

Dr. Lynn McPherson:

Hello, this is Dr. Lynn McPherson and welcome to Palliative Care Chat, the podcast brought to you by the Online Master of Science and Graduate Certificate Program at the University of Maryland.

Dr. Lynn McPherson:

I am very, very excited to introduce our guest today, Dr. Joe Rotella, who is the Chief Medical Officer for the American Academy of Hospice and Palliative Medicine. He self-describes himself as a medical humanist. He's also an outstanding hospice and palliative care physician. And I have to tell you, he makes my personal shortlist of one of the nicest people in the universe. So Dr. Rotella, welcome. How are you today?

Dr. Joe Rotella:

Well I'm doing very well, and thanks so much for having me.

Dr. Lynn McPherson:

Absolutely. We're delighted that you're here. So let's jump right in here. I think I was sharing with you before we started recording that I hear on TV, "We're all in the same boat," but I've also heard, and it makes sense to me, we're really not all in the same boat, we're all in the same storm because I know the view from my boat, where I'm sitting at home, looks a lot differently from a doctor or a nurse or a respiratory therapist in the COVID ICU. So I'm sure you share the same sentiment, that we're all kind of having a different experience here.

Dr. Joe Rotella:

Well I agree. I think that's actually a really important point. In some ways, we are all in this together. I don't think there's anybody who's not touched by this. Our home and work lives have been impacted. Some of us have actually had to deal with the illness directly. And some folks are in places that are real hotspots, other folks are in places that are prepared and waiting for a surge that may not be coming.

Dr. Joe Rotella:

So the fact is that we can probably all share a sense that things have changed. They've changed really fast. A sense of maybe worry or dread, a sense of sadness or grief for things that have changed and things we may not get back anytime soon, but we're not all having the same experience at the same time.

Dr. Lynn McPherson:

Right.

Dr. Joe Rotella:

And particularly when I think about representing an association that has over 5000 professional members, I have to keep reminding myself that it's not the same experience for all of us.

Dr. Lynn McPherson:

Sure.

Dr. Joe Rotella:

And I think about myself, and I learned something as the outbreak sort of crashed over us, and that is that I could identify with many, many things. I could identify myself as an association leader, I could identify myself as somebody with some business experience and expertise, but when this happens, you sort of find out where your primary allegiance is. And for me, it's being a doctor, and it's being a palliative care doctor.

Dr. Joe Rotella:

And my heart just immediately went out to all the frontline healthcare workers and to the people and families that are coping with, or trying to manage this illness. And yet, I'm not a frontline palliative care doctor anymore, and so this creates a tension in me, which is, am I doing enough? And it seems like we can't possibly do enough, particularly when we hear from our colleagues in places where it has become overwhelming, places like New York City-

Dr. Lynn McPherson:

Right.

Dr. Joe Rotella:

Where hospitals are just full of COVID patients on ventilators. And I have to deal with this personal tension between am I doing enough and what's my role? How can I contribute? And we don't all contribute the same way. Some of us are clinicians, some of us are program leaders, some of us are educators or researchers. We all have our part, but discerning what is my part and how can I do enough I think is a real challenge in a time like this.

Dr. Lynn McPherson:

Well, of course, I think we would both agree that AAHPM is a leader in hospice and palliative care. So how would you describe what is the role or responsibility of a leading organization in this crisis?

Dr. Joe Rotella:

Well, the Academy really had a challenge when the outbreak burst on us. Firstly, we had had to make the very difficult decision, along with the Hospice and Palliative Nurses' Association, to cancel our big annual assembly, which is really the marquee event for the hospice and palliative care community.

Dr. Lynn McPherson:

Right.

Dr. Joe Rotella:

We spend years preparing each annual meeting. And that had to be done in a very thoughtful way. We were going to hold the meeting if we could do so safely. And there's so much financial liability around a big meeting like that, that you have to be very careful in how you make that decision and how you navigate.

Dr. Joe Rotella:

So we had to focus on that. At the same time, all of our staff and many of our volunteers and leaders were suddenly moving to working from home or they were taking on brand new roles in response to the

pandemic. And then we had to see what could we do right away to meet the needs of our members and the needs of the public responding to a pandemic.

Dr. Joe Rotella:

And our initial response really focused on three things. First, combing through all the information, resources and tools that are available to find the best ones and make sure that those were available to professionals in hospice and palliative care, and in medicine in general. It doesn't help to drown people in a hundred resources. One thing we learned in associations is that people appreciate curated information, information that's been vetted and that's reliable and trustworthy. So the first goal was to make sure that we could create a resource page and connect folks to the best tools, resources, and information.

Dr. Joe Rotella:

The second was to recognize that particularly at a time when things are changing so fast, we, the professionals, need to connect with each other. We need to be able to talk to our peers who might be experiencing something different than what we're experiencing in our community, where we could share observations, even provide emotional support to each other. And that needs to be a safe place where you don't have the media or attorneys or other folks involved.

Dr. Joe Rotella:

And that's where we found that we were really able to use our Connect platform, which is for our members. And where we would have, at the assembly, had our special interest groups and other communities would have had their annual in person meetings, we quickly pivoted to a series of Zoom meetings that allowed those communities to continue to meet. And no surprise, mostly we talked about everyone's response to COVID.

Dr. Joe Rotella:

So the third area besides connecting people to information and resources and tools and connecting them to each other is that we would be able to advocate for their immediate needs. And in particular, we work with a lot of coalitions, including the National Coalition for Hospice and Palliative Care. We have strong relationships with the Council of Medical Specialty Society, the American Medical Association, other medical societies, and we work through coalitions because when we can join a larger group of folks aligned around a key issue for our members, it really amplifies our voice.

Dr. Joe Rotella:

And it was very clear early in this pandemic that there were some things that really needed to change if our members and others in the field were going to be able to care for people with serious illness, with COVID or not, and do it safely. And the first was this terrible shortage of personal protective equipment.

Dr. Lynn McPherson:

Yeah. That was so brutal.

Dr. Joe Rotella:

Yeah, brutal, and still is, you know, the lack of testing, potential medication shortages, but also things like the flexibility to use telehealth and making sure that there's going to be financial supports in place for hospices and physicians' practices.

Dr. Joe Rotella:

And so this has been unprecedented time for advocacy. I don't think I've seen in my five years so many sign-on letters, so many opportunities to reach out to CMS, to reach out to Congress, to reach out to administration leaders to advocate for what we need. And we've been pretty successful. I mean, for one example, hospice has really needed the flexibility to perform many of their visits, including the administrative face-to-face visit, through a telehealth mechanism. And we were happy that we were able to get that. It's going to be interesting to see what happens when Medicare tries to put the genie back in the bottle and the emergency is declared over. Some of the things that have happened I think are going to be hard to undo.

Dr. Lynn McPherson:

Sure. Like putting the toothpaste back in the tube, right?

Dr. Joe Rotella:

Right. Or it's like once you've opened Pandora's box, and probably the biggest one in that area is around the use of telehealth. Telehealth was driven partly by the lack of personal protective equipment, that it's actually unsafe for patients and staff to make visits that are not totally medically necessary, that don't have to be physical visits, and the fact that the visitation has been limited in facilities and hospitals. So we've often thought telehealth would be part of the answer of the future and we've been advocating it for a long time, but I didn't think we would be doing it in the ICU-

Dr. Lynn McPherson:

Right.

Dr. Joe Rotella:

That you would have somebody doing a telehealth visit, you know, connecting a family member to a sick patient in the ICU with a tablet computer. Boy, things change fast.

Dr. Lynn McPherson:

And I think that's one of the most brutal things is you watch these heartrending video clips on TV of a nurse in the ICU holding up an iPhone, doing FaceTime between the patient and their family so they can say goodbye, and the nurse is crying hysterically. And of course I'm sitting at home crying hysterically watching the nurse cry. You know, I always, I'm sure you agree with me, that Dr. von Gunten has described primary, secondary and tertiary palliative care skills, and I've long been an advocate that every healthcare professional should possess primary palliative care skills, but I think certainly at this point in time, this has become extraordinarily clear.

Dr. Lynn McPherson:

So when we think about that poor nurse doing that FaceTime call, when you think about these primary palliative care skills and think about the resources that the Academy has posted here, what do you think

are the most pressing needs of practitioners today from a palliative care standpoint? Like having that [inaudible 00:11:53] like goals of care conversations. What do you think?

Dr. Joe Rotella:

Well, it turns out that communication and symptom management, which have really been sort of the cornerstones of what we do as palliative care teams, have never been more important. And so when I think of communication, sometimes I think of sort of the different phases of it, advanced care planning being something we can do in advance of a crisis. It's never been more important for people with serious illness and those who are just at risk of getting COVID to have those conversations, and they don't necessarily have to be with palliative care experts or specialists. We acknowledge that we don't have the workforce to provide this at a specialty level across the board.

Dr. Joe Rotella:

So among the tools that we've seen people really reaching for are these sort of quick communication guides around how to have an advanced care planning discussion. And in this era of COVID, we actually are having people interested in just COVID-specific conversations, like, "Well, I've already done my living will and advanced directive and I've chosen my healthcare surrogate and made all that clear, but if I actually get COVID and become critically ill, that's actually a different scenario than six months from now if my cancer gets worse."

Dr. Joe Rotella:

So we actually have people clamoring for COVID-specific tools. You know, my thoughts about whether I'd want to go in a hospital and be on a ventilator if I'm COVID-positive and 85 and have three chronic conditions might be a whole lot different than my thoughts about whether I want to go to the hospital if my diabetes and heart failure got a little worse.

Dr. Lynn McPherson:

Sure.

Dr. Joe Rotella:

So we see that that real kind of COVID-specific communication tools.

Dr. Joe Rotella:

And in this all hands on deck situation, particularly in places that are hotspots, we see that the palliative care specialists are spread thin. In some places, they've created hotlines so that they can give, just in time, clinician to clinician support to their colleagues who may not have had any palliative care training, but now need to have these tough conversations or figure out how to manage shortness of breath. We've seen long distance volunteering where palliative care teams have provided direct patient consults through telehealth. So you could have a team in San Francisco providing support in a New York hospital.

Dr. Joe Rotella:

The innovation in the last few weeks has been absolutely phenomenal and I've been so proud of how people have been creative and committed to doing what we can.

Dr. Joe Rotella:

Behind all of this though, there's just this tremendous emotional toll. So I get to listen on these community calls with say our Hospice Medicine Council or our Academic Palliative Medicine Council or some of our special interests groups. I hear what people are saying from around the country, whether they're in hotspots or not, and there's a tremendous amount of fatigue. People are tired, they're worn out. In some places, we're feeling grief. Even the experienced palliative care doctors in hotspots are saying they've never experienced that intensity of suffering and death and dying in their careers. And I am a little concerned about the mental health wave that's going to follow this and is already starting-

Dr. Lynn McPherson:

Yeah.

Dr. Joe Rotella:

The wave of grief, the wave of moral distress, the wave of secondary trauma.

Dr. Lynn McPherson:

Yeah.

Dr. Joe Rotella:

And I guess to punctuate that, I'm really heartbroken this morning to see in the news that there was an emergency department physician in New York City who had been part of the COVID response who died by suicide.

Dr. Lynn McPherson:

Oh, no.

Dr. Joe Rotella:

And it's taking its toll-

Dr. Lynn McPherson:

Yeah.

Dr. Joe Rotella:

Not just on patients and families, but on healthcare providers.

Dr. Lynn McPherson:

Yeah.

Dr. Joe Rotella:

So yeah, we need to give everybody sort of, as quickly as possible, the basic communication skills, the basic symptom management, the essentials of that, but we also need to immediately support them because this is a hard thing for healthcare providers to go through.

Dr. Lynn McPherson:

Sure. And then looking at your webpage, and also I want to stress that this is not all hidden behind a members only wall, this is widely available, freely available on the internet. Not only do you have a whole section for clinicians, you have resources for educators, researchers, I love the team and self-care, telehealth, ethics and for partnering organizations. So really kind of span the waterfront there. I think that's amazing.

Dr. Lynn McPherson:

And you did mention what comes next. You're talking about the mental health issues. My personal example there is I was emailing a good friend who owns a needle point store and I am a rabid needle pointer, and I had started this extremely elaborate Christmas stocking for my brand new little grandson, but I stopped working on it because it's too hard. So I have defaulted to going to easier projects and I told her, I said, "I've got to get back to that stocking." And she's like, "Take it easy on yourself. We're going through a tough time. It's hard to concentrate." And I think we forget that. I think that even though I'm in a pretty good boat right now, this is hard. Do you agree?

Dr. Joe Rotella:

Oh, absolutely. And it's funny, we can hold two feelings at the same time, right? We understand this in palliative care.

Dr. Lynn McPherson:

Yeah.

Dr. Joe Rotella:

So on the one hand, I can feel a tremendous gratitude that the boat I'm in, as we're weathering this storm, is solid. I'm used to working from home. I've never been more productive. I'm physically healthy. I'm not on the frontlines getting battered. I have everything I need. I can look out the window and see a bird on the bird feeder and still appreciate the beauty of nature, and I can really say I feel gratitude and don't take any of that for granted. And then at the same time, I can be aware that I'm anxious, that I'm sad, that I wonder if I'm doing enough, that I am susceptible to survivor guilt. Every time I hear about a frontline healthcare worker who gets sick or can't find PPE or who dies, I feel a personal responsibility for them.

Dr. Lynn McPherson:

Sure.

Dr. Joe Rotella:

And so, we can be in a solid boat and still be stressed.

Dr. Lynn McPherson:

Absolutely.

Dr. Joe Rotella:

And not only is this a time that calls for kindness and compassion for everyone, it calls for it for ourselves. And so, I'm not surprised that you don't actually have the mental and emotional energy to do a really hard project.

Dr. Lynn McPherson:

Yeah.

Dr. Joe Rotella:

I don't think it's ever been more important for us to pace ourselves. This feels like a sprint, but it's not a sprint, it's a marathon.

Dr. Lynn McPherson:

Absolutely.

Dr. Joe Rotella:

The virus isn't going to dry up and blow away in a couple of weeks. We're not going to have a vaccine right away. This problem won't be solved, and if we're going to be able to do our part over the long haul, we have to take care of ourselves.

Dr. Lynn McPherson:

Yeah, absolutely.

Dr. Joe Rotella:

And we need to take care of each other. I am worried about, I mean, worry is a natural feeling right now, nothing unusual about that, but I am aware that we have this initial response, but we're going to be responding to an evolving crisis. And it's already starting to change. In the first few weeks of this, it's how are we going to prevent a surge or manage a surge? How do we plan and get ready? But now we're already starting to see, in some of the hotspots, there are a number of patients that have gone on ventilators who have neither died, nor have they been successfully extubated, and now they've had a tracheostomy placed and they're becoming longer term ventilator patients. And it turns out that we don't have any place for them to go.

Dr. Lynn McPherson:

Yikes.

Dr. Joe Rotella:

So there's going to be this next wave of folks that have residual and longterm problems related to COVID infection.

Dr. Joe Rotella:

And then I'm concerned about the folks that have had acute problems that they've not sought help for because they've been hunkering down at home.

Dr. Lynn McPherson:

Right.

Dr. Joe Rotella:

Or all chronic illnesses that they've been putting off, and at some point, they're all going to come flooding back in.

Dr. Lynn McPherson:

Yes. I know that my husband has had carpal tunnel for a very long time, and of course he kept putting off doing anything, putting it off, putting it off, until finally I said, "You've got to do something about this." So he went to a surgeon and he said, "Yeah, you've got a bad case in both hands, so we should do a surgery. We'll do one at a time, in-out surgery." So it was all lined up and then this all hit the fan. So now, every couple of hours I wake up and he's sitting on the side of the bed trying to get his hands to stop being numb.

Dr. Lynn McPherson:

So I do think when you think about whether it's just having your teeth cleaned or in-out surgery, I think there are a lot of things that have been backed up.

Dr. Joe Rotella:

Oh absolutely. And I'm used to working from home, but I'm not used to spending eight hours solid in Zoom meetings. And the truth is, if I weren't in a Zoom meeting and I was on a call, I might put my headphones on and go take a walk. But for a Zoom meeting, you're supposed to sit in front of your computer-

Dr. Lynn McPherson:

Right. Right.

Dr. Joe Rotella:

So the truth is that I've never been more sedentary in my life.

Dr. Lynn McPherson:

Yes.

Dr. Joe Rotella:

And I'm gaining away and this isn't good for me, right? So there's a challenge to all of us, which is, when we can get beyond the initial crisis response mode, and in some places, that's what has to happen is let's get through this and just survive, but when we get beyond that and we are getting ready for the long haul, we need to take good care of ourselves and each other.

Dr. Lynn McPherson:

Yes. Absolutely.

Dr. Joe Rotella:

We have to find a way to exercise. We have to find a way to spend time with people we love. We need moments of mindfulness. You know, I look out my window and I see these little goldfinches on this bird feeder. They don't care about COVID at all. They haven't noticed anything about this. And if I can spend a minute with them, then I can come back a little recharged-

Dr. Lynn McPherson:

There you go.

Dr. Joe Rotella:

And take on this unprecedented challenge we're all working on.

Dr. Lynn McPherson:

It's been a doozy, that's for sure. Well Dr. Rotella, you are a prince among men. I appreciate your time. Any last closing thoughts you want to share with our listeners?

Dr. Joe Rotella:

Well, I just want to come back to this idea of kindness. Right now, I've never felt closer to all my colleagues in hospice and palliative care and primary care and medicine in general. And I think this is taking us back to why we do this, why we chose these professions. I moved into palliative care and hospice partly because I was able to live with the idea that I couldn't hear everything, but that there is still something I could do, and now that's being put to the ultimate test.

Dr. Joe Rotella:

We're facing something enormous. We can't always fix it. We can't even do all the things that we used to do or wished we could do or that we would say are standards of the best specialty care, but there still is always something we can do, and sometimes that's bring ourselves as full human beings to the task and provide that kindness, that compassion, that message that you matter. And it's never been more needed than right now. And I think this is the time when we can really make a difference by making sure that people always know, whether you're a patient, a family member, a colleague, the grocery workers down the street that put bags of groceries in my trunk, everybody matters.

Dr. Lynn McPherson:

Absolutely. I mean, I've long held the opinion that palliative care, this is why we all went to pharmacy, nursing, medical, social work, whatever your school of choice is. When young learners say, "Oh, I just want to help people," that's what we do. That is what we do. I personally hold the belief that after this whole storm, palliative care is going to emerge with even greater respect from the medical community because I think we live and breathe this stuff, like you say, taking care of each other, taking care of patients. So I'd like to thank you for your personal efforts and certainly the Academy for what they have brought to the entire healthcare community. And thank you so much for being on our podcast, Dr. Rotella. I appreciate it very much.

Dr. Joe Rotella:

Thank you. This was a great pleasure. I really appreciate it.

Dr. Lynn McPherson:

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