00:00:00 So just to kind of a review. So we want to talk about your new research really, right. We want to really focus on this end of life stuff. Um, yes.

00:00:09 And you know, it's, it's really new. So I've got lots of questions and I have lots of thoughts and experiences. I have a little data, so that's what we're operating in right now.

00:00:22 That's great. Um, but to get into that, uh, we start with a speed round curtain. I'll start with a little speed round and where we just ask really quick yes, no questions. Uh, and um, because uh, anyway, so I want to end the speed round with talking about, uh, your old stuff, which is, you know, still near and dear to my heart. Your cash versus tangible rewards work. Okay. I know that that's like old hat but, but w but I'm, I'm hoping humor Tim for the little, yeah. Humor to them and then we can get into the really interesting stuff. Yeah. We haven't talked about ad nauseum.

00:00:59 There is humor in people.

00:01:03 Oh, okay. Wow. I was that a dis or was that, yeah, pretty much

00:01:12 what I do for a living so I can do that.

00:01:14 Okay. Right. So Victoria, is there anything that you want to make sure we cover? Obviously we'll cover the end of life stuff, but is there anything that you definitely want to make sure we get to and then anything that we want to definitely stay away from?

00:01:29 I can't think of anything to stay away from. Um, I think one of the things that I'd love a chance to talk about is, um, kind of what I think the problem is in end of life care. Cause I think right now we have a better sense of where, where we can intervene and what the issues are and how, and so it's, I, I had told Tim, um, and I'm not sure how much he's told you. A couple of two year, almost two years ago, my father was diagnosed with stage four cancer. And so part of what's been informing my research agenda, um, over the last couple of years has, was being his caregiver. And so I have a lot of experiences with the disconnect between what the literature says and what we experienced as patients and caregivers. And so that's been a really eye opening. That was a really eye opening process for me. And I think I'd like to talk about that a little bit cause I think there's, you know, I understood more about the gaps in what we could be doing and better, um, with that. So that would be something I'd love to talk about, if that would be okay.

00:02:29 Yeah. And I think the, the, that aspect of having that personal component is, is a compelling story for the listeners. And that's really what we try to do here. So you know that all right. Yeah, definitely. Good. Okay. Any, any questions before we begin? Anything?

00:02:44 No. Is there anything I should stay away from?

00:02:47 Nope. No, you can S you can say any words that you'd like to say if you, if you feel compelled to, you know, to use the F word, you are welcome to do that. And you don't need a pretty background,

00:03:00 right? Cause you're just doing it right.

00:03:01 No, this is [inaudible]. It doesn't even record the video. We're only recording the audio.

00:03:05 Okay. Cause I have my kids' art work over here. That's much nicer than,

00:03:09 well, I can switch cameras. I've got no, fine. Okay. So let's, let's go ahead and get started and we'll do, we'll do our, you know, we have a whole preproduction where we'll do your, your formal inter introduction, various things and all that fun, all of the great things that you do. So we'll just kind of get started in. So Tim will start that and then we'll do a speed round and then we'll just have a conversation, so, okay. And you're good to the top of the hour?

00:03:37 I am, yes, I have. I'm good.

00:03:39 Okay. Okay, great. Victoria Shaffer. Welcome to the behavioral groups podcast.

Thank you. I'm so excited to be here.

Yeah, it's so good to see you. Oh my gosh. Okay. We're gonna start with little speed round. All right. All right. So, a bike or unicycle, which would you prefer?

Bike.

Which would you prefer to give up for the rest of your life? A phone or a laptop. Phone.

All right. Coffee or tea?

Coffee.

Which makes a better reward. Cash or a hedonic luxury.

Hedonic luxury.

All right. Oh, that was a tee up. So this goes back to some of your earliest research. Can you tell us a little bit about why that is the case and under what circumstances, uh, cashes is outpaced by, by something that's not cash.

00:04:31 Sure. So this goes back to my dissertation and this is something that I was interested in, uh, when I was at Ohio state many, many years ago. Um, but one of the things that I noticed reading through the literature was that, you know, it goes back to this principle that a lot of people, people in general, um, don't understand what they're best motivated by. So, you know, we choose one thing but often the optimal choices and other thing. And so if we think about this in the context of performance and motivating performance and providing incentives, um, you, it would be rational to say, Hey, let's ask the employee what would they like to have? Um, what kind of rewards would be most rewarding to them? And when you do that, people say, Oh, I'd like to have cash every time, hands down. However, when you look at performance relative to the different kinds of incentives you could provide, people generally underperform when you give them cash relative to, um, something fun that they wouldn't buy for themselves, like a spa trip or a gift card to a luxurious restaurant or something of that nature. So I've generally been interested in this principle of we don't have a lot of great insight into the things that motivate and effect our behavior. Um, and that was one really interesting example to me for awhile.

00:05:43 Why is that? Why, why don't we have a better insight into our own motivations?

00:05:49 I don't know that we know the why for sure. Um, there was a paper by, um, Shelley Taylor many years ago, uh, that I thought was really interested in which suggested that a lot of these biases we have a self-serving purpose. And so one of the things that kind of goes along with this is that we tend to be very over confident in our abilities. Um, and so this is one of the things that we're, we don't have really good insight into our true abilities in a lot of things. And we tend to think we're better at driving at, you know, any kind of skill we can think of shooting a basket, right. Um, we're all above average is how we view yourself. And in this paper she talked about how folks with clinical depression actually tend to have much more accurate perceptions about what they're capable of. Um, and so there's been some thought that maybe some of this is just kind of a self-protective mechanism that it would be really depressing to know exactly all of these true things about our nature and ourselves. Um, so I don't know that anybody knows per se, but that seems to be how we're wired.

00:06:45 That's an interesting component. I need to research up on that. But the fact that the more realistic you are about your abilities and different things is a correlated to psychological depression

00:06:57 and this interesting paper

00:06:59 that that's fascinating. So, well, I know that you haven't been necessarily working on a cash versus non-cash. Uh, for the most of your career and what have you been, what is some of the more recent work that you're doing? Cause you're doing some really cool stuff with, uh, some end of life care from, from what we've talked about.

00:07:19 Yes, I transitioned from a, this more business-related work to medical decision making, but the same principles are applied and that's what I think. It's interesting to me, these underlying principles about how we make decisions for ourselves and how we don't often have insight into the best mechanisms for making these decisions or we don't know what's the most useful piece of information. So a lot of the psychological mechanisms are the same across my topics of interest. But, um, I slowly shifted over towards an interest in medical decision making. Um, my advisor in graduate school who I did the dissertation research with also did work, um, in medical decision making. And, um, I really liked the applied application. Um, you know, the idea that by the way, yeah.

Hal Arkes.

And so as I kind of came into my own as a researcher, um, I ended up looking at more of those kinds of choices that I thought had really important real world impacts.

00:08:12 And it seems like that was a place where decisions psychologists hadn't been, um, in these medical decisions. So there's a lot of other spaces of decision making in marketing and business and whatnot that decisions psychology has historically been a strong part of. Um, and medicine was a place where it seemed like, you know, we could really fill some gaps in. Um, what I saw to be some of the issues with medical decision making. So I've been had a long standing interest in that concept. Um, and then more recently, so I've been helping create decision support tools for patients, um, who are making decisions around cancer care and decision support tools for physicians who are helping to support patients who are making decisions. Cancer has been one place, um, that I've operated one context a while.

00:08:56 Can you give us an example of, of what a decision support tool is?

00:09:00 Yeah, yeah. Thanks for letting me clarify that because I just threw some jargon right at you. Um, so there are a lot of decisions in the medical field that are what decisions psychologists call preference sensitive. So that means there isn't a single medical treatment option that it clearly wins. Um, there are actually multiple treatment options that are very similar in terms of their clinical outcomes and they have very different pros and cons to individual patients. And so in that case, the doctor can't say, Hey, here's the best treatment. You should just have that. Rather, they typically say, Hey, here are three treatments. They are fairly equivalent in their effectiveness, but they each have different, um, harms and benefits. And it's really up to you as the patient to figure out what best suits your needs, your interests, your preferences. And so that's a really hard thing to do.

00:09:50 That's been a big shift in how we ask patients to make decisions in the last 20 years from being the person who just does what the doctor asks to doing. The person who has to make the decision with all of this complicated information being thrown at them. So broadly decision support tools are created for that context. When there's a real choice that the patient has to make and it helps them kind of get up to speed with the physicians, it gives them the information about the data that we know, whether it exists or not. If there's uncertainty in the data, um, it tries to present statistical information the best way possible. So we know better now about how to communicate risk in a way that is more understandable to patients. And so we use a lot of those premises and tools to construct a, um, often it's an online forum, but it used to be paper-based. Um, that's something that patients can have that can help them be informed before they try to make these difficult choices.

00:10:41 Are there culturally, are there cultural differences in a these decision tools or maybe, maybe, let me ask it this way. Are there cultural differences in the way that these decisions are made? Um, you know, between patients and physicians?

00:10:57 Yes. Um, I don't, it's not an area that I spend a lot of time operating in, but for sure, um, some of the things, some of the research that I have read suggests that that's very much the case. Um, generally the U S is a, you know, now we've sort of shifted over the last 20 years to be a place where the patient wants to take the lead in decision making. But even within the U S there are age differences in that so many older adults that has not historically been the way they operated with their physician. Um, and it feels very uncomfortable to them to change that. So even in the context of, you know, the U S environment, there are a number of differences in how patients really want, you know, whether they want to be the decision maker or not. But I'm absolutely, there are cultural differences. I, there is a book by a tool Gawande called being mortal, um, and his family is from India. And he describes how in that particular cultural setting, you don't generally even tell the patient the prognosis. You tell the family members, they make decisions, they do stuff and the patients kind of kept in the dark. Um, and so, you know, there clearly are, you know, different ways to approach decision making in medicine, um, across the globe. But even within the U S as well.

00:12:09 So you mentioned this, uh, up at the beginning like that you're, you're really studying how people don't understand what they're motivated by or some of the outcome components of this. And so these decision support tools, are you using those to help people to better understand their long-term satisfaction with the outcome? How, how are they, how are they being utilized from, from that perspective? Is that part of it?

00:12:34 Yeah. So there's, there's a couple of basic pieces. I think one first premise is when you're first diagnosed with something, and we can just take cancer as an example, there's an information gap between you and the physician. And so a large part of this is simply informational, right? How can we present the knowledge that a patient needs to get up to speed? You know, this physician has all this history and knowledge. Um, and so can we, when I went down two critical elements that a patient needs to be informed about. Um, and then beyond that, we also know that there are a number of psychological processes that come into play that can bias our decisions. So one in particular that I've been interested in is effective forecasting. And so we make **affective forecasting errors** and that again is more general phenomenon, which means that we are pretty poor at predicting how we'll feel in a future state.

00:13:23 Um, and that applies to medical decisions as well. **So a lot of times, you know, we're, you know, we have to make a choice between treatment A and treatment B and we heard what the side effects are, but it's really hard for us to imagine how we're going to feel experiencing those side effects**. And so, um, one of the more controversial aspects of a decision aid, but that I've been interested in exploring is providing stories from other patients that can help try to, um, fill in that gap. So here's some experiential information. So, in addition to, you know, what does it like to experience, um, say when you have radiation or chemotherapy, sometimes you get sores in your mouth, right? And so it's one thing to say to somebody, you can get sores in your mouth. And another thing for another patient to say, I couldn't eat anything.

00:14:07 It hurts so bad I couldn't move my mouth. I could only mumble. Um, that's what it feels like to have sores in my mouth. Right. Um, and so a lot of times there's this disconnect between what, you know, how he would describe the concept of a side effect or something you might live with and then what it feels like to have that. So I think that's one element where **decision aids** can also help, um, with these psychological challenges to making decisions. And we're still working on that. We're still, I'm interested personally in narratives and testing, whether in the long run they do improve people's ability to forecast these future health behaviors. But, um,

00:14:42 so when you said that there, you said that there's some controversy over Ave those patient narratives as part of this, what's the controversy part? Cause it seems pretty straight forward to me. I mean, as I'm listening to you, I'm going, Oh, I would want to understand what, you know, mouth soreness and what it really impacts. Right. And I think it goes back into, you know, some of the components of w as you said, we're not good at forecasting what, what a, you know, that affective component and you know, just having understanding how other people have experienced things is a better predictor than our own kind of judgment out on that most of the time. So

00:15:17 yes, I think the, um, **the controversy comes in when you have to pick stories**. So whose story gets chosen and is that representative of the experiences? If, you know, sometimes we end up choosing a really severe side effect cause we want people to understand it, but it's something that's really unlikely to occur. And when we do that, we can actually, um, make people feel like experiencing that side effect is more likely than it actually is. And so we can mess with how people perceive the risk of things by what stories we tell them. Um, where in the, you know, if you can think of the distribution of possible experiences, you know, where do you select from that distribution? Um, usually you only have time and a decision for a couple of stories, and then it becomes, you know, whose story and then that's where people start to argue, right?

00:16:07 Well, you're gonna if you give them that story, they're never gonna want to choose X treatment because all they're going to hear about is this 1% side effects and they're going, it's gonna really scare them, you know, whereas 99% of people don't get that. And that's a, you know, so there's a lot of concern about bias, um, when you talk about stories. So if you have a health state where there's more of a uniform experience, it's a lot easier. Like uniformly, people experienced X, it hurts, or this is what it's like. Um, it, but my favorite example is childbirth, right? Every birth story is unique. So is it helpful for me when I was pregnant to hear every other woman's birth story? Probably not. Cause that for sure is not gonna happen to me. Um, so that's, you know, that's where it comes in. It's like I, you know, if you, when do you share stories? What are they helpful? When can they be harmful and biasing? Um, and we're kind of sketching that out. [inaudible]

00:17:00 interesting. Yeah, there are a lot of, there's a lot of trouble. I mean, a lot of challenges I suppose, in, in trying to help patients and physicians in this decision process. Right? I mean, there really are some, some big challenges that go along with, well actually, you, you've, you're enumerating the, the, the problems. What other issues do you see with this? Or what are the core issues that you see with it?

00:17:24 Yeah, I mean, I think all of it relates to framing, framing effects and information, presentation effects and bias. And so with the narratives, it's really easy to see how bias can be introduced by which story you select. Um, but there are other elements of sharing information that feel much more objective, but can also be equally biasing. So, for example, if we think about how we present probabilistic information, if I say something has a 10% chance of occurring, that actually feels less risky to people than if I say a one in 10 chance of occurring or attended a hundred chance of occurring. Cause if I say a 10 and a hundred chance of incurring, you're like, wow, there's 10 people that had that thing. That sounds so scary and 10% actually feels less scary. But mathematically these are equivalent. And so even, you know, in how we choose to talk about risk, um, we can introduce bias or change how people feel about something and it's unclear what's the right presentation, right?

00:18:19 What's the right way somebody should feel about it? Should you feel like a one out of 10 risk or should you feel like a 10% risk but you know what best maps on. And so then also things like order, like the order effects of information. What do you present first? What's your present last? We know that that has an influence on how people make decisions. Um, and again, so these are things that feel less, um, less obvious, you know, to people. But all of these things kind of come into play when you're trying to communicate information. You want to be unbiased about it. You want to say, here's the fair, you know, here's everything you choose. But every decision you make about how you present it has some slant to it. Um, and some are more obvious than others.

00:18:58 It's, it's interesting to me that you said that, you know, this decision science part hasn't been part of this medical kind of world because it seems that the question that like what you were just talking about are really important components of how that, that doctor patient interaction is. And I'm pretty sure that most doctors are not thinking about this in this way. And so, you know, and they want to be able to do this, but it's, those are big issues of, you know, life and death or health and various different things versus, you know, are you selling a candy bar for 28 cents or you know, a dollar 50 cents or whatever that would be so, right. So my, my, my analogy probably is not the best there, but all right,

00:19:42 it is interesting because the psychological principles I'm talking about have been around for a long time. You know, inflammation affects, right? So it's not that we're learning kind of new things per se, but it's, you know, this is the place where it really matters and we should really be thinking about it. I'm Peter Ubel, I don't know if is a physician that who you know of, he dabbles in, um, more than dabbles. He does a lot of behavioral economics and he's at Duke. Um, and he wrote a book called critical decisions and he was really, he is particularly critical about the medical school curriculum and how it does not, you know, it has all of this very, um, deep focus on pathology and biology and, um, you know, all of the, all of those kind of neuro cellular level sorts of things. And practically no focus on risk, communication, relationships.

00:20:29 Um, how do you get, how do you have a hard conversation? You know, he describes when people are first asked to give bad news, it's often like, Oh Hey, here's the intern your turn go, you know, go, you know, good luck. They'll give somebody this bad news that they're done and see how it goes, you know, and it's sort of trial by fire. Yeah. And so there really is mean I, it is a place where we can be doing so much better because we know a lot of great information. Um, and it's just about making it into part of this culture.

00:20:56 So when you're talking to physicians, uh, I'm, I'm curious about two, two conversations. One is when you see this with patients, what kind of effects do you see? How do they respond and, and what about physicians? I remember you, you, you did a study on, on defaults with a physicians and, uh, and as I recall, um, when the, when the default was to have all of the tests checked, the physicians were more likely to prescribe more tests. And yet they said, no, no, no, no, that's, that couldn't be me because I'm a physician. I'm a professional in this, in this realm, and you can't tell me that I would prescribe more just because you defaulted to, to all of them.

00:21:33 Yeah. It turns out physicians are human too and somehow like that that was missed for a really long time. So I'll, you know, expertise doesn't override a lot of these basic biases that we talk about. And I think that might be surprising to people that we haven't really dealt, you know, gotten into that, that there's there, you know, we're still human and even if you have great clinical expertise, these things like the default, you know, still meaningfully matter. So in that study, this was a great study by a PhD student of mine. This is his dissertation. And um, he created an electronic medical record interface mock-up. So it was designed to look like, um, the interface of this medical record in a children's mercy hospital in Kansas city. And so he was interested in how we could influence what orders physicians put in. And so he created three different conditions.

00:22:25 One was just sort of the status quo. You could, you need to just check the things that you want to order. One, as Tim mentioned was everything was preselected so you had to uncheck it. And then the third was we got a group, a panel of experts on a few different disease topics and we said what would be the recommended tests and orders that you would place for a patient who is suspected to have, you know, X particular illness. And so then there would be meaningful defaults that were selected. Um, and so you would think, you know, from a sort of neoclassical economics perspective, it shouldn't matter if everything was checked or nothing was checked, that you should have an idea of the optimal order set and you should do that or not do that. Um, but when we checked everything there were, I'm trying to remember the exact number.

00:23:05 I want to say it was like two to three tests on average, more than were ordered per fictitious patients. So we had these little mock cases that a physician would read and then go through and order, make orders for patients based on this description of information. Much like you had an emergency room situation. So there were, there were more tests that were ordered, but that wasn't necessarily a good thing because they weren't necessarily the recommended tests. And so, you know, our argument was that the best version of this was the third condition that had the recommended test pre-selected because they didn't order statistically more tests than the control condition who had no preselected ones, but they were more likely to choose the ones that the experts deemed to be appropriate. Um, so you get less bloating and costs and you get more accurate choice. But again, you know, this is, um, these are physicians who have really great expertise and it's just, these are just not things that you can keep in your brain all the time. You are going to be influenced, particularly when you're working on the fly by all of these heuristics that, you know, we all are influenced by.

00:24:07 Yeah. Availability, heuristic, all of those different pieces. So, yeah. So, uh, so do they, if physicians are humans do, and I guess they really are the head. Do they, they take to these ideas and suggestions and the work that you're doing with open arms and Oh my gosh, we're so glad to be trying something different and to improve the relationships that we have with our clients and improve the decision making? Or is there some resistance?

00:24:35 Generally I think physicians want to do that, know their goal is not to harm their patients at all whatsoever. Right? Um, I think the challenge is how do we do that and does that, um, change the way they're doing things and, you know, change the way they operate with the environment or their patients. And so sometimes when we, when changes are suggested and they have to change their clinical workflow or work around something, a lot of times these changes make life more difficult. And so, um, that's when I think people get really irritated. Is this really helpful? Do I have to actually rework my whole clinical workflow to get this in there? Um, and so for example, if you take the idea of the pre-selected defaults that are informed, that takes a lot of effort to develop a national panel, people are going to be lobbying about which of these things should be preselected cause they're more likely to be chosen.

00:25:24 Um, you know, the American college of radiologists will have a, you know, we really want the, you know, the anything with x-rays to be preselected. Right. Um, so when you actually get into the nuts and bolts of it is a, it's a challenging thing to do. So you have to have, you know, for the example of the preselected defaults, um, yeah, they have to be best choices there and there's not always best choices. And then what happens when you don't have a clear cut clinical case? Um, you know, which defaults apply and who gets to choose the defaults. Right. Um, so those are all, you know, again, it's, it's in the details. I think, uh, physicians are open to the concept of improving decision making for sure. Um, but then it's like, how do we actually put this into play? And that's where I found things to be much more difficult. When you have things like decision AIDS, if it takes, you know, people are concerned, it's gonna make the visit, take longer, you know, we're gonna have to have all this discussion. Um, and so those are the kinds of things where people start to get a little, you know, uninterested in, in these new advances.

00:26:23 So relative to the patient, is the patient more open, different [inaudible]. How did the patients respond to these relative to, to the doctors?

00:26:33 I think patients generally are excited about this. Um, you know, again, I think there are individual differences in preference for involvement in decision making. Um, and so part of the way the field has tried to understand, um, this concept of shared decision making, which is, you know, these decisions are now shared between a physician and a patient. So this is a dyadic decision versus a unilateral one. Um, is they want to assess with patients how much do you want to be involved. Um, and more often than not, patients really do want to be involved and they like taking ownership of their choices. Um, so broadly this is something that is well received for patients.

00:27:11 What, um, let's get back to, uh, end of life stuff. This stuff that you're working on now. Victoria, can you, can you share with the listeners a little bit about, uh, what you're working on right now?

00:27:24 Yeah, so I am really interested in how to promote advanced care planning and discussions about patients preferences at the end of life. Um, this was a particularly sort of personal shift for me in research agenda. Um, in December of 2017, my father was diagnosed with stage four oral cancer. Um, and it was an interesting, at the time I thought, Oh gosh, I can help. Like this is the thing I can, you know, as a daughter, like, um, I don't have a lot of skills that are going to be helpful to aging parents, but this one, you know, I can do. Um, and so I can help them sift through the literature. I can help them understand all of these, you know, the data. I can help them understand, you know, all of these kinds of things that are going to be confusing and overwhelming. Um, and then when we got into it, I realized I was actually not very helpful at all and there's still a lot that we need to be able to do.

00:28:17 So, for example, um, pretty quickly because the cancer was so advanced when my dad was diagnosed, he had to make some treatment decisions and we did not have very much time to do that. Um, and so one of the things that we had to make our decisions based on was physician's best judgements about, um, the chances that my dad would survive given the different treatment options. Um, and while there was some data that existed, so he had stage four oral cancer, um, in a five year, five year timeline for survival, only 25% of patients survived. And so in his is clearly pretty aggressive. Cause then a few months it had gone from a to thing to, it had, you know, sort of gone through in his jaw and there was bone involvement. So we had to make decisions. The first one was pretty easy. He needed to have his job replaced and he, you know, he felt like that was a straight forward, yes it hurts.

00:29:09 I'm ready to do that. But after that we had to make a decision. Once he healed from us, they took a bone out. Th they removed his job, they took a bone out of his leg and, and implanted that into his face as this whole 14 hour procedure. And so he ended up recover from that. Yeah, it was, it was really tough for it. You know, just the surgery alone was, was a big deal. And then after he recovered from that, it's about six weeks later we, he had to make a choice about whether he wanted to undergo chemotherapy and radiation. And so the surgery alone was not going to be enough, particularly because when they went in, they, that his lymph nodes, um, it had already spread to his lymph nodes. His lump one lymph node had actually, um, there was evidence that it had gone past that lymph node as well.

00:29:50 And so it was probably, you know, circulating. And so they were pretty certain that if he wanted to have any chance of surviving, he would have to have chemotherapy and radiation. And so in my read of the literature, um, it was, it was a really depressing read because it didn't seem to have a huge benefit. And in fact, so the, the survival rate, you know, was not very much larger in the group that underwent chemotherapy and radiation and, but in fact it was a really, really painful, you know, course of illness. So this was going to be concurrent chemotherapy and radiation for six weeks. Um, and when you have radiation to the face, um, it has a whole lot of other additional things. And so, you know, I could read and bring to the table this information, but what we couldn't figure out was how likely it was my dad to survive given this additional, you know, sort of treatment. So we had to make these tradeoffs of, do you want to endure this really difficult, painful procedure, and if so, what's the likelihood that you would survive after rights? And so, you know, we asked our, his first, the radiation oncologist at the hospital here, and he said, um, first he then didn't, nobody ever volunteered this information. So to me this is like, this is the thing I want to know, but no one volunteers in. So I said, you know, what, what do you think my dad's chances of survival? Are we going to say something?

00:31:08 I got to ask why, why wasn't that volunteered? Why wasn't that? Seems like, doesn't that seem like sort of a natural like let, let's talk about the odds here.

00:31:18 You would think so. But um, physicians are very reluctant discuss prognosis and part of it is because they're going to be wrong. You know, it is a probabilistic judgment, um, and people, you know, and it comes back to bite them a lot when they get real specific. Um, and so I think that's part of it, but there's a real reluctance to give that information. And there is a perception that patients want hope and want people to be positive. And so when you have bad news to give, you're diminishing those things. And so there's, um, there's a real bias towards, um, either overestimating survival or not even discussing it at all. So I had to ask in each situation, what do you think has survived? Chances of survival are. And so the first radiation oncologist at first asked my dad, do you want to know, cause I'm not just going to answer her question, I want to know if you want to hear this.

00:32:06 And he said, okay, I'll, yeah. Okay. And he said, I don't think it's very high single digits, um, maybe 8% at the most. So he would go through six weeks of chemotherapy and radiation concurrently for an 8% chance of survival. Um, he for sure wasn't gonna survive without it, but he only had an 8% in his perception. Um, but then so my dad started thinking maybe I don't want to do this. I don't know if it's worth it. Um, because it's a real, I think the chemotherapy and the radiation were worse than the, um, cause when you have radiation to the face, you just get this second and third degree burn all over here and it can, um, take your pridal gland as well. So you have difficulty. You don't, yeah, your salivary glands get destroyed and so you can't swallow. And you know, there's a whole eating becomes a problem.

00:32:56 A lot of people need a feeding tube. That's a huge quality of life thing that no one wanted to talk about. Again, that was the other thing that no one was talking about. What does it feel like to have chemotherapy and radiation? And so I kept asking these questions that I just felt like should for sure be on the table, you know. Um, so my dad and after having this initial conversation was thinking he might want to forgo this. Um, and his surgeon then heard about it and she said, well, I think your chances of survival chemotherapy radiation is like 40 to 50%. Like, I think you need to go for this. I don't think you should not do this. Um, and so it would then it was like, Oh, who is right?

00:33:35 Yeah. Oh boy, that's, yeah, that's, that sounds really troublesome to have to have these two competing years. Yeah.

00:33:43 And then we went to a second opinion. So in 10, MD Anderson cancer center, and they have a slightly different version of a radiation, um, that they're promoting and the physician, their radiation oncologist, they're thought my dad was more likely 60% chance of survival. And so again, it's, um, how, how do you evaluate right? Who is going to be correct and which place do you do treatment? Then? Um, and so what really troubled me was that there was no basis for making this decision. There was no data to support any of their, um, you know, prognostic estimates. And so, you know, I could only look at the data and the literature with suggested that he was probably more in line with the first 8% guy. Um, and I can only look at the, the data on prognostic information and literature, which suggests that physicians tend to actually double their estimates.

00:34:39 So, not necessarily consciously, but they give twice as long prognostic estimates than people actually live for twice as long chance than people actually have. So I know that physicians naturally are more positive than is accurate. Um, and I know that, you know, the five, the five year survival rate with stage four cancer is 25% and even less with all the characteristics that my father had with the idea that it had spread already. Um, but that was the only thing I could offer. You know, I don't know how else to help him choose between these competing opinions and these different facilities. Who all,

00:35:13 yeah. So are you willing to be more dismissive of MDM, D Anderson 60% and the, and the surgeon's 40 to 50% where you could, could you step back sort of objectively and say, no, actually the literature is really leading us in a different direction. You

00:35:29 know, it's interesting. So this is the, this is what decisions psychologists struggle with. There's this tradeoff between the, you know, sort of epidemiological literature, the population, and then the individual patients sitting in front of you. So I would say, well, why are you so positive given the literature suggest that, you know, the base rate of survival is just even based rate, you know, not considering his pathological history with respect to the, you know, cancer spreading. Um, why, why do you suppose that? And I said, wow, you know, he's in really good health. You know, everybody else who has oral cancer tends to be drinkers and smokers and he was never any of those things. And, uh, you know, so they had, they each had these really individual reasons. Um, and again, you know, I got no, there was no data to support that. You know, the vast majority of people who have oral cancer are heavy drinkers and smokers and so, or have HPV.

00:36:20 And so, you know, he did not. So does that mean he was actually gonna be better off? Or maybe it was worse because, you know, as it was a different, developed an absence of this, these risk factors. Um, and so that was really tough. Even when I pushed back a little bit, they had reasons that sound sounded reasonable. Um, and I knew probably, you know, just from the larger literature probably were not accurate in the sense of, I know that people tend to overestimate. And so this is probably still represented an over estimation and just the justification of the overestimation. But I had no reason for saying you're wrong, you know,

00:36:56 so your experience in this, given your background in your history, and like you said when you started this, it's like, Oh, I have something to offer here because you have this background in this, the, I will, I would estimate that 99.5% of the rest of the population isn't going to be even thinking about some of these things that you're doing. And so they're just going with that first component. So, so what is some of the research that, I mean, so, so what did you come come out of this and how is it being applied in what you're doing now?

00:37:27 Well, I came out of this first thinking we need to be collecting more data. You know, so for all of the people we interacted with, they had judgments that they were giving and they presumably did this for every patient that asked on a regular basis all the time. And they were not writing down their predictions. Right. Um, and they weren't writing down, you know, so one thing that you could do as a physician to say, okay, I said 10% for this person and these reasons, you know, these are the characteristics of that person that made me think that let's, let's record that. Let's record that for every patient that comes through, then I can make a decision, let me see the base rate of success in my own patients. Let me see, you know, how does that, you know, fit relative to patients that, you know, in the larger population.

00:38:09 And, um, so there's a lot of data that each individual physician could be keeping that could allow them to make a more informed. It doesn't have to be from the gut. Um, and people aren't willing to, that's not part of our culture in medicine right now, is to keep these kinds of judgments as part of the data. Right? Because people also, physicians also tend to think of this as providing patients hope. So if I give them the more positive number, you know, there is even some upward skew as well, which is I want to give my patients hope and patients want hope and they don't want me to be totally, you know, most pessimistic, worst case scenario guy. They want me to be best case scenario guy. So I think we can do better not changing anything but collecting more data. Um, but that definitely goes against the culture of um, physicians. Again, being hope givers and life givers and not being, you know, sort of particularly accurate or right on the nose.

00:39:07 Well, it goes back to what we talked about at the very beginning with, you know, the, the, the depressive, you know, people with depression have a more realistic view of their abilities and different things. And then see that component offering hope is, you know, allowing these, the male potentially. Yeah, it might be not as realistic, but is that quality of life at the end with that feeling of hope? Better than, than, than not. And they get those, those are judgment calls, I would suppose. And probably some of the stuff that you're looking into.

00:39:40 Yeah. And so it's, it's, it was just a real, yeah, personally it was, it was a real frustrating place to be. And, and I should tell you how the story ends, um, so that we can kind of step through the consequences of that. Um, so my dad ended up choosing to go to MD Anderson where he got the most positive prognosis. Um, and so he did six weeks of chemotherapy and radiation. He had to, um, they had to move down there and I flew down, you know, every other week. And, um, he got really, really sick. He lost 30 pounds. He couldn't talk. By the end, it hurt too much. We drove him home, you know, back to Missouri. He was just probably the worst I'd ever seen him in terms of his quality of life. Um, and he was really as well. He was taking fentanyl.

00:40:28 And, um, all kinds of opioids, you know, to just make it through the day. Um, and so, um, you know, he got through that and then six weeks later, um, he called me, it was in June, so he got finished his treatment in mid April, first week in June. He called me. My mom had gone out for the first time to a book club with her friends as the first night she had left him and he said he thought he was having a heart attack cause he was having really bad chest pain and back pain. And so we got him and we took him to the emergency room and it turned out that the cancer had recurred and it actually fractured his back. And that was the intense pain. They had recurred so quickly and spread and grew a tumor so large that it fractured a vertebrae, which was the thing that was calling him this causing him this intense pain.

00:41:15 So six weeks later it had returned with such intensity, um, that it had already fractured his spine. And, um, then at that point in time there just wasn't anything left to do. So he, he died two months after the cancer recurred and I really struggled with he did he have to go through all of that. You know, he went through all this chemotherapy and radiation and it was absolutely miserable for him. Um, and then he died two months later, you know, and if we had, if, if he had gotten more accurate prognosis, would he have gone through that? Um, and you know, we can never know. You know, we can never know if those individual point estimates were accurate. Cause you know, the person said 60%, maybe he was one of the 40%. Um, but without data, you know, I think we'll never be able to make better informed choices.

00:42:06 And so that's part of my frustration. I, you know, we were able to, I was able to kind of emotionally move past that because my dad made his own decision. You know, he felt like at the end, um, you know, he was like, Hey, I made the choices and this is what I chose and I don't regret it. And everyone tried their best and wanting to give me the best quality of life. And this is just the role of the dice, you know, for me right now. So I don't think there was any resentment there, but I, I did struggle a little bit to think. I don't know that he needed to go through that. Um, and so that's definitely, um, it has encouraged me to think more about let's have these conversations. How can we promote having these conversations where we talk about prognosis, where we talk about what is the course of the disease.

00:42:51 Um, we don't wait for patients to ask. We, you know, we have these things. Earlier we asked people how they, to think about how they're gonna feel. Um, so that the choices, you know, don't occur too late. So as the one thing that I could do, um, as the daughter of somebody who studies medical decision making, I know that, um, people tend not to have these conversations about what their preferences are until the very, very end. And it makes it difficult because oftentimes when those conversations need to occur, the patients now nonresponsive and they can't make the decisions instead of family member has to come alongside and make them for them. So the one piece that I knew is that we need to have, we needed to have these conversations. You know, when you get to the point of, um, you know, we have to make choices for your health. What do you, what choices do you want me to make? What our guiding principles that are important to you. And so part of my research now is trying to promote this advanced care planning earlier in the course of the disease.

00:43:46 Is this a tantamount to a medical directives that, that, that people, at least in the U S you know, fill out pretty regularly to say, if I get to this point, please do this.

00:43:58 That's a great question. And I do, I dislike the advanced directives. Um, so I think that's a really good clarification is that I don't think advanced directives are the solution. I think this is more of a conversation about goals. And so the reason I think that is that advanced directives are very specific. I don't know if you've had the occasion to fill one out, but they ask you, you know, if your heart stops, do you want to have CPR? If your heart stops, do you want to have, you know, and there's sort of this, this list of very specific things. Um, and the challenge is that most of the time we, the choices a family member has to make for a patient are choices that has to be made when they can't speak for themselves are not ones that you've discussed. And so the advanced directors are very specific and they really require you to, again, aspect of forecasting.

00:44:43 There's a problem here. Um, you don't know what you're often going to want until you want it. So what can we do instead? And, um, what I'm advocating for is, this is not new to me, but I'm, uh, they're a group of researchers that are advocating for goals of care discussions instead. So you have these regular ongoing goals that you say, what are your goals for your treatment? So we'll never be able to walk through all of your very specific choices that we'll have to make. But if I know your broad overarching goals, I can make decisions based on that. So for example, with my father, the two goals for his treatment that he identified were, one, he didn't want to place extra burden on my mom and number two is that he wanted, um, towards the end he wanted pain relief to be the most important thing.

00:45:26 Earlier he was willing to trade off any kind of life extending measure for more pain. But towards the end he said, you know, at this point I just want to be as pain free as possible. Um, so when he became unresponsive, we had to make some choices about what would make him more comfortable. And we were able to kind of go back to those, you know, particularly guiding principles. So for example, when towards the end, his cognitive function, um, was diminished and he was confused and he didn't know what was happening. And so we have the hospice nurse came in and she said, do you want to put in a catheter? It's going to be uncomfortable and he's going to be scared. But I think he's really uncomfortable. I think he has to go to the bathroom but doesn't know and doesn't know how anymore.

00:46:08 And this will make him more comfortable. But it's, you know, he's not, it's going to be a little bit of a challenge to do this. And so my mom and I said, okay, well let's think about those guiding principles, right? What, what was important to him? Well, one is this comfort. While it might cause him more discomfort in the moment, I think he's going to feel better. And then two, this will make it easier for you because you know, she was having to clean up a lot of incontinence issues. And so this, you know, this would be, this would fit both of those things. And so we decided to go ahead and do that. And that was sort of how I think these things can operate. You don't, you know, we, we never had a specific conversation about whether he wanted to have a catheter at any point in time. Um, but you need those principles to kind of guide that. So I think that's very different than an advanced directive, which is very specifically oriented. Um, and is going to, I think bring up more issues than it's actually going to be helpful. But the goals of care are more, again, around these broad guidelines and then identifying the person who you want to implement those for you when you're not able to communicate.

00:47:03 So Victoria, you, you talked about how those goals kind of changed as as your father was going through this, have you looked at before people even get a disease, is there, is there any benefit for people it, you know, who are healthy at this point to start saying, well at some point I, I may end up in, in a situation like this and here's the types of goals or is that so distant, so far removed from what is actually happening that it doesn't really have any relevance once that actual disease, whether it's cancer, heart disease or whatever else is coming into the end of the equation.

00:47:40 Yeah, that's, that's a tough one because that's where people who are not proponents of goals of care discussions would say, you're never going to know. You need to have just in time decision making. We don't, if we do anything in advance, you're going to be making predictions for yourself, um, that aren't, that may not be accurate once you actually get there. Um, and I think so I think I would push back and say there is value to having an ongoing regular series of conversations. So this can't be a single decision that you make when you're healthy and 20 and then when you're 80 people are, you know, saying Hey, she said she never wanted advanced, you know, wanting me to CPR or wanted all the things. Um, so clearly there's evidence that we do change over the course of age and illness about what, what our preferences are and they think the best process would be, you know, a relationship, an ongoing relationship with your care provider who routinely asked you to kind of update and share how you're feeling about these kinds of tradeoffs that you would make.

00:48:38 Um, so yeah, I think there is danger in thinking you can do an advanced directive one time and then it solves all of our problems because there is real issue with effective forecasting. And then there's also experience, you know, for a lot of people when they get cancer the first time they're willing to do a lot of heroic things and then later they go, I'm not, I'm, I can't do that again. I can't do that anymore. You know, and it changes. Um, I don't know if that's an effective forecasting error or if there, if people are really willing to try it one time, but then not again. You know, there's clearly a, um, you know, a change over time and what we think is important and what we want that needs to be captured there. So there, that is the danger.

00:49:16 It sounds like it's more, this is, this is like more than one study. I mean there are, there's a whole body of research that needs to be developed here.

00:49:24 Yeah. And I think so if I could outline kind of the pieces that I think needs to be done, you know, folks have done research on prognostic information, so how well the physicians, you know, predict how long you have left to live and what are your chances of living. Um, and physicians are pretty poor prognostic indicators, but we know that they are biased in a particular direction, which is they tend to suggest you have more life to live or will, you know, are more likely to survive than you actually will. Um, so what can we do to improve prognostic estimates, right? Those are pieces of information that decision makers probably want to have. Um, so I think kind of the first input is what can we do? Are there algorithms that we can use? Um, and there are, there are some, some very, there are better prognostic algorithms, um, that can be used and brought to bear on the process.

00:50:13 Um, and then how do you communicate about it, right? When, when do you start talking about prognosis? When you talk about the side effects, how do you talk about the side effects? How do you talk about risk of the side effects? How do you present information? So beyond decision on a conversation level, can we train physicians, primary care, palliative care, oncology, cardiology to present information in a way that's most understandable to patients and then having these ongoing discussions about preferences with the idea that they should be frequent, they should be updated, they should be part of your regular care plan. Um, and that's where I'm spending my time right now is can we promote goals of care discussions earlier in the course of illness. And so I've, there's been a lot of difficulty in implementing those kinds of protocols in the, um, the non-primary sector in the, um, sort of specific specialty clinics like cancer and cardiology and whatnot.

00:51:18 Um, those folks are really reluctant to have deep dives on goals of care. And so I've been thinking about where could we put that then? Um, and the primary care relationship is one that I think is probably the most fruitful for having these goals of care. So you've got a relationship with, ideally you'd have a primary care provider for a long period of time. Even when you go off to see oncology and cardiology, you returned to your primary care and they can be the person that facilitates these conversations. So some of the work that I've focused on last couple of years is developing interventions to promote advanced care planning in primary care setting, identifying people who have life limiting illnesses, not necessarily that folks are going to die in the next year or two. Um, but you know, that have these disease courses that will limit their life. When can we start having conversations?

00:52:08 Can we kind of prompt or nudge, right? Using some behavioral economics terms, primary care providers to begin the conversation. Because I also think it's a process, right? We talked about this a little bit, but just even, we haven't talked too much about how patients feel about having these discussions and there's not a ton of data, but in my own personal caregiving experience, um, patients tend to be reluctant to have them. So they're not often going to be the person who says, I think I'm going to die. Let's start having this conversation. Um, and so there needs to be a time to allow that to, uh, to develop and into, you know, a fruitful discussion for my, for my dad's example, you know, I had pushed him to get into a palliative care, um, facility after he was diagnosed, which is earlier. Usually palliative care comes later in the course.

00:52:59 But I knew that, um, the palliative care physicians would be really good at thinking about quality of life. And so when he went to, for the first time to see the palliative care physician, um, he started asking him about his goals, care, what, you know, what are going to be important to you as the disease progresses. What do you want us to, what do you know about your prognosis? Um, you know, what do you want us to know about how you know, what your preferences are? And my dad got really upset and he, he was, why are you asking you this? I'm not going to die tomorrow. I'm not gonna die next week. This is way too soon. And I remember thinking to myself, gosh, if anybody should be having to go as a pure discussion at somebody who has stage four cancer, you know, this is very appropriate. This is not inappropriate. You know, and he's a smart man. You get a PhD in psychology. He, you know, it was clearly not an issue of not understanding the situation, but it was an issue of not wanting to understand the situation. And so, yeah, so he just, he was just like, no, we're not having, we're not doing this right now. But then the next time he came in, you know, he said, so I thought about what you asked me last time and I've been thinking, you know, and so it was, it was like,

00:54:00 and I, he had the, he had to process that.

00:54:03 He had to, he had to get there. And so I totally, I've, yes, he did. Anecdotally, I've heard from physicians that that's more common than not. And so there's clearly some process that has to go through on the patient's end as well to be able to think about an access and have these kinds of discussions.

00:54:19 Well, it, it is, I think from that patient perspective, and I'm going back again to, to just an N of one with my, uh, my aunt who, um, you know, went into the hospital, felt like it was a flu like symptoms and basically found out it was cancer and died three, three days later. It was that progressed and it was really bad. And, and subsequent to that, you know, we've kind of found out through looking at our journal and different things, she had been having symptoms for months and months and months. But because of that, I think that psychological fear and that, you know, death and on all of that, just refuse to even kind of acknowledge any of those symptoms and to go in and see a physician. And those are real pieces that we are human and it's, as you said, we aren't necessarily built to be able to, to understand all of that and to be able to process our own emotions around that in a way that is beneficial for our long term, you know, health and satisfaction and success. Yeah.

00:55:22 Yeah. And I think that there's a real open question about whether it's beneficial to everyone to have it advanced care planning discussions. If you don't want to talk about it. Is there a benefit in me making you, you know, or is it the best care for you to do what you think is best? And I think those are the kinds of questions we still have. Will we always be doing people a service to force them to take a look at their own mortality? Um, will that always end up, you know, giving them a better perspective or will that actually stress create greater undue stress? I mean, I think there's a lot to be learned about how do we approach the end of life, you know, in the best way possible. And are there individual differences and can we develop flexible approaches and who knows what's best here? You know, we know patients don't always know what's best for them. So do we let them lead or you know, or not. And so these are all the open questions I think exists.

00:56:13 I'll tell you what, I want to make sure that the discussions are happening in the doctor's offices and not in the, in the attorney's offices. I mean, I filled out my healthcare directive a couple of years ago, the first time, and it was an, it was in the lawyers office. It wasn't even with the physician. It was, it was the checklist that, that an attorney handed over to me and said, check, check, check, check. Just just work through this. And, and I didn't even think about it until after the document was finalized that I should not be having this discussion with a physician. Should I actually be talking to a doctor rather than a lawyer about this? It seemed crazy.

00:56:47 Yeah. And it's interesting. I'm not sure that physicians do that much better. Um, you know, there's, there's real bias in how you frame those choices. You know, we've had a couple experiences. My dad would be hospitalized and he didn't fill out an advanced directive and you know, they would say, do you want us to save your life if your heart stops? And so he's like, Oh yeah, that sounds good. And then some of them come in and say, do you want us to pound on your chest and break your ribs and then attempt to bring you back to health? You know, and then he was like, no, I don't want that same thing. You know, so it, I mean it matters what, how you describe it. You know, the all framing effects there. So it's, you know, I don't know what the optimal version of that would be. Cause clearly again, a physician has a bias. Like, you know, some of them think it's a terrible quality of life after CPR for someone who's terminally ill and other people think we should do this all the time. And how the way you word the question is going to influence the response you get. Um, and is that, is that any better, you know, now that you have the response but it was free, you know, you chose X response because it was framed one way. Have we made an improvement? I don't think so, but yeah.

00:57:50 Well this, this is a, this has been a terrific discussion Victoria for a whole bunch of reasons. One is just really great, uh, being in touch and, and connecting with you on this topic. And I think it's, it's really great that you share your observations with these listeners with our listeners. Thank you for that.

00:58:04 Well, thanks for giving me the opportunity. I appreciate it. It's, you know, I haven't done a lot of work in this area, but I have a lot of strong feelings about what needs to be done and you know, doors that are open. So it's fun to be able to talk about that and think about where we could go in as researchers.

00:58:19 Yeah, I think it's an important component. As we said, it's, it's, you know, these are decisions that have a tangible impact on not only quality of life, but also life and death. In some instances. And so it, you know, it's, it's, it's a, it's an area that definitely needs to be, be studied more and to be taken seriously. So thank you. Thank you for your work and thanks for sharing. So

00:58:42 thank you guys.

00:58:44 Okay. We'll end the recording there and really has been such an absolute pleasure to catch up. Really. Uh, you look,

00:58:51 I have enjoyed it as well. Thank you. I know it was trying to decide. It's been like at least 12, 10 years. No, not 10 years cause Lyla is 10. But my, I had a, she was, you know, like a little little one when the last time I saw you

00:59:03 was, I don't think she was, well

00:59:06 she might've been toddling at the very most

00:59:08 at the most. Yeah. My gosh. And, and who, and you and ed have more than Laila, right?

00:59:14 Yes. My son grant just turned seven. I think the last time I worked with you, I was pregnant with grant. Um, yeah, I think that was like, cause I came out and, um, I remember being pregnant cause I have a heart condition that was really exacerbated by pregnancy. And so I was having, I, I had this very clear memory of trying to get this talk and like having to sit down in the middle of the talk like [inaudible] lady and having like, I remember compensation,

00:59:40 Hey, remember that Betsy Schneider was so worried. Just like, okay, we gotta make sure that there's a comfortable chair at the front of the room for Victoria to sit in. And I'm like, I, I think that's a good idea, you know? Yeah. Oh man. Well Victoria, it was really great. Thanks so much. And um, this, this was really one of the most emotionally and heartfelt, um, recordings we've ever made. This was just terrific. Thank you for relating your story. Yeah. And the research potential that's coming out too. Yeah,

01:00:09 yeah. Well, and it was fun to talk to you guys. You guys make this really easy, so I appreciate it. Incurred. It was nice to meet you.

01:00:13 Nice to meet you. After all these, I mean I literally have heard your name for for 10 plus years and all that great stuff. So cause they're super excited about that.

Yeah. Kurt actually started his, well didn't start your career, but he was at BI before he got his PhD and so he had a, he and I over time. Yeah. So he wrestles with the cash on cash thing. He's done that for years and years now. So that's fun. Okay. Thank you very much. We are in Kia. We're going to, um, I'll, yeah, we'll, we'll cut off here.