Dr. Lynn:

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:

Welcome everyone. We are having another one of our podcasts for our Palliative Care PhD program. I'm Connie Dahlin one of the faculty for the University of Maryland. Graduate program of Masters in Palliative Care. I'm joined by Dr. Lynn McPherson who's the Director of the Graduate Program and the Palliative Care Masters at the University of Maryland. We are really, really honored today to be talking with our colleague Dr. Nessa Coyle.

Nessa has been a nurse leader in the United States for many years, and I don't think people understand the depth of her involvement. She'll get to tell us more, but just to give you a sense. Actually, Nessa's career began in England and she was actually looking at the other spectrum of life when people get being born. She came to the United States and really was involved in palliative care before we even called it.

She was at Memorial Sloan Kettering and providing care to cancer patients and working in pain management really in the sense of doing right for the patient. But we hadn't really established what was hospice, what was palliative care, what was supportive care? She really had left a mark at Memorial Sloan Kettering because she became the director of the program. She started a nurse fellowship program there, which was one of the first in the country.

She and Betty Farrell wrote a book on suffering in the area of nursing. She and Betty also started authoring the Oxford Textbook of Palliative Nursing, which is now in its fifth edition. She has been teaching nationally and internationally. So has just had such a wide effect both on nursing as a field but on so many different clinicians in helping them learn this art and science of palliative nursing. So, welcome Nessa. We are so pleased that you were able to join us today.

Dr. Nessa:

Thank you Connie, I'm delighted to be here and to be part of this conversation.

Connie:

So when you think about your career... Which I will just also have to tell everybody that Nessa now lives in New York and when you walk with Nessa, she uses one of the few people I know who can walk a block faster than anybody else. So when you're going to take a walk with Nessa, you better be ready. When you think about your career, and you came over to the United States, I'm sure you had no intention necessarily of ending up where you did. What was your intention when you came here and started working with cancer patients?

Dr. Nessa:

No, I enjoy traveling and qualified in London at some autonomous hospital in London, and then did I guess a midwifery up in Scotland in Edinburgh, Scotland. Then actually I'm a little bit later spent a year as a health visitor in the slums of London and working with really high risk mothers and small babies. So that was the trajectory. Then I went to Australia just to see a little bit of that country and to Malaysia and Cambodia.

So I was in this traveling mode, as I think many of us are when we first graduate and we're young and seeing the world with fresh eyes and enormous possibilities. Then I think it was very much my focus and my interest was in neurological nursing. I did I guess postgraduate at the Montreal Neurological Institute.

So that was really my focus interest of great interest. Then just in a way travel lost, I ended up in New York city where I had friends and spent a year at New York Hospital on the Neurology Unit. It just wasn't a good fit for me. I did about three months holding up in a friend's attic in Connecticut. Then there was an opening, a neuro oncology unit was opening at Sloan Kettering cancer center. A friend of mine said, "This may be a good fit for you." So that's how I ended up in Sloan Kettering just by chance.

Connie:

You thrived. I mean, you did so much there in terms of I know you had a partnership with Dr. Cathy Foley and Dr. Richard Payne, but you were really in the avant-garde of really thinking about this pain management and thinking about the field.

Dr. Nessa:

I think you give me credit where it's not really due. I think it was just this natural evolution of being in a setting which was incredibly nourishing for me. And being in an area where the issues of pain and suffering where just very evident. It was on the neuro oncology floor where a lot of people with pain were admitted because pain wasn't really a specialty in those days.

Kathy Foley was recruited by Dr. Jerry Posner really to look at pain and to try and understand and looking at the science of pain and to address its management. So it was really I was in the right place at the right time. In a way had a common spirit in a way of feeling in the world as Kathy Foley. So we formed really a nice team.

So it was a natural course of events which wasn't pre-planned, it just evolved. Just I think in a way that supported palliative care and the way it's being looked at now as really an integral part of care. It's just has evolved. So surely there's been some planning along the way, but it's been this natural evolution of a need was there. I was in a setting where the need was recognized and could be addressed.

Connie:

I think you mentioned something that I don't think some people would know is that, many people would take pain management for granted and think about the cancer floor would be the right place or something else, but you're saying that nobody knew that much. So it was in fact, the neuro-oncology floor that was thinking about the pain of the neurological pathways and looking at it that way.

Dr. Nessa:

Exactly. It was looking at the science and just as now in palliative care, we look at the science as well as the art and try to understand it. Understand what is it that people need and what is it that people are addressing. I mean, it's interesting because all the way through this idea of that's why nursing is very much in the forefront. I think of this idea of listing and trying to understand the meaning behind the words and to recognize suffering and to be quiet, just to sit and listen and to be present.

Then to try and sort it out in this multidisciplinary interdisciplinary way but what is it that people are asking for them? What is it that we're seeing here? Then how can we best address it? So lots of conversations about what we were seeing. Those conversations were part of both the art and part of the science.

We needed to understanding the art, needed to understand the science, we needed to understand the language, we needed to understand all of those. You're right, this was in the setting of neuro-oncology. Then because that's where patients with pain are usually admitted. That's where then there's this tremendous amount of suffering, not only on the part of patients but also on the part of families and when they went back into the community. In a way, it was this story, this picture Connie which was slowly unfolding in front of our eyes.

Connie:

Well, and I think that the other part of letting our students know that you had this clinical interest, but you also really felt about the ethics and the rights of patients. So getting your PhD and the students to know that I had worked with Nessa on a particularly important position statement, which is physician assisted death site. So I had to really see how Nessa's mind worked in the ethical part.

But if you can speak to your dedication to patients and what their needs were, and then getting into that ethical realm, I think would be really, really interesting for our students to hear.

Dr. Nessa:

That's another really focused interest in me. So it was the communication that was aligned with what were people asking for. That's what I focused on, that was my PhD research on when people in a cancer center where most people go wanting to live as long as they can. But there's a subgroup of people who are asking for hastened death, what were they actually asking for? And what was that language from them?

Then as all of this unfolded, I became again increasingly interested in bioethics and really the obvious nature that everything we do is underpinned by bioethics as the nature of our practice. Again, these folded into each other and I did, I guess, a certificate program in bioethics. The major person who set that up was Nancy Dubler.

So these were, again, all natural fits. As the issues of pain and understanding pain and the mechanism of pain try to sort out the tissue damage response of pain and suffering component of pain and trying to sort those out. Then how would revive management approaches to address this different etiologist.

Then it became very, very clear that we had to sub group of patients who when they came to the outpatient clinic, the pain clinic, there was enormous suffering expressed by them and the family was falling apart. They've come into our emergency room, the agile care for symptoms which could have been controlled with earlier intervention. So that we recognize that we needed to be able to identify this subgroup of patients and families who needed an extra level of support.

So we then developed a supportive care program which was an outreach program to these patients and families who were specifically in need. Actually at that time for one particular patient we did develop telemedicine and we have this whole telemedicine set up in his house which was really interesting. Now telemedicine is really such an integrated thing particularly with COVID.

So again, Connie, this natural evolution of these things built on it and the next, next, next. It was really the need to have one's eyes wide open to see what one was seeing and not just keep on going in the same old away but recognizing that things need to change. There's something that needs to be addressed here. That's both the ethics and the rights of patients rights to families and the importance of a team working together. So all of this initiative was under the department of neurology and they were very supportive of this program and it was teamwork and very much teamwork.

Connie:

Well, I think you speak to the importance of understanding the context. Being asked by you recognizing a need wasn't being met, working for the institution to offer some solutions and may not have been-

Dr. Nessa:

Yeah. I didn't interrupt you there because again, things that one could do early on, I was able to do it would be more difficult now and I acknowledge that. So as I learned that it's best to do something first have it working and then ask permission.

Connie:

I think that's what a lot of palliative care has been about, right. That we used some of our parts and we move forward. What's the saying, don't ask for permission ask for forgiveness.

Dr. Nessa:

Yeah, so that was a really there and it was easier to do in those days I think but perhaps not so many in us, so I recognize that.

Connie:

No, I think people still are trying to figure out when we want to do something different, people are so-

Dr. Nessa:

They do.

Connie:

... yeah, same to the cloud of stew. They want to just do what it has been and I think that's been some of the conversation I've been thinking about recently is that, we keep saying healthcare wants to change but everybody's saying, "But this is how we've done things." So it's this real part of knowing where we need to go, but people are afraid to change. The whole way our payment structure supports the old way and not moving forward. So that's a whole other issue. But I think when you think about-

Dr. Nessa:

Also... Sorry.

Connie:

Go ahead.

Dr. Nessa:

Again, there was a lot of institutional support from the neuro oncology unit, incredibly supportive it because it was working, it was effective and it was the right thing to do. That was recognized by everyone within the group.

Connie:

Well, then I think for you though, if you made this evolution from doing midwifery to neurology and then you also became a nurse practitioner and then you received your PhD. I mean, so you also continued to grow as a clinician, as you were gaining all of this and moving this program along as well.

Dr. Nessa:

Right. That's correct.

Connie:

So when you think about... And you've talked about being able to start this and getting a support, but were there other things that you felt were going on in the larger world of the development of palliative care that were significant for you as you were thinking about both moving the program along and your own practice and becoming more of a leader?

Dr. Nessa:

I think to begin with the program was very small and it was recognized that within institutions the need was huge. So the program needed to get large and needed to expand. I think that was one of the reasons and that had been already a fellowship program for physicians, this small fellowship program for physicians. There was obviously, because this was teamwork, the need for a similar fellowship program for advanced practice nurses.

Initially it was for clinical nurse specialists and then it became obviously very important that the advanced practice nurse was able to have prescription privileges and could move ahead in a collaborative practice. So then it became that it was nurse practitioners because in the State of New York, they had prescription privileges which clinical nurse specialists did not.

So it recognized that there was this expanding role that nurses needs to have specific qualifications coming into the program and that physicians or nurses needed to train together. So they both had specific needs which perhaps could be directed a little bit towards them, but they needed to have a similar background, develop a similar language, have the same scientific knowledge of how to address pain.

So that became obvious. Now the program's expanded so that now I think that there're five advanced practice nurses, as well as five physicians in the program. We've just started now to include a physician assistants in the program so that's new.

Again, so it's recognized the importance of nurses, advanced practice nurses in the role of palliative care. Also, with the recognized needs that also become responsibilities. So it's a very high level of practice that's required.

Connie:

Well, I think I'm impressed by that because I think one, we're still over many years later for our students to understand that physician fellowships started before their recognition of palliative care as a medical specialty. They weren't probably as organized and they're now some 70 or 80 fellowships, and some of the programs have seven and eight.

At any one time in the country right now in terms of APR and fellowships, there's like eight to 10. One is in the community. None of them allow for clinical nurse specialists, which is a problem because I think as far as APRNs we want to be inclusive and have both. There're some that have started to include a social worker or a chaplain, but I think we're still coping within hospice and palliative care. That ironically even though it was a nurse led hospice movement here in palliative care, it became very physician part and we haven't brought the non-physicians the same opportunities to have some of this training.

I think the second thing you spoke to is even when we have fellowships, we have to be very aware of the fact that there is content that all of us need to know and there will be role development that we need in each one of our disciplines. So, now I want all my students to hear from Lynn with all of the pharmacology part. She's not going to be able to tell people about the APRN enroll and I wouldn't be able to talk about the physician role, I mean the pharmacist role.

So we have to think about that. But we still haven't figured that out, I think and that's an interesting part that here we've been in this mode in this country if you just want to start till the hospice benefit we're looking at close to 50 years but we're still figuring out some of the education piece.

Dr. Nessa:

Right. Yeah. I think it's really important. I think that's particularly in this collaborative practice groups, it's whether or not both the physician and an advanced practice nurse sees every patient or does a advanced practice nurse have his or her own adaptive patients and the physician never sees someone that's not advanced practice nurse wants them to see that patient.

So all of that I think is unfolding and the issue of reimbursement and practice model of the particular institutions. I think all of that is unfolding. I think it's gone from just this evolution from pain and palliative care on the department of neurology, neuro oncology which is how it started at Sloan to palliative care which encompassed pain, although there's a separate anesthesia pain service.

Then over the last few years it's changed to supportive care. People have different views about that. I think it was because of this very difficult issue of that this feeling that palliative care was on the end of life care rather than being integrated throughout the course of the disease trajectory and not related to closeness to death, but related to need.

So that's from an oncological viewpoint even though it's clearly stated, it's still difficult for oncologists not to twin that with palliative care with end of life care. It became sometimes difficult for patients to be referred to palliative care, but it seems to be more acceptable to some, for supportive care. But I'm not sure the change in the language makes a difference.

Connie:

Well, it's interesting because you bring up... I mean, I think no matter what we call the patients we'll figure out what it is. So who are we palliating? Are we palliating the referring providers or are we palliating the patients? I mean, it's just interesting.

Dr. Nessa:

No, it is, I agree with you and it's not solved. But I think the other thing is there's such a huge need, Connie, that the reality is that. First of all, I think it's really important that everyone, every nurse and every social worker is a palliative care, a primary palliative care person. They have to have this basic skills on when you affect someone to a specialty palliative care program or supportive care program.

The reality is because the need is so great across the spectrum, that most people who've got referred to the palliative care specialty program have advanced disease, that's reality.

Connie:

Okay. I mean, and so that's also interesting because I think, where my work has been at least in my state in the last number of years is knowing what happens to the academic medical centers and then trying to bring it out to the communities.

In my small little state of Massachusetts, what happens in the community with a 25-30 mile radius outside of Boston versus the other side of the state, which borders on New York, Vermont, New Hampshire we still have patients there that don't have access to palliative care in their communities. They have to, believe it or not, Massachusetts is small I know, but they might have to drive an hour or two to get to a palliative care provider.

So that to me, I mean, speaks to your point about how do we ensure that all clinicians have these primary palliative care skills. But even also expand that, because when I think about the communities I think in some of these smaller communities the best refers are the physical therapists because they're seeing these patients. What do they have to do? They have to measure their function.

So what if we had them do a palliative performance scale or something like that, that would really push that. Or you might have the pharmacist in these small pharmacies who are noticing that all of these prescriptions are happening and going, "Hmm, they must be having more comorbidities, should I be sort of talking about that?" So it's an interesting evolution, I think, of where are we in this time of space of moving out the education and moving this whole concept of primary palliative care provider.

Dr. Nessa:

Right. I think that's, yeah. I think what's starting to being recognized in the oncology setting is most of the care now is at home and then the outpatient setting. So the need for really skilled and comprehensive palliative care, supportive care in outpatient setting in those clinics is absolutely essential. Then again, how the role of the nursing and the physician and advanced practice nurse and the RN, how those roles all work together and compliment each other.

People are still finding that out. The other thing that I think is incredibly important so it's a part of clinical ethics, but also this issue of communication and communication skills is absolutely essential. I work in the department of psychiatry and behavioral medicine as part of the communication skills team both teaching and facilitating in that for physicians and nurses and advanced practice nurses and RNs by the bedside.

So I think these skills understanding pain from a tissue damage response and from a suffering component, understanding clinical ethics and communication skills. Those communication skills really should be again, part of the skills that every single RN by the bedside, and also certainly advanced practice nurses.

Starting those conversations with patients early on, just early on so they're not frightened by palliative care. They're not frightened by this whereas this possible normal conversation you have with every single patient about their values, what's important to them. What care do they want and then we're addressing them periodically. So it becomes a normal conversation that you have with every patient and with every family.

So I think normalizing these things that we do as a way of practice as comprehensive practice is really important. I think that played a big role in this. So in skills, it's the science, the art, it's clinical ethics. Being a part of a clinical ethics consultation team and it's communication. These are all advanced practice nursing skills which are essential. The fundamental-

Connie:

I think also taking advantage of those educational parts. I don't if you remember this. So for our students Nessa came to visit me at my setting and I was asked to do a teaching session for case managers. I brought Nessa along with me, and we did a talking about palliative care and we were asked to do a role-play, so Nessa and I had not practiced. I think you were playing a woman with breast cancer and I was playing the nurse interviewing.

We did, it must have been about 10 or 15 minutes and by the time we were done the case managers were in tears. But it was so powerful because I think what they were allowed to see was you need to go deep sometime and that these weren't easy conversations, but that at the end you could do a much better care plan because you've actually asked the questions. But the power in that was the emotion, I think. I just remember you and I hadn't practiced, we looked at each other and said, "Okay, we'll just try."

Dr. Nessa:

It's best not to practice, it's best just to be spontaneous. But I think this idea of sitting with the emotion and listening and I think to be able to sit on to... The other thing I think that because some of these situations can be so distressing and so upsetting, but to recognize that I have always worked with an internal anxiety thermometer when I feel that going up and up and up inside me I've learned to recognize that and to quieten it down.

Because if you're anxious when you're sitting with a patient and your mind is full of self-talk, I don't know if I can do it as if I can sit here, you're not listening to the patient and not being present.

Connie:

Right. I think of that, I mean, and you have had so many different experiences. I would love for our students to be able to hear, you've traveled the world and teaching and you've taught in places where there was translators. But then you've taught in places where the conditions were just varied. I'm wondering what some of those lessons for you about teaching internationally in some countries that were more developed than others, how did that enrich your practice and what did you learn from that just in terms of global palliative care?

Dr. Nessa:

Well, I think, the principles of the same. Perhaps tell you, Connie, I mean, it's sitting by the bedside and listening and understanding what the nature of suffering is of that person. Then what's possible within that area. There's no point in talking about things which are not possible. So what do they have available and how can you teach people how to use those things?

So talking about pain, so talking to a patient who is lying in the bed, terrible bedsore, perhaps a paraplegic because of cord compression wasn't recognized knowing that person had terrible pain before they lost function of the lower extremities. Listening to those conversations and then addressing it as best you can within the cultural context.

Hearing the voices of nurses when talking to nurses, you this, you've done a lot of international work too Connie. Of knowing all the barriers are up against and really supporting them and encouraging them and finding out what are the tools that they have available and how can they best use them and how can they advocate for their patient.

So again, another big role for advanced practice nurses is advocacy and the different types of advocacy. Recognizing what's needed and then advocating for that patient and family. You might need to do it as a foreground, or you might do it in a way of making sure that that patient and family have all the information they need so they can make an informed decision.

Connie:

That's what I love Nessa. Because your last point is so important for all of palliative care providers. We are not trying to make them make decisions or to forego treatments or whatever. We're trying to give them the information so that they can make an informed decision. I think sometimes people get confused about that. If you think about when you get referrals to make them a DNR or to make them understand.

I always when I got those referrals of make them a DNR, I was like, okay, this is going to be a conversation where I'm listening to the patient, right? Because at a certain point in my mind have been harassed by people that they're not making the right decision. I think this whole interesting part that we're offering people a choice, but then we don't like their choice and so we get mad at them.

But then also just making sure that they do have the knowledge that they know they have a choice. I think the case that is the most to me visible for that was I was called, and this was early in the palliative care development when I started it with Andy I got called to the ICU of a woman who was probably in her early 50s. She had Adriamycin induced cardiac decompensation, and they were going to do a procedure on her.

What became apparent to me is that she might not survive this. That her heart was so damaged and her lung capacity was so damaged that either they wouldn't be able to put her on the vent, they wouldn't be able to take her back off of the vent or if she would die inter-operatively. My angst was whatever she needed to do was fine. She had two teenagers, but that she didn't even understand that she might not survive this procedure.

Where my role was if thinking about who was the best person to talk to her. So I called up her primary care provider and said, this is who I am. Don't know if you know about our service, but I got asked to be involved. You have this great relationship with her. Here's my worries and I wonder if you can help me to talk to this person. It wasn't that I wanted her not to do it, but my real part was probably because I was a mother.

Before she went into the surgery, I wanted her to have been able to say goodbye to her family knowing she might not came out. So that's what I think you're talking about is this advocacy part that it is ultimately their choice and we may not agree with it, but part of our role is to let it happen.

Dr. Nessa:

Absolutely is part of our role. But also to make sure that if someone is asking for something which doesn't make sense to you, it doesn't make sense just to be sure that you know what they're hoping for from this and is it likely to achieve. If it's not, so say that you can get them another way which would probably achieve it without an intervention which won't achieve it.

So I think if something doesn't make sense to short, what are you hoping for from this, what's important for you? This is another way that perhaps it could be achieved. So again, trying to because certain people particularly when their life is threatened sadly they make decisions based on fear. Most of us have made decisions based on fear and they tend to be not the right decisions.

So they try and sort those things out. I mean, we all have the right to make a bad decision. But I think just trying to understand what someone really wants it's hoping for from what they're asking for which in your mind doesn't quite make sense. If you know that's what they want, then that's fine but if it's based on something that they were hoping for just impossible to achieve in that way.

Connie:

You also make me think about, we're focusing the patient in a family, but also you could use your same principles for our palliative care teams that we also have to work as a team and be very cognizant of what we're hoping for and is that realistic, right? Because sometimes as a team we get pulled away into the psychosocial and think that we can fix some of these pieces that we can maybe help some psychological healing more than the physical healing, but we may not be able to do that.

Dr. Nessa:

Right. I think the other thing, Connie, that's really important and usually it's not a problem with advanced practice nurses but can be with an RN, the feel that voice is important. To make sure that they have a voice at the table and recognize that because they hear things that many other people don't hear. So a lot of things to recognize why a patient will tell them something in the middle of the night and yet in the day time when the family is there they're telling them something else.

So to understand about why sometimes people or families of patients will make a decision based on not what they would if they were just an isolated individual, but within the construct of their family it's a relational autonomy in a way. Then making this decision based on what they feel is best for the family. That's their choice. So it's for nurses to understand why you could have different things.

But also that they need to have a place at the table at these team meetings to talk about what they heard. But also to recognize that what they think is the best course of action may not be the course of action that's followed, but at least they'd have their voice heard at the table.

Connie:

Well, I think [crostalk 00:36:25]

Dr. Nessa:

Important thing for the nurses to learn sometimes.

Connie:

Well, and I think for the whole team, right? Because I think sometimes that's why we need to come together as a team. Lynn might go in and interview as a pharmacy and ask about medications and patient might just throw something out there because they feel like maybe she's not a threat. But then not say something.

I think my experience when we did the Temel study was, I would be in the room and Jennifer Temel would ask a question and the patient and family would answer. She would leave the room and I would ask the question again and I would get this whole different answer.

I would walk out of the room and she'd say, "I don't understand why are they not telling me that?" I said, "Because you're the oncologist and you will be prescribing their treatment and they're afraid if they say that to you, you won't do it versus I have a total different role." So what patients and families decide to tell different people is fascinating and why we have to come back to a team, right?

Dr. Nessa:

Right. I think there are a lot of other things that with a concept with the underlying principle that cash should be directed by the goals and values of the patient and not by technology that's available is going to really important principle. The how many of these things, what charting system do you have. And are these values of patients, these conversations held across a continuum where they were found in the chart. Are they buried in the chart so you never know so it's a new conversation each time. Or have to be developed at some standard of charting where there's a tab, which says values tab that you can go to right away and say, this is a conversation that you had. So you can pick up on the previous conversation.

Remember you told me six months ago, or three months ago when we sat down and talk that these are the things that were very important to you. These are real values. I just wanted to check that this still the case. This is where you are with the treatment options, this is where the situation is now. So again, this is ongoing conversation rather than a brand new conversation each time.

Connie:

Nessa, when you think about how things have evolved, what do you think are some of the current challenges we have right now to not necessarily fix, but to work on within the field of hospice and palliative care?

Dr. Nessa:

Oh gosh, I think that there're a lot. I think funding is certainly a huge one. I think what struck me and again maybe be improving, I don't know, but the quality of different hospice programs can be very, very different. So again, how that's evaluated and how this handoff, when a patient is discharged from an inpatient setting to home hospice. How does that happen? Is it just on a piece of paper?

There's always is as a standard that there's a conversation from an advanced practice nurse or a nurse who knows that patient well who will talk to someone who's going to be accepting the patient. Because again, I think recognizing that when someone, the patient is discharged from one setting that they're familiar with what their routine is to a home hospice setting for example. That's the type of high risk for patient and family distress and being overwhelmed.

So I think that's a huge area that needs to be addressed. I think the need for outpatient high level palliative care services. Then I think that all of us have a responsibility in a way particularly academic centers to be available to work with community nurses and community physicians. So to bring the expertise of an academic center out into the community.

So there needs to be a resource available that's readily available. You're seeing this a little bit in the COVID with some of the things that have been happening, for example, in India and that terrible crisis that they've had. That sometimes people from that country are doing their work here in palliative care oncology or whatever it is medicine. Then by phone, they are consulting with their family or colleagues in India to bring the expertise.

So I think that networking, that outreach is incredibly important because the need is so great and because we're living longer as we live longer, we're dying harder often. So there's this huge need. But I think that we could do it. I think if it's recognized and if there's a task force to set on, how can we do this automatically? How is this an automatic thing? Not just an add on if I have the time. But if you've got a complex patient who is in charge, is that always a verbal handoff? Is that always outreach to see how that person is doing? In a rural community, does an academic center, are they available to outreach?

So this network, just in a way with COVID when there was some hospitals which are totally overwhelmed and have no beds and other hospitals which were not so overwhelmed. Could then also be some network where people were organized to which hospitals those patients would be sent based on the availability of expertise, et cetera. So I think there's a way of looking at this, Connie.

Connie:

Well, and I think you bring up, there was a very interesting thing that happened with COVID, right. That a lot of things that people have been trying for a long time and hadn't been able to do all of a sudden it's a crisis and so people are willing to try that. I think you're right about some of the new models. I think there's this interesting part also that you bring up of beyond the patient and family, what is our responsibility to each other if we're palliative care specialists.

How do we act as a resource to our colleagues and do it in a healthy way so that we don't experience moral distress and burnout. But that we are doing it systematically because I think as we all know, there's a workforce shortage we're going to be having more aging people. I love the comment that you just said, we're living longer and dying harder.

I think that that's something really important for our students to think about because there's so many dimensions to what the future of palliative care is. Just also what you said, just because we have technology doesn't mean we should be using it. Do you have some other thoughts in terms of, if you were to look and you said, "Okay, when I see these things, I will know that palliative care in the United States and globally is in a good place." What would be some of those markers to say we've really arrived?

Dr. Nessa:

We'll never arrive because the situation changes. So I would think we're always looking, our eyes are open. We write, we have literature. I think that's incredibly important. I think they actually that the palliative textbooks or palliative care nursing and advanced palliative care nursing were incredibly important because before that, there really wasn't anything.

So I think that that was really important and that was put out by the Oxford texts. So I think that was really a landmark thing to do. So I think always learning, always observing because the nature of things are going to change all the time. So I think not being stuck in our ways and actually have to be open and to be observed and to be curious, and to learn from patients in front of us, not to assume.

You're always going to see something new. If our eyes aren't opened, you may miss it, but there's always going to be something new and to record it to talk about it. Yeah, and to work as a team.

Connie:

Well, I think you also, I mean, I think you are right that the landscape will continue to change why we did things 50 years ago was very different landscape in terms of the technology we have, or did not have as a culture. What we talked about, although I would, if you were to think about the needle that we've done on the comfort of talking about death I don't think we've really... That's still a place that we have a lot of work to do because we have still such a youth oriented culture. So we still have-

Dr. Nessa:

Otherwise we're hastening death. I mean, it's interesting Connie. I mean, that's the whole discussion in itself so that there's certainly, the youth orientations in every single way and in every way. [inaudible 00:45:17]. But I think it's this issue of just really and more than you can say it, but really to feel it. That that end of life is as important as the beginning of life. It's part of one's life story. To be able to really sit with that and understand it and each phase has a different beauty to it.

But again, society certainly in New York and I'm sure elsewhere in the country is this issue of, "I can end my life, I have the right when my life is fulfilled on my terms, then I should have to be able to have it ended." So again, it's rather strange thing I think that culturally we're looking at and made and all the rest of it.

I'm not saying I'm for or against it. Actually, I'm not for it I'll say that with my mind changed who knows, but I think it's just this natural letting life go its natural course. But we if accept that end of life is as important as the beginning of life and all the way through life, then the responsibilities that society has to put the money where their mouth is with that.

I was really, really struck that a couple of months ago, my brother-in-law in England died and he was a couple of months from his 95th birthday. So he's had a long life five children, lots of grandchildren, et cetera. He was almost blind and very much physically dependent for all his care which he didn't like anyone but my sister rendering him, which again is not uncommon in the elderly. So the family gets exhausted and his good kids were scattered and had young children of their own.

So he was admitted to the local hospital which was a good hospital for he wants to complete workup just to make sure there was nothing that it was reversible and that was okay, that was quite reasonable. Then it was clear that he was coming to the end of his life. So the hospital under the National Health Service then arrange this. Anyone to go home this time family wants him at home. They arrange this end of life package. It was extraordinary. They had a night sitter for 10 hours.

This was like a standard package for six weeks and then it would be reassessed to see how the person was doing. So there was a night setup for 10 hours. There were two carers who came in four times a day to turn him from side to side and just check on him change him if he needed to change. There was an RN who had a syringe driver who would come in on a daily basis adjust the syringe driver and would be available as often as needed on 24 hour call.

That care, the carers and that nurse were arranged through a local hospice, but it was all set up by the hospital where he was. None of it was at any charge to the family at all. So that amount of care I'm still [inaudible 00:48:49] and the idea that there would be someone to sit with him for 10 hours every night, seven days a week was I think, extraordinary.

That in a way it was putting your money where your mouth is. So the family, my sister was he wasn't allowed to give out any medication, anything. Her role was to be the wife and the children their role was to be the children. So it really I'm still amazed by that. It really struck me.

Connie:

Well, I think what you're speaking to is again and Lynn has heard me say this, in the United States in the 60s and 70s we made this choice of pulling care to the hospital because it was easy for us. But I don't think it was patient and family centered. To get that change, to get those community services has been so hard because we label that type of care custodial and we expect the families to take in and step in as healthcare providers with absolutely no training. And then wonder why it doesn't succeed at times when we're asking them to do things that in the hospital we would never ask them to do.

So it's a very interesting conundrum about what we've done with that. I think that's beautiful because I think in not only letting them be family caregivers, but the costs probably of that versus having your brother-in-law in the hospital for six weeks just got to be much less and a better experience, a better quality of life, better healing for everybody emotionally and physically.

Dr. Nessa:

Yeah. It's a humane cath because I think again, the families are much smaller. They're scattered throughout the world. So it's usually that care provided, care lands on one person with the most. How can they be available at night? They can't, so they get exhausted, they get [inaudible 00:50:47], someone would rather hurry up and die.

So all of these things within society, I think one needs to look at society as a whole and what are we asking for? The fact that we're asking for our death. For us to choose the time that we die and the responsibility of medicine to end our life. I think it's a societal thing which needs to be looked at.

Connie:

No, it's very, very interesting. I think you bring up this beautiful part that we haven't had this thing before of the ethics and really looking at the society of responsibility to us as citizens and what is healthcare really defined as. I think with a movement of looking at structural racism and social determinants of health, maybe we'll start really understanding that healthcare is broader. That there's medical needs and their social needs, and probably we need to work on them.

Dr. Nessa:

We need to be willing for our taxes to go to this. So it is a hard decision to make. These are really... We have to agree that this is what we should be spending our money on, that this is important. That end of life is as a natural ending of life is as important as everything. It's all part of our story which unfolds.

Connie:

So when you think then for our students who are entering the field now, and it might be clinical, it might be research, it might be ethics, might be policy, what is your advice to them as new leaders? Because I think by getting a PhD, you step into a leadership role. What is your advice to them?

Dr. Nessa:

I think that all of these are part of nursing. So it's not that they will need to know about policies, they'll need to know about culture, they'll need to know about clinical ethics. They'll need to know about the science and the art, they'll need all of these things. They can't just focus on one area. If they're really going to do advanced practice nursing, PhD nursing, whatever it is part of it is research, part of it is clinical care, part of it is understanding society, part of it is the humanities. It's all of these things, Connie, it's all of these things and all brought in together.

That's what makes it so rich and so rewarding. It's, non-linear in that way and that's why it becomes a lifelong career.

Connie:

I think also, I mean-

Dr. Nessa:

The way of being really.

Connie:

Right, I was just going to say that, that it's not only being pulled into this interesting specialty, but by doing this work, it actually changes you as a person. If it doesn't, then I would suggest that people aren't being reflective enough or something like that but that it does change your outcome or your outlook I think of the whole world and the way that it is.

Dr. Nessa:

Right and feeling of responsibility towards society as well as towards self and our professional and everything else. So it's not just this isolated thing is much about it.

Connie:

I'm just thinking, is there any other questions or comments Lynn that you have? I've just been watching you take all of this in.

Dr. Nessa:

One thing I just like to add again, I mentioned it, but just say that the humanities is really important as part of this.

Dr. Lynn:

Yeah.

Connie:

Okay.

Dr. Lynn:

I think one thing that you said that struck me that I think we've really tried to embody in the masters degree and of course in the PhD as well is the transdisciplinary nature of our practice. So it was Connie mentioned, if I go into the room as the pharmacist and ask a question, the patient may ask me a question back that has nothing really to do with being a pharmacist. I can't just say, "Sorry, that's not my jam, you're going to have to wait for the social worker."

So we do try to embrace that as a teaching philosophy in our programs to make sure that we can cross cover each other to a degree to make it more seamless care for patients and families.

Dr. Nessa:

Yeah. I think, Lynn, just start just towards that if I may because I think it's a really important point in thinking of. So patients might bare their soul to you, not because you're a pharmacist but because you are as a person. But I think it's really important for you to listen to them and then to say what you're telling me is really important.

We have specialists who really can address that, is it okay if I ask that person to come and talk with you. But I think sometimes teaching some of our students not to stop that conversation and immediately make a referral, but to really listen, because they're choosing you as a person and to bear their soul too. So it's a quality that's some of us will connect with one patient and not with another, for whatever reason and that needs to be honored.

Dr. Lynn:

Such an important point. Thank you so much for doing this.

Connie:

Thank you Nessa, this has been lovely.

Dr. Lynn:

It was a great time.

Connie:

Yeah. Well, we're just so grateful for all that you've done and all that you have offered the field and you continue to offer the field. I know with your ethics and just the richness and a wide perspective that you've offered. So on behalf of our students, behalf of all your patients, behalf of all of us as clinicians, as nurses, just thank you for all your contributions and for spending time with us today.

Dr. Nessa:

Thank you. Connie, I really like it and thank you Lynn. Good luck to your students. I have a lot to learn from them too.

Dr. Lynn:

We all, thank you. I'd like to thank our guests 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, to the Palliative Care Chat podcast. This is Dr. Lynn McPherson, and this presentation is copyright 2021 University of Maryland.

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