

Issue 1

TRANSFORMATIONS**Their Data, Ourselves: Illness as Information**

Rebecca Munson

October 2020

[doi:10.5281/zenodo.3713678](https://doi.org/10.5281/zenodo.3713678)

When I was growing up I liked to read about dying children. I'm not talking about the Victorian orphan kind of dying, not the dying of storybooks, but children who were terminally ill.

I was twelve and fixated on books written by an author with the improbable name of Lurlene McDaniel. The first book I encountered was *Six Months to Live*, which chronicled the life of a popular teenager in the wake of her diagnosis with leukemia. Not all of McDaniel's characters had cancer; they wrestled with all kinds of chronic illnesses (cystic fibrosis, hemophilia, diabetes) as well as the untimely death of loved ones from causes including suicide. McDaniel's books were about grief and communities formed through crisis.

These books would have been perfect for a budding hypochondriac, or for a reader inclined toward purple prose and melodrama, but I read them instead for medical details, taking mental notes on how to recognize signs and symptoms and stockpiling already-outdated knowledge about treatment options. Rather than imagining myself as the sick main character, I occupied the position of the doctor, a role I planned (at the time) to take on later in real life. It turned out, though, that I would have to be the protagonist anyway.

I was diagnosed with Stage 4 breast cancer in January 2019. I was thirty-four at the time, with zero family history and no warning signs aside from the lump I hoped fervently would be a cyst. Immediately, I was launched into a world at once familiar and alien. I had grown up among doctors and research scientists in the orbit of Washington University School of Medicine, largely because my father is a medical ethicist with an abiding interest in the practical applications of his work. I had even worked in a research laboratory there from ages sixteen to twenty, studying —of all things—the genetics of breast cancer.



...my best chance at coping with cancer was to make sure I was a research subject, to transform my body as rapidly as possible into the right kind of data.



Is it any wonder, then, that I investigated my treatment options as though I were the PI on an exploratory grant rather than a cancer patient? The type of breast cancer I have (triple negative) is particularly rare and intractable. At the time of my

diagnosis it had already progressed to its most advanced stage with metastases to lungs, liver, and bones. It was immediately clear that finding promising clinical trials would be my best

option. My parents and I (all academics) and circle of friends (ditto) kicked into research mode, scouring databases and firing off emails to friends from conferences, people from our past, even casual acquaintances who might have a line on newer, more successful treatments. The numbers were not good. We wanted some better numbers.

As I made phone calls to oncologists and combed through the clinical trials database, I performed a distancing maneuver that I first began practicing when reading Lurlene McDaniel; I became a clinical observer of a diseased body, only this time it was my own. I mentally dissected it, narrowing it down to the cancerous focal points that became all that mattered. I lay repeatedly in CT and MRI machines and held my breath through biopsies with only local anesthetics, willing myself out of the body I was at the same time trying so hard to save.

I became at once both object and analyst, alienating my self (with her feelings about her body and her illness) from my body as a source of information about potential causes and, hopefully, potential cures. In some ways it was the extreme of Cartesian dualism—I would think as the large magnets in the MRI machine echoed all around me—that my consciousness should roam so freely while I tried my hardest not to move a muscle in order to produce as clear an image of my body as possible. I was the mind-body problem made flesh, and then abstracted from flesh into numbers that could be either parsed by a machine or interpreted by a human.

Where did this data sit on the spectrum of mental and physical properties? My cancer was physical but, like an electron or snippet of DNA, it was not directly observable without the aid of technologies nor communicable without the intervention of an interpreter. In each of the two trials in which I've been a subject I have contributed both pieces of my body—samples of tissue to be used at the discretion of researchers—and data generated from it. Because I am a participant in clinical trials, the status of my embodied data possesses an enduring significance, since it has the potential to influence the funding and availability of future cancer therapies, even the lifespan of future patients.

We all agreed that my best chance at coping with cancer was to make sure I was a research subject, to transform my body as rapidly as possible into the right kind of data: not a mortality statistic but an experimental resource.



Cancer is invisible and so are data.

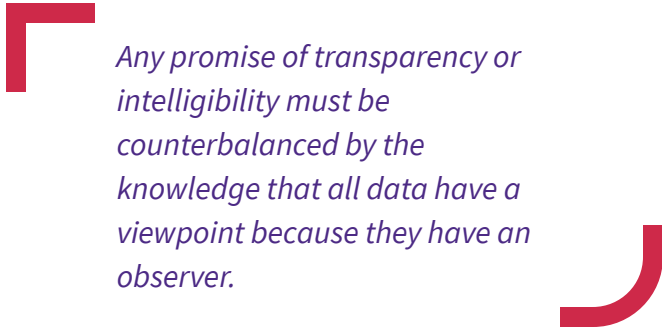
Neither exists in the sense of being detectable, nameable, or identifiable until plucked from their surroundings and marked out with a significance determined by the observer. The observer marks a data point as distinctive, distinguishing the “that” from the “not-that” of everything around it. Even if a data point is meant to be representative, to stand in for a larger phenomenon, the act of selecting it renders the data point distinctive. The data you select—and the data you don't—say something about you as well as about them. Data are not objective phenomena. It is for this reason that digital humanities scholar Johanna Drucker has suggested that it is perhaps more accurate to think of data as *capta* to indicate their situatedness—that they are seized and, from the moment of demarcation, imbued with an interpretive viewpoint.¹

The introduction of the interpretive viewpoint in medicine is called diagnosis. During the initial diagnostic phase, as I received phone call after phone call with more bad news, I spent some time thinking about how “diagnosis” sounded like a term familiar to me from my PhD in

Renaissance literature, one that showed up mostly in discussions of tragedies: anagnorisis, meaning “recognition,” referring to the moment of a critical discovery about a character’s own circumstances.

You will not recognize that you have cancer until someone tells you. You may have a suspicion that something is not quite right, but you require professional assessment. Assessment comes in the form of quantification, which requires abstraction. Your physical body is transformed

into radiological images by technologies that allow trained specialists to measure and quantify, to compare averages and standard variations, and to relay that information back to you in language that leads, invariably, to another set of numbers concerned with averages and likelihoods. Where is the line between “normal” and “pathological”? In whose view is a treatment “better” or “worse”? When the questions are of life and death, it is more than a little disconcerting to realize that the answer depends very much on who you’re asking.



Any promise of transparency or intelligibility must be counterbalanced by the knowledge that all data have a viewpoint because they have an observer.

Cancer exists before it is named, just like data. And even at its moment of detection (capture) its fixity is illusory: it is in cancer’s nature to grow and change, just like data. The moment of visibility for both is firmly situated in time, place, and the subject position of the interpreter. Take, for example, the open question of how extensively cancer may have spread to my liver. Unusually for my age, I was actually tested for cancer in 2016, in search of answers to a years-long chronic fatigue for which I still have no good explanation. The bone marrow biopsy showed no cause for concern and even though there was a lesion on my liver, measuring 29 mm x 28 mm, the conclusion was that it was a benign growth called a hemangioma. (I stand by this view, if only because a cancerous growth on my liver, a canary in a coal mine, would have become significantly worse over the course of three years given how aggressive cancer has been elsewhere in my body in the time since my diagnosis.)

My first CT after diagnosis in January 2019 showed the liver lesion to be 29 mm x 35 mm, a finding that the radiologist remarked might represent growth (and therefore metastasis) or might not, since a difference of 6 mm could be caused by different positioning during the scan or different measurements by different doctors. The lesion continued to remain stable on my next CTs, but in March 2019 an additional spot was detected on the right inferior lobe, measuring 12 mm. By June 2019 that spot was reported to be 28 mm, confirming that my liver had been affected. In December the second lesion was measured under 5 mm, part of a larger pattern of regression that meant the treatment was working (which it had been doing but would not continue to do past that month). A third spot on the left lobe was recorded in three scans, showing up as 5 mm August 2019, 4 mm in September, and 3 mm in November. By December that third spot went unremarked. The large lesion from 2016, however, merely waxed and waned, never clocking in at more than 35 mm or fewer than 27 mm, numbers easily attributable to variation in imaging or interpretation.

So was the original liver lesion a benign hemangioma, a coincidence unrelated to the cancer that would metastasize years later, or the first sign that a breast cancer concealed in single, unmassed (and therefore undetectable) cells had already done so? Did the 2016 scan produce

bad data, or rather bad *capta*? Was the interpretation of the image biased by the fact that I was young (thirty-one) and, aside from mysterious, debilitating fatigue, healthy? Should I have acted differently? Should my doctors? The ramifications of these questions for my diagnosis and emotional response to it are profound: a cancer that had been present since 2016 would look relatively less aggressive compared to one that was new as of 2019; being misdiagnosed and living with cancer for three years would compound my fear (and guilt) that my situation was preventable.

There is no way to know, though the probability is strong that the first lesion was and remains benign. But that uncertainty is the constant condition of the body as data. Any promise of transparency or intelligibility must be counterbalanced by the knowledge that all data have a viewpoint because they have an observer.



In *The Undying*, her account of treatment for triple-negative breast cancer, the poet Anne Boyer writes that “a patient is a system-containing object within a series of interlocking systems full of other system-containing objects” and that “to take a thing or set of things from one system and reclassify these as elements in another also resembles diagnosis, which takes information from our bodies and rearranges what came from inside of us into a system imposed from far away.”² Cancer is caused by the body’s own cells growing out of control, a hostile takeover from within that violates the rules of the system already in place. Reclassified, your own cells are a disease and your own body a weapon. Reclassified, you are not an individual but a patient and your body not a collection of sensations but a rich mine of information.

Living your life as medical data is an alienating experience particularly if, like me, you look bad on paper.

Once you enter the systems of modern medicine you become data to be ingested, part of the larger dataset of those who have previously been ill, been treated, and lived or died. This is not the “violence of abstraction” of

which Marxist theorists wrote, yet the phrase seems equally applicable to the anonymity—the interchangeability—of those subsumed by the medical-industrial complex. Part of the reason that I sought clinical trials was that I felt that it was the best way to enable physicians to see me as an individual whose life, and whose treatment, mattered. I was eager to make myself an object of study and contribute to thwarting the disease that is threatening my life. But I was equally eager not to be simply tagged, processed, and swept through the prescribed (and not very promising) series of treatments that constituted the “standard of care” for my type of cancer.

Living your life as medical data is an alienating experience particularly if, like me, you look bad on paper. Boyer describes herself as “a patient made of information, produced by the work of women,” remarking on the “paradoxical simultaneity” of the care work and data work performed by the overwhelmingly female nursing staff in their interactions with patients.³ It is crucial to focus on the significance of the word “made” here. None of us exist as free-floating data points; medical data are *made*, are in fact *capta* that depend on nurses and technicians, radiologists and pathologists, and, perhaps most of all, on patients.



Cancer is invisible, and so are viruses.

I have worked on this essay over the course of the COVID-19 pandemic. I began it in March 2020, days after my workplace went remote and fourteen months after my initial cancer diagnosis. It is now October 2020, my third line of treatment has failed, and I am moving on to another. The pandemic still ravages much of the country. Conceiving of bodies as “made of information” (and participating in the quantification of illness and the violence of abstraction that accompanies this process) has become a national way of life.

I have lived nearly two years tolerating the same kind of existential uncertainty and fear of an alien invader in the body that the world as a whole is now experiencing. I have played my own doctor, watching my body for signs that a treatment is working, or that it is not, in much the same way we monitor ourselves for symptoms. I have tried to anticipate what will happen if I become severely immunocompromised and have given up many of the pleasures that made my life better before (traveling, going out with friends) in the name of my health. I have offered my body up as data to research scientists with the goal of furthering not just my own treatment but survival prospects for the future.

I did not know that I was in training for a time when we would all of necessity be regarded as bodies with the potential to produce valuable data about the spread and effects of COVID-19. We are constantly starved for numbers, for data on infections and recoveries and for statistical models that may relieve us of the uncertainty we feel about the future. I cannot provide that. But I can tell you to be cautious readers of data and statistics that speak with any pretense to authority right now, even though I crave them too.

We are in the middle of the data. Some of us clamor loudly to be heard, to be seen and counted by institutions that deliberately overlook and under-report. For some of us, visibility entails vulnerability and the threat of unemployment or detainment weighs so heavily that illness must remain invisible, ignored or hidden. We are the data, but we do not always speak for ourselves.

Susan Sontag wrote in *Illness as Metaphor* that “everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.”⁴ A pandemic transcends borders but does not do away with the kingdom of the sick. As someone already resident, I can say to you: welcome. The hardest thing about being here is the grief for what we have lost, including a sense of normalcy. The best thing, though, is what we may find: community in a time of crisis.

1. Johanna Drucker, "Humanities Approaches to Graphical Display," *Digital Humanities Quarterly* 5, no. 1 (March 10, 2011), <http://www.digitalhumanities.org/dhq/vol/5/1/000091/000091.html>. ↩
2. Anne Boyer, *The Undying: Pain, Vulnerability, Mortality, Medicine, Art, Time, Dreams, Data, Exhaustion, Cancer, and Care*, (New York: Farrar, Straus and Giroux, 2019), 65, 14. ↩
3. Boyer, *Undying*, 55. ↩
4. Susan Sontag, *Illness as Metaphor* (New York: Farrar, Straus and Giroux, 1978), 3. ↩