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Data Rituals in Intimate Infrastructures: Crip Time and the Disabled Cyborg Body as an Epistemic Site of Feminist Science

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Abstract

While much feminist science and technology studies (STS) has focused on science and laboratories as sites of critical engagement, feminism and feminist theory have recognized alternative sites of knowledge production and engagement. These alternative sites of doing science out of feminist theory can sometimes, but not always, turn inward onto a careful reflection on the lived, intimate, and personal experiences of scholars themselves. This essay draws on new materialism and on feminist theories of materiality, temporality, embodiment, and technology in order to analyze the disabled cyborg body as an epistemic site of feminist science. In particular, I analyze my own experience of adopting and using networked technologies—specifically, an insulin pump and glucose monitor—to manage Type 1 diabetes and the kinds of practices that I engage in on a daily basis. These intimate human-machine relations, as well as the spatio-temporal practices that are performed along with them, deserve attention in terms of what they can teach us about common discourses around science, innovation, and infrastructure and, ultimately, about ourselves. This article introduces the concept of *data rituals* as a feminist data practice. Data rituals include the quantitative tracking, measurement, and transmission of data

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along with phenomenological lived experiences and labor around these practices. Together, these practices expand notions of *crip time*, illustrating the ways in which the disabled cyborg body is experienced as out of sync with the normative temporal orders of everyday life. I argue that a deeper understanding of the temporal aspects of the lived experience of difference in the case of Type 1 diabetes is an important example of doing science out of feminist theory.

On Thursday, March 30, the alarm clock on my iPhone stopped working. I woke up with the sun in my eyes—piercing through the metal slats of the blinds—a few minutes after my alarm was set to ring. I was puzzled. I have been using my iPhone as an alarm clock since 2007, when the phone was first released. Usually it is on my nightstand but sometimes I even keep it under my pillow.

I Googled for a fix. I followed various recommendations from tech websites. I closed and re-opened all the apps, I restarted the phone, I tested the various features of the clock app, I upgraded to the latest operating system. Nothing seemed to work. If anything, after several hours of troubleshooting, my actions seemed only to cause even more problems.

After an appointment with the Apple Genius Bar, I restored the phone from a backup. When I restarted the phone, I found that the data from a few applications had been erased. I also needed to log back into more than 240 applications; for the most part, I had forgotten my usernames and passwords. The alarm clock still did not work.

The following day, the Dexcom G5 Mobile app, which I use to check my blood glucose in real time, began to fail.

Screeeeech. Screeeeech.

The app let out a high-pitched sound, crashed, and needed to be

reset every few minutes. This was distressing. As a Type 1 diabetic, I need to check my blood sugar regularly throughout the day.

Introduction

This article begins with a narrative about a clock and its participation in a system of technologies—the other applications, the operating system, the hardware, the satellites, the sensor embedded under my skin, and the transmitter (to name the most obvious digital and material components). The narrative is rich with the many temporalities, materialities, meanings, affects, and contingencies that are ever present in these systems as well as in my lived experience as a disabled cyborg. As such, my body is networked and dependent on a system of technologies that is fragile, vulnerable, and prone to breaking down. Like the iPhone nestled under my pillow, the disabled cyborg exists within, between, and out of sync with *intimate infrastructures* in which the world collapses onto the body and, at the same time, the body expands out into the world.

From these personal narratives, we can begin to understand, in new and different ways (and in ways more faithful to feminist science), questions about data, infrastructure, and the multiple human experiences of time. The ways in which it is possible to see the self in the system (Slavin, 2016). As Alondra Nelson (2008) writes in her ethnographic work on race and genetic testing, such scalar projects “take form at the interplay of macro-, meso-, and micro-level processes” (p. 776).

As a disabled cyborg, two medical devices—the insulin pump and continuous glucose monitor (CGM)—mediate my experience of the world. One might argue that this is no different than wearing eyeglasses, a prosthetic leg, or a hearing aid. But I am a networked hybrid, wirelessly sending and receiving data through a patchwork of analog and digital objects. I cannot go more than an hour without being plugged in. I can be no more than twenty feet from the CGM receiver. Such intimacies keep the system functioning, however imperfectly. When I spend too long in the bathroom—for example, when washing my face or brushing my

teeth—the CGM loses track of me. I wait fifteen minutes and it rediscovers the streams of data flowing from my body. I am not a set of parts fused together as one. Rather, I am a living system in which capabilities are distributed and shared in a human-machine collaboration.

These devices introduce industrial clock time to my internal biological processes and thereby mediate my social interactions as well. This lived experience allows me to challenge the binaries of nature and culture in line with much feminist science. The insulin pump regulates the amounts and times of day that insulin is circulated into my bloodstream. The CGM provides me with real-time data about my blood glucose. In the healthcare field as well as in the Quantified Self movement, there is much focus on the transmission, sending, receiving, and protection of data. Data is tracked, measured, and transmitted in order to manage chronic disease and disability. It is used to actualize self-knowledge and safeguarded around privacy concerns. Drawing on Alison Kafer's notion of *crip time* (2013), I describe the everyday rituals that emerge when living with real-time data around sociocultural norms. This is significant because, as Kafer points out, diabetes has been understudied and overlooked in disability studies and, in addition, many diabetics themselves shun the association with disability. While I have adopted the disabled identity in my previous writing on this topic (Forlano, 2016), temporality is not one of the most obvious aspects of the lived experience of diabetics.

In this article, building on James Carey's ritual view of communications (1988), I advance the concept of *data rituals* as a feminist data practice—a way of doing science out of feminist theory. *Data rituals* operate at the intersection of qualitative, quantitative, and technocentric ways of knowing. These rituals reintroduce the lived experience of the disabled cyborg to the practice of data gathering, interpretation, and knowing. The labor of caring for and attending to data and devices as a significant part of everyday activities mediates human-machine relations as well as social relations. Exploring data rituals as feminist science complicates and critiques common techno-deterministic

promises of the control of humans and culture over (and separation from) the environment and nature, which are pervasive in studies of systems, technologies, and infrastructures. This line of reasoning opens up questions around posthuman subjectivities with respect to experiences of time.

Becoming as Knowing Differently

I began this research in March 2011 but, unlike my other projects, I did not choose it. Instead, it chose me. With this investigation, the site was not a scientific laboratory, a design studio, or an urban space: I conducted this research on my own body and in my own domestic space. It followed me wherever I went. I did not have any theories, notes, questions, or arguments. For many months (if not years), I wished it would just go away. March 2011 was the month I received my diagnosis: I had become [Type 1] diabetic.¹

The exact details of the months and years that followed were frustrating and complex. The diagnosis was alarming. I was born in a macrobiotic “study house” (some might say commune) in Brookline, Massachusetts. Yet here I am with noticeable traces of a somewhat thorny love affair with networked medical devices written all over my body: a round, purplish bruise here; a crusty scar, still clotted with blood, there; a tube protruding from my stomach (in what I like to call a “port” in order to emphasize the cyborg qualities of this existence). Nearby is a small, brick-like transmitter about half the size of a box of matches.

My original excitement about writing on this topic was to expose the daily comedy around the lived experience of chronic disease and disability. After all, laughter is thought to be therapeutic. I take my own partial, situated (Haraway, 1991a), and intersectional (Crenshaw, 1991) perspective as a disabled cyborg body as an epistemic site. Yet my first attempts to publish on this topic met with resistance. Even the most experimental journals and platforms demanded that I *write my body out of the narrative*. Feminist science studies holds space for these concerns

and perspectives in ways that science turns away from and often outright rejects. According to science, this way of knowing the world differently as a mode of knowledge production is highly suspect.

Becoming diabetic is a way of knowing the world differently. We must know the world differently in order to design multiple possible alternative futures that advance feminist concerns around social justice. There are many temporal questions suggested by the empirical case of the disabled cyborg as a way of doing science out of feminism.

Click. Click. Click.

Like the clock, these questions are ticking away in the mind during the most mundane moments of everyday life. For example, what kinds of intimate relations are present in the everyday life of the disabled cyborg? How can multiple subjectivities align and realign around networked medical devices? In what ways does the disabled cyborg “keep up or fall behind” around sociocultural norms? In what ways do these spatiotemporal relations traverse different scales and lived realities (Pollock & Subramaniam, 2016)? How is this knowledge cooperatively and collaboratively produced—by human and nonhuman actors—in everyday interactions and practices? Who might benefit if we validate these forms of knowledge? Who might be left out? For me, the answers to these questions as well as the knowledge that I gain from reflection is a necessity of living-dying (to trouble the binaries and “stay with the trouble” of life itself) (Haraway, 2016).

Cyborg Intimacies

Science fiction films are rife with accounts of cyborgs, a term that emerged in the 1960s as a blend between *cyber* and *organism*. The *Oxford English Dictionary* defines *cyborg* as “A fictional or hypothetical person whose physical abilities are extended beyond normal human limitations by mechanical elements built into the body.” Here, images of

humanistic robots and “supercrip” athletes come to mind.

Yet, while the cyborg has traveled widely in science fiction as a representational, discursive, or linguistic object, feminist scholars argue that there has been little attention to the material-semiotic realities of living as a cyborg. The embodied material-semiotic relationships were intended by Haraway’s reframing of the cyborg as “a cybernetic organism, a hybrid of machine and organism, a creature of social reality as well as a creature of fiction” (Haraway, 1991b). She describes three boundaries that are transgressed by the cyborg: human and animal, animal-human (organism) and machine, and physical and nonphysical. According to Haraway:

From one perspective, a cyborg world is about the final imposition of a grid of control on the planet, about the final abstraction embodied in a Star Wars apocalypse waged in the name of defense, about the final appropriation of women’s bodies in a masculinist orgy of war....From another perspective, a cyborg world might be about lived social and bodily realities in which people are not afraid of their joint kinship with animals and machines, not afraid of permanently partial identities and contradictory standpoints. The political struggle is to see from both perspectives at once because each reveals both dominations and possibilities unimaginable from the other vantage point. (pg. 154)

Despite this reframing and Haraway’s desire to overcome all manner of binaries, the cyborg cannot escape racialization and the associations between race, structural inequality and injustice. Specifically, Alexander Weheliye (2014) argues that race has been overlooked in discussions of the cyborg and the posthuman in the humanities and social sciences:

The volatile rapport between race and the human is defined above all by two constellations: first, there exists no portion of the modern human that is not subject to racialization, which determines the hierarchical ordering of the *Homo sapiens* species into humans, not-quite-humans, and nonhumans; second, as a result, humanity has held a very different status for the traditions of

the racially oppressed. (p. 8)

In order to account for race in sociotechnical assemblages, Weheliye introduces the notion of *habeas viscus*, which attends to the ways the oppressed occupy “distinct assemblages of what it means to be human in the modern world” and to

the importance of miniscule movements, glimmers of hope, scraps of food, the interrupted dreams of freedom found in those spaces deemed devoid of full human life (Guantanamo Bay, internment camps, maximum security prisons, Indian reservations, concentration camps, slave plantations, or colonial outposts, for instance)...*habeas viscus*, as an idea, networks bodies, forces, velocities, intensities, institutions, interests, ideologies, and desires in racializing assemblages, which are simultaneously territorializing and deterritorializing. (p. 12)

Weheliye does not specifically use the figure of Haraway’s cyborg in his discussion; rather, he draws on Rosi Braidotti’s notion of the posthuman (2013). While the cyborg is a useful shorthand through which to navigate my own experience, in fact, the technologies I use do not allow me to transcend “normal” human limitations but restore abilities that I previously had. These technologies merely attempt to simulate the work that my pancreas once did on its own.

While I do not explicitly address questions of race (or the racial experiences of temporality) in detail my account of the disabled cyborg, implicitly, I am speaking about my own experience as someone who “reads” as white, along with the associated privileges within a society that is infected with deep structural inequalities. At the same time, I believe that my experience of disability and difference aligns with Weheliye’s critique. I acknowledge the extreme privileges that I have in reflecting on these experiences from a position of relative power, including a tenured position at a university; health insurance with a pre-existing condition (at least for the time being); the finances to be able to afford the thousands of dollars for doctors’ appointments, insulin, medical supplies, and device upgrades that it costs per year to stay alive;

a committed partner who takes good care of me; an apartment located in a downtown neighborhood in Chicago just five minutes' walking distance from my endocrinologist; and a higher education that demonstrated to my doctor that I was intelligent, responsible, and well-organized enough to manage my condition independently. None of these privileges have been earned through meritocracy; they are the product of structural inequalities that illustrate the benefit of having been born white and growing up in a nice college town in upstate New York. This is very significant, since diabetes disproportionately affects people of color—especially Latinx and African Americans—and, furthermore, can lead to many other complications and disabilities, such as stroke, heart attack, blindness, or the amputation of a limb. With respect to race, in my previous feminist scholarship and design practice, I have attempted to hack, trouble, and question racial binaries and my own relationships to structural inequality (Forlano & Halpern, 2016; Forlano & Jungnickel, 2015). Some of these realizations have come more slowly than others. Elite university training fosters many interrelated cultures of oppression, based not only on race but also gender, class, ability, sexuality, and age—not to mention speciesism, the overattention to human needs and the human condition.

Like the words *cyborg* and *posthuman* and their critiques, the word *intimate* has a number of definitions that are relevant to unpacking feminist science. These include associations with related terms such as *close*, *familiar*, *private*, and *personal* (*Oxford English Dictionary*, 2017). It is also used to understand the possession of detailed or thorough knowledge. This term appears frequently in feminist technoscience with respect to its characterization of embodied, located, situated, and multiple sociotechnical and multispecies relations. In Donna Haraway's latest book, *Staying with the Trouble*, she discusses the making and conjugation of kin with an example about pharmaceuticals that are used for menopause. She states:

The relations of *intimate* [emphasis mine] care yoking together one woman and one dog rampaged virally into all sorts of publics. Sheer contagion. Companion species infect each other all the time.

Bodily ethical and political obligations are infectious, or they should be. Before my dog and I could get out of the story, we were in the nonoptional company of—and accountable to—heifers in labs, beef cattle in feedlots, pregnant women in all sorts of places, daughters and sons and granddaughters and grandsons of once pregnant women, angry and well-informed women's health movement activists, dogs with heart disease, and bebies of other spayed leaky bitches and their people in vet clinics and on beds. (Haraway, 2016, Chapter 5, Section 4, Paragraph 2)

According to Lucie Dalibert, STS has considered the ways in which “tools and technologies shape and (re)configure our actions, intentions, and subjectivities—our lives—they have scarcely accounted for implanted technologies and their ever more *intimate* [emphasis mine] relations with humans” (2016, p. 2). Her study of neuromodulation technologies, which are invisible implants illustrates the importance of the concept of intimacy. Specifically, she writes:

Concerned with the ways in which technological artifacts mediate the relations between humans and their world, the concepts of script and technical mediation are silent about the ways in which these technological artifacts might transform bodies and the relations between someone and his or her body. While they enable us to apprehend how technologies affect our actions in and perceptions of the world, they tend to ignore the matter of intimate human–technology relations: bodies. (p. 9)

Oudshoorn (2016) draws on feminist studies to give an account of heart defibrillators and the internal forms of vulnerability experienced by hybrid bodies. She discusses the “lived intimate relationships between bodies and technologies” made up of “sensory experiences, material practices, and cartographies of power” (p. 1).

These experiences of intimacy described in human-machine relations can also be extended to alternative ways of doing feminist science. For example, in the essay, “A new form of collaboration in cultural anthropology,” the Matsutake Worlds Research Group offers an

alternative mode of doing anthropology that can draw on collaboration for the purpose of understanding into account global, multisited phenomenon. Unlike big science, which requires universal, standardized methods, Matsutake's approach allows the project to grow generatively, shift, and expand. The authors write:

One way to plot such diversity might be to contrast big-science and *intimate-authorship arrangements* [emphasis mine]....In practice, a good deal of heterogeneous territory lies between big science and creative authorship. The Matsutake Worlds Research Group is an experiment in making one piece of this territory livable. (Choy et al., 2009)

They enact this experiment through joint fieldwork, simultaneous analysis, and collaborative writing.

In my engagement with cyborg intimacies as ways of doing science out of feminist theory, I attend to the visual, temporal, and material-semiotic aspects of my lived experiences. One aspect of material-semiotics that is particularly relevant is my active participation in processes of calculation, which require access to, interpretation of, and even sharing of real-time data.

Quantifying Multiple Selves, against Our Will

Many recent empirical accounts about big data, the Quantified Self, and the internet of things from both academic research and the mainstream media focus primarily on the transmission, storage, and analysis of large quantities of data. With Type 1 diabetes, measuring, counting, and tracking became a necessary part of everyday life. But, for me, they were not a welcome part.

More recently, cultural anthropologists and qualitative researches have turned their attention to gaining a deeper understanding of the sociocultural, political and economic aspects of self-tracking and sensors (Dow Schüll, 2016a, 2016b, 2017; Howard, 2015; Neff & Nafus, 2016). In order to describe the more qualitative ways these data practices are

being experienced, researchers have developed a rich language around thick data (Wang, 2013), the qualified self (Humphreys, forthcoming) and, lived data (Kaziunas, Lindtner, Ackerman, & Lee, 2017).

Here, Carey's ritual view of communication is valuable for understanding differences between the lived experiences around data (rather than merely the transmission of data). He writes:

A ritual view of communication is directed not toward the extension of messages in space but the maintenance of society in time (even if some find this maintenance characterized by domination and therefore illegitimate); not the act of imparting information or influence but the creation, representation, and celebration of shared even if illusory beliefs. If a transmission view of communication centers on the extension of messages across geography for purposes of control, a ritual view centers on the sacred ceremony that draws persons together in fellowship and commonality. (Carey, 1988)

Building on this definition, I argue that *data rituals* allow for the creation of human and nonhuman fellowship as a feminist data practice in line with related modes of engagement such as feminist data visualization (D'Ignazio & Klein, 2016) and feminist human-computer interaction (Bardzell, 2010).

Clock Time and Crip Time

In fall 2013, I opened a flat, white, rectangular box with a minimalist design, the kind that usually contains an Apple device. The experience screams: "Designed by Apple in California. Assembled in China." It's the embodiment of high-tech, Silicon Valley culture. Inside was not a new iPhone or a red iPod, but an upgrade for a medical device: the MiniMed 530G, an insulin pump produced by the medical technology company Medtronic. While these technologies differ from those commonly invoked in Silicon Valley rhetoric and innovation discourses, they are deliberately marketed, packaged, and branded in order to fit in with other high-tech

products. As a researcher of emerging technologies, I am interested in the ways in which technological language, meanings, and metaphors—such as a particular white box and its telltale sans serif font—are translated and replicated throughout seemingly disparate realms of society.

Shortly after receiving the box, I received an email from Medtronic's head of customer experience:

Earlier today, my team received positive comments on the packaging for our new MiniMed 530G with Enlite from a customer on Twitter, *"Nice set with the packaging of the new pumps @MDTDiabetes! It reminded me of opening a new Apple device."*

This compliment came after we worked to put ourselves in the shoes of our customers and understand the overwhelming experience they had opening their first shipment from us. (J. Anglin, personal communication, Nov. 7, 2013).

The MiniMed 530G—approved by the Food and Drug Administration (FDA) on September 26, 2013—is a system of technologies that includes the pump, a CGM, a glucose meter, test strips, and software. The CGM is comprised of a sensor, a transmitter, and a receiver. The glucose meter communicates wirelessly with the pump and the transmitter communicates wirelessly with the receiver. While Medtronic markets its own proprietary system that includes a CGM, I use a monitor that is produced by another company, Dexcom. The two proprietary systems do not interoperate, except through third-party applications that allow the uploading of data from both devices.

While insulin pumps have been used to manage Type 1 diabetes since the early 1980s, they often go unnoticed in everyday life; today's models are relatively small and resemble other mobile technologies—many people do not want to call attention to their medical conditions.

According to the American Diabetes Association, an insulin pump is:

an insulin-delivering device about the size of a deck of cards that can be worn on a belt or kept in a pocket. An insulin pump connects to narrow, flexible plastic tubing that ends with a needle

inserted just under the skin. Users set the pump to give a steady trickle or basal amount of insulin continuously throughout the day. Pumps release bolus doses of insulin (several units at a time) at meals and at times when blood glucose is too high, based on programming done by the user. (American Diabetes Association, 2015)

The first wearable insulin pumps—invented in 1976 by Dean Kamen—were very large and impractical (DEKA Research, 2017).

The MiniMed insulin pump is produced by Medtronic, a company that was founded as a medical equipment repair shop in 1949 and soon after created the first wearable, battery-operated pacemaker. In 1979 the company began to develop plans for an insulin pump when it was learned that heart problems are linked to diabetes; in 1983, it created the first MiniMed pump. In the past thirty years, Medtronic has made many incremental improvements to both the software and physical design of the pump. These upgrades include the ability to detach the pump from the body temporarily without having to completely change the infusion set (the tubes that connect the pump to the body). In 1999 the FDA approved the first physician-use glucose monitoring system, which relies on inserting a sensor into the body (Medtronic, 2015).

The MiniMed 530G is the first insulin pump in the United States that can be called an “automatic pancreas” (also known as an “artificial pancreas” or “smart pump”). Its defining feature is that it can automatically shut itself off when one of its monitored biometrics drops below a set threshold: for example, in the middle of the night. The menus—bold black lettering on a glowing green background, navigated by buttons marked with up and down arrows—seem archaic when compared to today’s interactive touch screens and voice-controlled artificial intelligence. They are reminiscent of a 1980s Casio calculator watch. But the pump itself is actually a sophisticated computer that can wirelessly receive information about blood glucose from a special meter and calculate the proper amount of insulin to administer. In order to “deliver” insulin, it turns a small screw inside the device, which pushes

the insulin through a long tube that has been inserted into the body. With only five buttons, it is simple enough for a diabetic of any age to use.

My insulin pump is on clock time. It leaks insulin into my body at set times and in set amounts: 12 AM, 3 AM, 6 AM, 4:30 PM. When I eat, another set of times, conversions, and amounts. When I make adjustments, another set. According to these settings, the insulin remains active in my body for precisely four hours. Here are two examples of how the clock time of devices interrupts lived experience.

On March 16 at 7:49 PM, my pump displayed a “Low Reservoir” alert. At 11 PM, when I returned home from dinner at an Italian restaurant with a new writing group, I checked to find that only 2.9 units of insulin remained, which would last just over five hours, according to the pump’s settings. I decided to refill and reset the pump before I went to sleep rather than getting up in the middle of the night or very, very early.

My glucose monitor, on the other hand, announces with a high-pitched alert that it will need to be reset in two hours. Never mind that I am teaching on Wednesdays and am in the middle of a lecture in my Designing Futures class. I dismiss it but again, about ten minutes later, a shrill beeping sound and no way to silence it. It seems to sound louder and louder every time, unaware of its surroundings.

In contrast to clock time or lived experience, according to Kafer, there are several reasons for developing the notion of crip time. For example, the medical field frequently describes disability in relation to time as well as duration of symptoms. Yet there are also other, more generative reasons to explore crip time in order to understand different experiences of time. This might mean expecting things to take more time due to slower physical mobility, or requiring more time on a test. Kafer (2013) argues that crip time is in fact “a reorientation to time” characterized by the need for flexibility, since the speed of everyday life is determined by normative

bodies. “Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds” (p. 45).

Data Rituals and “Fitting in with the Flow of Things”

Like crip time’s proverbial bending of the clock, data rituals envision the ways in which both medical devices and the broader society might more deliberately accommodate disabled bodies and related socio-cultural contexts. In this section, I will describe the social practices and my own lived experiences around tracking, measurement, and calculation over the past five years. During this time, I learned to manage a complex mesh of calculations, routines, and relationships that make life possible—and sometimes quite impossible. These narratives represent different phases and contexts with distinct features that configure unique temporal relations between people, technologies, and spaces. Briefly, these can be characterized as: pre-insulin-pump (spring 2012 to summer 2013), pump and CGM device (fall 2013 to spring 2016) and pump and CGM iPhone application (summer 2016 to present). In the pre-pump phase, it was necessary to use both a glucose meter to check my blood glucose (BG) and an insulin pen in order to administer the correct dosage at mealtime. In the pump and CGM device phase, I could check the monitor and administer the insulin via the pump. Finally, in the current phase with the pump and CGM iPhone application, my husband can also access the data from the CGM in real time.

Waiting, Interruptions, Delays, and Cold Pizza

Once, when dining out with a group of (newish) European friends, I waited for the food to arrive, sized it up quickly so as not to attract attention, did some calculations in my head, and rushed off to the restroom. There I tested my blood sugar with the glucose monitor. I took a small test strip out of a plastic canister and inserted it into the monitor. Next, I pushed a small blue lancet into the lancing

device, replaced the cap, and pierced my left pinky.

Now I had the information that I needed in order to determine the correct amount of insulin to administer: my blood glucose and the amount of carbohydrates I was planning to eat. I was always good at math in high school, but I was an awful bank teller and cocktail waitress, often coming up short at the end of my shift. For me, doing calculations on the fly did not come easily.

I stood in the bathroom stall, trying to balance a glucose monitor, the insulin pen, and my iPhone while repeating my calculations until I was sure that I had reached the right result. Then, to inject the insulin, I took the protective seal off of the needle and attached the needle to the pen. Next, I took out an alcohol swab and wiped the area of my stomach where I was planning to inject the insulin. Finally, I lifted my shirt while twisting the cap of the insulin pen. I returned to the table having administered what I hoped was the correct dosage. Meanwhile, my friends were gritting their teeth and watching the pizza grow cold.

Sociocultural norms, temporal patterns, and rituals around food and eating are very specific, relational, and situated (Suchman, 1987) with respect to the type of food, time of day, and context (including the diner's gender, race, age, and class). It is difficult when one falls out of sync. In this context, prior to adopting the insulin pump and CGM, crip time refers to the slowing down, interrupting, and violating of the social norms around dining in order to accommodate processes of measurement and calculation. By abruptly leaving the table as soon as the food arrived, I had violated a social norm that indicates that when the food arrives, it is customary to begin eating together as a group, sometimes after uttering a culturally appropriate phrase such as "*bon appétit*." Here, data rituals are the embodied processes—inserting, pushing, holding, balancing, lifting—required to access the data, create meaning around it, and act on it in the context of eating a meal. When using medical devices such as insulin

pens, glucose meters, and lancets along with everyday digital technologies such as iPhones, one is managing a complex set of interactions that are required in order to proceed with the meal. I was trying to manage these interactions accurately while feeling rushed and stressed. I wanted to complete these tasks quickly so as not to delay the meal further and attract attention. This attention to the affective state around data and calculation exemplifies how these mundane, everyday activities can be understood as feminist data practices. As ways of doing science out of feminist theory, we can develop deeper understandings of the temporal experiences of difference in order to allow for flexibility around social norms.

To avoid these social interruptions, I eventually developed some shortcuts and skipped some of the doctor-recommended steps. Instead, I relied on my own situated knowledge of cleanliness, safety, and risk. For example, to save time, I stopped using alcohol swabs altogether and only replaced needles once a day (rather than every time I needed to inject insulin). Both steps are time-consuming and awkward.

In particular, many public bathrooms are not well suited for procedures of this kind, because they are often poorly lit and lack clean flat surfaces (especially within private stalls). Since these processes require so many different devices and parts, it is also not unusual to drop things onto the floor. This is especially gross in a dimly lit bar with purple mood lighting (likely to intentionally discourage needle users of another kind) or an airport bathroom. Due to bad lighting, I have often stabbed myself in the finger with the needle or dropped the pink plastic cap on the grimy floor with my pants down around my knees. Trying to pick up small parts while simultaneously holding my pants and not touching anything became something of an art—one for which no doctor, nurse, or medical professional ever prepared me. Eventually I started doing my injections under the dining table, but this was really only possible if I was wearing a skirt.

Now, with the insulin pump and CGM, I can check my blood glucose on the monitor screen, glance down at my pump before I eat,

and administer the correct dose of insulin without getting up from the table or managing many different devices and parts. Technology “fits in” in public settings much better than needles, vials, and other medical devices. Most people scarcely notice when I take out my insulin pump and begin quickly punching the buttons. In the worst case, I am mistaken for a very important doctor (which I am, but *not that kind of doctor*) or, even, a kind of modern steampunk Luddite. Some of the calculations (namely, the insulin to carbohydrate ratios) are built into the device so I only need to compute the number of carbohydrates that I am planning to eat (rather than needing to multiply them). In addition, I can manage this process more easily with only three buttons that I can press with my thumb using one hand. This is much faster, but still requires some thought and takes my gaze away from the conversation.

Slowing Down/Speeding Up

I chew very slowly when my blood sugar is too high. I try to delay every bite for just a few minutes. I want to give the insulin more time to kick in. This can happen when I've just had breakfast or, really, for any number of reasons that can cause blood sugar to spike upward: drinking coffee, exercising, coming down with a cold, being stressed, having your period. Insulin works better when you allow at least fifteen minutes before eating. But, much like my slow chewing, this is a noticeable interruption in a meal.

On the other hand, when my blood sugar is too low, I eat more quickly—starting with fruit or anything that is high glycemic (absorbed quickly) and high in carbohydrates. I frantically grab for orange juice, lemonade, or even, in desperation, a Coke. In the worst case, I can take four orange-flavored glucose tablets, but I prefer to avoid them. I detest their chalky texture on my teeth

Like the interruption described in the previous section, my need to slow down or speed up based on my BG (or, even abstain from eating

completely) can sometimes feel like an awkward pause, an inconsiderate manner or an inability to “fit in” with the flow of things. When I check my BG on my monitor, I can see the speed at which it is rising or falling. If it is rising quickly, I might try to eat more slowly. As described in the narrative above, in this case, *crip time* denotes a slowing down of social norms around meals—for example, during a one-hour lunch meeting, if my dining companion has already finished their meal but I have only eaten a few bites. In this case, the data rituals relate to checking the data and having a sharp awareness of the speed at which I am chewing. While movements such as Slow Food might celebrate slowing down, these breaks in daily interactions can also signal a misunderstanding of social cues around dining. In the United States, a professional lunch meeting is often limited to an hour. The inability to eat quickly (in order to avoid an additional spike in blood glucose) can result in anxiety around not being able to keep up with professional norms.

On the other hand, if my BG is falling very quickly, sometimes, I am quite fearful that it will drop much too low. I will become sweaty, uncomfortable, confused, and pale. I hope that drinking or eating something high glycemic will allow me to recover quickly enough to carry on a conversation without causing attention. Whereas, in some cases, *crip time* can be about slowing down or needing more time, this example illustrates that it can also be applied to speeding things up. Of course, if my BG does suddenly go much too low, sometimes I need to rest for a few minutes, an hour or even several hours, due to feeling exhausted by the extreme fluctuation. This results in an interruption or a need to slow down again, which unveils how *crip time* and data rituals are configured differently in different situations and contexts.

Things That Go “Buzz” and Flash in the Night

In May 2016, I upgraded to the latest version of the CGM, which connects the data from the transmitter directly to an iPhone application. The integration of the data into an existing device means that the data

and alerts are quieter, less noticeable, and hidden. The previous CGM device had loud alarms and buzzers that would go off to signify low or high BG, low battery, sensor disconnection, and the need for sensor replacement. These alerts were particularly intrusive in public settings (faculty meetings, advising meetings, class sessions, conferences) as well as during the middle of the night.

One of the more distressing features of the system is its disruption of sleep cycles. While I have always been a very good sleeper, the CGM has consistently interrupted my ability to sleep through the night (as well as my husband's). Some nights, the CGM would repeatedly go off because my "number" was too low. This happened even if it was only slightly low (or even incorrect altogether). Other nights, it would go off because my BG was very, very low, prompting the need to chew glucose tablets or get up to drink juice. Here is an example:

The other night, I found myself standing in the kitchen drinking juice in the middle of the night in order to keep my monitor from continually beeping. It signals that my blood sugar is 52, which is very, very low. Too low. "It is 4:11 AM and my monitor needs juice," I think to myself. But, I am feeling just fine. I check my blood sugar with a glucose meter to verify that it is low. At 4:30 AM, it reads 65.

While 65 is indeed a low reading, there are other times in which the application might signal a low BG but, when I test with a meter, my actual BG is twenty to sixty points higher; there had been no need for the device to wake me up in the middle of the night. On other nights, the CGM alerts me that my "number" is too high—usually after heavier meals eaten late at night or meals that combine a lot of protein or fat with a lot of carbohydrates or sugar—meaning that I need to administer additional insulin via the pump while squinting, bleary-eyed, at the glowing green screen. Sometimes the CGM wakes my husband but not me, and he crawls out of bed to pour me half a cup of orange juice.

The iPhone application version of the CGM allows more customization of the loudness, type of alert, and frequency of alert. While

there are still some annoying features—like the fact that it makes a faint buzzing sound (rather than merely flashing an image of a drop of blood as in the previous version)² if you do not input new BG data every twelve hours—it fades into the background more easily. It limits the number of devices I need to carry around and calls less attention to my disability.

Here, crip time is about sleepless nights and the data rituals around attending to the maintenance, repair, and care of the devices (Forlano, 2017). It is about a temporality that considers the calibration of internal processes with machine processes. Rather than clock time or lived time, the data creates a liminal time that mediates bodies, data, and technologies in the middle of the night.³ With frequent sleep interruptions, I find myself irritable and have difficulty concentrating the following day.

Love Notes Made of (Blood) Sugar

A final temporal feature of the CGM iPhone application version worth discussing is the availability of real-time data sharing. While the previous device was typically in my control—for example, in my purse or pocket—now my husband can check the application on his phone. When my BG is too low, it affects my mood and my ability to get through everyday tasks and situations, such as walking quickly down the street in a hurry to get somewhere, doing household chores, exercising, or working. My husband's access to the data allows him to participate more actively in the practice of care (Mol, 2008). For example, soon after we started using this feature, he spontaneously texted me with the following note: “BG holding @ 134.” I was sitting nearby reading, in the same room, but this act of care was about much more than the transmission of data or information. Similarly, sometimes on a busy day when my husband cannot reach me by phone, he can check the application and “see” one measure of how I am doing. He might text me to let me know that he is checking.

In this example, crip time can be shared time: the creation of empathy, community and care through data rituals of a partner, friend, or

family member checking in on a loved one. In this case, rather than an isolating disjuncture in everyday life, crip time can be a way of creating a shared experience or worlding (Haraway, 2011) together. In addition, data-sharing practices distribute the invisible labor of constantly checking BG. While the sharing feature could be viewed as an attempt to control or surveil the day-to-day life of a diabetic—for example, scolding a person for eating something that might have caused blood sugar to rise too quickly—in my experience, it is more of a demonstration of everyday care.

Conclusion

This article argues that lived experience of Type 1 diabetes—partial, situated, and embodied—can be understood as a feminist data practice. Specifically, this article expands on the notion of crip time in order to understand four different ways time is experienced around data practices: slowing down, speeding up, liminal time, and sharing time. I introduce the concept of data rituals to describe how the transmission of data is not (or not only) all that is required to engage in everyday activities such as eating, sleeping, and being in the world. Instead, I describe the day-to-day rituals required to participate in social norms, care for oneself, rest and recuperate, and even maintain relationships with loved ones. This subtle awareness of the temporal constraints and affordances of disability allows for the rethinking of existing categories, a way of doing science out of feminist theory. In writing this, I have expanded my own understandings of the experience of difference—but, after nearly two months, I still have not been able to fix the alarm clock on my iPhone.

Notes

¹ In fact, my original diagnosis was Type 2. It was not until July 2012—nearly eighteen months later—that I received the Type 1 diagnosis.

² This feature has been fixed in the latest version. Now, rather than buzzing, it merely lights up the screen every few minutes with an alert. While less intrusive, sometimes the screen itself is enough to wake me in a dark room.

³ Before using the CGM, I often woke up in the middle of the night alone, drenched in sweat, and too weak to get out of bed for juice. When BG is too low or too high, diabetics face a risk of coma. For nearly two years, I went to sleep just hoping that I would wake up in the morning.

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