

Dr. Lynn McPherson:

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

Hello, this is Dr. Lynn McPherson and welcome to our continuing series of leaders and futurists and founders in palliative care. We're very excited about our series. My name is Lynn MacPherson. I'm the program director of the online PhD masters and graduate certificate program in palliative care at the University of Maryland, Baltimore. And I'm joined by my good friend, Connie Dahlin, who is a faculty member in the PhD and the master's program. She will be introducing our guests today. Connie, take it away.

Connie Dahlin:

Great. We are so pleased today to have Terry Atilio who is trained as a social worker, but has really been a leader in many other ways. She has been leading in New York City. She co-edited the first textbook of social work, palliative care or palliative care, social work, which was really an amazing feat for any of you have embarked upon doing textbooks. And also, Terry continued to be a leader in New York City in terms of leading at the Beth Israel Palliative Care Program, but she did a really amazing job at thinking palliative care early on in different dimensions having an inpatient unit, but also really thinking about how it was training and educating that the clinicians of the future. Terry, really welcome today and we look forward to hearing your thoughts. Would you like to tell us how you were in palliative care and social work and where you felt like you were going to step in and say, "Okay, I need to be a part of this and I need to help sort of foster the next generation."

Terry Atilio:

Yes. Thank you for allowing me to think about this and to talk about it. I was really blessed in some ways, although I didn't understand it at the time, to be working at Memorial Sloan Kettering when the project on Death in America got off the ground with Kathy Foley and George Soros Foundation funding a large number of what were called faculty scholars at that point in time. What was most interesting about that is I watched as Russ Portenoy and Kathy Foley began to represent and present palliative care at Memorial Sloan Kettering, which is just interesting in itself because you know and I know that oncology has this interesting banter that goes back forth with palliative care about what they're going to call us, whether we're going to be allowed to be palliative care, or whether we have to call ourselves supportive care.

My fantasy about that is folks don't believe that people can actually learn what palliative care is and after they learn what palliative care is want it because it is so humane and so expert in terms of how he cares for patients. I was back at Memorial Sloan Kettering, and the project on Death in America began with physicians and nurses. It did not begin with social workers. It took a number of years before social workers were engaged in that and we were not called faculty scholars. This is all interesting to me and perhaps to others who are listening, because it has to do in some way with the place of the disciplines in this work. And most people feel and see that social work is not a majority discipline in hospital settings. They are the first line of mental health, but they are not a majority discipline.

In fact, we are a minority discipline in hospital settings, and that's a very interesting place to be in because what it requires, and certainly what it required of me, was to figure out what is my place in

this. Part of that was affirmed when the project on Death in America decided they were going to call us social work leaders. We were not called faculty scholars. We were called social work leaders. When you think about our origin story of palliative care, for me, this is part of it. This is part of the origin story and what we continue to work on, if you will, as a specialty.

They finally decided they were going to put a lot of money into what was called faculty scholars and through the whatever of Russ Portenoy, visionary guy, he suggested we should have a fellowship at Beth Israel, a social work fellowship. That was the project on Death in America Social Work Leadership Award that we got was to establish the first social work fellowship, postgraduate fellowship in palliative care in the country. It also was used to establish a social work listserv, which has been in place, believe it or not. I just had to check this out because we have to find a new home for it. We just checked this out. It's been in place for approximately 20 years.

Connie Dahlin:

Wow.

Terry Atilio:

It has exchanged 23,000 messages.

Connie Dahlin:

Wow.

Terry Atilio:

We created a listserv and we created a social work fellowship, which in some ways, there are now a couple of fellowships in the country. Not a lot social work fellowships, post-grad fellows, social work fellowships. The fellowship has continued through the philanthropy of a private person whose daughter we cared for. Russ and I cared for her and a consequence of that care and that commitment she funded the fellowship. I'm going to say for 15 years, for a really long time. All of that said, the true thing, I think, that began to give me a voice and social worker voice was the text. The text of palliative social work. And we would not have had that text had it not been for Betty [Farrow 00:06:23]. Betty Farrow, wonderful nurse. Well, she's more than a nurse. I don't have to tell anybody with Betty Farrow's credentials are. You all know Betty Farrow. She motivated us and encouraged us and encouraged Oxford to support a textbook of palliative social work. That is a very concrete thing. It is a concrete thing and a concrete message to the world.

And we're now doing the second edition, which I will not talk about. It's like, "Yes, we will do this." It's an amazing experience in one sense because it really does reflect the growth in the field of palliative care and it also reflects the enhanced expertise of social work and the enhanced expertise that we need if we are going to continue as a specialty. What I had eventually come to was that silence gives consent. I had to figure out how to have a voice because social work has a unique way of viewing the world. We've used persons in environment that really is essential to palliative care. It is a basic social work tenant. And not only do we view patients in their environment, which we all know has become so much more essential when we talk about social determinants of health, when we talk about the inequities in our country. Understanding a person's environment is essential.

The second thing that we come at this work from has to do with starting where a patient is and that became very important to me when I saw how de-legitimized many of our patients were, especially in their reports of pain and their experience of pain and symptoms. I finally decided that I could not be

silent anymore and that I had to stop feeling sorry for myself. I was either going to have a voice and the consequence of that. This is a challenge for social work because we are a minority discipline in the settings in which we work and yet we have amazing perspectives that frame how palliative care in my brain is at its best. It's at its best because it's talking about human beings, how they live their lives, and how that all relates to medical decision-making.

Finally, and I don't know what it was, probably after the book or maybe a little bit before the book, I just decided that we could no longer act as if we didn't have the autonomy and the authority to take a larger place in this work, because it wasn't going to be given to us. I will tell you, if you look at the origin story of palliative care, it's quite hierarchal. It's quite white, we know that, and it wasn't going to be given. That meant there would be some kind of tension and there continues, I think, to be some kind of tension in terms of the important work of how we work together, how we understand. And I know that your program will support this.

How we understand that while there are shared skills, we come at this work from a different discipline specific training and we are not to give that up. I know I learned a ton about pain, but I didn't know what my doctors knew. I had to count on them for certain aspects of the work that we were doing and they had to count on me. And we had to count on nursing and we had to count on chaplaincy. This idea of egalitarian process between us all is something I think we have to be careful at. I think we need to be the experts at who we are, the discipline that we have chosen, and weave all that together because palliative care is a beautiful place where it gets woven all together. Social work is unique in that sense, as this chaplaincy. You're certainly a minority discipline in the work. The worry and I've had this worry for a long time. I continue to have it.

I think the fusion of palliative care and hospice is challenging and creates both opportunities and also challenges. I think that hospice, when it started to call itself an industry, crossed some kind of a line that I don't understand. It must have something to do with profit making. I think that we have to be really careful about how we bridge that relationship. Not only careful, but I think that we have to become a voice because there is something certainly about calling the care of people who are coming to the end of their lives, an industry that, for me, defeats what palliative care has been intending to build over the last two or three decades. That's like a worry that I have and I'm saying it here because you're doing this course. I don't know where it's going to be.

Oh, the other worry that I have about where palliative care is going. One of the questions was about what's the tipping point? What was the tipping point in palliative care? The tipping point, I think, for social work was the book. It was concrete. It was on a shelf with physician, nursing, and social work. There was something about that representation that was important for us. When I think about tipping point, I get a little nervous about that because I think I've listened and read Diane Meyer talking about the tipping point, perhaps, that we achieved during the pandemic when everybody needed us in a way that they had not needed us before. And what I worry about is that that is going to skew the whole process that we were working toward, which had to do with primary palliative care.

How do we balance that? Yes, we are important. Yes, we've done tremendous work during the pandemic. We had their backs, as the quote says, "We had their backs," but how do we now get back to what we hope will be some semblance of normalcy in terms of care? How do we get back to this idea that palliative care specialists will never meet the need that we are talking about in this country and certainly around the world. How do we now get back to the idea that primary palliative care that we have to support our colleagues or physician and nursing colleagues and social work colleagues? We did a second book, which is a guide and the guide is for health social workers. It's our version of primary palliative care for health social workers. It's based on the eight domains, Connie. You're intimate in the eight domains. Based on the age domains. Each chapter is a domain of palliative care.

The message of that book was you have skills. You cannot walk into a patient room who's just been diagnosed with metastatic cancer and begin the conversation with discharge planning. That is not social work. That is not social work. How do we blend? How do we figure out how to move ahead primary palliative care, as well as continue to build the specialty, the experts, the leaders, the researchers, and so on and so forth who will lead the specialty forward? I don't want to lose that because we will never be able to care for all the people that need palliative care, certainly not around the world. Just forget the world, forget the numbers.

Connie Dahlin:

You brought up some interesting points though because, first of all, I think that you have witnessed to this real growth. I think your role in social work ... I think this part that you bring up Terry is this sort of equity amongst the team. We talk about equity, but we haven't talked about equity really with the team and what does that mean? And I would suggest to you that I've had social workers who are better at assessing pain than some of my interns or residents. And so, I don't want to also minimize the sense that there's an assessment piece and whether social workers can prescribe is one thing, but then sometimes they do and chaplains as well, do a much better job of assessing because they're really meeting that patient where they're at and understand the context.

And so, I just really want to acknowledge that. And I think you're right about some of the hierarchy, particularly as you think about palliative care coming out of the academic medical center. It's very different when you go into a community or a rural setting. And I think it changes a bit because there isn't such this rigid part of it. But I also just want to think about when you've talked about this primary palliative care, you bring up this important point that I think for our students to think about. And yes, we were part of the pandemic. It wasn't ours because it was really critical care in the ED folks and we were teaching these skills. But when I go back and look at some of the resources that we're putting out there quickly we had to get things quick and we didn't have the time.

But we have to go back and look at some of those and say, "We did that because we were in a pandemic and we still are, but we have a little ... some places right now or in a little bit of a lull. We'll see what happens in the fall. But is that the highest quality that we want to have?" We put stuff in place, but I go back and look at some of it and I'm like, "Ew, is that what I want long-term? There's a quality part, but then there's also, to your point of saying, "We do have to go back to that" and we have to make sure that we're, I would say, inculcating it in all areas. And I think for me having started off in the community in hospice, then growing a hospice in rural areas and a home care part of a ... palliative care part of a home care back to a hospital back to the community. I have worried a lot regionally because I've been across the country because I see some such skilled social workers who are relegated to discharge planning.

And, sometimes, I'm saying to them, "Well, can you do this part of your role?" And there's this part of saying, "Well, I'm not allowed" and that just breaks my heart. And so I guess my comment to you is, so how do we around that help empower our social workers to work to the top of their education and their license? And then, how do we as a field continue to think about that?

Terry Atilio:

You know what's interesting to me about that observation is that from my point of view it is not just social workers that need folks to advocate for them. I think it is our doctor colleagues who are expected to see people in 15 or seven minutes and provide compassionate care. I think we, as a specialty, need to think about the level of advocacy rather than what I often see is accommodation to crazy things in our system. Crazy things in our system like the hospitals that are running around trying to sign somebody on

to hospice before they die so the mortality rates are not what the mortality rates might be. Why would we accommodate to that? I think that we need as leaders and as future leaders, and this is not an overnight thing. Those social workers who are doing discharge planning and some of them are saying that's because what they tell me, this is all I can do. And others are quite comfortable in that place, so we need to make them uncomfortable. We need to create discomfort around that.

I think it is broader. I think that there is a level of advocacy that we need to be taking on and maybe we are, and I just don't know about it, on a national level where we, as specialists, are saying, "You can't possibly do this kind of work in 15 minutes." What we expect and what we hope will become care of human beings rather than care of bodies. I appreciate how that fixes on social work and it was really interesting to me is as I see it also. I'm not sure why this would be. I see it also quite painfully in my physician colleagues and perhaps in nursing as well.

I don't have the same sense about that and maybe also it is because when we talk about how we work together as a team and an equity and so on and so forth, we are not always morally distressed by the same thing. We are not always upset by the same things that we see in our world, because we have different responsibilities. I say when I teach social workers, "You will never write a prescription that is by a person's body when they're found dead because they took all those pills." Anyway, it makes me profoundly sad, but it also is really, really important that while we can talk about equity between the disciplines we do not carry the same risk.

We need to be talking that. We need to talk about it out loud, because you cannot have an authentic conversation if you can not talk about the difference in risk. You cannot have an authentic conversation if you're not talking about money and who's doing the billing and who's not doing the billing. We don't bill. Most of the time we don't bill and a lot of my colleagues want to start billing for advanced care planning. Everybody's going to be running around trying to figure out how to bill for advanced care planning, because it can now be paid for. What is the matter with that? I think that that equity is very interesting in teams, what it means, and how we achieve authentic conversations.

I had a doctor once said to me, "You will never understand, Terry, what it feels like to do something like a resuscitation that you feel is medically, morally, and ethically wrong, but you do it because you don't have the, whatever, the legal authority, the whatever authority, or the family has not agreed" and I got that. And then I said, "Then you will never understand what it feels like to have a family coerced into a decision because of the way we use language and the way we talk to patients." There is a difference in how we see the same event and I think that's beautiful to talk about because it really reflects our different training. And that's why we bring people together in his team. That's the richness of team is the different training.

Connie Dahlin:

Well, what you also bring up is this interesting context and there's a couple pieces to it. One, I have been working with some people because this whole part about billing is crazy because there is no data and it's not been done on palliative care and it's been brought over there from ED or whatever, but not really about our practice. One, it isn't even representative of the intensity. Two, as you know, it isn't equitable because we aren't necessarily charging for everybody's time. Three is this interesting part that I see. I'd be curious and I think for our leaders, it's really important. We, in palliative care, really focus on this very personal engagement with patients and families. We like it, of course, to be in the same room but, of course, COVID has taught us that telehealth is part of it. I do think there's some positive things about tele-health.

I think in terms of an equity lens, there is some potential that we need to pay attention to. And other people will, "No, no, no." I always maintain, if it's easy for us, then that means it's hard for the

patients. It should be hard for us because this is hard work. But where I was going with you was I find that teams are not willing to put in that time and energy that it really to have those hard conversations, they're willing to do it with the patients and families, but as a team to sit down, it's like, "Oh, we don't have the time. That's not important." And yet, we know that face-to-face time as a team is critical and will make or break a team in the long run. Or also, we saw in the pandemic, the teams that were well-established did better than the ones who had not done this because they got pulled apart.

And yet, with generational differences and age differences, it's a very interesting part about the work that's necessary and appreciated by the uppers that like spending an hour with your team is well worth the investment, even if it's not done. We get into this whole piece. How do we help our leaders understand we need at all? You're going to need to spend time as a team so you can stay together in these difficult times. You are going to disagree sometimes and that's okay. And if you don't, if you're constantly looking outward instead of inward, then your work isn't going to be very good and you will get into more of this moral distress because there's no place to even mention it. It's an interesting thing for the future that I don't think we thought about as much, maybe 10 or 15 years ago. I think it was like, "Oh, of course, if you work together it'll be fine" but I think that's not true.

Terry Atilio:

Mm-hmm (affirmative). I was listening to you. I was also wondering, and you have to know you're talking to somebody that does not have a smartphone. I only have a flip phone that I take out when I travel. I do not carry a phone with me. I do wonder the technological connection that people have all the time. They're texting each other, all kinds of connecting going on, not necessarily in the same physical space. You're not necessarily seeing each other, seeing each other's facial expressions and all that. And I do wonder if part of what we've seen change over the years has to do with this idea that we are communicating, because there's a lot of communication going on, but it's not necessarily in the same spot and it's not necessarily putting the technology away and actually talking to each other face-to-face.

Dr. Lynn McPherson:

That's interesting because I've noticed that I'm not content with a phone call anymore. I at least want FaceTime or Zoom because I want to look at people.

Connie Dahlin:

No, I think that's true. I mean, I think that it was hard to get people to do Zoom calls, whatever, because they were like, "Oh, you're, you're trying to invade my space." And yet, I think we saw after that, when you can't see somebody's expression to what they're saying you can't put that whole non verbal language together with what they're saying. And I think that perhaps this substitute, if we can't be in the same room, how does that ... And it can work for a bit of time, but then I think there's a sense of finally needing some sort of time. I know that with my own team. We didn't see each other for over a year and then we had a socially distant masked party in somebody's backyard. No hugging was allowed or anything like that, but there was something just about being within six feet of each other and laughing and joking and all being together.

I was thinking about how long it's been and thinking, "Okay, it's been like seven or eight months. Like, maybe we just need to meet outside in the park again." But I think it's funny how those things ... what holds us together. I think the other part, Terry, that I think a lot about is this use of all of the teams and I think our social work and chaplain colleagues are so important for just this emotional intelligence that many people don't have. And yet, I don't want them to ever have to be responsible totally for the

team health because that's not fair either. And I see a lot of teams saying, "Oh, well, since we have social workers and chaplains, they're responsible" and yet it puts them in this place of not being to be part of it because then they have to pull back and monitor. That's about that.

Terry Atilio:

What's really interesting about that is it always makes me nervous when I hear the social workers or the wellness people or something. I don't know. They have titles for people who watch out for the wellness of a team. My thought is always, "And what about my wellness? Who's watching out for my wellness because why would we assume that mine is any less? How many less vulnerable than other folks?" We take it, which is so interesting to me. I have a worry about us doing advanced care planning. My brain, you can't do advanced care planning unless you've got good medicine. Unless this patient understands their medical circumstance. We are not the experts on that. We certainly are the experts on the emotional and what will happen with your family if you do it this way. I get a little nervous as we try to figure out how to be part of this constellation, how we accept things, and engage in things that we need to be more cautious about. We just need to-

Connie Dahlin:

That's interesting, because Respecting Choices would say they taught volunteers how to do advanced care planning. I've just listened to all seven modules and they use the example of in case you get hit by a car, which I thought that's not necessarily what I would use. And in this time and age, I think I would say, "COVID is around, have you thought about that?" They're very clear that it's not a clinician and in fact the clinician can be clearer. I mean, the volunteer can be clearer because they don't have a bias. It's going to be really interesting, I think, of like who out in terms of different roles. And guess in that the other part that you brought up earlier is what is the status of education for social workers? You mentioned there not very many fellowships. And when I do an online search, I can't find very many graduate programs in social work. So do you want to speak a little bit about that?

Terry Atilio:

Yeah, sure. There's a post-grad program at NYU. There's a post-grad program at Smith, there's a post-grad program at the University of California, San Marco. In terms of pure social work, Fordham and NYU have, at the master's level, selected students who are supported in a palliative care track, if you will. Maybe they're given some kind of financial support, I don't know about that, because I stay away from it. I teach in all of them. Those three I teach in and I teach it for them. And so, the Fordham program, the NYU program are at the level of master's degree with a specialization in palliative care. UCSM is across the country, so it's done through the internet. It's not even Zoomed. Most of it is writing really. It's a course that goes on for, I think, eight months. Eight months, it's a long course and I only teach a very small part of it.

And the course at Smith has been in existence for a long time, since the project on Death in America. I believe NYU and Smith's course were initially funded in part by project on Death in America. I can't swear to that, but it seems to me there's some kind of a link there. They continue to have a program which before COVID was people came to North Hampton for a week and they studied together and learn together. And then they went back to their various places in the country and had mentors and so on and so forth. I don't know how to get this out there. I find it really interesting because you're very involved in palliative care nationally and across organizations and so on and so forth. I'm going to tell you, there are 100s of social workers who have been specialty palliative care trained.

Connie Dahlin:

Are those same social workers ... I know that we've heard a lot in terms of the future of trying to get certification for all the disciplines and we have it for medicine. We have it for nursing. I know social work has it. I don't know of the numbers because I know at first it was under NSW and then it's moved over to [inaudible 00:32:22]. I know Lynn dreams of having certification for pharmacy, but that's a whole political beast. Thoughts about how or how the field is getting social workers to get certified to kind of demonstrate that.

Terry Atilio:

Yes. I don't know. Maybe certification got off the ground three years ago. I'm not sure how many social workers have been certified, but I know how to find that out. It's a test-based certification, which is very different than the NASW certification, which really was watered down and had no test. It had no demonstration of what perhaps you need to learn or need to understand to be a palliative care social worker. The certification is in place. Certification, in order to be sustainable, has got to bring in money. In our country, everything comes down to money. And now Vicki left. She's the executive director of the certification program. That's a step in the right direction. That means, to me that there is enough financial foundation, if you will, to have somebody in that role.

I think it's maybe three years we've had the certification. That's really important. My fantasy was that the primary palliative care, so palliative social work book would somehow be integrated into health social work curriculums in master's degree programs. That's still my fantasy. I don't think it's happening, but it would be wonderful because what we learned when we did that book is that in some ways, by creating the specialty, and I don't know if this has happened in medicine and nursing, because there's so many more numbers, but that by creating the specialty, perhaps we did not honor our healthcare colleagues in the way that we needed to honor them. And so, we created another hierarchy, essentially, not intentionally in an effort to join this hierarchy. It's really so interesting when you think about power and you think about identifying with a power structure and how one does that.

I can say that the best thing that ever happened me to social work was to have the book on the shelf. But by having the book on the shelf, what we also did was we said, "We have a skillset that you do not. This is a specialty skillset, like oncology and nephrology and so on and so forth, but palliative care, many of the skills of palliative care are skills that health social workers either have or ought to have." I feel like we need to sort of backtrack or we need to recover that connection. And I think about it as fluidity that we need to help social workers to recognize the power of their work, the opportunity that they have.

They're wandering around the healthcare settings all the time. The rural social workers that you're talking about there, some of them are grounding the programs. Some of them are grounding the programs. How do we help those social workers to understand the responsibility in that? The responsibility in that, not just the power in it, because it does have power tattooed, but more than that, the responsibility as a social worker.

Connie Dahlin:

Well, you bring up a good thing, I think, though also of I think we do have to be careful and not be arrogant at times because when you get involved with patients. We have marketed ourselves to say, "We have the time to have the conversations that you don't," which I think to some people can be a bit insulting and that we know the patients better. I do worry sometimes that you have primary care people who've known these patients for years. You have oncologists, who've known them. We don't know

them better. We know them differently and we've been allowed in quickly. And so, I do worry sometimes, that issue that you've said that we come in and pretend that we're on the white horse and going to save everything when people have been dealing with this for a long time.

And that whole issue, I think that you're bringing up in a really interesting way of palliative care does have a specialty of pain and symptom management. And the last NCP said that we have pharmacy, social work, chaplaincy, medicine and nursing, and we'll have to think about how to expand that for each time we do. But is there something that we're also trying to say, we're in this with you together. We're partnership and we're not taking over because I think that people do feel like we're a threat and I think sometimes our communication skills with our colleagues maybe are not as inclusive enough that as they should be right. It depends on your setting and what they're wanting, but I feel like that's one of the issues and I think that's what you're getting at in this primary care of how to honor the skills that if we think of palliative care is good care that we're expecting everybody to have.

And then, we need each discipline to help articulate that, What is the expected stuff? And I think the second part in, and Lynn and I are involved in this project, you mentioned early on there's this content piece that I think we all need to know that's a common base for all the disciplines. What we will do with that we both need role models in our discipline to tell us the extent of our roles and the scope. But also to start understanding that, in fact ... I can remember Terry that I was go rounding with my social worker every day of our patients and we would see them all together and have our notes and comments and then we'd come back. Now, each of us would write a different note, but we saw that patient together, we were talking with a case manager. We did all this stuff for the floor, so there was a common, really a sense of working together, rather than us just jetting around seeing different people. And sometimes I feel like that also has gotten lost as well of that partnership.

I know we say in the name of time, we are delegating people but what is that about? I don't know. It's an interesting thought. I'd be curious what your thoughts and, Lynn, I'd be curious, your thoughts as well, because I think pharmacy even has an interesting role in that.

Dr. Lynn McPherson:

You go first, Terry.

Terry Atilio:

Yeah. I think that I can remember going into ICUs and starting to consult on a case of a patient who may have had a primary care physician for 10 years. Nobody ever calls the primary care physician. I think that we went and we talk about fluidity and history, we need to broaden how we look at history because oftentimes the work gets totally detoured. It has a changed path when you talk to people who have history with a patient and that's the beauty for the patients and the family, I think. I think it's also the beauty for us because we are validated in the fact that these folks that we're taking care of have histories. They have stories and those stories don't begin with us. Those stories started a long, long time ago.

I think the shared work ... If you're not a narcissist. It doesn't matter what the profession is. They just need to be the center of everything. They have the most special relationship with the patient. Nobody could ever have this kind of special relationship with the patient and you put those people in a parking lot. The richness of understanding of the circumstance that you're joining. That's what we do. We join as palliative care consult services. We join with others. How you validate and discover what went before. For me, it has an amazing richness to it, amazing value. And I think also, and I don't know a lot of the data about this, I think that burnout is a really interesting thing. When you look at burnout

with docs and nurses and social workers, there's difference in the data and so on and so forth. I have this idea that if you value process and social work is a process discipline, we are not an outcome discipline, really.

We would like to have an outcome that we can feel proud of, but the process is very important to us. How you enter the room. The first question you ask, if you ask any question at all. The process is very important and I have this idea, and that's why for me team meetings are so important, that if you can learn to value process, the outcome is important, but you don't base your moral distress on the outcome because the process was meaningful. The process was valuable. The outcome might not be what you hoped it would be, but you equalize the importance of those things. I think people would be less distressed by the work because what happens, I think, with palliative care is we were a consulting service.

I've only worked in a consulting service. That's all I know. And somebody has an idea about what we should do. They want us to get a DNR. Let's get real. A lot of times the referral it may be cloaked in quality of life, but they would like us to walk out of that room with a consent or an assent for a DNR. And so, we also have to balance all of that in terms of consultation etiquette, giving people what they think they want, enriching the work and feeling authentic and ethical about how we join with other people in terms of moving the family forward. And the whole idea of process and outcome is interesting to me because I think it may have something to do with how people do or do not feel valued in the work. Lynn, you were going to say something else about this?

Dr. Lynn McPherson:

I was just going to say with pharmacists, I've made the comment on somebody else's podcast that we work at the big university center and the patient may want a dose of morphine or Dilaudid or whatever. Nobody ever thinks to call the community pharmacist to say, "I'm sending Mrs. Smith back to the little community here and just wanted to give you the heads up that this was really what she needs to control her pain" because the pharmacist is the most frequently encountered healthcare professional in the community. Everybody goes to the pharmacist, probably because it's free. You can get free advice. You don't have to pay any ... You don't have to give your name and get free advice. I do think it's important to loop in the pharmacist.

Terry Atilio:

You know what's so interesting about that? When we talk about discharge planning and migraine discharge planning is a therapeutic activity. If you're talking to somebody, who's going to go into a nursing home and may never see their home again, if you don't think that that's a therapeutic activity, I don't know where you got your social work training. But we've whipped that out of people. We said, "You just do discharge planning." We've done it too, to each other. You don't just do discharge planning. Discharge planning is a therapeutic activity when we know that pharmacies don't often have these medicines. It is part of the discharge plan. In migraine, this is what I teach because I teach a lot about pain and symptom management. It is part of the discharge plan to call the pharmacy. You don't have to do it.

The family can do it. Make sure the meds are in the community, so we don't send somebody out, create a crisis that we have enough knowledge to know that there's a possibility that we're going to create. And then they bounce back and then we're into readmissions and all that data collection that people start to do. his linkage, I think, it's interesting, Lynn, because to me I was talking about linking historically, but you're also talking about linking forward. We linked to history. Who's a primary care person? Who's a person that knows this patient the best over time? Blah, blah, blah, all that kind of

stuff. And what you're talking about is linking forward. How do we make sure that this person gets what they need and has what they need when they go home?

Dr. Lynn McPherson:

Well, they have enough stuff going on without ... We owe them a seamless transition of care.

Terry Atilio:

Right, right, right. That's a wonderful phrase. I don't know how close we are to being finished, but I also just want to take this opportunity to wonder, and to think about, and to ask others to think about why we keep defining what we do. I don't know if you've seen the international definition for what palliative care is. Many, many people on that committee, not one social worker. Many, many important people on that committee. And the definition came out and there are people who are unhappy with it. I don't quite understand why it is that we can't settle on a definition. And I don't know if it's because we've attached ourselves to the hospice and we need to sort of just say, "This is hospice. This is palliative care. Hospice does palliative care and it does it this way."

But I find it so interesting that we keep over and over, what are we going to call ourselves? How do we define palliative care? It's an interesting dynamic. And I don't know if it's because we don't work with a body part, so it makes it a little more complicated. I don't know or a specific disease. We don't work with a specific disease. We work with humans in circumstances. It makes me smile, but on another level I'm not sure symbolically what it means about us.

Connie Dahlin:

Well, I think you bring up for our students of thinking about where's our best time spent. I think reinventing the definition, we really should be thinking about the work and working together and thinking about creative parts. And I think that you've brought up this whole part about what are some of the roles that our students can be thinking of teamwork, how do they need to be working together, really thinking about what is our history, tell us in terms of moving forward. I think this whole part about moving this moral distress and really thinking about process over outcomes just feels really important for our students to be no matter what discipline they are, of really not just focusing on the business aspects, but that we are caring for human people. And I think this other part of how do we think about in bringing in everybody and in saying that everybody has some palliative care skills. Maybe they get into primary palliative care and then they get into specialty and so kind of that trajectory. I think you've really offered some really lovely themes. Lynn, do you have anything else that you can think of?

Dr. Lynn McPherson:

I'd like to ask my very ask question of the interview. What advice, Terry, do you have for our PhD graduates as they embark on the next stage of their career with this degree under their belt?

Terry Atilio:

Think about the setting that you're going into. You're asking that question and I'm just going to use it as an opportunity to say something that I said on the AHPM forum. We need to know the history of the institutions we're going into, the history of the palliative care team, the history of the researchers that did palliative care, what came before you, the racism history in the institutions you are going to work in. If you want to make change in a certain institution or you want to create equity, or you want to do something that's going to change the climate, the environment of what happens to marginalized folks in

the settings that you're going in, learn the history. Because if you don't know the history, you have no idea what it is that you are.

The Echo talks that are funded by Cambia. There was a chaplain, Jason, I always say, Cameron, I don't know. I think it's Cameron. It's very close his last name. And he talked about ... He's an African-American chaplain. He talked about going down to the city where he works and it's somewhere in Virginia, West Virginia, maybe. And he said, what he learned there was the fact that he was black was not sufficient to bridge relationships and we know that. Once you get past color, you want to know who's this human being I'm talking to. And he said, I had to learn the history of the institution in this community. No matter where your folks go, where your learners go, where your graduates go, they need to learn what they're walking into. It's was a great interview question. It's reversing sort of interview question.

Tell me a little bit about the history of the palliative care team in this institution or tell me a little bit about the relationship between this institution and the community and the larger community, because that will help me to know though the focus I need to have in my work or at least begin to know. Begin to imagine the focus I might need to have in my work.

Dr. Lynn McPherson:

Thank you.

Connie Dahlin:

That is great advice, Terry. Thank you very much for spending this time with us and giving us your thoughts I will just say that it's been interesting for Lynn and I, because even the interviews of the different disciplines are so representative of where they come. Again, I think, social work process is so interesting versus all the outcomes, so thank you again for spending this time with us.

Dr. Lynn McPherson:

Yes. [crosstalk 00:50:38].

Terry Atilio:

Thank you. Thank you for asking me and good luck in your course. It's very exciting.

Dr. Lynn McPherson:

Thank you.

Terry Atilio:

Have a good day.

Dr. Lynn McPherson:

I'd like to thank our guest today and Connie Dahlin for the continuing journey in our podcast series titled Founders, Leaders, and Futurists in Palliative Care. I'd also like to thank you for listening to the Palliative Care Chat podcast. This is Dr. Lynn McPherson and this presentation is copyright 2021, University of Maryland. For more information on our completely online master of science, PhD, and graduate certificate program in palliative care or for permission requests regarding this podcast, please visit graduate.umaryland.edu/palliative. Thank you.

This transcript was exported on Aug 20, 2021 - view latest version [here](#).