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The 3 T’s and 2 C’s 00:55

I spent some time last week with colleagues in the **Clinical Decision Support** space at the Patient-Centered Clinical Decision Support Learning Network conference. I participate as a paid patient expert. We’ve been working together for a few years. I’d like to share some of it with you. Frankly, it’s been a lot to take in. I alternate between feeling inspired, confused, and troubled. I hear **technology, artifacts, patient-centered, large data sets, standards**, and networks of experts in **computable biomedical knowledge**. I think **humanity, best health, shared decision-making, controlling my own data**, and **collaborative care plans**. Sometimes I have a silent scream of, *so what?* I need to get my head straight, so I can best contribute and advocate. Bear with me. I’m going to try to make some sense of this crazy, huge, overwhelming, risky, and lucrative world. I’m going to walk us through the who, what, where, and why of clinical decisions and Clinical Decision Support? Why we should care and what can we do? I’m going to spend more time on clinical decisions than Clinical Decision Support because there’s no support without decisions. I’m also going to talk about uncertainty, the three T’s (**Time, Trust and Talk**) and the two C’s (**Control and Connection**). Keep in mind; I may be expert in that I know a little bit more than some of you do about clinical decisions and clinical decision support. I am less expert than many. I just want to make some sense of it. You will likely agree with some of what I say, disagree, and scratch your head. It’s all good. OK, here we go.

Clinical decisions – Choices about medical care 03:19

**Clinical Decisions** are choices made about our medical care - what to do next about what ails us or prevent something from making us feel worse. Often these choices are made by clinicians alone based on professional training, experience, and research. I say ‘often’ because everything in that last sentence varies widely – training and experience for sure. There’s so much research; it’s impossible to keep up with it. I would suggest that even though there’s a ton of research out there - too much for any one super person to follow - many, if not most medical decisions lack any research at all. That’s a different problem for another day. When we think about clinical decisions, we have to figure in inertia, availability, money, too. I’ll get to the alone piece in a minute.

### How certain? 04:21

We're talking about decisions where the choice is not certain. If you're bleeding, put pressure on it. That's a certain choice. Even if you're on blood thinners, you apply pressure. No decision needed. If it's not certain, it's uncertain. Uncertain means that A **might** be more likely than B to be the right thing for you to do. Research may tell us how likely for specific groups of people under specific circumstances (for example, white men in academic medical centers). Not necessarily for you. Your conditions, genetics, circumstances, environment, and preferences figure in, too. So, **might** can mean pretty darn certain, a little bit more likely, or something in between. Whether or not to have a mammogram or take cholesterol medicine or have surgery for whatever are such decisions. William Osler said *Medicine is a science of uncertainty and an art of probability*. He said that because few medical decisions are certain. Often clinicians making decisions about your medical care alone – without you – even though for most clinical decisions, the decision isn't certain. As a culture, admitting uncertainty can be seen as weakness. Many patients and clinicians don't have language for uncertainty, so we don't often talk about it.

### Time, trust, and talk – the three T's 06:06

Making decisions together is also called **shared decision-making** or **informed decision-making**. Good decisions made with more than one person takes time, trust, and talk. It's hopeful to expect good shared decisions to make it to routine action without the three T's (time, trust, and talk) Almost impossible. Think about it: Should I take this drug or that? Should I change this habit? Should I go for another appointment? Time to discover what's going on, time to learn, time to talk and agree, time to plan. Time to build trust. Trust can take months, can happen in a flash, and sometimes will never happen. I don't think I need to explain trust to you. You know in your gut when you don't have it. I'm a different person when there's no trust. My head and heart are closed. I need to trust to be at my best. Time, Trust, and Talk are the three T's of shared decision-making.

You may have noticed that I haven't talked about Clinical Decision Support yet. I'll get to it shortly. Start thinking about how complicated this all is. We need support to make good clinical decisions.

### Ink on paper unless we do the work 07:36

Making decisions is only one step toward best health. (Remember, best health is living at peak capacity given your genetics, conditions, circumstances, and environment). Decisions are necessary but not sufficient. Another way to look at it: Take a piece of paper, list some choices (about anything - like a shopping list). Check off what you decide you need to buy - apples, toilet paper, sandals. Now leave the list at home, don't look at it when you go to the store, or forget to bring your wallet. The choice was necessary, but not sufficient. You've got to do the work of going to the store and buying what's on your list. The list - the decisions - by themselves are ink on paper without doing the work.

### Outcomes – What matters to us 08:32

We make decisions about something that matters to us. We make decisions to accomplish something with our health, individually or in our communities. These are **outcomes**. I have secondary progressive multiple sclerosis. My outcomes are to progress as slowly as possible, to maintain my pathological optimism, to hang out with my family, and to keep playing the baritone saxophone. For communities, the outcomes can be the **quadruple aim**: improve the health of populations, enhance the experience of care for individuals, reduce the per capita cost of health care, and attain joy in work. When we make decisions about something uncertain it helps to know the outcome we desire. Then we can see if the decisions we made worked to get us to our outcomes, or not. We might need to make different decisions.

OK. Let's take a quick music break and let this sink in a bit.

#### Collaborative, Integrated Care Plans 10:04

In healthcare, the lists I mentioned a minute ago are known as **care plans**. Care plans contain tasks: Who does what? When do they do it? Did they do it? What gets in the way of doing it? Plans often lead to even more decisions. It's circular. Plus, most people make many decisions and have many plans, medical and non-medical. Some tasks in the plans are more important than others and some even conflict with one another. And plans change day-to-day. It's the rare person, no matter their status, expertise, or circumstances who can keep all their plans straight and up to date. We need help keeping it all straight, prioritized, tracked and shared with whoever needs to know when they need to know it. That's called a **collaborative, integrated care plan**. Most of these plans contain too much information for any one person to manage. I'm getting closer to Clinical Decision Support. Bear with me - almost there.

#### Control and Connection – the two C's 11:18

I want to add two C's to the three T's (time, trust, and talk). These two C's are **Control** and **Connection**. I'm interviewing people about learning to be CEO of their health for this podcast for a reason: A good CEO is in control of herself, her life, and her business. I'm more open to trusting when I feel like I have some control, some power. If I feel like an ant ready to be crushed by a big foot, I'm not in control, and I don't trust. I'm more likely to decide from weakness, "Yah, sure, I'll do that." Right. If I don't feel in control, even if it's on my list or my plan, I may do it once – maybe. But it would be like expecting to win the lottery to think I would do it twice. Control.

Let's add **connection** to the mix. Life is hard. I have a progressive chronic illness. You could say we all have a progressive chronic illness - aging. It's called life. *OMG, I'm not going to be as fit in ten years as I was ten years ago. Woe is me.* Absolutely, we can still have best health, live a best life, even if we have chronic illness or are aging. Yet most of us have bad habits, demons, frustrations, dips, and ruts. Connection helps us to keep moving forward with the tasks in our plans toward best health. Connection as in someone greeting you as you cross a threshold. Connection with someone who has lived experience and can inspire, share, partner. Connection to professional or lay knowledge about and experience in scary places. Connection - the kind you need when you need it to keep putting one foot in front of the other.

Now a word about our sponsor, ABRIDGE.

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#### Clinical Decision Support and Google Docs 14:29

Finally, now that we understand a bit about clinical decisions let's talk about **Clinical Decision Support** (CDS). There's a ton of data from many sources, people, and settings in the process of making

clinical decisions – research, plans, tasks, tracking, questions, answers, communication. CDS tools can help us find meaning in the firehose of health data, suggest next steps for treatments and habits, alert us to available information we may not have seen, or catch potential problems, such as errors or dangerous medication interactions. The only way to sift that enormous amount of data is digitally with technology. Experts in Clinical Decision Support (CDS) try to design, build, use, and sell electronic tools (which they call artifacts) to automate CDS. Remember, Clinical Decision Support informs someone on a foundation of shared decision-making and trust. CDS experts usually design artifacts for medical people to use, not patients and families. But, think about Google Docs. If Google Docs was designed so only bosses could read, write, suggest, and edit and not their staff, not much would get done. Look at error correction. What if errors couldn't be corrected? An important document could go out and decisions made based on those errors. Yikes. Think of health data and CDS like Google Docs. Permission to read, write, edit, suggest, and correct vary with the purpose and use of health data. There is no one-size-fits-all approach. Health data and Clinical Decision Support (CDS) technology affects everybody at the center of care (clinicians, patients, and people that support them) in intended and unintended ways. Think errors. CDS experts tend to focus heavily on technology and data. It's their expertise and comfort zone. But it's only a slice of the pie. They often don't know what they don't know. Do you know of any CDS artifact that's designed to correct errors? That's why people at the center of care should sit at the table when technology is being researched, designed, tested, and rolled out. Humans use CDS in their workflow and life flow. Without humans, the technology is useless. Nobody to use it. Without trust nobody will use it - also useless. The challenge for me in the Clinical Decision Support world is to encourage my colleagues to start with humanity, build stuff manually, and then apply technology. The tendency is to start with technology and add humanity when they discover it doesn't work, or they're underwhelmed with the use of the CDS artifacts. "We spent millions, and nobody uses it." However, I do know that the technology part of CDS is important stuff. I know the human part. That's my expertise and comfort zone. I only know enough to be dangerous about the technology part. I will invite a guest to discuss the technology piece in more detail on another podcast.

Now what? Putting it all together 18:14

In summary, we try to accomplish something medically and/or personally (outcomes). We make decisions, alone or with others. Some of us would like to make these decisions with our clinicians – shared decision-making. Most decisions contain some uncertainty. Research can help, sometimes. But there's too much research to manage alone. We need help making decisions, all of us – Clinical Decision Support. Decisions aren't the endpoint. Doing the work is. Plans and tasks help us do the work. Much of this happens whether we recognize it or not. Again, it's called *getting through life*. The three T's and the two C's figure in the mix. Also, whether we recognize it or not. Time, Trust, Talk, Control and Connection. Humanity and technology go together.

Reflections 19:34

So, what's my soapbox and what can you and I do because we care?

1. **Define success** before we start: Personal health goals, medical goals, or the quadruple aim? Pick some **outcomes**. Measure it before you start and along the way. **Adjust** when you're not getting there at the speed you want to. How can CDS help us measure and adjust?
2. We make decisions to try and reach our outcomes. Decisions lead to **care plans**. Decisions without **doing the work** leads nowhere. How can CDS help us create **integrated, collaborative plans** that inform doing the work?

3. **CDS** is for patients, direct care clinicians, and those that support them (**people at the center of care**). Include people at the center from **end-to-end**. End-to-end is the whole process of tech development - strategy through design, testing, production, dissemination, and evaluation. How can we scale end-to-end participation in CDS?
4. **Health equity** means everyone has the same opportunity for best health. Evidence, guidelines, and tools are usually designed and developed for specific groups of people in specific settings. Consider who isn't included and needs it. Design CDS for and include them as well.
5. Build without technology first to solve a decision-making problem people at the center need to be solved. Then scale it with technology. In other words, **human before technology**.
6. **Technology accentuates**. It can make good faster, and available to more people. It makes bad faster, too. Faster bad gums up the works, frustrates, and burns people out.
7. None of this works without **time, trust, talk, control, and connection**. These need to be part of the decisions, the plans, the technology, and the product.
8. **Participate** where you can. **Ask questions**, especially the dumb ones. Experts can forget about common sense.

And of course, drink plenty of clean water. If your kidneys are working, whatever you're feeling, will feel a little better with clean drinking water You've heard my spiel about water. It's relatively easy if you have plenty of clean drinking water. If you don't, #1-8 above don't matter. Just sayin'.

What do you think? Make sense? Talk to me.

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