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Stranger in a Strange Land 00:55

I felt like a Hobbit listening to people speaking Klingon. I started a new consulting gig as a patient expert for *Clinical Decision Support (CDS) for Chronic Pain Management*. The team includes pain management clinicians, research scientists, engineers, and medical information technology folk. I'm a stranger in a strange land already – first meeting. This won't do. Although I'm hired as a patient expert, in my heart of hearts, I represent people at the center of care (patients, direct care clinicians, and those that support them). We're a team, after all. I need to get a grip so I can provide value in my role. Let me think this through with you. This episode builds on my rant in podcast #45, *Humanity before Technology - Clinical Decision Support*. If you haven't read or listened to it, check it out [here](#). The link is in the show notes.

Outside the CDS bubble 01:50

When I'm lost, I go back to other people at the center of care outside of the Clinical Decision Support industrial bubble. We live with clinical decisions every day. But I'm only one brain and one voice. So, I ask folk, *What do you think about when you hear Clinical Decision Support?* The conversations get complex fast. I channel my inner Rosetta Stone. People say, *What does clinical mean? Which clinicians are we talking about? What is a clinical decision? Aren't there different kinds of decisions? A decision is a moment in time. There's a before and an after the decision. How far upstream and downstream do we include in thinking about the decision?* Direct care clinicians, patients, and caregivers, all ask, *are we talking about what I want or what they want? Is the actual decision as important as we think it is? Isn't doing something more important?*

I try to explain, *well, someone has a problem that needs to be solved – discomfort, reduction in abilities, unhappiness, or worry. They might have tried something and weren't satisfied with the result – they didn't get better, or they're worse. They need to make some decisions about what to do next.* A common reply is: *Did they try something to make it better on their own or was it prescribed? Was a treatment or procedure done to them that made it sort of better or made them worse?* Good questions.

Are we talking about doctors, nurses, and PAs only? What about other clinicians – therapists, acupuncturists, nutritionists, chiropractors? Also, good question.

I ask, *what do you mean, What kind of decisions?* I hear back, *aren't decisions about surgery, a procedure, therapy, prescription drugs, over the counter drugs, behavior change different? Some are one*

time, some repeat over and over, and still others lead to many more decisions. Some are made by the clinician; some by the patient; some by one, then the other; and some by both. Yikes, too true.

I ask, say more about decisions, and doing something. I hear back, well, except for surgery or a procedure, patients still need to do the work—take the med, change the habit, go to the next appointment, etc. A decision without follow-through seems like a waste of time. Good point.

I ask, say more about what came before the problem got to the clinician. Responses include, did they take anything or do anything before the doctor saw them – something not medical, over the counter, illegal? How much do they think they know before the visit? Patients, caregivers, and direct care clinicians all ask this, too. Gosh, that seems important.

Then I hear, *what about us caregivers? Where do we fit in?*

Wow, more complexity, not less, and we haven't gotten to the Support in Clinical Decision Support or technology.

Broadening our focus, a bit 05:42

I'm exercising my mind here with you now because I care about best health – living life at peak capacity considering my environment, my circumstances, my genetics, and my conditions. I want to make the best decisions for best health. As I pointed out in episode 45, the likelihood of best decisions increases with the 3 T's and the 2 C's: Trust, time, and talk. Control and connection.

We, advocates and activists, have an opportunity when Clinical Decision Support experts convene to draw on their good heart, good intentions, skill, and vast experience. Remember, though, by necessity and training; experts narrow their focus to their expertise. Our focus is narrow as well – ourselves and our well-being. Let's broaden their focus a bit and ours as well. But how and where? We can control ourselves most, so let's start with us.

We can't solve healthcare's massive, entrenched problems around this CDS table, so let's focus on what CDS is and can do. CDS primarily serves clinicians managing in constrained circumstances – too much to do in too little time with a firehose of data and only sometimes helpful technology.

Tell your story in 30 seconds 07:34

Individually, we want clinicians to know us. They need to learn about us quickly – in a matter of seconds. OK, a minute. We can help with a brief story about ourselves and our preferences, goals, abilities, complaints, and circumstances. Here's mine.

I am an old white man of privilege with a diagnosis of multiple sclerosis. I am the CEO of my health and I want access to and control of data about me. I need help making decisions to function as best as I can, but without trusting you and data about me, I can't. I want to progress as slowly as possible, contribute to my community, and play my saxophone. I'm upbeat and want to stay that way. When I have a plan that I'm part of creating, I stick with it. That took less than 30 seconds.

Do the work 08:43

Besides telling a brief story about ourselves, we can do our homework – learn about our conditions and the options out there that might help us. We can log what we've tried, what worked, and what didn't.

Despite what anyone tells you, Clinical Decision Support (CDS) is an experiment. It only gets better with use. We, patients and caregivers, should try it, whatever it is, and learn. Learn what helps us make decisions and what doesn't. What approach, what technology, what websites help us? Which medium do we prefer (written, sound, video, cartoons)? Which people, which services help, and which don't. Then share. Give feedback, however and wherever you can - on social media, to the doctor, to your family. Join advisory panels at your hospital or clinic or with start-ups creating CDS tools when you can.

A pipeline of Patient Family Advisors 10:21

Patient/caregiver activists, we need to increase the pipeline of experienced advisors and help organizations, teams, and companies use them as more than window dressing. If you can't join, recruit someone else from your community (however you define that) who can. Learn more about Patient Family Advisors at the [Patient Family Advisor Network](#). Seek opportunities to get paid for advising with [Savvy Coop](#) or [WEGO Health](#). Links in the show notes if you're listening.

Include people at the center end-to-end 11:01

CDS experts, invite and actively listen to people at the center of care end-to-end. End-to-end means in governance, design, testing, evaluation, and dissemination of your tools, products, and research. This maximizes usability, sustainability, and health equity. It's more work and you have to budget time and money for it, but you'll end up with a superior result. Explain what you do in CDS to your spouse, partner, parent, or children. If you can't explain it to them, you're likely missing something in your work.

OK. That was a rant. What do you think? Talk to me.

Now a word about our sponsor, ABRIDGE.

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