

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 and the PhD in palliative care offered by the University of Maryland, Baltimore.

Connie Dahlin:

Good afternoon, everyone. My name is Connie Dahlin and I'm one of the faculty with the PhD program at the University of Maryland. And this is another one of our podcasts for the PhD, the first course. And I am joined here by Dr. Lynn McPherson, who is the director of the master's and PhD program of the Graduate School of the University of Maryland. And our guest today is Denise Hess, who is... got quite a number of personality. She's a faculty member for the master's program. She is also a chaplain by training, which she'll talk about that. She's also been leading the Supportive Care Coalition as it was, and is in this transition. She has a wealth of experience to offer us.

And so we're going to be thinking about all of this wide spectrum in palliative care of the different entry points and the different work that still needs to be done, which as you're thinking about your leadership and pursuing your PhD, just really understanding that it's wide open. So Denise, would you like to introduce yourself and give us really much more of an in-depth background of where you've come from and entered this field and what you're doing now?

Denise Hess:

Sure, happy to. So yeah, I stumbled into palliative care during a summer internship, in chaplain language it's called clinical pastoral education. A summer internship in a hospital near my house, happened to be a Catholic hospital, happened to be a community hospital. During my summer there, I was assigned to the oncology ward and met the quintessential patient in denial, if you will. She was a woman in her sixties with widely metastatic ovarian cancer, who was sure she was going to beat it, no doubts in her mind. Everyone else around her, her family of course, the nurses on the unit were all angsty because they knew she wasn't going to beat it, and so how were they going to get her to see that? One of those classic challenging patient situations.

So I was new to the hospital setting in this role as a chaplain. And so I was chatting with the nurses at the nursing station and saying, "So what happens in a situation like this? How does this usually unfold?" And they said, "Oh, we were really worried about what was going to happen, but just today her oncologist consulted the palliative care team. So now we're confident that everything is going to go swimmingly." And I was immediately doubtful. I couldn't possibly imagine how any kind of team could work with this intractable situation. And so I said, "So what is this team?" And they described and said that sure enough I would see them on the unit shortly, and they would be meeting with the patient and her family. So they appeared, the team, at that time it was just a doctor and a nurse, and I introduced myself to them and found out that they were really important characteristic of a palliative care team.

They were just natural teachers. They really believed in that just in time each one teach one model. So I said, "Here I'm, this baby chaplain and had been spending time with this patient. The nurses are so excited you're here. What is it that you're going to do?" And they said, "Just come along with us. Come on into this meeting, we're going to meet with the patient and her family," this is a day later, "and you can see what we do." So I went to my first palliative care family meeting. Back in those days, I think it was like an hour and 45 minutes long, we had this real luxury of time. Afterwards leaving the room

after sitting through the meeting with the patient and her family, I knew two things. First I knew what kind of chaplain I wanted to be when I grew up. I was still in seminary at the time.

Secondly, I knew that if and when I'm seriously ill, that's exactly how I want to be treated, because of course she went home, she was discharged to hospice. I got to make a few home visits with the team too, and see that she went from being the quintessential, patient in denial, to being the mythical good enough death at the end. Got to do the unfinished business, all that kind of stuff. So that's how I got started. I had great relationships. So eventually fast forward... Gosh, how long did it take? Five years, seven years? Anyway, it took quite a while. No, five more years before I was actually the full-time dedicated palliative care chaplain on that palliative care team. Because at that time in the field, their palliative care program was really new. It was only about a year and a half old, I think at that moment when I encountered them, hence their hour and 45 minute long family meeting, back in the day.

And they had funding for a physician and a nurse. They didn't even have a social worker, and there was no plan to ever have a chaplain. It just was seen as not even a luxury, just not even something that you would do. So we had a long way to go before I would eventually be a part of that team, and ended up being the first chaplain on that team. And at that time across the US, I didn't really have many colleagues. And so there was some additional issues around that too. We were similar to I think the medical world. In the spiritual care world, if I were to introduce myself as a palliative care chaplain, we would get that same comment that medical professionals get of, "Well, wait, but we all do palliative care. What makes you so special? What do you mean to say you're a palliative care chaplain? I'm that too?"

So we had that whole era of, "You guys aren't doing anything different than we all do." So those were the beginning challenges. The hospital loved the team. Initially the team as it grew, they were beloved, which helped with culture change immensely, but really big struggle in the first several years to be anything other than the comfort care. We had these VIP dying sweets. And that was really what everybody thought palliative care was at that beginning stage, is we were, "Oh, someone's dying. Nobody knows what to do. Nobody knows how to manage the meds. Call palliative care." So it took years of work and those just-in-time educational moments they brought me in to educate and transform the culture of that hospital so that they knew to call us way earlier to where that program now is, emergency room, outpatient, all the settings where you actually have a chance to, as a palliative care team, do so much more than just brink of death care.

Connie Dahlin:

Well, and I think you've, in that description, described the process that we've had to go through of explaining people, and that in fact, we did start with end of life hospice care, and that moving it upstream and having people understand that it is an interdisciplinary process and moving it out. It's interesting because as you were talking, I was swirling in my mind. So for many of the students to understand, I started taking... I had to take a year long practicum in hospice, and then started in an urban hospice, and then did community hospice, and then palliative care. But I think what you were speaking too also it was when you talked about the patient with... And it's funny because you were so relaxed about it. And when we get consults for patients in denial, right? We always get those consults. And the interesting part I think about, people still quote Kubler-Ross's Five Stages, but we know that in palliative care, that's not really true anymore. But also for people to understand meeting people where they're at, and there are some people who will always stay in that place and that's their hope, right?

Denise Hess:

Absolutely.

Connie Dahlin:

And so, in my mind I wouldn't be calling you just for the patient, I would be calling you for me to say help me go into that room to be in the space where that person is, because we are living this differently, right? And so I think about how much chaplaincy is so important to the team, not just to the patient.

Denise Hess:

So true. And again, thankfully, I feel like I did not have a representative experience as a palliative care chaplain, I think I had an exemplary experience. Because as when I was finally... So just to backtrack a bit, I think there's that phrase. I don't think it's common just to Catholic health care, "No margin, no mission." In my story, it really ended up being, "No sister, no mission," because the team fought for years to fund my position. It was just an uphill battle until one of the Catholic sisters who was still walking the halls of the hospital at that time said, "You know what? Chief exec of said hospital, you are going to make this happen." And then it happened. And thankfully I was... So my team fought for me to be there for a long time before I got there, which is a wonderful thing. Because then when I got there, my physician and the nurse manager, colleagues, they already had a really well formed vision for what a chaplain could be and do on a team.

And the main component was exactly what you just described, team wellness. I mean, yes, of course it's assumed you'll be there for the patients and their family members, their loved ones, and their spiritual, and existential, and meaning-making, and suffering related needs. But they had this huge vision for Denise. You know what? What can we do so that as a team we can thrive? And our team mantra, if you will, was the quality of our work is only going to be as good as the quality of our team. And that was what we lived by. So we had, gosh, these thematic reflections, we had regular offsite retreats, we had lunches together every day and then offsite lunch every Friday, and they were just so open.

They would pretty much have gone with just about any wellness idea I had. They were really fun and experimental. So, long before it was popular, we were sitting in the hospital chapel practicing mindfulness meditation every day at lunch for 10 minutes. So, they really got that vision and it was such a source of job satisfaction to me, because folks drawn to this kind of program, we all sensed that palliative care is a team sport. And to the degree that we really lean into that team and let each other practice at the full scope of our expertise and license, just the better off, we're all going to be and feel about the work. And my team really did that for me.

And I'm assuming, I hope of course, that it benefited the team, but it made me from the beginning have a very expansive view of chaplaincy, just beyond the, "Well, Denise, the meeting is now over. Will you say a prayer?" Oh, I would have died on the vine if that was the extent of my role. Or, "This patient's crying, will you go see them and talk to them?" I mean, yes, of course I'm happy to do those things, but if that's the extent of the chaplain role, you're missing out. Everybody's missing out.

Connie Dahlin:

So you bring up two questions from what you've said. One, I worry though... so this wellbeing. Because I also feel we need to think about the team health of the chaplain and the social worker. And I am always worried that they're "responsible" for the team, and yet they're part of the team. So where do we say they're in, they're not responsible? Because I have always thought about, you have your family of choice and then you have your work family, but your work family, you have to think about how do you take

care of all the members of the family, and you can't... In the work part, you don't want to have parents, right? You want all be siblings that are working together. So thinking about that, how do we help people think about not only what you were saying, the expertise needed to do that, but the wellbeing is important and there has to be an investment that it doesn't fall on other people? And if people were thinking even about research in that area, just some thoughts on that.

Denise Hess:

Yeah. So practically I would say to my chaplain and social work colleagues out there, with regard to wellness, I think it works so well to lead by following. So any kind of thing that I came up with or came across in the literature or read a new book on, I really tilted towards things that were group led and all hands on deck participatory. Because I think just intuitively I knew that I needed this as much as my team members. I wasn't somehow exempt or made of Teflon, and therefore didn't need these things. So I think it's really important in crafting team wellness, whoever does it, that it really feels group led, and of course it is birthed out of ideally group consensus and group acknowledgement. Team acknowledgement that, "Yeah, this is what we need. And this particular format I think would work well for our particular team composition at this moment." Feedback is a really good example.

So I would include honest and constructive feedback as part of team wellness. We had different iterations of our team, because of course there's always team turnover and changes in leadership, where we had to take team feedback off of the table because we had some folks on our team who had come to us prior to us so wounded by really poorly done feedback. And so when we talked about, "Hey, let's have this team feedback and we're going to put these really nice, cushy, safe, trauma informed cushions around it." They were like, "Uh-uh (negative)." And so we put that to the side. Now, is that ideal or the best for the team health overall? No, I mean, of course we have to readdress it, but yeah, it has to organically emerge out of the team and it has to be created in such a way that everybody can interact with it as a participant. That's my, as you can tell, strong bias.

Gosh, I would love to see more research done on this idea of what is team wellness? What can it look like? What is actually beneficial and not beneficial? All I have is anecdotal firsthand experience in a very little tiny Petri dish, if you will, that was given to me. But wouldn't it be great to know, especially post COVID, especially amidst all the talk about, "Hey, don't just tell us we're burned out, because burnout has a lot more to do with systemic and structural issues than whether or not I'm doing enough yoga." So there's a lot of potential to look at wellness, possibly intersection points with burnout. There's got to be an interplay there, but to do it in a way that... I just think palliative care there is potential because we are so interdisciplinary and interprofessional to learn a lot more possibly than other types of teams in other settings.

Connie Dahlin:

Well, you've mentioned so many great points. I mean, I think one of the things for me in nursing, I think saying self care activities, there's nothing worse to say to a nurse, right? They ought to have a time to use the bathroom.

Denise Hess:

Yeah.

Connie Dahlin:

So you're going to make them feel guilty for not doing [crosstalk 00:20:06].

Denise Hess:

Exactly.

Connie Dahlin:

So your part about integration. I think the other part that you mentioned that is so important is that, I think in palliative care we make this assumption about people in palliative care are being, spending time in Oregon, earthy, crunchy, and really feeling and all that. But you and I both know they're very different teams, and P teams very much react to different parts. I know I've worked with some teams that their wellness strategy was humor, but it was really dark.

Denise Hess:

Oh, so dark.

Connie Dahlin:

[crosstalk 00:20:43] I would say, "We need to use as a barometer. If somebody came in and listened to this and this got printed in the paper, would they be okay with this?" There are times... And I was like, "This is not appropriate." And there was a little bit of sarcasm and a little bit of sexual connotations. I mean, it just went there. Thinking about that, and then I've had other teams where there's one person who wants to be very woo-hoo, and they'll do that and the rest of the team, because that relationship hasn't been built, you just watch people physically pulling back.

Denise Hess:

Shut down. Oh, yeah.

Connie Dahlin:

And so, that how do we do that? I think the other part you are really speaking to is that, we get so focused on what we do for patients and families. And the whole part about an effective team is interesting. And I would be also curious, because you've mentioned this a couple of times, does it make a difference of what the team does for wellness if there is a mission and a religious context to people holding on to, right? Because you are working in a hospital with that framework, then without. And I'm not making a judgment of better or worse, but you just know that there's a different ethos, right?

Denise Hess:

Mm-hmm (affirmative).

Connie Dahlin:

So those are just some things that I think came up for me about that. Any thoughts about that, or does that just...

Denise Hess:

Yeah. I mean, I guess to the first point, yes. And that's why I think it's got to emerge from the team organically, all hands on deck buy-in. I know one of the teams I worked with in the past, one of their primary wellness strategies is thankfully they have a pretty soundproof office and it's like a dance party. So they just flip on some really loud music and they just all start dancing their little what's off. So there

isn't a framework. There isn't a formula for what it has to look like. But you're right, probably some parameters around not getting fired for some HR violations. But to your second point, it's hard to... I don't know, I'd have to think about that a little bit more.

Connie Dahlin:

[crosstalk 00:23:19].

Denise Hess:

Yeah.

Connie Dahlin:

Just a thought.

Denise Hess:

I mean, on the West Coast, where I forever and always practiced, were probably one of the main spiritual but not religious centers. So even though I've always worked in faith-based healthcare, I feel like I've worked with pretty much more humanists and atheists and agnostics than probably some other swaths of the country. So for me, I've never really felt the connection between what we did or did not do for team wellness, and are the hospitals faith-based identity. Yeah. So I'm not... Yeah, but I know, again, and this is switching into some of the roles I've had on a national level with regard to palliative care programs within Catholic health, that that is not true across the country. Yeah.

Connie Dahlin:

So I think it's just interesting to think about. You were speaking about you learned this, so it sounds like you didn't have that much mentoring. You were learning it as you went along.

Denise Hess:

Yeah.

Connie Dahlin:

So you do want to talk about how did you figure out who could mentor you? And then as you became more of a specialist, what was that road for chaplaincy? Because I don't think we hear about the certification for chaplaincy, or because of the different faiths, I find it humorous of there has still been some splitting of different face of how they go towards certification, although there has been some joining together. So you want to speak a little bit about that?

Denise Hess:

Yes. So it is a machete in hand blaze your own trail. Definitely when I became a palliative care chaplain, I became certified the first when the certification went live through my certifying body, the Association of Professional Chaplains. And at that point, and it's not too much different now, you cobble together your own real life fellowship, if you will, is how I looked at it. So I happened to land in this amazing team. My mentor, and now more colleague and friend, was my physician colleague at the time because I always teased him. He was really just a chaplain who happened to go to medical school. I forgave him for it, of course, but he was my mentor. He was my thought partner. He was the one who encouraged me toward leadership roles, and still does to this day.

And so with that, by the time that the advanced certification in hospice and palliative care for chaplains had gone live, I was ready to apply because I'd been part of a quality improvement program... That's one of the requirements for certification for chaplains, by the way. Thanks to the Livestrong grant where we first met you, where our team became... we got the joint commission advanced certification in palliative care, and you were our mentor through that process. So, because I had been fully included and just expected to be a leader, when that certification came around, I already had all the pieces of it and was ready to apply and go. But that, again, I'm the exception and not the rule for most chaplains who would want to pursue that advanced certification. So it's been live since 2014. It's gone through several iterations, as you mentioned, the most exciting of which now is that it is the pathway toward that certification can be accessed through multiple different chaplain certifying bodies through the National Association of Catholic Chaplains, my associating body, and some others.

So there is some unity coming our way amongst those feisty chaplains, but I'm on that certifying committee. So I can tell you from firsthand experience that each and every chaplain we certify as a hospice and palliative care chaplain has put together their own pathway to that certification. So someday maybe we'll have fellowships, someday maybe we'll have a more robust, thorough educational practical pathway. I should say, there are a couple chaplain fellowships. I think the VA is one of the places that have it. There are some educational pathways, but they're not systematized or standardized in any way just yet. And all that to say, just to level set expectations for people thinking, "Oh, I want to get a palliative care chaplain on my team," there are only about 50 of us certified in the United States as we talk today. And lots of reasons for that, and that would be where I'd put on my national leadership hat, but again, it points to how my experience was so rare on the whole chaplain.

So you have to already be board certified to apply for the specialty certification. And chaplains aren't necessarily given the resources, the support, and the incentives that other disciplines are to get this certification. I mean, for example, just brass tacks, my role... I haven't heard of anyone's role or pay grade changing after they get the certification. And again, wouldn't you hope that chaplains would do it just for the love of humanity? But there is a practical aspect of where chaplains come to us and say, "So, why would I get this certification? Because I have to do all this extra stuff, I pay this money, and my hospital is going to treat me exactly the same, or my hospice is going to treat me exactly the same." So there are some systemic, some reforms that could potentially help us in that way that I hope will happen someday.

Connie Dahlin:

Denise, I mean, I did not realize that the number was that low, so I'm still stunned. And that speaks to me of a big area of leadership that I think in my mind, we've talked to some of the other people, if we're going towards quality and thinking about that, we can look at programs who have gotten certified, and now besides joint commission, there's DNV for hospitals. In the community, we still have the joint commission. We have the Accreditation Commission for Home Care and Hospice, and they'll do those programs and respite programs. And then CHAP will do any sort of community programs. So there's some good players, but that's expensive for programs, right?

Denise Hess:

Yes.

Connie Dahlin:

And then you have to keep maintaining it, so for smaller programs that might not be financially viable. I think for larger programs or that, I mean, then we really think about let's get our palliative care

specialists certified because that's a mark of excellence. But from what you're saying, there are so few that you can imagine that even that alone it's such an interesting statement, because usually at least people will pay for you to take the exam if you pass it in some of those incentives of education. I mean, I think one of the things that you're saying to me is we have looked at this model where hospice started out really as pretty nurse-driven, and palliative care became academic and more physician driven. We're talking about healthcare reform. And if we're going to do real healthcare reform, it means that we have to change things as they were. And that means really embracing the whole teams.

But I think the part that you've talked about that I find inspiring is, I mean, you have this wonderful leadership role now in taking palliative care to the Catholic health system, and I'll let you explain it so I don't get it wrong, but I think your role as a chaplain to do that is really important. So do you want to talk to us a little bit about that?

Denise Hess:

Yeah. So Catholic health care, thankfully were early adopters, first of that realization that happened in the nineties that people were dying badly in hospitals, death had become so medicalized. And because of the mission that's embedded in the DNA of Catholic healthcare, and specifically many of the sisters who founded the orders, their special focus or charism as it's called in the Catholic world was care of the dying. So it was hugely insulting to Catholic healthcare systems to find out, in some early focus group studies and things done in the nineties, that... Sorry... people were dying badly in their beds in their hospitals. So they did not like that. And were early adopters in prodor palliative care really hospice at that point and better comfort care in the hospital. So they were also then early adopters in this new thing called Palliative Care, the organization that I first stepped into a leadership role with the Supportive Care Coalition. So back in '05, that organization pivoted to have its focus be exclusively on standing up palliative care programs within Catholic health care entities of all sorts.

So by the time I came into leadership in that organization, I think the current CAPSI data were that 97%. So I think that everybody numbers, 94% of hospitals over 250 beds now have palliative care programs. Well, Catholic health care was even an inch further across the finish line with that. So they really whole heartedly embraced this idea of whole person care for everybody with serious illness. You shouldn't have to wait till you have a prognosis of six months or less to get this whole person care, body, mind, and spirit. But then in my leadership role, and so my organization Supportive Care Coalition, as of January, 2021, became a part of a larger and really the only association for Catholic health care in the United States, and it's called the Catholic Health Association. And we'd been partners and friends since the Supportive Care Coalitions beginnings back in the early nineties.

And it just made sense for us to work together as one unit. And as we embrace and reboot, what does it look like for Catholic health care to continue to lead the way, to walk our talk that palliative care is just integral, it's standard of care for people with serious illness? The next wave I believe is standardization. So Catholic health ministries can check box, yes, we have a palliative care program, but we all know what that means in real life. That means there is a hospital that has a hospice nurse that comes Monday, Wednesday, Friday, and sees palliative care patients. And so they say, "Yeah, we have a palliative care program." And then that means you have a team like the one I was a part of, and they check the box and say we have a palliative care program.

Those two programs don't resemble each other much at all. So I really see that as the next wave of leadership that Catholic health has an opportunity to really participate in, what does it look like to standardize palliative care? Or as my colleagues at Providence, where I worked for many years, Providence Health on the West Coast, would say, "How do we reduce clinical variation? How do we ensure that if you pop into a Providence hospital in Washington State or Southern California, and you



need palliative care, those two experiences mirror each other?" They're not identical, it's not a cookie cutter, but they both uphold the National Consensus Project guidelines and standards, and again, back to my special focus, which means they include spiritual care. Betty Farrell, every time I hear her speak on spiritual care, she will say that, her famous line, "If you're not providing spiritual care, you're not providing palliative care." It's true.

Connie Dahlin:

Well, and I think it's an interesting part because... So a couple of things, I mean, I think that's why we developed the National Consensus Project to say we knew what hospice was. The CoP, conditions of participation, delineate that and that. So when we say palliative care, what does it mean? What is specialist palliative care? I think now obviously we have conversations about primary palliative care. I think what you also make me think about, and I know you're thinking about this too, so we have different entities that have different resources, what you can do in an academic medical center is very different than what you can do in a community and rural. And I say that having co-founded a program in academic center and now I'm in a community hospital. We don't have a designated social worker, we don't have a designated chaplain.

And when I cover, I am covering by myself, which is so interesting to me when I think about team, right? So this is an interesting part about what does it mirror, and then what is the responsibility if you don't have all the players that for me as a provider specifically means that I actually have to have a more of a skillset to not replace the chaplain, right? But to address some of the spiritual needs. To not replace the social worker, but at least how to assess and say, "Okay, wait, we have some needs here we need to address." I think in a smaller setting, I have to say that sometimes when I bring those up, I am not a popular person.

Denise Hess:

Right.

Connie Dahlin:

So it's just interesting. But I think that's... I think what you're doing and what you're saying for the future is, what can you do? And as you were talking, I was thinking, well, in one sense, if you have this mandate and it's within the Catholic Health Association, there's certainly something to be said because that's what happened at the VA, right? They said, "Okay, we're going to have palliative care across the system, but as we all know, there are different visions and they all have different things going on." So what it looks like will be different, but there was that mandate. And I think the next part for it, specifically to nursing, that was cool now is within all of the VA systems, that an APRN, no matter what state they practice in, is practicing to full scope of practice because they said we need to elevate this. And so that's affected the palliative care. So that's an ambitious. I mean, I think that's great and it has ramifications. And I think it also ups the ante, right?

Denise Hess:

Yes, it does.

Connie Dahlin:

And also thinking for you as a leader, being a chaplain maybe you can be more grounded and help people wade through this more. I don't know.

Denise Hess:

Yeah. And both of the things you said are true. So yes, every healthcare setting where people are living with serious illness will not have a fully staffed interdisciplinary team. That will never happen. Yet, I will say that I am seeing some really cool things being done with telehealth and palliative care teams. I know some of our systems are experimenting with having a fully remote team, that all they do, their palliative care team, they are interdisciplinary and they are available for consults to these rural settings, mostly rural hospitals, that would never have any member of a palliative care team designated onsite all the time. So I think technology will be an equalizer of sorts. And I do have to say too, that this is really near and dear to the heart of the Catholic health mission, is we get very upset when we find out that people are being left out, disenfranchised, marginalized, not receiving certain services because of their zip code, or of course, because of their ethnic or racial or cultural background, that those things really irk us.

So we get real creative about how to eliminate that. And to your point though, I mean, I love that you are a troublemaker making good trouble, right? When you serve as a solo clinician, we know it's not the ideal, but we are working toward a field where everybody does have some level of palliative care generalists skills, and that does include psychosocial and spiritual care. I mean, folks who go through the masters program and the class in spiritual psychosocial care, we want everybody at the end to say, "Okay, hot, deep breath." The minute they say something about God or religion, or why is this happening to me, I don't need to immediately, "Get a chaplain over here [inaudible 00:42:31]." I can pause and I can say something like, "Gosh, tell me more."

It's not rocket science, and we all can be whole person care providers. And I think that is the beautiful contagion of palliative care that we little by little hopefully are infecting the entire field of medicine with our good virus, which is pay attention to all of the person, not just the organ, not just the diagnosis, but who they are, and do it skillfully but with generalist level of skill. Which I think is attainable, I think is possible. But I'm a super duper optimist.

Connie Dahlin:

So you said some things and maybe you've answered the question. How will you feel like you've succeeded that this is... because it won't always be done right, we'll have turnover. But what do you see as a measure of success?

Denise Hess:

Well, yeah, you're right. It everything I've said, but I think... I also want to say... I don't want to put all of our success in the future. I also want to acknowledge we've succeeded a lot already and I don't want to discount, or not take a moment to savor and be content with the wonderful successes that we've had. I mean, just that the three of us are here doing this podcast under this umbrella is a massive success for the field. And sometimes I think about, "Gosh, palliative care we've been around forever, laboring in the fields, sweat on our brow." But then I think about, "Gosh, no, we really haven't been around that long, and look how far we've come."

And so yes. Do we have so far to go? Yes. And I think success is going to look something like what we just talked about, these specialized teams alongside these very well-trained generalists. It's exciting to hear the changes that are happening in education for physicians, as physicians grow up through med school and beyond, and for nurses, and for social workers, and for chaplains. It's exciting to hear that finding out about palliative care potentially happens early in your educational formation. And I just think through, again, those slowly infiltrative ways, success will be that palliative care is normative,

it's the standard of care, it's expected, it's just a part of how medical care works when you have a serious illness.

Dr. Lynn McPherson:

Can I jump in with a question?

Connie Dahlin:

Of course.

Dr. Lynn McPherson:

So Denise, you teach in the master's program, 604, which is psycho-social spiritual cultural care. And I teach the pain and symptom management course, which is 605 right after it. And we make all the students take both. And I'm curious about your experience in 604, because in 605, the social workers and the chaplains are like, "Why do I have to take this?" And there is a level of discomfort, but I'm a big fan of transdisciplinary preparation. I think the chaplain needs to understand what constipation looks like. And I think the pharmacist needs to be able to do a basic spiritual assessment. So what's your experience been with that in 604 with the non-social worker chaplain crew?

Denise Hess:

Oh yeah. They're terrified. I mean, many are terrified. And just a sense of, if I grouped folks into two very broad generalization groups, and there's nuances in here of course, but there's the ones of, "Oh my gosh, I don't know anything about this and I'm scared to say something wrong." And then secondly, there's a little bit of what you described at the chaplains, "And why would I need to know anything about this?" So yeah, we get both of those. I have to tell you, and I haven't told you this personally or out loud yet, I am having such a great time in this course because I love to see the arc. So they start there, and then we start to talk about, "Well here's really why spiritual care matters to patients," and light bulbs go on. And then, "Oh, and here's how to just ask a few fairly normal conversational questions to suss out is there spiritual distress," and light bulbs go on.

And then suddenly by about week three or four, you can tell through the discussion posts through their assignments, that they are probably irritating everyone around them because they've become like evangelists or first spiritual and psychosocial care. You could tell they're talking to their pharmacist colleagues saying, "We should really be asking about this," or, "Our professional standards should change. We should have some reference that pharmacists should be paying attention to psychosocial spiritual care." And then you see by the end, the full circle of where they come to this, really just I love this place, is really important. It's important to impatience, but you know what? It's important to me too. And now I have some tools in my toolkit where I feel a bit more comfortable because this stuff's going to come up and I feel like I have a handle on what I might do or say. And so it's fantastic. It's a really fantastic experience to be a part of this program. Because that to me is what it's all about, right?

Dr. Lynn McPherson:

Absolutely.

Denise Hess:

Yeah.

Dr. Lynn McPherson:

I've had the same experience in 605. I recall in our very first cohort, we had a chaplain who's from Trinidad and Tobago, and he was just amazing. And at the end of 605, he put in his reflective post, "I get it now. As a chaplain, there's a thing called anxiety that you can diagnose. It's not just somebody being cranky, it's a thing, and then he can be treated for that thing." And he's actually gone on to get his PhD in palliative care from one of the colleges in the United Kingdom. He's a semester too late in getting this one off the ground for him. But it's so fulfilling, as you said, to see them come full circle and realize why we need to be transdisciplinary. So exciting.

Denise Hess:

Exactly.

Connie Dahlin:

And I would just say from my perspective was like, when I worked with my nurses and my social workers and my capital lines and whatever, I think sometimes the chaplains and the social workers have done a better job because they're not in the prescribing mode, they're in the assessing the person. And so it actually comes out in a different way sometimes. And so I think some of them are better skilled than some of the clinicians I've worked with.

Denise Hess:

Yeah.

Dr. Lynn McPherson:

And I have to say that if I had to pick a one woman palliative care team, it would be Connie Dahlin. Don't you think [crosstalk 00:50:25]?

Denise Hess:

Absolutely. Connie Dahlin, course Cicely Saunders isn't available this week?

Dr. Lynn McPherson:

Totally.

Connie Dahlin:

You guys are too funny. Denise, I think that what you're doing though, is just so important because I think you represent leadership, you represent pulling in your profession thinking about that, and also saying, "Okay, where do we go differently?" And this whole part about language, right? So I've been pretty inspired. Lynn knows this, that the last future of nursing report came out 2030, and it's called Charting a Course Towards Health Equity. And there are a couple of things in the report that are really important in my mind. One is it's taking from patient and family centered care to patient, family, and community centered care. Speaking about that, because we all live in a community, and that affects how we do. And however you want to define community that's okay.

The second part of it that was fascinating to me, because I look at these things and then I do a word search, they never mentioned the word medical care. It was healthcare with medical needs and social needs. And that to me was huge because I think it is about what you're talking about, there are

these, you could say psychosocial spiritual needs, that if we address those, the medical needs would change, right? But rethinking, what you're talking about, this holistic care, which we know that most patients need that more than anything else, right? And so I think what you're speaking to is creating this space where when you were saying mirroring it's that people are getting the assessment that they need, and hopefully there's alignment with the services that they get. But you might have more to that. If there's more of what you're thinking of outcomes, you might not be that far yet.

Denise Hess:

Well, when you bring in community, I mean, you're so right. And I mean, I think of Don Berwick as the guru and the prophet for the moral imperative of providing healthcare, not sick care, and how so much of what happens by the time someone enters a health care facility with a serious illness. So much of what happened prior to that out in the community remains and addressed, and it goes back to all those old aphorisms about, let's not just catch people as they fall over the cliff, let's actually build a fence at the top of the cliff so people aren't falling over. And the social needs, AKA social determinants of health, all the different phrases being thrown around about that, are to me, I guess, back to your question about outcomes.

I mean, if I thought of the most expansive way that palliative care could help medicine re-envision itself, I would think that it would be that, that we would push our vision outside of our walls and into... Gosh, well, I mean, I hope I'm not getting too political here... what COVID has revealed. We don't have a public health system.

Connie Dahlin:

Right.

Denise Hess:

We have a medical system that you can access when you're sick. And for many people you don't get access to it until you're way too sick. Hence, I think it's Stuart Farber's quote, many people say palliative care is a workaround. It's filling a gap of a broken part of the medical system that ideally would be fixed. And again, that is one of the exciting things about our new work within the Catholic Health Association is their primary strategic focus right now. And they have issued a call to all members of the Catholic Health Association, which includes almost every Catholic hospital in the United States to make specific commitments to diversity, equity, and inclusion, so that when they also at the same time adopted this expanded vision for hospice and palliative care, to me, those things are of a piece. They're not even two different things, because that's exactly where much of serious illness lives, are in those... the same communities, the same groups of people who are not already getting equitable access are overlooked, are under-resourced.

So to me, that all fits together. And I guess, thanks because you helped me think of my most expansive vision for palliative care is that it would change the way we conceive of medical care and push it out into these social needs that create the conditions where so much illness comes from.

Connie Dahlin:

Well, I think what you're bringing up is that traditionally, again, when you look at our evolution, first we were trying to get care in a different way, then we're trying to make the care more accessible by going from hospice to palliative care. And we focused on the clinical. And as we evolve, there are certain

things that happen as you become more mainstream, if you will, that have to happen in terms of metrics and payment issues. We have to work out and all that.

But we are also saying is then we still have to think about this health equity piece. And it's interesting when you... Well, first of all, I haven't heard Stuart Farber's name mentioned a long time, but I'm glad you did. And it is interesting that somebody could say that that's a work around, because think about what we're trying to say, is not that it's a workaround, but saying that it has been forgotten that the patient and family and goals of care concordance is at the center. And yet, I guess you could say, "Because the support study failed miserably, here we are. We're still working on it 30 years later," right? So there's a lot in that if you're offering the students places to think about where they can lead and be thinking about some of these pieces together.

Denise Hess:

Exactly. And one of the things I haven't talked about in my role and that I actually interject regularly into the spiritual and psychosocial course because many of the students recognize, of course, these same issues we're talking about, just the brokenness of our systems to provide whole person care. So one of the most exciting parts of my role prior to this integration and now has been in the advocacy space. And there are, of course PCHETA, the Palliative Care Hospice Education and Training Act is working its way, potentially getting introduced in this session of Congress. Again, hopefully past, I think we're on year 10 of working on that bill now, which folks on The Hill tell me is not that unusual for a bill of this size and focus. But alongside that, we see the home and community-based services legislation being proposed. We see some great things coming out of Medicare demonstration projects, and concurrent care, and ways that people are recognizing and addressing at federal levels, lots of good work going on in states to make this care part of care.

You're right. And not in the Stuart Farber sense of a workaround, but in the sense of it's always going to be here. Palliative care will always be here yet the philosophy and the call back to the heart of what health care is, again, will hopefully infiltrate, will transform all of health care to a degree. So, it's a space that requires a lot of patience and long suffering, but I am hopeful about the advocacy space too. There are some exciting things happening. And more and more allies on The Hill, more and more people from Congress who have had a mother, a father, a grandmother. Well, gosh, even our own president had a person, his son, with a serious illness, who get it on a deep and visceral level, that things are not ideal for people with serious illness. So I hope for change on that level too.

Connie Dahlin:

Well, he also understands grief and loss since he lost his wife tragically too. So that sets a different tone. Without you having to reveal any secrets or work, are there certain things of your strategy in terms of doing this from an association? Because I think that's a really important part of leadership of understanding you have this mandate, if you will, to infiltrate this in the association. But what are some of the tangible things that you're trying to help bring forth change of actions?

Denise Hess:

Yeah, good question. And yeah, I can speak to that on a high level. So part of our strategy continues to be the same strategy we had when we were Supportive Care Coalition, is we really do believe and see great things happen through the simple power of convening. So as we are able to get people working in this field around the same tables, sharing their war stories, if you will, sharing their successes, and creating places where this cross pollination can occur, a lot of good comes out of that. That's a key part. Continuing of our strategy is convening people who are doing this work in networking and educational

ways, cross-pollination ways to share. It's just that simple, almost back to how I was raised up as a chaplain, an each one teach one. There's a simplicity and beauty in that, "Hey, this is what we did and how it worked," and, "Oh really, we have that same problem. Let's talk more. Tell me how you overcame this challenge."

Secondly, though, we have a great opportunity before us in this collective of people working in Catholic health care to really venture into. I don't know, it might go as far to use your word as mandates or calls to action toward standardization, toward quality. I'm hoping and I'm planning that that will be part of our strategy, how we work that out, the devil is in the details, but the convening and then also the shared commitment. So some walking of our talk to actually staff up to have more than... Gosh, last count, there are 13 Catholic health hospitals that have the joint commission advanced certification in palliative care. Now I think the grand total is still under 200 ish. Does that sound right to you? So not a terrible showing given that certification remains challenging for many programs as we talked about earlier. But my hope and vision would be that, again, that would be a place where Catholic health care would lead the way. Not only do we have programs, but we have programs that meet the national standards and we can show it in these ways.

Connie Dahlin:

Wow. Denise you're... I mean, it's an inspiration and thinking of you as a chaplain in this wonderful vision of people and in the nurses' leadership role of showing this wonderful collective leadership coming from a very mission-driven, internally North Star way. I mean, you convey that. And so I think that that's inspiring, because I think we need to see leaders other than physicians who are doing this work to role model the change. And I just think your perspectives on where this has come from is really important for people because it's the different voices of how people can step in and make a difference. So I have really enjoyed just having this time and hearing your voice. Lynn, do you have any other questions that you would like to ask?

Dr. Lynn McPherson:

No, I think you're awesome and I'm really delighted that you keep trust. Thank you.

Connie Dahlin:

So-

Denise Hess:

It's an honor. It's a great fun.

Connie Dahlin:

Thank you so much. This was lovely. And I know that for our students, you've really heard a lot of different points from thinking about the individual, to moving from a program, to thinking of national, to think about different associations, and thinking about the different steps. And so, as you're thinking about moving into your next leadership, and we're asking you to say okay in this PhD program, where are you going to go? You've had yet a really another great example of different places that you can step in. So that is all for today. Thank you.

Dr. Lynn McPherson:

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Thank you Denise. I'd like to thank our guests today and Connie Dahlin for the continuing journey in our podcast series, titled Founders, Leaders, and Futurists in Palliative Care. I'd also like to thank you for 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](http://graduate.umaryland.edu/palliative). Thank you.