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Through blogs and comments, patients and experts explore what it takes to find good health care and make the most of it.

Clinicians are from Mars, e-Patients are from Venus

Danny van Leeuwen | June 10, 2013



Are clinicians from Mars and e-Patients from Venus? My experience is that e-patients and clinicians can agree that they seek "best health". Yet there is such a disconnect, such frustration, so much of the time. Participatory medicine strives to bridge the gaps between patients, caregivers, clinicians and health care systems. Caring about best health and getting to best health are very different.

In my journey with multiple sclerosis I find that each member of my very supportive and effective health team experiences the elephant differently. My physical therapist's goal for me is to strengthen my left leg, ensure my ability to walk safely and balanced with a cane. My neurologist tracks my medication compliance and side effects, my limb strength, my brain scans, my exacerbations. My primary care doc tracks my weight, my immunizations, my cholesterol, my liver enzymes. My acupuncturist balances my chakras. My wife watches my mood, my balance, my energy level. For my 2 year old grandson, it's "Opa no go kaboom." My 4 year old grandson wants me to be a jungle animal with balance. The health team views me through the lenses of their particular profession, skill, and compassion. I care about all these things, but they are not me. The parts do not make the whole. Most important to me is that I can live life: be with my family, play music, work, think, write, contribute. I don't want to be more than a little bit of a burden.

Effective clinicians identify patient problems that they are trained to help solve, develop plans of care, track progress, and communicate in a hand-off to the next clinician or agency. Today's state of the art technology initiatives (such as Meaningful Use and Blue Button) are successful when they create usable tools for the listing, tracking, and communication of the problem list. Human success would be all health team members contribute to and track the same problem list. Clinicians look for and measure clinical outcomes – no post surgical infection, no readmission, up-to-date immunization, stable blood pressure, compliance with treatment regimen, no errors, etc.

As an e-patient my frame is my health goals and aspirations – maintain a weight of 170 pounds, play music 4-9 hours per week, spend time with at least one of my grandsons every week, travel several times a year with my honey, be pain free, not sad for more than a day at a time, experience no falls with serious injuries, and only short interruptions and minor embarrassments in my normal activity. My outcomes are life outcomes not clinical outcomes.

A pervasive gap exists between the way clinicians and e-patients approach best health: problem resolution and clinical outcomes (clinicians), goals, aspirations and life outcomes (e-patients). My health team knows about my goals and aspirations. I'm fortunate that I could find and stick with team members that appreciate this. We are aligned. I accepted walking with a cane, I started losing weight because my physical therapist and my PCP knew about my life goals and aspirations.

How can patients help their team use the frame of life outcomes? Patients will never think like clinicians. Can clinicians learn to think like patients? My friend, Rebecca Archer, a nurse, asks every patient, "What is the most important thing in your life?" Then she designs her care and services to help them remove barriers to attaining that goal? Is that cool or what?

How can we help clinicians to ask that question and manage the answer? Can we be in the same solar system?

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