

Hacking the Feminist Body

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Abstract

This article develops feminist understandings of hacking the body through a personal engagement with socio-technical systems that are used to manage chronic disease. Drawing on science and technology studies along with feminist studies about the mediated body, this essay will develop a feminist understanding of hacking through an ethnographic account of the first year of living as a Type 1 diabetic with an insulin pump and continuous glucose monitor. In particular, I will describe the ways in which these devices discipline everyday activities, the tensions of being embedded with competing proprietary systems, the ways in which I disobey the devices and they disobey me (as well as the ways in which we collaborate), the invisible labor required to navigate everyday life, and the ways in which this experience challenges and extends notions of what it means to be human during a time of networked things and bodies. This critical analysis of the embodied experience of medical technologies will serve to complicate the revolutionary claims about hacking and technology and, rather, bring to life the ways in which these technologies reconfigure definitions around what it means to be human, enable unique socio-cultural hacking practices even among mundane activities in everyday life, reshape the boundaries between public and private, allow for failure, and create new kinds of bodily labor. Through this analysis, I will argue that a feminist hacker ethic(s) will feature the body (along with all of its features and bugs) as an important site of socio-technical engagement.

Introduction

I am not a hacker or a maker. I do not tinker or tailor, knit or bake. I'm more likely to buy it than DIY it. So, why should I write an essay on hacking the feminist body? In fact, it is only through my own body's failure and break down that I can hope to contribute to the redefinition of the socio-technical practices that constitute hacking and (un)hacking. While I may disavow the hacker and maker identity, I do geek out. Quite a bit. Mainly about infrastructures and architectures, Wi-Fi networks and networked things, wearables and laser-cut fashion. I'm interested in the ways in which these socio-technical systems shape even the most mundane details of everyday life -- their politics, materialities and aesthetics -- as well as what it means to be human in this context. In a way, the best thing to ever happen to me as a scholar was finding out that I am Type-1 diabetic four years ago. In line with much feminist theory, which elevates the importance of embodied ways of knowing and making sense of the world, my research quite literally landed on directly on my body. So, what does it mean to hack the feminist, diseased body?

Since academic scholarship and professional practice are rife with comparisons, competition and politics, turning research and reflection from my mind (in studying others) to my body (in studying myself) was in some ways a transgression in itself. It was

a project that no one could take away from me, take credit for or repeat in any authentic way. It is a narrative of becoming and hacking into a diseased body, everyday rituals, failure and breakdown, and the invisible labor that contributes to its maintenance and repair, which points towards a feminist hacker ethics as well as important considerations for the design of socio-technical systems. For example, in what ways do the devices discipline everyday activities such as eating, sleeping and getting dressed? In what ways do intellectual property debates play out on the diseased feminist body? What does it mean to disobey the devices (and their norms and guidelines) and what are the repercussions of such disobedience? What new kinds of labor are required in order to navigate everyday life in tandem with these technologies? Finally, how does this experience challenge or extend what it means to be human during a time when more and more networked things (Ingold, 2010) are augmenting the mind, home and body?

Theorizing the Feminist Body

Due to their relative lack of diversity and inclusion (Bueno, 2014), which has been well documented both within Silicon Valley as well as from afar, masculinist approaches to hacking, tinkering, geeking, and making focus on places and projects that continue to create explicit divisions between traditional Western dichotomies of male and female, mind and body, work and personal, and public and private. Specifically, feminism has a history of contemplating the body as the site where socio-technical tensions and ‘matters of concern’ (Latour and Weibel, 2005) play out in everyday life. More recently, scholarship on new materialism (Iovino and Oppermann, 2012, Parikka, 2011), object-oriented ontology (Bogost, 2012), the new aesthetic (Berry et al., 2012, Bridle, 2011) and digital materiality (Dourish and Mazmanian, 2011, Gillespie et al., 2014) has engaged with the ways in which objects matter in the shaping of everyday life as well as the ways in which the digital shapes physical bodies, objects and environments.

These technologies can be understood as a socio-technical system of human and non-human actors or the inhuman (Hird, 2012) as it has been referred to in Feminist Science Studies such as test strips, needles, insulin vials, canula, tubes, blood tests, doctors visits, glucose tablets, lancets, food scales, cables, AAA batteries, carrying cases, measuring cups, adhesive surfaces, sensors, receivers, transmitters, lab visits, Excel spreadsheets, conversion rates, charts, alcohol swabs. In this way, diabetics can be understood as a kind of cyborg—a hybrid of flesh, bones and blood along with sensors, tubes and external devices. Since Haraway’s (1991) account of the cyborg self, scholars have argued for the important role of hybrids (Michael, 2004) in mediating discrete, rational categories such as the digital and the material, black and white, rich and poor, gay and straight. These cyborg narratives have only become more relevant as humans have become increasingly augmented with networked technologies such as mobile phones, the quantified self and augmented reality glasses. Yet, most discourses around these technologies that originate in Silicon Valley make positivist assumptions about the importance of certain kinds of sites of innovation such as hackerspaces, incubators, coworking spaces, startups and Maker Faires (Suchman, 2011) as well as the value of the transmission of data (geolocation, calories burned, video captured) rather than a more qualitative description of the rituals (Carey, 1988) and the mess (Law, 2004) of data and devices when juxtaposed with human systems in the everyday life a cyborg body. Drawing on science

and technology studies along with feminist studies about the mediated body (Cárdenas et al., 2009), the narrative that follows illustrates that rather than acting as smooth (Kang and Cuff, 2005) operating systems for the body, these devices are rife with frictions (Tsing, 2005), dissensus (Mouffe, 2003), conflicts (Hillgren et al., 2011) and agonism (DiSalvo, 2012).

Becoming Diabetic

Being diagnosed with chronic disease is not a matter of 1's and 0's. It's not a binary condition of now you have it or you don't. It is a process of becoming a different person with new rituals and practices over a long period of time. My process of becoming began about 4 years ago. I returned from a trip to Israel and Jordan, got a tenure-track job offer and a Fulbright grant. As part of the grant administration process, I was required to get an annual physical in order show that I was fit enough for to undertake international research. It was then that I learned that I am diabetic and what was to become a long process in the diagnoses and management of chronic disease, which involved 4 different doctors over several years.

Unsurprisingly, the most immediate adjustment was enrollment into various the processes of calculation including how much of any given food I could eat, what I could eat and how to test my blood sugar six to eight times a day with an assortment of devices including a glucose meter, lancets (tiny needles), test strips and alcohol swaps. For about a year, I was told that I could only eat carbohydrates in 15-gram increments. Like you, I had no idea how much this was. I had never counted a calorie in my life. What I did know is that I loved carbs! Especially *soba* noodles, clear Korean *jap chae*, ramen, Chicken noodle soup, linguine a le vongole...OK, let's be honest, any kind of noodles...Neapolitan pizza, Chinese dim sum dumplings, peirogis. I was never one for desserts and, in fact, I usually skipped it completely. Yet, naturally, there were a few things that I did like: Japanese red bean cakes, tiramisu and mint chip ice cream or just about anything with caramel. As an Italian-American with a study abroad in carb-crazed Japan and Italy, this Distributed Denial of Carbs was going to be rough.

Well, I've digressed. 15 grams of carbs is equivalent to 4 oz. of orange juice, ¼ of a bagel or ½ of a banana. Now, I don't know about you but there was no way that I was going to go into Russ & Daughters on Houston St. on New York's Lower East Side and ask for a quarter of a bagel with schmear. And so, life went on, my diet became a steady supply of nuts and cheese (two of the only things that I could manage to find that had no effect on my blood sugar because they were entirely comprised of fat). Despite this, I lost 20 pounds by the end of the year and the numbers (blood sugar) were still rising steeply. When, after about six months, my first doctor, a Russian woman with an Italian last name, wanted to put me on a medication, I found another one, always having an aversion to medications and doctors of all kinds.

This doctor had an esteemed reputation but he looked sickly and was easily over 80 years old. He said that I could eat carbs (bread, for example) and prescribed me insulin delivered in a pen-like device with screw on needles. The insulin was "long-acting" and it remained in your body for about 12 hours so I did a shot in the morning and one in the

evening. This was relatively easy to manage since I was at home in my own environment at both times. The numbers got better and that July, I was tested and learned that I was a Type 1 diabetic. As a result, the insulin regime changed and I was prescribed two different kinds of insulin. One before meals and one in the evening.

In August 2013, at the advice of a fourth doctor, I decided to transition to the use of an insulin pump and continuous glucose meter. One morning, I went to my doctor's office and there I met a representative from the company that helped me connecting the pump to my body. Remembering the steps for changing the infusion set (the system of technologies that joins the pump with the body) was difficult at first. The process often took up to 15 minutes. Each time, I took out the instruction sheet and followed along carefully. But still, at one point, I managed to forget an important step, having attached the tube to my body before I had filled it with insulin. I pulled out the infusion set and started over again, not knowing that I could have actually just screwed off the cap and filled the tube that way as a workaround.

Everyday Rituals

While much attention is placed on monitoring, tracking and transmitting the more quantitative aspects of the disease – uploading and downloading the data, measuring and inputting the blood glucose (BG) number -- living with it requires the creation of new sets of everyday rituals and practices. Not only eating but also getting dressed, showering, exercising, sleeping, having sex. Each of these requires a certain negotiation with the device related to the context of use. What does it want to wear today? Where will it be seen/unseen? How long can I go without it? For example, taking a shower requires that one unscrew the cap that is fixed to the body and leave it on the counter before stepping into the water.

Hacking into the Body

Hackerspaces have recently become interested in the biohacking as a site of practice. Starting to use an insulin pump and continuous glucose monitoring system, is a practice of literally hacking into the body by piercing it with little blue lancets and long silver needles, and punching holes in the abdomen for the insertion of sensors and canula. The interaction with the body is fairly clinical in that one is prevented from seeing the needles by caps, covers and insertion devices, which obscure their view. But, occasionally there are reminders – mainly bruises and blood -- that the interface between the body and the device is a living surface. One day last September, I was having lunch with a new colleague in a small Vietnamese restaurant in Wicker Park. But, before I could eat, I needed to refill the little clear plastic vial of insulin and reinsert the tubes under my skin. When I yanked out the old tubes, to my surprise, a steady stream of bright red blood came gushing out of what was ostensibly a very small hole. This had never happened before, even after a year of being “on the pump.” I grabbed several paper towels and pressed down hard and used an alcohol swab to clean it. It took a good ten minutes for the bleeding to let up and I was finally able to change the tubes to another spot. I returned to the table and pretended that nothing out of the ordinary had happened.

Skin as Human/Non-Human Interface

Choosing to adopt a medical device for the management of chronic disease challenges, contradicts, extends and expands notions of what it means to be human. In a time when more and more networked things (Ingold, 2010) are augmenting both diseased and non-diseased bodies as well as domestic, public and work environments, my experience hints at emergent understandings of human-non-human relations. My internal data is streaming through these devices in real time, 24 hours a day (except for the intervals in which I am resetting or reinserting them. As such, I am part of them, and they are part of me. Such claims were made in the late 1990's about cell phones being a kind of prosthetic extension of the body, an intimate relationship to be sure. Yet, even with other medical technologies such as eyeglasses, it is possible and even desirable to get away from them. With an insulin pump, you can only be detached for an hour or two before glucose levels begin rising quickly and dangerously. It becomes part of you and is literally attached in a way that your cell phone will never be. While one would think that it would take some time for the intimacy and attachment between the human body and the technological device to develop, in my case, it was almost instant. That first night, sleeping with the device latched onto my pajamas, I felt very safe and secure. My pancreas was broken and my body was toxic (Chen, 2011) but this new part made me whole again. Sometimes, I leave the house and suddenly think that I have forgotten to reattach the pump after getting out of the shower. I quickly clutch my belt in a panic as if looking for a phantom limb.

Bodily Intellectual Property

As a hacker of the feminist body, intellectual property debates play out in a most intimate embodied form, literally under your skin. While many areas of software and (increasingly) hardware have benefited from the work of open source communities, medical devices and software have been slower to develop open source solutions in the healthcare field due to the high cost of research and development, lack of competition and concerns over security. In my case, this meant making the decision to adopt two competing and incompatible devices in order to monitor and manage chronic disease. First, the insulin pump is made by a company called Medtronic – it is one of the largest companies that produces this device. While the company has its own proprietary sensor technology that communicated blood sugar measurements directly to the pump, my research and conversations with several different doctors at various hospitals suggested that its performance was less accurate than their competitor, a company called Dexcom.

The monitor (a receiver with a screen) illustrates blood glucose levels based on interstitial fluid on a chart that is visible in real-time. It alerts you when the levels are too low or too high, visualizes the speed at which the levels are rising or dropping and illustrates this on a timeline. While I'd been using a FitBit on and off for over two years but watching the effects of different foods on your blood sugar levels is another way of entering into discussions of the quantified self. In order for the monitor to display information from the sensor, which is inserted under the skin and fixed in place by an adhesive cover that holds the transmitter, one must always be within about 20 feet of the receiver. This means carrying it with you to the bathroom and sleeping with it next to your pillow or in your bed. In choosing to adopt the Dexcom monitoring system, I decided to negotiate between two different proprietary systems, which required carrying around an additional device with me at all times, making payments to two different companies and downloading data

in two different formats that could not be integrated.

Some seemingly mundane parts of the system, like that plastic clip that attaches the pump to one's belt, bra or jacket pocket, could not be easily replaced without ordering a new one directly from the company by Fedex. While the part actually looked quite similar to the holsters that were used to carry pagers or cell phones around, it was not possible to easily find a clip that could be used to carry the pump in an electronics store. It was such an insignificant part of the system (or bodily infrastructure) that I nearly forgot that it was even there, until it broke while I was away at a workshop abroad. As with other infrastructures, they only become visible upon breakdown (Star, 1999). To be sure, the breakdown in the system was inconvenient. The pump did not fit into the pocket of my skinny jeans but I had a pair of sweatpants that had the right size pocket. The only problem was that I was a bit embarrassed about wearing sweatpants at the workshop since I feared that it looked much too sloppy and unprofessional. To make things worse, they were the sweatpants that I'd worn on the plane and for 24 hours straight.

Disobedient Devices and Anti-capitalist Practices

In choosing to adopt this particular socio-technical system, I was conscripted into a capitalist cycle of consumption of the various parts – tubes, needles, sensors, little plastic vials -- that make the system function, which must be replaced every three days for the insulin pump and every week for the glucose monitoring system. These parts were shipped to my home like clockwork in three-month supply. Slowing down the shipments by overfilling the vials and thereby reducing the overall cost of the supplies became a way of hacking through the creation of an anti-capitalist practice.

There were a few reasons for changing the tubing and insertion spot every three days. First, the small plastic vial of insulin only contains a finite amount, which can become rancid due to its exposure to your body heat. Second, the insertion spot could become infected or aggravated. Yet, I found that instead of changing the tubes every three days, I could easily go for or five days without needing to use additional supplies with no apparent repercussions. As such, the boxes of supplies began to pile up and the customer service calls began. Similarly, with the glucose monitoring system, I found that rather than acquiesce to its commands to use a new sensor every seven days, I could actually just restart the old sensor and use it for another few days. In fact, it was not the sensor that required replacement but the adhesive that held it in place that would eventually peel off after multiple showers and workouts. While not opting out from these technologies all together, this kind of disobedience is a way of reclaiming the body from the logics of capitalism.

Chronic Disease and Invisible Labor

Hacking relies on many kinds of unpaid and volunteered labor; for example, participation in hackathons and hackerspaces or joining specific communities focused on developing open source software. We know that these socio-technical practices – while often heralded as free and open meritocracies – limit the participation of many in that they are often structured around white male identities, norms and behaviors. Furthermore, they require participation in time and skills that are biased by gender, race and socio-economic

status.

In a similar way, managing chronic disease requires a great deal of invisible labor, for which I will never be compensated (except through hopefully living a longer healthier life). Counting – carbohydrates, insulin units, grams, cups, tablespoons, ounces, fiber, tubes, canula, insertion devices – is one kind of invisible labor that takes a great deal of time and attention on a daily basis. It requires mathematical skills that are distributed across multiple devices: glucose meters, continuous monitoring systems, kitchen scales, operating systems and smart phone applications to name just a few. As such, the human must work in tandem with the non-human devices in order to delegate (Latour, 1992) the various calculations and labor associated with everyday activities such as eating and exercising. In adopting the insulin pump, rather than needles and injections, I was able to offload some of the mathematical calculations to a feature called the “Bolus Wizard.” The wizard could multiply the number of carbohydrates times the amount of insulin needed per carbohydrate and could adjust these numbers to accommodate high or low blood sugars. It also requires significant coordination and organization skills – making sure that you have all of the necessary parts of the system when you are traveling, making sure that you have enough of each component to last for the number of days that you will be traveling, making sure that you order and pick up your prescriptions on time. If only one component is missing, the system will fail to function properly.

When traveling to professional conferences and meetings, it is common to spend a lot of time socializing with colleagues and, therefore, paying less attention to yourself and your own needs. One night at a conference, I was invited to dinner with several colleagues. We decided to meet in the lobby 15 minutes later. I rushed up to my room to drop off my things and realized that I had only enough insulin left to eat dinner, which meant that I would need to “infusion set” by refilling the vial and reinserting the canula. I grabbed the supplies and took them with me to the restaurant. After dinner, we went straight to a party and I headed to the bathroom. I looked around the bathroom. As usual, there was no sanitary surface on which to put the supplies, just a grimy-looking white porcelain sink. It was then that I realized that I had forgotten the insertion device. I had everything that I needed except for a way to get the tube under my skin. As a result, I didn’t eat anything at the party and cut the night short to get back to the hotel.

Like hacking, living with/being part of a system of devices requires a skill of repairing, maintaining, fixing, adjusting and troubleshooting. For example, when you are too far away from the Dexcom (continuous glucose monitor) or when the transmitter that is attached to the body pops out in the shower, the receiver malfunctions and must be reset. The monitor must be calibrated at least twice a day to remain accurate but, even with regular calibration, it is not uncommon to get strange readings once in a while. Like, off by 60 points strange. This is especially problematic when it repeatedly wakes you up in the middle of the night – with low alarms buzzing every few minutes – despite the fact that the data is actually completely wrong. While the “snooze” feature lessens the intrusion to every few hours, it is not always clear whether the device is taking care of me or whether I am taking care of the device.

From time to time, the doctor might recommend some adjustments, which require toggling through various menus and changing the settings. Sometimes the AAA battery in the pump dies unexpectedly (for example, while rushing to campus to teach with little time to stop at the pharmacy) or the glucose meter or monitor loses their charge. In order to live with chronic disease and manage it with medical devices, one must be prepared for a constant process of breakdown and repair, both for the body as well as for the technology. Like hacking, the invisible, unpaid and volunteer labor that is needed to manage chronic disease discriminates. It favors those with better educations and higher incomes, which we know is also linked to race, and it is gendered in that it requires a certain kind of care, time and attention.

Interruptions and Breakdowns

First, interruptions, the less severe of the intrusions that these devices make on your everyday life. During my first week using the insulin pump, I was at the movies. In the dark. All of a sudden, the device started buzzing. Every few minutes. Bzz. Bzz. Bzz. Bzz. I had no idea what was going on. What did it want from me? For it was not a cell phone with a human on the other end that was seeking my attention. I fumbled around. I recalled that there was a light on the thing but I could not remember which button to use in order to activate it. After some trial and error, I found the green glowing light. It was the “LOW RESERVOIR” alarm. This alarm activates when you have less than 24 hours of insulin left. I successfully turned it off and got back to watching Lee Daniel’s *The Butler*.

The continuous glucose monitor has an equally intrusive alarm. It buzzes for high and low readings and, in the worst case, after several attempts to alert you, it resorts to making a very high-pitched screeching noise. This is particularly unwelcome when dining or conversing with colleagues at conferences and the like. While, in general, the devices fit in and resemble other personal, mobile technologies in that using them is not much of a distraction, they do not behave in the same way. Their sounds diverge from the familiar family of Apple iPhone ringtones. They speak in tongue. The uninvited stranger at the dinner party.

Like any socio-technical system, participation in (and becoming part of) a network of medical devices can be defined by inherent frictions, failures, limitations, breakdowns and interruptions. However, in contrast to other technologies, which are claimed in a revolutionary manner to provide smooth, seamless and efficient operations for management and control, the representative from the company that produces the insulin pump acknowledged that this technology would never be perfect. This, of course, is because of the many factors that can influence one’s blood sugar: sleep, stress, food, hormones etc. Thus, even with the same objective measurements and inputs, the results might still be quite different. Unlike other technological systems, the interaction with the human body itself is what produces the system’s lack of accuracy in a very observable way.

Furthermore, on a day-to-day basis, many things can go wrong even when the “right” steps are followed. Here’s one example. One night, I changed the infusion set right before hosting a dinner party. The infusion set, is the system comprised of a short tube that goes

under the skin called a canula and a long tube that connects it to a small vial of insulin that goes into the pump. The insulin is pushed out of the vial with a little screw. I was running a bit late so I did everything quickly before the guests arrived. Throughout the evening, I noticed that the numbers were rising but I assumed that I had made a mistake in the calculations since we were eating a lot of unfamiliar foods in unfamiliar amounts. By the end of the night, the numbers were so high that they rivaled only the results of a 13-hour flight to Japan taken before I used the insulin pump during which I'd eaten white rice and a turkey sandwich without being able to leave my seat in order to do an injection.

Despite corrections and re-corrections, I woke up several times throughout the night to the monitor's buzzing but the numbers barely changed at all. I forwent breakfast not wanting to cause any additional problem. Around lunchtime, I decided that something was definitely wrong. I checked everything to see that it was working properly and found that the insulin was actually leaking out from under my skin. I yanked off the bandage-like device and found that the little tube was completely bent in half.

Towards a Feminist Hacker Ethic

How might we characterize a feminist hacker ethic and how might such an approach shape practices of design? A feminist hacker ethic is necessarily a deeply personal reflective practice about one's own participation in socio-technical systems. Unlike sweeping, revolutionary calls for collaboration, participation and openness based on an assumed meritocracy, a feminist hacker ethic pays specific attention to inherent inequalities and invisible labor present in these relationships: human/non-human, proprietary/non-proprietary, digital/material, smoothness/friction, broken/unbroken, quantitative/qualitative, visible/invisible, public/private. Rather than seeking these as binary categories and, in keeping with feminist science and technology studies, a feminist hacker ethic seeks to transcend these categories with specific, nuanced hybrid modes of existence.

For example, rather than understanding the world as human-centered, as is common practice in the field of design, a feminist hacker ethic would integrate the human and non-human in a manner not unlike the everyday rituals associated with my use of the insulin pump and continuous glucose monitor. I am not only a user of this particular medical technology, I am participating in and negotiating the world with it at every moment (Alaimo, 2014). It is constantly shaping my everyday interactions I am shaping it (Bijker et al., 1987, Bogost, 2012). A feminist hacker ethic would decenter the human, reject the user and make room for a new kind of hybrid stakeholder. Rather than hacking writ large, feminist hacking might embrace small everyday rituals and actions that seek to transgress and call attention to inequality and introduce alternative sets of values and possible futures. Design, approached from the perspective of feminist hacking, could pay special attention to these rituals as well as the frictions and breakdowns in order to contribute to the transformation of the medical field around more open practices and non-proprietary systems.

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