

MY DATA & ME

Using readily available health monitoring devices to track and report real-time symptoms



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In the beginning: just keep moving!

- Cancer for IBC 2009
- Recovering my health afterward:
 - Formal exercise program at the hospital
 - Continued exercise after program ended
 - Up and down stairs at my office several times/day
 - Upkeep on my 4.5 acres and home



Down the “Up” Staircase

- Recovery? No! Continued decline.
 - As the months and then years rolled on, exercise, stairs and property upkeep more and more difficult
 - If I pushed on anyway, the resulting symptoms were hard to make sense of or manage.
 - Doctors didn't seem to believe statements about declining functional capacity.
 - They would run their little tests, which I always passed.
 - Then they'd enter the “normal” results and their judgment that I was “fine” into my medical record for all their peers to see.
- I knew they were wrong.
 - I didn't care what their tests said. I lived in this body, and I knew that something was amiss.



Faking It Became a Way of Life

- For 7-8 years, I sought an answer from various medical specialists. No answers were forthcoming.
- With each fresh declaration of my “good” health constituting yet another piece of my formal EHR, I went back to work, where I was now struggling to climb the stairs to my office.
- At home, things slowly fell into disrepair as I was unable to muster the energy and endurance to take care of the normal and necessary tasks in my life.



I'm faking being sick?
You must be confused, because what I'm actually doing is
Faking "being well"
I don't always talk about all my symptoms, I don't always admit when I'm not feeling well and I often put on a happy face because it's just easier that way.
@misswatches
Any idiot can fake being sick
IT TAKES REAL TALENT TO FAKE BEING JUST FINE WHEN YOU FEEL LIKE HELL.

I Think I Can? I Think I Can?

- Cutting down saplings with my chainsaw.
- Within 5-10 minutes
 - Heart racing
 - Breathing rapidly yet felt oxygen starved
 - Muscles weak and burning as if I were running a marathon
- Yet I pushed onward.
- After all, I was healthy, wasn't I? That's what all the doctors and their tests said! That's what my EHR said!



I Was Wrong

- Chainsaw kickback!
 - Only time in a decade of using this dangerous tool.
- If that chainsaw accident had been worse, I could have been dead.
- I was clearly *not* healthy.
- But just as clearly, I was on my own with all this.



Cardiopulmonary Stress Test

- March 2016
- My best effort. I pushed.
 - Predictably enough, in the end the pulmonologist, too, pronounced me healthy and fit.
- Yet I wasn't.



An Hour or so Later...!

- Same old post-exertion symptoms set in
- This time, though, a doctor knew how much energy I had just expended.
 - Would a doctor take my symptoms seriously, now?
- Message to the pulmonologist via my EHR patient portal:
 - Feeling very weak, rapid and shallow breathing, racing heart, cold from the inside out....
 - Explained this is a typical post-exertion reaction
- 20-30 minutes later, sent a second message:
 - Symptoms unabated
 - In fact, exacerbated with new ones:
 - Extreme weakness, shaky, a little spacey, weepy



But Remember...!

- I might get this one doctor's attention, but what would that mean in the long run?
- **None of THIS went into my official health record that would be consulted by the next doctors who opened my chart.**
- It was just a private communication between this one doctor and me.
- No way for it to be tracked as relevant data.



“Seeing” is Believing—This Time

- Doctor called me at home three times that night, trying to convince me to go to the emergency room.
 - I refused, because I knew from experience that these symptoms—whatever they were—were not a heart attack.
- So she looked at my exercise test results again.
 - A tiny anomaly suggesting a possible problem with my heart’s stroke volume?
- I promised I’d get a cardiology consult.



A Tale of Two Cardiologists

- Two different hospital systems in two different states, two different doctors, two different sets of tests (= \$\$\$).
- Cardiologist #1 (my regular cardio doc)
 - Maybe a little bit of left ventricular hypertrophy? (“Old Ladies’ Heart” = not very important)
- Cardiologist #2 (at a very highly regarded cardiology clinic in the US):
 - ***“There is nothing wrong with your heart.”***
 - “In fact, you have the heart of someone 10-15 years younger!”
- In short: still no answers....
I’m officially “fine.”



Sleep Apnea? No. But...

- Though sleep apnea already ruled out, friend advised me to get a pulse oximeter. So I did.
- O₂ levels great
- But HR had changed
 - Resting HR noticeably higher than during after-cancer exercise class just a few years earlier
 - Working HR changed dramatically:
 - Right after cancer: 120 bpm after walking 15 minutes on a treadmill
 - Now: nearly 140 bpm after walking up just one flight of stairs
- And the doctors said, “Eh....”
 - After all, my heart rate was fine when I was sitting in their office.
 - And, “You’re getting older, after all.”



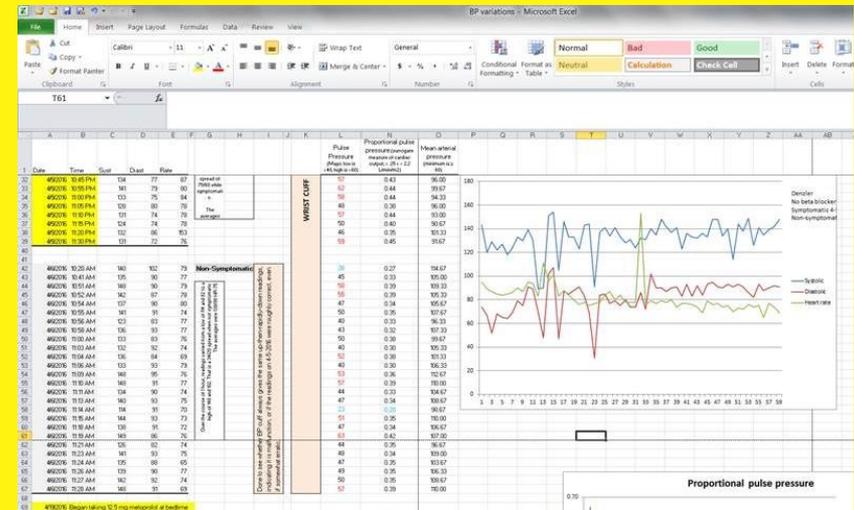
Blood Pressure?

- Another medically savvy friend: What's your BP during the worst of the symptoms? My excuse to shop!!
- Wrist BP cuff:
 - Post-exertion symptoms, BP was quite a bit lower than normal and my heart rate was quite a bit higher.
 - Doctors: "Eh.... Wrist cuffs are not very accurate."
- Shop again! An arm BP cuff:
 - Same post-exertion results
- Doctors: not convinced these instrumented observations medically meaningful
 - "Probably cheap and inaccurate cuffs"
- I calibrated both cuffs against the doctor's own equipment.
 - All three within a couple of points of one another
 - Doctors: "A couple of weird, one-off readings. Not too important."



Getting Deliberate & Systematic

- Began dedicated program of sequential (every few minutes), instrumented health data collection
 - During symptoms
 - Without any particular symptoms
 - Heart rate, BP, blood sugar, O2 sats, etc.
 - Bought new measurement devices to improve data
 - Kardia mobile EKG monitor, for elementary heart function info
 - Fitbit to track heart rate 24/7 & monitor sleep quality
- Compared all this data to baseline data gathered in the cancer survivors' exercise program
- Recorded it all in various places and ways



Result: Data Invisibility & Asymmetry

- **NONE of this data was entered into my official EHR.**
 - No place in there for patient-furnished data
 - All I could do was communicate it piecemeal to my doctors.
 - This meant that whatever I contributed was fated to remain in the invisible realm of “private communications”—not hard data.
- The result was **data asymmetry**:
 - I could (sooner or later) see the lab and imaging results that my doctors contributed to my health record, which made up the health profile other doctors and nurses would see.
 - They, however, could not all see the real-time data I was trying to contribute to the picture.
- Thus, I was the only one with a synoptic, global view of the problem.
 - Not surprisingly, then, I was the one who finally got some kind of handle on what was going on:



What I Discovered on My Own

- Upon exertion, for a few minutes my heart, lungs and blood vessels worked in concert to respond to the demand I was making of them and to keep me moving, just as they were meant to.
- Within a few minutes, though, my BP would start to drop.
 - I could lose 20-30 points of blood pressure in 2-3 minutes.
 - My HR would increase to offset the drop.
- The closer the numbers for my tumbling systolic BP and my rapidly rising HR got, the worse I felt.
- In addition, it felt like my breathing could never come fast and deep enough to give me the oxygen I needed at such times.
- It was quite miserable...and a little scary.



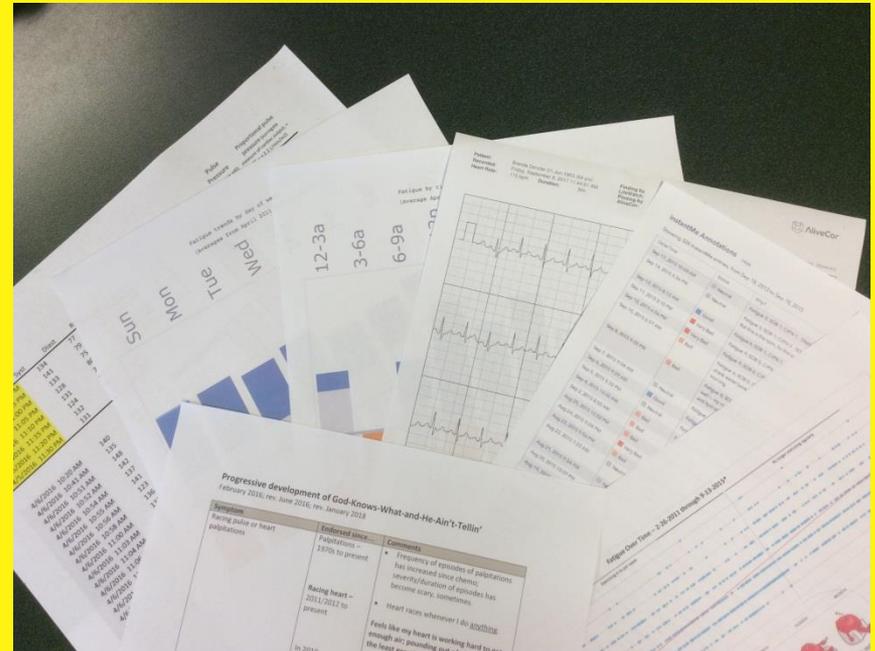
Nancy Saves Me Again

- Nancy had alerted me to my possible IBC diagnosis; now she saved me again.
- Exercising: after 3 laps around a small pond, I couldn't keep up with her.
 - “Your symptoms remind me of my neighbor, who has dysautonomia.”
- THAT was how I found a name that described the data I'd been collecting.



Grounds for a New Conversation

- Armed with my data tables, my graphs, my one-lead EKG readings, and a tentative diagnosis that could account for it all, I went back to my doctors.
- I knew more or less what was happening.
- I had identified a plausible diagnosis.



Maybe now, I hoped,
we could figure out how to make things better.



What I've Learned from All This?

- Convinced of the need for active patient involvement in the creation and maintenance of their health records, to-wit:
 - **First**, patients should immediately be able to see, comment upon, and easily submit addenda or corrections (if necessary) to any and all information entered into their formal health records by medical personnel.
 - Lab tests, imaging, visit notes, intra-operative reports, anesthesia records, pathology reports, nursing notes...EVERYTHING.
 - **Second**, they should have the ability to gather real-time health data on themselves and make it a part of their official, clinical medical record. (Not just “patient notes.”)
 - *This is my point here today.*



A Growing Trend = A Growing Need

- The fact is, people already gather health information on themselves.
 - Fitness trackers
 - BP cuffs, glucose monitors, pulse oximeters and even simple mobile, personal EKG devices – all of which are more and more affordable
- What all these people need is a way that **THEY** can organize their real-time data and make it a complementary, important part of their clinic-derived health data.



The Parameters

- Real-time, patient-generated data needs to be:
 - Preserved...
 - By including it in the clinical data part of the EHR, alongside the snapshot health data physicians typically get from in-house lab tests and imaging...
 - With all details available in spread-sheets and as quick visuals via graphs...
 - And as readily available and manipulable to patients as to physicians and other stakeholders



The Payoff? Partnering with Physicians to Improve Our Health Outcomes

- The nature of the physician-patient relationship has changed a lot in the last 50 years.
- The nature of the relationship between patients and their health data is changing, too.
 - More patient demand for accessing and managing their own doctor-generated medical info
 - More patient demand for generating & using their own health data, too
- All this = **Opportunity!**

But...Why?!!

1. Patient can add useful data as well as details about a particular health datum, like “after 10 minutes on exercise bike” or “after X medication.”
2. Patient can use the data to better manage their health conditions.
3. Patient can make sure their care is coordinated among various physicians.



Must We Only Dream?



Kevin Costner in "Field of Dreams"

If you build this kind of patient-driven functionality into EHRs, they will come!



Me, dreaming of my real-life, real-time health data being a part of my clinical record

