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.

Connie Dahlin:

Welcome everyone. My name is Connie Dahlin, and I'm one of the faculty for the University of Maryland PhD program and this is another of our PhD podcasts. I'm joined by Dr. Lynn McPherson who is the Director of the Palliative Care Program at the University of Maryland. We are thrilled today to have Dr. Arif Kamal, who is from Duke University. He has many roles. You will see Dr. Kamal's name in a lot of the articles that you're reading, and also thinking about, and you might have him as a faculty member as well, but we are inviting him here to think about the future in our What Comes Next: The Future of Palliative Care series.

Just to give you a little flavor of his background, he is still practicing as a physician in medical oncology and the section of palliative care. He is board certified in hospice and palliative medicine. He has really focused a lot of his work, both in clinical care and in business, because he also has his MBA. He's been really thoughtful about thinking about quality measures and was helping with one of the registries, of course, they've all come together and he can talk about that. He's really been a consultant for many groups in terms of the Agency for Healthcare Research and Quality, the Cambia Health Foundation, the CMS Centers for Innovation.

And I think for you to understand that he's been a leader in the American Society of Clinical Oncology. He's also a board member of the American Academy of Hospice and Palliative Medicine and also looking at measures, has also been a Cambia Sojourns Scholar, which is also how I know him. So he has many more things that he can talk about. But just to give you a sense of the breadth and the focus of quality for you, as students, to know how important, we can do the care, but then what do we need to do with that? So we're going to kind of go from there. Arif, do you want to introduce yourself a little bit more? I give a broad perspective, but are there other things that you think the students should know that kind of helped form your thoughts for today?

Dr. Arif Kamal:

Well, I think just my passion for palliative care comes from a very personal space, sort of my family's intersection with hospice and palliative care was early on in my training. And so I think for like a lot of professionals in our world, you have something very personal that drives you here and I'm not any different than that. For those of you who are doing a PhD program, I congratulate you for taking that next step in your career to really establish yourself as a national leader and expert in some component of how to make this delivery better. We need everyone on board committed to doing this, because there's several challenges, which we'll talk about, that need bright people like yourselves to be a part of.

Connie Dahlin:

So we do also ask the question of the people of the future, what's one fun fact that most people don't know about you?

Dr. Arif Kamal:

Yeah, I think, it's funny. When I talk to people, they presume I'm a super serious guy, and I think I am in some contexts, but man, I love horsing around with my kids. I have an eight year old and a four year old. I love playing golf and tennis. I love watching sports of all kinds. The last trip I took, prior to the pandemic, was to Miami for the Super Bowl, because I'm a big Kansas City Chiefs fan.

So we love to travel as a family. We love to eat good meals. And so yeah, I don't know, I'm a pretty laid back person. I think most people who meet me over time and get to know me, even though they oftentimes see me in a suit and other things, recognize that actually, I'm... Tickle fights are a common thing in my house, and I love to be a part of them. I don't love receiving them, because my wife will tell you, my feet are very ticklish. But also another thing most people don't know about me. But anyway, so yeah, we have a lot of fun.

Connie Dahlin:

Well, that's good, because I think we also like to know that people are human, and they have all different sides to them. So you talked a little bit about how you got into palliative care, you are doing a lot of things right now, so you're in the middle of it. What do you love, kind of what drives your passion in terms of what your work is right now?

Dr. Arif Kamal:

Yeah, so we are so fortunate in this field to have such great leaders kick this thing off over a period of 30, 40 years, right? And now... I did fellowship in 2009, which to me was not that long ago, but was in the sort of the first crop of physician fellows coming out, taking the board exam, and so on and so forth. And so the excitement really is around saying, "Gosh, as a formal recognized [inaudible 00:05:20] physician field, it's only been about 10 years or so." Right? 10, 12 years. That means there's a ton of potential.

To me, palliative care in the US is very much still an unwritten story. We're probably in chapter two, to be completely honest of sort of where this book is going. I think a lot about palliative care. 1.0 is really the hospice movement, palliative care 2.0, to me, was sort of the birth of true upstream multidisciplinary care, fellowships and certifications across all team members, and really the growth of hospital based palliative care, and to a certain extent, community based palliative care. But now I love to think about what is particular 3.0 look like? Right? What is the natural evolution of what we're doing in many different ways? How do we get to the right patient at the right time, in a just in time way, before they hit crisis? How do we prevent crisis? And how do we completely utilize all members of the team in a way that is both recognizing their important contribution, from a financial to research perspective as one place to start, but also actually utilizing all of our team members in the right way, because I still think palliative care remains to be quite physician centric in its delivery.

The challenge with that is that physicians aren't good at everything, there are particular things we are okay at and then it varies. But gosh, we have to think about systems that actually embrace the idea that complex clinical situations need a lot of people involved. That team-based care means that we have to really think about what are everyone's real strengths and opportunities? And how are we using those folks in the right sort of targeted, deliberate way? So to me, palliative care is this largely unwritten story and sort of in its second draft, needs this 3.0, and a lot of people are now thinking about it. I think the other part that's exciting is we're going from really trying to advocate, "Can we have a seat at the table?" To sort of saying, "I think we do have a seat at the table." But now, to a certain extent, we have to figure out who are we in terms of what we're advocating for while at the table? Because the argument five years ago, "Was we need more consultations, we need more business, we need to be invited to more rooms." And now it's sort of saying, "Well, I think we've done that, to a certain extent."

Now, it's sort of saying, "Well, which of the patients most need our help? And how do we get everybody sort of in some sort of triage mechanism to figure that out?" And importantly, then, of the patients where we can't directly face to face help them, "How can we be change agents within health systems, so that we can," you know, rising tide lifts all boats, right? Well, so the point is that there are particular boats that we may go after and try to lift, but every patient with a serious illness needs some philosophy of care that we can bring. I think our role as educators and change agents, as QI experts, as researchers, as clinicians, as colleagues, and others can really make this an entire healthcare movement. Because I think fundamentally, that's what we're trying to change is certainly one program at a time, but in... One plus one is three. When you put the whole thing together, it's trying to change all the healthcare. That, to me, is super exciting and I hope your students find that to be super exciting to be a part of as well.

Connie Dahlin:

[crosstalk 00:08:43] during all that, I think you can do it single handedly?

Dr. Arif Kamal:

No, no. That's the thing, we need the entire village, for sure.

Connie Dahlin:

I have two questions based on that. Arif, there's a really interesting thing, because I think we think of ourselves as really novel, and we did change that, you're right. But I also think it's been very interesting to me, and as we move with a health equity lands, and you try to move things, and you say to people, "Okay, we have to change in order to do that." But then you even have palliative care teams who are saying, "Well, this is the way we've always done it and these are the roles that we've always had."

I sometimes find that incredibly stunning, because I'm thinking, "Okay, we changed and we've had to evolve, so how do we help this change with this lens?" And you kind of mentioned, it has been very physician centric, and I think with incentives are, that's the most threatening, and yet we also know that to rise everything is to rise the whole boat. You kind of point out some really complex things that every day when I'm talking to people, it's like, "We want to change, but we're not going to change that." Right?

Dr. Arif Kamal:

Yeah, well, I think it's like a family, right? So I see palliative care as like a family, and a family has to have both sort of an inner voice and an outer voice. The inner voice is the one that's truly honest with itself. As a family, you might say, "Look, blah, blah, blah, this particular uncle is struggling with some particular demons, blah, blah. His kid's not getting the greatest grades, blah, blah."

The point though is, I learned this from my family early on, when you go to a dinner party, you largely say everything is great. The thing though is knowing the difference between the two voices. I think palliative care is a field, when sitting at a table with cardiologists, and surgeons, and others, yes, we are doing a fantastic job. The reality is we are right. The reality is I think we are, but it does not mean that you ignore the inner voice that says, "The National Consensus Project for Quality Palliative Care," which by the way, is a must read for anybody in palliative care, and I hope your students read it-

Connie Dahlin:

I didn't say that.

Dr. Arif Kamal:

No, you didn't, but it's a must read. Connie was part of that for sure. Is that if we say, for example, that the definition of palliative care is the patient and the caregiver as the unit of care, then our outer voice says that's everybody, that we take caregiver needs as being just as equally important, and we will pay attention to them. Our inner voice should say, "As a field, are we really, really in a standardized, regular way assessing caregiver needs?" If we've got that figured out, great. I'm going to contend that I don't think we've got that figured out.

What that means is that we have an honest conversation as a field and sort of say, "Gosh, we need leaders to really take this charge of implementing standardized caregiver assessments, for example, and figuring out where skills are, and where the needs are, the gaps are, and so on." That's a way to get better, and this is from the Principle of Quality Improvement, without having to demonstrate that you're not good enough. Because it's a false choice, right? You can be really good and still want to get better. I think that's the ethos of what palliative care is anyways. Many people came into this field in the last 10 to 15 years, because they saw something in healthcare that just didn't jive with their own sort of moral compass, I think that's really true, because you didn't come here for the money.

If you did, I'd be interested to see who did that and where they found that money to exist. You came here because you said, "My moral compass is pointing this way and the way I see healthcare work is not jiving with that," and that's great. Now, what that means though is keep looking at that compass, because that compass has a true north that really says, "Caregiver assessments, let's look at other areas that are blue ocean areas for our field." Financial toxicity, really, really important to patients and caregivers. And yet, as a field, I don't think we've really figured out how do we intersect ourselves in there?

The answer cannot be get a social worker and have them take care of it. We have to really understand. When we think about total pain as an example or total distress, finances are a really important part of that. I think about finances, I think about caregivers. Connie, you brought up sort of diversity and inclusion. If we, again, our inner voice asking ourselves, honestly, do I... I'll just start with me to start with. Do I know how to do a palliative care assessment in a Latinx patient, versus a Hmong patient, versus a Cambodian patient?

Can I fine tune my instrument to meet the needs of that population in a way where I can walk away and go. "Yeah, I did that right?" No. To me, clearly, the answer is no. We're all trying to learn. What that means though is, from a discovery perspective is, I think we can sit at tables, and look across to pulmonologists, and say, "You need more of us in the ICU, let's figure out how to make that done." But also sit at tables with our own colleagues and go, "Hey, so what are you doing? What are you guys doing so well at your institution that we can learn from about how you manage patients, or assess cultural issues, or religious issues, and other things?"

I think you're starting to see in our field stuff like the top 10 tips series in the Journal of Palliative Medicine that Chris Jones and I co-edit. That was really the impetus for that. Just for your students, the idea was that we want to give people just in time access to information about taking care of patients in a really personalized kind of way by teaching them something that they may not know. In the top 10 series, we focused on Muslim patients, on Jewish patients, on patients of Latinx background, LGBTQ patients, et cetera, to sort of say you can both be really good at what you do, and at the same time, hold that we can be doing it better. I think if any field in medicine, and in nursing, and in social work, and chaplaincy, and pharmacy, et cetera, any field can understand that, and hold both things simultaneously, which is pretty darn good, and I think we can do better, it's us. I think we should feel shy to embrace both things at the same time.

Connie Dahlin:

I think also what you're getting at is that, and I can speak for this having come from hospice and stepped into palliative care, when it was going, was this whole thing that there is this continual learning, right? You brought up the Cambodian patient. I mean, I just remember when I would get a referral, and it was from a Cambodian family, I also had to stop and say, "Is this even culturally appropriate? In this culture, you do not talk about death and dying. So what's going on? And what generation are they?" Right? Because first generation, absolutely inappropriate for palliative care to be involved.

Dr. Arif Kamal:

Right. Right.

Connie Dahlin:

Second and third generation, I can talk to the children, but I still have to be very nuanced. I think the worry that I have of what you bring out, with this quality, which I think is so important, is yes, we do a good job and we still can improve. And so I think sometimes even when people are picking quality indicators, and they want to pick the 100%, and we're like, "Well, then don't do that." Right? Like, "You're not learning from that." Picking something that you can. But I also think of this part about how do we sort of know, even amongst our team, who has the strengths, not even by discipline, but strengths in different areas, right?

Dr. Arif Kamal:

Mm-hmm (affirmative).

Connie Dahlin:

What I mean for that is for the team, because I helped start, I actually had a really good relationship with a lot of people, because I knew their styles, I'd spent so much time. It wasn't that if you'd quiz me, was I the best person on COPD or heart failure? No. But I had that palliative care skill of that relationship building, right?

Dr. Arif Kamal:

Mm-hmm (affirmative). Mm-hmm (affirmative).

Connie Dahlin:

And so I think, when you're talking about the quality part, there's the qualitative data and the quantitative data, and we still as a team need to hold both of those. And so sometimes, I think what I worry about is we still have a lot of people who feel like, "Well, if I'm a good clinician, and my heart is in it, it will all be fine."

Dr. Arif Kamal:

Yeah, that's a great point, Connie. Look, the time where we got points for just showing up has long since passed. It's tempting to give ourselves credit and a pat on the back to say, "Look, I did 10 consults today and aren't we great." At a time where you weren't getting any consults, when the baseline was zero, then 10 is fantastic. And so you are, at your point, getting at a quantitative outcome. It's really tempting to kind of get stuck in the quantitative outcome, partially because healthcare oftentimes measures its success in a quantitative way, by number of consults, number of visits, et cetera, et cetera. I think we're clearly interested in the quality component of that as well.

The thing about any new-ish specialty, I still think we're kind of newish certainly in the way that a lot of clinicians are now consulting us is, I learned early on in my career that consistency builds trust. For people who have children, you know this to be true, because my eight year old watches how I disciplined my four year old and vice versa. What they're saying is, "Well, when he did blank, you didn't do blank, but when I did blank, I got blank." Right? What they're saying fundamentally, even as children, is, "Because you're not consistent, I can't really trust the process of," in this case, "you disciplining us." Right? "So I'm going to kind of pick at the process, because I don't inherently trust it."

I think that goes for a lot of different things. Consistency builds trust in a lot of different components of the world, because people want to see consistency, at least from a trust perspective. So obviously, when people talk about quality measurement, they say, "Well, look, palliative care is an art and some of these things are hard to measure," and so on and so forth. The mantra in quality improvement, actually is, "First worry about doing it the same and then worry about doing it right." I say that, not because doing it right doesn't matter, but what happens is that people make the lack of clarity about how to do it right be the argument for not worrying about doing it the same.

And so look, if an entire palliative care team said, "We're all going to," I'm going to do the caregiver thing here for a second, "assess caregivers using this instrument by..." "And all of us are going to do it by the third visit during the hospital and we're going to use this method to, you know, if we identify this in this need we'll bring in financial counselors, or case management, or navigation," or other sort extended aspects of the palliative care team, blah, blah. That is a huge step forward for our field to even hear and if that were to happen.

Connie Dahlin:

Right.

Dr. Arif Kamal:

But what happens, and this happens in oncology all the time, and that's where I'll make my analogy to, is what people do is say, "Okay, well, we have breast cancer and let's figure out what are the three chemo regimens we're going to use for all patients with early stage breast cancer." What will happen is people sit there and talk about arguing of the side effects and the cost of each particular regimen. And you go, "Can we just agree to all do three same things? We'll worry about later about the nuances of whether it's the right thing."

What I see is practices sitting there, going, "Well, should we use this instrument or this instrument to understand caregivers?" Just pick one and do it. Then once you've all done it the same, then later, you can sit there and kind of poke at the edges about whether it's the right one or not. I think to a certain extent, consistency builds trust, consistency in what we do is really important, and importantly, there's a pervasive undermining of what we do when all you need to know is that in a particular health system or hospital, that a particular clinician or group will place a consult if X, Y, and Z person is rounding that week.

I hear that all the time and what they're telling you is, "I don't trust the service that I'm going to get, because frankly, it's not consistent." We had all imagined on a clinical service, but when this person is on, they're really into ketamine, and methadone, and they're just all about the pain, but maybe not necessarily do some of the advanced care planning stuff as well, and vice versa. Whatever those flavors look like. I think where we are now in palliative care 3.0 is really trying to understand. When people think about quality measures, quality measures is just verbalizing out loud the things that you think are important.

If you said, "What are the 10 quality measures that we should all be using today?" Well, HPNA and HPM have put out the Measure What Matters project as a place to start. But even if you said, "We disagree with that, we want to use our own," fine, find the 10 things that you think are the most important thing that should happen every single time your team intersects with a patient and their caregiver. The point is figure that out, and then do it consistently, and say, "This is what we value and we value it so much that we're going to hold ourselves accountable by measuring that, and then doing some improvement around it."

I think too many teams are honestly so worried about perfection that it is actually becoming the enemy of the good. I think for us to be change agents, we have to be willing to change ourselves, because everybody wants other people to change, it's hard to change themselves. This is a really good example of that. I think as change agents, we can be within a health system, we can be the role models of this to sort of say, "I think we're pretty good, but we also noticed, for example, we think spiritual assessment is a really important component of health care delivery.

What we recognize is less than 25% of our consults are we actually documenting a formalized spiritual assessment or screen. We're working on that. Hey cardiologists, when you console to us, we guarantee you this is what you're going to get. We're going to check in on your heart failure patients spiritual background," whether that's driving some of their decisions about particular things. Again, when that consistency builds, then the trust builds. And when the trust builds, we go from not only having a seat at the table, but actually being asked our advice about how to do particular things.

Connie Dahlin:

I would go for two places. One, when you're talking about the seat of the table, we get to create the menu. We're not on the menu, we get to create it. So you're right about that power. Arif, you bring up a really interesting point. When I started the team at the academic center that I co-founded it at, literally started with nothing. I started with a telephone on the floor, we didn't have a desk or chairs.

Fast forward five years, I'm still the only MP and I'm working with seven or eight different physicians. Now, I asked for a meeting, because they're all practicing differently. Two weeks on, two weeks off, and I'm saying, "You guys, consistent messaging. Can we talk about an algorithm?" Well, that was the wrong word to use, because what I was told is exactly what you're saying. "Connie, there's an art and a science, and we all want to practice the art."

I said, "That's great, except for I'm trying to work with all of you, and we haven't even agreed upon what as a team are the types of medications we're going to use. You all are practicing differently." To your point was I also saw, in the same way you're saying, what different other people are on when you get the consults. I also noticed that when physicians were on when we got the consults. It was a [crosstalk 00:24:54].

Dr. Arif Kamal:

Oh yeah.

Connie Dahlin:

It's very interesting to me, because I feel like while we've had a movement, and we are really looking at the patient and family, and then the work that I'm doing of health equity, it's the patient and family and the community [crosstalk 00:25:09], we have really almost been allergic to algorithms, because somehow, we feel those are bad.

Dr. Arif Kamal:

Sure.

Connie Dahlin:

Rather than saying, "Algorithms force us, as a team, to have a conversation about, as a team, what do we agree are sort of our first and second line ways of treating different things?" Not to say it's exact, but we're kind of coming in with some consistency. We have an allergy to that, and so it makes it hard sometimes to have these conversations because I feel like people will say, "Oh, Connie, you just don't understand." Exactly what you're talking about, the chemo, "My patient is different. We can't..."

Dr. Arif Kamal:

Mm-hmm (affirmative).

Connie Dahlin:

Okay. So it's been going on. [crosstalk 00:25:50]-

Dr. Arif Kamal:

And I-

Connie Dahlin:

... watch, and so when you talk about quality in those terms, it makes me excited, because I'm like, "God, I wish we just use that language," so people would understand the reason of it. We're not trying to make them mechanics and we're trying to still have them be real. Thoughts about that?

Dr. Arif Kamal:

Yeah, I mean, look, a component of palliative care practice, right, is we ask patients sort of what's important to them. To me, quality measures are just an out loud communication of what's important to the team. Right? And so you measure the things that are important to you, that's just, frankly, what it is. If your value is that we're all going to do it differently, and you're willing to say that out loud in a team meeting and say, "There's really no reason for us to do the same, because this is an art."

Well, I think from patient and caregiver and referring clinicians perspective is, they don't necessarily want to play the game of let's just spin the wheel and see what comes up. Right? That may feel great to you, because it's fun, I guess. But I can promise you, the referring clinician wants something that they can trust. I think, if you're able to express out loud what is important to us as a team that we make sure all patients get, and you might say, "Look, three components of it is a standardized component of it and the rest of it will be art."

Well, at least that's a start. Again, let's first decide which parts we're going to do the same and then we'll worry about whether it's the right parts or not, but let's first decide. And so we say, "All patients should have an assessment of pain, and emotional assessment, and spiritual assessment." Well, gosh, that's still three steps ahead than where most people are right now, because what we haven't done a great job of is really comparing and contrasting practices.

I'll give you a sense part of this is, so my brother is an orthopedic hand surgeon, and he and I were talking, not about palliative care, but he was talking about taking his board exam. Surgeon's board exams are experiential, they actually pull your cases, and you sit in front of a room with a bunch of people who read what you did, and they ask you questions about it, and there's this back and forth dialogue. So it's almost like an M&M about the cases that you operated, "Why did you choose this? Why did you do that?" Blah, blah, blah.

Connie Dahlin:

Wow.

Dr. Arif Kamal:

And my brother said, "Don't you guys do that?" And I said, "No, I don't even know how much people would shake." And he said, "Why? What are you afraid of?" If you're doing it right, maybe there's many ways to get there, but the point is, you got there. And so I think that culture of reflection, I mean, as a field, I think we're very reflective, particularly when we're helping other people reflect. I think there is a moment though, where we sort of say, as a field, "We should be reflective amongst ourselves." And again, inner voice, outer voice. Outer voice says, "Look, we're doing a great job." Let's not change that.

When I think about this, in the quality vernacular, there is quality improvement for accountability and external reporting, there's quality improvement for sort of internal improvement, right? And you do have to separate the two things, right? Quality improvement for external accountability and reporting, you try to put your best foot forward. Actually demonstrating a lot of gap is not necessarily in your best interest, particularly based on what you're reporting for.

But those honest moments is the internal stuff where you say, "Let's close the door and let's talk about this. So did you notice that when you're rounding, we get consulted. When you're rounding, this happens..." Da-da-da-da-da. Instead of seeing that as a threat, I think that's really important to see that as an opportunity for growth, because I think most people in palliative care do have a growth mindset.

The other reason to do that is a more practical one, though. It's that from the ecosystem of what we're talking about in serious illness, is payers and health systems are, and this is hard to hear, agnostic as to who does the work. They just want it to get done. And so if we want palliative care to be a self-preserving group, then it becomes a trade society. Right?

What's a trade society? A trade society is, "We really think that styrofoam cups are better for the planet than plastic, so I represent Styrofoam cups and when I go lobby Congress, I talked about how it actually costs more money to recycle a plastic cup than styrofoam. And blah, blah, blah, blah, blah, and actually not that many sea turtles are dying from styrofoam." The point is, I'm representing my own interest when I talk to other people. Notice that the styrofoam cup lobby, for example, is interested in the proliferation of styrofoam cups.

It has nothing to do with whether people actually get a cold or hot beverage, right, that's not necessarily what they're focused on. If you take that analogy, which I know was a little obtuse, but if you apply that to palliative care, we have to be very careful. Are we advocating for our particular version or brand of this delivery? Or are we interested in saying, "Look, all serious illness patients and their caregivers require really good high touch compassionate support that is importantly after their goals, preferences, and values."

If so, if it's the latter, then it may include versions of team composition and care delivery that may honestly feel a bit uncomfortable than where we have been before. So examples of that in our field can be NP based telehealth palliative care delivery. There may be certain team members who kind of gristle at that idea and say, "How could that blah, blah, blah." The reality though is that's happening, that's neither good nor bad, I'm just saying that's happening.

There's lane navigator versions of that happening as well. Everybody who has a stake in this game, not just palliative care specialists, is trying to figure out how to provide the best care to those people who are oftentimes largely homebound or have difficulty accessing services in person, and trying to figure out that... So palliative care has to decide, I think with both its internal and external voices-

Connie Dahlin:

Okay, we're back on.

Dr. Arif Kamal:

Okay.

Connie Dahlin:

Arif, what you made me think about is... So we've focused on like quality metrics for clinical, but I think it's really important for you to talk a little bit about the other types of metrics that a palliative care team may be responsible for. These are PhD students and we need them to look beyond the clinical, right?

Dr. Arif Kamal:

Yeah. I'm just going to pivot to research for a second too. Palliative care is in a unique space, because a lot of the things that we do are not based on very large randomized control trials. Importantly, for those who do understand sort of how large randomized control trials are resourced is they either come to the NIH or they come from industry or pharma. Generally speaking, we're not using a lot of cutting edge drugs that are still on patents in particular, where you're going to find a lot of interest from pharma to do that. We have to be creative in our evidence generation.

You'd mentioned earlier, Connie, registries and real world data is going to be really key to what we're doing. I think as palliative care specialists, we have to, and as researchers, think creatively about where that data sits. For example, do the payers have that data? Do clinical research organizations have that data? Do quality collaborators like the PCQC, the Palliative Care Quality Collaborative, have that data? Do health systems have that data, and networks, and so on? Where does that data exist? Because what we're seeing, for example, in other fields, is that in places where randomized control trials cannot get done, you essentially have this essentially randomized control trial within a data set.

You can follow populations of people who got this drug versus this drug in a palliative care setting over a large registry, and you can follow them over time, and sort of see what happens in a real world kind of way, because palliative care, essentially, is real world delivery. We're doing real world problem solving based on the resources we have and where we are located. I think that what that means also is that QI and implementation science are really important to our field as well. So let's talk really quickly about the difference. So research is novel data generated that is generalizable to most settings.

Oftentimes in palliative care, we worry about generalizability, because we're talking about, "Well, this is my institution's experience with seeing patients with head neck cancer by palliative care and their average pain score is this," and so on and so forth. You ask yourself, well, would that be the same in a community hospital versus a tertiary care hospital, et cetera? But what we can learn from that is, even if it's not generalizable, what we can learn from that is what are the lessons? What worked well?

What didn't work well? We as a field have to get better at sort of saying, "We need to create a library of things that don't work well."

Even though it's uncomfortable to publish or share with others, because you feel like it's a failure, is we have as a field, because we're so particularly young and new, we need to create a library of the things that don't work. We have to have brave people in our field raise their hand and say, "Yeah, we tried that thing. It didn't work for us and let's tell you why," so that other people also don't make the same things, because to a certain extent, you're like salmon swimming upstream. You're kind of like figuring out, "Well, that's not the right route, that's not the right route," but we're swimming nonetheless.

I think putting new datasets together, figuring out what doesn't work, thinking about QI, and also thinking about implementation science means that we can also help figure out, in a particular organization or geographic location, if this sub-specialist is in short supply, or man, it's really hard to get a pharmacist to go to Billings, Montana, as an example. It's how you still get that function, that skill, which may be sort of med reconciliation and looking at interactions, how do you get that still addressed in a way that's novel and unique?

I think in palliative care in particular, one of our great strengths is we are good communicators, we love to share and we love to network. You sort of think about palliative care working in that kind of networking way, where you say, "Gosh, there should be centers of excellence with hubs and spokes." Right? Where we're really trying to help each other out and doing case review and doing other things. And trying to understand we cannot make palliative care 3.0 be about having, I'm going to pick on pharmacists for a second, a certified pharmacist on every palliative care team in the country. That, in and of itself, you can get so stuck on that, that you actually sort of lose the forest for the trees.

The forest is we want to make sure all patients have reduced risk from interactions, and so on so forth. We want these things titrated on the right way. And maybe there's ways, through distance based ways and other ways that we can collaborate and work on that together. To me, the reason why palliative care 3.0 will be successful is we'll be creative and thinking about how do we come together as a field to solve these problems in unique creative ways, I think in the same spirit that got us to where we are. Because for those of you who founded the field, like Connie, and Lynn, and others, right, you know that 15 years ago, this seemed pretty daunting.

Because we were like, "Well, how are we going to get a hospital palliative care consult team into any large hospital?" Well, we figured that out, because we learned to message things in the right way, to the right audiences. I think we have to do that same too as we think about growing the workforce as well. And really embracing the folks who I think oftentimes are on the sidelines sort of saying, "Well, I'm not fellowship trained. I'm not this. I'm not that." It's like, "Look, you're an ally." We use the term ally, for example, in DEI. We need allies or champions to palliative care. We need to identify them, embrace them, bring them in, not focus on the differences, like, "Well, you're not certified, you're not this, you're not that..."

No, no, no. If you have an interest in you want to be a part of our team, by all means, you're all welcome. Because this is, right, a revolution. This is a philosophy. This is not a tribalism issue. I think the more we can get away from that, the better we'll be served as well.

Connie Dahlin:

You also speak of the fact that we also need to be creative, because have we created barriers within some of the certification recommendations, particularly for physicians, right?

Dr. Arif Kamal:

Sure.

Connie Dahlin:

That you have to have fellowship. I understand it, and thinking, and in nursing, we're thinking about that, too.

Dr. Arif Kamal:

Right. Yeah.

Connie Dahlin:

You have such a great, broad knowledge. What do you think is, you've kind of mentioned some of the challenges, that we've got to kind of come together, and we've got to be more thoughtful, and think beyond our institutions, and think about the payers, and thinking about policy. But what keeps you up at night? What's your biggest worry?

Dr. Arif Kamal:

The thing that actually keeps me up at night is the most precious resource we have in palliative care is the human capital, is the people who do this hard work. I worry about them a lot. Not just from a burnout perspective, because I think you know, and others know, in some work that we've done, and Dale Lupu, and others have done too, is that we can project in a lot of different ways how we won't have enough clinicians. And so we worry, certainly about who's going to do this important work, and how are we supporting them and recognizing their efforts?

I worry about what are we saying to the social worker in a medium sized hospital that says, "Well, you can't bill but you're important, so I guess we'll kind of keep you around until we run out of grant money, and then we can't." What are we saying to that person? Right. What are we saying to the APP when we say, "Well, the physicians get to go to the annual assembly, but you've got to stay here and hold down the fort." What are we saying, right? What are we saying to the pharmacist where we say, "Well, if we get a grant, we'll put you on the team. Otherwise, can you just curbside constantly all the time and help us out, but we won't recognize that effort in some way."

What are we really saying to people? I think what we have to do is recognize that the most important resource here is not our clinical skills or credibility, because I think those go without question, it's really sort of saying, "What happens to this field if people, particularly in the era of COVID, just get burnt out and don't want to do this any longer, or realize that they don't have the protective mechanisms?" I was thinking a lot about this, our family, we went on vacation to New York. We went to Niagara Falls. If you go on the boat under the falls, they give you a raincoat. And so you recognize, "If I'm getting on that boat, I'm going to get wet, because I'm getting really close to a very large waterfall."

But the point is, you take the raincoat, not because it's not wet, not because you're not going to get a little wet, but you're doing everything you can to not be completely soaking when you come off that boat, right? And so I think for a lot of people in palliative care, what we're saying is, "We're getting on the boat, and we're getting really close to this large waterfall of distress. And we're going to do it every single day and that's what we signed up to do." But the point is, we need to make sure everybody has a raincoat, we need to make sure the raincoat is intact, we need to make sure when it gets wet that we switch it out, and we need to think about better ways to have better raincoats, as well. Right?

And so I think that's our challenge just as much as anything else. I think, in a lot of ways, what we just talked about in terms of having people practice at the top of their scope is going to help with that, having a really good sense of team dynamics, really trying to work in matrix functions, as opposed to top down. And really, again, recognizing the value and contributions of all of our members of our team, whether their coat says MD or not, it doesn't matter to me. Those things can be really, even done in small ways, but really important.

I think in some of the work we've done with focus groups, for example, of non-physician colleagues, what we've heard is some of the things that I just mentioned. That, "Gosh, certain people will get opportunities to education and I don't." When you start to see disparities in opportunity, then what you start to say is, "We value our team members in a different way." That becomes a very slippery slope, to at that point, then saying, "Well, we value everybody in different, way we pay them in a different way, we give them opportunities in a different way, well, then you're not going to have a team for that much longer."

Because that underlying concern may turn into resentment, it may turn into other things. I think a real important focus here, and what keeps me up at night, is thinking how do we make sure everybody feels like an important and valued member of this community? How do we hit that from a payment perspective? This is why it's so important that from a payment perspective, we're really thinking about bundled payments or capitated payments, we're really saying, "The entire team is getting paid for doing this important work, how do we think about other policies that sort of recognize all the work the people are doing and their contributions?"

And then, "How importantly, do we get people to really find the joy and the love in the work that they do, and that we're able to support that system ways, but also an individual ways too?" I would love everyone's thoughts about how to do that, because I don't think we have figured that out yet, but it's a really important question for us to get to the bottom of this.

Connie Dahlin:

Pre-COVID, I feel a little bit heartened in the sense that the Institute of Health Improvement had started thinking about this with their joy of work. They were deliberate about naming it joy, because they didn't want to focus on the negative. That the National Academy of Medicine had started looking at clinician burnout. I think in COVID, everybody has started looking at this more, and I think depending on what your discipline is, some of that. I will be very intrigued to kind of see what happens coming out of this. I think everybody knew it coming in, to your point, what's going to happen when... I mean, because we're not done with this pandemic. I know people are relaxing and doing whatever, but I don't think... In a few months, maybe we'll have a better sense of what's really going to happen, both internationally and nationally. How's that-

Dr. Arif Kamal:

Yeah, yeah. Imagine our clinicians start doing consults in patients dying of COVID in an ICU who chose, themselves or their family members, to not get vaccinated. That level of moral distress we will have to be present for. We may have our own thoughts about, "Boy, that was a silly decision," whatever that is. But the point is we have to be available, and there, and help those folks. I actually, in this moment, worry a lot about that for ICU clinicians and toddler care clinicians, because we're going to walk into situations where we might have thought, "This is a completely avoidable and preventable thing, and yet, here we are talking about suffering."

Importantly, we may be dealing with survivor's guilt or guilt of family members and caregivers who may have given that advice, for example, and are now saying, "I can't believe I told her not to get vaccinated. Now, here she is on ECMO, blah, blah." I agree with you, Connie, I don't think this actually gets easier. I think it actually gets harder before we get to some level of normalcy over the time, because the thing is, we are still on the boat, and there is still a waterfall, and we're still just floating around near that waterfall.

Again, the waterfall is not going away, and hopefully we're not getting off the boat. You just realize that that's the challenge that's there. It may be gun violence. It may be climate change. The point is when there is crisis, palliative care is going to be called to be a part of that. That's never going to change. I think really great leaders in our field, including yourself, have established that really hard over the last 20 years. But the point is we say, "We may not know what the next crisis is. What we can do though is be prepared to meet that as a field and do all the things that we can so that our most precious resource, which is our human capital, is emotionally, and physically, and logistically ready to meet that challenge."

As much attention as we want to give to which patients with advanced dementia should get palliative care? I mean, that's an important clinical question. My question though is who's going to do that work? Regardless of whatever the threshold is for that consult, who's going to do that work? How are they going to work together? What's going to keep them coming back to tomorrow, and the day after, and the day after that?

Dr. Lynn McPherson:

Can I go back to where you were saying that we need to value everybody on the team? It's easy to say because both of you can bill for your services. So here I am, as a pharmacist, and the C-suite can say, "Well, I mean, pharmacists are adorable, but they can't bill." I mean, I understand you're saying it's the team's responsibility to pick up that job function. But even if we as a team value everybody on the team, how do we sell that to the C-suite?

Dr. Arif Kamal:

Well, certainly more research about, and there is now, research on the return on investment for the involvement of pharmacists on the palliative care team, one. Two, I think from a policy perspective, we say, "This has to be a per member per month payment that just says, look, and we're going to roll everybody's efforts into that in some way." So if you think about it, hospice, hospice is great hospice is great, let's just start with that. Hospice is great, but at $170 a day, which is a conservative estimate, for 30 days, you're talking about $5,100 a month, okay? The average Medicare patient in the country is eight to 12 grand a month, hospice looks like a really expensive program.

Now, that's not a critique on hospice. What it's saying is, "Sometimes it costs that much money to do this kind of interdisciplinary work." And we've already recognized that in the hospice world. So I ask you, "Why couldn't we take some version of that and do it in the palliative care space?" Right? It may not be $5,100, certainly, that would be tough to sell to begin with. But the answer may not also be $300 a month, or $200 a month, or something like that, right? There's probably something in middle, where you say, "We find a number that works, but we bring everybody on the team to do what they're really good at doing."

I think the answer is somewhere there. We just have to convince policymakers, and others, that that investment exists. I think they're small battles that we're trying to win. So for example, in North Carolina, we have a 50 to $80 copay for Blue Cross Blue Shield patients to come see outpatient palliative care, and somewhere between 15 and 20% of our patients no show to our clinic, specifically, because they don't want to pay that copay. Now, when I call the chief medical officer of Blue Cross Blue Shield in North Carolina, you know what he says to me, "Oh my gosh, Arif, do you want us to waive that?" Because those patients will come. I said, "They will come if you waive it."

So there's moments like that for your students, and our community, and for us to say that's a no duh thing. But the reality is a lot of people, and payers, and other places don't understand that that barrier exists, and it's our responsibility to point that out. So again, Lynn, to your point, if we said, "Well, gosh, if you paid an extra $100 a month and we could get a pharmacist to help manage the care of 100 patients in a population health level way, blah-blah-blah, and that could reduce da-da-da-da bad outcome." Again, it's up to us to put that imperative and that calculus in front of decision makers, and we can't be shy about doing that, because we might get a no for an answer.

Look, all answers are just no, in that moment. It doesn't mean that the next week, or the next month, or the next year, the answer is going to be no again and I think that's what we keep doing. But us, as change agents, have to be advocates. So Lynn, to your point, we have to put that evidence in front of policymakers and say, "Look, if you pay $100 more a month, these are great things that can happen and this absolutely needs to happen. And if you say no today, we'll come back tomorrow and the week after that and the week after that."

Dr. Lynn McPherson:

Okay.

Connie Dahlin:

It's been fascinating, Arif. Because I think where I expected you to be more metrics, I mean, you're really talking about the metrics of human capital and we haven't heard that focus. And on another discussion, I'll just put forward that it's been interesting, because we talked to some of the people who helped create the Medicare benefit, and they would say to you they wish they hadn't, so that's a whole other different discussion. But in terms of thinking about our students, and they're going to be starting in the field, what would be some of the, any last advice that you would give them? Because they're going to be leaders in one way or another.

Dr. Arif Kamal:

Of course, they are. Well first, congrats for doing the program. Second, thanks for being in the field, we need as many people as we can get. Third, my challenge is, define what you think palliative care 3.0 should look like. What I would say is, "It's a blank slate." I mean, we have a lot of great leadership and direction, and so on, and so forth. But the hospice Medicare benefit is not going to stay the same, so it's changing.

The way we think about a lot of the delivery of serious illness care is changing, either from the government side, or from the nonprofit side, or from the private sector side. I think now's a really awesome time to sit down and say, "I think palliative care 3.0 should definitely do..." and then fill in the blank, and tell me what that is. If that's caregivers, if it's financial toxicity, if it's access, if it's equal pay among clinician members, if it's equal access among different disparate patient populations, et cetera. Yes, I think we should vision all of that, and sort of say, "Yeah, that's what we need."

If it's technology, if it's predictive analytics, I mean, the answer probably is it's all of those things. But for each of your students, they're going to lead some aspect of any of that, and many other things I didn't mention, going into the future. I would say, "Be creative, be open minded." Because just like in QI, we'd say, "Simple problems are okay with simple solutions." Taking care of 150 million patients, persons with serious illness and their caregivers in a really dysfunctional healthcare system is not a simple problem and it's going to take, right, not a simple solution. So we're going to need complex solutions to these complex problems, and that's going to require creativity.

Creativity requires a deep knowledge and expertise. That's what your students are jumping into. Right? To say, "I want to really understand the space." So I would say, "Take all your experiences from your life and other places that you've worked and think about how we can apply that here." Because that's what we need, is really good intelligence from our other areas. So people who've done things in other areas, try to bring that over here and see what we can be doing differently more creatively, because we'll need it. We'll need those smarts in terms of what we're trying to do.

Connie Dahlin:

Well, that was amazing thoughts for us and for our students. I think you've really helped them A, be creative, because there isn't one path, but to be assured that there's enough room for everybody to make a difference. So thank you so much, Arif. It's been a pleasure.

Dr. Arif Kamal:

Yeah. Likewise. Well, I hope some of them take our stats course, Lynn. And otherwise, I'm happy to be a resource, as I know all the faculty are, to ensuring the success of wherever your students want to take our field, and there's a lot of room for leaders, and I'm super excited that they want to be a part of this group, it's going to be a great ride.

Connie Dahlin:

Absolutely. Thank you so much, Dr. Kamal.

Dr. Arif Kamal:

Okay, take care.

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.