

Vanderbilt Health DNA: Discoveries in Action
Season 2, Episode 9
'Think Deeply:' What Matters To You? Dare To Have Tough Conversations

Dr. Jeff Balsler: I guess my message is I think the deeper learning from COVID is the deeper learning about what does it mean to be alive, and what do we really as human beings want to be thinking about when we think there's even a significant chance that might be taken away from us.

Dr. Mariu Duggan: We don't always take a step back and ask patients, "What matters most to you? What do you want healthcare to do for you?"

Dr. Uchenna Anani: There's this terminology that goes around called the hidden curriculum. I find that very triggering because I'm like, why is it so hidden? Compassion and care and respect for others should not be this unsaid thing.

Clark Buckner: You're listening to season two of Vanderbilt Health DNA: Discoveries in Action. I'm your host, Clark Buckner. And the reasoning behind the show's name is quite simple. The path to better health lies in our DNA. Discoveries in Action is about the big ideas and breakthroughs happening right here in Nashville, Tennessee, from Vanderbilt Health. Our drive to discover, care, learn and share is in our DNA. It defines who we are, just as your DNA defines you.

In this episode, we're exploring why it's crucial to take stock and assess from time to time what's important to you when you get to the end of your time on this planet. We're not getting too morbid or melancholy. Don't worry. The conversation will touch on loss across the spectrum of life, and that may be difficult for some to hear. I invite you to take a breath and open your mind to a special kind of trust and hope, the kind that comes from tackling big challenges and coming out on the other side, stronger than before.

With almost two years of living in a pandemic, the fragility of life probably hit you at some point. Maybe you thought about, "What if it's me?" Although the novel coronavirus slapped this conversation on the table for society as a whole, it's a conversation that's had every single day by doctors and family members around the globe. There is a sentiment that's as endearing through time as the night sky: "What if this doesn't turn out like I hoped?" Dr. Jeff Balsler, president and CEO of Vanderbilt University Medical Center, is well acquainted with that question and the outcome that people hope against.

Dr. Jeff Balsler: Some people don't know that the early part of my career was in ICU medicine. I was an intensivist in a cardiac surgical unit for years before I moved into medical center administration, so I saw a lot of end of life. It was an interesting time because I did that in the late 90s and early 2000s when cardiac surgery was probably in a Renaissance, and most people were surviving. Sound like COVID? Most people were surviving.

I would spend a week as the attending in the ICU, and then I'd be off for a week to recover because it was a pretty intense week. During that week, we might have 50 patients come into the ICU, and 47 would fly through in two to three days and three or four wouldn't. There were always reasons why some people wouldn't, and we knew what those were. But it didn't explain all of the deaths. Some people just died, and we never knew why.

It reminds me now of what we understand about personalized medicine and precision medicine, where we know we have DNA polymorphisms, or variants, in our own DNA that cause some of us to react really well to a drug or respond really poorly to a disease versus other people do just fine. Well, surgery is just like that. And we're beginning to learn what those DNA variants are that predict how you do in surgery, but we certainly didn't know that in the 90s and two 2000s.

And so now what we're seeing with COVID is, and what we have seen is, you may be in an age group where your risk of death is 5%, if you get COVID. Are you an optimist or a pessimist? Well, most people look at that and go, "Not a problem. I'm not going to die." That's just how we're wired. And it reminds me of how it felt in the ICU when those three to four patients every week died, because they weren't expecting to die either.

So there is the pragmatic advanced directive, which is so important. And we should talk more about that, where we really need patients ahead of time to have those conversations with family where they specify do they want to be fed if they're unable to, do they want to have a ventilator. It's the pragmatic aspects of dying. But there's this other piece that we're really not very good at, either in healthcare or in society in general, and that is preparing for the possibility we might die as we encounter something in life that puts us at some risk, such as, "I'm 68 and I just got COVID. Maybe I need to talk to some people. I'm going to have cardiac surgery, and the survival rate is 92%. Maybe I need to have some of those discussions and some of those more emotional kinds of interactions with people I care about before I have that surgery, not just assume it's all going to be fine."

When I would talk to Melinda about the people we'd lose after my week in the ICU, the pragmatic stuff bothered me, but this other stuff felt even worse. To have a 52-year-old come for a routine cardiac surgery and then do poorly and die and not even have a chance, it was just awful. And so COVID feels like that to me because very few people who died because they got COVID thought that was going to happen, even though we knew the statistics. Right? So I guess my message is I think the deeper learning from COVID is the deeper learning about what does it mean to be alive, and what do we really as human beings want to be thinking about when we think there's even a significant chance that might be taken away.

Clark Buckner: Dr. Balsler is an advocate for advanced care directives. Simply put, it's an end-of-life care plan that allows doctors and loved ones to know of your wishes. Those plans help align your care with your values and can alleviate the burden of speculation and decision making from those who care most about you. I asked him if healthcare providers should be helping patients and families better understand the risks and initiate these thornier conversations.

Dr. Jeff Balser: I honestly think people need support, the kind of support healthcare's not accustomed to giving them, to A, understand it and B, then help them think about how to have those conversations and who to have them with. Because if you're the physician, you really don't want to scare people, so you want them to feel good about having the procedure. Maybe somebody else needs to come in and say, "Look, Dr. Smith is really talented, and you couldn't have a better doctor. And the chances are you're going to do fine here, but there's this chance that you might not." Let's talk about what that might mean, because if you throw the dice a hundred times, eight times you're not going to make it.

So we have to be realistic about that. It's not the same as driving to work in the morning, and I don't think we've as a society really effectively worked on that. And some of the people that are talking in this podcast are people that have. The people who are really working on the ethics and on the care of those who are facing death are really thinking deeply about these issues, and other specialties coming and growing around medicine in the social work areas and in the public health areas, I think are starting to get their arms around this. And I just think we all have a lot to learn. But healthcare is a team-based activity, and this may be part of what the team does is helps people prepare for surgery.

I'm an anesthesiologist. My initial training was in anesthesiology before I trained in the ICU. And in anesthesiology, it's all about preoperative preparation, not having the patient smoke for a period of time before surgery, doing all these things to optimize their physical outcome. Well, what about optimizing the mental outcome? And part of that might be preparation for a bad outcome, and that's something that we've avoided. Or you might spend not three days in the hospital, but three months. What does that mean for you financially? You may have health insurance, but you may not be able to keep your job.

There are all kinds of things that happen to families and people when somebody ends up unexpectedly in the hospital for a long period of time. We've had people in the hospital for practically a year in some cases from COVID 19, and we've had their lives devastated even though they survived because they've had cognitive problems, not unlike what Dr. Ely describes around ICU cognitive decline and cognitive impairment. You know we have these sorts of things that happen to people with COVID.

Clark Buckner: To hear more from Dr. Ely on what happens when patients are in critical care units, be sure to check out the second episode of this season, titled "ICU, Humanizing Critical Care." Both Dr. Balser and Dr. Ely emphasize getting to know the patient as a person and understanding the patient's mindset because, as with most things in life, healthcare outcomes are often not black and white.

Dr. Jeff Balser: It's not just preparing people for death. It's preparing people for some other than the optimal outcome. Honestly, some of these outcomes are harder to prepare people for than death, depending on how we're wired. There are a lot of people who will say, "I understand I might die, but if I'm actually going to go blind, I don't want to have this procedure." So really

understanding where people are and really helping them think deeply about what the possibilities are, I think is really important. What it means is that we have such an awakening of our population around what life and end of life mean that we get comfortable with the conversation.

Think about mental health. It's a similar issue. The reason we struggle so much with mental health now isn't because we don't have good treatments for depression and anxiety. It's because people are afraid to engage the system to actually get the help they need. They're afraid, and there's a stigma, and it's uncomfortable. There are all kinds of reasons why people don't report that they need help with depression and anxiety. Well, end of life is a little bit like that, right? We just don't want to deal with it. And it's like anything else. You learn to deal with things that are uncomfortable. My view is that if when we're 30, we start to get really comfortable talking with a doctor or a loved one or a sibling about what our end-of-life preference is, it becomes normal. It doesn't become scary and weird, so that it's so much easier to then be thinking about that and having those discussions as we age, where it becomes more and more important.

Clark Buckner: You might be thinking, "Yeah, I've thought about what I want or what I don't want." So what did you do with that decision, if anything? Did you tell someone? Did you put it in writing? And if it's on paper, do you even know where that paper is? Let's hear from Dr. Balsler explain why it's important to have these discussions with ourselves, but to be environments that make it seamless to document our choices.

Dr. Jeff Balsler: The concept of advanced directives helps us and maybe in a way that we're not quite thinking of. First of all, we call it an advanced directive. Most people think that's something that might happen to you in school, and you're not sure what it was. It's a terrible term. It's a legal term. What it is, is an end-of-life care plan. And so we now call it that at Vanderbilt because we want people to understand what the thing is. So we changed the labeling of the advanced directive to end-of-life care plan on our website and on our My Health at Vanderbilt portal, mostly so our patients would understand what the heck it is we're talking about.

And what I really think we want to head toward is having it be a regular part of healthcare for people to have end-of-life care plans all the time, for a couple of reasons. One is, if something happens, you know whether they want to be fed, whether they want to have extraordinary measures taken. And it's amazing the spectrum of what people want when they fill out that. But something else very important happens when they simply download the form and spend some time talking with a spouse or a friend about what their wishes are, because two people, and they can be anyone, have to attest that you signed this. They're your witnesses. It can be anybody. But those conversations are so important for the person who's filling out the form because it causes them to have to articulate a little bit of the emotional side to this.

And then what we do at Vanderbilt is we have a followup conversation once they upload the form with their primary care physician. So that offers another opportunity to have a meaningful conversation about end-of-life. And what it does is in addition to kind of gathering the key information for when something happens, it starts to regularize the notion that you might actually talk about this stuff, which is a bigger deal, because what we really want is a society that gets a lot more comfortable talking about this so that it's not seen as negative or scary or something to not be gone near. It becomes something that we embrace and use the knowledge of to enrich the life we're living.

And that's just not the way America thinks about death. But one of the reasons we're spending enormous amounts of money in the last 18 months of life, doing things people weren't really sure they wanted in the first place, is because we've been afraid to have those discussions. We need to start much, much earlier re-educating people about how to think about death, not just to do the mechanics of figuring out whether people want to be on a ventilator or not. And I'm just hoping that by regularizing the end-of-life care plan as part of healthcare, we might start to make some moves in that direction.

Clark Buckner: Dr. Mariu Duggan, the clinical director of geriatrics at Vanderbilt University Hospital, works with patients and families constantly to honor their end-of-life care wishes. Doctors have families and feelings, too, so sometimes she tells them of her own experiences caring for her elderly grandmother.

Dr. Mariu Duggan: My grandmother, she is 92. She has advanced dementia. And I went to go visit her because she was declining. She started to get complications of dementia, like immobility, was taken to the bed more, was falling and had some pressure ulcers, some bed sores. So as a geriatrician, dutiful granddaughter that I am, I went to Puerto Rico to go see her and held a family meeting with my own family, which is something that I do for my patients, thinking about what are Grandma Tata's goals? What do we think she would want if her mind was clear? And if she knew what she was experiencing, what would she want? So we're not making decisions or thinking through what we want for her. We are helping discover what Grandma Tata would want if she was in this condition, what are her values, and then trying to make decisions as best as we can that align with who she is and what she wants.

And so when I first arrived, I actually took an advanced directive on the plane ride down to Puerto Rico and was going to go through it with my family. And the most important thing we did was just to start the conversation, just to explore what does everyone think is most important to our family member and how can we best honor that. We didn't come out of that family meeting or series of meetings with an official witnessed advanced directive, but we still made progress in getting all the family on the same page about what are our treatment goals for our family member, and how are we going to align her care, her medicines, home health services, long-term care. How are we going to take all of this complex medical intervention and align it with what's most important to her?

So I think, while advanced directives can be an incredibly helpful document for healthcare providers to respect what's important to patients when they're in their clear mind and they're able to put down on paper what matters most to them and what burdensome treatments they may not want to have, I think the most important is for patients to have those conversations with their family members.

Clark Buckner: For Dr. Duggan, the most important question she and her colleagues can ask is this, "What matters to you? How can we align your healthcare to your goals?" The answers run the gamut.

Dr. Mariu Duggan: Yeah, everybody's different. We have some folks who tell me, "Hey, I'm 85. I've lived a really great life. And when it's my time to go, I'm ready. I'm at peace." And then we have other patients where they want to be here as long as they can. They have a lot of unfinished business. And they are willing to go through more burdensome treatments, even if the chance of reaching a goal, even if the chance of getting some potential benefit is lower. They're willing to undergo that burden. So we're often asking patients where they are on that spectrum. Are they more along the end of the spectrum, where they feel like they've accepted their eventual oncoming death and they're ready when it's their time, or are they further down the spectrum, where they are not yet ready, either because maybe some unfinished business, some relationships that they feel like they need to repair, or simply denial.

That's a very normal part of the grieving process of acceptance is denial, and so people take their time as they need to. And everybody is aging to some degree. I feel like I'm aging much more rapidly now than I was when I was 20. In fact, they say after 30, everything starts to accelerate in terms of your aging. And so I have some 90-year-olds who are aging a little slower and they maybe have a decade left to live, and I have some 67-year-olds who are aging a little bit faster and their death is impending within days. We take a step back and we think, who is this person? What are their values? What are their goals? What's going on? What's the prognosis? What's the family situation? And how can we best serve this person to preserve their dignity and to give them medical care that aligns with what's most important to them?

I hear a lot of people telling me, "I want to be as independent as possible." I hear a lot of people tell me, "I want certain symptoms to get better," whether it's pain, whether it's anxiety. I had one patient that was really surprising, actually. She's one of my favorite patients. She was, I think, in her 90s. And she said, "I just want to be a light for all these nurses and doctors on this unit." And so I was expecting her to tell me, "I want to try to get to rehab and get stronger so I can go home and be with my family," but in that moment, what she wanted was to make an impact on the providers that were caring for her. And so what we did was reframe our conversation with her, and every day we'd see her and ask her about her medical problems. But we would also thank her and tell her how she was making an impact on us.

Clark Buckner: Loss hits hard at any stage. So what if it's on the outset of life when the world should be brimming with dreams? It hits different when the reality upends our vision of what was going to be.

Dr. Uchenna Anani is an assistant professor of clinical pediatrics in the Division of Neonatal Perinatal Medicine at Monroe Carell Jr. Children's Hospital at Vanderbilt. She's also part of the core faculty of the Center for Biomedical Ethics and Society, which researches parental and ethical decision making in the NICU and counsels families with high risk pregnancies.

Dr. Uchenna Anani: I like to think that, although as a neonatologist, I am taking care of the baby, the infant, I'm really also taking care of the entire family, just because the baby – How do I explain this? The baby is a part of the family, and it is the parents and the family who are involved in decisions and caring for the child mutually, alongside the medical team. This is something I also carry in my heart when I address pediatric or neonatal ethics. I'm not just focusing on the ethical concerns surrounding the baby, but also the family as a whole, because that matters.

For me, when I'm counseling about the medical issues surrounding their infant, I'm really talking to the family too about how is this going to impact your family. And when I address goals of care, I'm not just focusing on the specific needs of the baby, but I'm really focusing on the needs of the family because the child at this moment can't really speak for themselves. The parents, the mother, the father, the guardians, they are the ones who are speaking on behalf of their child and doing what they believe to be the best interest of their child. So I really am communicating with them and trying to get an understanding of what really matters to them.

Ultimately, every parent/guardian wants their child to live. And if we're talking about a life-limiting diagnosis, knowing that we may not be able to control that, what's the next best thing? What's the next most important aspect? And a lot of that, a lot of families tell me is really about, "I want them to be a part of my family," and what does that look like for them in this situation. And so it varies for everyone a little bit about what that's going to look like, so whether or not that end-of-life process is going to be a short period versus a long period, is it something that will take place just in the hospital or is it something that they'll be able to go home and be able to spend more time and enjoy life at home. So it all varies.

And luckily we have wonderful colleagues, our pediatric palliative care specialists and physicians, who do a wonderful job with helping address a lot of those needs, particularly outside of the hospital, since I work primarily in the hospital. It's all about really talking with the families and really getting an understanding of how can I make this unimaginable situation still something special and memorable that they can hold onto, even when the child passes away.

Clark Buckner: Families under Dr. Anani's care often face gut-wrenching decisions, ones that no parents dream of making. I wondered how she helps families begin to think about, to decide

what the route looks like for them, what aligns with their situation and their values, even as their heart is breaking.

Dr. Uchenna Anani: A lot of times, I will say they don't necessarily know what questions to ask. So I may provide them with a kind of introductory, "Let me tell you about what I understand," or, "Can you tell me about what you understand thus far?" And let's meet in the middle and kind of go from there. Reassure them that they are in the best of hands in terms of care. Trying to provide some level of comfort, knowing that what really matters to families when you're counseling them, if that makes sense. So what is the ultimate goal when we're trying to provide counseling and comfort and care to families?

There's a lot of research on the medical side about, "Oh, these are the things that you need to say. These are the content that we need to go over." But at the end of the day, a lot of the decision making that's happening is very emotional. It's based upon your personal values. It's based upon your family unit, based upon your experiences. And so I guess my goal, or I guess question I'd like to answer is, what really matters to you, and how do we streamline that care so that we best address your needs effectively and with compassion and respect?

Obviously we're working towards that in lots of different ways, but it would be nice for us to just – I don't know. There's this terminology that goes around called the hidden curriculum. I find that very triggering because I'm like, why is it so hidden? Compassion and care and respect for others should not be this unsaid thing. This should be something that we actively teach and understand and grow in our field of practice each and every day. And I want to be able to bring that forward as a more tangible, obvious learning objective and goals for all trainees and continuing education for physicians. And how do I take that and streamline that specifically to my patient population and make that counseling experience most effective?

The word that comes to mind is empathy. So I'm going to be empathetic to your situation. Whether I truly understand it or not, or I personally understand it or experienced it or not, I'm going to be sympathetic or empathetic to your situation. And so ways that I try to connect with families, just being a new mother myself, I think that has changed my practice entirely. I will say the last few sessions, counseling encounters, that I've had, a lot of the family members said thank you. They said, "Thank you for taking the time to talk with me. Thank you for caring." If I get a family member that can say that and will smile back and say, "I really appreciate it," that to me tells me, okay, this was really helpful for them. This really met their needs.

Clark Buckner: Since we're, as a society, not great at these conversations, and if you recall that Dr. Anani mentioned a hidden curriculum of sorts, maybe we're not adequately prepared to navigate these conversations. Doctors and care providers are people too, and we all need training or guidance in dealing with heavy conversations. I asked Dr. Balser, "Where do we go from here? What's the next step for medical training programs like Vanderbilt?"

Dr. Jeff Balsler: I had my first discussion with a patient who was dying when I was an intern, and I was the only one there. It wasn't like I got any practice. I just figured it out. That's not optimal. We are now thinking very differently about what the curriculum is around these issues, and some super progressive and neat stuff is happening around medical education, around not just requiring this as sort of an expectation in training, but actually building observed practice opportunities. We use people who function as actors for patients, as they pretend they have appendicitis, or they pretend they have gallbladder disease, and then our medical students examine them. We are actually going to start using that across all areas, including people that need to have end-of-life discussions. So we're just getting better and better at this, but it's going to take years before that generation of physicians is actually out there practicing because the generation you've got right now is pretty much on their own.

Clark Buckner: In addition to practical training, technology is making it easier for patients and providers to put an end-of-life care plan on file. No longer will advance directives gather dust when they're needed most, and that could be some revealing news for people who are in dark moments. With all change comes adjustment, and technology, as you'll hear, means new avenues of trust and ownership with the patient. And sometimes that's uncomfortable for physicians.

Dr. Jeff Balsler: This is a huge deal, I think, because I don't think very many people when they're about to die, the first thing they think of is their lawyer's address and phone number to tell people. That's where most people have their end-of-life care plans, locked in a lockbox in some attorney's office, which is sort of useless at the time it's needed. The more advanced electronic health records systems, including ours, allow you to upload this information. And what we've done at Vanderbilt is make it super easy for people to do it. So they literally can do it on their laptop, and they can download it themselves. They can fill it out when they feel like it, and they can upload it themselves, just like if they were doing anything else with the web. And we really needed to make it that simple.

And so there's this paternal or maternal view of medicine where, "Oh my gosh, we can't let patients do this alone. They have to do it with us in the office." And we all needed to get over that because it turns out that it wasn't getting done. And the only way to get it done is to let patients, to trust patients, to encourage patients to do it, and then counsel them on the discussion after they've uploaded the form. And that's where we've moved to, and I think that's where a lot of healthcare systems are moving. It wasn't very long ago when we wouldn't let you see your lab results. Boy, has that changed. This is the same. We're letting patients manage this, and I think that's healthy because the more people are expected to do and initiate, the more ownership they take over it. And what we want patients to do is own this. That's success.

Just a week ago, a close friend of mine got a "You've got cancer" lab result that triggered them to call the physician before the physician called them. And that was fine, but it was just different. We all need to reframe, I think, how we think about the way healthcare is delivered. The system needs to be designed around the patient. And the healthcare system is the support structure,

not the command and control structure. We've designed healthcare so the edifice of healthcare is the command and control structure, and that's not what people want. And frankly, it doesn't work very well. What we're talking about with end-of-life care is very much the same as what we're talking about with letting people figure out when they need to go to the doctor and where to go, and making that really easy for them to make an appointment online, those kinds of things. Making end-of-life care planning that simple is going to be key to making it such that everyone will want to do it and can do it. It's got to be easy and it's got to be normal, just like going out to dinner.

Clark Buckner: If you haven't known how to bring up this conversation with your family or friend or doctor, then put it on us. Take this episode as your sign to prioritize your values and wishes. Taking that leap will leave everyone feeling more confident about the uncertain, yet inevitable. And isn't that what it's all about, living with confidence and enjoying the moments we have on our terms? Let's make sure we're leaving on the same note. Thanks for joining us today. Take care and be well.

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