

Dr. Lynn McPherson:

This is Dr. Lynn McPherson, welcome to Palliative Care Chat, the podcast series brought to you by the online master of science, PhD and graduate certificate program in palliative care at the University of Maryland. I am delighted to welcome you to our podcast series titled Founders, Leaders and Futurists in Palliative Care. A series I have recorded with Connie Dahlin to support coursework in the PhD in palliative care offered by the University of Maryland Baltimore.

Hello everyone, this is Dr. Lynn McPherson, I'm the program director of the online graduate certificate, master of science and PhD in palliative care at the University of Maryland Baltimore. I'm very excited to be joined by Connie Dahlin who is one of our faculty members teaching the first course in the program with another colleague, and most importantly our guest professional Clark. Welcome, Prof. Clark, how are you today?

Prof. Clark:

I'm very well, thank you.

Dr. Lynn McPherson:

Well, thank you so much for joining us. I printed your bio but I was afraid I was going to run out of toner before it finished printing, but I will start off with the very first sentence, which is you are a professor of medical sociology at the University of Glasgow School of Interdisciplinary Studies Dumfries and you have wide ranging interests in end of life issues in the global context. I know that you are incredibly well published, I have your latest book here on Dame Cicely Saunders. I think I learnt some new words just in the prologue alone, but very exciting. You made it a very conversational style, I've enjoyed what I've read so far very much.

I know that you're a great historian in end of life care, obviously talking about Dame Cicely Saunders, what else would you like our listeners to know about your background? It's incredible.

Prof. Clark:

Well, first of all Maryland, just to say I am now retired. I'm an emeritus professor at the University of Glasgow. I retired in the autumn of 2020. But I continue to have major interest in some of these areas. I originally studied sociology, anthropology and history. Even as an undergraduate in the early '70s I got interested in end of life issues. I was reading the work of Kübler-Ross and others as a final year student. I wrote a dissertation on social aspects of dying. But subsequently I worked quite a bit as a graduate student in the sociology religion but I continued to be interested in aspects of death and dying expressed through religious rituals in particular.

Then later on after that I worked for quite a while in sociology, the family. And I kind of fell into work on end of life issues by chance because I was asked to join a group of people who were going to form an academic center for research and development in what was still being called terminal care at that time. This was around about 1988, '89.

I found myself drawn more and more into the world of palliative care as an academic, over the next couple of years. And I started to drop some of my previous interests and people said to me, "David, you seem to be going down a rabbit hole, what is this palliative care business you've got involved in? It seems totally narrow." I said then, and I would say now, that the contrary is the case because I found that my interests in sociology, history, anthropology, specifically in religion and family, along with my growing interest in sociology of health and illness all sort of came together in the palliative care world.

I was lucky enough to join a small group of people who went on to establish an academic department at the University of Sheffield under the leadership of Prof. Sam Armitage. He was one of the very first professors of palliative medicine in the United Kingdom. I think he was probably the third that we had.

So from then onwards, late 1980s, I concentrated all my efforts in this sort of area in terms of the research and academic work. Obviously as time went along I took on other wider academic responsibilities, I was head of a research unit at Lancaster University and when I moved to Glasgow I became the director of a rural campus that the university has in southwest Scotland. So I had broader responsibilities over the years, but my specific academic focus was very much on end of life issues, palliative care.

Gradually broadening out from palliative care to include other things. More recently, I have... I was very fortunate to have a major grant for the last five years of my career from the Wellcome Trust and this has enabled us to branch out into a lot of new areas. So I did much more work then on cultural aspects of death, dying and bereavement. For example, we looked at phenomena like death cafes but we also engaged in studies of assisted dying.

I became particularly interested in how the palliative care world was reacting to assisted dying, where it was legal in any given jurisdiction. I still think this is a very unfinished conversation, that what we've seen over the years has been very oppositional positions taken up by palliative care towards any form of legalized assisted dying. I think there is great scope to look more closely at how a conversation between the two could lead to some sort of [inaudible 00:05:52] and so we did some work around that as well.

And of course as you said in your introduction, I've had this longstanding interest in the history of the field, wrote a book on that, that was published a few years ago, and in particular I've had an interest in how you map the global development of palliative care in more recent times. I can talk about that. And in relation to the history I had a close relationship over the last 10 years of my life, I worked very closely with Dame Cicely Saunders to ensure that the papers were properly brought together and archived, and the biography that you kindly held up there at the beginning is actually the final volume in a trilogy of books, the first was a collection of her letters which I edited, then a collection of publications and then finally some years later the biography.

So I've been very, very fortunate in my career to range widely over these issues, and to work with some incredible people. Not just in the United Kingdom but much further afield and around the world. One aspect of that was that I got drawn into writing the history of The Project on Death in America. You mentioned when we were talking before the interview that you had interviewed Diane Meier and others, and I got to know some of these people when they were faculty scholars on PDIA. I interviewed them all myself and I wrote a book about the nine years of work that was PDIA and what its legacy looked like.

So I've been very, very lucky in my career to have these opportunities. The position I've taken up in this work really from a very early stage was to regard myself as a critical friend of the field of palliative care. As a non-clinician, as a social scientist and historian, I wanted to do work that would seem to be relevant to the field, but not simply be at the beck and call of the field. Not simply there as a social scientist to do studies that were framed by the field, although sometimes I did, but also to do work that problematized the field.

When I was writing my grant application at the Wellcome Trust, I said that I thought that the position of social science with regard to the palliative care and end of life death field was somewhat problematic. On the one hand there are a group of people who are so embedded within the field as

researchers that they couldn't be critical of it. They were simply doing work that was almost determined by the field. Researching the questions that the field was throwing up.

Then at the other extreme there are a group of social scientists who are too remote from the field, too conceptual and esoteric to be relevant to it. So what I've been trying to do is to find the position that's somewhere in the middle of these two extremes that remains critical in searching and asking sometimes difficult questions, but in ways which are supportive to the development of palliative care. Not simply sitting on the sidelines or sitting in the ivory tower, kind of we would say nitpicking about how things are. Being critical in a robust way but in order to bring about improvement.

And I don't know, it's terribly difficult to know whether you've succeeded in that role. Now looking back on that career, it is hard to know to what extent those worked, but it's been my orientation and it seems at least to have drawn the interest of quite a lot of people over the years.

Connie Dahlin:

There was so much in that, so thank you for that. I'm going to go back a little bit because I think one of the things, Prof. Clark that you brought up that nobody has really focused on before, is that you were intrigued a lot by this relationship of the family and religion to palliative care, and what was it that sort of brought that into the end of life interest that you had of understanding why it was so important to bring those two together in end of life in a way that people hadn't focused on before?

Prof. Clark:

Well, I'd been studying in those fields prior to getting involved in the end of life work. So I was interested in structures and change in patterns of family life, but also in the role of religion in society. And if you look at the early writings, particularly of Cicely Saunders, there was a very strong emphasis on both of the things. One of the things that I think was really key in Cicely Saunders' approach as she formulated the ideas around St Christophers Hospice, which opened in London in 1967, but had like a 10 year gestation, was that she wanted to be able to focus not just on the indexed patient, the dying person, but on the family and the social network of which that person is a part.

So that was really very important, because I think if you read Cicely's work you would see that as she gained her experience at St Joseph's Hospice in Hackney. She was very impressed with how the patient was cared for, but she didn't see much scope for the family to be involved in that care. So St Christophers really tried to break that mold.

So that was interesting, what opens up when you actively involve family in the care of a dying person and don't try to sideline them and take over from them. And of course, she, Cicely, was a profoundly religious person herself. Had a fascinating religious journey in her own right. She was always interested in the role of faith and the absence of faith in how people come to terms with their own mortality.

So I think that if you think of, for example, Cicely's concept of total pain. First formulated in 1964, with its dimensions of the physical and social, the psychological, the spiritual. You can see how religion and family and why the society are all incredibly important in shaping the experience of giving and receiving care at the end of life, in addition to the more obvious dimensions of physical care, clinical interventions, the relief of pain and so on.

So as a sociologist with an interest in these things, I think I found a ready kind of fit with palliative care. I felt comfortable exploring issues around religion and family life and the wider social context.

Connie Dahlin:

The reason why I think it's interesting is because I think we're finally really, at least in the United States, realizing that if you don't include the family or however the patient defines it, you're kind of not going to be successful, right? And yet, at least in our society and the way that our healthcare is, we set forth a lot of these principles of caring for the caregiver or doing all the support, but they aren't covered by insurance and they really vary by community. So there's no consistency.

So we, I think, have set up this ideal that dying at home is the thing you strive for, although we would say in the literature we're actually seeing here, because you may or may not have the supports, it really depends on where you live as to what type of hospice care you give, for some families they're actually traumatized, right? So we've set up this dichotomy here, dying at home good, dying in any other place bad, which I think is not fair to families. We've got to look at that.

But at the same time, what do we offer to the families? We here send people home expecting them to be like healthcare providers, and they don't have that education, right? In our society we deem that quote "custodial" so that we don't have to pay for it. So I think where you come from is so important because they are the ones left with the experience, they are the ones who left... if we're going to think about psychological healing going forward. So I think you maybe have been looking at something that was sort of so ahead of its time, and we're just, it feels like, starting to get that emphasis. Do you have any thoughts about that?

Prof. Clark:

Well, I think the United States context is very specific. All thinking about palliative care and hospice, really has to come back to your financial system. I think this has been... it's important in any society. But I think the particular nature of the American healthcare system has been so crucial to the way modern palliative care is being conceptualized in a sort of market economy, and where often the patient and family are treated as sort of consumers of a service.

So when Diane was doing that work on trying to find a new language definition of palliative care, that really was all about what would be seen as desirable and acceptable to consumers of this product. That, for me, led to some problems because I think it, in part, has led to a sort of masking of mortality and death. The notion that palliative care becomes an extra layer of support as you progress through the stresses and strains of your disease, and the side effects of its treatment. I think that's a very particular version of palliative care that could only really emerge in the context subtext of the American healthcare system. It doesn't make quite the same sense in a system like the one I live in where healthcare is free and paid for from taxation and is free to everybody at the point of delivery, and where there is a much wider social dimension to our thinking about care, rather than a financial driver to it, which always seems to be so important in the US context.

So I've come to the conclusion that the way that palliative care is being shaped in the US can only be understood through the lens of the financial system that has produced it. I think it's probably the most extreme example of that of any country in the world. Many poor countries, palliative care is being shaped by the absence of resource, and the absence of financing and income streams and so on.

So one's not trying to deny that, but I think the debates that have developed in America and the way in which the issues have been framed, particularly among leaders in the field, is how to convince others that palliative care is cost effective. And there's some new work out on this, a new book which I've got on my shelf somewhere but I haven't got round to having a proper look at. But it seems to be arguing that the whole impetus for development was about cost reduction.

And that was never the impetus certainly in Britain and it's not an impetus that I see very, very widely in European societies. But I think it has been very, very compelling in the US and has had particularly kind of consequences for where palliative care sort of begins and ends, what it's defined as being.

Connie Dahlin:

And I think it is an interesting concept because here also people change the name, they figure if you make it more palatable, but I think many of us who have been in the field a long time would say that's really for the clinicians, right? Once the public knows what it is they'll either embrace it or not. Whatever name you have, people figure out what the services are. So it is about our death denying culture and our economics.

But I think, I would wonder, you've said a couple things also that were interesting. I think this whole part about us being able to look at ourselves and critique ourselves, and you were talking about if you're too embedded you can't be objective and if you're too remote you don't understand what's going on.

In terms of really critiquing ourselves, what are some of the areas that you think we really do need to look at ourselves a little bit more and think about for the future? Because I think that's important for people to say we did the best we could, we may not have gotten it right but we want to keep moving forward to making it better?

Prof. Clark:

Yeah, well I have some thoughts about that and I preface them by saying I'm not speaking now purely in relation to the American healthcare system. I think that there are some wider issues that you see occurring in other places. I suppose what has been going on is that we have a field in hospice, palliative care, that begins on the margins of the mainstream system. It has to battle its way into the center in some way.

I wrote a paper on this called From Margins to Centre, a long time ago, in The Lancet Oncology. This is pretty common in most countries that things begin on the margins and try to work into the center. Getting into the center involves a number of things. It involves clinical recognition and respect from others, in other areas, and there's a lot written about the problems that have occurred as palliative care enthusiasts have tried to persuade their colleagues in other aspects of medicine healthcare what they're doing has value.

So that's a dimension. Another one is policy recognition. Trying to get into a position where the work that you do in palliative care finds recognition in policy, whether that's at a very local level in the hospital where you're working or whether it's globally with recognition in the World Health Assembly and the WHO. There's an enormous number of struggles that have gone on over the years to try and get that recognition.

And I suppose there's a little bit of romanticism about the experience of the pioneers in the early days. It's tough being on the margins but it's also very exciting. You're trying to break into something and offer something new as an agent of change. Where the issue sort of starts to get a little more problematic is when you've begun to do that, and there's a very famous paper written years ago by David Field and Nicky James where they use some of the ideas of Max Weber to talk about this very process. They called it the routinization of hospice.

It's when the hospice idea starts to become mainstream. And then I think some of the founders get concerned that something's been lost here, that perhaps paid rather a high price for this. It could be

that you have to shape everything to the constraints of the healthcare system, its funding structure, its systems of evaluation, quality assurance and so on. Or it might be that you have to pair back on the holistic vision of palliative care and give less emphasis to, let's say, the softer dimensions of spiritual care or psychological distress in favor of dealing with the most immediate and pressing issues of pain and symptom management.

So that kind of debate that goes on about whether it should be called palliative care or supportive care, is in that territory, because supportive care is unequivocally about this sort of whole... very strong emphasis on pain and symptom management. So I think these are quite interesting areas that the field has been traveling through.

But I also think that there have been new injections in more recent times of fresh ideas that come from elsewhere that sort of relocate or resonate some of the founding ideals of the hospice and palliative care leaders.

For example, the whole interest that's grown up around the world in compassionate communities, the idea of framing palliative care as a new public health issue that doesn't begin and end with clinical services but is something important in society that's about debating end of life issues more openly, having conversations about these things. Using that as a platform for thinking more proactively about advanced care planning. These types of things.

They seem to me to have been rather fresh ideas that have been exciting and developing in recent times that somehow reinvigorate the field that might be in danger of becoming as one person within it said many years ago, Michael Kearney in an article in Journal of Palliative Medicine. Are we becoming just another specialty?

So you might say, "Ah, David, this is all a very romantic view of hospice and palliative care and the real deal is to get out there and give the best possible end of life and palliative care to as many people as possible." And if that means it being a rather basic form of it, well so be it because we want as many people as possible to benefit, rather than... I wrote an oral history book about hospice care in Britain. We called it *A Bit of Heaven for the Few*, which was a quote from one of our interviews that the hospice world is doing a wonderful job but it's only reaching a very small number of people. Palliative care is designed to reach potentially everybody that could benefit from it.

If you look at The Lancet report on pain and palliative care, came up with this notion of health related suffering. Suddenly you find that 50 million people in the world every year could benefit from palliative care. Indeed, whether or not they die.

So this then becomes very, very broad. So I think some people feel that when the field is broadening in that way some of its initial essences get lost. So one thing we've been trying to do over the last couple of years is to establish a Cicely Saunders Society, to hold on to her memory and to salute that, but also to explore a legacy and what light it perhaps can cast on these sorts of dilemmas.

And I've noticed that the people that are drawn to the society from around the world often say this is a way to kind of reconnect with the early ideas so that we don't lose sight of these in our drive to be recognized, to get reimbursement, to professionalize, to have training programs and specialty recognition and all these things.

I think this is a fascinating dilemma for the field, and I think it's commendable that there are still people within it who want to just alert their colleagues to this, and say, "Well, hold on a minute, we're making progress down this particular road, but are we losing something in the process?"

I would hate this to sound unduly romantic, that it's just making an appeal to the good old days when in fact very few people got palliative care. That's not what I'm saying. I think there is a risk of

losing sight of some of the deeper and more profound aspects that this field is interested in, in a way that many other fields of medicine are not.

Connie Dahlin:

Well, where I think you... I mean, I think what you've talked about is this sort of like when you start off with a core group and you do, for lack of a better word, try to go mainstream, there's a compromise because in order to go mainstream you have to think about that. Where I also thought what you were talking about is I think that the World Health Organization, talking about palliative care as a part of primary health, right, as a part of...

Those, to me, are so important because exactly what you were saying, because the other part of this is I think if we think about health equity, if you look at the statistics at least in the United States from the 2020 National Hospice and Palliative Care Organization, we're still only reaching 80% are white people, we haven't moved into the African-American or the Hispanic or the indigenous population, so there's something about that, Hispanic as well.

Then you think about COVID, so we have this pandemic. It's not ours, right? We're helping the critical care, it's really theirs, but has that been an opportunity? Which I think it has. Or is it also going to make people think that we're taking care of only people at end of life again, right? But you're sort of speaking about how do you move forward, hold on to some of your primary ideals, which in my mind is this interprofessional part, where we have this group of people looking at all the perspectives, right? Because you've already brought up that it really needs to be social, spiritual, biomedical as well as thinking of the cultural and all of those pieces. That's what makes it so special. But we also have to figure out what happens in the real world, and maybe also in the United States as you've said before, because of our financial status it is different than maybe how the rest of the world is going to go.

But I also think that there's so much for us to think about and the rest of the world, particularly in developing countries, because we really haven't done a lot in this country on community health workers, of thinking about those alternative things. So it is a yin and the yang of holding on to the ideals that got you started and recognizing that as you move forward, you are going to have to change. That's just the evolution, right?

Prof. Clark:

Yeah. But of course, the history of hospice in the US is about community services, and the route that was taken in the early days in New Haven was not to build a bricks and mortar hospice, but to develop a home based service, which becomes your paramount model in a way that it didn't in Britain.

St Christophers developed a home care service fairly quickly by 1969, it was up and running. But it wasn't at the center of the thinking until the building was up and the beds were in and... So I think that that is an important difference, that when you talk about hospice most of the time you're talking about care delivered at home, whereas in Britain when people talk about hospice they think about a hospice, a place you go to and where you might go to die or occasionally go there for respite for your relatives and that kind of thing.

I think the British hospice movement is really deeply challenged by this now. I wrote a blog about this a little while ago. For the first time, we've been seeing hospice closures on financial grounds in Britain in the last couple of years, and there's some interesting ideas emerging from that, but I was arguing that really the one way forward for our independent hospices, which are independent nonprofit charities, very much rooted in their local communities. We've got a few hundred of these across Britain.

That they should really try to divest themselves of their inpatient facilities, relocate those to the local hospital, have the NHS meet the cost of them, and then the hospice could focus more on community interventions of various kinds, bringing people in on a daily basis, reaching out to them at home, engaging with wider communities that surround the hospice in all sorts of ways that would be helpful to local society. So it is a bit of a turning point for the hospices in the United Kingdom at the moment.

When I was thinking about talking to you today and I was looking back to when I sort of really first properly got drawn into this field in about 1989, that was coming to the end of a decade when... it doesn't sound many in American terms, but in Britain it's quite a lot. Every year 10 new hospices were opened in Britain throughout the 1980s. There was 100 new hospices built in that period. There have been very few new ones built since then, though many of them have rebuilt, put up new buildings.

But it was a very dynamic time and that was also the period when in 1987 palliative medicine was recognized as a specialty for the first time, it was in Britain. It was when the first journals started to emerge, the late 1980s and so on. It was kind of a golden era for hospice in this country. But in the last few years, that has really turned around. What was seen as a kind of real virtue that our hospices were very substantially supported by local funding from the community, over the years that fraction hasn't changed much. The sector as a whole still relies on about two thirds of its funding coming from charitable sources, and only about a third from the NHS.

But now this is really beginning to break down and it's meaning that hospices are struggling to pay their way in the provision of inpatient care. And it's raised a lot of negative commentary where people are, I think rightly saying, why are we still funding two thirds of our hospice endeavor, which we're so proud in Britain, from charity shops and people running marathons and all of these kinds of things. I mean, it seemed okay at the beginning but here we are now 50 years on or more since the opening of St Christophers and we're still doing this.

So whereas I said at the beginning about the financial arrangements in the US being particular salient, but they're salient in Britain as well because although we have palliative care being delivered through the NHS that's free at the point of delivery, and the hospices deliver free care but they are struggling to actually generate enough income to provide the services that they want to.

Now, my opinion is that because they're still hooked on the idea that if you don't have inpatient beds you're not really a hospice, and I think they should try and drop that and let the local NHS take the strain. We do have some hospitals in Britain that have palliative care units that look like hospices and which are funded through the NHS, and it wouldn't be difficult to have more of those.

So the field is changing in all sorts of ways and I think that's where the role of somebody like me can be useful in laying out milestones, turning points, the paths not taken, the dead ends and so on. And the new opportunities. Because for clinicians, clinician managers and leaders, they're often very much pressurized by their day-to-day responsibilities, and it's not so easy to step outside of that. We have this expression here, when you're holding a hammer everything looks like a nail.

I've regarded my job as being to try and help people to just, however briefly, step out of what way of thinking, and just to try to think again about what's going on. There's been quite an interest in Britain in this whole idea of taking design principles in order to redesign services. It's quite seductive but I've not yet seen any real evidence of where it's worked, but the concept that you sit down and look at your service from a design perspective and you think about how it's built and how it operates and whether changes to the design would be desirable and beneficial.

I think that's kind of a helpful way of doing this. It's a slightly more process driven approach, but I think having the ability to step back is important. At two levels, really. One is to understand where you



are in the historical context, over the longer duration, where why are we like this, and then the other one is to be in a better position to respond to the opportunities and threats and that are around you right now. Doing both of those I believe is helpful but when the pressure is on it's often very difficult to do that.

Connie Dahlin:

I think you bring up a really, really important point in what you were saying. I think this redesign is important because we have a whole different generation coming up with very different values. So what we based it on was 50 years ago and what people want is different. I think the other part is that you mention this clinical part. I know there's still research and all that but I think we sort of have the clinical piece down. We know what to do and how to do it and some of the medications. We can fine tune that.

I think your part about process is really important because how do we use the resources that we in fact have in a very... being a good steward? And I think in my mind this whole part of community is really interesting because you're talking about inpatient houses. We don't have as many of those for the exact reason that people often can't get the support.

The flip side of that here is I think what we're really trying to think about is you have these acute care settings, crisis oriented, how do we keep people in the community where they want to be knowing that every community will be different, but how do we give sort of a blueprint for these community partnerships that really are engaging that community with those resources and those populations that speak to them, to be helping us do this? And whether at that also means is that we have to sort of let go of that control, right? That if we're engaging with faith based communities or engaging in community health centers, we're going to have to let them guide some of that because they're in that community. We are kind of brought in as a partner.

So there's a lot of these themes that I think you're bringing up of really where we need to... One of our key roles is to be a partner and listen to other people's ideas about it because we don't know what everybody needs, right? We have to have people be telling us. But you've brought up some amazing parts for that.

Prof. Clark:

For me, one of the really interesting examples of that giving up power, is to be found in the state of Kerala in India, where you have this massively effective community based approach to palliative care, often referred to as the neighborhood networks in palliative care. It's been initiated and led by Suresh Kumar and his colleagues over many years, and they started off right at the grassroots and that's where they've stayed.

What Suresh has often said to me is that to empower people in the community, you have to be willing to give up your own power. I think this is something that medicine finds very difficult to do. But what you find in the model of palliative care in Kerala is that the doctor doesn't have any higher status than the volunteer or the fundraiser or the community activist.

But what I also like in the Kerala model is the way that they've engaged with groups in society it's complicated in the state of Kerala, there are Christians and Muslims and Hindus. But they've also engaged with the trades unions, with the police, with the political parties. And this is something quite different to anything we see in most other places. There's a kind of literacy about palliative care in the state of Kerala, in the society as a whole, that you don't really find elsewhere.

It's been enormously successful there and there's a lot of good data now on its coverage and some data on its quality. But paradoxically it's struggled to develop anywhere else. Even in other parts of

India. So we did a study a few years ago where we looked at an attempt to transplant the model from Kerala to the state of West Bengal. Much poorer state with much lower levels of literacy and education in society, and the model got going but it looked very, very different and didn't succeed as well as it has in Kerala.

The hope that this could be a model not just for the rest of India but for the developing world or even for the world as a whole, is still to be realized. There are people in many countries in Europe, Britain and Switzerland and elsewhere, who have taken elements of the Kerala model and are trying to foster them in their own context.

But that's a radically different approach to the ones we've been describing and it's been enormously successful in one state but for reasons that aren't properly understood, it hasn't flourished when it's been transferred and translated elsewhere. And this has been a theme that's interested me a lot over the years, particularly in more recent times. I think in the global context of palliative care there's been and remains a view that you build a model that can be tested out somewhere, usually in the global north in an affluent country, and you come up with something you believe to be robust and then all you need to do is roll it out all around the world and you do that through getting WHO endorsement and Lancet endorsement and that kind of thing.

But I think the reasoning here is very, very flawed. Not just because good ideas come from the poorest countries as well and you get this kind of reverse innovation at times where an idea like the Kerala model transplants to more affluent settings. But it's just that there's a naivety and almost an imperialism as well, that in the global north we have access to all of the solutions.

Now, we wrote a couple of long papers on about this in relation to the Liverpool Care Pathway. So the Liverpool Care Pathway gets developed in Britain by enthusiastic palliative care people with brilliant hospice credentials, and it gains endorsement from governments or for governments of the UK endorsed it, and it became very, very widely used in Britain in the local care pathway for the last 48, 72 hours of life. And a lot of people were on the pathway when they died, when it was at its height. My own mother was on the Liverpool Care Pathway when she died.

But then suddenly there was this huge backlash that blew up from outside the field. Journalists and newspaper people and reporters and things. And then a lot of stories emerging about discontent on the part of family members who's had a relative put on the pathway. And eventually there was an inquiry into the Liverpool Care Pathway and it was withdrawn.

But, that wasn't before the perpetrators and developers of the pathway spread the message to 22 other countries that were also using it, some more or less extensively than others. And they were then left wondering well, we took this idea that came from Britain from people with excellent credentials but now the British government has abandoned it, but meanwhile we've adopted it.

So there are examples where things have not worked out very well. This is the first one we know of where palliative care intervention was actively banned by a government right here in the United Kingdom. So these things needs to be understood better and for people who were studying on your course, we have written two long papers on this published on Wellcome Open Research platform, so they're free and open access.

I wrote them with Jane Seymour, Jane led on the first one and that was really telling the story of the rise and fall of the LCP in Britain. Then the second paper I led on and that was trying to tease out how it had spread in the meantime to 22 other countries and how they'd used it and what they had learned as they tried to adapt the intervention to their own context, and then what they did when they discovered that it had been abandoned in Britain.

So I've had the luxury of being able to look at these things in detail but to me there are enormous lessons to be learned from that particular example. But there's, I would say, a slight unwillingness to go too far into exploring that. I looked recently at the first papers being read by 17, 18,000 people, which is a lot for a paper in our field. I hope that those who have read that have been able to take away some kind of lessons from the dangers of perpetrating a model rather hastily and without the best evidence, getting it adopted by the policymakers and then rolling it out at the population level. It looks like a great achievement until it goes wrong.

Connie Dahlin:

Right. Well, I think also what you speak to is this thing that I've been struggling with for many years, of that I think in the United States we had this hospice model and then we moved to palliative care which was very hospital focused, and then I think the other part is you've spoken about this dimension that we have, interprofessional, and we have had sort of this equity issue for a long time, right? Of kind of thinking about okay, what happens in an academic medical center versus what happens in the rural community, and models don't work that way and they don't have the resources.

Then the language is different when we think about this Eurocentric model that we talk about, death and dying, here unless a patient says death and dying we don't think they've accepted it, and you and I both know culturally they may never say that, it may not even be appropriate. So we very continued that.

And then I even think in amongst the team, and you sort of have hinted at that, I mean there's very much still this part about who has the power at the table. We talk about it in a professional team but we still haven't worked out the dynamics in the team of are we really equal in this and what happens when you do that. So I'm just curious if you have any other thoughts about this sort of equity at this micro-level and then you kind of talked about this [inaudible 00:48:25] level too of global response.

Prof. Clark:

Yeah. Well, I think a lot of people continue to be engaged with the whole question of equity and fair access to palliative care and certainly there is work going on in Britain around that and there's a big acknowledgement that people from black and ethnic minority communities are far less likely to gain access into a service that's free.

So I think that remains a big issue, equity just as fairness. But it's still to be resolved. Something to do with the messaging that goes on about palliative care, and I suppose this is what Diane Meier was very keen to do, to get clear messages to specific audiences. But it sounds like from what you've said, and it would probably be the same here, that messaging to ethnic minority communities in the United States and in Britain has not been particularly clear or particularly compelling.

So I think that there's a lot still to be done there. And progress on that has been rather slow. But of course at the same time you've got growing need. The aging population's producing these huge spikes in demand for palliative care as well. So yeah, I think the equity issue will... I sensed recently, there's a renewed interest in addressing this and trying to do something about it. It's been swept under the carpet in various ways and hasn't demanded a lot of attention. But it has to be tackled.

Connie Dahlin:

Well, I think for here in the United States, I mean COVID just laid it bare. We were pretending that it wasn't there but when you look at all the COVID cases and care people received, even for people who don't believe it, there is so much... Well, I can't even say science because we have people who don't

believe science. So we can just say there's evidence to suggest that's so strongly correlated that if you wanted to ignore it before maybe you could get away with it, it's just such an elephant in the room now.

So maybe that's one of the 50 years later types of things of the things that we do need to address in a very different way, and having the students in this class who are coming from all over different things, they might offer a different perspective. I just think that's important.

Prof. Clark:

Yeah.

Connie Dahlin:

Dr. McPherson, you have a question, I can tell.

Dr. Lynn McPherson:

Yeah. So I would like to know what Dame Cicely Saunders was like. Was she a grandmotherly type, was she spicy to the end? What was she like?

Prof. Clark:

Well, she's a pretty intimidating person in many ways. I knew her pretty well but I wouldn't say I felt relaxed in her company very much. She didn't do smalltalk. She was very earnest and focused, and I asked her about her mental acuity in the later years of her life and she thought in many ways that she was sharper in late life than she'd been earlier.

Yeah, I remember her saying to me though that she did look back at times and she could remember times when she'd been a bit too sharp in dealing with people, over hastily making judgments about what should be done and shouldn't be done. But she had a tremendous mind, she read very, very widely. You'll get to the end of the book, you'll see that she still went, even in the last few months of her life she was receiving lots of visitors and they were getting questioned about their views on this or that issue that was around at the time.

Lord Joffe was trying to bring an assisted dying bill through the House of Lords in 2005, and Cicely was following that very, very closely right up to the time that she died and asking people what their views on Joffe were and would it succeed and so on.

But for me, she's an endlessly fascinating person. It was a huge privilege to spend time with her, to collate her papers, to do the trilogy of the two edited books and the biography. And also the little book Watch with Me that I did with Cicely, which is tiny five chapters that really... Well, it was described by Robert Twycross at her memorial service as her autobiography. It's five pieces that she wrote over five decades that bring together her personal journey with her work and her faith and her practice of hospice care. That book was translated into Danish just a few months ago. I saw Connie had a Danish poster behind her.

Connie Dahlin:

Yes.

Prof. Clark:

Is that Ross [Kilburn 00:54:01]?

Connie Dahlin:

Yes, that is.

Prof. Clark:

Yeah, there we go. So yeah, some of my colleagues in Denmark have translated the book in Watch with Me into Danish. It's been translated into seven languages now. So I find Cicely a pretty intimidating character but endlessly fascinating. What I'm trying to do at the moment, when I'm not responding to podcast interviews, is I'm trying to write a play about some aspects of her life, and that's going quite well working with some young theater people and also a nurse colleague of mine who knew Cicely very well and worked at St Christophers, but also knows about theater. So there are four of us working on this and I'm writing the script.

Our goal is that we will try to premier it at the Edinburgh Fringe Festival next summer in 2022. She fascinates me, I finished writing the biography some years ago but I still keep coming back to her work reading and rereading things that she said and wrote, I think there's an enormously rich legacy there that should be of interest to anyone in our field.

Dr. Lynn McPherson:

Absolutely. I'm sorry I did not meet her. I think Connie did have the chance to meet her.

Prof. Clark:

Oh did you?

Dr. Lynn McPherson:

But she strikes me as somebody who did not suffer fools gladly.

Prof. Clark:

Oh, that's absolutely true. Yeah. You'll see that in the book at times in the way she responds to people who ask silly questions in letters or want to come and visit the hospice from America on Christmas Eve. Things like that.

Dr. Lynn McPherson:

How did you know?

Connie Dahlin:

Yeah, I had the opportunity. I did the Hospice Education Institute with Michael [inaudible 00:56:02], who you probably knew.

Prof. Clark:

Oh yes.

Connie Dahlin:

Michael and I went way back and then also when she came to Boston we had a conversation with her and so I would agree with everything you said, intimidating and you wanted to be thoughtful. I'm sort of fascinated, I think, when I think of what was going on of her career as being a social worker, a nurse and

a physician. That part of, how that... if she could ever differentiate how each of those changed her practice. But then also thinking about that she... this triangle of her and Elisabeth Kübler-Ross and Florence Wald, these three very strong women.

Prof. Clark:

Yeah, absolutely.

Connie Dahlin:

Wishing that you could be a fly on the wall when they had some of their debates, must have just been pretty amazing.

Prof. Clark:

Yeah. She could get quite snippy with Elisabeth. I think they butted heads a little bit. But with Florence Wald it was a lifelong friendship. They were very close to each other and corresponded regularly right up to the time of Cicely's death. So yeah, in fact I've been reviewing the correspondence between Florence and Cicely just recently. There's a couple of massive files of letters in the archive between them. Fewer with Kübler-Ross, but a huge amount with Florence. And also with [inaudible 00:57:41], a massive correspondence, and with Sam Klagsburn who was the psychiatrist who used to visit St Christophers once a year from the States to give advice on organizational matters.

These are really rich sets of correspondence, they're not like just the modern email, they're pages long and they're reflecting on issues and something I've read and something you should read. Yeah.

Connie Dahlin:

Which is interesting, even though as you were saying that, and you kind of jumped to it, the transition of people writing those letters and being like that and now just trying to get access to people's emails.

Prof. Clark:

Yeah.

Connie Dahlin:

Just trying to think how different that is.

Prof. Clark:

Yeah.

Connie Dahlin:

Amazing.

Prof. Clark:

Okay.

Connie Dahlin:

Yes.

Dr. Lynn McPherson:

As we wrap up, Prof. Clark, any advice for our PhD graduates as they move forward into this field?

Prof. Clark:

Well, I think it's great that you're doing this kind of course. I'm a great believer in this approach. When I had left Lancaster University where I established the International Observatory on End of Life Care, I left there in 2009 to move to the University of Glasgow, and one of the last things I was able to push through was a taught doctorate in palliative care. It's been enormously popular.

I've subsequently employed people from the US who graduated from that program because it's also a distance program. So I think it's great that you've got students on it and I would encourage them to use the space that the course provides them with to think widely and to read widely and reflect. Try to get out of their own bubble wherever they can, out of their own comfort zone, to explore matters of difference and contradiction in an active way, which of course this really provides you with an opportunity to do. It's not simply a training in how to do something, it's a questioning of why we do it and how it might be done differently. I think to really enjoy that experience in a creative way would be a wonderful starting point for students on the program.

Dr. Lynn McPherson:

As a lifelong qualitative researcher I guess you are firmly behind the idea of always maintaining a good sense of curiosity.

Prof. Clark:

Absolutely. Yes, always wanting to know why things are the way they are and why we do things in a particular way.

Dr. Lynn McPherson:

Definitely.

Prof. Clark:

But as I say my approach has not been in order to demolish things, it's been to try to improve them rather than destroy them.

Dr. Lynn McPherson:

Definitely. Connie, any last words for Prof. Clark?

Connie Dahlin:

Oh, thank you so much. This was such a great, rich conversation and to hear the different places and to know that we still all have a place to do some work in this field as we move it forward in whatever iteration it goes and whatever community we're in.

Dr. Lynn McPherson:

Thank you so much.

Prof. Clark:

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Yeah. Well, it's been very pleasant talking to you both. Thank you for the invitation and best of luck to all the students.

Connie Dahlin:

Thank you.

Dr. Lynn McPherson:

[crosstalk 01:00:37]