Transcript: Part Two | The Missing Middle in Healthcare—And Why It Matters

Jeff Haffner: 00:00
Welcome to TCNTalks and Anatomy of Leadership. We continue our conversation in part two of "The Missing Middle in Healthcare and Why it Matters" with our guest, Bridget Sumser and Sonya Dolan with Mettle Health. And now, here's Chris Comeaux.

Chris Comeaux: 00:24
Well, as we go into this next segment, it actually is another reason why, again, you were mentally in my space. You did not know it, Bridget, but I'm like working out, thinking about you guys when you're doing this podcast with Dr. Attia. And I was I was observing how you and BJ were navigating, speaking with a brilliant physician, but lives his world. I mean, his great book is Outlive, like how to live to the very end to be to thrive. And that, you know, length of life doesn't equal quality of life. And you're taking it in like a whole different realm. And I could tell like his lexicon didn't perfectly align with what maybe we're kind of jiving with very quickly because we've lived in this. I've got 30 years now in hospice empowered care. But all that to say that that's why this, the, the lexicon, the words, but also reinventing them. Um, I was uh in 2018, a group of us got to go to England and we met with the top hospice people in England, which is so cool, right? St. Christopher's in London. They are the the matriarchs, the patriarchs of this work. So, I'm sitting at a table with them, and one of them said, we got to educate people more. And I just had this moment where I sat there and was thinking, I think we have educated people, not intentionally, but that the word especially hospice has become synonymous with death. And that then defines people in a way that they just don't exactly agree with. Um, because number one, we this this innate desire to survive, but to truly live. And so, I think it creates it's create, we've done a beautiful job. More people have gotten care, but unfortunately, it's just created this interesting barrier that then we can't even enter into them when they probably need us the most. People quite often will say, we wish we would have chosen you sooner. Well, why did you not? I think part of it is that word

Chris Comeaux: 02:10
creates a barrier that I'm not sure we could even overcome. And so, so I love, again, what you guys are working on because I do think that the language has actually not served us well. And and it's not that we run away from what this concept of care. So, I'm just curious, uh it which I see Bridget smiling and wonder if you have a reaction to that.

Bridget Sumser: 02:30

Yeah, you know what it's bringing me back to is uh I was really, really fortunate to do um an interprofessional fellowship after my master's in social work and studied under Terry Altilio and was highly mentored by her. And I remember one of the physician fellows was um putting on his badge and he had covered up with a white sticker hospice from the hospice in palliative medicine part of his badge because he was getting such a negative response, right? He was going in to do a palliative care consult, and people were looking at his badge, and the hospice word sunk them, right? And so, we got into this whole conversation about, you know, some of our tendency or maybe not even a tendency, but the temptation to manipulate our own language in order to increase access.

Bridget Sumser: 03:25
Right. Oh, okay, I'll leave the hospice part out of my training. Or I won't say palliative care, I'll say supportive care, right? Like we've really created some conundrus for ourselves because of the implications of our language. And um, it's tricky. I think it creates conflict internally. I think it creates confusion for patients and families, and and you know, we belabor language intensely or labor around language intensely. And there aren't perfect words for these things that are cross-culturally appropriate and intergenerationally appropriate. It's just not a possible thing to actually do.

Chris Comeaux: 04:06
Yeah. I'm so glad you said actually the name Teleios. Um, Dr. Rich Payne, who maybe you guys may or may not know about, he's now passed on. He had a special weekend at the Duke at Duke School Divinity at the Dave Thomas Conference Center. And it was hospice leaders from all over the U.S. And his cool thing is he had this blackboard, and he would get on the blackboard, but he started the weekend and he wrote the word Teleios on the blackboard. And I'm like leaning forward and he said, This word means the purpose beyond the purpose. And I wrote it in the little mole skin that they gave us, and when we create it, now our interesting, unique way that I'm working with nonprofits all over the country, they said, What are we gonna call it? I'm like, I know exactly, because it's a really cool way to frame this work, but but you also kind of poke in something good, right, Bridget? We're limited by words, but yet as humans, we think in terms of pictures and concepts. And our English language is not as well suited as some other languages in the world that'll look a little bit more kind of pictorial based. Um, but high five for you guys. We'll keep both wrestling with the language and forever.

Bridget Sumser: 05:09
Yeah, forever

Sonya Dolan: 05:09
Yeah, let us know if you land on any solutions for that for sure. It's it comes up all the time. And what you said, Chris, made me realize that hospice is more synonymous with death than it is with care, which is an issue. That's what we think of versus this is support, this is guidance, this is care for me, versus this this place is death

Bridget Sumser: 05:28
is a how I die.

Sonya Dolan: 05:30
Yeah.

Chris Comeaux: 05:30
Yeah, which I share with you guys in the beginning of the show. This amazing woman who interviewed me, and kind of in my youthful arrogance, I was thinking, oh, you know, this frail olderly woman taught me in just one little statement that we finally reluctantly became hospice certified in '88, was teaching that lesson of there's this broad space of needs. I mean, she was like a huge fan of Kubla Ross, went to some amazing conferences, went to the very first hospice in America, actually was one of the first in North Carolina. She was just a dynamo, and she foresaw this in 1978,

Chris Comeaux: 06:06
actually, some of these challenges we're wrestling with today. So, anyway, I could go on and on about that. So, good segue. One of the critiques of modern healthcare is that it treats disease, dis-ease, but not the human experience of illness. What kinds of needs do you guys find patients and families have that the current healthcare system doesn't address? Or where are those gaps that you're addressing?

Bridget Sumser: 06:31
It's like big breath because there's so many. Um I think we could we could go down so many roads with this question, but I think um, and Sonya knows that this is sort of my bend. I feel like we do not do grief justice, right? We have, and it's part of why we think about illness, grief, and dying is that we have landed grief on the other side of death, right? We have sort of packaged it as the response to a death, to bereavement. We've made grief and bereavement synonymous. And I think that what we know about the experience of illness and bodies changing is that even before diagnosis, this is a grief process because something is different. And maybe we have the language for it, and maybe we don't, and maybe we get more precise in our understanding about what's

happening, but it kicks off perpetual change. And that might come rapidly, it might come over a decade, it might be highly anticipated. So, I think I think a lot about the way in which we serve the folks that come to us as a grief intervention and as a fundamental responsibility that we have to increase grief fluency in everyone, right? So that we can recognize, you know, so many times I've had the privilege of teaching grief loss and bereavement to social work students. And these beautiful, often young folks come to class, they're like, I don't know anything about this because I don't know anybody who's died. And my response to them is open the newspaper and read one headline and tell me what you feel in your body. That is a grief response most of the time. Right. And if we could collectively enhance how we identify grief, how we give ourselves space to express it, to share it with one another, culture would change massively. Right. So, I I think of a lot of this as grief, grief work. Um and I think that there's so much life there because I really hold dearly this idea that like the more grief we know, the more grief we make contact with, the more joy we know, the more beauty we can know, that these things sort of expand our capacities equally on both sides. Because some people hear me like, I get so energized talking about grief, and they're like, ugh, no, it's so scary.

Bridget Sumser: 09:05
And it's like, I promise, like its ok

Chris Comeaux: 09:08
oh, I've got a I've got a homework assignment for you now, Bridget. You have to go and watch The Madison.

Bridget Sumser: 09:15
Oh, I mean, I'm gonna binge it tonight.

Chris Comeaux: 09:16
Yeah, you're gonna have to binge it tonight and let me know what you think. Because I think in some respects they did a brilliant way of like, I love your analogy, go read the newspaper, but they do such a beautiful storytelling and suck you in with the characters. The setting is amazing. In fact, there are a lot my wife will not watch a show if she knows the end is bad. This is one she binge watched, which with me, and she even told someone else, I usually don't like sad shows, but it just sucks you in in a beautiful way. And there's several storylines throughout that are basically introducing you to their grief.

Bridget Sumser: 09:47

I think this is also the beautiful thing about the zeitgeist of the moment, which is that there's a lot of stuff out there. A lot of people are trying to get personal story and fictional story out into the world to say, like, this is happening.

Chris Comeaux: 10:01
Yeah.

Bridget Sumser: 10:01
It's happening collectively, you know, wherever you sit politically, um, even just in the in the wake of the pandemic, right? We all had this massive grief experience, this massive loss experience, even if no one you knew died, because of the radical nature in which our lives changed for a period of time. And we still haven't made sense of that. Like we haven't found collective language to talk about what that was and how we adapted and adjusted and how scared we were and how it continues to inform our lives. Like we all we all have current proximal experience to this.

Sonya Dolan: 10:39
Yeah. And I think, you know, what Bridget's pulling out about the grief piece applies to your question, Chris, about um treating the illness versus how we kind of think about the person as the center of the care versus the illness. So, I think about it often of like, you could have 73-year-old woman who's had children, who's seen her grandchildren, who's watched everybody get married, has had a beautiful marriage, receive a stage four cancer diagnoses. Her griefs of what she's going to miss in the rest of her life, what she hasn't done, are very different than 29-year-old mother with two young children who has much life to live. Those griefs are completely different. The things that they are going to think about, the losses are different. And those losses need to be tended to differently. While healthcare is saying, I'm going to treat your disease. Your disease is the same. You both have the same disease. I'm going to give you the same treatment. This is how we treat your cancer. And there needs to be a place for people to come with their unique experience and griefs so that we can tend to those as well. So that's kind of the opposite of how we see it.

Chris Comeaux: 11:44
Good deal. Well, I want to definitely want to ask you this. And good thing is, our show has really gotten traction over the past year. So there are a lot of people listening. And I really do listen to feedback and it listen to the kudos, but also listen to the criticisms. And there are a lot of our listeners that think that my job is just to affirm hospice. I love the hospice model. I've grown up in this model. I love what Bridget
said in the first part of the show. There's so much of positive impacts now, even from healthcare, that we have impacted, like team-based care and things that we really were

the pioneers in. But I think you guys are you're addressing some of the gaps that maybe we never could have anticipated. So from what you're seeing on the ground, what lessons might hot leaders, and we got a lot of good people at the actual bedside listen as well, what what might they learn from a model like Mettle Health? Kind of speak to them a little bit.

Bridget Sumser: 12:38
That's such a humbling question.

Sonya Dolan: 12:40
Yeah. Yeah, absolutely. You know, it's people that we think of as like partners in our care, you know, instead of verses, like we really want to create something that, that everyone working within healthcare feels like we are also in connection with them, not in competition, not we're better than or, you know, we're doing it differently, and that's the way to go. So, it can be hard to think about, you know, what um what places should do differently. I think for me, it comes down a lot to it's things that they wish they could do. You know, like I don't think any hospice out there is thinking, like, oh, I don't need to do anything else. Like we're set, everything's wonderful. It's resources and people and ability and regulatory burden and all of these things that I think make it difficult to expand on the care that is provided, to expand thinking on how things are provided. And we have the privilege of being outside of the space and getting to be curious about what we could do differently. Um, so I I tend to think of this question, I'm like, yeah, more caregiver stuff. But then I think, you know, how does how does that get implemented? Who are the people who would do that within those hospice spaces? So, there's, you know, there's the I know that most places would love to do more things, you know, for caregiver groups, for the people who are attending to the patients who are dying. And it's hard. So, I just want to recognize that too, is like we get to make this thing that the way that we want to because we're outside of the healthcare system, but there's a lot of there's a lot of regulatory and restriction within that makes it difficult.

Bridget Sumser: 14:12
I think, you know, um, I've thought about this story you've shared a few times about this woman who sort of hesitantly made her hospice in 1988 on some level, like a verified hospice. And I imagine that part of what they had to give up in that process was the way in which original hospice teams jumped into the Jeep together, right? Like Ira Byock has all of those stories, went to the house and folded into community, right? Folded into family, right? And I think hospice is overwhelmingly the best benefit and entitlement that Americans have, healthcare wise, I think. And it's not what we need, right? We need community. Like dying happens in community. Dying happens with

many people from different stations of life wrapping around a person, wrapping around a family, wrapping around a couple. Hospices are not positioned to do that, right? So I think, and honestly, Mettle's not positioned to do that because what we need to do is sort of re-stitch together the way in which this is a community happening, that it's held in community, it's recognized in community, in in perpetuity. Um, and so I think all of us need to be thinking about how does every single person start to build the skill and the capacity to show up for one another. Right. Because hospice will have its place in symptom management, in in education, in beautiful support. And what happens in between? It also won't be us, right? We will be a layer that helps to weave the in-between together. But the in-between happens with moms from school and folks from church and your next-door neighbor and your upstairs neighbor that realizes you haven't left your house in a couple of days. Like that's that's where the bulk of care will come from, especially in the coming decades with the with the sort of population demographic change. And that's the work we need to do together.

Chris Comeaux: 16:24
Yeah, well said again. I'm so glad we've done this show because uh my theory was that um, in fact, we had Dr. Byock on um right before Christmas, and it was like meant to be a gift to the hospice and palliative care field, almost like just Dr. Byock speaking to the field. Because as you know, he's very concerned. He wrote the strategic framework out of that care and just zealousness that we need to make sure, because there's some warning signs where this thing is not going in a good way. But you also just brought something to the surface, Bridget, that I'm realizing in a moment I may have been raised in a hospice that we believed part of our job was to stitch the community, not in an arrogant way, but in a humble way that we're a facilitator of sorts of that. And I just realized that it's just part of the way I think in a lot of the hospices we work with, again, it's not from this arrogant space. It's just more of a space of this event of someone's demise, just it does bring people together, unlike many other things in life. And actually, again, you're really gonna want to go right watch The Madison because they do depict that part beautifully. It's rough to get there, but if you stick through it, you start to see like death does break through barriers that things in life just don't help us come together in certain ways. And then there's societal things now that are community is disintegrating in many respects, but there's something about death that creates a necessity that people in a good hospice, especially the ones I'm fond of, community-based nonprofit hospices, can be like conductors of the orchestra in certain ways for that to occur. And I never realized till this moment that that that lady who was the matriarch, that was part of her ethos that she believed. And she like put that kernel in that culture that I later inherited. Now there's another amazing CEO's taking it forward. But I do think a lot of community-based hospices, I think, but you're also

poking on there's some warning signs because there's a lot of the regs and the no-margin, no mission stuff that has pulled people, I think, away from that. Are you kidding me? I got documentation issues and EMR issues, and I got 20 patients I gotta go see, and this dude's talking about community.

Bridget Sumser: 18:36
Totally. Totally. I mean, the pressures are really real. And I appreciate your nod just back to like this is the stuff of what hospice, many hospices still are, and what hospice is meant to be, which is like the sort of interstitial mending.

Bridget Sumser: 18:51
Right. Yeah.

Chris Comeaux: 18:53
And the other thing that strikes me just talking to you two ladies, that Dr. Byock actually said, I can't remember what year it was in the early days of hospice. They had like almost like a retreat, it wasn't a true conference in Colorado, and they were sitting around the campfire envisioning a day that there would be textbooks and people actually specializing in this. And like now, right? We and but then the thing that was kind of hitting me when I was listening to him is what are we dreaming about? And I feel like you are poking on, you know, that spirit of dream and innovation is what's created this thing. And you're not coming at it from a standpoint of, well, this is wrong, this is wrong. You're just seeing a need where there are gaps. So, here's a good segue to as we're gonna land the plane in one of our final couple questions. Fast forward 10 years from now, what would success look like? How would you hope the landscape of serious illness care evolves so people get the kind of care that Mettle is providing?

Sonya Dolan: 19:46
Yeah. Ooh, so many. So many. I mean, I can speak to like the actual mettleness of it, and then there's the, you know, our entire society of it. Like, I hope that we become a space where people go just to get a hit of support and accompaniment in whatever way feels appropriate for them. Like, I would love to be known as the space where whatever you might be coping with, you know that this is a safe spot to go, to get information, to get help, to talk to someone else who understands it and to feel like you have a place to go to do that, that this is just recognized as a spot to go talk about mortality, to talk about the stuff of life and death, that this is a safe space for that. And to Bridget's point about a complete change in society around communities and people, that we can help influence those people who come to us to also speak to their friends and their family and their communities and start to build what we were talking about earlier, a lexicon, a vocabulary, a shared experience, that this is a human experience,

this is not a medical experience, and that we can show up for each other in these moments in ways that feel really, really beautiful and helpful. And it can look like sitting next to somebody and not saying anything, that there is not an insane intervention that needs to happen, that our humanity and how we show up for people is actually a quote unquote intervention, that that's something that everyone can do. So, to envision a world, a united states where this isn't understood, like there are griefs everywhere. There's grief everywhere, there's loss everywhere, and we can show up for each other and support each other in that. And then just, you know, across infrastructure, I would love a day when death doulas are much more integrated into care and that places like us who operate as a virtual accompaniment space can point to more support in someone's geographical area and say, great, we're gonna talk about this here. And then there's this is how you can get this care into your home, that there's more of that, that there's more stitching together as places like hospitals close and clinics close. Who are gonna be these people who hold you in those illness moments, in those end-of-life moments, in those grief moments? So, there's other. You know, places that are building this type of care. And our my hope is that we as palliative hospice mortality people can start to link ourselves more versus being different silos and start to build, you know, like a quilt of connection for everyone where they understand where that connection is available to them.

Bridget Sumser: 22:21
I'm so curious about the next decade. I feel like there is a tremendous, a tremendous amount is going to change. I think when I think about metal and I dream about metal, what I hope for us in 10 years is that we are a very well-known resource for folks across culture, that we've sort of really get our hands around how do we meet anyone who walks in our door and respond to their the moment that they're in in their life. And one thing that we know is that that will not be by only one-on-one Zoom calls, right? That that people need different things at different moments. And that can b

Bridget Sumser: 23:05
b ite-sized information, that can be created spaces with other folks and similar experiences with them. That can be the opportunity for peer-to-peer mentorship, right? But that we are really a facilitator across cultures of people getting the type of information connection and care that they need. Because if we don't, like we gotta. And I know it's scary, and I know it's intimidating, and like we are the folks that should be leading that charge because we think about whole people, because we think about the context of real lives, because we think about the implication of bias.

Chris Comeaux: 24:24

You'd love this, Bridget. I was we have a we do a top news story of the month podcast, and I was doing it with Cordt Kassner, and I kind of was in the moment inspiration, and we were kind of joking about you know, Terminator and the AI supposed to kill us off. And I said, if we use AI in root ways that you just talked about, maybe we'll teach the AI that we actually should survive with them, actually. Um, if you take them into the context of even advanced directives and you know, people's hopes and dreams, you'd be teaching the language model at the same time, the beauty of this life in this world and people's internal passions and unique purpose and giftedness. And then maybe the Terminator won't off uh off us off as some of the uh minds that say the scary part of AI. Well, ladies, final thoughts.

Sonya Dolan: 25:09
So many. I mean, the old I'm gonna I'm gonna add one note to the 10-year plan is on a frivolous but also beautiful idea. I would love to see us celebrate ourselves. And I when I say again with Bridget saying, the collective us, like the people doing this work, the people caring for people, the Oscars of hospice and palliative care and illness, like there needs to be more here, I think, for us that we also recognize each other. I would love, I would love that in the future. That's not my final thought though. I want a better final thought.

Bridget Sumser: 25:42
I I guess I want to end with a final thought that's like, and I'm articulating this on the spot, so it probably won't come out perfectly, but like I want for all of us to be really audacious in our dreaming of how this could be more beautiful. Right? Like, which is bold. It is bold in this moment in time to think that that's a possibility when so many of us spend so much time, personal time, after hours time, trying to band-aid huge gaps and huge cracks and um make meaningful difference in individual lives. And I think many of us, there's a great moral distress about the state of um the world and the state of healthcare. And can we carve out some time every day to think about like how beautiful could this be?

Chris Comeaux: 26:32
That's a really good final thought. And that whenever again in our conversation with Dr. Byock, that to me is the type of spirit that we need more these days than oh, doing all these audits suck and you know, all the fraud, some of the fraud stuff that's got national headlines. That's not that's the spirit that we need going forward. So, hi five, Bridget. Sonya, you any other final thoughts?

Sonya Dolan: 26:55

Yeah, I think my final thought, and I'm gonna represent the people who aren't clinical people here, um, as someone who doesn't come from a healthcare background, is the reason I have come to love hospice and palliative care so much is because much of what I see coming from those um practitioners and clinicians is stuff that any of us can access, that it's about conversation, it's about accompaniment, it's about meeting someone where they are, it's about seeing them, hearing them, and witnessing them. And I find the fact that I can access that, that a librarian can access that, that your neighbor can access that, something really beautiful about this care. And it just leads more into why the community piece of it is so important. That we can, we can build these muscles in ourselves. Like we can take a lot of the learnings from hospice and palliative care and apply them to our everyday lives. And there's something in that that I think is so wonderful and amazing that links all of us to this. So that's that's my final thought as just someone who comes at it from a non-clinical background, is it's beautiful because it's there for each of us. We can we can all learn to accompany people in a different way, to make space for the hard stuff to sit with them, to help them cope. Um, and we can all build additional muscles in the process. Like we all get to learn from each other. So yeah.

Chris Comeaux: 28:13
That's well, thank you, ladies. This was I really enjoyed this. Thank you. Um tell BJ, tell BJ I said hi, and thank you for giving both of you the time. To our listeners, we want to thank you. At the end of each episode, we give you a quote, a visual. We actually call it our Brain Bookmark. The idea is to be a thought prodder about our podcast subject to further your learning. We're going for a brain tattoo. We're hoping that it sticks. Please be sure to subscribe to our channel. We're also going to ask Bridget and Sonya any links they want to include. We're going to include those as well. Tell your friends, your family, your coworkers about our podcast. You know, it's easy for us to rail against the world and be frustrated by things. Let's be the change that we wish to see in the world. I feel like that's what Bridget called us to with her final thoughts. So thanks for listening to TCNTalks / Anatomy of Leadership. And here's our Brain Bookmark to close today's show.

Jeff Haffner: 29:00
"The most meaningful care happens in the in-between moments" by Bridget Sumser. "We're not here to fix you, we're here to help you build the muscle to endure" by Sonya Dolan.

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