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Proem

Welcome to another installment in my series on medical decision-making. I doubt this series will ever end. How can it? Our experiments of one or societal experiments of medical action or inaction never cease. I met our guest, Dr. Daniel Matlock, at a conference recently. Dr. Matlock is the Director of the Colorado Program for Patient-Centered Decisions at ACCORDS (The Adult and Child Consortium for Outcomes Research and Delivery Science) and the interim Director of the Division of Geriatrics at the University of Colorado. He is board-certified in Internal Medicine, Geriatrics, and Palliative care. His research aims to fundamentally change and improve how patients decide about invasive cardiovascular technologies.

The fragility of life strengthens 01:50

Health Hats: Dan. Welcome. Thank you. It's very nice of you to join us today. I wanted to just start with getting to know you. Can you think back about the first time you were aware that health was fragile? What was happening at that time in your life?



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Dan Matlock: That's such a great question. You did warn me about this question ahead of time. So, I had some time to think about it, and I couldn't come up with a specific event, but I have some thoughts on it. I grew up in the suburbs, pretty safe, white kid, not any challenges growing up. My grandparents lived in Texas. They died when I was in high school or later. I didn't deal with a lot of deaths growing up. I was a healthy kid and didn't deal with many illnesses growing up, myself or my family. And as I think of the things that drove me to medicine, it wasn't like some experience of the fragility of life. But then I will say when I got in through engineering training, and I get into residency, and I'm seeing patients, I don't think I got officially depressed, but I was down about the culture of medicine. And it was just how we do things to people instead of with them. And it was because they were fragile. I didn't like what I was seeing. And that's what has driven me into the research I'm doing. Because we haven't done a good job as a medical culture, acknowledging the fragility. In many ways, we're in a fight. Somewhere in the last hundred years, people getting sick and dying went from being sad and tragic at times to being a failure of science or a failure of medicine. And I think somewhere that well-intended thing that happened when away. That's what pushed me into palliative care, geriatrics, and hospice because I felt like these were underserved people. Cause we weren't dealing with the fragility. And then I think, especially the hospice and palliative care work, I've always said, yes, some of these things are hard. I've had patients that I've teared up with, and I'm not a big crier generally, but real experiences. And I think it's made me a better husband and a better father. Because it does just remind you daily that life is fragile, and that daily reminder for fragility enriches my life. It reminds me that, okay, this was a bad day, but I need to put a smile on cause my kids need that. And I'll be happier, too. And it's that reminder that does that.

Early health decisions for the family 04:22

Health Hats: On your LinkedIn page, you say I'm trying to improve how older adults make decisions surrounding invasive technologies. What was the first decision you had to make, or what was an early decision you had to make about your health or your family's health?

Dan Matlock: Yeah. That's the thing there. There haven't been many in my own family, my personal life. I will say lately, I have had to make medical decisions. I'm a little overweight and have some challenges now that I'm getting in. I'm getting a little older and have sleep apnea, take I have mild diabetes. So, most of the medical decisions I've been facing with these, you might say, small decisions, but they have big consequences over time.

Health Hats: So, like lifestyle decisions?

Dan Matlock: Lifestyle, medicines. There's a new weight loss medicine they pose to me that I was looking for a decision aid. Did we know if this is good and those kinds of decisions that I've been faced with personally? What are the pros and cons of this? And so lucky personally, my wife's been healthy. My kids are healthy, though, although, through the pandemic, some of my kids' mental issues have started coming out. I'm starting to wrestle with some decisions there. I have a kid with gender dysphoria who's 14 wanting to take hormones. I want to support him for who he is, and I know hormones aren't that great. Testosterone hasn't been all that great for men, in some ways, certainly from the



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cardiovascular perspective. It hasn't been that great for men. I'm wrestling with now, and my wife and I are. But yeah, it's a hard question because I'm not one of these people who has this experience. It was hard writing essays in med school. Cause that's what many people write about is some beautiful experience. And I just didn't have that.

Endless questions about decision aids. Who, why, what, how? 06:18

Health Hats: But so here you are. And your focus is on making decisions and working with people. So, what goes into that into developing decision aids? What does that mean? Like how do you decide what to work on? What goes into developing something. How do you know it's any good? Who's it for? I just get all these questions.

Dan Matlock: Yeah. The whole idea of the, a lot of the work I do in decision aids are a bit of a hot topic. How I got into them was funny. When I was a geriatric fellow, I did my residency, debating whether I wanted to do geriatrics or palliative care? And I was thinking of trying to get boarded in both. And I am boarded in both, but I only did a fellowship in geriatrics, but during my geriatric fellows, I was working at our VA nursing home. And there were two patients that I was caring for who was there for hospice care. And both had these defibrillators, which is one of those cardiac interventions that I have gotten into. One of them had metastatic cancer, colon cancer, and he was dying. And the other had an incurable infection that had been seeded several of his artificial joints and was not clearing with weeks and weeks of antibiotics. And he was getting weaker and couldn't stand it. So, he moved to hospice, but both didn't want to turn off their defibrillator. So now I have these two people in the nursing home dying of other causes with this device that will potentially shock them once they get to that phase. I talked to them, and all their goals are doctor make me comfortable. But when we turn to this defibrillator, I would hear things like, oh, like one of the patient's spouses said, the VA is now trying to kill my husband. Or one of the others, one of the others thought I was playing God. And we did a three-hour family meeting with him I remember. One of his daughters said, dad, we're not playing God. We're turning it over to God. And then he paused and leaned back and said, okay, that makes sense. Maybe let's turn this off and let me go naturally. But that those experiences through training made me think, wow, people have no idea what we're doing. Yeah. And these are guys with permanently implanted resuscitation devices that didn't even know you could turn them off. They didn't realize that the potentially life-saving benefit is also potentially harmful. And that's when I said, you know what, I'm going to work on this. I want to work on this problem. I think this could be. This could be a career for me that wouldn't make me sad about our culture fighting a piece of our culture that I don't like, which is this culture of doing things to people instead of with them? Then I go into a research fellowship, start designing some projects, it's interviews and surveys, and just really learn. That people didn't know much about them. So that's how I got into the decision aids. This group of people making decision aids and decision aids are just tools. They're just tools to support a conversation. It's about empowering patients to understand what's going on and getting docs to be honest, not that they're dishonest. We tend to oversell the benefits downplay the risks. We do a lot of research because we mean well by our patients, and we want them to feel safe and comfortable. I'm not sure that's always right. We're adults. Life is fragile as you started. Maybe if we could be honest, people could then make accurate decisions. And that's what got me into decision aids.



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So, you asked what goes into developing them and making them. I think that was your question give a long answer.

Health Hats: It's good background. Go ahead.

Stakeholder participation developing decision aids 10:17

Dan Matlock: So then, making decision aids about stakeholder input. We try to design these tools for both patients and doctors. There are hundreds of decision aids effective in clinical trials sitting on shelves. One of the problems is they were mainly designed with the patients in mind. Then, because I've heard from docs, I saw that tool. I don't like it. That's not how I do. And we didn't use them. And then we also hear from patients they want to hear from their doc. And so, we've tried to design tools that docs are willing to use. You have two groups of stakeholders, and then we iterate. We do rapid prototyping iterating making tool. We haven't based on some theory. There are international guidelines and things. But really, we start with those, make a version, and then iterate, trying to get it accurate. And that's the easiest piece, but then to get them accurate and readable.

Biased to what? 11:08

Dan Matlock: That's where the debate happens because the docs always want to add more nuance that doesn't help the patient. The hardest piece is making sure it's unbiased. Patients think it's good but slightly biased towards the intervention, and the docs think it's good but biased somewhat against the intervention. And then that's how I know maybe we'd hit a sweet spot of something people are willing to use. And most of the tools we have by the time we're done making them work for patients and docs.

As the stakes go up, enter the caregiver & family as stakeholder 11:35

Health Hats: So, in my view, it isn't necessarily two parties. It's more often three. There's the caregiver, the family member, a partner or a child, or a parent. How does that figure in when you're thinking about perceptions of stakeholders?

Dan Matlock: Yep. I think that's a key question. And honestly, my answer is it's different for different decisions. And that just comes from experience. For example, my weight loss medicine, I mentioned for myself. I talked about it with my doc, and maybe I mentioned it to my wife, and she's certainly supportive of it, but she wasn't involved in that one.

Health Hats: You started with the defibrillator with the family. That was significant.

Dan Matlock: Exactly. As the stakes of the decisions go up, differentiators or we do some work in the heart failure space with these partial artificial hearts—some of these like chemotherapies and things. As the stakes go up as the illness, as the person gets sick, the family just becomes more and more critical. And I do primary care in a seniors' clinic right now, and we encourage families to come to every visit for that very reason. Because somebody is involved in helping a person navigate, even somebody with mild



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or moderate dementia can still make some decisions for themselves. They often need a family. As the patient gets sicker and the decision, as the stakes of whatever decision go up, the family becomes much more critical. So, for some of our other decision aids, we even have a page for the family because they're so important in this.

Changing level of agency. So many decisions, like putting in a kitchen 13:12

Health Hats: In my earlier podcast, the first series I did in my podcast was about young adults with complex conditions who were transitioning from pediatric to adult medicine. And so, it was the other end of it. They were either young adults or had been recently young adults, and they talked, and there, it was like a parent, and they talked about the taking; I was going to say taking back as you get older when you become a teen. You start reacting to decisions made on your behalf. Or the parent is trying to guide you into some agency. Some take control of your care, where they've had the habit of making decisions for you. So, it's interesting this is coming into decisions. I'm a person with multiple sclerosis, and I see six or seven different specialists, and I'm a nurse, and I'm knowledgeable about all this stuff, but there are so many decisions to make. And I put my effort into building the team that I trust, and then I'm just delighted to let them make the decisions because it's like putting in a new kitchen, there are just too many decisions to make. And, I don't want to like, decide about all the knobs and hinges and finishes. Do you know what I mean? It's you're my neurologist, what do you recommend? I'm going to do it unless it has something to do with specific things that I'm cautious about. I guessed when I was thinking about who our decision aids are for and who aren't they for? Like, how do you navigate that?

Who are decision aids for? 15:07

Dan Matlock: I think you're right. Nobody with pressure chest pain and you go to the ER. You don't want a decision aid. Should you take aspirin or not? When you have a heart attack, you just want to trust the people taking care of you. I think that's a lot of it. There's a subset of decisions where decision aids have a nice place. And I tend to think those are some of the more significant decisions with big trade-offs like a defibrillator or a left ventricular assist device. Or I'm working with a neurology faculty member who wants to do the deep brain stimulation for Parkinson's Disease, a surgical implant that can help. But it doesn't help with the mood. It only helps with movement. And there are trade-offs there, and it needs to be patient-centered. And so, I think decision aids can help in these complex decisions. Help slow things down a little bit so that the patient can look at them. Maybe read it at home, maybe share it with a family. And help the doc have those discussions. So, you have richer conversations. I think those are the niche, I think, for a decision aid. Yeah, you'll get varying opinions on that. Some people think we should have a decision aid for everything. Although I think people are starting to realize the impracticality in that. So, I like them for the big high-stakes decisions.

Shared decisions 16:21

Dan Matlock: But I think that shared decision-making approach is what I use in the clinic when talking to somebody with multiple chronic illnesses and medicines. Now and then, a little shared decision pops up. For example, many people have incontinence, and we have meds that help, but they have side effects. They're not going to save their life. They're not going to do anything for this person. Maybe I can help



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you not wake up five times at night with this bit of medicine, but it might make you feel dizzy, or perhaps I can help you stop avoiding that urge sensation, but it might make your mouth dry and your eyes water. And so, then I switched into this little approach of I can't make a recommendation. I can see what you're getting into, and then let's talk about it. And if it doesn't go well, let's we can stop it. We can try it. Some of those, and I would say that's a lower stage decision because the medicine is generally not life-threatening and can be stopped. And the side effect goes away. But I think that sort of shared decision-making of not seeing that I just need to recommend everything to that person. But I need a little here, a little from you. Is this so bad? You're willing to tolerate some dry mouth and dry eyes. Okay. If it is. Let's try it. And then, some people say yes, and some say no. And I don't think we in our culture, our hidden curriculum of medicine doesn't teach that our hidden curriculum of medicine teaches that we need to recommend things. And people came to us for care just as you said, which is true. And even within that person's goals and values often matter. So, we're moving some of the grants, and things I'm writing now are, how can we use these tools? But how can we get it to be more than just a check box that you used a tool, for at least one of the tools that are mandated. It gets you to have that rich conversation where you explore, what are your goals? What are you hoping for the rest of your life, Danny? You're like, what do you want to get out of the rest of your life? Let me, and then instead of making a recommendation based on the medicine and evidence, you need this based on the medicine and evidence and based on the fact that you want to live as long as possible and don't mind getting shocked. I think he had tried a defibrillator. What do you think the, with you I'm sharing it I'm I still made a recommendation, but I didn't just recommend it based on your medical chart eligibility? It was also based on your life, goals, and values.

One-time decisions, ongoing communication 18:50

Health Hats: Another thing you're saying is that sometimes whether you're going to have surgery or not is like a one-time decision. Cause you can't take it back. You had the surgery, but most of some of them, I better not say how many, because I don't know, but many of them are not about one decision. What I look for in my team are those responsive clinicians so that if we decide, we know when we have to talk? When is it good to talk? Because like you said, maybe the dry mouth is so bad that it's affected my blood pressure cause I'm like hypovolemic, I don't have enough fluid. So, it's more longitudinal, meaning its over time.

Tracking decisions and their impact 19:51

Health Hats. I've just been trying to get my head around this for 20 years. So, when we use decision aids and make decisions, it doesn't seem like we have a systematic way to. Okay, we made this decision, so then what happened? Now you're my doctor, you and I can do that because we have a relationship where we're still seeing how it goes. We're in the middle of the experiment of one. And we're keeping track of it. But on a population basis, on all the people who made defibrillator decisions or all who made prostate surgery decisions or whatever, how did it end up going? And it seems like we don't consistently take advantage of that ongoing experience. I'm finding it harder and harder to talk about because I learn more about it because it's complicated. Yeah. But as a, from the point of view of a clinician, a decision aid person, a researcher, how do you look at that? Do you know, how do you look at what did people do with that decision aids I had a hand in developing?



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Dan Matlock: Oh, yeah. There are a lot of questions there. For just the first thing you said that we're talking about, most decisions are not single one-off decisions. I think that's true. And in some of the decision aid innovation we're trying to do, we're getting into this roadmap space. Okay. You got diagnosed with heart failure. Here are some of the main things you might expect, and your map, your road, your travels may go this way, or that you might go towards a transplant or not. And just to prepare people. And then it's all about goals and values. But again, we make another decision aid. How do we get people to use it? How do we get it into the electronic system? How do we learn from other people as we go? That gets into the learning healthcare system stuff. That's a hot topic right now. And we learned from the ongoing activity that we're doing because there's a lot of knowledge there that is just getting lost daily. A lot of experiential learning. It's just getting that. We, I don't know. I don't know. I don't know how to capitalize on that except to empathize that you're asking the right question. How can we learn about how this is being used? We have not done a great job integrating our tools within our electronic medical records. I work at the University of Colorado, and we work with UC health hospitals, excellent hospitals, but their priority now is expanding across the State of Colorado. And so, my little research project is just low on their list. When I talk about their electronic medical record programming. We're trying to open new clinics and support the staff, so it's been hard that's those are hard stakeholders to work with to get the things in the system and nothing against UC Health. I'm not saying that it's right.

Health Hats: No. It sounds like you're not alone. Your system isn't alone as a clinician or a researcher. You're not alone in this. It's the competing priorities. Yeah, that's just the way it is. I was interested in this 20 years ago and spent five or six years trying to promote this with zero success. But then recently, meaning the last few years, I became more interested in health equity and the diversity of people's lived experiences. I thought this was a way to study the impact of decisions on diverse populations by doing some sort of systematic, even though the original research might've been done in this particular setting with these specific circumstances because that's what research wants. But then, does it work with women? Does it work with people with a rare disease? Does it? It's like the people who weren't part of the research. And so, this is an opportunity to test it in that diversity.

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We decided what? How'd it gone? A black box 25:35

Dan Matlock: One of the big challenges, especially with communication, patient communication, and shared decision-making research, is there's nothing in the chart that tells you how the conversation went. So, you either have to record the encounters or survey people, both of which are hard to do on a big, broad system scale. And that's in the research space. One of the subsequent grants I'm writing



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about will be doing recorded encounters. So that we can see did these tools make that conversation better. And did the docs ask about your goals. Because that's really what we want? That's the behavior we want to translate across all decisions. But yeah, that makes it versus shared decision-making, and the patient-centered kinds of questions that I encounter are such a black box. Even if it's the patient, the family, clinicians, and nurses, it's still, once it's done, nobody knows what happened from the right perspective.

Health Hats: Which like this makes me crazy. I get the challenges, but, oh anyway, so what do you think we, in this area, what do you think we should have been talking about that maybe we haven't covered? If you're thinking about people who are listening. My listeners or readers are broad because they're like my hats. Some people are patient activists. There are patients. People are caregivers, clinicians, decision scientists, researchers. But they're all similar in that they're really into the connection between real life and clinical decisions. So, if you think about that audience and you're thinking about what we're sharing about decision-making and decision aids, what do you think, what else do you think we should be talking about?

Design decisions – in the clinic or outside 27:32

Dan Matlock: The purpose of these things is to get the patient's goals and values into the decision and make it easier for the doc to have that discussion. And also, I think decision aids, if they didn't work in the past, I think there's a lot of room for innovation and improvement, a lot of design decisions that we haven't studied very well, that might make more effective tools, more effective conversations. And I guess the best is, don't throw the baby out with the bathwater there.

Health Hats: Design decisions. So, some examples

Dan Matlock: One of the big things is, do you design something that the patient reviews out of the clinic or in the clinic? Oh, I said, if it's out of the clinic, it could be a video we've made some of these. Is it a clinic? Maybe it needs to be a little short one page. A group at Mayo has done some beautiful tools designed for in the clinic. But there are also tools that a patient wouldn't have an easy time reviewing at home. And so that maybe we need to rethink our design decisions on what these things should look like.

Where do I go to get questions answered when I have them? 27:32

Health Hats: Okay. Yeah. One of the things like I had a gig working with some people on MS treatments. And one of the things that I found myself advocating for in my patient expert hat was where do I go to get my questions answered? Because while I'm sitting with you, the clinician, we're together if we're lucky if we're together for half an hour, with five minutes related to this decision. That would be like a lot. But then I go home, and I'm slow, and it takes me a while. I got to talk to my wife about it, maybe I would have recorded the conversation, and then I would go home to my wife and, he wants to give me Gabapentin for whatever, and it's then the questions start to come. And it's not like at the right time. So, one of the things I tried to advocate for on those decision aids was including how you get information when you have the question. Is it okay to go to Dr. Google, or is there a helpline, or should I go to the



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portal, or what should I do to and so to me that needs to be part of the design question when I have them?

Dan Matlock: Yep. I think that's a great comment. I think it's hard to know you give a tool to somebody, and that person may not be in their head deciding at that time. And then the tools are not that helpful. We had more success in the intensive care unit, where people faced the surgery right then. And we knew we could get in there when they were wrestling with it. No, I think you're right. And I also, I'm a perseverator, too. Like I must go home and think through, just me trying to buy a car is a month-long decision. And so maybe that's what got me into decision aids.

Health Hats: That's funny. In my relationship with my wife, she's afraid to suggest something to me because I'll just want to make it happen. And she needs some time to think about it. But I'm not always like that. And I'm aware sometimes that I am, I'll just make fast decisions, and then I'll wake up in the middle of the night, and I'll go, oh my God, what did I just decide? Like I just spent all this money on this new toy. So anyway, it's those things that go into decisions. This has been great. I appreciate this, and I think that'll be helpful. It's both some of the basics about what's involved. But it's also about some of the challenges for individuals, society, and clinicians.

Dan Matlock: Oh, yeah. Thanks for having me. I listened to a couple of your other podcasts beforehand to make sure I knew what I was getting into. You've given some voices to thoughtful people who probably wouldn't have obtained some voices otherwise. I thank you for what you're doing, too.

Health Hats: Thank you so much, Dan. I appreciate this, and I'm sure we'll talk again.

Dan Matlock: See you.

Reflection 31:49

Perhaps this wide-ranging discussion covered too many facets of decision-making. I couldn't decide what to cut. We talked about decision aids at many points in life-before surgery, in the ICU, at death. We spoke about stakeholder participation in aid development with different perceptions, perspectives, and biases. The more complex the decision or the severity of the illness, it's more likely families, and caregivers will be stakeholders. Agency to make decisions increases as people go from children to adults and then reduce with dementia. We shifted to one-time decisions and continuing decisions requiring ongoing communication. I couldn't stop beating my drum about the black box of recording decisions and learning from the outcomes of those decisions. Finally, we talked about people don't make decisions on schedule. They may have ongoing questions that need answers when they have the questions. My questions remain, who is decision-making for, and how do we keep learning from decision-making? We, as individuals in our experiments of one, as providers, and as communities?



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