Transcript: Part Two - This Global Healthcare Lesson Could Change America

Lead With Purpose Program Message

Chris Comeaux - Teleios University Commercial 0:00
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Welcome And The Global Healthcare Claim

Jeff Haffner 0:41
Welcome to TCN talks, and Anatomy of Leadership. We continue our conversation with Dr. Mark Stoltenberg. This Global Healthcare Lesson Could Change America. And now, here's Chris Comeaux.

Scaling Care For An Aging America

Chris Comeaux 1:02
You know, one of the just major challenges faced in the United States is some people call it the silver tsunami. I try not to call it because you can't do anything about a tsunami, but there's just this huge aging population. And we've got clinicians that are being burnt out, workforce shortage. So from your global experience, where have you seen communities successfully extend how to cure just beyond the specialist alone?

Kerala To Uruguay Community Palliative Models

Dr. Mark Stoltenberg 1:25

Yeah. And so this connects to some of what I was saying before about thinking about education and different levels. So there are examples around the globe that have done this really, really well. And a big part of it is coming up with a more stratified way that we're meeting patients' needs that doesn't all just depend on the specialist. So some other really great examples. So if you look up the global palliative care literature, Kerala India and Pallium will be one of the main ones that you see. So they have done an incredible job, now reaching 80 to 90% of patients who are suffering or have palliative care needs in that region have access to basic palliative care. This is an example. It is deeply embedded in their culture. It is deeply embedded within their politics. There's an enormous amount of community support. It's been a hard model to replicate in other places because there are unique things about the context of Kerala, culturally, historically, that make it, it was sort of very fertile ground for this. But I still think the message is really important. Other really great examples on this side of the planet, so Costa Rica and Uruguay, have also done an incredible job of integrating palliative care across their healthcare systems and really thinking about what are the core things, equipment, training, access to medications at a primary care level, and how do we have referral networks so that they can get access to more specially trained people when they need it. And I will say a thing that comes up in Latin America a lot, and I some of my colleagues have been wonderful, sort of bringing this up. And so I want to reflect what they have taught me and shared with me, is so similar of this push and pull between our values and innovation, Chris. I also think there's a push and pull between access and quality. And so we can say 80% of patients have access to palliative care, but what do we mean by that? Does that mean, and so one example that I'll just briefly give you so in Colombia, so um uh I had an experience of a uh family member. So is uh my wife is from Colombia, um, and so it was an uncle that had a serious cancer, was nearing the end of his life. Um, and we went to one of the hospitals in Bogota um and he needed palliative care. And I was a palliative care fellow at the time, and I was like, oh, thank goodness, palliative care is gonna come. Um and they came and they saw him for about six minutes, and they asked him about his pain and they gave him the opioid uh prescription and they said, okay, good luck. And as far as the hospital was concerned, he had access to palliative care. Go to the other side of Colombia and a different hospital in Manizales or one of our close colleagues, Paolo Ruiz, um practices. And there, if a patient in the same spot as him would come into palliative care, which I got to witness because I spent some time with her team, they get a full assessment with a psychologist, a spiritual care expert, a social worker, a nurse, and the doctor, they come up with a clear home-based plan. And that same type of patient a week later was having all of those people visiting in their home, tracking out a plan of how they were going to manage his existential distress, how they were gonna communicate with the caregivers to prepare for what we on ahead, and also the opioid prescription. But it was true, comprehensive interdisciplinary palliative care. And if on paper, if we were doing a country evaluation, we would say both had access to palliative

care. I think that is really, really important that we need to push access, but we also need to be thinking about what do we mean by access and how are we setting quality standards

When “Access” Means Two Different Things

Dr. Mark Stoltenberg 4:26
as well.

Chris Comeaux 4:26
Yeah, that's a good segue then. So you've just talked about you witnessed profound disparities, maybe variety uh and access to pain management all over the world. How has this maybe shaped your perspective on equity? And maybe here's the crux of my question. What blind spots do you think we still have in the US healthcare system?

Dr. Mark Stoltenberg 4:47
Yeah, it's a good question. Um, I think first just to give sort of context. So, yes, they're in places where there is still net access to even basic palliative care. I think the suffering is something that once you see, you don't forget. Um, so some of the cases, too, that I'll never forget. So one was he was probably 11 or 12, but so a young patient with osteosarcoma in Rwanda that finally made it to the referral hospital in Kigali, where I was working with the residents to do basic palliative care training. Um, and he got low doses of IV morphine. And the next morning his parents came in and were smiling and hugging the team, and we were trying to figure out what's going on. Um, and the family said we have not seen our child smile in months because he had been in so much pain. And tiny amounts of opioid meant he could finally smile. It's absurd that we are not making sure that every child has access to something as basic as basic palliative care. So that's one case that I carry. Another one, so I worked in Kenya for three months, working at a rural hospital as the medicine attending, and there was a 22-year-old female with advanced cervical cancer, um, history of very complex relationships, um, including sexual violence and other things. And her her cancer was now incurable and she was in immense pelvic pain. And I remember slowly trying to titrate the opioids and help her and leaving and just feeling the trauma upon trauma and the injustice of somebody at that age suffering under all of these things that were in no way her fault. Like life had happened to her, and she had suffered in so many different ways. It just felt so deeply unfair and wrong. And now trying to care for her, there's just a piece of it that um I still carry with me. So those are some of the cases that you see. I think the first thing that I would say is I don't necessarily would say that my colleagues have blind spots. All of my colleagues here are deeply compassionate for the patients in front of them. They maybe just haven't had the

opportunity to be there and to see those patients. So I would say the first thing is it's not that we have blind spots. I think we need more robust, clear opportunities for more in our workforce to have the opportunity to see what palliative care looks like around the world. Um, so I would say that's the first piece. If there was one thing that I have learned that I feel like we don't always see, and that has impacted me a lot, and this is also one of the most important things I've learned from some of the colleagues we work with the most, is the role of trust in these encounters. So I think we often practice in the US, I can specifically say at Mass General and in Boston, of assumed trust. Most of our patients do trust us. I think we actually miss it sometimes when there is mistrust. But I think a lot of our communication frameworks, how we think about responding to emotion, how we think about working through a guide for how we communicate, just assumes that trust is there. Um and the reality is in many other parts of the world, and I think quite commonly actually here at home, there is immense distrust. And what it takes to earn that back and think about that, I think the world can teach us. And so specifically, our colleague from Brazil, Dr. Daniel Forte, um, we have been working together now for six years. He had a very thoughtful way of thinking about this and describing this that he started during COVID, because in the midst of COVID in Brazil, the amount of mistrust that normally was pretty substantial in the public sector there was on steroids. And so he needed a new way to be thinking about this communication. So he's taught us an immense amount of how to think about trust and how it's really at the root of good communication and connecting with patients. My favorite part of this story is we ended up getting a research grant that he actually got to come to teach Harvard medical students about this. But we also brought our colleagues from Jamaica and Chile. And as we were talking through it and sort of explaining when we get stuck, how we would go back lower to try to respond to trust in this hierarchy that um uh Dr. Forte had described, and our the founder of Palliative Care in Jamaica kind of looked at us and looked at it. She's like, but I don't know if this is right, guys. Tell us more, Dr. Spence. She always has something great to share. She's like, Don't you just start your visits with tell me more about you and who you are? And we all just paused and were quiet. She lives in a place where there is often a lot of mistrust, and it's why people haven't engaged with the medical system. So she has a way of the way she meets her patients. She starts from trust. She doesn't even ask what's your understanding of her illness? What have they told you? She starts with, tell me about you. Who are you? Like what brought who are you before this cancer came along? And because she recognizes the role of trust and had this beautiful enculturated way of building it from the very start, the idea of having a structure to think about when you get stuck, she never gets stuck because she starts in a completely different way. So I just I share those two stories because it's beautiful of how our colleagues from Brazil, Jamaica, and Chile have taught us how to think about this differently.

Chris Comeaux 9:17

That is so cool. That just I shared with you in the beginning. And uh, I want to give John Master John and Lacey Ahern at Global Partners again a shout-out. That this hypothesis of we could learn so much from global. And sometimes our American, I'll just call it maybe I don't call it arrogance, but when we have so many resources, we think we must have all the answers. But resource less countries may have more profound principles embedded that could teach us. And that was kind of the hypothesis I was just bringing you on the show. And yeah, I think you just proved it in

Trust As The Hidden Equity Issue

Chris Comeaux 9:51

that. Well, Mark, I'm super passionate about leadership as well. And wrote a book about leadership. So doing global palliative care requires leaders across governments, NGOs, faith communities, local cultures. So I gotta imagine leadership traits become essential, building trust and influence across such a diverse coalition environment. So can you just speak about that a little bit? Maybe some leadership lessons from your perspective.

Dr. Mark Stoltenberg 10:17

Yeah. I would say so. Um, this has been an important one working across countries and with various partnerships and parts of the world. So I think when I first started in this work, um, I think I really strived to think things like power dynamics and money and race to try to be blind about them and just say, we're just here and we're trying to work together. And I think an essential lesson that I've learned from my colleagues is that power is only invisible to those that already have it. So it was easy for me to say, I'm not going to see power because I'm a white male coming from Harvard, coming from the US. The power was all on my side. And pretending like it doesn't exist is making me blind to the way that those dynamics might impact my colleagues, might impact them and their conversations with the Ministry of Health. And so it doesn't mean it's good that I that that power exists with some of those structures or I deserve them at all. And the reality is that they're there. And so my my choice is not do I ignore them or not, how can I be aware of them, be sensitive to them, and then use them if they are there to better support my colleagues and to better support the shared mission and vision that we have, which is providing equitable palliative care access to all. And so I think that was a really important lesson of recognizing yes, if I show up, the minister might listen to me differently than my colleague who's been saying the exact same thing for 20 years. So, or I can know that, go in, find out exactly what it is that my colleagues and partners have been wanting, where they think the top priorities are, and then come in and make the statement and very clearly use the support that might come from someone being in the country and uh having it be applied and supported for our partners so that we can move forward. So I would say that's a really

important piece of being cognizant of how various power dynamics can play in global health. And uh, I think another piece is they are inevitable. There's gonna be misunderstandings. There's gonna be times I'm trying to be aware of them and I'm gonna stump in the mud and say something wrong or not realize that there was another dynamic that I didn't realize. So again, investing in really deep longitudinal um partnerships. And then we often say friendships, because for many of them they have become friendships, so that when I do have an idea, my they feel comfortable enough to say, Mark, that's a dumb idea. That's not gonna work here. Or I can bring something and say, hey, this has worked in these three other places. Help me talk through or let's think through if this would work here. And if not, help me learn why so I can now learn more about this context. So I would say being aware that those dynamics exist, whether you want to acknowledge them or not, and it's a luxury to not acknowledge them. And then also building trusting enough relationships that you can have honest conversations when misunderstandings occur, or where expectations or overall goals might be slightly different so that you can discuss them.

Chris Comeaux 13:01

Very cool. I'm so glad I asked you that question. So if you were advising American hospice powder care leaders preparing for the next, let's say, 10 to 12 years, what lessons from global powder care would you say are most urgent for us to embrace now? And I want to throw a little add in there, Mark, that I thought of as I was hearing you talk. You know, one of the challenges, I remember sitting with, again, when we went to England and we were sitting with the folks from St. Christopher's in London, and we were just lamenting that the word hospice has become synonymous with death, and how that word becomes a barrier to us getting care to people. And I remember the guys from St. Christopher who are incredible, but they were saying, well, I think we got to educate people more. And I remember just sitting there going, but you guys are the guys that created it. I don't think we intentionally educated them. It just happened that we become synonymous with death. And quite like unfortunately, our political discourse in our country, pick your side, and I just automatically assume you're in whatever corner, is like this automatic barrier goes up and we can't communicate in our political discourse. In a way, when you equal hospice equals death, uh, I'm death adverse. And so then we go to health care and serious illness and we create all these other words to kind of get around that barrier. If there's any lesson that you've seen also globally that you could weave into that answer, I'd love for you to weave

Leadership Power Dynamics And Partnerships

Chris Comeaux 14:22

that in.

Dr. Mark Stoltenberg 14:22
It's a good question. Um, so if I could give advice to any leaders, I think I would say having seen what this can look like when you're in big integrated systems, because most of these countries are that, I think we absolutely need population health level strategies for how we're gonna do this. And we need to move more towards integrated serious illness care for our patients. Um, and I think how we're gonna get there is gonna be slightly different in different places. Um, but I think the older model of the hospice carve out, the way it was legislated, the way that it's been written, I don't know is meeting the needs of our patients as well as it could. Um, and how we're gonna get there and move towards the future where both the legislation changes and what we're able to do, it will be complicated. But if I had to say anything, it's having a top-down approach of where do we want to get? What do we want the experience of a patient with a progressing heart failure or a new diagnosis of metastatic cancer? What will we ideally want that to look like? What would be the best possible care? So the best curative intervention so they can live as long as they can, and then the best transitions when we're not quite sure, and then the best support for maximizing comfort and other things either at home or in facilities, depending on what the patient wants. I think we can work towards that. And I think the other piece is in some places that might be one big integrated health system. I also think we're likely going to need an ecosystem of good partners, of nonprofit partners that are coming together to say our goal is to make sure that this sort of community or this neighborhood has what it needs. So I think working towards having a population level strategy of how nonprofit partners can be coming together to try to meet the needs of patients, I think that's probably would be a core thing that I would suggest.

Chris Comeaux 16:02
Okay. Do you want to address my challenge of the linguistic challenge?

Dr. Mark Stoltenberg 16:06
How do you describe it? Sure. Yeah.

Chris Comeaux 16:08
But I usually make the joke like everybody wants to go to heaven, nobody wants to die. That's the way of encapsulating that linguistic barrier, hospice equals death.

Dr. Mark Stoltenberg 16:17
So I think a couple of things. So I think the challenge is this challenge is common all over the world. So anytime that you're delivering care that is largely targeting people near the end of life, whatever you call it, people start to perceive that's what the service is. And so I

think it can come with those negative connotations. So I think um, and I will often say for certain patients that uh have a understanding of hospice or things that I don't think are accurate to what it is today, and it's preventing them from getting care. Me using that word is actually causing them to be more confused, not clearer. So I think we can be flexible and call ourselves supportive care. We can call ourselves um a comfort care team or a quality of life team. I think what matters is then how we're describing it to the patient, what we're doing. And I think one of the most important ways that I think we can be both in our practices and then ultimately perceived as the serious illness team and not just the end of life team is I think we need better integrated systems where you start working with our teams while you're still continuing to maximize both quantity of time and quality. And we become just also the team members that start to do more and more as the interventions that we're doing that could potentially get quantity are being less and less helpful or potentially harming you more. I think the more that patients perceive us that this is just one big integrated way of maximizing quality of life, no matter what happens in the face of your serious illness, unless we're the team that comes in when everything else has stopped working or where now it's time to focus on dying, I think we will be better received.

Chris Comeaux 17:45

I didn't tell you I was going to ask you this question, but you've been so fascinating to listen to you talk. This one occurred to me. Um, we were talking about that whole thing about preserve the core, stimuli progress. And I have an article uh when it wasn't called CMS back in the day, it was actually called HICFA. So it was the actual head of what is now CMS, a guy named Tom Hoyer. And he wrote this amazing article, and it's like really old. It's like been photocopied so many times, it's like sideways. And I've got it, and I've actually shared it with several people, including the current chief operating officer of CMS. But in that article, he talks about the history of the benefit. And one thing that was critical in their design was the election of the benefit and listening to you talk. So when you elect the hospice benefit, you are foregoing aggressive curative care. And that was a critical design. It wasn't a bug, it actually was a feature. And so I wonder listening to you and all of the exposure

Hospice Language And Integrated Serious Illness Care

Chris Comeaux 18:41

that you get internationally, but you come back to the states and you know, every day we have this new treatment, this new thing, and all the technology, which more so probably in the states compared to other places that are maybe lower income countries. And if we go into this future where we design the future of the benefit, if we eliminate that, I

wonder if we're going to come back and go, we actually pulled out one of the key linchpins that allowed us to do the most amazing work at the end, because when you elect the benefit, now it shouldn't be probably two or three years. It might only be a 60 or 90-day length of stay. And so push back on that if you disagree. Does my question make sense?

Dr. Mark Stoltenberg 19:20
It makes complete sense. Uh, and I think I have a clear answer for it. So, um, one, my understanding, talking to some of the folks that were in the room back in the 80s that were making this decision, all of the demonstration projects for hospice were for concurrent care. So it was never meant to be a carve out. And when it was presented to the Reagan administration at the time, the it was felt that it was going to be too expensive, and this was a way to cut costs. Um, the the quote was they can't have their cake and eat it too. That's what it was quoted to me. So I will throw that out there to be controversial, but that had been shared with me that that was a good thing.

Chris Comeaux 19:51
That's good because that's not in the article. So that's actually really good.

Dr. Mark Stoltenberg 19:54
Um, I will also say we are the only country in the entire world that I'm aware of. So I I have never heard of another country that hospice cannot be done concurrently with ongoing interventions for their care. Um, so and I I think after seeing what integrated palliative and hospice care looks like in many, many other countries, I think that was a lens that I brought back here. I think it is absolutely, I think it made it workable, maybe initially. I feel like now, and especially for non-cancer care and things like heart failure, non-concurrent care is not meeting the needs of our patients. Um, I think we will have to be very thoughtful about how that might be regulated, um, because there are a lot of challenges in the hospice community of how we're being regulated and the shift from nonprofit to for-profit hospices and how that would happen if we got rid of the no-concurrent care allowance. So I think those will be important things that policymakers much smarter than me will need to figure out. But I absolutely feel moving away from you have to move from your primary insurance to hospice, I think would be absolutely a brighter future for serious illness care in the United States.

Chris Comeaux 20:59
I'm so glad I asked you that question, Mark. Well, thank you. Well, after all the places you've worked, all the suffering you witnessed, what continues to give you hope about

the future of palliative care globally and here in the United States? And weave any final thoughts you want into that answer.

Dr. Mark Stoltenberg 21:13
That's great, Chris. Um, again, thank you so much for the opportunity to share a little bit about our work and to highlight some of our wonderful partners and the things that they've taught us. So I think what gives me hope is a couple of things. So, one, this work is just so profoundly beautiful. I think every day when I'm still on the palliative care unit and just sitting with our patients and talking through what the right plans are, I just have to pinch myself that this is what I get paid to do. And I know I'm not the only one that feels that way. We have stresses and things are getting harder and things are complicated, but the core of what we do is so deeply human and so deeply rewarding that that gives me hope because I know the thing at the core of our hurricane, as you were describing, is so incredibly valuable. So I would say that's the first piece. The second piece is I have had the opportunity to meet honest to God saints. Around the world. The founders of palliative care, the people that just decided in their own time were going to start responding to the suffering of patients because it was what the world and what their country or what their community needed. They are some of the most compassionate, creative, and also quick to laugh and fun people that I've met. So we also have this team of incredible humans around the globe. It's like a secret language that you go somewhere, you're like, oh, you do palliative care, and we immediately know this whole list of values that we share. And we all recognize we work really hard, but it's so we can enjoy the dinner on a Friday night because that's what we're fighting for for our families and for our patients. So we also know we should go out afterwards and talk about how fun this is and share about what's important in our own lives. Um, and then I think the last thing I would say is so I am deeply hopeful about palliative care. I am deeply hopeful about palliative care global leaders. I am deeply worried about the direction a lot of things globally are headed right now. I think politically we are seeing more wars. I I think the degree to which we're becoming

Hope, Big Tent Global Health, Closing

Dr. Mark Stoltenberg 22:59
polarized, that we're not listening to each other, the impacts of social media, the list goes on and on and on. Um, so that concerns me, but I'll connect to the first two things I'm saying. I am genuinely convinced what palliative care brings, this human connection, and especially if we aim towards global palliative care collaborations. I think this is a way to take what's best about humans of sitting with each other, bringing presence and focusing on dignity. And if we can start to connect across borders to share how we do that, how

you do that, how you can teach me how to do it better here. I really do believe we can be a meaningful, of course, not the only, and we're going to need a whole bunch of solutions, but we can be part of the solution of starting to pull our world together, trusting each other a little bit more and remembering why we're all here in the first place, and that we're all here together.

Chris Comeaux 23:46
Well said. Very well said. Feel free to use that Arnold Toynbee quote because it's got great implications this way.

Dr. Mark Stoltenberg 23:52
Yeah, I really like it.

Chris Comeaux 23:53
Yeah. Mark, I have a feeling. So if folks listen to this and like, I want to see if I could do something with Mark globally. Can uh can we include your email? Absolutely. Any links that you want, we're gonna get those from you. We're gonna put them in the show notes. Um, and if we could ever help you magnify the work you're doing, you please let us know because you're doing great work. You really are.

Dr. Mark Stoltenberg 24:14
Yeah, I would maybe the last thing I'll say, Chris, absolutely. I mean, we are very intentional. We want to have a big tent strategy for global health. Of course, we don't want people parachuting into communities they don't know, thinking they're gonna help for three days and come back. That's sort of an older version of global health we all want to move away from. But I also don't want it to be you're not welcome in this work unless you're gonna commit five years to it or you're gonna move somewhere. I think if your heart is saying, I want to learn more about this and I want to participate, I think we are aiming to build partnerships and infrastructure for people that can come and maybe dip their toes in the water. You probably won't help a lot. That's okay. You're coming to learn. You're coming to learn and better understand what's out there. And maybe over 10, that builds into a partnership and a friendship that projects can come out of. But I want to be intentional. We want to be big tent global health leaders that we want to welcome anyone who is interested that wants to get involved. We are committed to figuring out ways that folks can get involved because we need a world that is more connected.

Chris Comeaux 25:06
Very cool. Well, Mark, again, thank you. You're doing incredible work. You are a treasure. So glad you said yes to doing this. So again, thank you.

Dr. Mark Stoltenberg 25:13
Chris, thanks again for the opportunity. Really appreciate it.

Chris Comeaux 25:15
And to our listeners, we want to thank you. At the end of each episode, we always show a quote, a visual. The idea is to create a Brain Bookmark, a thought prodder, but our podcast subject to further your learning and growth and thereby your leadership. We're hoping it sticks like a brain tattoo. Be sure to subscribe to our channel. We don't want you to miss an episode. Pay this one forward, especially to your fringe or coworkers throughout the hospice and palliative care space. You know, it's easy for us to reel against the world and be frustrated by things. Let's be the change we wish to see in the world. So thanks for listening to TCN talks Anatomy of Leadership. And here's our Brain Bookmark to close today's show.

Jeff Haffner 25:48
Ultimately, we talk about how do we define palliative care? It is a response to suffering. Period. Full Stop. Thanks you USI for Sponsoring our podcast.