Maintaining,
Repairing and
Caring for the
Multiple Subject
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Dispatches from the “Always-Almost-Falling-Apart World” of a Type 1 Diabetic

On a Thursday morning in late-August, I was walking to work in downtown Chicago. The sun was shining. It was warm. There was no hint of the cold weather that I’d left behind the previous Spring. I had an iced coffee in hand that was the ideal shade of caramel brown. Having just returned from three weeks in Europe, I was excited for the upcoming semester, happy with the writing that I had accomplished over the summer. Things seemed absolutely perfect! But...all of a sudden, I turned a corner. My laptop and shoulder bag suddenly seemed excruciatingly heavy and my feet--clad in black pumps with very worn knobby kitten heels--hurt. I was confused and didn’t recognize where I was or what I was doing there. I was sweating profusely. I wondered whether I could make it to the office. Was I having a panic attack? I thought.

This autobiographical account describes the “always-almost-falling-apart world”[1] of a Type 1 diabetic experiencing an episode of extremely low-blood sugar. Most of the time, these episodes are not serious and can be fixed relatively quickly by drinking 4 ounces -- a very small amount -- of orange juice or chewing four, chalky, purple grape-flavored glucose tablets. This time, however, a confluence of factors including being back in Chicago after a three-month hiatus made the familiar symptoms of low-blood sugar unrecognizable even after four years as a Type 1 diabetic.

Steven Jackson’s exercise in “broken world thinking” asks “what happens when we take erosion, breakdown, and decay, rather than novelty, growth, and progress, as our starting points in thinking through the nature, use, and effects of information technology and new media,”[2]. My response is a reflection on the decay of the human body. A pancreatic breakdown in an infrastructure of glands. An emergent state of disability. Caution: Auto-immune system not working.
New technologies promise to help you to ‘manage’ the disease and ‘control’ your blood sugar. In my case, I made the choice to use an insulin pump and glucose monitor. Within 2 years of my diagnosis, I became a disabled cyborg body.

![Medtronic MiniMed 530G insulin pump and tubing that connects it to the body.](image)

The insulin pump and glucose monitor are only two of the technological components of a larger networked assemblage made up of a range of objects and entities including: test strips, needles and lancets; insulin vials and pens; sensors, receivers and transmitters; coiled 20” tubes that get stuck on the knobs of kitchen cabinets; nutrition information, measuring cups and food scales; Xerox copies, Excel spreadsheets, charts and manuals; glucose tablets and orange juice; cables and AAA batteries; carrying cases, plastic packaging and cardboard boxes (oh, so many, cardboard boxes!); adhesive surfaces and alcohol swabs; online platforms for training, tech support, ordering supplies and getting test results; doctors offices and testing labs; and, lastly, corporations (both device-manufacturers and heath insurance companies) and hospitals. This assemblage participates in everyday rituals around data, monitoring and measurement as well as the lived experience of eating, exercising, bathing, getting dressed and sleeping.

**Broken Body Thinking**

Like broken world thinking, broken body thinking complicates common discourses about around science, innovation and infrastructure and, ultimately, about ourselves. This lens reveals the ways in which new technologies maintain, repair and care for the disabled cyborg body. At the same time, I can reflect my own participation in the maintenance, repair and care for these technologies. These intimate infrastructures are composed of both human and non-human patients and caregivers.

In noticing these everyday human-computer interactions, the disabled cyborg body becomes an epistemic site of inquiry. A site that suggests different forms of knowledge and practice related to human-non-human relations. For example, we might ask about our own problematic becoming with technology – filled with bugs and glitches – to provide an alternative account of the lived experience of what might be understood as the posthuman or the more-than-human. The disabled cyborg body reconfigures the role of the human, offering an alternative narrative from which to critique normative positions. It collapses and blurs the boundaries of familiar binaries such as subject/object, digital/physical, local/universal and nature/culture. It is in this decentering that we can create multiple, diverse ways of knowing that can inform the development of critical approaches to research and design. How might this posthuman and more-than-human subjectivity inform the way we do scientific research and build socio-technical infrastructures for future worlds?

The socio-technical assemblage described above participates in the construction of one’s identitie(s) as a disabled cyborg. Both the body and the technologies are in a constant state of change and deterioration. They are both, so to speak, disabled. At the same time, they are being maintained, repaired and cared for. In the end, they share a common trajectory – whether as a human corpse or as e-waste. Neither will ever be “new” again, making discourses around maintenance, repair and care ever more relevant.
Dexcom G4 Continuous Glucose Monitor (CGM) receiver showing an error when it has lost the connection with the transmitter on the body.

Living with an assortment of devices that must be embedded in and/or in range of one’s body (sometimes referred to as “body area networks”) engenders forms of intimacy and attachment that recall notions of care. Care includes collaboration, cooperation and support as well as a care ethics that “engages with the ethical, moral, and value implications of care.”[7] This ethics of mutual care and responsibility places the moral burden not only on humans but also on the things that we are entangled with and dependent on.[8] This ethics plays out in a variety of mundane everyday rituals such as getting dressed:

When I get dressed I carefully consider the possible arrangements of human, garments and medical things as well as the kinds of social situations that I anticipate during the day. Will the sensor be too visible on my stomach through a sheer material? Will the pump create a lumpy block on my chest that will call attention? Will it be easy enough to access during a lunch meeting? Will I be dining with superiors or strangers? I change my clothes several times or add and remove accessories such as belts or scarves that can render the medical things invisible but, at the same time, accessible. Why do I feel the impulse to cover up these medical things that have come to participate in the construction of my identity as a person? I hide my disability in an effort to appear ‘normal.’[9]

The social world(s) of humans and the social world(s) of things meet in my closet every morning. They perform, negotiate and navigate expectations around gender and profession, united in their experience(s) of disability. It is in performing these everyday rituals that these multiple subjectivitie(s) are formatted and reconfigured around their various functional needs, aesthetic aspirations and political commitments.

Living on AAA Batteries

Like other high-tech products, these devices are also prone to failure and breakdown. These key moments in which these critical bodily infrastructures fail make them even more visible to the self, even when they have faded into the background of everyday life and routine. At the most basic level, this means insuring that all of the devices are consistently sufficiently powered and properly connected. For example, the glucose monitor has a USB cable that enables it to be charged when plugged into a computer. The monitor receives data from a transmitter that is attached to the body with an oval sticky gauze patch. Underneath the patch is a sensor that is inserted into the body. On the other hand, the glucose meter has a USB on one end for charging. The meter is necessary in order to accurately test your blood sugar twice a day in order to calibrate the glucose monitor. It also wirelessly sends the data directly to the insulin pump.

While the monitor and the meter can be charged periodically, the pump, on the other hand, requires a single AAA battery in order to function. The pump’s battery indicator has only four bars – a very imprecise measure to say the least. Even when stockpiling AAA batteries at home, and carrying them around in a travel case along with other necessary supplies, it is easy to be caught – at a conference, during a dinner, on the way to work or in a class – without any power for the device. Without a constant stream of insulin as well as the ability to administer the correct amounts at mealtime, which is coordinated through the pump, a Type 1 diabetic risks dangerously high blood sugar levels after just a few hours. It is not blood but numbers that I imagine coursing through my veins.

In late September, I was at a work dinner at a Russian restaurant near Michigan Avenue in Chicago. I noticed that the pump’s battery had suddenly died, inconveniently in the middle of a
conversation with a senior scholar in my field. I whispered to my husband. I needed a new AAA battery and a quarter as soon as possible in order to avoid awkwardly interrupting the dinner. With these two things procured, the process of restoring the system to order is relatively simple. First, you use the quarter to screw off the cap. Then, you replace the battery, and screw the cap back on. Assuming not much time has elapsed between the battery dying and the new battery being inserted, you should be ‘fixed’. But, on the other hand, if too much time has elapsed, you must reset the time and date, and check all of the insulin settings to make sure that they are correct. The settings include both basal and bolus (mealtimes) doses, which means that there are multiple different conversion rates at many different times of day and night.

This functional act of maintenance reveals the complexity of the socio-technical system and its vulnerability to breakdown. My care for the pump also reveals the significance of the attachment and intimacy that I feel for these medical things. Yes, there are times when I can be without them, such as when showering or going for a swim. But, for the most part, I am with them and they are with me. In the words of Susan Leigh Star, “For material artifacts, this goes beyond the instrumental or functional relations that usually characterize the attachments between people and things. Care brings the worlds of action and meaning back together, and reconnects the necessary work of maintenance with the forms of attachment that so often (but invisibly, at least to analysts) sustain it.”

The provision of energy is only one example of the kind of caregiving that makes the life of the disabled cyborg possible. There are many other forms of invisible labor that are required to keep the system of networked medical devices functioning. These include: checking the glucose monitor for a blood sugar reading every hour (and, sometimes, more frequently); responding to and dismissing the various alarms that keep the devices beeping and buzzing 24 hours a day (a very unwelcome guest at the Metropolitan Opera to be sure); recalibrating devices with the correct data at least twice a day; replacing tubes and sensors every few days including refilling the ‘infusion set’ from small glass bottles of insulin; ordering and picking up prescriptions every month; counting and reordering supplies every few months, and; uploading data to online platforms for doctors.

In caring for myself, I am enlisted into a practice of actively participating in, maintaining, repairing and caring for multiple medical technologies (rather than using them passively). Is it really possible to empathize with things, to see the world from their perspective? With respect to my insulin pump and glucose monitor, often, I am not really sure whether I am taking care of them, or they are taking care of me.

**Broken Body Thinking and the User-Repairer**

What can be learned from reflecting on the lived experience of the disabled cyborg body? First, there are multiple ways of knowing that reside in the broken body. These modes – consisting of mind, body and technology -- challenge the kinds of knowledge that lies in the head, in the rational mind and in the objective, serious and scientific self of the academy. While this approach may be unconventional, there are, in fact, many precedents. For example, drawing on feminist science and technology studies, Susan Leigh Star’s well-known account of trying to order a hamburger without onions at McDonald’s serves as an excellent example of what can be learned through a reflective analysis of one’s own experiences with standardization and conventions as well as heterogeneities and multiplicities. I am no more a significant participant in this narrative than I am of any other writing or research that I do.

Participating and becoming are ways of knowing that have been already recognized in the academy – from participant observation in anthropology to participatory design as well as more emergent practices such as hacking, making and citizen science. ‘Users’ of technology can now be understood as participants and, even, producers of knowledge (in contrast to ego-design or, even, human-centered design where the designer assumes the role as expert). But auto-ethnography and, even, participant observation have not yet been broadly incorporated into design research. Like other forms of observational research, auto-ethnography of this kind requires constant attention to and reflection on very small details that make up everyday lived experience – 24 hours a
day – not only when you are ‘in the field’. There is no ‘other’ that you are studying or designing for. There is no interview protocol or consent form. Furthermore, attending to the theme of breakdown as I have in this essay (and in other writing on this topic), draws on specific moments that are often stressful, exhausting and, sometimes, even traumatic (as is fieldwork in many settings). Participating in this way cultivates a different sort of empathy and care than is commonly practiced in design research. An empathy that resists “othering” and, is, instead aligned with becoming. A more recent precedent is autobiographical design, which is described as “design research drawing on extensive, genuine usage by those creating or building the system.”\[14\]

Second, broken body thinking collapses the scale of broken world thinking. Large scale, long-term, important and complex problems in adaptive and dynamic socio-technical systems can be understood through their intimate entanglement with mundane, moment-to-moment decisions of everyday life. When one’s body is networked, it is simultaneously a bounded and embodied in a physical place but also constantly existing in a space of flows, traversing time, space and scale. (My husband just called to tell me my blood sugar. He checked it on an app on his iPhone before calling.) Like climate change, chronic disease itself might even be reframed as a kind of hyperobject in its vastly distributed manifestations.\[15\] Disability studies and infrastructure studies make for valuable companions in this investigation.

Third, understanding the disabled cyborg body as a multiple, posthuman and more-than-human subject illustrates a capacity for empathy with things – artifacts, collectives and complex systems. Things that are embedded in and connected to the body participate in, act out and become part of performing everyday life. And, thereby participate in the shaping of identity. This agency and participation extends existing notions of thingness from actor-network theory, object oriented ontology and speculative realism. Yet, these theories have been criticized for their failure to account for gender, race, class, sexuality and ability in their characterization of human and non-human agency. My account places value on the situated, materialist and embodied multiple subject inline with feminist new materialism.

In sum, broken body thinking transcends scalar questions – micro, meso and macro - by offering a way of understanding oneself in systems and systems in oneself. The self multiplies as it incorporates human and non-human subjects. By maintaining, repairing and caring for these life-sustaining systems, one cultivates empathy for things. Rather than identifying as a user of these technological systems, you become them – both metaphorically and literally. And, in order to insure your/their daily functioning, you also become a user-repairer of these systems. These frequent failures and breakdowns are a constant reminder of the ways in which the world is “always-almost-falling-apart”, reinforcing the need for broken body thinking.

REFERENCES


[2] Ibid., 221.


It is important to acknowledge that disability theory, feminist science and technology studies and queer theory aim to complicate and resist what is understood to be normal. While I agree that this is a necessary move for theory and for society when it comes to my own personal experience, I am challenged. In order to mediate the tensions between theory and practice, I must learn to resist my own impulse to fit in.


