Designing Tools for Navigating between Our Health and Disease: Symptom Predictions and Return of Agency

(from prevention and empathy)

“Just listen to the patient, he is telling you the diagnosis”
- William Osler

Stephen Friend
Feb 8 2018
It would be nice if we could make individual assessments that could guide us.

It would be nice to find other individuals whose paths in their lives health/disease could inform ours- sharing.

It would be nice if we could learn how to nurture each other sharing data and insights so as to return to each of us “Agency” with empathy.

It would be helpful if we could provide ways for people to gain a sense of mastery around their health and act on their individual assessments.
health
health as absence of disease?
Wiring Diagram for 1940 Ford Passenger Car
Modern Practice
give up agency, in return for being healed
well  sick
let us consider alternate ways
to navigate between health and disease

let us find new ways to generate needed information

why not center to from and each of us
"Nothing we use or hear or touch can be expressed in words that equal what is given by the senses"

Hannah Arendt
the power of us with our sensor enabled devices
current efforts are offering better sensing, better data, more insights

enabling navigation of health and disease
Intra-individual Diversity
among patients with Parkinson’s disease

Changes

Pre Med Taps
Post Med Taps

Time

Significant Improvement with Medication
Marginal Improvement
Regression
Abstract

Using Instagram data from 166 individuals, we applied machine learning tools to successfully identify markers of depression. Statistical features were computationally extracted from 43,950 participant Instagram photos, using color analysis, metadata components, and algorithmic face detection. Resulting models outperformed general practitioners’ average unassisted diagnostic success rate for depression. These results held even when the analysis was restricted to posts made before depressed individuals were first diagnosed. Human ratings of photo attributes (happy, sad, etc.) were weaker predictors of depression, and were uncorrelated with computationally-generated features. These results suggest new avenues for early screening and detection of mental illness.
let us consider risks endemic in emerging digital health phenotyping
risks within existing health assessments
collect single or multimodal data streams
validate that device approaches match existing standards
use device approaches to guide existing therapies
assumes agent is the physician
assumes symptoms should be assessment currency

emphasis more on diagnosis that prediction

who says existing standards best anchor

aggregation to the mean smothers individual data
risks within existing suggestions
the purpose of the app is to collect data
data to be shared with physician
give “them” back data
soon AI will tell you what to do (autonomous)
who is it that actually needs to be able to take actions?

who says people will take heed?
Sub-Conscious

mind work

Conscious
Without Constraints
...at an individual's discretion

Parochial AI machines

v.s.

Central AI machine

As AI can gleans insights in health - who is looking out for whom, and for why?
shaping different ways of enabling people to navigate between health and disease
persuaders dream - individual’s nightmare
Considering Alternatives
A Personal Health Assistant

Allows you to understand yourself
self-navigate before and after symptoms arise
provides the freedom to act with more certainty
nurtures actions in times of strength
contributed by each for each other
Navigating Personal Health

some think humanity needs:
Google Earth for Health

provides a corporation’s world view
really hard (to build & maintain)
not what most people need

we think humanity actually needs:
Turn-by-Turn Directions

provides suggestions relative to individuals
better aligned with personal device capabilities
provides just the right amount of information to go somewhere
Fundamental Questions about Assessments:

move beyond one dimensional maps

find actions that modify disease (in whom)

find signals emanating from us proceeding symptoms

Fundamental Questions about Suggestions:

devices in realm of protecting vs entertainment-

apps to enable sharing fueled by empathy

limits to our devices enabling individuals to act
CRITERIA FOR DEFINING BOUNDARY CONDITIONS

FREQUENT TRANSITIONS

RAPID TRANSITIONS

RETURN TO STARTING STATE

TIED TO EXISTING CLINICIAN VISITS

NOT ENCUMBERED BY OTHER CONDITIONS

RELATIVELY YOUNG PATIENTS (FEMALE)
all-day sensing & recording

- heart rate
- breathing
- voice
- facial expressions
- app usage
- motion & orientation
Deep Learning
multiple stages of non-linear feature transformation

Feature visualization of convolutional net trained on ImageNet from [Zeller & Fergus 2013]
“Mimicking a user’s online behavior is far more difficult than breaking down a wall.”

TechCrunch, August 2015
“Next-Gen Cybersecurity Is All About Behavior Recognition”
scalable organizational construct

cohorts

data flow

device & apps

assessments

suggestions
CLUSTER OF SYMPTOMS

(in common among pregnancy and those receiving chemotherapy)

FATIGUE

EMESIS

GAIT

EDEMA

MOOD

COGNITION

GLYCEMIA
### Health Assessments I Signals to Symptoms (examples)

<table>
<thead>
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<th></th>
<th>Accelerometer</th>
<th>Gyroscope</th>
<th>Steps</th>
<th>Pedestrian Distance</th>
<th>GPS Vectors</th>
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<th>Messages</th>
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<th>Exercise &amp; breathe minutes</th>
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<th>Voice pitch</th>
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#### Cognition
- Decreased ability to navigate
- Driving slowly
- Decreased vocabulary
- Change in grammar
- Disruptive speech cadence

#### Mood
- Typing speed
- Decreased vocabulary
- Disruption of normal cadence
- Reduced social engagement
- Apathy

#### Sleep
- Sleep disruptions
- Sleep fragmentation
- Lower amount of REM
- Heart rate variability

#### Gait
- Gait speed
- Variability of gait
- Arm swing

#### Fatigue
- Heart rate
- Total activity
- Reduced mobility
1 → 3 Years | Linking Feedback Loops

Assessments
- cognition, mood, sleep, gait, fatigue

Guidance
- lifestyle suggestions: calm, focus, positivity...

loop 1

loop 2
“In an ever-changing, incomprehensible world, the masses had reached the point where they would, at the same time, believe everything and nothing, think that everything was possible and nothing was true.

Hannah Arendt, 1906 - 1975

Source: The Origins of Totalitarianism
For the things we have to learn before we do them, we learn by doing them

Hannah Arendt
Suggestions: High-level architecture

Build out playful spaces where people can explore and in doing so find the support they need to regain the agency they need to make actions.
The new always happens against the overwhelming odds of statistical laws and their probability, which for all practical everyday purposes amounts to certainty, the new therefore always appears in the guise of a miracle.

Hannah Arendt