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TRANSCRIPT - GR **01 10 25** *"**Telehealth/Remote Home Health Monitoring for Palliative Care and Pain Management**"* guest speaker Leslie Blackhall MD, University of Virginia

Internal Medicine Grand Rounds

- All right. Hi, everyone welcome to medical grand rounds. We're delighted to have Dr. Leslie Blackhall from our palliative care section within the division of general medicine. Speaking with us today on models of palliative care. Delivery for patients with advanced cancer, take us through our accreditation. Cme. Slides of Leslie's presentation objectives. If you're looking for Cme. Credit for faculty
- again, today's session code and our chief resident, Dr. Shaina Hassan will introduce Dr. Blackhall.
- Thanks. Dr. So. Good afternoon, everyone. It's my great pleasure to introduce our grand round speaker for today, Dr. Leslie Blackhall. So Dr. Blackhall is our current section head for palliative care. Here at Uva she grew up in upstate New York, and attended Yale University for undergrad, and she went on to earn her medical degree from New York University, and afterwards completed her residency and fellowship training in Internal medicine and medical ethics at Boston University.
- She also earned a master of theological studies from Harvard Divinity School, with concentration in biomedical ethics, history, and philosophy.
- After a decade of work at the University of Southern California, Dr. Blackhall joined us here at Uva in 2,001 as an associate, Professor Research Coordinator at the center for Biomedical Ethics and founder of our palliative Care Clinic, she has led the palliative Care division since 2,012,
- and she has had a lifelong interest in improving end of life, care for seriously ill patients with a focus on community-based palliative care.
- Her research has included topics in early integration of palliative care into the treatment of those with advanced cancers and other serious life limiting illnesses, monitoring and assessing cancer, pain, and the use of opioid medications and communicating regarding advanced care, planning, and elders of different ethnic backgrounds. Under her leadership Uva has been named one of the 1st national palliative care leadership centers for community
- and outpatient palliative care by the center to advance palliative care.
- We're very excited to host her for grand rounds today. So please join me in welcoming Dr. Blackhall.
- Can you guys hear me?
- Okay,
- So I usually try to start this out. These talks out by just
- talking about what palliative care is from a population health point of view.
- And when I was
- medical student there was no such thing as palliative care, at least none that I had ever heard of. So it's a relatively new field.
- and many of us who are my age, who are into palliative care were into bioethics before that. And I'll talk about that a little bit. So 1st I'm just going to talk about what the goal is of palliative care. Why, why we have this thing called palliative care. So I

can put into context the work that I've done most of my career and what we've been doing here at Uva.

- And so the 1st thing I have to tell you is the bad news is.
- everybody dies. Everybody in this room is going to die. I'll die sooner than most of you, because I'm old.
- and it's good to be old, because
- you're lucky if you get old, but nevertheless, these are the causes of death. In 2023. If it was 2021 or 22 Covid would have been up there heart disease, cancer.
- unintentional injury, stroke. But if you
- look at those age 45 and above which is where most of us will die.
- you can see that it's mostly
- cancer and heart disease. Heart disease takes over as the leading cause of death after about 55, and if you get older than the age of 85 dementia starts to become one of the most common causes of death. So the most common causes of death, cardiac disease, advanced cancer.
- chronic lower respiratory disease. You know, pulmonary disease of some kind
- is below that. And then there's stroke.
- And then, in the old, old dementia, aside from stroke which can happen abruptly for somebody who is otherwise feeling. Well.
- All of these are what we call chronic life limiting illnesses. When you get metastatic pancreas cancer. You do much better. Many people do much better than they used to do. People with metastatic melanoma used to die very quickly and with immunotherapy. They live longer. But we know when you get those and same thing, people with heart failure, with Lvads and new technology, they do better.
- But these are chronic life limiting illnesses, which means, sooner or later, people who have them are going to die, and it shouldn't be a surprise when they die. We know these are incurable illnesses.
- Nevertheless, in the last year of their life, people with this kind of chronic life limiting illness, have worsening symptoms. They tend to come to the er the hospital, the Icu out of the Icu, back to the regular floor.
- into a nursing home, back to the er so multiple transitions of care and admissions and readmissions. And there's a reason why that happens. The reason it happens is that they're reaching the end of their life, which means
- the treatment for their underlying illness is no longer working.
- When you're at early stages of your heart failure
- you get come into the hospital, you get better, and you can do. Tweak your medications. You can do well for a while, but towards the end that stops working.
- And so that's why they're in the hospital. So we're
- so maybe that's what they need. Right? Maybe it's okay that they come into the hospital. That's where they should be.
- Dartmouth Atlas is a was a project that was done in the early 2 thousands. But
- studies like this have been going on for a long time. So what they do is they compare like different geographic areas. And if you look at end of life care, some geographic areas are much more aggressive, like New York City
- somebody. I
- I was born in New York. Okay? So I can say this about New York. If you, some doctor tells you you're going to die in New York, you just get in a taxi and go to another place. Okay? Because, like what the hell do they know? So there are places. So more people die in an Icu in New York in general, than they would

- here in Charlottesville. But if you look at people, places with the most aggressive care and the least aggressive care. The mortality rates for those illnesses aren't different. You're not living longer when you spend more time in the Icu in the last months of life.
- and not only that, you know.
- studies that look at quality of life for patients, and then how the families do afterwards have shown that the people with the most aggressive care tend to have a worse quality of life which is not so surprising. So people are coming in and out of the hospital because the things we are doing are working less and less well.
- and they're not getting much benefit out of it. And so that's that's the goal is to try to change that, to make care at the end of life be more appropriate to the stage of illness and provide better quality for patients.
- And so this is just this will be about cancer. Our palliative care clinic is in the cancer center. Although we see other patients and the data on the benefits of palliative care for cancer are more established, really, than for any other illness.
- So this is just 2 ways of looking at the same thing. Both costs of care and hospitalizations which end up being the same thing. So you can see, as months go prior to before death. The closer you get to death, the more frequent the admissions.
- And if you look at the reasons why cancer patients get admitted, it's almost always symptoms.
- And you guys know this right? You you worked on, you know, on oncology. And what brings people in is things like pain, nausea, vomiting, failure to thrive, dehydration, etc. Etc.
- Pain being the main one which we'll talk about later.
- So now, one of the things that's difficult is that
- all of the things that look at admissions prior to death, and
- you know, we can only determine that someone is to determine. Someone is 2 months prior to death after they're dead.
- So that's the problem is trying to prognosticate. If you look at like prognosis for people with any illness, it's a bell curve, right? So it's difficult to say for any individual patient how long they have to live with that illness.
- but
- for any individual patient. This is what's called illness, trajectory. You've probably all seen this. This is sort of the way a palliative care. Doctor looks at these chronic life limiting illnesses.
- This is the natural history of what happened. So with cancer patients. The best predictor of mortality is functional status.
- So it's see how this is like sort of relatively stable, and what all the new treatments and cancer have done is they have extended that period of functional stability, sometimes really for a long time.
- But in the last months of life that's when things start to go downhill disease, progression, more symptoms, more pain, more nausea and vomiting.
- That's sort of how how we think about it.
- So
- I'm just going to go here and then come back up. So here's a history of like sort of what the movement to improve end of life care
- how that that proceeded.
- You know, when I was a medical student many years ago

- graduated in 1984. I remember going on rounds, for you know, I was like just starting my 3rd year, and we went to the patient who was bowel obstructed from colon cancer. She was an Ng. Tube, and she was writhing in pain, and we stood at the doorway and the President looked in, and then he closed the door.
- and he said, She'll be dead tonight, and the do not resuscitate order was written in the blackboard in the nurse's room, because they were not sure if it was legal to have a do not resuscitate order.
- So the initial efforts of people in my field, and many of them who are still sort of, you know, started and led palliative care programs, was simply to clarify that it was legal
- to not put somebody on artificial life support or take them off. That may be hard to believe. But that was considered when Karen Ann Quinlan, who was one of the 1st famous cases when they wanted to take her off life, support. The the police came to the hospital and said they would arrest anybody who did that.
- So that was the 1st level.
- you know. That helps maybe the last little bit of life. And so the next thing was the Hospice movement, which originally started as a volunteer movement without nurses or doctors. It was just volunteers who are helping the family out.
- and as the movement to improve end of life grew. In 1982, the Hospice Medicare benefit came.
- But again, that's the last weeks of life. And so, and I was a hospice medical director in La before I came here.
- and you know at that time 2 thirds of oncologists in California did not have a license to prescribe opiates.
- and my patients used to say, why did I have to wait till I was on Hospice to get pain management?
- So that's when we started trying to move upstream even more. And that's when palliative care, as a field began. Uva is one of the places where I had early palliative care, and that was in the 19 nineties. I came here in 2,001 as the second palliative care person, and I started the outpatient clinic.
- and the thought at that time.
- and sometimes. Still now was that people had the right to choose to have life prolonging therapy, or they could prioritize comfort, care, you know, being comfortable over living a long time.
- and that's often the way you know, it's still, I think, presented to people
- first, st most palliative care programs were inpatient. But then we gradually realized that if patients needed advanced symptom management we needed to be able to provide that in the outpatient setting. And that's we started the palliative Care clinic here as a half day a week and
- went from there.
- So obviously, we know what palliative care is here. We're focused on symptom management, quality of life. And
- so this was the 1st study. That sort of changed the way, especially oncologists, thought about palliative care, and where it became more standard of care, and, in fact, now to have a Nci designated cancer center, you have to have palliative care, was Jennifer Temel and Vicki Jackson was a palliative care person. Did a study out of mass. General, where Jennifer Temel is a thoracic oncologist.
- and so what they did, which is a study you could never replicate now is, they took people with metastatic non-small cell lung cancer, and they randomized them to palliative care. Starting from the one month out of diagnosis to no palliative care

which is, you couldn't randomize somebody to a no palliative care arm now. And so the main outcome they're looking at was quality of life. But they also looked at other things. Mortality, hospital admissions, place of death, hospice, utilization and length of stay.

- So I mean, if you have a service, who's
- goal is to improve quality of life. It shouldn't be surprising that you had a whole nother person seeing them every month. Their quality of life was better, and there were less anxious and depressed than people who had no palliative care, and that would have been really embarrassing if that wasn't true.
- Then they were not well powered to look at these things, but I just want to in the end of
- it's sort of little. But
- if this was published in New England Journal in 2010. But you can see that
- the rate of patients getting chemotherapy in the last 14 days was 24% in the standard care versus 17%.
- And then last month of life
- it's a hospitalization. In the last 30 days of life was decreased ed visits and
- hospice enrollment and length of stay, and I want to point out that the Median Hospice length of stay
- at Mass for mass. General patients was 4 days
- for the standard care, and it was 11 days, and I'll say it's like 18 days in general for all cancer patients now. So it's
- you can get Hospice for 6 months prior to your death, and Jimmy Carter lived a year and a half.
- but because of the way the Hospice Medicare benefit is written, which is, you can't. It's a per diem, meaning you get paid a certain amount per day to take care of people. You can't get advanced therapies. There's some talk of trying to improve that.
- So that's why.
- But this is the reason the study was published in the New England Journal of Medicine is that people who had the early palliative care, not only didn't die faster. They lived about 3 months, 3 to 4 months longer than
- the people who did not get palliative care.
- and so studies. After that you you can't really replicate that study, because, as I said, you cannot do a study where you.
- you know, have people not get palliative care. But many studies after that looked at it in different ways, and it's pretty clear at the very least, the palliative care at the end of life. So these people got less chemotherapy. They got Hospice earlier. They were in hospice longer and lived longer, and that has been shown, maybe not the mortality benefit.
- but that general rule has been seen since then. Here's 1 on
- another. Study was done on clinic-based palliative care, and so that also showed the improvement in quality of life.
- And this one
- I like, because what it showed is that people with early, outpatient palliative care cancer patients were less likely than those seen only in the inpatient side by palliative care to have er visits, hospitalizations, or icu admissions.
- And so

- that's not surprising. But that's what made the American Society of clinical oncologists come out with a position statement that all patients with advanced cancer should have access to outpatient clinic-based palliative care.
- In 2012, Paul Reed of radiation, oncology, and myself go to Cms. And myself and a couple of other people who are in
- informatics. Medical informatics
- got a Cms innovation award to expand the palliative care unit here and use some advanced techniques to monitor patients.
- so what we did was we did. We did a symptom assessment pro tool at every visit, and we compared patients with advanced metastatic cancers who are seen in palliative care to a control group of those who are not seen in palliative care. So it wasn't randomized. It was just a group of patients with the same diagnostics and same diagnoses.
- And then in that control group it included patients who were seen by palliative care, but only in the hospital and the outcome. Measures were hospitalization. Use of Icus in the last month of life. Hospice referral Hospice, length of stay and deaths in hospital.
- and part of that was we developed supportive Care tumor board. So this is still going on to this day every Friday at 7 30 in the morning.
- which is early.
- but we have the anesthesia pain people there, and that's late. That's like lunch for them. So we meet and we discuss mostly cancer patients who have are highly symptomatic, usually with pain, but also with other, you know.
- psychiatric issues, nausea and vomiting, or who bring admitted frequently and have
- problems surrounding their goals of care.
- And so that meeting is attended by the palliative care outpatient team, the palliative care inpatient team, the anesthesia pain team, social work, often the chaplains, sometimes a nutritionist. If you look. That's the back of my head. Josh Barkley is sort of there. And mostly this is really an old picture.
- We're the only 2 left, and here. But Carol Havrilla is a nutritionist.
- And so here's the data. This is Uva data. So this was published in, I think, 2,000
- something or something 1415, something like that, whatever.
- It's a long time ago, before most of you were born or something. Okay? So this is what we found that that the people we saw in the outpatient clinic were a lot
- less likely to die in the hospital, and they were less likely to be hospitalized in the last month of life, which meant also, they were less likely to be in the Icu in the last month of life, or
- and if you looked at Hospice care, so in general, it
- 69% of the patients we saw had hospice referrals at the end of life compared to about 50% of people we didn't see.
- And then the length of say, that shouldn't be a percent. That's days
- I made these slides. And I'm just not good with Powerpoint because
- I'm old. So 23 days versus 12 days.
- I suspect
- I'm not sure how different that would be right now. But the one thing that we did find that was similar to many other studies is that if you looked, if you broke the control group down to controls that were not seen, and controls that were never seen in palliative care clinic, but were only seen in the hospital.
- The people who were only seen in the hospital did not have benefit.

- But I think that's because
- people who are only seen in the hospital. They were consulted on the last hospital stay right, because most of those died like 2 days after they left the hospital. If they left the hospital at all, because people who we see in the hospital who are referred to palliative clinic.
- I mean, who are not dying, that admission are are referred to our clinic, and we have a very good
- system for doing that.
- So in summary, I think we can say that there's I presented a little bit of data. There's a lot of data on this that patients with outpatient palliative care get cancer patients improved quality of life, decreased hospitalizations at the end of life increased. Hospital hospice, utilization and length of stay, you know, if somebody gets hospice for 2 min
- or 2 days, it's probably not
- doing them that much good so longer is better, and you have to have outpatient and not just inpatient palliative care to have those benefits, and at the very least we can say that it doesn't shorten people's lives.
- I'm not going to make any claims that we lengthened their life.
- but you can see the the reason why. I think most people who've looked at the Tamil data think this is so is that the they stopped getting the treatment that wasn't working.
- and therefore they had less side effects from it. And I think this is what most of the oncologists would say. Now, you know, like at certain point in your functional status.
- Chemotherapy, or even immunotherapy, can shorten your life because you're just getting side effects rather than benefits.
- So here's the problem. So Asco said that all patients with advanced cancer should have access to outpatient palliative care, clinic-based palliative care, which was a great thing for them to say, there is no way.
- that's very hard. We'd have to have as many palliative care docs as we have oncologists.
- And here are some of the access problems that were immediately apparent. A is the workforce, B, you know, although
- almost all large hospitals now have at least some palliative care. Outpatient palliative care is much more limited.
- If you have Nci designated cancer center, you have to have outpatient palliative care. So most large institutions have that, but much less for smaller institutions and those that have it sometimes have one day, a week, or half day a week, which means that people with cancer come in for their chemotherapy on Wednesday. They are not going to come to a palliative care clinic visit on Thursday.
- so if they don't have it all time, it's much harder to get to the location like we. We're embedded right here in the cancer center.
- which was fine for a long time. But now there's infusion centers that are, you know. There's the ones in Culpeper and the ones in pantops and the ones in Amc. But many palliative care programs. It would be as if our palliative care clinic was in Fontaine
- cancer patients. That's a lot. And patients with non-cancer. This is even more people with cancer. If you can catch them in the.
- you know, if you're working in the cancer center, it's easy. They're here all the freaking time. But if they don't, aren't, you know, if they're somebody with end stage

copd or pulmonary fibrosis or Als, or end stage renal disease on dialysis. It's a lot harder.

- So this is just showing that
- you know it's much that this has to do with access. It's very
- small print, but most if you have a comprehensive cancer center and Nci, you have to have some palliative care.
- But you definitely, but not all the palliative care programs are embedded, and in many locations the local hospices have just set up a freestanding palliative care clinic. At the request of the
- the local cancer center. And so it's just not as available. And so that was the idea. Behind this study
- which was comparing telehealth versus in-person, palliative care. This was set up, this they got funding for this study
- prior to the pandemic.
- Let me tell you, the pandemic really screwed with randomization for a while of this
- and this is why they thought that this would be the way to expand access.
- So this was a multi-site national study, comparing telemedicine versus inpatient. So all of these patients had some form of palliative, clinic-based, palliative care. Again, it was metastatic non small lung cancer. They randomized patients to you had to be.
- You had to be within 12 weeks of diagnosis to be part of the study, and after that you had to have monthly visits, and even if you're on the telehealth arm, the initial visit was in person, and we were one of the study sites. Initially there were 16, but due to recruitment issues, there were 22, and eventually 1,200 patients. And they've got data from their caregivers as well.
- So why, why is telemedicine a good idea for palliative care? So I mean, it's good like right now. It's made it a lot easier for us. We don't have to necessarily have a provider in the Pantops, you know.
- oncology center, although we probably will, or Culpeper, or oncology.
- Katie Waybill, who's a pulmonologist, is also board certified in palliative. She's doing one day a week in clinic with us, and pulmonary patients, though, are, they're short of breath. They don't want to come out if they can possibly avoid it. People with end stage renal disease. Als, so it's much more available.
- And the characteristics are of palliative care that we focus on symptom management. I always tell my patients you know your report of your symptoms is my cat scan
- like.
- So you need to tell me what you're doing, because if you just say you don't feel good, it's like a cat scan that says abnormalities are noted.
- But because of that, you know, I don't have to do a pap smear.
- which you can't do by telemedicine, as far as I can tell, at least now and and so that makes it sort of
- a good candidate for being able to do this also. If you need to do the physical exam, I will say that cancer patients are a population where they have more imaging than any other
- right? I mean, everybody has a lot of
- imaging. So these people were mostly 65 years old was the average age.
- Little more than half were women.
- 2 thirds were married, and 83% were white.

- Half of the sample under half of the sample had to travel at least an hour to get to the cancer center. Which is true here, right? 40% of our patients are from more than 100 miles away. So it was an issue for them.
- and in terms of their mortality, about 10% died by the 12th week
- and 19% by the 24th week
- main outcome measures were comparing video visits, palliative care versus inpatient palliative care on quality of life measured by the fact, L functional assessment of cancer therapy, L. Questionnaire. And there's another whole issue of what of these quality of life
- scores are. And actually, David Ling and I are working on that a little bit and secondary outcomes for mood, prognostic understanding. So that means, are people aware that their cancer is not curable? It's not like? Do they know how long they have to live? Because who the hell knows? But it's just? Do they understand that the treatment is not for cure
- and satisfaction with care and things like that.
- So, just to
- summarize, there was some quality of life improvement in both study groups similar to the initial efficacy trial of in-person, early palliative care, and it was no different between telemedicine and
- in person. This is a tiny little slide which I apologize for, but same thing that there was improvement in anxiety in both groups and telemedicine, and in person were equivalent. Same thing with depression measured in 2 different ways. Although measuring depression in cancer patients is a
- a fraught topic, because a lot of the symptoms that are used to measure depression or things. Every
- patient in the cancer center has. But nevertheless
- depression was improved, and they looked at coping styles. So you know, in general, there's the avoidant approach, which is
- the way I'm approaching the news right now, which is, I don't want to know. Please don't tell me versus
- you know.
- being willing to consider and talk about what's going on. And so there's there's a scale to measure that. And
- and similarly, that those there's an improved, less avoidant coping
- in both groups. And that was equivalent.
- So you know, in summary so far. And there's data, analysis is still going on in this in person and telemedicine palliative care had equivalent impact on quality of life. Anxiety, depression, and coping. Prognostic understanding was also equivalent and satisfaction with the palliative care was equivalent or better.
- And so there's another. This has not been released yet. But the next abstract that's being written has shown that.
- You know, we thought originally that older people like me and people who are not good with computers.
- would have a much harder time with telemedicine, and might get less benefit from it. I think the pandemic changed that because everybody wanted to see their grandchildren, and so they got very comfortable, and also the telemedicine platforms got a lot better.
- you know. We were using these very clunky, weird platforms to begin with, and now they're built into epic, and they work very well.

- so that didn't end up being affected it but black and Hispanic slash, you know, Latino patients had a quite a bit more quality of life benefit from early palliative care
- delivered via video. And so there, more data analysis is happening. And that's
- and it could be because of costs of travel and things like that that it was.
- you know, better. But
- I think there's a known disparity in both in access to palliative care among non-white patients. And so that that's felt to be a hopeful sign.
- So I think in summary, we do a lot of telemedicine visits.
- Almost a 3rd of my patients are still being seen by telemedicine.
- and that is either they're in outlying infusion centers, or they have an urgent need, and they don't want to come in. They're feeling sudden increase in their pain. Or are non-cancer patients like we see a lot of a fair number of Als patients, and I have a project with end stage renal disease folks.
- and I also follow my patients on Hospice on their Hospice attending, and I'll do a telemedicine visit once a week if they're able.
- until death. So that's summary is that telemedicine is good. The other model of delivery for palliative care is home-based. Palliative care which we do have in this area from Hospice to the Piedmont, and the problem is that that will never be a widely applicable thing because of what they call windshield time. I did a lot of home visits when I was Hospice medical director. You're lucky if you can do 4 a day.
- See? It's it's a problem. However, they can go to nursing homes and other places that are really good.
- so the last thing project I want to talk about is a project I'm doing with Virginia Lebaron, can you?
- Virginia Lebaron is a fabulous human being, and a Phd. In the nursing School, and when she applied for a job at the school of nursing, I called the Dean and said, If you don't offer her a job, I'm offering her a job. Okay? So you better do that. And she's done a lot of research in
- palliative care, but especially around symptom management. Now that's the project she and I and the School of Engineering have been working on since. When was our 1st grant, like 8 years ago, something like that.
- So
- just to remind you, when we looked at, why do people get admitted at the end of life? It's symptom management, and the most common symptom is pain
- and and pain is difficult to treat, and also the risk benefit ratio of the drugs we use is daunting.
- So this is a home monitoring system. It's called Bessie C.
- That we're using to try to help, just like the stuff they have for cardiology to try to monitor patients pain when they're at home. And
- so Bessie C. Stands for behavioral and environmental sensing and intervention for cancer pain. So it consists of smart watches.
- Which collect. I'll go through the data and environmental sensors as well. And and this is the type of data that's collected. The timing of the pain like, when do they have their pain? The number of pain episodes per day, the intensity of the pain
- impact on the quality of life use of pain, medications and efficacy of the pain medication. So when they have an episode of breakthrough pain, they'll answer a questionnaire. I'll show you a little bit about that, and then it dings them back in

what 40 min and ask them to report what their pain level is, then, so you can see if it was an 8. Did it go to a 7. Did it go to a 2, or did it not budge

- if they didn't take a pain medication, why didn't they?
- And also environmental factors like light temperature noise. What am I missing here?
- Okay? And yeah. And it also measures things like heart rate and other factors related to the patient. Here's the what the watches look like
- we went through these a lot. When we 1st were doing this.
- you were supposed to take these environmental sensors and plug them into your router. And I said, I don't even know what a router is to the engineering students. They looked at me like you just are the stupidest human known to man, and everybody knows what a router is. And then they went home and asked their parents, and they came back and said, Okay, nobody knows what a router is if they're not us. I mean, I know that there's a router in that in a closet in the basement, but
- there's a lot of stuff in there, and it has lights, and my husband might know that
- maybe my son knows. So these are the questions. You know. We don't have to go through them. But are you in pain? And the caregiver also answers, because, especially in hospice, the caregivers are giving most of the pain medications and
- tend to be helpful. What's your pain level? How distressed are you?
- etc.
- Those are the type of questions in a pro. There's a lot of different one of the things we're working on now is how to give the information to doctors.
- And so this would be one that would just look at how many episodes of pain per day has this person had in the last
- 2 weeks or so, and how severe was the pain
- you can do ones that look at. What's the average efficacy of the pain medications when they do take them. Here's some more which are.
- I'm not going to go through all of these.
- But you can. You can do a lot of different visualizations. And the goal eventually is develop this remote monitoring system that can measure the patients and caregivers, experience of pain and the effectiveness of pain, medication, and that includes, like timing of it when it is so that it can be easier for us to treat pain.
- and eventually Virginia is going to make epic put it into there. But I don't know how you're going to do that, Virginia, but I I believe that you can. And so the the real goal is that
- if the reason cancer patients get admitted, the end of life is symptoms, and the most common symptom is pain. At least some of those admissions might be aborted if we could measure it better at home.
- And so that's that's it. And I want to say 2 things. Why, why am I doing this? Why are we doing this end of life is part of the continuum of care for all patients, not all of us will die of cancer. But all of us are going to die of something, and we're going to need medical care when that happens.
- Therefore, improving care of patients is important.
- So, and as people with life limiting illness get worse, the treatment of their disease
- is working less, and palliative care is more important, but palliative care doesn't have to be delivered by specialists, oncologists, cardiologists, neurologists, primary care doctors, all are doing palliative care as well and you can utilize those things

without increasing mortality. It's just part of normal palliative care, and people are often referred to me, and they come in, and I know they're afraid of me.

- You don't have to tell them they don't have to be afraid of me. Okay, they really don't. You know. Once I start talking to them about their bowel movements. They're relaxed like finally, somebody's talking about
- that.
- And the last thing I just want to say is that I've been at Uva since 2,000, and I just was talking to Mitch Rosner. Uva has actually been a leader of the field. I came there here because of it. And so I really want to thank the Department of Medicine. And I want to thank my division.
- If Moe's on somewhere and and the cancer center. They I got permission to come here a half day a week. I just started
- coming here like 4 days a week and then putting more providers in, and they kept giving us more resources. They've been very welcoming and good partners in this way, ahead of many, many cancer centers, and also the school of nursing, and Dory Fontaine was the Dean when she hired Virginia and many other nurse researchers in palliative care.
- and when she left I told her she was my dean, but I just want to thank them because
- I don't think I could have done anything I've done without the support of all those people. So I'm going to stop. We've got about 5. We've got a little more than I guess. It's almost one. I'm happy to answer questions or talk about any other topics you might have.
- Yes, that is your
- is there a role for palliative care at all for the people dealing with like dementia?
- I would say that. Yeah, yes. Okay. So one of the
- one of the things. And and
- so geriatrics and palliative care are closely related, as you might imagine.
- although I once was at some conference about this, and you know the geriatricians have a thing about healthy, successful aging.
- which sort of given who I am, rubs me the. So I said, I'm the unsuccessful aging person. Okay, because I just feel like it's like it's not good. If you feel like you're unsuccessful because you can't play tennis anymore. Anyway, that's just my prejudice in life.
- So I'd say the thing that is geriatricians, you know. Justin Mutter, who's just an incredible person has done amazing things with geriatrics, has now added geriatrics to the memory clinic and doing that kind of testing. That's that's the role for geriatricians. Geriatricians are very good about looking at polypharmacy, and Justin has a polypharmacy clinic. That's doing that. However, I think like an end of life.
- One of the things that you know sort of been my thing for a long time
- has been that again, that we are constantly talking to people about. Do you want your life prolonged, or do you want to be comfortable? And I think almost always that is not the question.
- The reason that we have that sort of framework.
- I think, is that all the early bioethics cases that established the right to remove care were of people in vegetative states
- who you could keep alive a really long time in a bad quality of life. This is going to answer your question eventually. Okay?

- So that so that that's sort of the framework, and I think it's not a good framework. I think the better question is, what's the best way to care for somebody whose illness is no longer responding to treatment of the underlying illness. I think that's just a better framework, and it's less likely to cause
- guilt in family members. So this is not done so much, but like, say, 10 years ago I would get a consult for a patient with dementia who had been aspirated and was in the Icu
- and had an Ng tube because they were intubated. And now they're out of the Icu, and they have met song because they're delirious and they have the Ng. Tube, and it would be like, How can we make this person sleep through the night? And
- can you talk to the?
- And we did a swallow study, and they can't swallow. And can you talk to the daughter about whether
- should have a you know peg tube tube in or let the patient die? I used to say, like everything about this consult is wrong. 1st of all, if they were in the Icu with an
- aspiration pneumonia.
- they don't need a swallow study. We know that they aspirate, and they all do. If they're not doing it now they will. And and the second thing is
- that the American Geriatric Society and my organization both. You know they had a
- what was, you know, like sort of a list of things that you should question why you're doing them. And one of those were was that the American Geriatric Society does not
- advise
- even mentioning peg tubes to people with them, you know, for families of patients with dementia, because it doesn't prolong your life. They aspirate the tube feeds, they pull the tubes out, they end up being less active, and they end up.
- You know, just, you know, it doesn't improve morbidity or mortality.
- So I think that perspective is an important perspective that we, you know, have to, and we know what Hospice offers, although most of the geriatricians here, too. So I think, from that point of view, in hospital, talking about end of life, and how you tell and what the you know. My perspective on talking about advanced care planning is to talk to them about illness, trajectory.
- because, you know, if you look at advanced directives, I know there's a big push to get advanced directives. You should in Uma Clinic, or wherever do, an advance directive on anybody who's listed. Surrogate
- is not their spouse.
- You don't want to be in the mic, you? When the girlfriend, who's but of 40 years.
- is there, and the mom hates them, and they're you know what I mean. We've seen this. So the part where you list a surrogate is very important. But then there's the part says, if I'm dying.
- you know I don't want artificial life support, or I do want artificial, or I want it for 6 months, which is just
- sort of stupid, if you ask me. Because why would you, anyway? Never mind, I have a lot of opinions, but
- studies have shown it doesn't really change care.
- Because what does that mean? Dying right? Do we even know what that word means?
- But what's better is to do disease, specific advanced care planning, and what I tell patients early on is you. Everybody should have advanced care planning with

dementia when they get diagnosed, because we know they're going to die of it, and that they won't be able to. They won't, you know. They'll lose the capacity to make decisions and the main decision that you have to make is, are you going to get your

- continue to? You know people come into with dementia and uro sepsis right, and we treat them.
- and we send them out, and they get delirious when they have that, and they get a little better.
- But usually they don't. Towards the end they don't get all the way. Better right.
- You have to decide at some point
- treating those infections is keeping you alive. So you get to the point where you no longer recognize your children.
- Do you see what I mean? That's the decision tree there.
- Does that make sense? So that's sort of my perspective on you know part of what we offer as palliative care doctors is our
- weird perspective.
- Okay? And I'm sorry. You know, I know that I'm sort of weird. I'm the sort of person if they cured cancer. I think I guess I have to die of dementia now. Okay.
- that's just the way I think I'm not going to die of heart disease.
- It's probably be dementia or cancer. And but anyway, because I think about that, we're treating this infection, we can treat this infection. But what are we keeping them? What is it going to look for them to be alive with that? Does that make sense?
- So I think that's a perspective. We tend to have many geriatricians have it, but some of them are really focused on. You know, they have a different agenda that has to do with
- successful rather than unsuccessful aging. And I say, and you know so we have a place. I think the good the geriatrics department here, which has grown and is doing great things under Justin. Mutter is probably in many ways better.
- Some palliative care. Fellowships are combined, Jerry Pally, you know, so that you have 2 years?
- That was a long answer to that question. But I anybody else.
- We have a few minutes.
- Thanks, Leslie, while you're in reflective mode. I will just comment myself, and many generations of Uva residents appreciated learning our approach to difficult conversations from yourself. Back in those very early days of palliative care at Uva. I was going to ask if you could expound a little bit more on the Bessie again, just the device, and just obviously learning a lot from it. But what are some ways? You might
- imagine some of the data being collected from a device like that impacting disease. So I'll tell you. You know Virginia can answer this, too. I often see patients, and they'll say I'm taking my oxycodone every 3 h. They got 90 pills a month and a half ago.
- They they're just overwhelmed. They have no idea what they're taking, and they often have trouble telling me, because you know, like how well it's working. Some of my patients are really good like that, and a lot of them aren't. And you know, when you have somebody in the hospital, you can watch them. You know what I mean, and you can feel comfortable that they're not going to take too much.
- But this is like I'm sending people out into the community with a bottle of oxycodone or a Fentanyl patch, and I don't know how they're doing it. I don't know where what

time it is. Sometimes people are only having pain at night, which means putting them on long acting morphine twice a day is probably not a good thing, because it might be too much.

- So I think it's like timing and use of medications for me. That's how I imagine using it. I think the nurses, when we were having these discussions feel like also, and especially in hospice talking. You know what like, what's usually going on when the pain is worse is that there's a lot of people in the room. And you know, it's like there's a lot of stuff going on, and maybe that's need to be careful about that. Would you agree with that? Virginia
- also collected data from
- life data about the caregiver's experience.
- sciatic effect. And yeah, and I think one of the things looking back on it would have been
- important is, you know, like on Hospice, when the caregiver is giving all the medications, it's very stressful for them. So I think for me. It's like managing pain. But I think you're right. The quality of life. How how distressed are they with that pain, level
- lot of parallels it would seem to our Cgm, exactly. It's exactly like that.
- Thank you. So 2 questions in the chat, both from Dr. Wolf 1st is, do you feel American society is more accepting of death since you started off in practice. And the second question is, are there any particular tools you recommend to help clinicians prognosticate more accurately. Okay. Well, the fact that I have a job here as the head of palliative care means that they're more accepting from the days
- when actually, I interviewed a guy who was even a little bit older than me, believe it or not, for a job here, and he had been an oncologist, and when he first, st and then he became palliative care. Doctor, when he 1st started talking to his patients about, did they want to stop chemotherapy? He got pulled into his
- you know, the head of oncology said, you're murdering people.
- So. Yes, I think that we routinely have these discussions about putting people on life support. We don't do Cpr. On every single human being, which was sort of what we were doing back in the day.
- So I do think in a certain way we are. But there's this woman.
- There's a letter to the editor from a famous study bioethics study
- which they did this huge intervention to try to get early decision making, which had 0 effect. It was called the support study, and everybody was shocked. But what she wrote was that people want a peaceful, comfortable, dignified death, and they're willing to talk about that. But they want a peaceful, comfortable, dignified death, but not yet.
- And so I think that there's a general
- We've made progress, but in some ways not that much progress. And I think about this a lot. It's probably not a topic to talk about here. But I think there's an underlying cultural belief
- that there's always a way to fix something. Do you know what I mean? Like, even though we sort of accept that people die. Maybe we don't have to die just yet.
- I mean, there are all those people in Silicon Valley who think somehow they're going to live forever. I don't know if you've heard about.
- They want to. One of them want to upload his brain to a computer. I'm like, I've never had a computer that live more than 5 years. What is that about? Never mind, that's a lot of opinion. So I do think, in a certain way, absolutely that I ask all my

patients who have metastatic cancer. What do you understand about your disease? And what are you hoping for when I 1st see them. None of them say they almost none of them say that they think they're going to be cured.

- Then sometimes they say I'm hoping for a miracle.
- and even the ones who are not like hoping for a religious miracle. They're hoping for a
- you know, scientific miracle.
- But yes, I do think absolutely, and doctors certainly are much, much better feel better about having these discussions. So in terms of prognostication, I don't really like those tools that tell you how long you have to live. So I just want to ask you guys
- what I use is illness, trajectory.
- And so when people ask me, how long do I have to live which happens less than you might think, because studies have shown.
- you know, about half people want to know their prognosis, but almost everybody wants to know what's going to happen to them.
- so people might not want to know exactly how long they have to live, which is hard to tell for an individual patient, but they do want to know their illness, trajectory, and what we can do about it. Do you see what I'm saying? So if somebody, if I have a patient with metastatic pancreas, cancer or breast cancer, for that matter, or any kind, and they ask, Well, how long do I have, or more commonly, the family asks, how long do they have? I'll say, well, Dr. Brennan.
- you know, knows the data on your type of cancer more than I do. But I'll tell you how we know when you're getting close to the end of life. You get weaker, you lose weight. You're going in and out of the hospital more. You need help getting out of bed.
- you know. You need help getting to the toilet and getting dressed. Those are things they can see.
- you know. Maybe they don't understand what their Ca, 125 is, although actually a lot of my patients do, or the exact, you know how like somebody today looked. And there was some little red thing in their labs. And I, you know, I used to tell them it's okay. If that Rbc thing is like as a red
- but that's but they can see that.
- And if you have heart failure, for example.
- you're going into the hospital more, and when you get out you're a little bit better, but not
- fully back. And then you're back in the hospital again, and that's how we know that things aren't working. Does that make sense, Andy? That's what I do. And I talk to people with dementia about dementia as a physical, as you know, like a physical illness as well. Right? You get weaker. You stop being able to. You know you need help in your activities of daily living.
- and that also helps people in other ways like to make plans. If you're living by yourself.
- you know, you're going to need to have a plan for what you're going to do when everybody needs 24, 7 care at the end of life.
- Some dementia is notorious for that being a long time, and cancer is probably less long most of the time.
- Do you see what I mean? So it's help with decision making. So I just want to say that, like. I understand why people don't want to know their prognosis.

- So if I could tell you guys like by magic or AI, which I guess is sort of magic, or whatever exactly the day you're going to die. How many people here would want to know?
- There is no way I would want to know.
- I'm just telling you I'd be standing in the grocery store a line, and somebody would be fumbling with their coupons, and I think I'm going to die in 2 years, 3 months, 2 days and 5 min.
- Hurry the hell up, you know I'd be grumpy. But when I get my cancer or dementia, or whatever I'm going to get, then I will want to know sort of what the average, you know, sort of what the trajectory is like, or if I get something neurologic thing that I don't.
- you know know about? Does that make sense? I want to know? Sort of what you can we do, and what does it look like towards the end?
- And the other thing I'll say is, I do a lot of you know I've done a lot of talks with the oncology fellows, and a lot of them feel very strongly that they should be way up front about prognosis.
- And so they all tell their patients when it's not curable, and it's in the oncologist's notes. I think they do that because my patients know that they've been told it's not curable.
- but one of them was struggling whether he should say, Hey, average life expectancy is less than a year.
- and so he said, he started out by doing that with everybody.
- and then they come back the next time and say, Why are you so negative?
- You're so depressing.
- That's what they're supposed to say to me.
- But you know what I mean. So I think people struggle with that. And in truth.
- I have a patient who's had advanced Pancrea Tree lays. We've been taking care of her for like 4 years with advanced pancreatic cancer. Nobody got more
- full fox than her. Okay? And she's doing great. So do you know what I mean somebody's going to be that person on that end of the bell curve, and somebody's going to be at the other. But illness trajectory is usually the way to tell which way you're heading. I just think that's a
- that's the way I do it. I don't know if you disagree, Haley, but I had a
- there's a palliative care fellow here who swore by some of those prognostic calculators.
- I just I don't know.
- Everybody dies of something. Mostly we're going to die of something that we know when we get it. We're going to die of, and you don't know if you're going to be the person who does great with an Lvad or not that you get a heart transplant, and you do fabulous, or you don't make it out of the hospital. Do you know what I mean.
- So we can. There are ways we can tell. And and this is to to say the last thing. This is something you can do in the Icu in a shorter time scale.
- you know, if somebody gets intubated, not just on bipap, or whatever for Copd or heart failure.
- You know a lot of those people die in the hospital.
- but not all of them. And in the beginning it's you can't tell which ones you really can't pick. Well.

- so it makes sense. And there was a good study about this to tell the families out front. We're trying to get them through this, you know, they're here because they have
- exacerbation of heart failure or pneumonia on top of their copd, or whatever it is.
- and this is what it will. But it might not work.
- and this is what it'll look like if it works. So let's say that they've got a pneumonia. You know. Their temperature will go down. They'll be off the blood pressure medicines. Their breathing will be better. We'll get bring them off the stuff, you know the pressers and etc. And go down on the
- or
- it won't. That will happen. And in x amount of time a week we should know week, 2 weeks. Whatever you want to say, we should know which direction it's going.
- The study that did that with people found that families were much more able to handle.
- you know, like making those decisions.
- because otherwise you're just going full bore like full steam ahead. And then all of a sudden, you're pulling the plug.
- Do you see what I mean? People need to wrap their mind around, and they say, do everything you can tell them you're doing everything and everything might not work.
- You can do that on a long-term basis or short term in the Icu.
- I have many opinions, feel free to talk to me after this is over, as my children. I'm
- but that, but I think that it was called intensive communication, and it was done in Beth Israel Hospital. And the thing that was amazing about the study that used. This is, they went back 4 years later, and they were still using it in the icu.
- So usually, if you do some intervention like that, the minute the study is over everybody stops. But they found it helpful enough that, having these discussions upfront continued for at least 4 to 6 years.
- so I think that's a reasonable thing to let people know you're not choosing to pull the plug on your mother.
- We're doing everything we can. We're not sure it's going to work. And this is how we'll tell.
- And that same thing along, you know, like we can give you chemotherapy. We're not sure how well it's going to work. We have to reassess.
- I think that's you know. That sort of conversation is probably the way to go.
- It's 1 17. I'm 2 min over.
- Dr. Ulaut and his very impressive Bowtie are about to yank my thing.
- Okay, guys.
- it's no
- great job, Leslie.
- Thank you for coming. Thank you.