One Patient’s Point of View

DANNY VAN LEEUWEN

Empowering people as they travel together towards best health
An action catalyst **empowering people traveling together toward best health, wears many hats** in healthcare:

- **patient** with Multiple Sclerosis,
- **care partner** for several family members’ end-of-life journeys
- a **nurse** for 40 years
- an **informaticist**
- a **QI leader**
- a **mentor** to leaders and advocates
- A **patient/caregiver activist**

Writing, speaking, and advising on learning what works for people in their health journey: informed decision-making, patient-centered research, communication at transitions of care, and technology supporting solutions created by and for people.
Determinants of Health
- Individual Behavior: 38%
- Social Circumstances: 23%
- Genetics & Biology: 21%

Medical Care
- Physical Environment: 7%
- 11%

To Read the Care Map in more detail, go to Health-Hats website:
Decision Making

Shared

Informed

Choices
Decisions take **time**

- Many decisions occur **outside** the office and away from the bedside
- A decision is just the **beginning**
- Clinical decisions are made in the context of a **trusting** relationship
- Decisions imply a balance of **power**
- Grease or sandpaper? **Technology** is not a substitute for time and relationship
People Need Information to Make Choices

I’m the child, Custodian and Healthcare Proxy of my 89-year-old mother, Alice. I live in a different state. My mother has diabetes and is depressed. Her care team, besides herself and me, includes medical providers in various health settings, community support agencies, and a full-time caregiver that helps her schedule and get to health-related services. My problem is to understand what my mother wants for herself and to track who says they’re doing something for her (including my mother and me), what they’re doing, and when they’re doing it. I want to know what it takes to do it (Can she afford it? Can she get there? Does it agree with her? Who will be with her? etc.). I want to know if the actions have the effects we thought they would. I want to know what her risks are and how we plan to prevent or respond to them. I want to able to keep track of all this and keep it current. I want to share it or have it shared from day-to-day and from setting to setting even if I’m not present. I want answers to my questions about what’s going on and how she’s doing when I have them.
Information People Need to Make Choices

- Care Team
- Personal goals
- Plan Who, What, When
- What does it take?
- Did it work?
- Risks – Prevent and Respond
- Up-to-date tracking
- Share day-to-day, setting to setting
- Answer questions when we have them
CDS Five Rights
✓ Deliver the right information
✓ To the right people
✓ Through the right formats
✓ Via the right channels
✓ At the right times

Thanks to Jerry Osheroff
One Size Does Not Fit All
People at the Center of Care Vary

**Patients**
(and those that support them)

- I’m the CEO of my Health Team
  Help me find several solutions to my pain, so I can live the best life possible

**Clinicians**
(and those that support them)

- The relationship with my patients is most important to me
  I want to know what works for my patients so I can share solutions widely.

**Less Engaged**

- Just give me a pill to eliminate the pain.
  There’s nothing else I can do

**More Engaged**

- Just get me through the day, I’m so tired
  I’ll write that script
• **Imagine** that you have **all the information** you need to make decisions about your medical treatment including cost of those choices.

• **Imagine** that you can talk about your **life's goals and challenges** and that your doctor can hear you.

• **Imagine** that you have **time to talk** and share with your doctor without distractions.

• **Imagine** that your doctor **trusts you to be the expert** about you.

• **Imagine** that you have a **care partner** who goes to doctor visits with you, listens and advocates for you.

• **Imagine** that you have **access to medical advice** and can get questions answered when you need it, in a manner that you can digest.

• **Imagine** that if you try something and it doesn't work, you can **adjust quickly** with your health team to try something else.
Advice from Patients Managing Pain

- Discuss **pain goals and concerns**, including financial & emotional
- **Describing pain** is frustrating and limiting
- Use **palliative care** experts
- **Compensate providers** for pain decision discussions
- Refer to **local non-medication** resources
- **Pay post-op patients** $200 to spend on a Pain Plan approved intervention if they don't fill an opioid prescription.
- Give a **list of evidence based non-pharm options** to every pre-op patient, and with every new opioid script
- Refer patient to **integrated BH support** to address coping skills
- Design usable pain **eJournal**
- Pain management is a **continual experiment**. Nothing works every time you’re in pain, including medication
Some people want drug free relief. Where is the evidence? Some want a silver bullet.
Expertise and Evidence

Patient Expertise

Life Goals
- Stay Well
- Get Over It
- Live Best Life
- Function
- Milestone
- Safety
- Relationships
- Spiritual

How
- Team Decisions
- Plans
- Share
- Learn
- Adjust

Medical Issues
- Cure
- Treat
- Prevent
- Drugs
- Procedures
- Therapy

Making Choices
- Individual Behavior
- Social Circumstances
- Physical Environment

Clinical Decisions
- Medical Care
- Genetics and Biology
What does the CDS Industry Need to Do?

1. **Step out** of the clinical, academic, technology frame
2. Promote **time** for and **trust** in clinical relationships
3. Listen for and study **non-medical, non-biological solutions** that work for somebody
4. Influence those allocating $$ to pay for **non-medical, non-biological solutions**
5. Everyone at the Center of Care needs **just-in-time information**
6. **Invite** people at the center of care to sit at the tables of governance, design, operations and learning
7. **Design for variation** in people, life flow, and workflow
8. **Enable** personal, clinical, and technological **continual learning**
You have all experienced pain.

What would you want your professional selves and colleagues to know as they design pain management clinical decision support?
THANK YOU

MORE RESOURCES:

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