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On Healthcare

HEALTHCARE

ENVISIONING END-OF-LIFE CARE DELIVERY

Announcer: Welcome to Navigant on Healthcare, offering insights for healthcare leaders striving for success in an evolving industry.

In this podcast, we explore the topic of end-of-life care delivery as it relates to the provider, as well as the relationship between provider and consumer. Navigant surveyed 150 individuals in its healthcare practice to gain insight around people's understanding of end-of-life care and discuss the topic and the survey results more broadly with the following subject matter experts: Navigant director, Katherine Ziegler; Navigant director, Dr. Christopher Stanley; and Dr. James Bulot.

Ziegler is the director in Navigant's strategic healthcare transformation department as deep provider and care experience as well as extensive experience helping organizations strengthen provider and payer partnerships, drive innovative solutions to problems and develop and integrate improvement strategies that result in sustainable cultural and operational improvement.

Dr. Stanley has more than 25 years of experience in value-based care. He is a sought-after expert in alternative payment models including episodes of care, global payments, and pay-for-value programs.

Dr. Bulot is considered a national expert on aging and disability services, long-term services and supports health policy. Please enjoy listening as we envision what end-of-life care delivery might look like in a world where we redesign healthcare.

Host I: Okay, well, thank you all for being here. To our listeners, as you just heard, we have three, very distinguished healthcare leaders in their respective practices. They all come from value transformation. We have Katherine Ziegler, we have Dr. Chris Stanley, and Jay Bulot, all with value transformation. Again, we are discussing end-of-life care.

First, we'll have Katherine start. We sent the healthcare practice a survey and given that 86 percent of the practice thought the U.S. healthcare system values quantity over quality, do you think this perception currently influences the way providers deal with end-of-life care and those discussions?

SPEAKER

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Katherine Ziegler: Yeah, it's an interesting question. Just as I thought about this conversation we were going to have today, I did a Google search on quality versus quantity in the end-of-life, and if anyone has several hours, you're welcome to do that. This is a debate that has raged for decades and I think that the perception of our practice is not unlike the perception in the country. I do think that there are many influences over the way providers deal with end-of-life care and, not being a physician myself, Chris, I'll look to you to weigh in here, as well. When I think about providers from a system perspective, there are certainly influences. We've had conversations, for example, with some large health systems as we've looked for opportunities for them to improve the cost of care, value transformation, often working with that total cost of care dynamic and things like hospice, palliative care, end-of-care.

In reality right now, if a system starts a program like that, it actually degrades their revenue. It isn't even budget neutral. It actually hurts the system. They hire resources to do these programs that help people through the end of life and, as a result, they provide less care, there are fewer patients in their hospitals, and there's less revenue to the system, so there's a real financial dilemma that occurs. That's the financial value.

I think the cultural value is an even harder question to really pin down because everyone defines this quantity versus quality at a personal level for all sorts of cultural reasons. For some people, duration of life is quality of life and for other people it's they define quality by what they're able to do and how they're able to live their life and spend their time. When you get to the provider question, it'd be, it's not like every person thinks of it the same way as ... I think it gets challenging for providers to raise the question until they know patients really, really, well.

Dr. James Bulot: Yes. I would add to that. I think for a lot of consumers who weren't very educated about the healthcare system, they often-times equate quantity with quality — not understanding that there are nuances and differences to it. End-of-life care, it lends itself that same discussion: how much is enough and is the volume of care we receive the quality, or is it something that's less tangible than that? My work prior to Navigant and then in an academic setting...people generally don't want to talk about end-of-life care anyway, so they just assume that quantity is the value. I'm getting a lot of care, so that's good care. It doesn't matter what the outcomes necessarily are.

Dr. Christopher Stanley: Yeah, so this is Chris. I totally agree with my colleagues on this. I'm going to add an additional point of view around this as well. If we think about this from the concept of what gets paid, what gets measured gets done, similar to that is what gets paid for it gets done. From a micro-economic viewpoint, physicians or providers who need to be and should be discussing with their patients and family members about end of life issues, the reimbursement at a patient visit is significantly lower than what it would be if that very same patient were having a medication administered, having a procedure done or actually having a more...a quicker visit related to a specific sickness, illness or injury. While I don't think that providers are necessarily wanting to try to drive more quantity, at least at a physician or practitioner level, they're not trying to drive quantity over quality. The micro-economics are such that it doesn't make sense. You actually can't stay in practice if you are spending a lot of time on non-reimbursed, or very poorly reimbursed services.

I think that plays into this as well, there's a macro piece that Katherine brought up. There's the larger perspective of cultural dynamics, but then there's just the day-to-day tangible piece that I think does directly impact, for economically, where, again, it's hard for physicians, or hard for providers to provide counseling-based services, spending the time that's needed and still be able to remain in practice.

Katherine: I think we had all hoped that, as the transition to value-based care happened that this was going to be one of the questions, one of the dilemmas, that could be resolved...is this notion of aligning the incentives around this because doctors don't want to cause their patients undue pain, suffering, misery. They want to support them through those times with supportive care and with services and approaches that make someone's life better, whether it's short or long, but if the system can't wrap those services around it in the current predominantly fee-for-service environment, it becomes challenging. When value-based care started to evolve and total cost of care and those sorts of things, that conversation started to happen, I think there was a real hope that that would allow systems to really begin to think differently and to prioritize that, the quality of life and the delivery of services in a way that enhances quality of life.

We've got one example where a system put a relatively low-cost program in place to work with their pre-end-of-life patients and had a profound impact, but even quite low-cost, until those patients were in value programs, even that investment was difficult to justify from an ROI perspective. I think, if you think about system innovation and the evolution of healthcare systems, this is where that alignment and that pay-for-value, or contracts that provide these kinds of alignment and incentives, can really help drive this in a way that...a doctor can want to do all sorts of things, but if the system doesn't have the programs, it's very difficult for a physician alone to do some of the things that the palliative care and end-of-life supportive program...those are services that the doctor needs to leverage, not do themselves.

Host I: Definitely. Bringing some things together, and in the spirit of this podcast series being about how we might reimagine healthcare delivery with ours, specifically around the providers and even more specifically for end-of-life care, do you all think that the transition of value and potentially stressing more quality-based, regardless of reimbursement, will more quality-based, end-of-life care delivery system would be more beneficial than what we might see now?

Katherine: Well, I think we see a lot of systems that want to be quality-focused now and we see people doing really, good things for their patients, but I think that it's, you have to be kind of a trendsetter to do those things and be willing to go out on a limb. In healthcare today, survival is really important. I think that conceptually, I don't think any health system out there would argue that they want their patients to have the best possible quality of life. I think most health systems would say this isn't about quantity, we would never prolong someone's life without value, but it's, how do you do that? End-of-life care is about a completely different way of thinking about care. It's a complete redesign of the healthcare system. That takes real innovation and leadership and that's hard to do in today's environment, I think.

Dr. Bulot: Well, and I think it's also difficult because as much as we want to focus in on being a gerontologist, right? We want to focus in on end-of-life and quality of life. At the end, no health system wants to advertise themselves as a great place to die. It's not a very good marketing slogan and people don't want to go to healthcare to die. They want to go there to live, and how do you blend that and make it an approachable topic that can be discussed within the healthcare system with individuals.

Then, and I think we talk about it at the provider level, but it goes way, way back and a lot further. You got to do the work, whether it's when we're training the workforce to discuss it, end-of-life care decision-making with the doctors, with the nurses, nurse practitioners. None of them feel comfortable having those discussions with their patients. Patients don't often want to identify that they're at a point where they make those types of decisions. I think bundling it, the value-based approach for some makes a big difference, but it's also tricky in that it looks...I used to be a state administrator, a state director in a couple of states and we tackled this a little bit and whenever it's done right, it looks like rationing of care, because people make decisions and the end-of-life that result in lower costs, but as a state you can't promote that because you don't want to say that we're reducing services at end-of-life.

Dr. Stanley: Just to build upon those comments a bit, this is Chris. The way that we measure success in quality in end-of-life right now is — as Katherine was describing is, and Jay as well — it's: what are survival rates? Or, think about oncology or cancer, what's your one-year or three- or five-year survival rate? Or, how much longer can we prolong your life? The metrics that we measure our palliatives quality are not quality of life, it's measured in months, or on things that we do to people, so it's a physical measurement. It's not a patient-centered type of overview to say: what are you really looking to get out of your end-stage, end portion of your life? I think part of it is, we do need to, as an industry, almost impossible, but as an industry we need to start measuring, or at least reporting out differently some metrics beyond just month and year longevity, and more about: are you living your last year, last months of life, the way that you would want to do it? That's key at redefining the quality.

The second piece, at least for me, there's a bit from Jay's comment. As also a physician, I was never trained to have those types of discussions. I don't think most physicians are really trained to take that, how do you withdraw care, or how do you do not provide care? We are trained primarily on — if there's any hope, or any possibility — let's go ahead and error on the side of doing more. Unfortunately, that frequently is not what a patient would choose if they knew the pros and cons for all of it and the success. I wonder, just to introduce it, if our physicians are really the best resource, or discussion area, to be having these types of end-of-life discussions, or is it really more of a social worker, community worker, or possibly an advanced practice physician, who can free up the physician to do other types of things. Really, sort of this redefine the talk of life approach, let's focus more on the social behavioral aspects of end-of-life, not just on, is there a procedure or medication I can do?

Host I: Yeah. Thank you. That's very ... some great insights there. To take us back to some of these survey data that we had within our practice: over 60 percent of our respondents have thought about their own end of life care and 46 percent have spoken to a family member or a friend about their end of life care, but only five percent have talked to, or have been talked to by a provider about end of life care. Do you think there is a lack of provider education around end of life care and how to discuss it with patients?

Dr. Bulot: I guess I'll put on my old academic hat and say, yes. Across the U.S., almost every medical school now has some form of fashion of end-of-life care, advanced directives. Those types of discussions are included as part of their coursework, and I say that as part of, because I don't think there's any academic medical school that has a full academic coursework around end of life, unless that's the specialty that you're choosing. It's anywhere from three hours, six hours...some of the more progressive schools might have a two- or four-day workshop around end-of-life where they're practicing how to have those discussions, but by and large, it's touched upon because we expect doctors and other healthcare providers to know this, but unless you're practicing it on a regular basis, it's going to be quickly forgotten, I think.

Dr. Stanley: This is Chris. I fully agree with that. I guess, I would say, even though over the past, let's say decade, or so, there's been a larger education push in medical school and residencies for new trainees to come out. The reality is, majority of healthcare that is provided in the U.S., is being provided by providers who are in tenures and further out, and so I don't think we can or should be waiting for a generation or two of providers or physicians to pass through before things really start to shift.

As an example, it's been a few years, but I don't think this is any different now. When I was talking with ... this is more when I was at the health plan, and would discussions with oncologists, cardiologists, about their patients who appear to be end-stage heart failure, or end-stage disease, and would question about readiness of clinical appropriateness for palliative care and/or hospice, and the physicians were very, very hesitant to take that advice, or run with that — especially coming from a health plan — which again, conveys this, trying to withhold care, as James mentioned, so they were almost never willing to actually enroll somebody in palliative care or hospice, even though the clinical signs were all there and clinical status. In fact, sometimes patients or families were even and requesting it (palliative care), but when I ask it a different way and said, "Would you be surprised if patient, Mrs. Smith or Mr. Jones is still alive in a year?" They (the physicians) would say, "Oh yeah, I would probably be really surprised. They're absolutely going to be passing away between now and then." And I'd say, well that's exactly the right time then (for palliative care). Maybe the question isn't, "Are you willing to throw up your hands saying there is nothing else I can do?" Doctors are never willing to do that. But if you reframe the question in a sense of giving alternative tools through providers to say, "Here's how you can engage with patients and families. Here's how you can think of it differently. Would you be surprised if they're still alive in a year?" And if the answer is, "Oh, yeah, I'd be very surprised," that's then the right scenario, the right time, and I think again, part of my belief in the education is it has to be what are some phrases, some tools and ways to think about it to engage (patients and families). And again, that may also be some other talk of life end approaches and having other people help support the physician, so it's not just one.

Dr. Bulot: Yeah. I know part of this is around innovations and end-of-life care and I'm wondering, with all the advances of the apps and on demand in the world, if there's a...I used to work with some physicians around dementia and planning and how to work with their patients who they identify as either some type of Alzheimer's or dementia, and it was a concept of the "easy button," just pressing this button and everything they needed to know when it's a dementia diagnosis, who they needed to refer to, so they felt comfortable having that discussion. Does technology, does EHR, does all the different things, can that play a part in it? I wonder, for individuals who are diagnosed to do some type of life assessment to say, what do you value and then work with the doctor around that on end-of-life care. That's not necessarily to start the discussion on palliative care/hospice, but what are your values from a person-centered approach and let's work on your treatment, so we can help you meet that instead of it being always...and that's how I think most people expect to be driven by the physician in telling the patient X, Y, or Z.

Katherine: You said a couple of things there, that I think are particularly...One is end-of-life does not equal, at least in today's world, does not equal palliative care and hospice. End-of-life can be the latter two- to three-years of your life and how you want to live it, but until the conversation changes, I think the reluctance when I've talked to physicians as well, "I don't want to tell anybody they're going to be dead in six months, because maybe a miracle will occur." And so, these length of stays in hospice of two weeks, or three days, or a month, are directly tied to keep a reluctance to set a time limit on someone's life.

The study I referred to earlier where a nonclinical person just spending time with someone in the latter two years of their life resulted in a completely different way of living. And I think that the conversation shift and the opportunity is to shift the conversation from hospice and even from palliative care and hospice, which is where we've gone in probably the last eight to 10 years, is added the palliative care piece in, but really how do you want to spend your final years? Because a person might not have one of those five diagnoses. If they do, it's super important to have the conversation, but someone may just have a series of things happening as they get older and you know they're in the later part of their life. Having the conversation then, before the crisis hits sometimes allows a little bit more clearheaded decision making because you're not in the midst of it.

Host II: We wanted to talk a little bit about advanced directives, as well, and about half of our respondents said that advanced directives should be a mandatory requirement, but surprisingly 18 percent of our survey respondents did not actually know what an advanced directive is. We did receive a couple of comments that were interesting that they voted no to directives being mandatory because of the word mandatory, which suggests that people think is a good idea, but they don't necessarily think it should be mandatory. Do you all believe that there should be some level of requirements with regards to advanced directives?

Katherine: Well, I'm going to tie on a thought I had with the last section. I know Jay, you're going to jump into this and have deep expertise, but I think the part that should, two things should be mandatory. One is, I do think that there should be a quality of measure, there should be a vital sign. "Have you thought about end of life? Would you like to have a conversation?" I think that simple question in a primary care office would go a long way. It doesn't mean the doctor has to sit and counsel for an hour, but opening the door.

The other piece, and this is the piece that I think is most mandatory, having just gone through something with a family member, is the mandatory part should be that somehow we have to find a way for the health system and I mean the entity, the technology, to store and have immediately recoverable, the documentation of those wishes. Because to have gone through and done all of those things and then have something happen and have that information unavailable to a medical care team that subsequently doesn't have that guidance, I think that's the part that forcing a person to put something in writing, probably not, but making sure we have a technical system that ensures that when the person does do that, but it's readily available to the entire care team. I think that's the part that we've got to find a way to make mandatory and critical.

Dr. Bulot: Yes, I agree with that and it's a conversation I've actually had. Both my wife and I work in long-term care. She works in a nursing home, I work as state director for aging services in a couple of different states. Advanced directives, even today, I think is maybe an older term that came about, I don't know, probably 30 years ago. An individual created a living will, or a couple different programs around how they wanted their directive care to be provided, but it was never followed through upon. Study, after study, research after research, once the person is unable to state their wishes, families tend to do what families want to do, regardless of the individual's wishes. We've tried to make it more clinical, make it more medical, make it part of the health record. You have physician orders for life sustaining treatment, but still there's the portability of it. I created it. It's in my medical records, but my doctor is not doing it at the hospital and they don't have access to that, or it's on my fridge. It's in that yellow or red folder, whatever color the state uses as their folders to let emergency medical, first responders know that I have something like this. It rarely follows the individual, so it can be used for decision-making for that person.

When we reach the ideal around electronic health records that are integrated and coordinated across systems and physicians' offices and hospitals and pharmacies all can communicate and have access to it, I think that would be great, and I think it would help to go a long way towards letting folks know, decision makers, whether they're family or the healthcare providers, that I have end-of-life wishes. I have documented what I want done for me, and you can follow through upon them.

The mandatory part is where it gets really, tricky. This is probably one of the biggest headaches that I encountered as a state director when we tried to pass and finally did pass state legislation on physician's orders because it always got tied to either religious, or a social issue that wasn't necessarily medical, but it was how it was framed. I think everybody remembers the death panels of the early iterations of the ACA. It was around advanced directives and having end of life discussions with patients. Different states have different rules around what they can and can't do. I worked in two states where the legislature passed the rules, but the governor's agency was not going to administer that rule because it went against his personal beliefs.

The mandatory part is, it's difficult I think, but I think it needs to be approached. I think people need to have an opportunity to offer or to know that the resources are there if they want to discuss the and document their wishes.

Dr. Stanley: Just to build real, quickly on that. Again, I think it should be mandatory. Everybody should have the opportunity to do it, but I think culturally it would be inappropriate to force everyone to do it, for exactly for what we've talked about, but the reality is right now, not everyone has the opportunity to even share their wishes. I think most people in this type of situation know what they want, personally, but they rarely are given the opportunity in a safe environment to have that end-of-life discussion, and that's — the opportunity I think should be mandatory.

Host I: That's a really, great point, and I think that's a great way to end the discussion unless...Is there anything else from the three of you? First of all, thank you so much for being on this discussion. It's been really, really, wonderful. Is there anything from the three of you that you would like to discuss more, or do we think we've covered what we would like? Any last words from anyone?

Dr. Bulot: I would like to share one thing. In years past, I used to teach courses on death and dying. I've been on hospital ethics committees usually around end-of-life decision-making for people who are un-befriended, but even within families, the document itself and the process helps relieve a lot of guilt for families and individuals. Usually, these heroic efforts are being made by families who have some either uncertainty about what the wishes are, and it makes the end-of-life process, the dying process, so much easier for the family to know what that person's wishes are. It's never fun to go through the death of a loved one, but to have had those discussions prior to, makes the end result and even the years later, so much more, and I hesitate to say joyful, but you reflect upon it and you know that person lived and died the way they wanted to without any regret or without any guilt attached to it.

I think there's a huge amount of value there. I encourage everybody in my family, my entire family — my kids are 12 and 14. They all know how I want to die. They all know how I want to be buried, and I remind them about once every two or three weeks about what I want done to me. I just think it's good practice.

Katherine: Well, and I will say, having just gone through it with a family member, what you're onto is the real first of all of it, because in the middle of the night when the phone call comes and the decisions are being made to have everyone in the family be able to say with absolute confidence, this is what he would want, it changes everything. It takes the doctor off the hook, it takes the health system off the hook. It takes the family off the hook, and instead you're all united around the person's wishes, and that I think is underneath all of it, health systems, doctors and people themselves, that's really what it's about.

Dr. Stanley: Yeah, and again, I totally agree to wrap that up to, we so often think about end-of-life around that individual whose life is expiring, but most of the value in the carry on is really related to their family, and their social circle. I think we need to reframe, ideally we need to reframe end-of-life discussions from being around what do I, as the patient want, to what's the impact and the value and the support around the family and the social circle? I think that's when it will engage in a much broader discussion, much more collaborative and supportive discussion, and not just kept in the dark.

Host I: Again, I think that was a really great conversation and discussion. I think the listeners are really going to enjoy it and learn a lot.

Announcer: That concludes today's episode. Be sure to check in with us for future installments of the Navigant On Healthcare podcast series on navigant.com/healthcarepodcast.

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