



Webinar Transcript

**ADVANCE CARE PLANNING
PERSPECTIVES AND
BEST PRACTICES**

A ROUND TABLE CONVERSATION

Dr. Stephen Bekanich, MD
Torrie Fields, MPH
Paul Malley, MA
Dr. Diane Meier, MD
Dr. Rebecca Sudore, MD, FAAHPM
Kathleen Taylor, MA, LMHC (Moderator)

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The Five Wishes Practice Community is a network of healthcare professionals who use the Five Wishes Program for advance care planning. The goal of the community is to enhance the quality and outcomes of advance care planning work through sharing best practices, resources, and information. The following transcript is from a Five Wishes Practice Community Webinar featuring preeminent thought leaders and influencers in the field. This hour of productive dialogue focuses on defining and clarifying effective advance care planning, ideal training competencies and techniques, ways to measure meaningful outcomes, and the importance of systemic approaches.

Welcome everyone, Five Wishes is pleased to present today's Practice Community webinar, Advance Care Planning Perspectives and Best Practices – a Round Table Conversation.

JOANNE EASON: Thank you, and thank you all for joining us today for the 10th Five Wishes Practice Community webinar.

Five Wishes started 25 years ago with the idea that patients – people – should have a voice in their care at the end of life, and that it shouldn't be difficult for that voice to be heard. Advance directives then, and some now, were hard to understand. And Five Wishes, well, the whole idea was to make it easy. And that's the idea behind our practice community. It's to make it easier for you to have the resources available to assist you in doing advance care planning on your day-to-day basis, and it's also here to help you have truly meaningful conversations with the people that you serve. We do that not only through our program resources, but mainly through sharing best practices, innovations, and highlighting thought leaders.

And speaking of thought leaders, we are honored today to have the group of people that we do, the preeminent thought leaders and experts in the field of advance care planning, and that they're gathered around this virtual table to help share ideas to inform

and inspire the work that you do every day. So, we're very grateful for them, and we're grateful for you for all the work that you do.

I'd like to introduce Kathleen Taylor, MA LMHC, who's going to moderate today's conversation. Kathleen serves as our Five Wishes Healthcare Program Advisor, where she brings nearly three decades of hospice and palliative care-focused experience in advance care planning, patient care, program design, community education, and professional communication skills training. So, Kathleen, thanks so much for making this webinar a reality.

KATHLEEN TAYLOR: Thank you, Joanne, and thank you everyone who's joining us today.

Just as a reminder, if you have thoughts or questions during our discussion today, please click on the Q&A button at the bottom of your screen and submit whatever it is that you'd like to add. The Q&A input is going to be moderated and captured today, so if your question or input isn't addressed during the webinar today, we'll follow up with you afterward.

Whether or not you read medical journals or listen to palliative care podcasts, you're probably aware that advance care planning is enjoying a period of critical thought and consideration right now. On the one hand, it's been required in some value-based models because of its benefits, and on the other hand, it's been criticized as ineffective in some research reviews. So, there is indeed a lot to talk about, and we welcome the conversation.

This discussion today is going to focus on what works. On best practices, adding value to the patient and clinician experience, and what advance care planning should mean and include in order to be effective in the evolving healthcare environment. And we have with us, as Joanne said, several experts in the field who think a lot, and know a lot, and influence a lot about all of this. So with that said, it's my pleasure to introduce our panelists today.

Dr. Stephanie Anderson, DNP, RN

Dr. Stephanie Anderson is the Executive Director of Respecting Choices, an internationally recognized, evidence-based system for person-centered decision making that transforms the healthcare culture by honoring an individual's goals and values. Respecting Choices is a division of C-TAC Innovations. Dr. Anderson has more than 30 years' experience in hospice and palliative care, home care, case management, and emergency medicine.

Dr. Stephen Bekanich, MD

Dr. Stephen Bekanich is Co-founder and Chief Medical Officer of Iris Healthcare. Iris, powered by Aledade, partners with primary care physicians to scale the delivery of personalized, expert-led Comprehensive Advance Care Planning. Dr. Bekanich is a palliative medicine

physician, was the CEO of one of the country's most successful Accountable Care Organizations, and has started and directed several palliative care programs across the country including University of Miami's Medical Center, University of Utah's Medical Center, and Ascension Health's largest palliative care program.

Torrie Fields, MPH

Torrie Fields is the Founder and Chief Executive Officer of Votive Health. Votive Health helps health plans and providers deliver high-quality care to people with serious illness through value-based agreements, facilitating better payer-provider integration. She also serves as Strategic Advisor to The Coalition to Transform Advance care. Her experience includes work as an economist and population health researcher in a variety of settings. She is an internationally recognized thought leader in value-based care and payment models for people with complex and serious health conditions.

Paul Malley, MA

Paul Malley is serving his 20th year as President of Aging with Dignity—the nonprofit organization that created the Five Wishes® program. As a national expert, speaker, and advocate for quality and dignified care at the end of life, he has guided the efforts of several aging advocacy groups to improve policy on advance care planning and patient rights, served on the Florida delegation for the White House Conference on Aging, and has testified before state and federal legislative bodies in favor of patient-friendly policies.

Dr. Diane Meier, MD

Dr. Diane Meier is Director Emerita and Strategic Medical Advisor of the Center to Advance Palliative Care, a national organization devoted to increasing access to quality health care for people living with serious illness. Under her leadership the number of palliative care programs in U.S. hospitals has tripled since 2002. She is a Professor in the Department of Geriatrics and Palliative Medicine, and the Catherine Gaisman Professor of Medical Ethics at Icahn School of Medicine at Mount Sinai, and Co-director of the Patty and Jay Baker National Palliative Care Center.

Dr. Rebecca Sudore, MD, FAAHPM

Dr. Rebecca Sudore is a geriatrician, palliative medicine physician, and advance care planning researcher. She is the Founder and Director of PREPARE for your Care, an interactive, web-based program that includes easy-to-read advance directives. The program prepares people and their surrogate decision makers to communicate their wishes and make informed medical decisions. She is also a Professor of Medicine in the Geriatrics Division at the University of California, San Francisco, and Director of the Innovation & Implementation Center in Aging & Palliative Care and the Vulnerable Populations for Aging Research Core of the NIA-funded Pepper Center.

Joanne Eason, MA

Joanne is the President of Five Wishes. Since 2014, she has strategically focused the Five Wishes program on creating unique new tools and resources, and building scalable programs to meet unique and specific advance care planning needs within organizations and communities. With more than 30

years of experience in healthcare and insurance communications, marketing, and relationship development, Joanne leads the program with a special emphasis on partner relations and collaboration, as well as insight into organizational decision-making.

Kathleen Taylor, MA, LMHC

Kathleen serves as the Five Wishes Healthcare Programs Director. She has nearly 30 years of healthcare experience with specific focus in advance care planning, palliative care, and end-of-life care. In her roles as a hospice clinician, program director, clinical trainer, and community engagement professional, she has fostered clear communication within families, care teams, and communities. Kathleen is a Florida Licensed Mental Health Counselor and Qualified Clinical Supervisor, and a Certified EQ-i 2 Emotional Intelligence coach.

KATHLEEN TAYLOR: Thank you everybody, we're so glad to have you all here. And now, to get on with our program.

I'd like for us to start with probably one of the biggest questions we might get to today, which is really defining advance care planning. Given all of the attention with the criticisms and looking at what works and what doesn't, there's been – this has been the subject of much thought, and some debate in recent months.

So, if we think about... I think everyone here can probably agree that good advance care planning is not check boxes and just aiming for completed advance directive forms. I think we've – we've moved past that as being what anybody would aim for. So, when we think about good advance care planning – when we think about the parts of it that work, how

can we arrive at some kind of definition that helps people understand? What is “the thing” that we’re talking about doing with folks? And I’d like to ask Dr. Sudore to start us off, because you’ve done so much work in this regard looking at the definition of advance care planning. Are you all right with that?

REBECCA SUDORE: Sure, yeah, and I’m also very interested to hear what other people have to say. But I think for your listeners to know, I think what’s interesting – you were talking about the evolving healthcare system, I would say this is evolving, and the definition of what advance care planning is, is evolving.

We had pulled together probably 50 different international experts on advance care planning back in 2017, and we realized quickly that – we actually convened them for something else, outcomes, which we might get too later today... And we found out that we had to kind of stop what we were doing, because these experts on advance care planning couldn’t agree on a definition. So, we came up with a preliminary definition. That was in 2017, and I can tell you that that’s still been evolving.

I can tell you very briefly what – how I define advance care planning, and that I’d love to hear from other people. So I think, simply advance care planning to me, is preparation for communication and medical decision making with a focus really on who that person is as a human being, what brings them joy and pleasure in life, and how they can sort of use that to make informed decisions for themselves or for other people to make decisions for them. So that’s how I think about it, really about that preparation.

STEPHANIE ANDERSON: Oh, I love it, Rebecca, and I, we completely agree. We see the definition evolving, and, preparing to make medical decisions – I would add to

DEFINING ADVANCE CARE PLANNING

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it’s a process of communication that includes understanding, it includes reflection, and discussion...

there “has” to be some foundation in the process where patients and families have an option, an ability to learn more about their illness and what we expect to happen over time as that evolves...

we may be making very different decisions every time we receive care, depending on what it is, depending on how we feel, depending on a lot of different things that are just not medically related at all...

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that the process of ongoing communication, and it being about conversations and

communications, and whether that's a digital experience, an in-person, virtual, whatever the modality is, but it's a process of communication that includes understanding, it includes reflection, and discussion.

So, not only just writing a name of a healthcare agent down, but discussing with that person so they're well prepared for that role. Thinking about what, you know, what attributes make a good health care agent. It's not necessarily your spouse or your family member. It's somebody that can make decisions on your behalf in difficult situations, emotional situations. And are going to elevate that individual that they're making decisions for - their goals, their values, their preferences - rather than their own preferences for that individual. So, I think I think our expanding thinking is that process as well as the definition to include more than just the individual, but the people that surround that individual that are important to them

KATHLEEN TAYLOR: Anyone else?

STEPHEN BEKANICH: I think there needs to be some degree of health care literacy woven in here.

Because you know, we've got lots of studies with... people who have serious illness, and they feel as though, you know, 70% of people with incurable cancer feel like they may be cured, right? And it's not because they're gonna go to Hogwarts hospital and be treated by Harry Potter. It really is because we use language that patients and families don't understand from the get-go. People hear the word treatment, and they equate that with the word cure, and so forth.

And so, I think there has to be some foundation in the process where patients and families have an option, an ability to learn

more about their illness and what we expect to happen over time as that evolves.

KATHLEEN TAYLOR: And that is, would be, to Rebecca's point, part of preparation, I would hope.

TORRIE FIELDS: I really appreciate that point, Stephen. I think I definitely don't have the expertise in parsing through the definitions of advance care planning like the others on this panel. But from - not only is this definition expanding and changing and evolving, but healthcare delivery is expanding and changing and evolving. And the treatments that people get and the choices people have to make are becoming much more complicated, due to medical innovation. Yay us, right? Yay healthcare. But that actually means that it really changes what informed consent and what treatment options mean for people.

And so, when I look at something like advance care planning, I think about it as planning in advance for your care, and if that is the truth, then we may be making very different decisions every time we receive care, depending on what it is, depending on how we feel, depending on a lot of different things that are just not medically related at all.

And that means that it really needs to be a conversation and discussion between you, your community, whoever that might be for you, and with your treatment team, who is going to do whatever they have to - whatever decisions they need to make for your care.

We often put advance care planning into this box of somebody who is seriously ill rather than thinking about somebody who has to make care decisions. And you just have to make more and more of them when you're

seriously ill. It's not that the process is really any different.

KATHLEEN TAYLOR: I think that's a good point, Torrie. And one of the things that I find a bit sometimes confusing is when experts in the field draw a line between serious illness conversations and advance care planning conversations. I understand that there are some areas of difference when a person has serious illness of course, there are pieces of the conversation that are going to have to do with diagnosis and prognosis, and with making appropriate medical recommendations. But my experience coming up doing this, you know, with hospice in the 90's and 2000's was really that that was part of advance care planning with anybody who was seriously ill.

So, I'm confused with what seems like a boundary between – this is an “advance care planning conversation” – this is a “serious illness conversation.” Are we – is it just words at this point? I mean the things that work, I think, are going to become the definition of what we want people to be trying to do. So again, what are the things that work? Preparing people for decisions. preparing people for the realities of some of those decisions... But is there also a role for people who aren't seriously, ill yet?

PAUL MALLEY: I would say, I would say yes, yeah. And Kathleen, you mentioned some of the early days and early years, and hearing some of the first comments today made me think back to when we were first creating the Five Wishes program in the late nineties. It was standing on the shoulders of the groundbreaking SUPPORT study from the Robert Wood Johnson Foundation that I know also inspired CAPC and Respecting Choices and many other programs that were aimed at trying to close the gap between – the dissonance between what people said

they thought they wanted at the end of life, and what they were actually getting.

And when we tie that to our own mission, what we see is a common uniter among all of us, that we have this united desire to take good care of the people we love, I think, across the board. Our friends, the people who we're committed to or have a responsibility to, our patients. And we saw how difficult that is when people feel like they haven't been able to do that. When there are family disagreements, when there are disagreements inside medical facilities. So, I think when I think about what is advance care planning, and also the difference between advance care planning discussions and serious illness discussions, it's are we moving people closer to that place where they can feel like they can say yes, I took good care of the person who I love the most, and fill in that gap.

For us, what we've seen is that that does include naming a decision maker, but also not stopping there because we've also over the past 20 years received a lot of phone calls in our office from people in emergency rooms who say, my mother named me as a healthcare agent and I just found out, and now I don't know what to do. I know I'm the decision maker, but I don't know where to start.

So, I think the magic that we've always looked for and why I think it's so useful to have this group together, is to find that sweet spot of how to have conversations with people today so that they can be ready to be a good caregiver, or a decision maker, patient, whatever the case might be, to give that good and right and best care at the right time.

And I love what Rebecca said about finding what brings joy to a person, because we also tried to pull that out in discussions of

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what good caregiving looks like, and who a person wants to be with them and those sorts of things. And although that's not the – kind of the biggest flag that flies on the advance care planning radar on the clinical or legal perspective, I think that that's what matters to people and families and friends and caregivers. So I think good advance care planning combines those things together in an effective way.

KATHLEEN TAYLOR: Yeah. And I think conversations early, conversations when someone's healthy, when they're young, when they've got nothing going on, I think, even though it may not directly relate to goal concordance of care right at the end of life, I think that's all part of the preparation, Rebecca, that you're talking about. If someone has the experience of talking about their values around end of life, of even exploring what the options are with some regularity, my belief – and I think what I've seen, although it's certainly hundreds of anecdotes, is that that does prepare people in some way for making those decisions when somebody in their family, or when

they themselves become ill. So, I'm hoping that we can define advance care planning still as something that's relevant across the lifespan and across the care continuum.

And that is going to lead me into another area that I want to talk about, which is professional training. If we keep in mind the things that work and what we hope people are doing, which is preparing all the people that we're talking about for making these decisions and what the realities might be, how do we train those of us who might engage in these conversations to have them well? And Stephanie, I'm wondering if you'd be comfortable starting with that because Respecting Choices is probably, you know, it's the most widely known training program out there. And we frequently hear people say that they use the Respecting Choices approach, which I know is very much about staging these conversations depending on where a person is... But what do you think the competencies really should be if we're going to be training people to do it well?

STEPHANIE ANDERSON: Well, thanks, Kathleen. I think there are several variables in consideration. One is a multi-modal approach. The second is, I wouldn't put the umbrella just over "professional." This can be a team approach including community-based organizations. We've seen amazing curricula using the Respecting Choices model in faith communities, for example – in trusted communities, communities of color and their faith trusted leaders holding these educational courses for those that it's appropriate to move this conversation upstream, as you've been talking about, that don't need the medical expertise in having conversations with a healthy adult. And the opportunity to help people learn how to listen first before teaching – so, listening and learning from the individual, exploring what

matters most of them, what cultural, spiritual, personal beliefs would impact their medical care, so, thinking about preparing for care.

I think another important component of the training is that if you have a skilled individual, whether that's a clinician or non-clinician journeying with an individual through a conversation, that individual becomes empowered to advocate for themselves in a way that might not otherwise happen.

And so, when you think about training, there are so many dimensions to it. There's the how to have the conversation. There's training on the system changes that need to occur so a conversation in a faith community gets documented and accessible to the healthcare team that would be providing care. There's the component of people that have a serious illness, and that then needs a – an additional component of training and how to walk with people about helping, you know, do you understand about your serious illness? How is that impacting your life? What does living well to you mean now with a serious illness.

And we would advocate that training includes – this is a point I try to make often, because we disagree with treatment menus in conversations and training – and so having a serious illness training that focuses on a conversation that is helping somebody to think about what an acceptable or unacceptable outcome of care is to them rather than specific treatment options related to whatever decision they might be faced with in the future, which is really impossible.

So, I guess I would summarize by saying multi-modal, multi-audience, not just education for having the conversation, but the system pieces around that make the conversation that education stick and work for the patient.

And then, finally, we have found a couple outcomes in our curricula. One is that you

can't just do asynchronous or tool kits and expect profound behavior change. There really needs to be a component of the competency-based skills acquisition. You know, role play, practice, we hear so many people say you know, I'm so uncomfortable doing this and by the end of practicing they have that comfort level that is now going to have behavior change. And so, I'm thinking about that again, speaks to that multi-modal and then scaling strategies.

So it has to be accessible, affordable, and scalable to the masses that are interested in and willing to be able to support the people they're caring for in these ways, whether that's in the community or in healthcare. Thanks.

KATHLEEN TAYLOR: Stephen, you train your facilitators with Iris. There's an intensive training there. And what they're doing, just to be clear, is really disease specific comprehensive advance care planning. So, it's in that serious illness conversation disease-specific realm. What are the competencies that you're training them to?

STEPHEN BEKANICH: Yeah. Well, let me just say I'm a Respecting Choices graduate and eternally grateful. You all were doing that before anybody else had anything to offer like that, and it's just had a huge impact on my life and I think millions of other people. And so, thank you, Stephanie. And Stephanie was one of my course instructors back in the day.

Yeah. So, I think at Iris, just there's certainly a lot of common elements to what Stephanie just went through. I would add, you know we're big on evidence-based communication techniques. And this is something – so I did palliative medicine training and went through Respecting Choices and CAPC courses, and so forth – this is something that

TRAINING

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negotiation, conflict resolution, demonstration of empathy, active listening, motivational interviewing, and so forth. There are these really rich techniques that we can use and apply to the rest of our lives...

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I didn’t get a lot of exposure to myself until later in life. And so that’s negotiation, conflict resolution, demonstration of empathy, active listening, motivational interviewing, and so forth. There are these really rich techniques that we can use and apply to the rest of our lives. Right? I use that with all my kids, use that with our animals, certainly use it in my relationship with my wife and friends, and so forth. That is a big part of what we do with the Iris training.

But I think that the other component here is everything that we do is recorded, and there’s a number of reasons for that. But everything we do with patients is recorded and I am a big proponent of – if you’re going to talk to people about this stuff, record it. And we may talk about that later with

standardization, and so forth. But, what this allows us to do in terms of training is create master facilitators, right? Because, you know, I cannot tell you how many people we’ve all trained collectively here on how to have conversations with patients and families, and the reality is, we cannot be in the room for all of those, right?

So, we have 3 or 4 trainees on our team. They go out and see the whole list of patients. We can only be in one place at a time, so we weren’t in the room to see the facial expressions, to hear the tone of people’s voice, to hear the words that they use – so we record everything. Every single thing. And in terms of training, we go back so our folks are on training wheels. And so, this is part of the mentoring program that we have – and we go back, and we first ride shotgun to all of their facilitations.

And then, even when the training wheels are off, we call it ears on. We’re an ears on company, like we are listening, listening, listening, even when you’re considered to be a master facilitator, because we can all get better at this over time, and we all need somebody to help us improve our communication skills continuously.

KATHLEEN TAYLOR: I love that we can always – we do always keep improving. I think these are skills that are deeply rooted, and as you said, useful in every aspect of life.

Diane, I wonder if I can ask you? CAPC has so many materials and resources about communication – also about advance care planning and serious illness conversations, but really communication overall. And I’m just wondering how you see this definition of what we should be training people to, what the competencies should be.

"the biggest barrier to initiating these conversations for clinicians... is this feeling that you're signaling to the patient that you're worried about them, and that you think they might die... So, my view is that the critical teaching is the routinization of these conversations, like seatbelts, bicycle helmets, vaccines... And by routinizing it, the valence, the fear valence goes down - and for both - especially for the clinician, because the clinician anxiety is the barrier - but also for the patient... We need to make this as core and routine and boring as everything else we would do in an encounter."

DIANE MEIER: It's a great question. Let me first say thank you to Respecting Choices, because our advance care planning content is Respecting Choices content, and our communication skills content is, as they say, powered by VitalTalk. So, we collaborate with the experts in the field and don't try to reinvent the wheel.

I would say the biggest barrier to initiating these conversations for clinicians, aside from time, which is a huge barrier, is this feeling that you're signaling to the patient that you're worried about them, and that you think they might die. And we don't want to scare our patients and we don't want them to feel like afraid to come see us for fear we're going to hang crepe and remind them of things they'd just as soon not think about, like most of us. So, my view is that the critical teaching is the routinization of these conversations, like seatbelts, bicycle helmets, vaccines. And

that's where I have the conversation, in that part of the discussion. "So, do you always wear your seat belt?" And you know, "have you been to the dentist? When was your last colonoscopy?" And then I say, "I discuss this with all my patients. Have you thought about who you might trust to make decisions for you if you lost the ability to make your own decisions?" Like I'm - I am literally checking off a list.

And by routinizing it, the valence, the fear valence goes down - and for both - especially for the clinician, because the clinician anxiety is the barrier - but also for the patient. I discuss this with all my patients. Not just you today, because I can see the writing on the wall and you're going to be dead within a year, but everyone. So, I think that's a very key message, you know we would never consider seeing a patient without checking the blood pressure and the pulse and the weight, and, you know, organizing the medication list and the problem list. We need to make this as core and routine and boring as everything else we would do in an encounter as opposed to something that has a drum roll and basses playing, because of the clinician anxiety, largely. Ok, so that's the first thing.

The second thing is, and everyone on this phone call knows it, it's very hard to honor patient's wishes in a healthcare system that only pays for acute care essentially, and the number of patients I've had who said, "I never want to go back to the hospital, I want to receive care at home," but they're not eligible because they don't have Medicare Advantage, or they don't have - they're not Medicaid - so no one's willing to pay for home care, the family member is exhausted and stressed, and at 3:00am they call 911. That is a system failure. That is not an advance care planning failure.

So, that is my belief that is why we can't show outcomes from all these advance care planning studies.

It's not that there's a problem with the advance care planning. It's that the healthcare system only delivers a glide path, and particularly for very vulnerable and sick people, their wishes are a very frail reed against the financial infrastructure and delivery models of the healthcare system.

And in a sense, I feel like that's where our attention should be. It should be on basically what Torrie is doing, which is trying to create a community-based care infrastructure and to help payers as well as health systems think about that, without the open faucet of hospitalizations in terms of money. That would really honor people's wishes way more than getting them to say what they would like in an ideal world. It's not an ideal world, and they're very likely not to get it because of that, and that's what frustrates me. It's like we're talking – I feel like we're talking to ourselves and not talking in the real world. So that's the first thing.

The second thing, and again everyone on this call has seen this, is the way in which someone like me might say, really, if I was significantly cognitively disabled, I really wouldn't want any continued life support. I'd want care only focused on my comfort. That's what I would say right now. I know and have seen enough times, people just like me change their mind when the alternative is death. And so, this notion that somehow what gives me joy and what I believe now has real salience for unpredictable future events in unpredictable future contexts, I think there's no data to support that. That people are incredibly resilient, and they shift what's acceptable based on the reality they're in. We don't have rigid autonomous preferences

and choices, we adjust. Look at all the people who are paralyzed from the neck down, who would rather live now. They've adjusted. Life is precious. There's still a lot of engagement and joy in it. Whereas from where we are right now, we'd say no no no, that's not a life worth living to me. And we shouldn't ignore that reality and one of my concerns is that we convey to patients, and I think this is why some patients are so resistant to this process, because they know they don't know what they would want in an unknown future.

And they're right, and we're wrong. They're right. They know that perspectives and choices and priorities change when circumstances change, and advance care planning has a very difficult time recognizing that reality. And therefore, what I do in my practice is that I discuss this with all my patients – who would you trust – and go into a little more detail on who that person can be, and that we have to talk to them, perhaps they could come in at the next visit.

And then the second piece is, I only ask one thing about their preferences. And that is, if you were to walk out of my office here today and be hit by a truck and be permanently brain injured and cognitively impaired, such that you could no longer recognize and interact with your loved ones and weren't expected ever to be able to do that again, so basically in a vegetative state or a permanent coma, I then say, some of my patients say in that situation they would want care focused only on their comfort. But others of my patients say, life would still be worth living to them. In that situation they would want continued care focused on keeping them alive. Which kind of person are you? So, I am not judging the "I want everything done" group, I'm offering it as an equally valid choice. Some of my patients say A, others say B, which kind of person are you? And it doesn't – the patient

"We've got points of care all over the place where these conversations could be revisited, and I'm really hoping that what people understand going forward about advance care planning is that it's never done. It's not done. You can't say I've done it with this patient, and so we don't need to look at that again. It just means we need to revisit that pretty much every time there's some kind of shift in this person's life."

can't pick up a judgment from me, hopefully, and that's enough. That's it. Those two things I think you could get a lot of clinicians to do, because it's pretty simple and pretty straightforward, and probably 5 to 7 minutes. If we were consistent and standardized in how we trained at the Medical School and Residency level and nursing school.

So, that's my speech on advance care planning.

KATHLEEN TAYLOR: It was lovely. And I really appreciate what you said about the routinization of these conversations, and a lot of what you said is the same language we have in the Five Wishes Conversation Guide for Clinicians, which is about the – the whole idea is if you're not going to get training where you can do the role plays and really get comfortable with this, here's just a simple guide and some things to say. And one of them is "I like to have this conversation with all of my patients." So I think, in addition to having it be routine, having it be regular – because people change their mind, and because their social support system changes, and because they may have had experiences

with somebody else who is ill and they've learned something about what they're afraid of, or they want, or they don't want – to have these be regular and routine. We've got points of care all over the place where these conversations could be revisited, and I'm really hoping that what people understand going forward about advance care planning is that it's never done. It's not done. You can't say I've done it with this patient, and so we don't need to look at that again. It just means we need to revisit that pretty much every time there's some kind of shift in this person's life. So, I like all of that for training.

REBECCA SUDORE: I just want to make another point, because I think it was really important that Diane brought up, which is this idea that you can change your mind, and I feel like we don't tell patients that. I think we tell patients it is a one and done thing, and we don't tell people it's a process. We don't tell people, hey, we have this conversation now, you could change your surrogate decision maker tomorrow because something changed in your life. You could change how you feel, and that's normal – that is a human process, and we'll go through the process together.

But I think we need to educate clinicians, but we also need to educate patients that that's part of the process.

TORRIE FIELDS: By making it, by making it more routine, Rebecca, from that perspective, then you're able to actually leave the clinician's office and have a conversation about what your cultural preferences are, what your family's preferences are, and you're able to come back as a more informed decision maker the next time around. And that's something that often is missed in these conversations because you're only having it once, and right when you need it, or you're

"I have a routine conversation using Five Wishes with my nieces and nephews who are children, and as part of that, they also understand that this is something that is part of life and that it can change over time as they grow older..."

only having this conversation introduced because somebody is diagnosed as ill.

And so, then it becomes a situation where you're forced to have to make decisions in this one situation, without the ability to consult others, or to really reflect on those things. And every day is a new experience, and it becomes a – something where it's very difficult to have these community activities around advance care planning where people are teaching one another, or they're documenting Five Wishes alone without a clinician present – because they don't have that in their regular workflow, in their regular routine – and that makes it really difficult for folks to understand – clinicians or patients and families – to understand how to use these tools. So, you have to be really educated in order to even know how to use these tools. Whereas, you know, I think I have shared with the Five Wishes team earlier, like, I have a routine conversation using Five Wishes with my nieces and nephews who are children, and as part of that, they also understand that this is something that is part of life and that it can change over time as they grow older, right? But if you're only asked that one time, it becomes – it becomes a situation where you're forced to make decisions.

PAUL MALLEY: And that's beautiful to hear, Torrie. And I think the connection between all of those comments is that it sets – the

frequent contact sets the context and also the motivation. It answers that question of why is my doctor talking to me about this, or why is my husband or wife asking me about this. And I think that sets the bridge that – if we don't set it, then it's an automatic barrier that we can't get past step one. And setting that context and motivation, I think, is critical, because otherwise you can't move beyond it.

KATHLEEN TAYLOR: I want to move us forward by blending 2 areas that I had originally thought of as separate topics. But, I kind of want to mush them together now, not only in the interest of getting to them with the time that we have, but also because I'm starting to think during this conversation they're really highly related. One of them is measures and outcomes. We talk to so many hospitals and health systems and clinics at Five Wishes, and I think everyone on this call knows that if you've seen one advance care planning program, you've seen one advance care planning program. Generally, systems struggle with what I would call ownership and leadership. Most programs are not truly programs, they're mostly intervention based and there lacks a programmatic support for doing these things – but what drives program support IS the measures. If people can't make a case to their organization about we should invest in this, then they can't get the systems in place to do the work in the way that we are talking about.

So, my 2 pronged question is, what should we be measuring? And how can we measure things that can help us put systems in place that encourage and support clinicians in having the conversations in the ways that we are talking about today? I don't even know who to start with I'm just going to let anybody who's got something to say jump in.

STEPHANIE ANDERSON: I'll jump in. We've had a focus on system redesign forever. Because without that the conversations, as I said earlier, sometimes don't mean anything because they're siloed and nobody knows about them, and they're not transferred etc. So I'm actually going to flip, Kathleen, you talked about measures first, then system – but I'm going to actually talk about the system, because the measures then, I think, work to support evaluating that system.

And so, from a framework standpoint, we have a philosophy of freedom within a framework. So, the framework is the system that, through evidence and experience, etc., seems to work. And then, the freedom to adapt to the individual organization, the culture, etc.

So from a system standpoint, thinking about 2 components within whatever system you're implementing. A health system, a single health organization, an entire state of organizations working together – there's a component of wide implementation that spreads across all, and a component of deep implementation that goes deep into where the actual individual is being served.

Right? So, there's those 2 components, and within both of those, leadership matters. That's one – you know, you can't do anything without engaged supportive leadership, and that needs to happen over time, not just, oh this is the new fun thing and I'm going to move on 6 months later.

Redesigning the systems – if you think about ACLS as an analogy, it's a very systematic process where the people know their roles. They know what they're supposed to do at the time they're supposed to do it.

The Meds are available. The crash carts are available. It's measured, evaluated, and

changes based on measuring that process, that system.

And then we've been talking about the team. Defining the roles and responsibilities. Who is on that team and what is their role?

The community engagement – what messages are working with individuals in the community that you're working with, what messages work with the providers on the care team?

And then that leads to the measurement piece of it. And I would advocate that you need both implementation measures to measure that process until you have it hardwired, scaled, and sustained, as well as the longer-term outcome measures.

And I want to give time to my colleagues here, but I do want to advocate for – I know the public comment period is open for the NQF's being heard and understood measure. I think it's an incredible measure, we're fully supportive of that. I thank Torrie for being a key player in that measure.

I also am putting a shout out, Diane and I talked about this not too long ago – we hear experiential evidence of the individual's experience in having quality advance care planning conversations, and it can be life-changing. It's powerful, it's profound if it's a skilled conversation and it continues over time as their goals change. I've not seen any research and if it's out there, let me know. But I'm looking for researchers that want to elevate the voice of the individual and this experience through this experiential, anecdotal... Every organization we work with – they tell these stories, they have these testimonials. And we're not capturing that and how powerful this work is. And it could be – from working through a Five Wishes document on their own, it could be a digital online experience, can be in-person – again,

multi-modal, but they're all having – not all – I'm hearing so many having such a profound positive experience in engaging in quality advance care planning conversations. So, I'll conclude with that shout out and ask.

TORRIE FIELDS: I'll share that Dr. Lauren Jodi Van Scoy, from the University of Pennsylvania at Hershey, has actually performed this research repeatedly, in partnership with an organization called Common Practice, in evaluating the tools for advance care planning in the community, particularly in underserved areas. So, there is evidence and research out there, it's just not widely disseminated, about consumer empowerment, and how people feel about making care decisions as a result of advance care planning tools and resources and these types of conversations.

KATHLEEN TAYLOR: Torrie, can you repeat the name of that researcher real quick? You blurred out on my audio a little bit.

TORRIE FIELDS: Of course I can. The researcher is Dr. Lauren Jodi Van Scoy, from the University of Pennsylvania at Hershey, and their partnership was with Common Practice. They created the Hello game.

And I agree wholeheartedly with Stephanie. I think that the way that I think about measurement is really around structure, process, and outcomes. So, in terms of the structure, I think it is important to track routinization of this type of event and care planning, and I think there's a lot of movement in this direction on the Federal level, requiring advance care planning as a part of models, as a part of ACOs, as a part of other value-based payment arrangements, so that these things actually are documented and collected. And that can be a count. That can be a start. That just says how often is it occurring in the workflow. The process piece, as Diane – as you were sharing, is really around

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– was care changed or impacted, and you can really measure that through referrals to other things or other services. And advance care planning is a great start to really understand what people need from the overall system or the system at large.

And there have been a lot of innovative models of tracking what the outcomes are from advance care planning, once that's initiated, to determine if somebody gets more or less of what they want, or things that are available. And HighMark – the Blue Cross Blue Shield plan – they are the leaders in this, really evaluating and measuring advance care planning as: how was the system changed, and was the care impacted. And I think ultimately all of that work came out of the value-based insurance design (VBID) project that they've had where advance care planning is a requirement for any VBID participant for Medicare Advantage. And we have a lot to learn from those participants there in how they're tracking and measuring things.

And then on the outcome side, I completely agree around the “heard and understood” measures, which is really around – how can we measure the patient reported experience or the patient reported outcomes? Because you can't change everything, especially if the underlying system is broken already, but what you can do is help ensure that somebody feels heard and understood, and that the

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trusted relationship between the person and their care team is at least intact through having these conversations. And to me, that is an end in and of itself, even if they change their mind, even if they can't get everything they want, we can't fix a broken system just with advance care planning. But what we can do is help build that trusted relationship and be that ongoing guide for someone. And now we have actual measures to be able to evaluate that.

And while the NQF measures are about "heard and understood" in the seriously ill population, I think there's a real opportunity to test out these measures in a more well population in an ACO type environment or a population health approach, because those are the things we want to measure. We want to measure how empowered our consumers are and if these conversations make an impact or a difference there.

KATHLEEN TAYLOR: I love that focus because I think there's been so much attention with advance care planning in looking at – not that there's anything wrong with this – but looking at reduced costs. And I think those are important, but it doesn't ever tell me, how did the care go? So, I really appreciate the importance that you're giving, and your underscoring the need to ask the people that we serve how this went for them. It reminds me, NHPCO – the old FEHC (Family Evaluation

of Hospice Care) survey used to have these confidence questions – do you remember those? – that went out to bereaved families that would ask them questions like, how confident did you feel in providing care for your loved one? And how confident did you feel in doing these tasks? And I think things like that really help us understand, you know, did we do what we meant to do? And I like what you're talking about with moving to measuring some of those things. And I'm hoping that the system leaders who are on with us today are hearing that, because it is possible. You can measure more than completions and number of conversations. And I hope that that people will, because those are really not outcomes, they're outputs. And they don't tell us much, and that's kind of the problem that got us to the conversation we're having today.

It's a big topic, but I want to – before we close – spend a couple of minutes at least talking about... kind of related to asking people what worked for them, how can we – how can health care providers better involve all of the stakeholders in advance care planning? Because the truth is that people are doing it without us.

They're doing it in their communities, they're doing it in their families, they're doing it with lawyers, they're doing it with financial planners. So, how can we better involve all of the stakeholders in what this is, and in how we build systems to support it and how we measure it?

STEPHEN BEKANICH: I'll go first. I will say that, you know, I think anybody who's been in palliative care practice, this has happened to them... where we see the patient during the day, it's during normal business hours, but the adult daughter or son who lives a few states away or was at work during the

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day was not part of the conversation. And so, you're speaking to them after 5 pm when they're free to update them on what you said to Mom. So we do this evenings and weekends. Everybody joins. Everybody hears the same information. Everybody gets to ask their questions. And I think that to do really high-quality advance care planning, you have to get the spouses, the adult children, the people from their faith community, their neighbors, whoever their caregivers are, whoever they want in their tribe here, to be part of this. And the delivery system that we have in place where it's, you know, 8:00am to 6:00pm Monday to Friday just does not work for most people. And so, I think that we've got to do this on the patient and family's time, not on our time.

PAUL MALLEY: And I would add, I love the idea of stressing the importance of being united in purpose. In the same way that we have to let our patients know, you know, here's why we're asking you this question, and it's to provide the best care possible

and know what's important to you – that's the same message that needs to go out to the faith communities and workplaces. And everybody who is flying an advance care planning flag, if we're united in purpose, people will respond to that, I believe. And we've seen it. And I think what we've seen over the past 10 years especially, is that things like, you know, making advance care planning reimbursable was the discussion, the VBID options that Torrie has talked about – these have all been helpful things, but they haven't fixed everything.

And so, if we add to those helpful things outreach on the part of health systems, not from clinicians who don't have the time to do that, but from others in the healthcare system who are educating the community, working with workplaces and faith communities and other existing communities, and helping families have these conversations on their own. And then be able to circle back and make sure it's documented and known within the health system. What I've seen from my own experience and the people that we've worked with and in our own family, is that the magic with advance care planning often happens when the person leaves that consultation. In the car, or at home, when they're talking with their spouse or their son or their daughter. So, helping them be empowered to do that, I think is key – and united in purpose.

KATHLEEN TAYLOR: I think that's very well said, Paul, and thank you for that.

I'm going to leave that as our closing words. Thank you, thank you, thank you so much to all of our panelists today. This has been, I think, a wonderful and productive and meaningful discussion. And I look forward to continued dialogue and partnership with all of you, and thank you again to everybody who's joined.

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