Lynn MacPherson:

This is Dr. Lynn MacPherson, 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 Dahlen to support coursework and the PhD in palliative care offered by the University of Maryland Baltimore.

Hello, everyone. This is Dr. Lynn MacPherson, I'm the program director of the Graduate Certificate, Master of Science and PhD in palliative care at the University of Maryland Baltimore, and I'm joined by Connie Dahlen, who is one of the co-course managers of the first course in the PhD and she also teaches in the master's program. And we are absolutely beside ourselves with excitement with our guest today. I am just so excited. This is Dr. Robert Twycross, who absolutely, clearly is one of the founders of the hospice and palliative medicine movement. He actually was best friends with Dame Cicely Saunders. Welcome Dr. Twycross, how are you today?

Robert Twycross:

I'm just fine. Thank you for inviting me. It's a great pleasure to join you.

Lynn MacPherson:

It wouldn't be a party without you my friend. This is so exciting. So I've given just a bare tip of the iceberg about your bio here. Can you expand a bit and tell our listeners about, who is Robert Twycross?

Robert Twycross:

Okay, well, I started life over here, well, I'm still over here in the United Kingdom. But from this program's point of view, I started life as a medical student. I came up to Oxford University in 1959 and began a six year course. And halfway through, I went to a major student conference held down the road in Bristol. And one of the speakers was Cicely Saunders. And she was giving a plenary address, but she was also a senior facilitator for a special interest group on health and healing. Well, that's the sort of thing you go to if you're a medical student. And I went, so, not only did I hear her plenary lecture, but I also had the value of some interaction in the small group work. But it was, I think, it was a plenary lecture, which really changed my life.

She had qualified a few years before in medicine at the age of 39 in 1958, previously a nurse, then a medical social worker, then a doctor. And the reason she became a doctor in her late '30s, was because a doctor she worked with as a medical social worker said, "You'll never change the doctors unless you become a doctor yourself." Now that may or may not be true, but that's what she was told way back in 1948, and 10 years later, she qualified as a doctor, and what she wanted to change was what she perceived as the neglect of dying patients.

So she began, if you like, a campaign to make better care for the dying. And there were one or two institutions in London, I think three or four in all, and she had an association with two of them after she qualified a year later, she took up a research fellowship at one particular London hospital, which allowed her to go to work at St. Joseph's hospice in the East End, where she had clinical experience and also began her research into pain management at the end of life.

And during that time, she was there, she was fulfilling her vision of establishing a new modern hospice, in which not only patient care would be there, but also teaching and research. And she achieved that in 1967, I guess. And we kept in touch after I met her at that conference of '63. Always at the back of my mind was, well, I really would like to do hospice care, but of course, what opportunities,

but to cut a long story short, I qualified. I had several years in general internal medicine. And then 50 years ago, beginning of March, 50 years ago, I moved from general medicine to the fairly recently opened St. Christopher's hospice in South London, where I was her research fellow in therapeutics for about five years.

Lynn MacPherson:

So what was it about her presentation specifically, that lit a fire in you?

Robert Twycross:

Well, you now how it is, and you may have the same experience, you look back and say, I have no idea, I have no idea what she said. But the point is, she was a very skillful communicator. And she also took photographs of her patients with their permission of course, to use in publicizing the concept she was pursuing. So these were illustrated lectures with anecdote, after anecdote, after anecdote to illustrate the principles of appropriate care of the dying. And I just felt, this is medicine, this is medicine, it's more than just physical care. And I can't say any more, I think a lot of people in their lives meet someone who do something, say something, and that changes the course of their future life.

Lynn MacPherson:

Wow, that's amazing, to think of your long career, all just on the turn of a dime by having to be in her presentation. That's amazing. Don't you think Connie? You're muted.

Connie Dahlen:

Yes. I mean, I think it's interesting also of, the saying that goes, you won't remember what they said, but you'll remember what they made you feel and what they made you think, right? I think that was Maya Angelou said that. And so what you're sort of saying is, there was something about the spark of what she said that kind of clicked. And I think, you also are speaking to something that is so universal, right? Not everybody will get heart disease, not everybody will have lung disease, but everybody is going to die. And so it's that universal experience, that in health care, at least in the United States, we actually don't like to admit that patients die still. And so it makes it a really interesting part of thinking about what is palliative care about.

Lynn MacPherson:

And I think that spark she ignited in you, calls the soul of so many people. That's why we have so many mid career people who want to move into palliative care. Absolutely. So tell me about your early research. When we spoke a week or so ago, we were talking about Ray Hood and so forth. So what did you do as a research assistant?

Robert Twycross:

Okay, Ray Hood will come a few paragraphs down the line. But I was in England and so it was the English problem which I was asked to investigate. Now, there are differences, we all know that, there are differences between countries, And there are big differences even between the United Kingdom and the United States, even though we share or sort of share a common language. But the point was, we had used a laudanum, an alcoholic extract of opium for centuries to relieve distress, particularly in the dying. Then, of course, beginning of the 19th century, morphine was extracted from the mixture. And so

people began to use that instead. But there were alongside, but morphine came to the fore, opium dropped back a bit.

And so we had a solution of morphine, but doctors being doctors, it got a bit elaborated, or shall I say, pharmacists being pharmacists Lynn. It got elaborated, and towards the end of the 19th century, we had the Brompton cocktail, which had morphine, cocaine in a vehicle of what? Alcohol, syrup and chloroform water, the latter is a preservative. And that was used, well, certainly in London at the Brompton Chest Hospital and down the road at the Royal Cancer Hospital for people with terminal tuberculosis, with severe breathlessness and severe cough, and it made sense, morphine and cocaine. And it was also used by some of the oncologists at the Royal Cancer Hospital for people dying of cancer.

But also, because morphine had the chemical structure had been identified, in wherever, let's say about 1840, then the pharmaceutical companies became interested. And they said, "Well, what happens if we modify morphine, can we make it better?" And up came diamorphine, diacetyl morphine which is eventually marketed in the 1890s and People were very enthusiastic about diamorphine. Oh, it's better, blah, blah, we can use it as a treatment for morphine addiction. Well, don't forget the diacetylmorphine, diamorphine is heroin. So just think of that, this wonderful idea, both in Britain and Germany that you could cure morphine addiction by giving them heroin. But anyway, that's how it was-

Lynn MacPherson:

[crosstalk 00:10:27] The dog so to speak.

Robert Twycross:

But let's move on, so we then had a divide, some people put diamorphine in the Brompton cocktail, but perhaps the majority continued with morphine. Anyway, Sicily landed while this debate was still going on, I think, possibly because of what she learned from one or two other people. She concluded that diamorphine was probably better and so, when she went to St. Joseph's after she qualified as a research fellow from a neighboring teaching hospital, she was using diamorphine. And when she opened St. Christopher's in '67, she was using diamorphine. But the point was, the rest of the world had outlawed diamorphine, heroin for medicinal uses.

This was the League of Nations, followed by the United Nations after the Second World War, saying it was too dangerous to use because of possibility of diversion. But of course, the amount which was being used by the addicts was about 100 times greater than the amount which is being used medicinally. So, anyway, we kept it. And so she was concerned because she got known and she was teaching and people began to say, well, you can do it because you've got diamorphine, but we can't because we've only got morphine. So she asked me to conduct trials, comparing morphine with diamorphine, and that was a major task. But of course, you do other things. And I certainly did other things, and I collected quite a lot of useful information.

Lynn MacPherson:

That's wonderful. And then you spent quite a bit of time with the World Health Organization, didn't you?

Robert Twycross:

Yes, yes. Okay, can I just say, do you want me to say something about Ray Hood?

Lynn MacPherson:

Well, I just found that whole conversation interesting, because I'm very interested as you know in opioid conversion calculation, and the very, very early equal analgesic charts that came out showed the 10 milligrams of parental morphine was 60 of oral. So maybe you can share with our listeners the backstory on that?

Robert Twycross:

Well, yes, it's history, and how much should we dwell on history, but I suppose the whole of this time together is history. Anyway, in the 1970s, the mid 1970s, that was when IS, the International Association for the Study of Pain was set up. And of course, Ray Hood, a researcher, a pharmacology researcher at the Memorial Sloan Kettering Cancer Center in New York, he was a member, and John Banneker, an anesthesiologist, who was also one of the founders of IS, he was a member, and Ray Hood had been doing in the '50s and '60s, and since studies in the use of opioids in cancer patients, but it was in fact post operative cancer patients. And they had come up with a figure that morphine was only one six, as potent by mouth as by injection.

And they said, "Oh, it's useless, don't give it by mouth, you can only give it by injection." Well, we know looking back, but we also know we all make mistakes, but looking back that this was a mistake, because actually giving six times the amount of milligrams by mouth and getting the same effect as the lower dose by injection, there's no problem the drug works, there are plenty of drugs where we have to bump it up. Anyway, this tradition got written into American pharmacological lore, L. O. R. E, and so when I got up, I think it was the first International Congress of IS in Florence, probably in 1975, and talked about our experience with the Brompton cocktail or its subsequent simplification, they just laughed, but five years later, they'd stopped laughing and certainly from the 1980s, it has been accepted that morphine by mouth is usually a very effective way of giving morphine regularly on the long term.

And of course, because you're giving the dose regularly, things build up. You mentioned the metabolite, morphine, six glucuronide, so when you give it on a regular basis, it's only something like two to three times less potent than the parental form. In effect, that, I suppose it was anecdotal, we'd never done at that stage a controlled trial, of course, they came in the late '70s. But the point was, we had this massive amount of anecdote of patients who looked in pain, and we're rolling in agony. And then we're on all morphine, and they sat up and began to live again. So, as I say, the plural of anecdote is data. So the data was there, even though it wasn't in a randomized control trial.

Anyway, that was a big step forward. And of course, the fact that the control trial showed that diamorphine was no better than morphine when given regularly by mouth every four hours in those days, because we had no controlled release preparations in an individually titrated dose, et cetera. Then, that opened it all up and to show that we believe the result of our controlled trial, stopped using diamorphine by mouth, and converted to morphine by mouth. So I think that's fair enough of the backstory there, but it was very interesting. And, well, I can move straight on to the WHO.

Lynn MacPherson:

Sure.

Robert Twycross:

Well, in 1980, Dr. Yan Stanford, a Swedish doctor, who I think at the time, was a professor of oncology in Kenya, he was recruited as the head of the cancer unit of the WHO in Geneva. And because he'd worked in Kenya, where resources a few, he knew that in most of the world, cancer presented at a late stage which was or is incurable. So when he set up the Cancer Control Program, Comprehensive Cancer

Control Program, which became on board about 1980, it had not only early detection or prevention, early detection, or curative treatment, it went through to pain control, because that's what he would have been seeing people end stage in distress, pain control, pain control.

So he set up this group, we met in 1982 probably outside Milan, a dozen of us, and we put together what became the WHO method for relief of cancer pain. And that was eventually published after field trials in 1986 under the title of Cancer Pain Relief, published, I don't know into a couple of dozen languages, and perhaps sold, well, several 100,000 copies or several 100,000 copies were distributed, one of the best sellers from WHO. And of course, if you look at that, it is entirety, it is, well, let's say it's holistic, but because a major part of it within that cancer pain relief document was WHO message relief of cancer pain, and what stuck out, what people grabbed on to was the WH3 step analgesic ladder. I think perhaps, people got a bit one sided, but the fact was, it was very important at the time, because people around the world were totally ignoring pain, because they didn't know what to do.

And almost every country didn't have morphine, and if they did have morphine, it was probably by injection and if they did have it by injection, it was probably hospital use only and not in the community. So this was a big step forward to have an analgesic ladder saying this is what you should be doing, non opioid, then add a weak opioid codeine, because most countries had codeine, and then if necessary go up to morphine. And that gave people a structure, wow, we can do something. And the aim was that if you didn't have morphine available for use in your cancer patients, you started advocating for it.

So it was very necessary at that stage. And of course, we've moved on since then, that was what? 35 years ago that that book was published. And of course, we know that sort of simplistic use of the analgesic ladder can lead to problems as well as benefit, but I guess, probably as many problems as benefit if you are using it strictly within a physical biomedical model. So, nowadays, if I were to teach on your course tomorrow, I wouldn't highlight the three step analgesic ladder, but I would highlight two, are they called centric circles? Anyway, I've got three circles, and they overlap. Okay.

Lynn MacPherson:

Venn diagram.

Robert Twycross:

Venn diagram, great, good, I'm getting old Lynn and I need your help. So there we are, you have in one circle, correct the correctable, this is true of all symptom management. In the second circle, non drug measures, very important. And the third circle, you have drugs. And as you know in a Venn diagram, they're going to overlap, and sometimes you got to have the circles overlapping, and sometimes you got three overlapping. And that's what happens when you're treating cancer pain. And then you take the drug circle, and you convert that into a second Venn diagram. And you start off. Well, it doesn't matter where you start, you have three circles, perhaps we should switch it around every day when we look at it. So one circle is non opioids, the second circle is opioids, and the third circle, using the term, language of adjuvant analgesics.

And now I would say, well, obviously, I'd emphasize, well, I do emphasize the need to evaluate the cause of the pain. If it's muscle spasm, don't go up the analgesic ladder, non drug measures, blah, blah, and if necessary, the modest dose of dia at night. So you've got night cover for anxiety and tension in the muscles and so on. So, what do you do, you work out, or you come to a probable diagnosis of the pain, the cause of the pain, even though it's in cancer, it doesn't have to be cancer, and even if it's

cancer, there're different mechanisms as you know, and then you pick the best drug in that circumstance.

And sometimes the first drug will be a non opioid, sometimes an opioid and sometimes an adjuvant analgesic. And that's how I would focus my approach to teaching now. But we must remember that historically, the three step analgesic ladder has played a very important part in moving things forward, and I wouldn't ditch it completely. But I think it has to be against the background of those two Venn diagrams.

Lynn MacPherson:

Yes, even though we've gotten far more sophisticated in treating pain, I think your point is very well taken. And we should not underestimate the value of the World Health Organization approach. I think, even today, I see cases where people would at least do what the WHO recommended with a three step ladder, it wouldn't be a benefit. But I was always taught that their guidance was, not only in clinical guidance, but as you said, it was almost like regulatory reassurance, or pushing the agenda for these countries to get their hands on morphine. So I think both of those agendas, the clinical guidance, and the regulatory perspective were invaluable. I think it was a quantum leap in pain management. And yes, I think we've certainly progressed beyond that original guidance, but huge, don't you think Connie?

Connie Dahlen:

Well, I was going to say, I still have people quoting that to me, which is always interesting. But I think the other part and I would say in the United States, with the opioid crisis and some of these small rural places, in order to justify their practice, they still go back to the WHO so that if anybody's questioning them, and Lincoln knows more about this, but where we decided that 60 to 90 milligrams of morphine after that, a day, you're an addict rather than looking at some of these conditions for the smaller programs, they do need to use something.

So I think the diagrams are helpful. And I also think that, to your point, Dr. Twycross, the other part about that was it codifies internationally, right? We're not just saying, oh, well, in England, you have diamorphine and morphine, so you guys are going to do this. In the United States, we had access to more codeine, which we now know we're all trying to get off. But we still have these developing countries, many of whom still don't have access. And so their first drugs that they get approved might be methadone, or fentanyl, which all of us would be like, "Oh," those are not first line medications, but people are trying to use something to get access to their pain medicines or to try to convince a department or Ministry of Health, that pain management is important. And it's not just about drug abuse or the black market.

Robert Twycross:

Let me just say that when you get to 1990, if you look at the who publications, 1990, 1996 and so on, then the second or third publications, there's certainly had guide to opioid availability. And one of the big champions for opioid availability, he traveled to many countries, let me think of his name, was he up in Wisconsin?

Lynn MacPherson:

Oh, Jim Klearly?

Robert Twycross:

Well, he's one but before Jim, but anyway, his name will come back to me. But I have many fond memories of the work he was doing to help people in different countries, and negotiate with the drug regulatory authorities to go down as recommended by the WHO. I got the name. How about this? David Jarocin.

Connie Dahlen:

Okay.

Lynn MacPherson:

There you go. I know I get upset when I see people in the US die on hospice. And I've got all these drugs leftover, I want to put them in a zip lock bag and send them to another country. But I guess I would go to jail if I did that.

Connie Dahlen:

Yes.

Lynn MacPherson:

So speaking of all the research that you've done, you my little kitten have been a prolific author, exhibit A, the first book that I ever bought in my career in palliative care, you wrote this book, you've written 300 articles, chapters, editorials, how many textbooks?

Robert Twycross:

Well, it depends how you count them. But I think, certainly the best part of 10, and then somewhere when they'd be multi author books, I mean, I think if you do a book with one or two others, you can say you're an author. But once you get to five, six, seven, eight, then you've just been editor. Anyway, I've written lots of books as you say, quite a number of the being translated into foreign languages. And if I put an addition of each book which has my name on the cover, then it almost comes up to, pile it up from the floor, it almost comes to shoulder height. So it's quite a lot, it's quite a lot.

And it's obviously been a major part of my contribution, because you say you found my book you so. That was the first by me, I've done one or two other books as in an editorial way. But other people have written to me, and this is my 50th year since I moved to palliative care. So I've had a number of messages. And a number of people have referred back to my book or the book they got in the 1980s, or early 1990s, and how it helped get them focused and moving in the right direction.

So yes, writing clearly has being, well, it could be the major way I have influenced the development of palliative care. Because when I teach, I'm not just wanting to give knowledge, I want the audience who will largely be clinicians, and largely be physicians, I want them to become better palliative care physicians, that's my aim, I want you to be a better palliative care physician. Oh, and by the way, that's one of my limitations, I am a doctor, I think as a doctor, I teach as a doctor, and therefore, if you're not a doctor, you probably have to decode what I'm saying and reapplied in terms of your own specialty. I don't know how true that is.

Lynn MacPherson:

I'm sorry, I don't agree. I think your writing is extremely clear to the point, I think you cut out all the fufu and you answer the question, at least for me as a reader, just tell me what I need to know. I've shared with you when I emailed you, I had no thought that you would remember me and I was surprised that

you did. When you were a speaker, I think I was a speaker too at the Cleveland Clinic thing, somewhere on the East Coast, I don't remember where, and we had a meet the expert at lunch, and everyone sat down at your table, of course, everybody loves beating each other up to get to your table. And they made an announcement that if you left your stuff in the other room, go get it. So everyone got up, but you and I, I thought I would faint from excitement. I was fan girling so badly, it's not even funny. I think you're an exceptional writer. So I'm just leaving it there, because that's that's my opinion, there you go.

Robert Twycross:

Well, thank you very much. I do remember being at the table for some time with just you and me, some things get imprinted on your memory. And you're quite right, it was at a Cleveland Clinic event somewhere down the East Coast.

Connie Dahlen:

Yes, exactly. So, when you think where we've come in research, and where we are now and where we need to go, what are your thoughts on the types of research that we need to be focusing on now or even in the future? Because I still think it varies in developing countries and developed countries. I find it almost unethical that the United States has access to most of the pain medicines in the world, that doesn't seem fair, but where do you think we need to go?

Robert Twycross:

Goodness gracious me. I mean, there's so much research being done today, it's unbelievable. No one can keep up with it. And it's just pouring out and that's because we've now got departments of palliative care and so on and so on. And you appoint people as researchers and researchers have to research, have to publish, have to go for the next grant and so on. So I'm not saying some of the research is motivated by the need to get the next publication. But on the other hand, it does mean, there is an amazing amount, and yes, I mean, five years '71 to '76 research was my top of the list job. Then for the next 15 years, it became second or second equal along with teaching.

But really, in 1990s, I said, "Oh so much else is happening around," now we've got university departments, and they're all doing research, but what we need is to teach to get better physicians. So really in the 1990s, I relied on other people's research, and tried to interpret it in a practical applicable way. And so, when I left my university post, 20 years ago, well, maybe a few since, but throughout my 15 years in palliative care, I've taught in 44 countries outside the United Kingdom.

And I've had long standing commitments to Argentina and India, Poland, and one or two other countries would probably like to claim me too, and I'd be happily claimed. I'm now working with Russia and the former Soviet republics. So teaching, teaching, teaching, is what I go in for. But as I say, there's so much research out there, there's so much research out there. Surely, everything's been covered. What do you think, Connie? What else would you like to see done?

Connie Dahlen:

Well, I mean, I think you and Lynn are geeks in the pharmacology and I think given the opioid crisis, it feels like that will be an ongoing issue of how do we manage that, the whole issue of buprenorphine and who's able to write it and how do we use it? I also think if we think about palliative care development, and we're doing this holistic care, I'm also in close proximity to a PhD researcher on placebo effect. And so it's also interesting to think about, what are the non pharmacological? What are medications really

doing? Do we need to kind of think about the spear because the challenge is, you know also, is we want to go for non pharmacological first, but at least in our country those are usually not paid for.

So we set the standard that, I don't know, I have no idea, but I'm going to say at least half of our population cannot afford, because you get four sessions of PT, or you get five social workers. So it's a very weird thing, a little bit with palliative care where we talk about total care, we still kind of focus on this pharmacological method, because that's what we're experts in. And yet, we haven't kind of figured out some of these other pieces of it. And I guess, then the second part of it is, and we are challenged, because if we're truly dealing with patients, serious illness advanced at the end of life, that's also an IRB nightmare, right? So there's just a lot of challenges. I think about thinking about this, extending the research on.

Robert Twycross:

Well, clearly, and I'd like to think I can leave that bit behind, leave it for the next two generations below me and so on. Yes, but the point is, we've got to teach. I've been looking back over the last few days and saying, "Well, what would I do differently if I had my time all over again?" Did I over emphasize the physical, maybe. But of course, if you have someone rolling around in pain, there's no point sitting down beside them and listening, because they're not able to talk, if I can put it that way, at its simplest. So we do have to get the symptoms reduced, relieved, to a greater or lesser extent.

But I think I might be more careful about emphasizing the other aspects of palliative care, okay, we've got the physical, but it also has to be applied within the psychological, the social and the spiritual. And I fear that some of the medical wiz kids in palliative care may be too focused on the physical, could there be a tendency for the doctors to become symptomatologists, rather than holistic palliative care physicians, and there's so much basic to learn about communication and interactions and so on, that I think I would teach more.

And I would probably, 30, 40 years ago, when I began a five day course every year with Sylvia Lag, one year in Oxford, the next in New Haven. I don't think we did anything specifically on communication skills. But communication skills are vital, but also they need to be retaught or re-emphasized or expanded or moved deeper when you come to end of life care. Absolutely, no doubt. So, yes, communication skills would be much bigger than it was then.

But of course, I was handicapped by the fact that I was never taught communication skills. And looking back, certainly before I went to St. Christopher's, I can tell you some horror stories, but I prefer not to, bad communication with patients. But in fact, it was only about 20 years after I moved St. Christopher's, now I was back in Oxford, I went back in '76, that I said to myself, "Well, Robert, you really need to brush up a bit because you're teaching medical a bit about communication skills, or you have to if the guy from psychology can't come that week, so you better go on a communication skills course."

And there's a guy up in Manchester, in the northern part of England, he ran communication skills courses, psychiatrist, at the Cancer Hospital in Manchester. And I decided to sign up for that. And by golly, you see, after 20 years, I learned all sorts of things. But perhaps a trigger was, let's see, maybe I as in my late '40s, and I had a patient of a similar age, not surprising, and she had breast cancer. She was lower, she was divorced, she lived on her own, she came in from time to time with bone pain, debilitating bone pain, and she came to us and we would adjust a medication, we would arrange radiotherapy, and perhaps after weeks, she'd go home.

And we had some research going on still, and she said to my research nurse on one occasion, "The trouble with Dr. Twycross is he's so charming," and that hit me, it was rather like going to Cicely Saunders's lecture in 1963, a bulb lit up or exploded or something. But I realize that being kind and

courteous, IE, charming wasn't the answer. Okay, it helped, but in her case, it put a barrier between her and me, because patients by and large, while certainly in this country don't like to upset those who care for them and they're doctors in particular. Oh he's so nice, I can't upset him.

So this woman, she couldn't share her deepest fears and anxieties about the future. So I was using my charm, my courtesy and kindness as a blocking technique to stop the expression of fears and worries. And of course, I realized that, but I needed to go to Peter McGuire's course, really, to get it out of my system and to move forward. So, the list of blocking techniques used by doctors, the world over, is almost as long as your arm, I don't know about nurses, but it is amazing. And so teaching communication skills is top of the list, I think alongside the basics and more than basics, symptom management.

Lynn MacPherson:

Absolutely. Absolutely. That was pretty profound. Can we go back to the history of the evolution of hospice and palliative care, tell us about when Dr. Belford Mount came to St. Christopher's, what's the story there?

Robert Twycross:

Well, yes, I was research fellow there. And the main person on the wards for me was my research nurse because I didn't want to get involved. I had my clinical practice and palliative care some miles away. So, yes, he came, what was it? '73 or something like that for a week just to explore and I think he'd been encouraged to come by Elisabeth Kubler Ross. And he liked what he saw and it reflected his, he was an oncological surgeon, but he had this holistic heart, if I can put it that way, and so he had the week, and then he went back and came back, did he come back for three months, the next year? Or something like that. But meanwhile, he'd started negotiating with the hospital, the Royal Victoria Hospital in Montreal, to set up an experimental unit, which became known as the Palliative Care Unit.

And he was given permission to start that at the beginning of '75. So he had to move fast when she came back to St. Christopher's in '74. But he did move fast. And then I think a year later, before the two years experiment had run out, the hospital authorities confirmed that it would continue on a long term basis. Now, although Cicely Saunders and I and no doubt others in Britain said, "Oh, you must call it Hospice Care," Hospice Care, it's got a tradition and so on in the United Kingdom. He said no, because although hospice is stretched back to medieval times, and grew up side by side with hospitals, in the French speaking world, they became the working house, the place for the indigent sick, either too frail, to impoverished or too ill, to be elsewhere.

So to say, hospice would be very negative, and he decided on Palliative Care and palliative care as you know has become the norm. That doesn't mean that hospice is obsolete. Indeed, in most countries, the two terms are synonymous. But I know in the United States because the funding came through for hospice first in 1983, Medicare benefit, and palliative care came later, you have distinct funding systems. And as you know, hospice in the United States started off as home care, and now some have their own inpatient facilities, whereas palliative care, started off in the hospital and probably as far as calling it a palliative care unit is just in hospital, but you can clarify that.

But the point is, all these movements, hospice or modern hospice in the United Kingdom, and hospice in the United States, and palliative care were protest movements. Now, the first two were protest movement against the neglect of dying patients. But in America, the main people in early hospice were nurses. Congratulations, Connie. And Yale New Haven hospice, Florence wold, Dean of Yale New Haven Hospital School of Nursing. And so in the 1990s, because the nurses were rather jealous

and sometimes perhaps, kept doctors on the edge, rightly or wrongly, that's for you to say, the palliative care unit, in the sense was a protest movement against the fact that doctors weren't welcome in the hospice world in your country. Now, you may say that's a caricature, but there's an element of truth in it, I think somewhere.

Lynn MacPherson:

There you go. So Dr. Twycross, as you think back to the evolution of the modern Hospice and Palliative Care movement, is there any other important piece of information you think our students should be aware of, or second part, if you had a redo, anything you would advise that we do differently?

Robert Twycross:

I think I've already emphasized the need for making sure that the subject is holistic, even if you have a pharmacological bias, and even though I as a physician, trained originally in a biomedical model, I have a fiscal bias, and that's my main expertise. Obviously, I had an interest in clinical pharmacology, or I wouldn't have gone to St. Christopher's in any case, I think. But, okay, we have our biases because of our basic training, and we can't ever remove that, and it's part of the gift to the team, of course. But we do need to emphasize, holistic, holistic, the four dimensions, and we all need to be involved, and I am concerned about reductionism.

And I've already mentioned the fact that doctors can become symptomatologist and for me as a physician I've always got to be thinking about these other dimensions. Now, of course, you don't do everything because you're working as a team, or the team may be quite small, it may just be you and a nurse. But if you're in a hospice service or a palliative care service, then you're going to have most, if not all, the range of a health care professionals. And, of course, rightly or wrongly, I never sat down with my patients and said, "Can we go through your geno gram," but there's big literature to show that having a geno gram is a vital part of understanding the patients.

But, I think if I had my time all over again, we might train volunteers, how welcomers in the outpatient clinic, as most of my patients started off as outpatients, many remained as outpatients. And, "Oh, Dr. Twycross will see you as planned in 20 minutes time, but to help him, can I take some basic information about you?" And, if you had someone to put together the geno gram, if you have someone, perhaps to jot down the three concerns, or three most major concerns the patient had, and that sort of thing. I mean, I think I might do that, but it's 20 years since I retired as a physician. And I really don't have to think about what I'd do. And I don't know what my younger colleagues do.

But all I know is, if you look up the literature, is a tremendous benefit from doing geno gram. But in a sense, I left that for our specialist palliative care nurses to fill in on their subsequent visits. Because in the outpatient clinic, I always had one of our specialist palliative care nurses with me, and they would follow up by phone or visit the next day or the second day, and I would normally see, one week later, and then three weeks after that with them going between wards, so I got the information. I couldn't get it all at once, literature show that this is in the Western world or the English speaking world, that the initial consultation range from, let's say 30 minutes to 75 minutes, with what an average of, 40, 45 minutes, or particularly if you're in non developed country, then there's no way you can spend 115 minutes.

So I did ask the Indian doctors, was some years ago, "How long do you find your initial consultation take?" And they said, "45 minutes." And I was very impressed, but we can't do it all, even if we take 45 minutes or 55 minutes, even that you can't do everything. So I think communication skills,

and of course, teamwork is not just having all your professionals working in the unit, it's teamwork together, really together, everyone achieves more, T. E. A. M.

Lynn MacPherson:

There you go.

Robert Twycross:

So yes, did we talk about teamwork in those days, way back when we started those courses in 1980, or whenever? Not enough, not enough.

Lynn MacPherson:

We talk now about transdisciplinary practice, where I'm not happy unless everybody goes from 10% pharmacist, and I'm 10% social worker and 10% nurse and 10% doctor. So I think we do need to have a little cross coverage here.

Robert Twycross:

Oh, inevitably because, we have a palliative care heart, and that means we are holistic. We want to be holistic, and we're bound to move into these other areas. I mean, there's been a tremendous lot of research published on spiritual care in your country in particular. And there was a discussion a few years ago about, oh I think, someone who wasn't a spiritual care person, whatever, you have a generic, I don't know, someone who wasn't, it was a doctor talked about delivering spiritual care, there was an angry response in the next issue of the journal saying, "Oh, you can't do it, you need us," sort of thing.

But of course, all of us are involved at basic levels. Yes, I'm concerned about rehabilitation, rehabilitation is very much part of palliative care. Oh, by the way, that's something else we need to emphasize. I think St. Christopher's here in London about five years ago brought out a report called rehabilitative palliative care. Well, that's a tautology as far as I'm concerned. In other words, you don't have to put the word rehabilitative before palliative care because palliative care is rehabilitative by definition. And rehabilitation means helping someone achieve their maximum potential in all the aspects of personhood. And there's lots of ways of helping them achieve their maximum potential, even if they're physically failing month by month. So rehabilitation is integral to palliative care. And yes, it's another subject I think I would have way up there. And of course, I'd bring in what we call the occupational therapist and the physio therapist, but I'd also emphasize rehabilitation much more widely.

Lynn MacPherson:

There you go. Well, as we wrap up, Dr. Twycross, I just want to say you've had an amazing, amazing career, you've been such a major force in the evolution of hospice and palliative care. And it's certainly been my great honor to be able to speak with you. And as we wrap up any last advice for our new graduates from this PhD as they go forth for their next 50 year career?

Robert Twycross:

Wow, I could duck out of that, say, oh, I need a week's notice. Anyway, the point is, I'm going to say that don't go into palliative care unless you have a palliative care heart. Now, I can't define that, but you have to have a holistic approach, you have to understand, well, you have to be empathic, you have to be able to imagine what people who are suffering are going through, even though you haven't been there

yourself. And because you can imagine what they might be going through, that you don't know for sure, you can have this, whatever surge of compassion towards them.

And compassion is a verb, sounds like a noun, but it's a verb. Compassion has to lead to action. So you need empathy, leading to compassion, leading to action, and you need to be prepared to stay around, because compassion isn't there to provide a solution, compassion literally means from the Greek, to suffer with me, it means companionship in suffering. So even when you can't do anything, anything magical with your professional skills, then you still stick around. So the basic message we should be giving as palliative care people is, no matter what happens to you, I will stick by you, to the end, I won't desert you.

Lynn MacPherson:

You're going to make me start crying here sir. Connie any last comments from you?

Connie Dahlen:

I mean, thank you for everything that you've done, for all this foundation that you've given. I think, certainly you gave so much in your service, I think it's going to be really interesting to see because I think we're in a very, this whole new technology and different generations about what they value. And so we're having to learn communication and in an interesting way we have to think about our new medications, we have to look at this whole part about how do we educate.

And I think one of the things that you made me think about is, it's really important we've got to stop having the disciplines not trained together, but have more together, the training even before they become teams. And I think to remind, you really spoke to the sense that we're actually all responsible, it's not only the physician, we have to work together as a team and take that responsibility. That's really the, I know legally or whatever, it may be the physician, but really, for the team to kind of step in and do what's right. And that is, I think when you went through your part of empathy, to compassion, to action, that's got to guide us in our clinical care and our teamwork care and in so many ways, so thank you for all of those really great thoughts for our students.

Robert Twycross:

Thank you.

Lynn MacPherson:

Thank you so much Dr. Twycross, will check soon I'm sure. Take care.

Robert Twycross:

Thank you very much, lovely to be with you.

Lynn MacPherson:

Thank you.

Connie Dahlen:

Thank you.

Lynn MacPherson:

I'd like to thank our guest today and Connie Dahlen for the continuing journey in our podcast series titled Founders Leaders and Futurists and Palliative Care. I'd also like to thank you for listening to the Palliative Care Chat Podcast. This is Dr. Lynn MacPherson and this presentation is copyright 2021, University of Maryland. For more information on our completely online Master's 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