'Health Data Obsessive Disorder'—A Modern Epidemic

"Low blood sugar" was his chief complaint, but Thomas was in my urgent care (UC) mostly because he was feeling anxious. It wasn't hypoglycemia that was making him nervous either. Thomas didn't have diabetes or take any medication for high blood sugar. Regardless, he was wearing a continuous glucose monitor (CGM), which he lifted his shirt to show me when I entered the room.

Thomas explained his primary care physician (PCP) had prescribed the device somewhat reluctantly earlier that week, and Thomas had deployed the sensor in his abdominal subcutaneous tissue the night before. He requested a CGM, he explained, because he had heard a podcast about how fluctuations in glucose might increase his risk of dementia. Thomas was 32 years old.

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Beginning that morning, he noticed that his glucose readings began to fall after his workout. He ate a normal breakfast, but the values continued to decline. They hit 75...60...55...and then the device just read "low." He drank orange juice throughout our conversation. I asked how he felt. "Anxious," he told me as his phone beeped and the device continued to flash "low." I could understand why.

Strongly suspecting erroneous readings, I asked our medical assistant to check capillary blood glucose (CBG) while I looked Thomas over. His CBG reading was 141 mg/dL from our device. I reassured him. This was what I expected: his device wasn't reading accurately. I told him it should be removed, and with some reluctance, he agreed. With only a short pause, he asked me, "But isn't 141 pretty high?"

Increasingly Affordable Devices

This story is not unique. The use of home health data monitoring devices of many varieties has increased rapidly over recent years, many without clear clinical indications. The COVID-19 pandemic fueled affordable finger pulse oximeters for home use with sales increasing by over 500% during the first quarter of 2020.[1] Similarly, in 2022, as many as 45% of Americans responding to a survey reported wearing a smartwatch (eg, AppleWatch, FitBit) regularly.[2] And, like Thomas, more non-diabetic patients are using CGM devices to track their glucose levels throughout the day.[3]

On initial appraisal, it's understandable that the lay public sees mostly, if not exclusively, upsides to the trend of increasingly affordable and portable health data monitoring devices. Certainly, there is an aspect of democratization with these trends; patients are now empowered to collect data that, until recently, was only obtainable with specialized equipment restricted to medical professional use. As these patient-facing devices have rapidly improved in both cost and accuracy, the question most often asked by device manufacturers, clinicians, and patients alike seems to be "How *can* we use these devices?" Yet, "How *should* we use these devices?" is discussed less frequently.

When it comes to data, the belief that more is automatically better is so widespread that few even recognize its presence.

Sigmund Freud introduced the psychoanalytical notion of defense mechanisms, which are unconscious behaviors we use to mitigate the pain of difficult feelings.[4] The urge to collect more data clearly is used by those like Thomas as a means of soothing fears about threats to health and death. Psychologists refer to this defense mechanism as intellectualization, and intellectualization can manifest in many forms.[5]

I share Thomas's story because it so clearly illustrates this phenomenon that has emerged as a predictable, natural result of this confluence of human psychology and technological progress. It's a situation that any clinician working in UC has undoubtedly encountered. Given

its increasing incidence, there's wisdom and value in developing a precise term for the experience I'm describing. As the adage goes in the mental health community, "you have to name it to tame it," and this form of neurosis has become so rapidly widespread that it deserves a label. I propose "health data obsessive disorder."

While health data obsessive disorder (HDOD) may not enter the next revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM), I'll offer a provisional definition here. HDOD would be classified as a subtype of obsessive-compulsive disorder, whereby those afflicted have persistent compulsions to monitor health data (eg, weight, blood pressure, heart rate, blood glucose etc.) in the absence of any clinically meaningful indication. Like other disorders defined by the DSM, HDOD can only be diagnosed if it matches the definition given, and the behaviors cause distress and/or impair function. Arguably, if the patient is sitting in front of you and fretting over data that you've assured them isn't worrisome, this would meet the criterion of distress.

Choosing Wisely

In 2012, the American Board of Internal Medicine Foundation launched the Choosing Wisely campaign aimed at "just distribution of finite healthcare resources" and avoidance of "superfluous tests and procedures." The movement has since spread through over 20 countries, and over 80 specialty societies have created their own Choosing Wisely lists of things that are not recommended. The movement was born from a recognition that unnecessary testing and treatment is very common and—worse than wasteful—it harms patients.[6]

While the Choosing Wisely movement has gained traction among clinicians, patient awareness of the potential harms of unnecessary testing is lagging. Think about the befuddled look on many patients' faces when you suggest that imaging for their acute low back strain is not helpful.

Catalyzed by the pandemic, on-demand, choose-your-own imaging study centers and mail-in kits for home lab testing have become growing trends in the United States.[7] This phenomenon is neither categorically good nor bad, however, the patients who utilize these services rarely become aware of the drawbacks of directing their own health data collection until they're alerted to "abnormal" results of uncertain significance. The more self-directed data gathering patients engage in, the more likely they are to get an unexpected result; hence, patients with HDOD, who are already more anxious about their health, are at the highest risk of such predicaments.

Given these trends, it is time for a sister campaign to Choosing Wisely directed exclusively at patients to raise awareness of the risks of excessive health data tracking without clinician guidance. At present, outside of individual interactions with clinicians, patients are only presented with marketing campaigns from the businesses promoting these products and services. A more balanced perspective is sorely needed.

Upsides of Widely Available Health Data Monitoring

Lest you think I have an entirely revisionist position on remote health data monitoring technology, I do feel it is worthwhile to define the benefits I see in these devices as well.

In the era before ubiquitous digitization, data collection and analysis were labor-intensive enough to be impractical, if not frankly disincentivizing. Challenges associated with patient data management, however, were not the only reasons why clinicians before the mid-20th century would have been dissuaded from emphasizing clinical metrics. The ability to accurately, affordably, and quickly measure vital parameters, such as blood glucose and oxygen saturation, which we now take for granted, were pipe dreams until recent decades. The pulse oximeter and glucometer, for example, weren't widely available until the 1980s and, as is the case with new technologies in medicine, early versions were costly and inaccurate.[8,9] Furthermore, the term "evidence-based medicine" was only coined in 1991, and the notion of using data collected in clinical research to inform clinical practice has only been widely accepted in the medical community in this century.[10]

During the pandemic, countless patients with chronic conditions who contracted COVID-19 were able to avoid seeking care in person by monitoring their respiratory status with pulse oximetry from home.[11] Patients with history of atrial fibrillation who wear AppleWatches can now determine when they've fallen out of sinus rhythm with reasonable accuracy.[12] And patients with type 1 diabetes who use CGMs have been found to have 30% fewer episodes of hypoglycemia than similar patients without continuous monitoring devices.[13]

Each of these examples represents specific clinical situations whereby patients, armed with easily accessible and relatively reliable data for clear indications, can make better informed decisions about treatments and care seeking. Given the recency and promise of these developments, enthusiasm for our capability to measure health data accurately outside of clinical settings is understandable. However, like any form of progress, there cannot be exclusively associated upsides.

Where Health Data Becomes Problematic

The first principle of diagnostics dictates that when we (or our patients) collect data that lacks actionable and meaningful value, attempts at interpreting this data will necessarily draw focus away from metrics with known significance.

To illustrate this, let's dissect an example we frequently encounter in UC and emergency medicine: lumbosacral imaging for acute, atraumatic low back pain (LBP). In the 20th century, with the advent of diagnostic radiography (XR) and even more so with cross-sectional imaging, such as magnetic resonance imaging (MRI), clinicians and patients saw hope for solving the ancient riddle of why people's backs hurt so often. And while such imaging studies have given clinicians and patients an abundance of data about the state of the spine, determining the significance of these findings has remained elusive. Clinicians' less-than-discriminate use of lumbar MRI in cases of LBP has generated abundant data, which tells a cautionary tale of the dangers of measuring before we know how to interpret.

New Data, Not New Insights

Degenerative disc disease (DDD) was a term scarcely used before MRI allowed vivid visualization of the intervertebral discs. I doubt doctors heard patients blame "degenerative disc disease" for their backaches before recent decades. But as the medical community began studying the issue, we discovered that degenerating discs are to the back as wrinkles are to the skin—evidence of aging and wear and tear, yes, but not necessarily the cause of pain. This insight, however, took years of real-world experience and focused research before we realized that the appearance of a patient's discs had very little correlation with location or severity of their back pain.[14]

This points to a fundamental challenge of data interpretation: differentiating signal from noise. When we receive data, we need to categorize each value as meaningful (signal) or meaningless (noise). Differentiating signal from noise, however, is not easy; it takes prolonged, intentional observation and analysis. We must continuously integrate our clinical experience with objective data from research studies. With this combination over time, we develop competence in identifying which of the countless datapoints available to us in each patient encounter we should be paying attention to and which we can safely ignore. For instance, it was long believed that chest pain relieved by nitroglycerin (NTG) was necessarily cardiac in etiology, however when investigated specifically, it turns out that pain radiating to both shoulders is the most predictive characteristic of chest pain presentations. Relief with NTG conversely has been shown to have no value for predicting whether acute chest pain is cardiac in etiology.[15] Without specific investigations into predictors of cardiac chest pain, we would likely continue to misclassify this data point, which itself only exists as the result of the use of specific healthcare technology (ie, sublingual NTG).

GIGO

You've probably heard the axiom "garbage in, garbage out," or GIGO. If we misinterpret data as signal rather than noise, it will likely result in errors in clinical judgment. Taking a patient for emergent coronary stenting despite a normal electrocardiogram because their chest pain is relieved with NTG, for instance, or performing a laminectomy on a patient because they have low back pain and a badly bulging disc on MRI are examples of how you may have seen GIGO play out clinically. In UC, I've seen GIGO drive many ED referrals related to erroneously collected or interpreted vital signs, such as a falsely low pulse oximetry reading in a patient with dark skin and nail polish or an erroneous determination of hypotension due to an over-sized blood pressure cuff.

A key facet of the examples above is that harm occurs without malice. In each case, a well-intentioned clinician misleads a trusting patient. The Hippocratic oath compels us to "...first, do no harm." There's no caveat for unintentional harm being excusable. But this is exactly the risk we take with our patients' well-being if we incorporate data of uncertain value into our clinical assessment.

What Makes Data Dangerous

In the evaluation of undifferentiated patients in UC, it is particularly tempting to grasp for as much data as possible, especially if seeking the particularly unlikely outcome of making a definitive diagnosis in a patient with vague complaints. This is the clinician-version of HDOD. I've previously discussed the pernicious and insidious nature of ordering non-specific tests (eg, complete blood count, metabolic panels) in the hopes of sorting out non-specific complaints (eg, dizziness, fatigue).[16] Such testing may reveal results outside the reference ranges, but these results rarely point to a cause for the patient's symptoms. The flagged results, however, do create situations where we feel compelled to act. This compulsion toward action is termed "intervention bias," and we face it both from within ourselves and from our patients.[17]

Let's consider a 2020 retrospective study of older adults with low back pain. The investigators found that patients who underwent early lumbar MRI (<6 weeks of pain) had

1300% higher risk of having spinal surgery and experienced worse pain scores a year later compared to similar patients who did not have an MRI.[18] This is a perfect example of how intervention bias plays out and leads to patient harms.

A patient has back pain and wants it "fixed." The clinician obtains data by imaging where the patient hurts. The MRI shows "degenerative changes" and "disc bulges." Since wanting to feel better generally is what motivates patients to seek care, they usually have a strong preference that something should be actively done to address their symptoms. We as clinicians are therefore motivated to act on abnormal data for several reasons: We want to do something to help our patients feel better, meet their expectations, and avoid blame from colleagues for not responding to abnormal findings. These factors dangerously converge to create a situation where patients are inadvertently put at risk for unnecessary hassle and expense; this is actually the best-case scenario. More commonly, however, the risks involve morbidity because the actions clinicians are compelled towards so commonly involve exposing the patient to more risks (eg, invasive procedures, surgery).

The United States Preventive Services Task Force (USPSTF) recommendations are largely based on a keen appreciation for this reality. For instance, serum prostate-specific antigen (PSA) testing was used for years to screen for prostate cancer. Observational studies, however, demonstrated that universal PSA screening led to increases in prostate biopsies and high-risk treatments for low-grade prostate cancer without corresponding improvements in morbidity or mortality. In fact, routine PSA screening was found to increase downstream harms associated with the understandable pressures to respond aggressively to abnormal results. This led the USPSTF to revise their guidelines and specifically recommend *against* the use of PSA for cancer screening, especially in men >70 years of age.[19] The harms of these false positive results aren't limited to the risks associated with subsequent testing and treatment either. Just ask any man who's received notification of a slightly elevated PSA. There is also considerable anxiety that patients face when confronted with an ambiguous, but potentially ominous, piece of data.

The Negativity Bias

With the development of new diagnostic equipment, both patients and clinicians are confronted with new types of data. When continuous telemetry devices became prolific in the 1970s and 80s, premature ventricular contractions (PVCs) were identified commonly in patients hospitalized for heart disease. Cardiologists presumed PVCs portended a poor prognosis and therefore should be treated with newly available anti-arrhythmic drugs like lidocaine. However, this assumption regarding PVCs was proven incorrect when the issue was formally studied years later—after many patients were exposed to unjustified risks of these potent intravenous medications.[20]

Not only is the intervention bias clearly at play when clinicians are confronted with new, abnormal, and ambiguous data, but another form of bias also contributes in a significant way: the negativity bias. Negativity bias refers to the tendency of humans to give disproportionate weight to anything which might be perceived as dangerous.[21] This bias probably conferred a survival advantage to our ancestors who assumed an unexpected rustling represented a hazard compared to those who ignored such possibility of peril.[22] This neurotic hypervigilance does, in fact, offer some protection against catastrophe, even if it is at the expense of peace of mind. A compulsion for certainty about the lack of danger when presented with ambiguous data, however, can quickly become a liability.

Indication Creep's Role

A relatively small subset of the potential clinical questions in medicine have been answered definitively–the value of aspirin for secondary prevention of myocardial infarction is one example. However, what about the healthy 45-year-old man sitting in front of you who's concerned because his father died of a heart attack? Would 81mg of aspirin a day be a good thing for him? The data is less clear.[23] Yet, we face these clinical conundrums continuously. This is where indication creep–extrapolating that testing or treatment proven beneficial in one group of patients will benefit a related, but separate group of patients–begins to influence our care.

Many factors predict the likelihood of indication creep, but perhaps the most impactful are affordability and accessibility. Let's focus on how these factors impact the use of diagnostic testing. Pulmonary embolism (PE) is a common consideration in a variety of acute presentations. Before the 1990s, testing for PE involved invasive pulmonary angiography or the use of the inconvenient and unreliable ventilation-perfusion scan. However, as computed tomography pulmonary angiography (CT-PA) became increasingly available, the use of this imaging study increased dramatically.[24,25] Ironically, despite increased testing and detection in the era of CT-PA, overall mortality related to PE has not correspondingly improved.[26] Indication creep, in this instance, has been facilitated through increasingly frictionless access

to CT-PA. Consequently, we've exposed lower and lower risk patients to large amounts of diagnostic radiation and questionably necessary anticoagulation and hospitalization (and, of course, worry) associated with the increasing number of irrelevant incidental findings and false positives.

The Hidden Cost of Higher Sensitivity

The rise in CT-PA use corresponding to increased diagnoses of small (ie, subsegmental) PEs also points to the final important factor contributing to the data problem we're discussing. Increasing the sensitivity of any test will not only decrease the rate of false negatives (the goal) but also, by mathematical law, necessarily increase the rate of false positives as well (the unintended consequence).[27] While optimizing for sensitivity to avoid missing diagnoses is prioritized by clinicians and patients alike for various psychological reasons, we are less inclined to appreciate the dangers of false positives until they are staring us in the face.

Perhaps nowhere is this phenomenon more apparent than in the practice of whole-body MRI for cancer screening. Patients, often those afflicted with HDOD, pursue this form of MRI imaging to allay anxieties about their health under the auspices of being proactive. However, incidental findings, which are rarely of clinical significance, are discovered with tragic frequency.[28,29] The same negativity bias that compels patients to undergo highly sensitive whole-body imaging in an effort to "miss nothing," usually will then compel those same patients to undergo invasive biopsy.

HDOD is a complex and novel problem that emerges from maladaptive psychological idiosyncrasies, advances in diagnostic technology, and elaborate direct-to-consumer marketing campaigns for health data monitoring devices. However, by labeling the issue, we take the necessary first step in mitigating its effects on the unsuspecting patients, like Thomas, who seek our assistance at the inevitable moments of perceived crisis. ■

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