REVIEW OF DISABILITY STUDIES: AN INTERNATIONAL JOURNAL
Volume 14
Issue 2

Forum - The Crip, the Fat and the Ugly in an Age of Austerity: Resistance, Reclamation, and Affirmation

Reclaiming the Margins in the Face of the Quantified Self

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Abstract: Through the lens of my own experiences with a chronic and painful condition, I consider the ways that quantified self devices and services normalize and classify, creating a new kind of relationship to our medicalized conditions. My project seeks to co-opt these technologies in the service of revealing proprietary and arbitrary translations relied on to make decisions using QS devices.

Keywords: quantified self, art practice, ethnography

Introduction

My diagnosis came from a doctor at Massachusetts General Hospital in August, 2010. She asked about my family and my love life, pinched my skin and prodded my scars, took copious notes, and then wrote up a thorough report with her verdict: Ehlers-Danlos Syndrome, a genetic collagen deficiency. The diagnosis was no real surprise—my sister, 12 years my elder, was diagnosed by the same doctor a year or so earlier. Her EDS had progressed beyond my condition at the time—her chronic joint pain, “stretchy” skin, and immunodeficiency were much more pronounced and took a more significant toll on her daily life. Our doctor, however, could not be more pleased with her recent findings: as a geneticist, having siblings present with similar symptoms at varying stages of severity was a goldmine of study fodder.

Until August 2010, Ehlers-Danlos looked like this: day-long (or more) pain after particularly strenuous exercise, scars that look like cigarette paper, “showing off” veins that bulge despite my non-muscular stature, skin that stretches further off my muscles than most, and limbs that bend awkwardly. A few weeks after my 18th birthday, my lung collapsed spontaneously. Later that year, I was diagnosed with Ulcerative Colitis, the kind of gastro-intestinally-based immunodeficiency often associated with EDS. For the years before and nearly a decade after, I simply considered myself an unlucky but relatively typical Ashkenazi Jew (I was often told that, “yeah, this sort of thing is common in white skinny Jewish boys”). But now there was a name for all of this, a doctor’s report, and an entry on the online medical reference, WebMD.

Efforts to quantify the body and self through the use of personal devices and services—efforts which are increasingly considered valid and valuable in medicine—are creating a new kind of relationship between ourselves and our medicalized conditions, one that leads to an exploitation of the self by corporate and regulatory bodies alike. I seek here to elucidate these exploitations through an autoethnographic pursuit that reveals the proprietary and arbitrary nature of the translations one relies on to make decisions in one’s life using quantified self devices. I use resources at my disposal as an artist, technologist, and scholar to consider questions of the hegemony of measurement and language, what it means to be in pain, and—most importantly—how one might reclaim our body from what I will demonstrate as a strongly neoliberal conceptualization of the self.

What follows is an exploration of my disease as seen through two self-health products built upon systems which collect and interpret data about the individual using them: 23andMe and the Fitbit Flex wristband. The project is informed by methodologies of visual and digital ethnography. The former, as outlined by Sarah Pink (2001), includes "the use of visual images in research and representation" (p. 31). And while the latter, per Pink et al. can incorporate the same methodologies as the former, it is complicated by the fact that digital technologies allow the ethnographer opportunities for mediation as well as observation (2015, p. 3). My project is further complicated by the fact that what is being looked at is not in itself visual representation, but a breaking-down of the technology used for that representation alongside a context of how that technology is designed, developed, and sold. As such, I utilize both code studies—wherein computer code is considered a "mechanical device for the production and consumption of verbal signs" (Aarseth, 1997, p. 21)—and material culture studies, understood by Pink et al. as based on an argument. The argument is:

> "That objects and things, the materials used to construct them and the properties of these materials are central to understanding culture and social relations: humans play as much of a role in the creation of objects as objects create the conditions of human life" (2015, p. 61).

All of this is being done in the service of subverting the biopolitical hegemony exercised by an assemblage of actors developing, designing, and selling products that purport to help me find the "one unique [me]" ("23andMe", n.d.-b) or to "find [my] fit" ("Why Fitbit", n.d.). At the outset, then, it is important to establish an understanding of what element of "me" I seek to explore.

Per Parapia and Jackson, individuals with (the yet-to-be-named) Ehlers-Danlos Syndrome were identified as far back as 400 BCE, when Hippocrates described a specific type of bleeding and bruising in his subjects (2008, p. 32). Twenty-five hundred years later, Edvard Ehlers (1901) and Henri-Alexandre Danlos (1908) began to connect formally the diagnosis of the condition to its symptoms: "lax joints, hyper-extensible skin and a tendency to bruising" (Parapia & Jackson, 2008, p. 32) and other various connective-tissue anomalies—all conditions that can be observed by a close physical exam (as opposed to being identified via, for instance, a blood test). Even after the genetic markers for EDS were recognized in the 1960s, EDS is still a disease diagnosed through observation and touch ("What is Ehlers-Danlos", n.d.).

If the disease is, in fact, hereditary, it follows that "seeing" one's genetic variants would reveal the presence of Ehelers-Danlos in oneself. This, then, is where my project begins: seeing the disease. What ethnographic methods are available to observe the presence of EDS in a subject? As the MGH doctor already demonstrated, poking, prodding, and interviewing are clinically sound approaches. But how might I discover, document, and understand a condition which is only barely perceptible to the trained eye? Corporations selling so called “quatified-self” devices or personal genomic services offer that their products will reveal insights not otherwise knowable or visible without the use their wares.

An Introduction to 23andMe

When I was diagnosed in 2010, Silicon Valley based 23andMe had already been collecting and genotyping human genetic samples for three years—though they were doing so at the prohibitively expensive price of $999 (Herper, 2011, para. 1). The company, which has received hundreds of millions of dollars in private investment (“23andMe”, n.d.-a), collects saliva samples from its customers via the mail and uses those samples to genotype each customer’s DNA. For some time, the resulting charts and graphs would include probabilities of being diagnosed with certain diseases (cancer, diabetes, et al.), chances of going bald, certain genetically determined physical traits, and other various facts (ancestry data, for instance) (Murphy, 2013). In late 2013, the U.S. Food and Drug Administration filed an injunction that prohibited the company from making disease-related predictions, though 23andMe and the FDA eventually agreed that reports could include carrier status and ancestry data (Ouellette, 2015). Under the Trump administration, the FDA loosened its regulations on how the company markets its “Health + Ancestry” kits, which, in late 2017, cost $199 (you can purchase an “Ancestry Only” kit for $49) (Keshavan, 2017). The kits act as a loss leader—the company believes that building as large a database as possible of genomic data will lead to profitability. Indeed, in early 2015, the biopharmaceutical giant, Genentech, paid $60 million for access to the genetic data of those “spitters” who opted-in to have their genome shared (at the time of the deal, that was 600,000 of 800,000 customers) (Herper, 2015; Ouellette, 2015).

In each human, one cell’s nucleus contains a three billion unit string of genetic data. Each unit on the string is a nucleobase represented by an A (adenine), C (cytosine), G (guanine), or T (thymine). Of those three billion or so bases, only ten million vary between individual humans; that is, 99.67% of our genetic data is identical to every other human. The ten million bases that vary, or single nucleotide polymorphisms, contain our genotype: the DNA data that affects how one looks or what diseases manifest in one’s body and so on. In an evolutionary biological sense, our genotype is what makes us “different” from one another. As of 2015, 23andMe's technology revealed the genotype of just over 600,000 SNPs (“Genotyping technology”, 2015).

My Experience with 23andMe

Understanding the technical details of 23andMe’s offering is critical to my project, especially as I consider the marketing rhetoric surrounding the product. On the 23andMe homepage for prospective customers (as opposed to those who have already spit), one learns that the company is “an experience that lets [customers] explore [their] genetics throughout [their lives]” and that “it’s just saliva” that makes the service work. The company promises to reveal the “one unique you” (“23andMe”, n.d.-b). On the “spitter”-facing site, those of us who have sent our DNA to the company (I did so in the summer of 2014) are presented with the lab-chic aesthetic of biomedical information design: simple in form and color, the work includes an integration of iconography with an emphasis on the graphical, rather than the textual, to convey a communicative goal, be it empirical observation, narrative, or instruction.[1]Pie graphs tell us the probability that I have dark hair or how likely it is that I consume more caffeine than the average 23andMe customer; ancestry maps connect me back to Neanderthals (via http://you.23andMe.com/ with a username and password).

Reviewing 23andMe’s marketing-speak alongside the technology behind its service highlights two poles on a spectrum: the colorful (literally) excitement of our results acting as the interface to the banality of saliva on a microchip. The data underlying the company’s inspirational rhetoric and seductive data visualizations can be described using Mathew Fuller and Andrew Goffey’s (2012) “grayness,” a concept they adapt from Primo Levi’s description of ambiguous internal politics in Nazi Lagers into a way to frame functionally banal technology. In their 2012 *Evil Media*, they write of grayness as, “A quality that is easily overlooked, and that is what gives it its great attraction, an unremarkableness that can be of inestimable value in background operations” (p. 11). The 23andMe designers, then, have taken the unremarkableness of one’s genetic data and dressed it in the excitement of an early-21st century biomedical startup.

Downloading and opening my 23andMe “raw data” file, I find 610,546 lines of text. On each line is tab-delimited data: an rsid (unique SNP identifiers), a chromosome label (1 thru 23, X, Y), a number representing the position of each SNP on my chromosome, and its genotype (a usually two-letter combination of A, G, T, and C). Considering my relatively new classification as an individual with a genetic deficiency, my immediate instinct is to seek out proof of my Ehlers-Danlosian status. I choose one of a handful of online genotype references, snpedia.com, and search for Ehlers-Danlos. The resulting page (“Ehlers-Danlos syndrome”, 2016) tells me that “EDS is caused by a defect in the structure, production, or processing of collagen or proteins that interact with collagen, such as mutations in the COL5A or COL3A genes” (para. 1). 23andMe allows you to search your data by gene through their online “raw data” interface, so I do this. Too many SNPs are listed to go through each one and find where my EDS is; the hints I do find seem too enigmatic to a non-geneticist such as myself.

Delving into their “gray media” concept, Fuller and Goffey are sure to point out that grayness does not indicate media which bears “some sort of hidden meaning that might be brought to light…but a certain recessiveness is often a crucial aspect of their efficacy” (2012, p. 12). The authors highlight this recessiveness as critical to their study and I will do the same here. Gray media is obfuscating: the rows and rows of text—be they genetic data, encrypted hex values (as I will demonstrate below), or the lines of code which generate these corpora—are not meant to be read by humans. They are banal in their obtuseness, lulling the brain that tries to read them into giving up. These are, to be sure, defense mechanisms; like the cephalopod’s chromatic camouflage, gray media stays unread as long as it is unreadable.

The Quantified Self

Keeping raw data and proprietary algorithms hidden as often as possible is key to protecting the intellectual property and “value-add” provided by corporations which sell products and services relating to the “quantified self”, or QS, movement.[2] The quantified self refers to the use of technology to track someone’s activity, health, or other personal metrics in order to improve upon quality of life. With roots in self-experimentation and self-science, the QS movement as understood today is built upon miniaturized electronic sensors—motion, temperature, and so on—embedded in consumer devices. This miniaturization requirement is critical to understanding why the market for these devices has grown exponentially in the past decade, especially alongside the development of high-density, cheap, and fast connected-storage technologies (often referred to colloquially as “the cloud”). When a device can log every minute movement, those data are relatively useless if they cannot be calculated and stored centrally. The same can be said for logging and interpreting 600,000 genotypes for over one million “spitters”.[3]

Until 2016, the majority of writing on QS was short-form—primarily works espousing the possibilities that the use of self-tracking devices and services brought to the fore. At the CHI 2014 conference, a group from the University of Washington, along with a number of researchers at Microsoft Corporation, produced “a qualitative and quantitative analysis of 52 video recordings of Quantified Self Meetup talks to understand what [participants] did, how they did it, and what they learned” (Choe, Lee, Lee, Pratt, & Kientz, 2014, p. 1143). Self-proclaimed “Technology Futurist and Academic Researcher” Melanie Swan published a number of papers between 2009 and 2015 which offer ways that the use of quantified self devices will “disrupt” (2013) or “crowdsource” (2012a; 2012b) health data . Professor in Communication at the University of Canberra in Australia, Deborah Lupton, has been similarly prolific, bringing a more academically-minded and sociological approach to researching the movement (2013; 2014; 2015).

By the end of 2016, however, a number of long-form scholarly works were published, each providing a range of theoretical and ethnographic explorations into QS. This collection includes *Self-Tracking* (2016) by a pair of American researchers, Gina Neff and Dawn Nafus, and *The Quantified Self: A Sociology of Self Tracking* (2016) by Lupton. These came on the heels of the Nafus-edited *Quantified: Biosensing Technologies in Everyday Life* (2016), an anthology of essays on self-tracking through varied lenses such as the social sciences, journalism, industry, and cultural studies. While these works are not necessarily historical in nature, they do note a relatively recent shift in a focus from “n of 1” studies—that is, tracking one’s own data for the purpose of one’s own improvement—into a more collective approach (measuring an individual’s data against an entire customer base, for instance). Lupton (2016) writes of a move to the “quantified us”, quoting a 2014 blog post by design consultants Matthew Jordan and Nikki Pfarr: “One of the ways…to have more impact [with QS], is to bridge the gap between Big [sic] and small data, and to heighten the collective relevance of the data we track about ourselves” (as cited in Lupton, 2016, p. 131).

The economics of scale provided by corporate QS systems and products, then, help make the data generated "valuable": albeit paradoxically, the quantified *self* depends on the actions of many *others* for "proper" scientific gains. In his 1981 article, "Self-Experimentation: A Call for Change," Allen Neuringer writes that in self-science, "as in science generally, progress depends upon the interaction between individual experimenters: to generate background information and hypotheses, to check results, to provide missing pieces for the puzzle" (p. 92). Thus, even though the quantified self movement was, for all intents and purposes, launched as just that—a movement—rather than "an industry", as Choe et al. note, barriers to finding value in the practices therein include the time, tools, and skills necessary to collect and analyze the data (p. 1143). These are all problems which corporate financing and market-based strategies can address.

Of course, there are problematics associated with the QS movement before or after the aforementioned barriers are overcome. It is not difficult to imagine some of these issues, especially in the case of 23andMe: a misinterpretation by corporate or consumer party, leading to taking drastic action (e.g., mastectomy in a perceived high-cancer-risk individual); an unauthorized third-party gaining access to one's DNA; or an *authorized* third-party using the data for surveillant[4] or nefarious purposes (denying insurance to a child due to her parent's carrier status). However, while these dystopian scenarios are certainly troubling, it is more productive to consider the greater power at work here.

In his essay, "How Should We Do the History of Statistics?", Ian Hacking (1991) highlights the bureaucratic power of statistics by referencing Michel Foucault's bio-power, or the state's control and discipline over the body:

> "One need not subscribe fully to this model [i.e., bio-power] to see that statistics of populations and of deviancy form an integral part of the industrial state. Such a politics is directly involved in capital formation through social assurance…" (p. 183).

Continuing on this theme, Hacking uses Marx's utilization of statistics in his own work when pointing out how statistical bureaucracy had changed the state: "It is a glib but true generalization that proletarian revolutions have never occurred in any state whose assurantial[5] technology was working properly" (p. 184). Hacking's piece was written around the same time as the publication of his larger work, *The Taming of Chance* (1990), which provides a more thorough investigation into the erosion of determinism and emergence of statistical powers of the state. But his essay is a good starting point from which to begin to consider the hegemony of statistics and how the grayness of large bodies of data may not only obfuscate to protect, but also to project an ora of truth. That is, if the file I download from 23andMe is too large to parse through myself, then the data within must be valid. As Chris Anderson offers, albeit facetiously, in a 2008 article in *Wired*, "With enough data, the numbers speak for themselves" (para. 7).

Another paradox presents itself: in QS-inspired "dashboards"—webpages with an overview of one's collected data, abstracted and interpreted to be most relevant to one's goals and motives—one finds the aforementioned seductive data visualizations. These graphs and charts are, purportedly, based on the troves of data sitting in a company’s database. The visual properties of the graphics, however, provide users with an abstraction that both makes the data more relatable and comprehensible than rows of numbers in a spreadsheet or database (see Neff & Nafus, 2016, p. 82; Kennedy & Hill, 2017, p. 2).

We are, then, at once seduced by the reductively simple and the overwhelmingly complex. And within this paradox sits our condition: our carrier status, our daily activity levels, our pulse, blood pressure, or weight. But who are the individuals who decide what to collect, how to interpret it, and in what form to display it? I wish to liken these individuals—product designers, developers, marketers, investors, and so on—to Elaine Scarry’s “torturers” as they turn a feeling or condition into something seen or heard, make it real, and take advantage of its apparent state. In her 1985 *The Body in Pain*, she writes:

> “If the felt-attributes of pain are (through one means of verbal objectification or another) lifted into the visible world, and if the referent for these now objectified attributes is understood to be the human body, then the sentient fact of the person’s suffering will become knowable to the second person” (1985, p. 13).

These torturers translate the intangible into the tangible, forcing its reconstruction in a purely visible form, giving us reason to doubt when a visualization may not adequately represent, to treat when a threshold is misplaced. Hacking (1990) shares a similar sentiment:

> “The erosion of determinism and the taming of chance by statistics does not introduce a new liberty. The argument that indeterminism creates a place for free will is a hollow mockery. The bureaucracy of statistics imposes not just by creating administrative rulings but by determining classifications within which people must think of themselves and of the actions that are open to them” (p. 194).

Once the bureaucracy of statistics is imposed, its subjects are objectified and normalized. They are stripped of agency and noted as a record in a database with millions of others.

My Process & Output

I return, then, to my search for proof of EDS within my 23andMe data. If I understand the larger implications of how power acts on me as a subject of 23andMe, why consent to having my DNA genotyped? Partly, I opted to send my saliva off to Northern California as research because I knew I could not critique a service from which I abstained. More importantly—and more difficult to admit—is that I harbored enough curiosity to submit (perhaps my two reasons are not that different from one another). Scarry (1985), once again, spoke to me: “To have pain is to have certainty,” she writes, “To hear about pain is to have doubt” (p. 7). After years of feeling as though there was something “different” about my body, I could finally “prove” it.

There was not much proof to be had—not, at least, in my 23andMe raw data file. The abstracted graphics on the 23andMe site proved even further from valuable: I *did* learn that I have the muscles of a sprinter (as opposed to a long-distance runner) without any warning of the long-term damage that said sprinting might do to my joints and tendons. I decided that, if 23andMe's version of the quantified self wouldn't indicate something critical which I already knew about myself, then perhaps I could express *myself* using my quantified self.

Neff and Nafus (2016) reference projects that "Satisfy aesthetic curiosity" (p. 80)—projects made by artists using data from their quantified-selves. These projects include Laurie Frick's "Frick Bits" (2014–2017) which use GPS data to create abstract patterns, as well as Stephen Cartwright's (1996–1997, 1999–ongoing) sculptural representations of his latitude, longitude, and elevation data. As Smith and Vonthethoff (2015) explain, some users of quantified self devices wish to go beyond the "self-knowledge" promised and instead construct narratives that can be shared in public space via the commonality of data (p. 12). I, however, was more interested in how I might be able to translate the data in a manner that would highlight its arbitrary and proprietary nature.

Putting 23andMe on hold for a bit, I began considering all of the devices and services available on the consumer market that would allow me to collect raw data. At the top of this list was the Fitbit—a wrist-worn motion tracker whose primary measure, "steps", has become a standard metric for most entry-level QS devices. If I sought out the *existence* of my Ehlers-Danlos Syndrome in my genetic data, certainly a device that measures my movement would help me "see" the *reasons* for my pain; my joints and muscles are loose and relatively slow to recover from trauma, often the loci of significant pain. Delving into my Fitbit data, then, made a great deal of sense. Secondly, Fitbit data is semiotically further from its referent than a service like 23andMe. Whereas genetic data represents a relatively widely accepted nomenclature (that is, the A, C, T, and G that makes up DNA), Fitbit "steps" are mostly engineered by the Fitbit Corporation. As such, I proposed, the data collected here would not be necessarily readable in the same way that 23andMe raw data was.

I was correct. Per the Fitbit website (though only in the Fitbit customer support section), the base Fitbit model (at the time of my initiating this project, this was the "Flex") uses one accelerometer—a silicon chip that can sense movement—which measures on three axes ("How does my Fitbit", n.d.). As the device is moved, Fitbit's software determines if a step has been taken. It then extrapolates the number of calories expended and distance traveled. This data is sent via Bluetooth, a wireless technology, to a smartphone or computer in an encrypted format using hex data—individual base-16 values equating to 0 through 255.[6] Software on the smartphone or computer then uploads this data to the Fitbit corporate servers, which are loaded with software to decode these hex values and store step, calorie, and distance data.

After wearing the Fitbit for a number of days, I began using software on my computer to intercept the raw data being communicated between the device and software on my laptop via Bluetooth. What I saw was a long list of base-16 values. These values, however, were not raw step data, perse. Instead, they were messages being sent in *encrypted* hex values—numbers being transmitted after being scrambled, only properly unscrambled via possession of a secret software-based key that exists on the Fitbit servers. After data was transferred from my wrist to my laptop, it was uploaded to those servers to be interpreted and added via database records. I could go to Fitbit.com and download a spreadsheet with the interpreted values (steps taken, minutes of sleep, minutes of strenuous walking, etc.), but nowhere could I procure the actual motion data collected by the accelerometers in the wristband.

In fact, this was exactly the scenario I was hoping for. By intercepting encrypted hex values, my step data lost all context. By definition, as digital data, the hex represented a set of numerical values which, in turn, could be used by any other program on any computer as long as that program was instructed to interpret data in the format I fed it.[7] For example, a basic computer image is made up of an array of pixels, each with three values—red, green, and blue—that range from 0 to 255. This system allows for millions of “RGB” combinations. Placing millions of those RGB combinations into a grid results in an image. In order to turn the step data into an array of pixels to form an image, I simply needed to arrange my Fitbit data in a specific pattern to convince my computer that it made up an image file. After one month of wearing and downloading data from the Fitbit, I had over 70,000 bytes with which I could build an image 88 x 268 pixels in size (see figure 1).

Figure 1

Image Description: Bitmap image made using Fitbit raw data. Each pixel is three sets of hexadecimal values, resulting in a seemingly random, but colorful pattern.

The image in figure 1 is, of course, nothing more than an array of three color pixels—the same as any image taken with a digital camera or scanned into a computer. The only true difference between figure 1 and those images is that the arrangement of pixels in those images make sense to the human brain. One recognizes patterns and sees their grandmother in the photo. In figure 1, I demonstrate the movement that a Fitbit measured from my wrist over the course of 30 days. Is this an any more “true” representation of me than the decoded step data uploaded via the Fitbit program on my laptop? Does it provide any more insight into my EDS than the line graph tracking my sleep cycles on Fitbit.com? It does not.

A number of my colleagues, when presented with figure 1, offered that I had “abstracted” the data, but I disagree. The hex data represented in the 23,584 pixels of figure 1 are no more concrete or abstract than the values which I had intercepted from the Fitbit—they are, in fact, the same exact values. Instead, what I seek to do with a piece such as this is to highlight the abstract nature of the metric being collected in the first place. Who decides what a “step” is? How do they identify a “lightly active” versus “fairly active” versus “very active” step? On a weather forecast, raindrops are present when the chance of precipitation is only greater than a certain threshold—in this case, what threshold delineates between “red” calories burned, “yellow” calories burned, and “green” calories burned?[8] I experimented with other forms: an audio file (that sounded much like the noise machine in a therapist’s office), a design in virtual 3D space (figure 2), and a 3D print (figure 3), all of which were built using my Fitbit hex values arranged in different patterns (though in the same order) and surrounded by different meta, or instructional, code. And all of which are useless as a means of training or diagnosis, but also completely valueless to those who may want to appropriate my condition for their gain.

Figure 2

Image Description: A thick line traces in three-dimensions in a computer graphic generated by Fitbit data. Each angle in the link represents a set of three hexadecimal values in the data set.

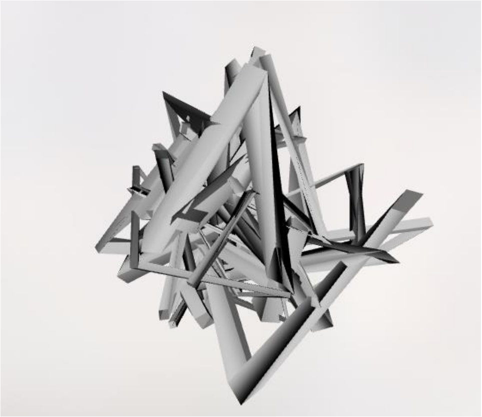

Figure 3

Image Description: Resulting 3D print of Figure 2 graphic. The lack of proper structural elements such as support posts means that the plastic filament produced a messy bird’s nest of think plastic string.

Inherent Contradictions Within the Quantified Self

I have already reviewed a number of paradoxical qualities of the quantified self movement: the simultaneous focus on self and aggregate and the reductivity of dashboards atop the complexity of datasets. One more glaring contradiction must be highlighted here, however. While quantifying the self is a practice that may trace back centuries (Neuringer, 1981) or even millennia (Swan, 2013), contemporary popular culture’s recent foray into the movement is often credited to an informal meeting of 28 individuals at the home of Kevin Kelly. Kelly, a noted neoliberal technologist, was also founding editor of *WIRED Magazine* and author of *New Rules for the New Economy* (1999) (“History of the Quantified Self”, n.d.).

It is no surprise, then, that so much of the quantified self discourse represents neoliberal tenets: remember 23andMe's consumer-facing homepage with its reminder that there are "23 pairs of chromosomes. One unique you." Or Fitbit's "Why Fitbit" page (n.d.) telling you to "Find your fit" and that "Only Fitbit gives you the freedom to get fit your way." Deborah Lupton (2016) agrees: "Self-tracking," she writes (p. 68), "Represents the apotheosis of the neoliberal entrepreneurial citizen ideal." Neoliberalism, as David Harvey (2005) notes in *A Brief History of Neoliberalism*,

> "requires technologies of information creation and capacities to accumulate, store, transfer, analyse, and use massive databases to guide decisions in the global marketplace. Hence neoliberalism's intense interest in and pursuit of information technologies (leading some to proclaim the emergence of a new kind of 'information society')" (p. 3-4).

It seems there is no better place for the neoliberal self to plan its success than in the quantified self movement. And yet, with all of the emphasis on the individual and their autonomy within neoliberal discourse, the quantified self depends highly on the aggregate. Further, an innate trust is required before sending one's spit off to a laboratory or uploading one's minute movements to an anonymous datacenter. For those with an ideological belief in the sovereignty of the self, neoliberals are extremely eager to hand that self over to other parties in order to become one in millions of other database records.

Resolving this contradiction requires a return to Ian Hacking, though this time in his much broader work, *The Taming of Chance* (1990). In the introduction to a chapter entitled "The Autonomy of Statistical Law," Hacking quotes Francis Galton, English Victorian scientist, mathematician, and father of eugenics. During a speech to the Royal Institution in London in 1877, Galton discusses normal distributions—statistical samples which fall in a predictable bell-curve—in relation to evolution. He speaks of "the ordinary genealogical course of race" and how outliers die "away at the margins…the scanty remnants of all exceptional members…revert to…mediocrity" (cited in Hacking, 1990, p. 180). Statistical laws, Galton says:

> "Show us that natural selection does not act by carving out each new generation, according to a definite pattern on a Procrustean bed, irrespective of waste. They also explain how small a contribution is made to future generations by those who deviate widely from the mean, either in excess or deficiency, and they enabled us to discover the precise sources when the deficiencies in the produce of exceptional types are supplied, and their relative contributions" (cited in Hacking, 1990, p.180).

Hacking begins his chapter with this passage in order to illustrate how the laws governing statistics extend beyond prediction into explanation—that is, it becomes easy to observe a statistical data set and see cause rather than recommendation (p. 182). If natural selection expects a regression to the mean (or, in the parlance of Francis Galton, a reversion to mediocrity), then both the deficient and exceptional must be jettisoned. Normalization as survival of the fittest, one of neoliberalism's most important ideologies and, in this context, a pitch-perfect example of Foucauldian biopower.

Neff and Nafus resist the use of biopower in an evaluation of the quantified self:

> "While we take the [Foucauldian] scholarship seriously, the clinical view is not an unreasonable one. It argues better decisions are made, physiologically speaking, when standard medical knowledge—the outcome of collective empiricism—is disseminated through the use of self-tracking devices" (2016, p. 52).

Their use of "collective empiricism" here refers to a concept from historians of science Lorraine Daston and Peter Galison as the pair explain a nineteenth century drive towards an unbiased, objective observer in science (Neff & Nafus, 2016, p. 50). Placing the type of data collection and analysis necessary for the success of consumer QS devices in the realm of collective empiricism, however, reveals a reliance on statistical technologies that normalize (the bell curve, regression, et al.). As disability studies scholar Lennard Davis (2006) writes, "The average man, the body of the man in the middle, becomes the exemplar of the middle way of life" (p. 5).

Pain, on the other hand, is exceptional. Chronic illness is an outlier. And to be sure, Neff and Nafus do not deny this. In their account of Nafus's use of a Fitbit during her rehabilitation from a knee injury, the authors reveal (2016, p. 41) that "she decided that 3,000 steps was an appropriate level of activity for someone with her type of disability"—drastically lower than the 10,000 step standard preprogrammed into every Fitbit device. They go on to note that, in their research, the Fitbit user who had *not* had an injury in recent years was the outlier. Injuries and disabilities are conditions, however, that resist the mean, and, as such resist expression in systems where regression is favored. "Whatever pain achieves," writes Elaine Scarry, "it achieves in part through its unsharability, and it ensures this unsharability through its resistance to language" (1985, p. 4). The standard off-the-shelf Fitbit or 23andMe package has no language to express a condition such as Ehlers-Danlos Syndrome. It becomes the role of the diagnosed to find a means to express their situation.

Viewed through the lens of an ethnographic practice, however, supplementing data-collection with self-reporting is nearly a requirement. As anthropologist Rosemary Blake (2011) writes:

> "The view of the researcher as necessarily subjective has led to the practice of reflexive extrapolations within ethnographic writing becoming almost an ethical requirement (Clifford and Marcus 1986) whereby anthropologists write against the representation of the anthropologist as all-knowing and unbiased. Formerly taken-for-granted notions of knowledge have come under scrutiny with anthropologists such as Michael Jackson using a focus on experience to challenge the notions of 'determinant systems of knowledge' (Jackson 1995: 160) espoused in positivist disciplines and sometimes implicit in the anthropological enterprise" (2011, sec. 2, para. 4).

Is there a more positivist practice than the quantified self movement? Rarely, if ever, can one find a “subjective” practitioner in the rhetoric of QS products and services. Instead, the emphasis is on the autonomous self, using the tools at their disposal to achieve “success” through some sort of quantifiable “experience”.

Further, an ethnographic practice that takes into account that multi-modal representations of the same information will strengthen resistance against the positivist disciplines. If, as Scarry writes, pain (and, by extension, other conditions nearly imperceptible by the QS devices and services) resists language, then our ethnographers must do all they can to liberate that pain outside of traditional language. Documentation of pain or illness will not relieve it biologically. But does the subject seek relief?

Returning to my own condition, I do not. I am fully aware that the way I sit, the way I walk, the things I carry, the frequency with which I carry them—all of these and more will effect the pain I feel. I could track my movements and more with a Fitbit or a notebook or a spreadsheet. I could pinpoint exactly how many pounds I lift in a day or how many steps I take and then try to correlate this to how intense my pain is the next day or longer. Remember, however, that the expression of pain in a means exploitable by the torturer threatens our patient’s subjectivity—something I value more than the relief of the pain itself.

Conclusion

This work is part of a larger project focused on questions of the medicalized self, with a distinct direction towards unsettling the power held by statistics and language, both pillars of the quantified self movement. These pillars are important in building a case for certitude: if it looks and sounds true, it must be. Ethnographic filmmaker, Paul Stoller writes:

> “[Jean] Rouch used a "cruel" epistemological acrobatics to tack between the sensible and the intelligible. Perhaps the way to the future of the human sciences is to follow Rouch's "cruel" path and confront the sometimes inspiring, sometimes fearsome world of incertitude” (2010, p. 133).

It is quite likely that Stoller’s vision of an uncertain sciences is just as utopian as the privacy warnings surrounding the QS movement are dystopian. As an artist and scholar, I am willing to heed both visions.

Tremain (2006) argued that, “Technologies of normalization facilitate the systematic creation, identification, classification, and control of social anomalies by which some subjects can be divided from others” (p. 186). This is an excellent summary of why products like 23andMe and Fitbit—products that rely heavily on the normalizing technologies of statistics such as the bell curve—must be understood through the lens of biopower. Later in her piece, Tremain reminds the reader that it is dangerous to focus so closely on an individualized conception of the disabled person, especially as neoliberalism attempts to use individualism as a smoke-screen for biopolitical control. The kind of reclamation of the self through subversion of QS devices that I propose and attempt here must be seen, then, as a collective goal—not the exercise of downloading and translating Fitbit or 23andMe data, per se, but the understanding of QS as problematic that comes as a result of this exercise. I offer these Fitbit "hacks" as a starting point to the same sorts of actions taken by the feminist self-health movements of the 70s and those of the AIDS activists in the 80s, and 90s:[9] the former preached self-experimentation and exploration (Ruzek, 1978) while the latter argued for inclusion in public health discourse through better knowledge of how that discourse operates (Epstein, 1996). Especially in the case of the AIDS movement, finding transparency in the systems of medical research and pharmaceutical development was of critical importance for its success (Epstein, 1996). It is my hope that the opaque and surveillant nature of the quantified self movement that I have demonstrated will inspire a shift away from the willingness with which bodies—both disabled and not—are offered to corporations promising knowledge and freedom.

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Endnotes

1. The preceding describes marketing copy and imagery from the 23andMe.com homepage in May 2016. A review of past homepages—possible via the Wayback Machine at archive.org—reveals that the basic message ("one unique you") has not changed drastically in the decade since the website first launched.

2. I use the lowercase "quantified self" here, as opposed to "Quantified Self", as to delineate between a broad cultural phenomenon and a branding effort on the part of its progenitors and device manufacturers.

3. It is, perhaps, a bit controversial to include 23andMe as a product used in the same vein as other quantified self devices and services. On the one hand, the service collects, interprets, and displays a user's data for the purpose of making changes towards a healthier lifestyle. On the other, the data will never change, and so it does not necessarily allow for "self-tracking". As the primary "material" of this project is data, the categorizing of 23andMe as a quantified self service makes sense.

4. See 2017 reports that police can request data from services such as 23andMe.

5. Hacking here uses the term assurantial to refer to "what Daniel Defert calls a technologie assurentiel which has to do with providing [or, assuring] a stable social order" (Hacking, 1990, p. 183)

6. Base-16 numbers are represented by 1-9 and A-F, allowing for digits which represent 1-16. Just like in base-10, which is the system with which is most familiar, multiply the left-most digit by 16 and add to the value of the digits to the right, and so on. For example, 11 = 17, AA = 170. As such, the system can store values ranging from 0 to 255 in just two characters.

7. Every modern computing system is driven by technology which interprets base-16 values as "commands".

8. Fitbit's online dashboard changes the color of your calorie burn value based on how many you have burned—from red (low) to yellow to green (high).

9. While the literature on both of these is extensive, for a good starting point, see The Women's Health Movement: Feminist Alternatives to Medical Control by Sheryl Burt Ruzek (1978) and Steve Epstein's Impure Science: AIDS, Activism, and the Politics of Knowledge (1996).