

Palliative Care Chat - Episode 13 - Interview with Dr. Jennifer Kennedy

“Short Stay Syndrome: Why it happens, and what hospices can do about it!”

- 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. I'm super excited about our guest today. It's Dr. Jennifer Kennedy, who is the senior director of regulatory and quality affairs at the National Hospice and Palliative Care Organization. Dr. Kennedy received her BSN from DeSales University, her MA from Trinity Washington University in health education and case management, and most recently and very exciting, her EDD from Nova Southeastern University in health care education and policy. This is one smart cookie we have on the line here. Welcome, Dr. Kennedy.
- Dr. Jennifer Kennedy: Hi, Mary Lynn. I'm so excited to be with you today. Thanks for asking me.
- Dr. Lynn McPherson: Oh my gosh. We're super excited you're with us. I understand your PhD dissertation was titled "Short Length of Stay in Hospice Care: Optimal Life Closure," which is the bane of every hospice in the world. Would you agree?
- Dr. Jennifer Kennedy: Yeah, it was and that was really the reason that I chose that topic because the frequency of short stays is increasing and I really wanted to take a look at what we could do for that and bring my research back to NHPCO to see if resources could be developed based on it.
- Dr. Lynn McPherson: Well, I certainly hope that was your finding, but let's not steal your own thunder here. Tell me, what does the data show about patients with short lengths of stay in hospice?
- Dr. Jennifer Kennedy: Well, our data from NHPCO 2016 indicated that 55% of patients received hospice care for 30 days or less. If you look at the MedPAC or Medicare Payment Advisory Commission data, it's a little more dated, but even back in 2010 and 2011, they were seeing 25% of hospice stays were only five days or less.
- Dr. Lynn McPherson: That's shocking.
- Dr. Jennifer Kennedy: I know. It's crazy and those of us who've been in and about palliative care for quite a while, we're worried that hospice is being reduced to a deathbed benefit and there's so much good that can come from a healthy length of stay within hospice. It's interesting to note that Medicare's data for 2017, which they cited in this year's Hospice Wage Index Proposed Rule, they said that the median length of stay was only 18 days.
- Dr. Lynn McPherson: Wow. That's amazing. What can you really do in two weeks?

Dr. Jennifer Kennedy: Yeah, it really is.

Dr. Lynn McPherson: That's pretty scary. I was sharing with some learners the other day looking at your data, NHPCO from 2016, and comparing it to 2013 and the admitting diagnoses to hospice. I was kind of heartened to see the gap closing between cancer and heart disease and it seems that every one of us has about a 50-50 shot of more likely than not dying of cancer or heart disease.

Dr. Jennifer Kennedy: There you go.

Dr. Lynn McPherson: I was happy to see that gap narrowing with cancer down to 27% and heart disease up to about 19%, but still, it doesn't matter what your diagnosis is if you're referred so late to hospice. What are some of the reasons why this is happening? Why are patients being referred to hospice so late in their disease trajectory?

Dr. Jennifer Kennedy: Well, that's partly what I wanted to learn from my doctoral dissertation and what I've learned from my literature review that there were a variety of reasons why patients arrived to hospice so late. Some of those reasons, of course, included the untimely referral. That was linked to physician hesitancy to actually prognosticate. "Is this the time to make the referral?" I think a lot of people automatically think, "Oh, it's a physician issue," but literature also showed that there's a patient and family side to the equation where either the patient and the family are in denial and they're not ready to make that commitment to acknowledge that they have a terminal illness and hospice care could be the way to go or they're just not aware of it.

Dr. Jennifer Kennedy: They don't have knowledge about what hospice care is and what it could do to help them. Then another prominent one is that "hospice hastens death" and I think that one's an old myth, Mary Lynn. That's been around since the 20 years ago I started doing palliative care. The thing is, is that we have to sort of take a look at all the reasons and we can't put all the eggs in one basket, being that the physician is taking their good old time in referring. There are a lot of variables to consider.

Dr. Lynn McPherson: I always thought that the reason cancer had a higher prevalence in hospice than heart disease was because cancer is easier to prognosticate the trajectory, which heart failure can be a little tricky and people can decline and then rebound, decline and rebound, but regardless, it just seems that I still do see people thinking ... My own mother told me until the day she died, "I don't like what you do for a living because everybody dies." I was like, "Well, mom, everybody's going to die regardless," but she said, "No. Once they're in that hospice thing, they're all going to die." I think people still automatically go there and, as a matter of fact, I think that's even rubbing off on palliative care because you hear about these conversations like, "Maybe we should change the name of our team to 'supportive care' instead of 'palliative care'." Do you really think that whole thing is a myth thing or do you think it's fading or it's still growing or still there? What do you think, the whole fear of hospice and palliative care?

Dr. Jennifer Kennedy: I think that there is a toehold there. I think that people do, if they have an inkling of what it is, they don't want to go there. You mentioned your mom. My mom died 20 years ago. She had hospice care and she was deathly afraid of, "Okay, if I actually say that I'm ready for hospice care, it's an automatic death sentence." She didn't sign her DNR until three weeks before she died, but on the other side, I felt her oncologist held her too long and didn't have the conversation, those advanced care conversations and those option conversations, about, "We could go that one more round of chemo or radiation or here's another option that will help you raise the quality of your life by taking care of your symptoms."

Dr. Lynn McPherson: Yeah, but I do think sometimes that's patient- and family-driven, too, where they want to go-

Dr. Jennifer Kennedy: It is.

Dr. Lynn McPherson: Full guns blazing to the bitter end. Don't you agree?

Dr. Jennifer Kennedy: I sure do. I sure do and it's driven by, it could be patterns of care that they're used to. It could be previous experiences in their family. It could be a cultural issue. It could be a religious issue. There are just a lot of different social determinants that also could have effect on when they actually decide they're ready for hospice or palliative.

Dr. Lynn McPherson: Sure. I think it's interesting. Of course, I'm located in Maryland, not too far from you and I know that some of the larger hospices in my area actually have ... One team is designated as the SWAT team for these patients who they know, coming into it, have ... "We hope they can live through the admission visit," basically. In your opinion, do hospice providers approach the care of a patient with an anticipated short stay differently, and how?

Dr. Jennifer Kennedy: Well, I think some providers do and really, that's what my whole aim of my study for my dissertation was, to find out how hospices alter their approach for a patient. I was really focusing on that seven days or less timeframe. What I learned through my study and what I've learned just being out and about and talking to providers every day, going to different states and speaking at meetings, is that more providers seem to be doing a more organized approach, either by formalizing a process or a protocol for patients that fall into that short stay box. I think that's encouraging that hospices on their own have recognized that, "Oh, this patient is unique and we've got to essentially really front-load services because we don't have a lot of time to work with this patient. Every one of my study participants felt like they were engaged in crisis deathbed care.

Dr. Lynn McPherson: Wow.

Dr. Jennifer Kennedy: And it was stressful.

Dr. Lynn McPherson: Do you think it's still worth making a referral to hospice when a patient has less than a week left to live?

Dr. Jennifer Kennedy: That's a great question, Mary Lynn. I think it's individualized. I think you have to look at it from patient to patient situation. I talked to a lot of providers who are getting even referrals from acute inpatient hospitals where the patient's imminently dying, and they just want them out of their acute bed, and I even have to-

Dr. Lynn McPherson: Yes, they don't want to die on the hospitals rolls so to speak.

Dr. Jennifer Kennedy: Exactly and most hospices will admit the patient even if it's a matter of hours. I even challenge providers to say, "What benefit is it really going to have for that patient and family if you're with them for three hours?"

Dr. Lynn McPherson: Yes, I agree. I agree.

Dr. Jennifer Kennedy: I don't know that we should have a broad brush sort of view on "Is it worth it, seven days or less?" I think you look at each patient and family individually and then you weigh it to see what impact or benefit you can have. Some providers feel like, "Oh, well, even if I can't spend a lot of time with a patient properly, I can provide the bereavement piece on the back end with the family."

Dr. Lynn McPherson: Which is not to be underestimated because that's critically important, too.

Dr. Jennifer Kennedy: Absolutely. Absolutely.

Dr. Lynn McPherson: Since I'm a pharmacist, I spend a lot of time thinking about, "How can we maximize drug therapy for people who have an advanced illness and they're close to the end of the road?" One of things when I'm, for example, teaching admission nurses, I'll say, "Your job is to not rock the boat. Your job is to get in there, do a good med rec history, and kind of open the door a little bit, saying, 'When I get back to work, your nurse case manager will take a look and work with your doctor and our doctor to make sure that your loved one is on the very best drug regimen possible.'" If the patient has a day or two left to live, they don't have time for the patient and the family to form that trusting bond with the nurse case manager and the rest of the team, so I think that's one consequence. Are there other quality consequences for patients and families with these short lengths of stay in hospice, in your opinion?

Dr. Jennifer Kennedy: Yeah, absolutely. My research really showed that in addition to not being able to have that trusting bond relationship that you just don't have time to form it, that caregivers of these patients with short stays tend to have prolonged grieving and they tend to have dysfunctional grieving after that patient's death. Also, when you're coming in so late to the party, so to speak, it really impacts how the patient and the family are actually perceiving the death emotionally, spiritually, and how they are actually even thinking about getting ready for the

acceptance of the death and, moving forward after the patient dies, how they're going to handle their grief. Those are just a few, I think, that we can talk about here today, but I think even depending on the patient and the family, there could be even additional, far-reaching consequences, but again, it's the patient's choice to choose at the end and the family's choice to choose at the end and that's good enough for them. We can't, again, apply all of the research to every patient and family.

Dr. Lynn McPherson: Not one size fits all, but I wondered if families ever see, even in that short time, "Wow. This was a wonderful thing," and do they ever feel guilty, do you think, for not accepting hospice sooner?

Dr. Jennifer Kennedy: Yeah, and I did find that in my literature review that some patients' caregivers really said, "Oh my God. I wish we would have had this sooner." Actually, I was just traveling and I talked to my cab driver. He had a recent hospice experience and he said, "Oh yeah, my father had hospice for three days and it was great. They were so wonderful and they did all these things for us and we can't say enough." They had an extremely positive experience and they felt good about it, where you could talk to somebody else and, again, with that guilt and, "I wish we would have had it sooner," that really impacts the whole grieving process for the caregiver.

Dr. Lynn McPherson: I'm sure it does, goodness. Now that we've beaten to death, pardon the pun, the problem, what are some suggested strategies for hospice providers to get the length of stay increased? How can we get people into hospice sooner?

Dr. Jennifer Kennedy: Well, I think education has a lot to do with it. We need to be talking about earlier referral with those physicians, your cardiologists, your pulmonologists, your internists, your hospital partners. Whoever a hospice has as a stream for the referrals, they really need to be doing that education and that supportive, "We'll be here to help you. You just need to ... Here are the indicators of when a patient might be in the window for that." A lot of education, I think, still needs to be done. We're not near where we need to be in terms of education. Also, I think when we're talking about education about proper referral to hospice, it even goes a step back, Mary Lynn, in advanced care directive care conversations. We know that physicians aren't comfortable with having those conversations. The best time to have those is when the patient is not in a crisis.

Dr. Lynn McPherson: Of course. Yes, of course.

Dr. Jennifer Kennedy: I think there's a lot of opportunity for that type of education. Also, in terms of hospice providers, as I mentioned before, we're seeing more providers develop a honed approach to managing these patients with a short length of stay so that they can do their best to give them the most optimal interdisciplinary holistic hospice experience that's possible. It's not easy to do by any stretch of the imagination, but what we're doing at NHPCO is we're looking at this short stay topic really carefully right now from a quality perspective and we hope to actually have a resource out by the end of the year for hospice providers to use

to help them build an approach or a protocol or a process of their own that works for their geographic area and their hospice population to help them manage these patients more optimally.

Dr. Lynn McPherson: Well, I'm sure that'll be a welcome resource in their armamentarium. As the drug girl, I'm often dismayed by direct-to-consumer advertising about drugs. Do you think hospices should employ an approach where they market, so to speak, or inform or educate the general population about the benefits of hospice?

Dr. Jennifer Kennedy: Yeah. I think that really needs to be done. We've even been encouraging and even providing even marketing materials on an annual month. November is hospice month and we, every year, give them the opportunity to use marketing materials that we develop to get out there in their community and get the word out that it's really a beneficial quality of life supportive service, and to really talk about what it is and what it is not and how helpful it can be.

Dr. Lynn McPherson: Absolutely.

Dr. Jennifer Kennedy: We will continue to do that.

Dr. Lynn McPherson: So many misinformed people out there, definitely.

Dr. Jennifer Kennedy: Right. At the national level, we do whatever we can. Primarily, we're educating Congress on the Hill. We're educating all of the players who make the regulations to understand not only the benefit of palliative care meaning hospice at that end of life palliative continuum, but, oh my gosh, wouldn't it be great to have a fully funded palliative care benefit?

Dr. Lynn McPherson: Yes. Yes.

Dr. Jennifer Kennedy: And are patients going to be [crosstalk 00:17:41]-

Dr. Lynn McPherson: I think that's one of the stumbling blocks is people not wanting to give up curative therapies. Once you get practitioners in the loop who can really explain the benefits and the burdens, then people may change their mind, but that is such a gun-to-your-head kind of moment. Don't you think?

Dr. Jennifer Kennedy: I absolutely agree. That's where a lot of our focus is going right now is really trying to open up the playing field for that out-of-the-box thinking, "Wow. Wouldn't it be great if we could have this continuum of palliative care that is funded by Medicare?"

Dr. Lynn McPherson: My gosh, yeah. Absolutely.

Dr. Jennifer Kennedy: And, "Oh my gosh, it'll save you money."

Dr. Lynn McPherson: What a concept, huh?

Dr. Jennifer Kennedy: What a concept.

Dr. Lynn McPherson: I know that we all applaud NHPCO's efforts and yours as well because this is sorely needed. Any closing thoughts, Dr. Kennedy, about this short length of stay issue that we have not already touched on?

Dr. Jennifer Kennedy: Well, I think first of all, hospices need to self-assess what their short length of stay is and then they need to start figuring out what strategy they want to employ to make sure that that patient has the best hospice experience that they possibly can have.

Dr. Lynn McPherson: Absolutely. Amen to that. Well, Dr. Kennedy, I'd like to thank you so much for being with us today in this informative podcast. We're very appreciative and I'd like to thank the audience for listening to our Palliative Care Chat podcast. Again, this is Dr. Lynn McPherson and this presentation is Copyright 2018 University of Maryland. For more information on our completely Online Master of Science and Graduate Certificate Program in Palliative Care or for permission requests regarding this podcast, please visit graduate.umaryland.edu/palliative. Thank you.