson:

Connie, I don't think is going to get any better than this. I think this was a wrap right there.

Connie Dahlin:

I think there's so much for our students to think about and thank you so much for just your vision and your steadfast commitment to this and the fact that you're still committed to going out and seeing programs. And this whole, as you said, architecture of thinking that. I think that's such a great metaphor. And I think again, you were the first person who was really thinking about this continued social change and our commitment. So, again, it's just really been such a delight to speak with you and an honor to kind of hear your vision from your perspective. So thank you.

Lynn, do you have any other last comments?

Dr. Lynn McPherson:

I just have to ask one last question. What is your background? Are you a business person? Are you a healthcare provider? How did you get this vision? Where did this come from?

Rosemary Gibson:

That's a great question. I'm a graduate of Georgetown, which I'm so grateful to have had that opportunity. And I had a good generalist education. And I didn't realize that at the time, the importance of that, that you just don't study a certain track, a certain professional line, you study life and philosophy and you study theology and history. Those were required courses back then.

Dr. Lynn McPherson:

Wow.

Rosemary Gibson:

And also it's how you live your life and your commitment to want to do something and to do it with humility. Someone said, if you do good with one hand, the other hand shouldn't know. So you can't have any ego in it, but just do good and find good people. And Mahatma Gandhi said this, "When there's a good cause, people will pop up." We had a good cause and people were popping up. And how do you give them something great to do? And it was such a privilege to be at a place where we had the resources to make that happen.

Dr. Lynn McPherson:

Well, we use one of Mahatma Gandhi's lines as the motto of our program, "Live as if you were to die tomorrow, but learn as if you were to live forever." So we're all about lifelong learning. So thank you so so much in-

Rosemary Gibson:

[crosstalk 00:47:42] Thank you so much, Connie. Thank you, Lynn. What a real pleasure.

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Dr. Lynn McPherson:

All right, thank you.

Connie Dahlin:

Thank you.

Dr. Lynn McPherson:

I'd 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. Thank you.