(UPBEAT MUSIC PLAYS)

ANNOUNCER:
You are listening to the AOTA podcast. Here is your host, Matt Brandenburg.

MATT BRANDENBURG:
Alright, welcome to the show. Today, we are joined by four very special guests to highlight how occupational therapy contributes to care for people living with chronic illness all the way through the end of life. We're hoping to highlight on this episode the lived experiences of those working in this meaningful space, which is hospice and palliative care. I'd like to ask each of our guests to introduce yourself quickly for our listeners, if you could share your name and maybe a brief highlight about something from your background and your current work. Lindsay, can we start with you?

LINDSEY BUDDELMEYER:
Hi. My name is Lindsey Buddelmeyer. I have my clinical doctorate in occupational therapy. I've been in the profession now for 20 years and dedicated most of my career to working in supporting people with chronic illness. I am currently leadership education and training specialist at Blanchard Valley Health System and still do a lot to help support our teams and patients, and families facing chronic illness.

HEATHER MCKAY:
I'll go next. My name is Heather McKay, and I was lucky enough to enter our profession through the community college door. I was an occupational therapy assistant for a few years before returning to graduate school to become an occupational therapist. My work with older adults and their myriad caregivers has been the lion's share of my career, especially with people living with dementia and dementia caregivers of all stripes. That was the population that really drove me back to school again to do my doctoral work in program development and workforce development in the dementia care space. I always say, don't ever say you'll never be back in school, folks. You never know. After ten years of work in hospice and palliative care, the questions that were most exciting to me were in that space. Right now, I'm a assistant professor in the new occupational therapy program at Appalachian State University.

DAVID BENTHALL:
Well, I'll jump in. Since I had the privilege of being able to work with Heather McKay in hospice for several years, she's been a wonderful mentor for me and gave me an opportunity to be able to explore being an occupational therapist in hospice and palliative care. So, I'm very appreciative of her. But I'm an occupational therapist, as I just mentioned. I've been an OT for 14 years. The home and community-based setting has

always been my passion. Particularly with older adults. And also supporting clients at the end of life to be able to engage in life as meaningfully as possible all the way up to the end. So, I've been lucky to work in home health and hospice and palliative care setting, and now I'm working in a home-based primary care setting where, again, we support older veterans to remain in their homes for as long as possible and ideally up until the end of life. So, thank you for having me.

MATT BRANDENBURG:
Thank you, David, we're excited to have you all. And Dr Christian Jacobus, can you introduce yourself?

DR CHRISTIAN JACOBUS:
Yeah. Happy to be here. I'm Chris Jacobus. I am the medical director for Bridge Home Health and Hospice in Findlay, Ohio. It's part of the Blanchard Valley Health System. I have been in this job for 11 years. Probably about nine or ten of those working with Lindsay Buddemeyer. I started out in emergency medicine, worked in ERs for about ten years before having a bit of a change of heart. Went back to fellowship and subspecialized in hospice and palliative medicine. And I've been here at Bridge ever since.

MATT BRANDENBURG:
That is wonderful. I am so excited to have all four of you on the show today. I'm really looking forward to learning from you. And before we dive into some of our foundational knowledge questions and the research that you've been doing together, I wanna ask, how did you all connect and form this interprofessional team and effort?

LINDSEY BUDDELMEYER:
I would say this really began several years ago with really a vision that I had from my work with chronic illness and palliative care alongside Dr Jacobus, as he had mentioned, and looking for evidence, honestly, in the space of palliative care and hospice for occupational therapy and being frustrated, not being able to find it and thought, well, maybe I could write a textbook or a book of some sort. And so, submitted a proposal to AOTA Publishing, and it was accepted. And one of the first major tasks that I had was to form a team and bring people together in these important spaces to align and create a body of work that really would help to define understanding of our role in chronic illness and palliative care, and hospice. And so, we're so lucky to have Dr Jacobus. And he was very willing. And then David and Heather alongside in the hospice space. And we just were able to kind of cross each other's paths in that manner. And it's just been a really wonderful experience.

DR CHRISTIAN JACOBUS:
Lindsay is definitely the linchpin of our group here.

HEATHER MCKAY:
She's a great caroler.

MATT BRANDENBURG:
She's the linchpin, the caroler. Those are some pretty good nicknames. Lindsay.

LINDSEY BUDDELMEYER:
I'll take it.

MATT BRANDENBURG:
Well, I'm really excited to dive into this topic. Thank you for sharing a little bit of that background about how you all connected and have formed this team, hopefully to fill some of the gaps that are pretty observable when you look for evidence of occupational therapy's role in this care setting. I know in preparation for our discussion today, I reviewed an official document from AOTA titled'The Role of Occupational Therapy in End of Life Care'that was published in a 2016 issue of the American Journal of Occupational Therapy. So, it seems like some evidence is starting to emerge. Your efforts have created more of a baseline, so hopefully other practitioners can begin to enter into this practice area and make an impact in people's lives in a similar way that you all have. Dr Chris, could you please help orient our listeners and myself by briefly describing and defining the difference between palliative care and hospice?

DR CHRISTIAN JACOBUS:
Absolutely. And for anyone listening, where that distinction is not clear, you are completely in good company. It's a really common point of confusion, really, even with a lot of my physician colleagues. So, hospice and palliative care they are very closely related, but they are distinct. Both hospice and palliative care really focus on palliation, on symptom management, along with discussion of goals of care. And goals of care, we can get into that a little more later, but really, it's talking to people, finding out what they want from their medical care, and then trying to match their medical care to that. Some of the big differences, though, are that hospice is a type of palliative care that is just for people who we think have less than six months left to live and who are ready to stop more aggressive, life-prolonging care. Palliative care, again, focuses on goals and symptoms, but you don't need to have a limited life expectancy in order to get palliative care, and you don't need to give up life-prolonging care.

So, for example, someone maybe with cancer, if you're coming on to hospice, you have to have that six-month prognosis, and you have to be ready to stop chemo, radiation, surgery, immunotherapy, those kinds of more aggressive treatments. On palliative care, we can be involved really as soon as you are diagnosed, no matter what the prognosis is, and we can do it alongside of life-prolonging care like chemo, radiation, et cetera.

MATT BRANDENBURG:
That sounds like a wonderful development for practitioners in the palliative care space, and I would imagine is really helpful for patients and caregivers, and families as well to receive this level of person-first symptom management, goals of care treatment, while still being able to access life-saving care that may be needed. How does occupational therapy fit into this picture? And what makes the occupational therapy lens distinct on these hospice and palliative care teams?

LINDSEY BUDDELMEYER:
I would say we have a very distinct role in helping to support our patients with everyday life activities and to be very patient-centric and caregiver-centric in that process, which really aligns beautifully with the essence of palliative care and hospice. When I'm starting to work with a patient and family, and they have been diagnosed with a chronic illness can be very unpredictable. So, having a team to surround a patient and family along that journey can be really impactful in so many ways, all the way up to decreased hospital admissions, readmissions, supporting aging in place, et cetera. But occupational therapy practitioners really are able to get in and really provide a support, whether that be through… And I would almost say more of a habilitative lens. We hear that term more so in pediatrics, but not as much with older adults and chronic illness. And OTs are in every space and every sector. It's really just putting our authenticity with that focus on everyday life, meaningful activities into a model that allows us to stay in along the staging and progression and ups and downs of the illness.

HEATHER MCKAY:
Lindsay's doing such a good job talking about this perspective, and I like to put it in sort of a nutshell, that OT brings this living until you die perspective. And our expertise is also in helping people engage, as Lindsay mentioned, in the occupations that give their life meaning even through the later stages of life and as the body declines. So what we're doing is looking beyond medical stability to what actually matters day to day, to people like routines and roles in these small acts that can help preserve identity and dignity for folks living with a life-limiting illness. And we're uniquely positioned that I think, and this is a time to just sort of pump up OT practitioners out there. I think that we're special in translating our clients' values into action, like modifying the environment or training caregivers, adjusting activities so people can adapt through these life transitions that Lindsay mentioned, and still do what they love or need or want to do. So, in that way, OTS just

operating in this space with the healthy recognition of potential disease progression and predictable functional declines.

But it's the opposite of giving up. Just together with that full interdisciplinary team, we're shifting from restoring independence to optimizing participation in all of our interventions.

DR CHRISTIAN JACOBUS:
And Heather, I love that you used that phrase, 'live until you die'. It's worth noting that Dame Cicely Saunders, who was really the founder of hospice as a systematized way to care for people at end of life. She had this really famous quote that we have on a plaque up outside of the door to our inpatient hospice unit that I just loved. She said, "You matter because you are you. You matter up to the very last moment of your life, and we will do all we can not only to help you die peacefully, but also to live until you die." I think that meshes so beautifully with the OT outlook and perspective and philosophy.

HEATHER MCKAY:
Yeah, it's targeting that quality of life rather than solely performance scores. And that's what inspired the title of this book. Fantastic.

MATT BRANDENBURG:
I love that. Thank you for sharing that and giving us some insight into the founding of this area as well. That's a beautiful quote from Dame Cicely Saunders. The more I'm hearing you discuss this model of practice and approach to care and caregiving within this setting, I'm seeing how occupational therapy is such a good fit. But I can't help but wonder why is occupational therapy underutilized in these areas? And what could help change that?

DAVID BENTHALL:
I think it's a really great question. It comes up a lot in conversations surrounding OT and end-of-life care. But I think you can boil it down to that a lot of our profession has occupational therapy practitioners that we are connected with a rehabilitation or a recovery model, where in many common traditional OT practice settings, we are supporting a person to regain lost skills, improve, and function, and maybe establish independent living skills. But that does not represent all of what we do as OT practitioners. And when we focus on our core, which is occupational engagement, how do people participate in life, it really broadens, and it opens up opportunities for OT practitioners to continue working in settings like palliative and hospice care because we're not solely focused on independence or a person's level of functional performance and as Heather said, some of those assessment scores that we often find in our practice settings. But we're helping people to participate in life in the meaningful aspects of life that a person wants to do, what matters.

And so, I think it's underutilized because we just have to continue advocating that our roles are much more diverse than our traditional practice settings, and that our billing and reimbursement systems actually support OT in end-of-life care. And I think that's also a myth or a misunderstanding.

MATT BRANDENBURG:
Absolutely. Thank you, David, for that clarification.

DR CHRISTIAN JACOBUS:
I can just say too some of the barriers to OT in hospice particularly have to do with the way that hospice is reimbursed. We get basically a per diem. We're kind of like an old school 80s or 90s HMO. We get a fixed rate per patient per day, and then all of that patient's care has to come out of that per diem rate. And when you sign on to hospice, basically, we are taking over as your sort of, almost like your insurance provider. So, when a patient comes on to hospice, hospice is responsible for paying for all comfort medications, all medications related to the terminal illness, all equipment, nursing aide, social work, spiritual care, et cetera. And those are sort of our core disciplines. And we can pull in other disciplines like PTOT, speech, massage, psychology, things like that. But with every additional discipline that we pull in, that's an added cost to the hospice organization. And so, for a lot of hospices, probably most hospices, adding something that they have to pay extra for is a big ask.

So, that's particular just to the hospice side, not to the palliative care side. It's easier to do it on the palliative care side, but for hospice, that is a barrier that we face.

HEATHER MCKAY:
David and Chris are really putting their finger on a systemic hurdle to cross. And so, the challenge becomes for OT practitioners to really demonstrate their value. And in order to do that, it takes that initial sort of shift in frame of reference that David mentioned first. And I think many still associate OT with that rehabilitation or getting better model. So, hospices might not realize just how much the occupational therapist has to offer when adaptation and quality of life are the goals over recovery or curing conditions. So, pulling in the OT for their expertise in our most powerful modality, which is occupation. And actually leaning on some of the work, I encourage folks to look into Norlin Pickens writes about occupation as the key to a good death. So, when what we have to offer aligns with the hospice mission and is truly what makes the hospice service effective, efficient, and satisfying to patients and families. Why? It's an opportunity to utilize that per diem on things that matter most.

DAVID BENTHALL:
And even when I worked in hospice care specifically, it did not necessarily mean that the

referrals came generously. It still required a lot of advocacy. And breaking down some misconceptions that maybe hospice interdisciplinary team members have, your core team members, your nurses, social workers, physicians, that may see your role as not necessary or not needed. Even in a hospice environment, advocacy is definitely needed to show how our unique skill set brings value to the table to support quality of life at the end of life.

MATT BRANDENBURG:
Absolutely. Thank you for sharing those perspectives. I love to ask Heather as well, if you could send me a link to some of that writing you mentioned from Norlin Pickens. As well as you and Lindsey have both mentioned textbook on OT's role in this care space. I'd like to make both of those resources as available as possible to our listeners to hopefully encourage them to take on some of those advocacy efforts and take steps towards demonstrating their own value and contributing to building the evidence base of occupational therapy's role in this space.

HEATHER MCKAY:
Be happy to share. And while we're just familiarizing ourselves with this literature base to the work of Janice Kishi Chow, another occupational therapist out of Texas Women's University, a colleague to Norlin Pickens and me has done a lot of interesting work revealing some of these systemic and sort of misperception barriers that address your last question, why the underutilization?

MATT BRANDENBURG:
Lindsay, I want to ask about your work with the Blanchard Valley Health System and your teaching. How have you seen this partnership and role of occupational therapy grow within this space through identifying and addressing functional decline for people with chronic illness or nearing end of life?

LINDSEY BUDDELMEYER:
So, before I took this current role, Dr Jacobus and I had actually started working together through a grant that I have received that was specific to pulling in occupational therapy services under a palliative care model. There was a need. There continues to be a need and a space for it. And so, we were able to - I was specifically providing OT services for patients with memory challenges and their caregivers. I worked for Bridge Palliative Care for four years while I was still teaching at the University of Findlay, and was able to take those learnings and teachings as it continues to evolve and healthcare policies change. But kind of in my current space, really just still seeing as I round in the hospital and working in different sectors that chronic illness, older adults are one of our highest admission and readmission rates. And so, OTs, when we are able to pull in and support at the time where

someone is battling chronic illness and being more proactive versus reactive, we can do some really great things.

And that starts, I'll take us in-house here at the hospital, where if someone is admitted, we have an opportunity, and our teams do when they're going in and working with a patient and family to address medications and how that's going. And we oftentimes find that it's not going too well because people are typically on multiple medications. They have a lot coming at them. Caregivers are managing a lot of responsibilities. And so, we're able to come in at that space and help with medication management and being proactive and intentional to tap other colleagues on our team and pull in that multidisciplinary care in that space. But if you just even think about our framework and all of the areas of occupation, we stretch far and wide. We are well beyond just an ADL, right? We have IADLs and again, helping to support caregivers in that important role. So, I see our teams pulling in and being able to support in different spaces. But I still go back to the fact of earlier is better and helping to support along the way of the chronic illness, so we can really empower patients and families to take on that illness and to have optimal quality of life by supporting and adapting.

MATT BRANDENBURG:
I love that. Thank you so much, Lindsey, and I wanna make sure our listeners are aware of the textbook you authored called ‘Quality of Life: Occupational Therapy and Chronic Condition Management, Palliative Care and Hospice’available in the AOTA store. It sounds like OT's role, like you mentioned, really encompasses so much within this practice area. David, how can we balance support for daily living with some of these deeper goals and interventions like legacy work life review or spiritual meaning that are often addressed in these settings?

DAVID BENTHALL:
And I like this question a lot because I see these two issues as being interconnected and not competing goals in OT practice. And specifically, for example, OT practitioners are very common with supporting a person manage their ADLs or basic self-care skills. And I think whether you're a student out there listening or an experienced OT practitioner, you are familiar that intimate conversations happen in these moments when we're helping a person with bathing or dressing or toileting routine, is where we oftentimes get to know people more, we help make people more comfortable and just... Sometimes clients feel more comfortable sharing things with us in these intimate spaces. So, there is an area where supporting a person's daily living skills is important. But it's also important to highlight that when a person, specifically in hospice, is approaching the end of life, a

person's priorities may also shift. Things that were important to them before may not be as important. So, we'll stick with the bathing example.

Person with very limited energy may not wanna prioritize performing shower routine as independently as possible, cause they may wanna use that energy for more things that they value or that they consider more important, vice versa. A bath may be very comfortable and calming for a person who has chronic pain. So, the key is what matters most to the person that you're working with. But in terms of legacy or life review, when you look at the OT literature, we call these end-of-life occupations. Sometimes, when people are approaching the end of life, they may consider things like life review, reminiscing, thinking about how they want to be remembered, having closure with loved ones, spending time with people that are important to them. And so, our OT interventions can broaden to support the occupations that are important to them. Just a quick example. I had a client that was referred to me in hospice care who had ALS. The only functional movement she had was her neck range of motion, and her communication was becoming significantly impaired.

A referral was generated to assist with functional positioning strategies, pain management, supporting functional communication with her family. But in our interactions, what developed with this client in particular was that she wanted to spend time and communicate with people that were important to her. So, if you remember back several years ago, when the ALS Ice Bucket Challenge was a big rave, everybody was donating and participating, posting social media videos, her goal was to gather her closest family and friends together to do a fundraiser, to give back, and to engage in that ice bucket challenge. So, that's where intervention unfolded. I worked with her to be able to plan this event with her family, that was very meaningful to her. And so, hopefully that little example goes to show that when you think broadly about what's most important to a person and consider that their values and goals may change as they approach the end of life, there's a lot of potential for where you can go in your OT interventions.

MATT BRANDENBURG:
Absolutely. That's a beautiful clinical example. David, thank you for sharing that experience you had with a patient and their family, their support system. I think that really highlights the role that caregiving has within palliative care and hospice. Heather, your work has focused so much on caregiving. What would you say is occupational therapy's role with care partners, especially when their burden might eclipse the client's needs in some situations?

HEATHER MCKAY:
Well, I had really found a home in hospice. And what I mean by that is it was a perfect place for my OT practice, especially with people living with dementia and their caregivers,

because I always say there was more than one important person in every story. And I think that I truly realized this value of hospice when I was a recipient of a hospice benefit, a time or two myself. It was a person nearing the end of life that I loved who had elected their hospice benefit. And then I realized that hospice was not just for the dying person, that hospice was there for our whole family. And it was an eye-opening experience to me when I first learned that my grandmother's hospice benefit would extend to the rest of us in the family, even after she passed away. So, it is in the foundation of the hospice philosophy that we see the caregiver and the client together as a unit of care, and that family is defined by the person receiving their hospice benefit. I mean, it's anybody and your inner circle.

You say who family is. And when you elect your hospice benefit, you can name the people closest to you that those services will extend to, because we realize that there's always more than one important person in the story. So, OT supports these caregivers through training creatively, simplifying tasks in ways that work in the family's home and community, not just for the patient, but for the myriad of caregivers in the story, OTs helping them maintain their own balance of meaningful occupations while caregiving. Another way of looking at OT's value and helping folks, I say, is we're helping folks step into the role of caregiving without sacrificing their own health in the process. There's a lot of practice areas acknowledge there are caregivers might even name caregivers as part of the patient's sort of or client's social circle. But not as intentionally focusing on supporting that caregiver to be well in that important occupational role as is in hospice. We're also contributing to bereavement care.

As I mentioned, the hospice benefit goes on past the death of a loved one, and OT can help families create healing routines and legacy projects that honor their loved ones even after their passing. So, I notice a lot of folks are like me, they're surprised to learn that the hospice benefit goes on after a person's death, when family caregivers and others in the person's inner circle can receive bereavement services for an additional year, not to mention all the ways not-for-profit home health and hospice agencies are giving back in the community service to families dealing with grief and loss, even if that family's loved one was never a patient of their hospice. So, I can't underemphasize work that Dr Jacobus's organization is doing in the community to support families, whether they have ever been a patient or not. And OT can play a valuable role in that occupation-based program development for communities adapting through times of grief and loss. So that healing power of bereavement occupations, I think, is a wonderful area for research.

Just to any aspiring OT or OTA students out there, I would love to serve on that doctoral dissertation committee if anybody is wanting to add to the knowledge of bereavement occupations.

MATT BRANDENBURG:
Yeah, absolutely. And what a beautiful way to grow the scope of service from solely focused on the individual to including the family and including the community as well. I agree, Dr Jacobus, we would love to set you up with some OT students to participate in some of your community initiatives. Could you tell us a little bit about what you're doing in the community as it relates to bereavement care?

DR CHRISTIAN JACOBUS:
Sure. And just to put out early, yeah, we would love to have OT students here. I think that'd be fantastic. But, yeah, Heather's absolutely right. Bereavement is a core hospice service. And the bereavement team is part of the core team. We say that bereavement services typically go for about 13 months after the death of the patient. And we do that so that people can get through, we call it the last of the firsts. So, after the loved one dies, you're gonna have your first Christmas without them and then your first Thanksgiving. And so, by doing it a little longer than a year, we can help support people through the last of those first anniversaries without the loved one. So, we do this in a variety of ways. We do have a full-time bereavement coordinator, and she can do some work early. We call it pre-bereavement. When we identify people who are at high risk for bad, long-term outcomes, complicated grief or prolonged grief disorder. So, we can do some early interventions there. But really, most of the bereavement work is done after the patient has died.

So, that includes things like doing bereavement groups and group work, one-on-one counseling sessions. And then we do some special things through the year as well. We have our annual sort of Christmas-time bereavement event called‘Light Up a Life’, where we have a memorial service, really, for all of the patients who have died in the previous year. We do other things like making mementos. We'll have classes where family will bring in pieces of clothing from the loved one, like a bunch of T-shirts, and we help them make it into a quilt or‘Grief Trails’, which is a program that we do specifically for kids who have lost parents or grandparents, or other close loved ones, that focuses on equine therapy. So, a lot of different ways to help support people through their mourning and their grief.

MATT BRANDENBURG:
Absolutely. It sounds like wonderful and important work and really highlights the importance of cultural humility in this setting, including caregivers including families supporting the community that you're practicing in. I wanted to open the floor here a little bit and ask each of you if you'd like to share an additional case or clinical example that really captures how your own practice helped improve someone's quality of life in a palliative care or hospice setting.

LINDSEY BUDDELMEYER:
I can sit here all afternoon and talk to you about the many cases, as I'm sure all of us can, that we just remember and feel like we've been so privileged to work with. But one that stands out to me, and this is what I really didn't even realize until we received the grant and started being able to embed OT and palliative care years ago now, is that when we were able to wrap around and support a patient, and the case I'm gonna speak about was a patient living with dementia. We started working together in the beginning stages of her illness, being a part of that for four years, and then when appropriate, passing the torch to My hospice friends. Is that, two along that stage, in our culture, a lot of times people are reluctant to go on hospice, just seeing that pattern of going on and then passing within two or three days, where best practice really says to try to target that six-month or less window that we mentioned at the beginning of the podcast. And so, what I was able to see with this specific case is that during my time with this patient and her family in palliative care, in the beginning stages of dementia, she was very independent initially, but then as decline happened, OT was able to jump in, and we supported a couple of ways.

She had a lot of difficulty with dressing independently, mid-stage, and being able to identify appropriate clothing. And so, we were able to come together and work with her husband and her daughters, and came up with a way to kind of approach that where it allowed this patient to participate in dressing, and not just take it away from her, which I think is really important. And that was to create the outfit on one hanger and have many options in her closet. But her husband was then encouraged to choose two hangers a day and say, OK, would you like to wear the blue outfit today or the pink outfit? And so, he was taking again, easier for him to identify the clothing that day and knew what the weather was like outside or the occasion that she was dressing for, and he was able to take those decisions off of her, give her two choices, and then was able to start that dressing, routine with her, to which again in the middle stages she was able to jump right in and just needed help deciding and getting started.

And that's just one of probably 20 examples over the span of 20 years where occupational therapy services really were able to support both her and him to encourage that engagement and participation and make their quality of life a little bit better, and to see that people are still very capable, even when they have memory challenges if they're supported right and so, that role again, of caregiver education. But then when it was time, and she was declining, we like to use called the fast scale. If someone has a diagnosis of Alzheimer's disease, it's a seven-point scale that we can use to speak to one another and to see if the patient is progressing and when they might be more appropriately served under hospice. And we have staging for that. So, it allows a space for us to communicate to as a team, and when it's time to have those conversations and pass appropriately. But I don't wanna talk too long. I know I've already probably talked too much about that, but those are just a couple of quick examples of points I wanted to make with that.

MATT BRANDENBURG:
Thank you, Lindsay, and I think everyone on this interview would agree that we very much enjoy you talking about this area of expertise, that you clearly have such deep knowledge and a breadth of experience in helping clients and caregivers, and families make these meaningful changes that can improve quality of life and function. Who else would like to share a certain case or clinical moment that has impacted their own practice or understanding of their role in practising within this setting?

CHRISTIAN JACOBUS:
I can jump in. The case that most comes to mind for me was one that Lindsay and I collaborated on early in my palliative care career here at Bridge. He was a gentleman, I think, in his early 70s, with a diagnosis of Alzheimer's. I was consulted for palliative care, so I went in and did a home visit, and really was pretty shocked and appalled at some of what I was seeing just the care was really, really lacking. And really, there were a lot of things that were just dangerous. The patient had moments of agitation and combativeness, he'd strike out at family members, wandered a lot, family was using a belt to restrain him to the chair when it was time to eat, hygiene was really lacking, and medication administration was just about nonexistent because their practice was basically just give him a handful of pills and tell him that he's got to take them. And he was essentially nonverbal at that point, and so most of the time, that meant that he just wasn't taking any medications at all. I was out of the house, probably about ten seconds before I was on the phone to Lindsey, and we coordinated our next visit together.

And after just a few interventions from Lindsay, particularly and the two of us together, really made a lot of headway. She did amazing work talking to family about how to better approach him in a less threatening manner. That would mean less chance for him to get combative tips on medication administration, like giving them one at a time with a glass of water and showing him how to take each pill individually. Counseling on things like not restraining him to the chair. So, in a few visits, we were really able to make a lot of progress. And I think for the time that we were in there, I think we're able to really improve his quality of life. But that was the one that most comes to mind when I think about collaborating with OT.

MATT BRANDENBURG:
Yeah, yeah. Thank you for sharing that. That truly highlights the team-based nature of this work and how your collaboration helped build a bridge to open the door to caregiver

education and counseling to improve outcomes. Thank you for sharing that, Dr Jacobus. Heather and David, was there an example or anything additional you would like to share?

DAVID BENTHALL:
A veteran or a client that stood out to me early in my practice was a client in hospice care. He had experienced a stroke, he had pulmonary fibrosis, and he had a lot of respiratory challenges, where any activity where there was physical exertion involved would considerably drop his oxygen saturation rates. So, he pretty much stayed in bed for six months, and his world just shrank around him. In theory, he was dependent in all areas of his care other than self-feeding, but everything else, like all he had control over was the television. An OT referral was thankfully placed, and it just allowed us to explore for this person, who appeared very sick, very frail, to discuss what was most important to him. And even though we probably in all our practice settings, have these big moments that really... There are just beautiful stories. This veteran just wanted to get out of bed. He wanted to eat at the dining room with his spouse. He wanted to sit in his favourite recliner. He wanted to go outside.

And so, these things that we take for granted that was what was most important to him. And so, using our same skill set as we would use in any other setting, focusing on wheelchair assessment, safe ways to lift the patient out of bed while keeping him safe, protecting his oxygen saturation, figuring out how to adapt the environment so he could sit comfortably and support his mealtime routines. Figure out a way to get him in and out of his recliner, but also thinking about the caregiver and how they were able to do this task when therapy or nursing staff wasn't present. So, these visits went over several weeks. What we found out was the meaning, the importance to him, was pretty transformational. To be able to have moments to spend together with his wife to enjoy a meal. He was able to spend Christmas morning sitting in his recliner, and everybody was opening up presents around him. And so, that story really stuck out to me 'cause very kind of everyday things that we might do as an OT practitioner, thinking about a person's function, how to adapt the environment.

But the meaning was so much more to this person. And I think and a lot of these situations and end-of-life care specifically about the concept of a good death. And how would this client's experience have been different if OT wasn't involved? His end-of-life experience probably he would have remained in bed. And so, we offer that additional skill set to understand a person's occupations, their potential to engage in daily life despite disability or limitations. So, I would like to believe his end-of-life experience was more positive by doing the things that mattered to him. So, that story really always stood out for me.

MATT BRANDENBURG:
Absolutely, absolutely. Thank you for sharing that story, David. That's a really impactful and a beautiful illustration of Occupational Therapy's role in this setting. Heather, was there an experience or story you wanted to share as well?

HEATHER MCKAY:
Yeah, I would love to share a story from my practice. But before I get into the nitty-gritty of that story, just as I'm sitting here listening to the others, all of those are new stories to me. I'm always amazed at how many just uplifting clinical cases this team has amongst us. But it's really, I don't know, making me reflect on the interdisciplinary collaboration that makes the OT intervention possible, whether it was Dr Jay picking up the phone right outside the patient's home or a nurse colleague putting in that occupational therapy referral that David was so glad to see come across. In the story that I'm thinking of, it was a social worker who reached out for an occupational therapy referral, maybe thinking beyond just what the rest of the team had considered thus far, because this is another story that comes from AOTA's position paper, Matt, that you mentioned at the top of the show. And this time the story, I believe, is also printed in the latest update of that AOTA position paper on OT's role in end of life in the 2016 and the 2023 version if folks wanna see more about the story.

But the social worker picked up the phone and made a referral to occupational therapy to help not just a patient, but the patient's husband, named Sam. So, Sam was a retired minister, devoted husband to his wife, Mary. The two of them have been living in a continuing care retirement community for quite some time. And by the time Mary came around to electing her hospice benefit, she was in the end stages of dementia. And Sam, in the condo right up the road from her dementia care unit, was her primary caregiver. He had a steadfast routine of visiting Mary every morning. He helped with her care. He journaled about their day, every day. And Mary's condition worsened, and her communication faded over the course of that hospice encounter. And the staff actually decided that they had noticed Sam's grief and fatigue were getting worse and worse too. So, the occupational therapist came in not to change Sam's whole commitment or devotion, but to help him find a healthier way to sustain that caregiving role.

And through their conversations, Sam and this OT, the OT learned that Sam's daily rhythm was his coping mechanism and it had deep meaning to him. He didn't want to rest more, and actually, the staff telling him, "You don't need to do this, stop doing this, we can do it instead, you should take care of yourself and not worry about this", those words were just rubbing Sam wrong. His top priority was continuing to be Mary's caregiver as long as he possibly could. He saw it as a way of fulfilling his vow to her. And together, the OT and Sam co-created an intervention that was a photojournal legacy project that documented Sam and Mary's life together and included photos and brief captions from Sam's journals and reflections about the everyday moments that Sam felt still connected him with his wife. And so, the process of assembling the journal became the therapeutic intervention. He gave Sam this creative outlet to express his love and to communicate more openly with the staff and the rest of his family, so they could kind of understand where Sam was coming from.

And he was able to reinterpret this caregiving role as storytelling rather than all obligation or heavy lifting. So, sharing that journal strengthened his relationships with the care team and actually offered his family a tangible legacy of the couple's life together when he turned his finished product into everyone's Christmas present. And Sam later said that the project helped him find new meaning while holding on to love with his wife. And his story just reminds me that OT's role in end-of-life care is not only to support the dying, but also to sustain those who continue living, and to help people like Sam and his family adapt and connect and carry that meaning forward.

MATT BRANDENBURG:
Wow. Thank you for sharing that, Heather. Sam sounds amazing. And that journal intervention sounds like a beautiful application, and lasting legacy and keepsake for him, his family, and the community as well. I wanna thank each of you for agreeing to be on the show, and also for the impact that you've made in the lives of the patients that you've worked with and their families in your communities. And thank you for your efforts and for your work in this space. And I'd love if our listeners and other occupational therapy practitioners, or whoever else may be listening, could learn more about how to follow your example and make that same level of impact by providing that same level of care to the people that they work with. We have mentioned already how advocacy and system change can be really important in this space. How do you recommend OT practitioners and other professionals of the care team could advocate for more integrated services in hospice and palliative care models?

LINDSEY BUDDELMEYER:
I think that really understanding the differences between palliative care and hospice are really an important space to start, and really getting familiar with that language and challenging yourself to be able to speak to what the place value OT brings to the care team. I know that a strategy that I use, particularly even when I was working on my doctorate program years ago and I still do to this day, is when I have an opportunity to be at the bedside or in a patient's room with a provider, I'm able to speak up at the right time and to share the breadth of what we can do. It's easy to get put into a box and to work in silos. And OT has every opportunity right now to stretch and expand into these very important spaces

as we look at population, health, age friendly initiatives. OT is critical to this work and supporting. When I did a visit a couple of weeks ago to a medical center, and I spent some time with a team who is looking at a new program called the Guide Model, the guide to improve the dementia experience, it was interesting because I watched the physician do an evaluation and had a great discussion with her.

And after the fact, I wrote down everything and sent this to her, everything that occupational therapy could do to help support that patient and that caregiver. So, she really understood what we were capable of. The patient was pretty nonverbal, but her caregiver had shared that she loved birds. And so, I proposed an exploration of leisure interests into how they could go for walks with her caregiver and talk about birds that they saw. The patient was incontinent at the time, and the caregiver was really struggling with how to manage that. And so, OT helping him to establish a toileting routine as well as where to buy incontinence supplies. The patient was also agitated at times, combative at times, and so helping him to understand how to prevent agitation and to identify certain triggers, but also how to respond to that, because he was very resistive and scared to take her to utilize any adult day or respite care because he didn't want her to get upset with someone else. And so, that's where OT can help to serve as a vessel and a guide.

And those are just a few examples. But saying that out loud and communicating that to the providers and our teams so they understand.

MATT BRANDENBURG:
Thank you, Lindsey. That's a wonderful example. I think we all hope to operate within a system and one day where we don't need to speak up to demonstrate OTs value but that's such a wonderful illustration of how coming with a plan and a written list in this situation of what OT can do to help someone improve their quality of life, can make a big impact, and can help us grow our scope as clinicians and as a profession. So, thank you for your efforts in that area and for providing a research base to help inform other practitioners to do the same. Heather, did you want to add something to that point?

HEATHER MCKAY:
What Lindsay is saying and really has me thinking about the breadth of our OT community and where OTs practicing with especially aging populations and larger populations with chronic conditions who may be nearing the final chapter of their progression and their life. They're not always in hospice or palliative care. And Doctor Jay mentioned at the top that he works for a home health and hospice agency combined. Under one roof, there's a continuum of care in his practice. And sometimes it could be the occupational therapist working in home health that has the first opportunity to clarify what are the most important things that a person wants or needs, or is expected to do, to talk privately with the

caregivers to get their perspective. I know we often talk about the limitations in our health care system, but I am so happy to report that there's an opening in our health care system that the home health benefit for occupational therapy is better today than it was six months ago, because now with the new CPT code, an OT working in home health can actually be reimbursed for their work just with the caregiver.

This is new. Everybody look into this because we used to be restricted to working only with the home health patient, and now our healthcare system and leaders and thanks to advocacy from all of our interdisciplinary colleagues and OT community, that OT is reimbursable with caregivers in home health. And those can be the initial conversations that help make the hospice transition more timely so we can demonstrate our outcomes not just by those of us lucky enough to work in hospice and palliative care, but all of our OT practitioners out there working with populations that we serve could be the first to ease that care transition. when we're demonstrating outcomes that matter to patients and payers alike, like improved quality of life satisfaction and lower costs from timely hospice transitions. The crew here might know the statistics better than I, but the average length of stay in hospice is not the whole six months of the generous benefit when people can get the most out of their hospice services.

In fact, it's more along the lines of days to weeks. And so, when folks can get at least offered and to consider their full hospice benefit, I think that we can get to a place of better outcomes for those patients and their families.

DAVID BENTHALL:
I think you raised a really good point, Heather. And I think that as OT practitioners, we look at palliative care and hospice care as these health care settings that are just distant. They're far-reaching away from us, and maybe think that we just don't have any connection to those settings. But the truth is, as OT Practitioners is that, it's not only a setting, as you've listened to the stories, a lot of these conversations about palliative care and hospice care is it's an approach. It's an approach to how you treat a person with a serious illness or with a terminal condition. It's not just a setting. And you're right, Heather, that there's gonna be people out there, you might be in acute care, you might be in skilled nursing. We're definitely probably focusing more on older adults, but even in pediatric practice, all clinicians at some point are gonna encounter somebody that may benefit from palliative care or may be approaching the end of life and may not even have access to these services as a resource.

So, advocacy just means that everybody is involved. It's not a separate setting that you think, oh, you know, somebody else is gonna do that. You might be the first person that brings up this conversation in a team meeting. You might be the first person who has that intimate discussion with somebody at the bedside where you're being an advocate. So, there's just so many opportunities. And as Heather mentioned, I mean, I could talk, we could all talk forever, but with the average length of stay for hospice being around 18 days, that means that a person is pretty much at the end, time is very limited. And when we think of the full scope of person in hospice care can qualify, if the expectation is that they have six months or less life expectancy, there's a lot more potential for conversations, to get people connected to services much sooner than what we're doing, where maybe OT services may be more appropriate. So, lots of opportunity.

CHRISTIAN JACOBUS:
Almost universally, palliative care providers, by job description, are typically friendly, outgoing and approachable, part of the job is rapidly establishing rapport and building trust. So, don't ever be afraid just to approach a palliative care provider and ask questions or say, hey, I've got this patient, what do you think about them? We're typically a pretty, pretty approachable group.

MATT BRANDENBURG:
I love that palliative care providers have a wonderful mindset. And as you put it, David, a wonderful approach to caring for the people that they work with. I love everything we've covered so far. Thank you all so much again for your time. I wanna wrap up our interview now with just a couple final questions, with the goal to empower our listeners to apply some of these insights into their own practice. I wanted to ask for those who may be interested in specializing in end-of-life care or transitioning into a role where they can apply this approach more fully in their practice. Where could they start, or what do you recommend they do to begin that transition?

LINDSEY BUDDELMEYER:
I just want to speak from my personal space of taking an opportunity to seek out grant funding, really leveraging data to drive your work. I took an evidence-based program called Skills to Care, which is a caregiver education and training program that was developed out of Thomas Jefferson University. I became certified in this and was able to leverage a space through the grant to provide these services, and we were able to continue to collect data to support that. This does, in fact, make a difference in terms of a decrease in caregiver burden and an increase in quality of life and patient outcomes. So, I think that you have to take opportunities like that. It's gonna take all of us to get there, and so that we are more of a standardized part of the care team versus an afterthought or a shared space, if you will, that maybe we can maybe we can't, that we show our value. And I think those are a couple of examples of how we can do that.

MATT BRANDENBURG:
Absolutely. Thank you. Lindsay. I wanna open it up now for final comments. Final stories or reflections that you each would like to share, as it pertains to specializing in end-of-life care, or what you hope listeners remember about occupational therapy and end-of-life care?

HEATHER MCKAY:
Well, I hope we've maybe planted some seeds and sparked some curiosity, maybe even excitement for this area of practice. But as David mentioned, no matter where you're practicing as an OTA or an OT, if you're interested in beginning that mindset shift that David mentioned to step into an approach rather than a new job title or different practice setting, I would encourage folks to think about, I mean, just with the nuts and bolts of our practice framework. Think about the kinds of occupations that may be new and even more meaningful as someone nears the end of life. I invite folks to look into the book 'Quality of Life', published by AOTA, as well as AOTA's position statements to learn more about what we call end-of-life occupations as a whole area of occupation, as well as look at some of the outcome measures that help us step out of independence or rehabilitation as our only measure of success. And just to maybe offer a few examples that folks might enjoy reading more about. Think about a frame of reference or perspective built around adaptation, like occupational adaptation, where we can look at change and quality of life, effectiveness, efficiency, satisfaction to self and others through a relative mastery measurement scale.

So, it may actually be a fairly reachable or accessible shift that folks could make in their current practice setting to think about frames of reference and other outcome measures to serve in this way.

MATT BRANDENBURG:
Absolutely. That's a wonderful recommendation for where to start and how to integrate this approach into your day-to-day. Chris and David, what would you like to share with our listeners to conclude our interview today?

CHRISTIAN JACOBUS:
I just wanna say that as OT practitioners, the work you do is so incredibly valuable. Thank you for doing what you do and being a part of healthcare. And if you are able to be a part of palliative or hospice care, thank you for that as well. It's a privilege to me as a palliative care physician whenever I get the opportunity to collaborate and interface with OT. So, I really appreciate the work you do. Thank you.

DAVID BENTHALL:
And I guess while it's just continuing to be present on my mind, I just wanna continue

emphasizing that, instead of thinking of hospice and palliative care, as Heather said, as a setting that may feel out of reach, we're all a part of palliative and end-of-life care in some way. And it may not be about the job title, but we all have a responsibility to support our clients who are facing challenging times, who may be approaching the end of their journey and I just encourage people out there, whether students or practitioners or people, again, just interested in the profession is to really try to stretch yourself and may feel uncomfortable. But when a person may be experiencing functional declines, when they may not be making progress to our traditional goals, to really dig a little deeper and explore as much as possible what is most important. What are the person's values and how may that be shifting as their health is changing. And that there's still an opportunity, potentially for your involvement, whether you're supporting a healthcare transition to a new setting or you're providing an intervention that supports end-of-life occupations or palliative care, that you don't have to look at it as some distant setting far off in the galaxy.

Wherever you're working, you can engage in palliative and end-of-life care through the approach that you use in your practice. And I'll just sign off by saying, I love I mean, these cases are very difficult, they can be very emotional, but there's so much joy and supporting people and their families in probably some of the hardest times of their life. It's just a privilege to be able to kind of ideally walk alongside people as they're navigating this difficult journey and to soften the decline, make their quality of life a little bit better, and try to make an impact on a person's life. So, can't recommend it enough.

MATT BRANDENBURG:
Absolutely. Thank you, David. Heather.

HEATHER MCKAY:
I'm good, thanks. Just a Wiley button. I must have been getting excited listening to all y'all. I appreciate you so much.

MATT BRANDENBURG:
How could you not get excited? I am excited after this discussion and really looking forward to doing more research into Occupational Therapy's role in this wonderful area and applying this approach to care. Thank you all so much for your time. It's been a pleasure learning from you and feeling empowered by your message and your examples. Last question. Are there any specific resources, funding opportunities, or communities that you'd recommend for our listeners who are interested in exploring more?

LINDSEY BUDDELMEYER:
Our book is certainly the first of its kind in our space. I will never forget our editor, Ashley Hoffman. After they had launched it at our national conference, she was there, and she

said that there was an OT practitioner standing in line. And she said, Lindsay, she was in line with the book that you all created, clutched in her hands. And I went up to her and said, you know, this is a new book for us. And she said she literally had tears in her eyes and shared she had been working in hospice for years, and that she's just been waiting for something like this to come out. And so, I hope that this body of work is one of many in the future to come. But really, we have to take what we have and also lean into other spaces. I've learned a lot through Dr Jacobus and his wonderful mentorship and guidance through the annual Assembly of hospice and palliative care and best practices in that community, as well as in the hospice communities and what best practices look like there. But those are just a couple of thoughts I have.

MATT BRANDENBURG:
Well, thank you, Lindsay, and thank you to all of our guests today. let's keep the momentum going. Let's grow a special interest section, a community of practice, and more opportunities for collaboration and exchange of information as it relates to occupational therapy and hospice and palliative care. I really appreciate your time. And thank you all so much for this interview.

HEATHER MCKAY:
That is wind in our sail. Thank you.

CHRISTIAN JACOBUS:
Thanks so much. This is great.

DAVID BENTHALL:
Take care everybody.

LINDSEY BUDDELMEYER:
Thank you.

SPEAKER:
Thanks for listening to the AOTA podcast. Tune in again next time. (UPBEAT MUSIC)