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Proem 00:52

Where do I make the most choices about my health? I have multiple sclerosis. I make choices about function, activity, pain, food, and mood all day, every day. Ok, I exaggerate, many times a day. How do I support myself in making these choices? I experiment, I track stuff, I worry, I connect and consult. As a person, I approach these choices for myself, sometimes with other individuals. Always as an experiment of one. On the other hand, clinicians work with thousands of people making choices, thinking first about people as a group aand then as individuals, or the other way around. An assumption of people who work on computerization of clinical decision support, CDS, (making medical choices) is that computerization will help clinicians make the decisions faster or more in alignment with research and guidelines. I like to question assumptions. I'm eyeball deep in this clinical decision support business because that's where a lot of time and money is spent and considerable potential sits. I met our guest, Dr. David Edwards, through RTI, that's Research Triangle International, a not-for-profit research organization. David and I both participate in a chronic pain management CDS project funded by AHRQ, the Agency for Healthcare Quality and Research, and conducted by RTI. I found him compassionate and curious and eloquent about pain management, clinician workflow, and patient life flow.

Introducing Dr. David Edwards 02:49

David A. Edwards, MD Ph.D., is a board-certified Anesthesiologist and Pain Medicine specialist at Vanderbilt University Medical Center and Chief of the Division of Pain Medicine. He oversees the care of patients in several urban and rural specialty clinics that treat patients for cancer-related pain, chronic pain, operative pain, and patients at high-risk admitted to the hospital with pain or substance use disorder. His research focuses on the transitional care of patients in the perioperative period, and the functional recovery of postoperative patients.

Health Hats: Good afternoon, Dr. Edwards, David Edwards. Thank you so much for joining me. How do you introduce yourself in a social situation?

David Edwards: Hi, I'm David or David Edwards.

Health Hats: How do you tell people about what you do, your work?

David Edwards: In a social situation? It usually comes up as where do you work? I say in pain clinics. What kind of work is that? I see lots of different people with pain conditions or surgical pain conditions.

Health Hats: You're a pain specialist, medically. I'm a person with pain. It seems like managing pain is an art, a science, and a never-ending experiment.

David Edwards: A good description.

Successful first visit. Acquaintance. Story. 04:27

Health Hats: How do you balance that stuff with your patients and with your team?

David Edwards: Well, with my patients, first, in the normal course of my work, I'll get patients referred to me from somebody that I know, a colleague or another physician and I'll get a bunch of paperwork, and I browse it, but I cannot anticipate my first visit with the person because they can tell me much better what is going on. It is hard to make any kind of judgment in this situation of chronic pain without the person telling me what it's like. Reading it on paper gives me a landing spot, but it doesn't give me a plan. So I just have to wait until I see a person with me and set it up so we have enough time to talk. Cause some people, that's what they need. You haven't asked me about my approach, but that's kind of how I manage it going into our first meeting.

Health Hats: You're looking to hear their story. Say more.

David Edwards: Sure, I can expand on that a little bit. One of your questions popped for me and made me think a little bit, too, about success factors with patients. What makes our first visit together successful without having known each other? We've got to get to know each other a little bit. It's going to be a therapeutic relationship. In my mind, chronic pain is not acute pain. Probably I've been with the person for some time, and there's a history there. I have to get an idea of what that is. So, it takes time just sitting there, and most of the first visit is a lot of just hearing and listening. The things that make that first visit successful in my mind, I've got to figure out the approach that that person wants me to take. There are a lot of different people with a lot of different experiences, and they prefer, they come in with an expectation of the visit that I've got to figure out. An example of that is just bucketing, and it's not everyone fits in a bucket, but with bucketing is some people want me to fix them. Tell me what to do. I'm going to do it. Thanks. I'm out of here. I'm doing it. Come back in a month. Other people are scared and apprehensive and they don't want you to do that just telling me what to do. Why don't you hear what I'm hoping that you'll do? And then some people want to learn about all the options and make a decision once they hear it. If we are short of time and rushed, we tend just quickly to listen and then prescribe a plan. That's the opposite of what works, what doesn't work. In my short time, I've got to figure out that first approach.

Health Hats: For me, the art that I see is those clinicians that can build a relationship in 30 seconds. Pretty amazing to see. As a patient who watches that happen, Oh my goodness, this person's good. The person who has been the most helpful to me has the approach that nothing works for everyone; nothing works every time, everything works for somebody. It's finding that balance. If I can have three things in my toolbox - this is the thing I'll try first, and if that doesn't work, here's the next thing. And then if I'm desperate... One person described that to me as pocket therapy, just to know I have it in my pocket. Just knowing it's there. I rarely use it.

David Edwards: Yeah, it's good to know it's there.

Useful technology of pain management 09:29

Health Hats: One of the things that never ceases to amaze me is how much the push is to computerize the relationship. Because if you don't have the relationship first, the computerization is not that helpful. But there's so much effort, put into computerization, like here are the guidelines and here's an app. And there are all these different apps to use. Because I am who I am – nurse, patient, informaticist - I like to try stuff. I don't think I've ever used a pain app more than twice, except that I use texting with the clinicians: This is happening. Just that, asynchronous - sort of real-time, meaning the same day. 'This is happening. I tried this; it didn't work. I'm freaked out.' You know what I mean, just having that communication? That's excellent technology as far as I'm concerned and then keeping track of stuff. Usually, I find paper and pencil, and sometimes spreadsheets are way better than apps in terms of 'let's look at what you did. What happened to you? How did it work?' So in your practice, how has that been for you trying to work with long term relationships?

David Edwards: Technology use in these longterm relationships has only been successful when it's short term, and we're both looking at it the next time we meet up. For example, sometimes you get a pain block, and we want to see how long it relieves or how much it relieves your pain and what you can do. So I formalized that a little bit in one of my research studies where people get a text every morning for one week, and that's it. I just want to know how they're doing and what their pain is and if they needed to use anything to help. And then we talk about it next time. You're right; I don't use a lot of health apps because you start not to use them anymore. They take up more time than you have. But some things help you. One that I used is called Daylio Journal, and I occasionally have my patients use it, too, just for a week. You put in your mood today? Is it meh, or is it fantastic, or just crappy? Then you'd select the themes or put in why you think that or what's going on in the day that is making this day so bad? Then together at the end of the week, we'll get together: 'Oh, look at this, you had this fantastic day here. What was going on there? How was your pain? Did you feel it as much that day? Maybe that's something we can use.' So I show them that I do it myself and I asked them to do it with me for a week, and then we don't do it for a year. We just do it a few times until we learn something. Suppose they're the kind of person who likes to be engaged and learn things about themselves. I'd say one of the things that I have appreciated, which is why I'm trying to help here in the RTI group is that I like it when I don't have a lot of noisy data, but I have a couple of personal things about the patient before I see them or meet them. What's bring them back now? Now, did something happen? Or if I haven't met them before, whatever they want to be able to do. Or what are they hoping to get from the first appointment? So I make sure I meet the expectations, give you your money's worth.

Health Hats: Yes, I think that's a part of quick, relationship building, knowing what's important. I know for myself having MS; whenever I see my neurologist, there are two questions: have you fallen, and are you still playing the saxophone?

David Edwards: Yes. Cool.

Care partner, family 14:26

Health Hats: They're excellent outcomes to keep track of together. How about including the key person on my team, my wife? I'm blessed that I have somebody that's family, somebody I live with that's on my team.

David Edwards: Hmm, that's a good way of putting it.

Health Hats: You were saying when you meet people, you can bucket expectations. But what about with the person that you live with that knows you sometimes better than you know yourself and is key to, 'Hey, try this, did you try this? It's in your toolbox.' But there's that range – some people are disgusted that their family member has pain. Do you know what I mean?

David Edwards: A lot of times, they come with a person, and sometimes that person is the one talking. So, it's a balance to see what the relationship is with the person that they show up with. Is it a supportive person that can be relied upon to help remind the person, to encourage them from visit to visit, to help them buy into some of the goals that maybe they haven't bought into, but they will willing to try. Some people need to step out of the room so you can hear the voice of the suffering person. That's not always easy, sometimes it's tough.

Health Hats: I can imagine.

David Edwards: My approach is usually to acknowledge and introduce myself to them, the person that they've brought or have at home, that's a support to them. But I make it a point of talking to the person whose problem it is. You're trying to hear their voice in their words.

Mutually agreed-upon outcomes 16:40

Health Hats: When you're working with people, do you do what I have with my neurologist? We came up with these two outcomes that are a thread through every meeting, even though we're dealing with pretty much different things every time. The constellation of issues changes, but there's a thread. I don't know that I've ever done that with pain specifically.

David Edwards: If I'm getting what you mean, your physician knows one thing about you that always comes up and brings it up. I do try to tell them, I know I need you to give me a pain score, but this is just a number. I want to know something about you that maybe you are doing now, or weren't able to do before that you enjoy doing. We can use that as our measurement. Usually, I'm bringing that up just socially to begin with, 'Hey, how's this, have you traveled this summer? I know you love to travel. What stopped you from traveling?' So the themes and the threads are usually the functional things that they're doing at home, not in my clinic space. I'll have physical exam things that'll keep coming up like, 'Oh, you're still hurting right there. Is it getting worse? How did you make out? Did you get out to the

mailbox this time? Or are you enjoying this beautiful weather, are you getting outside? This is a perfect time.' those were the themes are usually function-based.

What's a good day? 18:39

Health Hats: Yes, functional. When you go home at the end of the day, Oh my God, you've seen a bunch of people hurting. What's a good day?

David Edwards: I've learned that having a long list of to do's is stressful. Being as effective as we can in our time together, like you said, with our one, two, and three tools in our toolbox. You have your one, two, and three; you're going to call me or message me. If you're getting to three, because I want to hear about it a couple of weeks from now, right. Then we both have a plan in between the times when we meet. I feel good when each person has that, and you've been able to use our time effectively. So yeah, that gives me energy even though the system has brought us all together in a rush. Yes, that a patient will say, I felt like I had enough time and that I was able to communicate. I'm like, wow, I felt like I didn't have time at all, but you felt like you had time, so that's awesome.

3 Ts and 2 Cs in a marathon 19:55

Health Hats: Yeah. The pressure of time. In my work, thinking about people making decisions about their health, I talk about the three Ts – trust, time, and talk and two Cs - control and connection. I'm always working to maximize those. I'm more successful, whoever I'm working with is more successful with the 3Ts and 2 Cs. We've touched on talk, time, and trust. What is the control part? When I talk to people in pain or who had pain, not being in control is a significant factor. You know that the pain is in control or the doctor's in control. I can't get a script or whatever, but personally, feeling like we're in control makes a difference. I can't get ascript or whatever. How does that come up in your practice?

David Edwards: Yes. You know, having practiced for a while and seen enough patients, I have a perspective, at least from the physician side of things, that this is a marathon. And even control is gradual and small wins are still wins. Sometimes the fix isn't today. And that can be a frustrating message unless there's trust. It can be frustrating for a person who is expecting more than that.

Health Hats: Now the connection piece - In this work with RTI thinking about pain apps, the one thing - maybe I learned this in my behavioral health practice - is that connection makes a tremendous difference in the use of the app. When people use apps, when people have sustained success, that probably means that the ups and downs are not so peaked. Do you know what I mean? They go up and down at a lower level than saw tooth huge ups and downs. It's the connection with peers. You know that there are other people out there. Fibromyalgia comes to mind. Many strong fibromyalgia communities help each other manage pain, whether through yoga or meditation, or how to deal with the kids when you're hurting. Doctors aren't going to come up with that kind of stuff. Their toolbox is different. How does that get incorporated into your work as a pain specialist?

David Edwards: I know that you're right. There are Facebook groups and things like that. In our practice, how do we connect to social? We don't have much to offer. We understand it from the medical literature academically, right. Fibromyalgia is the perfect example, because one of the things when I go through there, I bring in a paper that I use all the time. I give it to the patient. I have it highlighted. These are things that work. One of them is being connected and educating yourself. If you don't do that, if you

do that alone, it doesn't work. If you have to do all these things together, you'll feel better. Occasionally I prompt, or I provide resources for them. We don't have many resources for that kind of social connection or interpatient connection.

Expecting too much from doctors? 24:16

Health Hats: That's just so interesting to me. I think, sort of like teachers, we expect too much from our doctors. They're good at somethings; they're really good at somethings. Then there are things that they are not good at. To expect them to be good at it is a waste of time. And it's sort of like expecting teachers to raise your kids. That's your job as a parent. Do you find that sometimes the expectation of you is beyond your skill set?

David Edwards: Yes, for sure, pain management is broad in the sense that most medical conditions present with one of the highest presenting symptoms, pain. It covers a lot of different things, but it's a narrow thing itself. It doesn't mean that I can fix your kidneys or your liver. But sometimes that's what is expected of me. Although I'm a specialist and I'm helping to manage pain, how am I going to fix a problem that's causing the pain that is way out of my control. There's a tendency to go down the road of I'm the primary care doctor driving all the things. It overwhelms them and me and it doesn't.

Health Hats: Yes, that's a tough one. So what should I be asking you about the work that you do that I'm not?

Pain specialist motivation 25:42

David Edwards: I think a good question always is, and you touched a little bit on that what makes a person do what they do or what makes a good day a good day? But I think to be more specific about what makes me do what I do is that because pain touches so much, is going to impact much. The challenge is hard. When challenges are hard, the benefits can be great. So I take it as a challenge when a person is lost, they usually end up in my clinic almost as a last hope, right? Some people are afraid of pain clinics, and what's going to happen when I go there? I don't even know what that is. I'm just going to get pain medicines, and we all know where that leads. But when you see a person that is down and you just imagine, in the bottom of the pit. Every other doctor has said, I don't have anything for you. I can at least provide hope and the potential, as you said, there are many solutions out there. Something will help somebody some of the time, a lot of the time. We have to find what that is and put someone back on a pathway where they can start looking up instead of going lower in that pit. This is why I do what I do. It's so hard. I can imagine if it's hard for me, and it's not a marathon for me, that it’s super hard for them. I just hope someone like you is treating me when I need it as a patient, is optimistic or at least doesn't give up. When you build that relationship with a person?, it doesn't matter if you're on vacation and you're not around, you feel an obligation for them, and you would do anything, just like you would for a good friend and that's the way it should be.

Health Hats: Well, thank you. I appreciate this conversation. Thanks for your time.

David Edwards: Can I ask you one question?

Health Hats: You may.

Evaluating success in an app 28:31

David Edwards: On the RTI thing you've seen it from their end, too, right? Like you've seen their prototypes and things like that, right? When I look at it at the very beginning, it started simply as how do we start? How do we communicate better? Shared decision making is the term, right? For me, it's one or two lines before a patient comes to see me about what they expect, and that saves so much and make sure that we connect on that. Now it's progressing to a whole huge, almost an EMR. I get it that more information is sometimes better. You brought it up to my concern, which is sometimes more information, just clouds it, and you end up not using it.

Health Hats: Yes. A conversation I've been having lately is how to evaluate success? As a patient advisor I belong to an organization called the Patient Family Advisor Network. A small group of us within that network thinks about the key success factors from a patient's point of view in terms of managing chronic pain. I've looked at wireframes for the app and asked, 'okay, what do you think about the features of the app?' I think that they have the same disease as others, which is, 'it could be so much more because people need different things.' The tendency is to go to more, more, more instead of thinking about what's the nut? Now we're talking about sustainability beyond the life of the gig to build this app. The app is just a moment. In three years, will anybody be using the app? And if they do, why? Not that they have to measure all that now, but could that also be part of the gig to think about the future? That's one of the reasons that, again, in my behavioral health experience, the only kinds of apps that I've ever seen that last are the ones that also include social connection. Because then people are using it because, while I have great relationships with the many doctors that I have and I have different communication, I only talk to them for minutes out of the year. Except what I'm in trouble they're not my go-to people. But I need go-to people because shit's happening every day. That's more of a social connection. I don't know if that's the right word, but to me, anything that doesn't include that... I liked what you said earlier, which is that an app can help build a habit and then be gone. I'm a nurse, and I've been a nurse for 45 years. My view of nursing is it's my job to put myself out of business over and over and over again. That's the job, at the heart of it, that's the job. In a way it seems like, unless it's about social connection, that's the job of an app.

David Edwards: Yes. I would say if you asked me, would I be using this app in three years from now? I would say only if it's still giving me that one or two pieces of information that the patient is wanting me to know. That's something I don't get consistently and be really helpful. Out there in the world, If this was on your phone or something, and you had all this fancy stuff in it that you could put in all of this information, if you really want it to. But yes, coming up to your next visit, you really wanted to remember emerges and you talk about the experience you're having right now. So you're gonna type in that one sentence and you're going to send it to me. And I'm going to handshake that I got it. We're going to talk about this next time. That's all I need.

Health Hats: What I really like about my primary care doctor is that's how she operates, that's the relationship we have. I'll send her a text that this is what's on the top of my mind. And she'll walk in and say, I read this and here's what's on the top of my mind and then we'll make sure to cover it. I might just see her for three minutes or I might see her for 45, but it depends on what those two or three things that are on the top of our minds. I agree that having for us, she and I, we do it through the text. But I

think it's because we're both into it. It wouldn't work otherwise. I don't think she does that with anybody else actually. I don't really know that.

David Edwards: I can't imagine a couple thousand patients texting all day long.

Health Hats: Right? That would be overwhelming. That's a whole different kind of overwhelming.

David Edwards: There might be as a way to take advantage of this technology to make that feasible in a way.

Health Hats: Well, the other technology that I really like, and actually in all fairness, it's the sponsor of my podcast, which is Abridge. It's an app that records the doctor visit and then gives you a transcript that breaks up the transcript, looking for key words, whether they're care plan words or treatment words. Frankly, I remember 5% of what happened in a doctor's visit. I just don't remember when I go home. My wife says what happened and I don't know. So it's helpful to have a recording. So then we can find the clip. We were talking about T cells today. Here's the thing about T cells. That's the neurologist talking or whatever, or it's about the immunization or what about a vaccine when it comes out? But that's been very helpful. And I use that with the chiropractor. I actually use it with my massage therapist, not just the doctors. It's Abridge, A B R I D G E.

David Edwards: Hmm. I'll look that one up.

Health Hats: Yes. Well, I have a feeling our paths will cross again.

David Edwards: You probably will, they have done it twice.

Health Hats: So thank you so much for your time.

David Edwards: This has been a great point of view.

Health Hats: Okay. Take care. Bye.

Reflection 36:23

Some of my podcasting buddies reviewed episodes in this CDS (clinical decision support) series. One comment pierced my heart – where is the decision support for patients and caregivers? Hint, they weren't asking about technology. I've also been asking patients and caregivers which electronic tools they use to help them make health and medical decisions. About 20 non-scientific responses included in no particular order: none, medical record portal (to communicate with clinicians that use it well), meditation guides, search engines and health system general info sites, and phone recording and pharmacy apps. The jury is no longer out. For medical choices, health decisions, human interaction trumps technology. I appreciate that David Edwards found that he most desired to use technology to hear the two or three things his patient wants him to know in advance of their visit and that he could hand shake that he received it. That embodies connection, control, time, trust and talk. All in one electronic interaction. Beautiful. Thanks for listening (or reading). Onward.