

# Best Practice – Goals of Care Conversations

## Transcript

[Upbeat theme music plays]

### **Dr. Clancy**

Welcome to Rounding@IOWA, a continuing medical education podcast developed by and for healthcare teams. I'm your host, Dr. Gerry Clancy, Professor of Psychiatry and Emergency Medicine and Senior Associate Dean for External Affairs here at the University of Iowa's Carver College of Medicine. In this end-of-life continuing education podcast, we will discuss guidance on best practices for goals of care discussions among those with serious illness and prognosis. Our objectives include: First, we hope our participants will be able to identify when the right time is to begin goals-of-care discussions with patients and family members. Second, we would like our listeners to be confident in advocating within their hospitals and health systems to develop and implement programs that promote goals-of-care conversations. And third, we want our listeners to gain new skills in having goals-of-care conversations with patients and family members. Our expert guests today are Katie Ries, Carol Harshman, and Bryan Struck. Katie Ries has been a social work specialist with the supportive and palliative care team at the University of Iowa Hospitals and Clinics since 2016. In this role, she is actively involved in goals of care discussions, family meetings, advance care planning, and hospice discharges. Katie has served on several committees at UIHC related to improving end-of-life care hospital-wide. Prior to UIHC, Katie had nearly 10 years of social work experience in hospice and case management for the elderly. Katie serves on the board of directors for the Hospice and Palliative Care Association of Iowa, which allows the opportunity to advocate for access to enhancement of palliative care and end-of-life care across the state of Iowa. Katie received her BSW and MSW degrees from the University of Iowa. She's an adjunct instructor at the University of Iowa School of Social Work and has taught several courses over the years, including Death and Dying and Aging Matters. Carol Harshman is a supportive care nurse on the Supportive and Palliative Care team at the University of Iowa Hospitals and Clinics. She pioneered the supportive care nurse role, which began in 2017 as a pilot project, partnering with the internal medicine hospitalists. The supportive care nurse team now has four nurses and expanded their service to the emergency department and intensive care units. The role offers primary palliative care, which includes advanced care planning, earlier in the illness trajectory. Harshman is a certified hospice and palliative care nurse.

She is a Last Steps Advanced Care Planning Certified Facilitator through Respecting Choices and is a palliative care resource and educator. She earned her bachelor's degree in nursing from the University of Iowa and has practiced in hospice and palliative care for 15 years. Dr. Bryan Struck is the director of the UIHC Supportive and Palliative Care Team. He is a clinical professor of internal medicine in the General Medicine Division. He attended his medical school and internal medicine residency training at the University of Texas Health Science Center in Houston. He then completed a geriatric medicine fellowship through Baylor College of Medicine and the DeBakey VA Medical Center in Houston. We both were in leadership at the University of Oklahoma before coming to the University of Iowa. To all of you, welcome to Rounding@IOWA.

**Ms. Harshman**

Thank you for having us.

**Dr. Struck**

Glad to be here.

**Ms. Ries**

Very excited to have this discussion. Thank you.

**Dr. Clancy**

Thanks for joining us and thank you for the work you do. I just provided our listeners your official title and the summary of your training. Could each of you give us a better idea of your daily efforts and what a work week might look like for you? And let's start with Katie.

**Ms. Ries**

Awesome. So each day and each week are a little bit different, but they do contain some similarities. Each day there are about four or five providers on the inpatient service. There are three of us social workers on the team, so we each cover one to two of those providers and teams. So usually we touch base with the provider, touch base with the teams, just to get an idea of any updates on the patients, what are the plans or the goals for the day for that patient? Are there meetings scheduled, et cetera? And then based on those discussions, I move forward with my day, which usually involves patient care of some sort or direct patient work. Usually it involves attending those goals of care or family meetings. We provide a lot of support and resources to patients and families. We also do a lot of hospice discharges, hospice planning. And so that can look like home hospice. We set that up. They go to a local care facility for hospice. We coordinate that as well as like a hospice house or a hospice facility. We also do a lot of general inpatient or GIP admissions either

here at UIHC or maybe like a local hospital closer to where the patient is. We do a lot of advanced directives, advanced care planning, so it's very common that we're helping fill out a healthcare power of attorney or honoring your wishes document.

**Dr. Clancy**

Great. Carol, how about you? What's a day and what's a week look like for you?

**Ms. Harshman**

So for myself and for the entire supportive care nurse team, we average about 45 consults during Monday through Friday work week. And the supportive care nurse team, we assist patients living with a serious illness. And our team is comprised of nurses who are specialized to work with patients and families to meet their goals. We serve as patient care and support advocates. We often are consulted to offer emotional support, active listening, encouragement, and an empathetic presence. During our consults, we initiate conversation about primary goals of care, and we assess symptoms. We teach about advanced care planning and help identify surrogate medical decision makers. Those are the basis of our consults. And each of us throughout our weeks, we attend different bed huddles on the teams that we serve, such as I go to the cardiovascular intensive care unit every morning. We also attend family meetings with the palliative care team. Each of the supportive care nurses have an active role in providing education. We're oftentimes giving presentations, such as tomorrow I will be giving a presentation with a nurse practice leader on end-of-life care best practices. So our weeks are busy and we are very thankful for the consults that we are able to do.

**Dr. Clancy**

Great, lots of variety. And Bryan, how about you?

**Dr. Struck**

Yeah, when I'm doing my clinical work, I can either be doing a clinic, either at the University of Iowa or at the VA, where I'm taking care of patients living with a serious illness. Mostly that clinic is symptom-related a lot of times, although we do have conversations about complex medical decision. If I'm on the inpatient consult service, I'm seeing patients that are in the hospital with a serious illness and having those conversations as well as processing what symptoms need to be controlled, working with the rest of the team as we try to figure out what's the best treatment plan to figure out what their goals are and figure out what treatments are aligned with their goals.

**Dr. Clancy**

Well, you've crossed paths with me on the psychiatry consult service, and I will say you do outstanding work, all of you, so well done. This is not easy work, and it's special. It almost takes a calling. What drew each of you to specialization in palliative care? And Bryan, we're going to start with you.

**Dr. Struck**

Well, I started life off as a geriatrician, and my interest was actually in the frail elderly, realizing that sometimes you just have to meet patients where they are and don't go looking for things if it's not broke, and just figure out what's important to them to keep them in place. And then that just naturally led over to palliative care, an opportunity to move over to the VA when the VA was expanding their palliative care program in Oklahoma City. And so I started creating that program, and that's where I spent the last 20 years growing that program.

**Dr. Clancy**

How about you, Carol? What drew you to this work?

**Ms. Harshman**

So you said the word early, calling. I felt called to this work. I was living in a small town in southern Iowa, getting my nursing degree at that time and doing clinicals at small rural hospitals where the population was oftentimes elderly. And I felt very drawn, very called to be at the bedside with those patients and families. I felt very comfortable. And in my early year of nursing education started to learn about hospice care. And it was at that time that I felt called to go into hospice care nursing. I spent many years as a hospice nurse, whether it be going to homes, nursing homes, and then moving up to the Iowa City area, was an inpatient hospice nurse. And then back in 2017, I learned about palliative care. And then it was at that time that I was hired to pioneer the supportive care nurse role. So it was a calling.

**Dr. Clancy**

How about you, Katie? You deliver care, you coordinate, and you teach. So how did you get to this point of this is what you're going to do?

**Ms. Ries**

I actually really like getting asked this question because when I was in college, I wanted nothing to do with this area. My professors and my advisor, they must have seen something that I did not see for myself. They encouraged me to, you know, you should really specialize

in end of life and take more of these classes and get a certificate. And I kept saying, no, I want to work with kids and youth. So I didn't even really entertain that idea. But when I graduated with my master's, I needed a job and pretty much I was going to go work for whoever would hire me, right? And that happened to be a hospice agency. And I couldn't believe that I was going to be working for a hospice agency, but I needed a paycheck. And when I started working there, I absolutely fell in love with it. And then from there, I started working at aging services with the elderly population, and that even grew my love more for this type of work. Social work, the field itself is very patient-centered care. We really get to draw on our empathy skills and our listening skills, the stories we get to hear from patients and families, and the advocacy we get to do as social workers. And this is very much what palliative care is as well. So I'm able to combine those two things. But yeah, I would say my passion for it definitely grew when I was working with the elderly and aging population.

**Dr. Clancy**

I too as my career has gone on have realized the importance of this and actually the fulfillment of work in this area as well. Hats off to all three of you. So how's your team organized? All three of you have mentioned team. So what does the team look like for someone from the outside looking in?

**Dr. Struck**

I would just say we have a lot of growth over the last 25 years. Currently, we have a total of seven different physicians that will work with our team. Some of them are full-time, some of them are part-time. We have four nurse practitioners, three social workers, four supportive care nurses, about one and a half chaplains that work with the team, and a music therapist. So that's sort of what the team looks like every week. We meet and we discuss more of our urgent patients and then we discuss how things go throughout the remainder of the day. It's key to have communication so that we kind of know what is going on.

**Ms. Ries**

Yeah, we were actually chatting about this yesterday. When I started in 2016, we had, I think, 16 team members total. And now we are over 30. I think we might be hitting like 32 or 33. We've doubled in size just in eight years. And I think that really shows the importance of our team and that the hospital values what we do.

**Ms. Harshman**

Yeah, and as both Katie and Dr. Struck said, the supportive care nurse is also part of the palliative care team. And then we also have our supportive care nurse team that's four

nurses and that we do our own independent consults, but yet we are also part of the palliative care team. We're connected to them. We're in communication with them. We're in collaboration with them. And we went from, in 2017, there being myself, one supportive care nurse, to now having a team of four supportive care nurses that are a part of the greater palliative care team.

### **Dr. Clancy**

Well, to begin our discussion on best practices for goals of care discussions, let's start with a case that is quite personal to me as the main characters are my father and myself. My father asked me to use his case as an example for future physicians and clinicians to learn from. Let's get started here. And then afterwards, we'll have questions and we can use this case as the material for answering some of our questions as we go further. The setting is 1998. Our patient, a recently retired physician, was a colon cancer survivor from 10 years previous with treatments for that via surgery and chemotherapy. He was able to golf and play tennis daily and enjoyed traveling back to his homeland of Ireland and wintering with his wife and friends in Florida. Shortly after returning from Florida in the early spring of 1998, he presented with acute aphasia and a hypertensive crisis with a blood pressure of 240/130. He was admitted to the medical intensive care unit where his blood pressure was controlled and his aphasia fully resolved with control of that blood pressure. Head CT, MRI, cardiac and cerebral artery angiograms were entirely normal, but abdominal CT demonstrated a large lower abdominal mass blocking a ureter and causing hydronephrosis in one kidney. Debulking surgery and ureter repair was successfully performed. Tissue typing of the mass noted adenocarcinoma. He began chemotherapy and radiation therapies and recovers fully from that surgery. His son, also a physician, served as his durable power of attorney and executor of his will. Of note, it was 1998 with a patient who believed he was totally healthy just a few weeks previous. No living will was in place, no advance directives were in place, no goals of care were discussed at this time. Instead, simply pressing on with an aggressive care plan as the patient had a very strong will to survive and to continue to enjoy the retirement he had worked so hard to reach. Six months into the treatment, the patient began to experience mid-level back pain. A repeat MRI is performed, and at 10 p.m., the patient's son received a call from the radiologist, who was a good friend, who informed the son that the MRI showed extensive bone metastases throughout the thoracic and lumbar vertebrae, as well as a new lower abdominal mass. The son immediately drove to his father's home and informed him of the MRI results, both knowing without saying too much to each other, other that this was proved that the most advanced stages of colon cancer with probable extensive multiple organ metastases was in place. The patient and son met with an oncologist the next day and additional debulking surgery was offered. The patient asked how long it would take to recover from this surgery,

with the answer being four months, followed by the question of how long do you believe I have to live, with the answer being probably four months. The patient was speechless and looked at his son for help. The son stated that we will decline the surgery at this time with a look of great relief from the patient. The next day, the patient's primary care physician was contacted. Home visits by that physician are arranged, and a full team of hospice services as well as Catholic Church support were initiated. The patient became bed-bound, received increasing levels of morphine and lorazepam for pain control. On an index card, he wrote the son a passionate plea to educate physicians on these issues, around end of life. Specifically writing, far beyond the highest levels of scientific knowledge and technical skill in medicine and surgery, for a physician to be most helpful, it is far more important for that physician to demonstrate the deepest level of care, understanding, and compassion in each and every patient. A few days later, the patient slowly drifted off into a coma. The patient died peacefully, without pain, at home, surrounded by family, seven weeks after coming home. So all of you, what are your reflections on this case? Remember, it's 1998, and just think how have things changed and improved here in 2023 regarding palliative care, goals of care discussion at the individual and at the system level.

**Dr. Struck**

Well, I was just going to say, you know, what kind of strikes me is that 10 years prior to 1998, you know, he had been living and being treated with colon cancer, and yet there hadn't been any discussion or forethought to actually start doing the planning as far as if things change and get worse. What are your goals? What's important to you? What do we need to focus on? And hopefully today that is starting to be more opportunities to have those conversations, whether it be, you know, with somebody on your healthcare team.

**Dr. Clancy**

Katie, you want to chime in?

**Ms. Ries**

I was essentially going to say something very similar to what Bryan said. Just the fact that your father had such a serious, life-changing, life-altering diagnosis, and no one on the medical team or oncology team thought or broached the topic of goals of care and what, like Dr. Struck said, what would you want if things were to progress or get worse or come back? So yeah, it just wasn't even, wasn't even broached, wasn't even mentioned. So that was pretty eye-opening to me.

**Ms. Harshman**

In addition to that too, you mentioned that there was no durable power of attorney for healthcare at that time. And so having those conversations with a surrogate medical decision maker about his wishes, his values about medical interventions, and just that ongoing conversation about what he would want and perhaps about what he would not want.

**Dr. Clancy**

I can say, personally, that this is an instance where hope was really a major central factor. Hope on the positive side that everything would turn out, but we did not venture into the territory of when hope is not nearly as possible, what then? What did you see? I know you've kind of touched on this, but did you see anything else that could have improved the course of care and support?

**Ms. Ries**

One thing that I thought of right away was, what was your dad or even your access to an interdisciplinary team to assess, explore, and address all aspects of his well-being and your well-being and care? Obviously, we know there's the physical aspect of his cancer, but I'm sure there were probably some other aspects that were definitely influenced and affected by his diagnosis. So the fact that it seems like there was a lack of maybe social work involvement, spiritual involvement, just exploring his overall well-being stood out to me first.

**Dr. Clancy**

It did feel like handed off from specialist to specialist back then. It really did.

**Ms. Ries**

I bet.

**Dr. Clancy**

And I did feel like I was the glue that at least tried to keep it together. How about barriers using this case? What are some of the usual barriers to effective goals of care discussions?

**Dr. Struck**

Well, I think one, as you were just talking about kind of the communication with the healthcare team, you know, nobody wants to say how severe the illness is. And nobody wants to say or ask if there may be other options that the patient wants, because especially from the physician standpoint, you've just always been trained to give out that next

treatment. And I think your case illustrates that you were offered that next treatment and you immediately said no, that's not the treatment that we want because it doesn't meet our goals. And then so hopefully things are kind of starting to change to be able to have that person that's delivering that serious news be able to say, I really want to know what's important to you before I tell you what we can do.

**Ms. Ries**

Yeah. And I'm gonna guess back in 1998, there probably, and please correct me if I'm wrong here, but I'm guessing there probably wasn't as much focus on the educational aspect, you know, with our medical students, nursing students, social work, et cetera, I don't think from what I've been told or what I've read that there was as much focus on adding this component to the curriculum.

**Dr. Struck**

No, you're absolutely correct.

**Dr. Clancy**

Yeah, very much so. As a medical student, yeah, we were miles away from learning these discussions. And later on, I was part of the start of having difficult conversations with patients. But that was 1998. We were just starting into that. And Bryan, you know this. I mean, you built a whole program in Oklahoma from virtually nothing to full teams as well. In this case, we had a patient and a family member with significant medical knowledge and health literacy. We are very well tuned, taking the conversation down to the level of the patient and the family when health literacy is a problem. But you see here where there are problems with actually almost too much medical knowledge on this one? And have you seen that before where everybody assumes because physicians are involved or nurses are involved, you know what's going on?

**Ms. Ries**

They say they make the worst patient. Nurses, physicians, social workers, anyone in the medical field can make the worst patients.

**Ms. Harshman**

Well, and it may have been assumed that you had all the knowledge that you needed, but not every healthcare provider is trained or educated in every area of healthcare. and they may not have realized the emotional impact that would have on a physician and his family going through some of the similar things that you had seen other families go through. Now it's your family and it's you.

**Ms. Ries**

Yeah, and to chime in on that, on our team, when we're meeting with patients and families, we talk a lot about the head thinking and head versus heart. And so you have, you are a physician, your dad was a physician in the medical field, and so you have your medical knowledge in your head, but you're also a son. He's a father, so you have throw in the heart as well and feelings and emotions, and those aren't always congruent with each other.

**Dr. Clancy**

Anything you wanna add, Bryan?

**Dr. Struck**

Well, I just kind of look at that from the standpoint of, I feel very comfortable in the hospital until I walk into the hospital, not as the physician. When I'm there as the patient or the family of a patient, it just kind of creates a very different scenario that you're not used to on a regular basis.

**Dr. Clancy**

So true, so true. I just had a total knee reconstruction. I was dreading the overnight in the hospital. And it went very well, it went very well, everybody was great. Let's kind of bring it back a little bit to the basics. So in the palliative care setting, with severe illnesses involved, what is a goals of care discussion? How is it different than other goals of care discussions when serious and maybe life-limiting illnesses are present?

**Dr. Struck**

I really don't think it's any different than any other setting. It really is just sitting down when you're faced with a serious illness. This may be a serious illness that has an outcome that you may actually get cure from. It may be a serious illness that we can really modulate the symptoms quite well, but it's going to be a chronic condition that you're going to be living with, to an illness that maybe there isn't a cure. But what you're doing through all that time is you're just always constantly asking what is important to you and are your current treatments meeting your goals? Sometimes that call may be, I need to get through chemotherapy, so I need some help managing my nausea so that I can get the outcome that I want. It may be that things are changing with mom's dementia and coming to the doctor is starting to be a lot more difficult for her. I think that she would prefer to actually be in a setting at home where she doesn't have to be bothered coming up to the doctor. And it's like, how would that look and what would we need to do in order to make that happen? So it's, I think why I like having these conversations about complex medical decisions is that there's just a high variety of options that people choose for themselves. And it's, and

that the fun is sort of the challenge of finding how do we wind up meeting those goals. And I think that that's kind of the crux of what we wind up doing.

**Ms. Ries**

Yeah, I like to argue it's helping put the patient or their family or surrogate decision maker in the driver's seat. It's letting them guide the ship here and telling us how they want to be treated and what interventions they do want or don't want. We don't want to be providing any type of care or interventions or treatment that are going to be incongruent with what their values, their wishes, their goals are. It's incredibly important, especially with individuals with these serious diseases and illnesses that we are exploring what is important to you. We don't want to be guiding that for them. We want them to guide it for us.

**Ms. Harshman**

And many of these patients have more than one chronic serious illness that they are living with and it's affecting their daily lives. And exploring their goals of care or their values doesn't always have to be in a formal setting. It might be or by a palliative care team. It can be done by the bedside nurse or the physical therapist or other people involved in their care. They can be exploring what's important to that patient now and then sharing what they have learned with those various teams. And then those teams listening to what the bedside nurse or other members of the team are hearing from the patients and their families.

**Ms. Ries**

One other big part of these goals of care discussions is also making sure the patient and their family or whoever understands their diagnosis or their illness and have a good understanding as that is going to help them make the best decision for them moving forward.

**Ms. Harshman**

And when we meet the patient and family, exploring with them right away, how do you like to receive information and then talking to them in a way that it's best for them to receive and then really listening to them.

**Dr. Clancy**

I know you have a rapid screening tool that we use here. You shared that with me. It looked very helpful. And sometimes these really important discussions have to happen in the emergency room or in the medical intensive care unit where there's not a whole lot of time.

A decision has to be made relatively quickly sometimes. For a young physician or a young nurse going into one of these goals of care discussions that really is pivotal as far as where we're going to go as far as treatment, what would be the goals of the clinician as far as the goals of care discussions?

**Dr. Struck**

Really, I think the clinician should keep up a very open mind. I mean, not really go in with an agenda. Really explore and find out who that person is all about. What do they do for fun if they can? Speak to that themselves, that's great, but then there where they don't have the ability to speak, then ask the family those sort of things. You know, really explore how the illness up to this time has impacted their life. Because part of the issue with living with chronic illness is you kind of lose track of when was the last time that things were really going well, because you've kind of lost that reference. So sometimes it's important to have that conversation of how that disease has just continued to progress along its natural course, and that we're now at a place we're expecting this decline, and it's time for us to make big decisions about what to do next.

**Dr. Clancy**

Here at the University of Iowa Healthcare, we're in the midst of needing to grow. Our demand for services is very high, particularly at critical care level of services, and we'll be adding some hospitals. As I did some background work for preparing for this podcast, I was really impressed by the systems that you've developed here. How do you develop a systems approach to goals of care and palliative care?

**Ms. Ries**

Knowledge is powerful and education and training is incredibly important. Somebody is not going to make a palliative care consult if they don't know what the palliative care service is or what we do. So I think that is probably one of the bigger things, which I think has significantly improved over the years. I think more and more teams and providers are knowledgeable about who we are and what we do, and they're more open to getting us involved. So I think that's a huge, huge step.

**Ms. Harshman**

And because the people here at the university are always changing, our doctors are changing, our nurses are changing, there's that ongoing education and conversation about what palliative care is, what hospice care is, what the differences are, just that ongoing education.

**Dr. Clancy**

So Bryan, this question's for you. Looking at the big picture and looking at really the past 25 years, what does the outcomes research say as far as the positive outcomes for families and for patients when they enter into an organized palliative care and goals of care type of system?

**Dr. Struck**

Well, one of the biggest things that comes through is just the overall feeling of being supported. There are so many patients just from an anecdotal experience that when we start working with, you know, they're like, I wish I knew about you six months ago. And there is data out there looking at cancer patients that supportive care wound up having patients live longer. Of course, that was before we got immunotherapy. So, you know, some of these things keep changing. But I think the big benefit is it's that patients feel supported, their needs are being met, and it's another place that they can come to sort of sort out what they need to do with their treatments and how do they figure out what those treatments, how they meet those goals. So I think that that's the biggest outcome.

**Ms. Ries**

Yeah. I would add that it also helps patients be in the level of care or the environment that they want to be in. And that is also shown in the outcomes in the data. It does show that if you have, if you look up CAPC and go to their website, there's data on there that shows if you have palliative care involvement, it reduces readmissions, it reduces admissions and ED visits and ICU admissions. So there is data there supporting importance of palliative care and having these discussions with patients and preventing them for maybe a hospitalization that they don't want.

**Dr. Struck**

And I think along with that, even if you have the discussion and somebody says, Yeah, I still want to do all these treatments and I'm open to coming back to the hospital, for me, that still is a good outcome because we've had a solid discussion and we know what they want. And that just makes me feel good because I know that they've made that decision with all the information available to them.

**Ms. Harshman**

Yeah, and oftentimes it's about planting seeds of education that as that patient progresses in their illness, they can think back to some of those seeds that were planted earlier on, and it helps them to face the decisions they have. And when you have palliative care

involved too, we're there to focus on their emotional, their spiritual, and the holistic, the whole patient, and the family. The patient and the family are a unit.

**Dr. Clancy**

We're a teaching institution. We teach students, and we teach residents, and we teach fellows. And for some of our younger clinicians, this work may be a little bit daunting to them. With your work with learners, what have you seen as far as clinician barriers to an effective goal of care discussion.

**Dr. Struck**

Well, I think part of it is just not, it's time, but it's also just not really having the skills to have these conversations because it's kind of daunting sometimes.

**Dr. Clancy**

It is.

**Dr. Struck**

You know, I'm telling somebody that a treatment may not be working, that it's not getting them where we want them to go. And so I think sometimes they get stuck there. Whereas there's lots of different programs out there to teach clinicians how to do that, whether it's from things such as vital talks to honoring wishes to the VA goals of care curriculum through the Ethics Center, these are all things that people can use to pick up their skills. And I think it's also important when we talk with clinicians overall, it's just not the physicians and the nurse practitioners and the PAs that are writing the orders, it's really anybody on that healthcare team. Because you don't know when a patient at three o'clock in the morning is going to want to talk to that bedside nurse that comes in to give them their pain medication about what does this all mean, where is it going? And so that nurse needs to have the skill set to be able to say, tell me more about what you think and what's important to you. And then that nurse needs to be able to transfer that information to the team that comes on during the day and be able to say, you know, Mr. Jones has some concerns. Doing treatments X, Y, and Z may not be meeting his goals. Can somebody continue this conversation with him? And it really does take a system to be able to pick up on, you have to implement those skills and those changes within the system so everybody knows how to have this conversation.

**Ms. Ries**

I also see two other in addition to that, because I think that really does hit it on the head there. And Bryan, you kind of alluded to this earlier about having an agenda when you go in.

And so I do see that sometimes the resident, the learner, or even the staff go in with an agenda and this is how it's going to go, and that's not how this—it doesn't work out very well that way sometimes. And that might be because of what I said before, time constraints and a big caseload and how many discharges you have to work on. So they go in there with their eyes on one thing and that can sometimes backfire. And I think another thing that we tend to see is people, providers, see this more as a professional failure on them. When we shift to exploring goals of care or maybe not pursuing treatment or whatever it might be, I think sometimes that can be felt as more of a failure.

**Ms. Harshman**

And I think too, even at a systems level, having these conversations just in the room layout and the way things are laid out in our hospital, oftentimes it can be challenging to have these conversations and to really be able to listen to the patients and families with all of the distractions and other things that are going on.

**Ms. Ries**

And so that's huge, actually. I'm glad you brought that up, Carol. It's really difficult to have a conversation as tense and as deep as we have sometimes when there's all this noise going on out in the hallway or on the other side of the room. And that's a huge point.

**Dr. Clancy**

I will tell you, I was called in to essentially question somebody's goals of care once. They made a major decision not going forward with the surgery, and the treatment team just didn't think it made sense and was wondering if this person was decisional. This person, there's just no way someone would make this decision. And I went up at 10:30 in the morning, and there was just no way I was going to have that conversation with that individual. There's a roommate, there was family around, the buzzers are going, there was just no way. So I learned that day that actually one of the quietest times around the hospital is around 5:30 or 6. Most of the teams have gone away. It's quieter. Sometimes roommates are walking the halls. And we were able to have a 90-minute conversation starting at 5:30. It was very clear to me that this individual was very much deep in thought about the decision that was made and fully, fully understood the ramifications, and it made sense. It made sense, but Katie made that point about time. Well, this took 90 minutes, and it took 90 minutes late in the day, and it had to be a quiet setting, so. Do you see any other system-related barriers? Clearly noise and layout. Are there other things? We receive many, many referrals. So I'm sure we see patients that have been cared for in a different setting with maybe not as robust of palliative care team and such. Do you see other system area that can be improved?

**Dr. Struck**

Well, I think one thing that you just said, Gerry, there about, you know, we've seen other systems that don't have the robust palliative care program. I think part of that is, you know, when it comes to palliative care programs, there's not necessarily a standard. There's voluntary joint commission, advanced certification for palliative care teams. You could be in a system where there is a nurse that works a 25% time and ask about symptoms, and that's your palliative care program. So there really isn't a standard that is set forth by you know, Medicare insurance to say, this is really what we need to have in every hospital in order to provide this care. And so you do wind up with a variety of things depending upon what resources are available in the system. And so resources are a big deal for this.

**Ms. Harshman**

Yeah, and resources in many parts of Iowa are different than what we have here at the University of Iowa. And I've often thought that many times these conversations could start in primary care physician's office, just with the doctors and the nurses and gathering information and learning about that patient at the time of those diagnoses. So like Dr. Struck said, utilizing what you have available in your environment and where you're at.

**Ms. Ries**

I also want to add some other barriers. Insurance. Insurance dictates so much of what type of treatment or resources are available for a patient or not available, and that includes resources in the community, including palliative care services, especially in rural areas. Not really an option to many people. So insurance you have dictating things or preventing certain things. You know laws and policies even are barriers. Here in Iowa, in our law, if you have a court-appointed guardian, they cannot make end-of-life decisions for the protected person, the ward, unless they get court approval to do so. And so that requires working with an attorney and petitioning the court. And usually we have to provide documentation to help support this. And it can take days to weeks to do that. And that just adds a lot of distress onto a very already stressful situation for those individuals.

**Dr. Clancy**

So we've assembled our experts here. Let's move into the discussion itself. What guidance do you have as far as best practice for the discussions? You're going to sit down with patient, maybe family. How do you set it up? What are some of the best ways to lay out what can be very unknown, but prognostic information and moving into getting to their goals? What's your advice in these areas as far as skills?

**Dr. Struck**

So one of the things that I teach the medical students, the residents, the fellows, actually anybody in healthcare can use this is something called REMAP. This was something that was developed by VitalTalk. It's been incorporated in many other goals of care training sessions and really it stands for, you know, reframing, letting them know that we're in a different place now, affecting emotion because when you tell people that things are changing, you're going to get an emotional reaction. And so you just have to be prepared for that. And I think it's important to teach healthcare workers how to respond to that emotion. And sometimes all you need to do is simply say, I wish I had another treatment, or I wish that there could be another way out of this. And then it really is about mapping out what's important to people. As I said, being curious, being able to figure out what they do for fun, what are they famous for? And then really doing active listening and reflecting what you just heard back to them. And then sitting down and making a recommendation based upon what you just told me that's important to you, these are the treatments that I think would support what your goals are. And if people decide that that's not really what their goals are, 'cause they don't like the treatment options you gave them, then you know, that's the discussion of, well, either my goals need to change or my treatments need to change because in order for both of them to be successful, they have to be headed in the right direction. And so it's just an opportunity to reflect. And I go into those conversations and I really don't care what the outcome is. All I want to know is that a quality conversation was had and that I had an opportunity to discuss this with the patient, with the family, to find out what's important.

**Ms. Harshman**

And oftentimes the patient and the family, they just need that time to reflect. They need that time to think about what they have learned from the doctors and the nurses about all of the medical interventions.

**Ms. Ries**

I think it's also important in making sure the right people are at the table to the patient, if they're able to, of course, if they have a power of attorney or a guardian, or if there's a different legal next of kin identified, making sure they're the ones that we're involving in the discussions and making sure we're including all of the providers and the teams that need to be there that are involved in the patient's care, just so we can pull in all of the information about all the treatment options, the diagnoses. That way we're not missing anything that would influence their decision.

**Dr. Struck**

And I think the other thing, why it's so important to teach people in the healthcare team how to do this is they also have to be able to say, especially for those who prescribe treatments, to be able to say, my treatment will not help you meet your goals. Not too long ago, I did this training with a group of surgeons and one of the orthopedists who had been in practice about as long as I have, he says, what this training showed me is that I now can go tell a patient, my surgery is not going to help you meet your goals. Therefore, you don't need to do it. And he says, that is very empowering to myself because I don't have to be worried about that I'm subjecting somebody to a treatment that I know is not going to be helpful.

**Dr. Clancy**

And then this is more generalized to very serious conversations with patients. The team is about ready to go in and one of the residents, I'm gonna let them lead the conversation. I have to remind them not to ask closed-ended questions. This is a time for an open-ended question, that you wanna hear the reflection from the patient. So oftentimes they get to a closed-ended set of questions way too quick. Leave it open for a while. Leave it open.

**Ms. Harshman**

I like what you said about don't lead them because oftentimes patients and families don't realize that they can make those choices, that they have choices to make, and that they can have input. A lot of times they're listening to the doctors and the nurses and they're just taking everything that they say, but not really thinking about, well, can I ask questions? Is it okay to ask questions? Is it okay to say that perhaps that isn't what I want, or that is what I want. Having those open-ended questions to allow those patients and families to be able to express what they really want or don't want.

**Dr. Clancy**

Yeah, I just want to emphasize something you all touched on is just the importance of summarizing what you heard so that you can see if you're accurate or not. And I've probably missed the mark 30% of the time. You know, when I'm summarizing the patient, no, no, no, I didn't mean it that way. And how important it is to come back and hear from them that yes, the confirmation of this is where I'm at.

**Ms. Ries**

Meeting them where they're at is so important. And reading the room is also so important.

**Dr. Clancy**

Are there any flags that should go off as far as particular conditions that maybe it's time for a goal of care discussion or a palliative care discussion?

**Dr. Struck**

Well, recurrent hospitalizations for COPD or heart failure, dementia patients coming in with sepsis or failure to thrive because they're not eating, and the discussions starting about feeding tube. People with stage four cancers that there's not a treatment for, they're starting to have complications. And then you can even take that further back a little bit as far as just anybody that has a type of serious illness, and you can even take that as far back as anybody over the age of 18, starting that discussion earlier about if you got into a situation where you weren't getting better, how would you want to be treated? What would be most important to you in those situations?

**Ms. Ries**

I think one of the more common questions that we used to ask is a very simple question of, do you expect this patient to have a bad outcome? If you can say yes to that, or you do say yes to that, then I think that warrants the discussion.

**Dr. Struck**

That's what Joanne Lynn has said in the past. It's asking yourself, would you be surprised if this patient died in the next year? And if the answer's like, no, I wouldn't be surprised, that's somebody you need to talk to.

**Dr. Clancy**

Absolutely.

**Ms. Ries**

They should be on the radar for sure.

**Dr. Clancy**

As I said before, early on, you know, sometimes hope gets in the way and hope gets in the way of honesty sometimes. Again, we've gathered the experts who have built a robust system here at the University of Iowa. What are some of the basic building blocks of a system of palliative care and responsiveness and getting involved at the right time for these individuals. Beyond the individual clinician, how does it work around here that people know to call you?

**Ms. Ries**

Education. I know right now we're doing a lot of education in the ICUs. So I know they're going down there directly talking with the different providers and staff and nurses. So I think that is one of the first steps.

**Ms. Harshman**

And then education of when to consult. Making it part of orientation for new staff about the screening tool that we have in place for a supportive care nurse consult and how to utilize that so that ongoing education about how to get the supportive and palliative care team involved.

**Dr. Struck**

And I think it's just about building relationships with your colleagues. They may recognize that there's an opportunity for palliative care to be involved, but knowing that they trust you enough to go ahead and call you in on that patient, even though they may not know exactly what needs to be done to get them where they need to be.

**Ms. Harshman**

I like that, building relationships, and that's where the supportive care nurse team, we attend huddles in the MICU, the CVICU, the SNICU, building those relationships with those providers, those social workers, care coordinators, and that whole team.

**Ms. Ries**

And we have a lot of learners that do a rotation with us. Sometimes it might be a two-week rotation, sometimes it's a full month. I think that definitely helps as well, just because they're getting a very direct view of what we do, the type of work we do, how we can help the patients and the families here in the hospital. I think that first-hand knowledge is incredibly helpful.

**Dr. Clancy**

Is this an area where the EMR can actually be helpful.

**Dr. Struck**

I think it can be, but I still think that there's a lot missing in the EMR, being that there's no registry available. When people do fill out these documents, it's, and yes, they may have brought you, but if it's like scanned into the wrong place, or it may not show up in the advanced care planning documents. So it's all these things are, you know, all this planning is actually done on paper, and then we somehow ask for it to miraculously show up in our

electronic world, and sometimes that can be a challenge, but we haven't quite always figured out how to manage that.

**Ms. Ries**

I'm glad you brought that up, just because that is something that I know myself, and I'm guessing Carol and other social workers and nursing staff spend a lot of time just trying to locate someone's advanced directive. You know, they completed it. We know mom did it. We know dad did it. It's appointing so-and-so, but we cannot get our hands on it. So calling to local hospitals, PCP offices, lawyers' offices, trying to get our hands on these documents is very, very common, unfortunately.

**Dr. Clancy**

I try to be a messenger to the rest of the system as well. When I'm working with a patient in palliative care or working with a patient in comfort care, that's usually my first line. This patient is in comfort care, just to remind everybody that the goals of care here are going to be unique and special. So Bryan, you as a longtime academician, we've heard for quite some time that the vast amount of healthcare spending is utilized in the last year or two of life. Do you see that changing with goals of care and palliative care and people more thoughtful as far as how far they want to go with treatment? Are you seeing it change a little bit?

**Dr. Struck**

Well, I'm still seeing a lot of sick people that are getting admitted to the hospital and in the ICUs. And some of that because sudden illness happens. And so it takes people by surprise. But I think it's also trying to still have to work on changing our mindset that these conversations just need to occur earlier. And, you know, we need to take advantage for those of us that are on the billing side of things, taking advantage of the things such as advanced care planning codes to talk about that. But I think it's hard when you're in the midst of a busy clinic with whatever specialty to kind of all of a sudden go out of that treatment mode to, hey, I'm worried where this illness is taking you. Do you mind if we take a few moments and talk about where we go from here? I always say as the geriatrician, I was the worst palliative care doctor around just because there were things about doing primary care geriatrics that took me away from thinking about where is the big picture sometimes.

**Ms. Harshman**

To piggyback off what he said about the big picture, I mean, sometimes the big picture maybe needs to start before the patient arrives on the helicopter. As we're triaging that

patient and coming to the University of Iowa, maybe some of that conversation needs to start earlier, as Dr. Struck has said many times. And I mean, I still meet and hear patients who are very advanced in age, late 80s, 90s, still talking about life-sustaining interventions and that have advanced disease progression and all of the medical interventions that we have to offer today.

**Ms. Ries**

I'm glad you brought that up just because it is very common that we will talk with patients and families that are here at the university and they'll voice, we never wanted to come to the university. Now we're three hours away from home and we got to try to figure out a plan to try to get closer to home, and that can cause additional distress to an already stressful situation. So yeah, I think it's really important that at outside hospitals and community hospitals and PCP offices that they're having these discussions with the patient and family before they're moving forward with a transfer to a higher level of care, because that might not be what the patient and the family wants.

**Dr. Clancy**

All three of you have been great, and thank you for your expertise and your willingness to share. For each of you, as we close, what are some of the take-home points you'd like to leave with our listeners? And Carol, let's start with you.

**Ms. Harshman**

I would like to circle back around to what your father specifically wrote to you at that time and the importance of a physician who demonstrates the deepest level of care, understanding, and compassion in each and every patient. And that as a healthcare provider, whether it's a nurse or whoever we are, to circle back around to what your father said and how important that is.

**Dr. Clancy**

That's a good one. You surprised me with that one. Good one. Katie, how about you?

**Ms. Ries**

I say this a lot, but I think one of the big takeaways that I want people to remember is that we are all human, and we all have 100% mortality rate, and we are all going to die as sad and awful as that is. So while it can be very uncomfortable, it can be very distressing to know that one of your patients are going to die. Just remember that it's a certainty for all of us. And so just to make sure that you're having conversations with your patients about how

do they want that to happen? What do they want that to look like? So they can drive that ship.

**Dr. Clancy**

So Bryan, you get the last words.

**Dr. Struck**

Well, I would just be when you're providing healthcare, just be curious about your patients and your families that you're taking care of so that you can understand what's important to them and check in with them on a regular basis to make sure that the treatments still are aligned with those goals and values. I think that that will take you a long way.

**Dr. Clancy**

Well, to our expert guests, thank you for joining us on Rounding@IOWA and for the work you've done helping patients and families through this important part of life.

[Upbeat theme music plays]

For our listeners, you can access instructions for CME and CEU in our show notes, and we hope you'll join us again for another session of Rounding@IOWA.