

Experts discuss how pandemic has changed palliative care

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Featured topic and speakers

In today's COVID-19 update, three palliative care experts talk about the importance for physicians to know how patients want to be cared for during an illness and the heartbreak of patients who died alone due to COVID-19.

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Speakers

- Thomas J. Madejski, MD, chief of medicine, Medina Memorial Hospital
- Toluwalase Ajayi, MD, medical director, palliative medicine, Scripps Mercy Hospital
- Ana Leech, MD, director, palliative support team, Memorial Hermann/Texas Medical Center

Transcript

Unger: Hello, this is the American Medical Association's COVID-19 update. Today, we're discussing palliative care and how it's changed during the pandemic. I'm joined today by Dr. Thomas J. Madejski, an AMA trustee, chief of medicine at Medina Memorial hospital and medical director at the Villages Of Orleans Health And Rehabilitation Center at Albion in New York. Dr. Madejski holds certifications in the areas of geriatric medicine and hospice and palliative medicine. And Dr. Lase Ajayi, medical director of palliative medicine at Scripps Mercy Hospital, and a community pediatrician at Rady Children's Hospital in San Diego. Dr. Ajayi is also chair of the AMA Young Physician Section. Dr. Ana Leech, the director of the palliative support team for Memorial Hermann-Texas Medical Center, and an associate professor of Geriatric and Palliative Medicine at the UTHealth McGovern Medical School in Houston. I'm Todd Unger, AMA's chief experience officer in Chicago. Dr. Madejski can you begin by telling us a little bit about palliative care pre-COVID? If we can remember that far back, what were

the challenges even before the pandemic?

Dr. Madejski: So there's always been challenges and I think the pandemic brought out some more and maybe some opportunities. So most physicians, both personal comprehensive physicians and specialty practitioners practice palliative care in some form. And as part of that as physicians, we should be listening to our patients, trying to understand their goals for their health and how they want to be cared for over time. Our system is not that well set up to do that, and it there's a lot of variation in how it's done. I think patients who had better planning prior to coming to this sort of crisis that we're in, maybe had an opportunity to get the care they wanted better. And I think one of the things that's come through in the crisis is the importance, on an ongoing basis, having discussions with patients about how they want to be cared for, what's important with them, for them to get the best care that they want.

Dr. Madejski: And that's very different with different patients in terms of where you are in your life, in terms of younger and healthier versus someone who's older and because they may have multiple health conditions have a poor prognosis. When we first started, my practice which does geriatrics and palliative care, I think we do a pretty good job of trying to get that information beforehand, but even there with the initial information that was coming out of New York City in terms of mortality and what the courses of these patients were, I went back through and looked at things in most of my patients that I encountered, whether they were well or not particularly in nursing facilities. And we had most of that right already, but there was probably about 25% that we did make some modifications in their plan of care, which I think hopefully gave them better care and enabled them to be cared for the way that they wanted to and did not enhance suffering in patients who were not going to do well.

Unger: Was there anything that characterized that 25% that you identified where there needed to be changes made?

Dr. Madejski: Yeah. So most people as they move along in life, have some understanding of prognosis in where they want to go. And part of our job as physicians is to give people information about how we think they would do and what treatment options are available to them. So COVID was an existential threat that had a really high mortality upfront and the data from New York City that I shared with patients initially, which has changed is that in somebody who had multiple health conditions, that they were sick enough to be living in a nursing home, if they got bad enough that they needed to be intubated, the numbers that I used initially were that there was probably about a 50 to 80% chance of them passing. And that was often after they had been on a breathing machine for a couple of weeks. So we went through that and some patients wanted aggressive treatment. Other patients decided based on that data, which again has changed. And I think is one of the key things in incorporating in conversations with patients, whose up to date with data made a difference in some of what they did.

Unger: Well, that's a good segue. Dr. Ajayi as COVID began to fill up hospital beds last spring, what

was the initial impact on palliative care both for those suffering from COVID as well as other terminal illnesses?

Dr. Ajayi: The biggest impact honestly, was the fact that families couldn't be with their loved ones. And you can imagine how challenging that was. We were lucky in California that Governor Newsom was able to shut things down pretty quickly, but that meant within the hospitals, patients were separated from their family members. So they were getting devastating news of a new diagnosis, or they were just scared or they had mild cognitive impairment, they couldn't have their advocate there for them to support them. And so the challenge is really within palliative care, those initial first bonds was how do you have these conversations when they don't have their person with them? When they don't have that support? And to Tom's point when they were truly end of life for them to be dying alone in the hospital.

Dr. Ajayi: One of the things that I saw, I had the first compassionate excavation within my health care system from a COVID positive patient. And it was hard because with their level of respiratory distress, the amount of medications they needed to make that transition easier and more peaceful for them was tough because we didn't have that data. And then to not have families be there to hold their loved ones as they were dying that was tough on our patients and their family members. I'd say that was probably the biggest impact during the early stage of this pandemic.

Unger: Dr. Leech, does that kind of line up with your experience as well?

Dr. Leech: Absolutely. I think we were very lucky because our system was able to secure a lot of iPads. And so we were doing video calls with people. There is nothing worse than having families tell their loved one, they love them or trying to get them to open their eyes because of a serious injury through Zoom, not being able to hold their hands, go into the room, not even come into the hospital. So it has been very challenging, communicating and sharing that precious moments with people through video conferencing.

Unger: Dr. Madejski?

Dr. Madejski: Similar experience, and actually in long-term care facilities where you have cognitively impaired patients, patients who have visual and hearing issues, iPads can be helpful, but it's not sufficient for many. One of the ways, again, looking at care planning that we were able to address that and try and provide some comfort is in patients who decided they weren't going to be hospitalized, who we considered to have a terminal illness. We would put them essentially into hospice. And at least in New York, we had a little more latitude in terms of being able to bring people in so families could be together was still very difficult and it remains difficult. I think one of our hopes with the vaccinations is that we'll hopefully, as we get nursing facilities done, allow people to visit with their family. Again. I mean, one of the silent tragedies of this, I think is the social isolation that's happened in so many populations, but particularly in nursing facilities.

Unger: We talked about iPads a couple of times, in terms of telehealth and technology, how has that influenced palliative care during the pandemic? And has it helped relieve some of the challenges or on the opposite has it increased isolation? Dr. Madejski, why don't you start?

Dr. Madejski: Yeah. So that has been actually a great tool. And actually, I think one of the areas we've improved care is being able to use telehealth a little bit more. In upstate New York, where I practice in a rural community, our hospice was really strapped or they did not have adequate staff, they weren't actually able to open cases for the first couple of months. And so using telemedicine in conjunction with a home care service, we were able to do essentially good hospice work. The other thing that I really liked about it, which was an unexpected benefit is hospice is, I would say more nurse driven in general once people get into hospice and physicians are consultants.

Dr. Madejski: And over many years as a hospice director and doing this, the execution of my palliative care plan is not always as nice as I'd like. And one of the real benefits is me having more contact with my patients in hospice, maintaining them at home, really being able to work with the family and the patient to maximize their comfort and make sure they get the care more promptly. So that I think is something that will stay in my practice. And I think will be something that we can use to do a better job for patients.

Unger: Well, Dr. Ajayi-

Dr. Ajayi: [inaudible 00:09:28].

Unger: I'm sorry, go ahead.

Dr. Ajayi: Sorry, I was going to copy that because I'm also a medical director for pediatric hospice within San Diego. And it's so true that with telemedicine, because a lot of my medical fragile children were petrified of going into the hospital, right? Because if you are on hospice and you choose to go back into the hospital for your end of life care and this time when you can't have your whole family be there. And could you imagine as a parent, as a grandparent, not be there for your dying child? That was terrible. So having the ability to really manage those symptoms aggressively using telemedicine, having our nurses be able to bring their iPads into the homes and actually limit contact so the kids weren't as exposed was so key and so helpful, and actually provide a lot of care that we want in palliative medicine and hospice to be able to help maintain those symptoms at home and not have them come to the hospital.

Dr. Ajayi: And kids were lucky because at Rady's we were great at making accommodation. There was one patient that was COVID positive, and we were able to allow the family to come and be with that patient at the end of life in the hospital. And it's lucky that children's hospital can have that flexibility because kids weren't that affected, but with the end of life aspect and having to come to those hospitals, we have to look at those restrictions and tell telemedicine was really helpful with that.

Unger: Well, Dr. Ajayi, we're 10 months into this now since the first COVID surge, how has palliative care changed or evolved over time? And has your advice to patients changed in that time as well?

Dr. Ajayi: How the practice has changed? Definitely kind of what we talked about earlier, the inability to not bring families into the hospital, or into the clinics. So when we see our patients in the outpatient side, having to have their advocate, their loved one, be there remotely has been a shift that we pivoted to a lot quickly. In the pediatric side, we've been using telemedicine for quite some time, but having to use that technology a lot more rapidly and helping our families get used to that. And I said earlier, I don't know that you can ever have a family member get used to saying goodbye to their loved one via Zoom, but having that be fully incorporated into how we care for our patients and how we teach our nurses and our intensive is also within the hospitals to use that technology, the best that we can has been helpful. But I think the biggest shift is really not being able to have family members with their loved ones, as we have these difficult conversations and, or as we transition them to end of life.

Unger: Dr. Leech, has there been any changes for you beyond what you've discussed already or any way that you advise patients that's changed?

Dr. Leech: Well, the superficial things to start with, I didn't look like this at all back in March. And we have now this extra layer of separation, we're all wearing scrubs. We are all wearing masks. So being able to have that empathy and communication with people has just been really challenging. We can't touch them, we can't hug them. We can't even have a smile or anything with his family. So it has been very difficult being able to communicate, obviously the Zoom or the telemedicine has been great, but we had challenges where people just didn't have the technology at home. So how do you have those communication when all they have is a regular landline and that's all they have, there's no computer, there's no iPhone, there is no technology. So it has been very challenging for some families, a lot more than others, but we've made do as best we can.

Dr. Ajayi: I think as she also exemplifies the health disparities gap that we have with our patient population, right? I mean, I care for a lot of Medicaid and Medicare patients, and the ones that don't have the access to the technology are also the ones who are dying more rapidly from this disease. And Ana has a great point that health disparities affects all the levels of care that we see in this pandemic.

Dr. Madejski: Yeah. And I'll echo that too. I think the digital divide, which is very apparent where I am

in rural upstate New York is one of the other things that from a policy standpoint, AMA has policy, but we need to work on and address that further. I can pretty much tell where people live in my area by their connectivity. And if they're above a certain New York state route number, I can only do telemedicine with them and telephone telemedicine. So we have some work to do there.

Unger: Well, Dr. Madejski, looking ahead, both in the short-term and the long-term, what do we need to do to make lasting improvements to palliative care? And what role should the physicians play in those efforts?

Dr. Madejski: So palliative care, it's a wide spectrum. Every physician who takes care of patients deals essentially with some focus on palliative care, I think the pandemic is brought out the importance of being prepared. So in our routine visits and annual wellness visits and periodic health checks we need to check in with our patients, make sure we understand what their goals for care are, make sure that they have done a health care proxy, they have some idea about whether they should have a will and a power of attorney and we want to have a discussion and probably document that discussion. The AMA and other groups have worked towards this, that actually physicians are encouraged to do that.

Dr. Madejski: There are codes that cover your discussions with your patients for those kinds of things and there's a reimbursement for that. So the system recognizes the real importance of that to help pay people get the right care and the right place at the right time of their life. So I think trying to get that word out a little bit more in terms of quality improvement, I think certainly looking at comprehensive or primary care physicians who coordinate care that needs to be something that really needs to be part of their metrics and internal quality improvement to know that they're hitting those things. I'd be very interested to get Dr. Leech and Dr. Ajayi's thoughts on that too.

Dr. Ajayi: I would just add that the partnership that the AMA has with the American Academy of Hospice and Palliative Medicine is really key, going to our specialty academy and the policies that we have put out, because that is really where a lot of us are looking as landscape is changing, looking at organizations like us and partnering with the AMA in putting out new policies to make sure that reimbursement is covered for the telemedicine, telehealth and allows us to reach a lot more patients sooner and really be able to meet them where they are, which is the cornerstone of our practice. And then also, like Tom said, having the conversations earlier and working with our primary care colleagues to have these conversations so when they come to us in the hospital, it's not a shock, it's not scary, and it's just part of the care that we give to patients in general.

Dr. Leech: These conversations, when they happen on a regular basis with every patient we have are not scary. But when we only talk about these things when someone is dying, then everybody knows, the doctor brought it up, therefore, I must be dying. It would be much better if we could have this conversations earlier, when people have a level head and they can make decisions that makes sense for them. And it might be that they want more care, it might be that they want less care, but it's

important to have those things set out. It's also important to have reimbursement for our support system. You would never dream of telling a surgeon that he can't have a scrub nurse, but we tell palliative doctors all the time that they don't need a social worker, or that they don't need a chaplain to help them out and it's just ludicrous to think that we can do our job without the support just like you would never ask a surgeon to do that.

Unger: Well, thank you so much. It is a heartbreaking scenario and like so many things, COVID has added a new layer of challenges to trouble that it's already existed in the past. We really appreciate your work there. And thanks for coming today and sharing your perspectives and thoughts, Dr. Madejski, Dr. Ajayi, and Dr. Leech. We'll be back soon with another COVID-19 update. For resources on COVID-19 visit ama-assn.org/covid-19. Thanks for joining us, please take care.

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