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Between beeps: An autoethnographic study on Type 1 Diabetes, intersectionality and the body in chaos

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Between Beeps:

An Autoethnographic Study on Type 1 Diabetes, Intersectionality and the Body in Chaos

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JAMES MADISON UNIVERSITY

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I came to the communication and advocacy program with a purpose, a hope to help those that struggle like me, with a story of Type 1 Diabetes. But at the same time, I came to the program with a worry, a worry that my story could be too selfish, that no one would want to read my story, or hear what my story had to say. I firstly thank my thesis adviser, Dr. Kathryn Hobson, for introducing me to a methodology that so perfectly matched my world view. For reaching out to me, the quiet one in seminar after a reflection essay, who saw a me that could do better things with her performative creative writing and knack for evocative aesthetics that I could not see for myself. The countless emails and texts, of epiphanies while writing in the middle of the night, and steady ear to hear my thoughts of self-doubt, for just as many meetings of self-care as there were meetings of thesis work, and for being the first I encounter in this program to say, “me too” and “I understand”, I thank you.

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Now, let's get to work.

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ABSTRACT

This autoethnographic study examines Type 1 Diabetes through the lens of intersectionality framework, power and discipline, and the chaotic story of the body. As an Adult Type 1 Diabetic at diagnosis, I explore the tensions between my already established identities as an Asian American woman in academia attempting to incorporate and accept another identity, an identity of illness. This study utilizes sensory discourses and aesthetic arrangement of ten illness narratives to delve into my experience, placing the points of tension between my identities in conversation with my body's silenced story of chaos as it undergoes acts of power and discipline. In teasing out my illness narratives, I invite the reader with me to sit with illness and to imagine the usually silenced affects as the muted body is engaged through self-reflection and interactions with others. Through the storied experience of my illness, I hope to evoke action in the form of reflection and mindful-action.

INTRODUCTION

“I beep.”

My heart rate speeds up and my cheeks brighten as I utter the same introduction, one that I know backwards and forwards because we do it in every class since the beginning of the program. I duck my head and look down at the cold piece of metal in my fingertips, attached to me in a tangle of plastic and glue. There has to be a reason why I start off every introduction I’ve made in graduate school with that sentence. Flustered, bashful, apologetic: it is never something I am proud of, much less something I want to say aloud. I beep. I beep to live. Look at me do it—right here, right now—as easy as breathing. Inhale. Exhale. Beep. It’s not as frequent or as rhythmic as the beeps of an EKG monitor, yet I feel the need to subtly apologize for it in my introduction to colleagues, as if to say I’m sorry for bothering you with the way in which I live.

I beep.

And it’s okay, there’s nothing wrong with that, right? The smooth plastic of my monitor is smaller than a first generation iphone, but it’s not a phone to silence. I need the beeps. My colleagues are people who would understand this best, who would understand me best. But why, before my own name, is this the introduction I choose to lead? I beep for a plethora of different reasons: my insulin dosage is complete, my insulin is blocked, my blood sugar is too high, my blood sugar is too low, my insulin reservoir is too low, I need to change my infusion site, there’s something wrong with my infusion site, there’s something wrong with the pump itself. There’s definitely something wrong with me.

I beep.

And sorry, sometimes I hate the sound because that means that something has gone terribly wrong and God, I do not have the time to deal with that right now. I beep because Type 1 Diabetes is about being a person with diabetes not a diabetic, and yet I can't escape the physical manifestations, the sounds that surround me even through sleep like numbered sheep. I beep and that comes before my name because I have an insulin pump and continuous glucose monitor that spell out diabetes more than crimson dots on my fingertips or bruises I hide underneath my shirt. I beep and sometimes that mechanical sound accompanies a sigh of relief: my body, working, despite its mechanical parts. I beep because it draws attention to me when I might not be able to take care of myself.

“She beeps.”

It's the smile on my face when my cohort knows what to say for me before I can even say it myself. It's the silent “I got your back” in their sheepish smiles. It's the pause in their speech right before they ask, “so, what is the difference between type one and type two?” or their hushed tones when they murmur, “okay, but is there anything I can do?” It's the look of wonder in my six-year-old niece's eyes before whispering to my sister “did you know she beeps? *Ah-tay* CJ is a robot” revealing the secret. My name is Cristal Llave and I beep. I beep because my Diabetes demands attention whether I like it or not, and the best way to convey to someone else is through my beeps that interrupt their daily activities too. There is no apology.

My illness needs to be heard, and here is why.

CHAPTER I – THE CONTEXT

My diabetes isn't the kind you hear of. It is not your cat you give insulin injections to. It is not your great aunt that lost her leg, and then her life. It is not me crouching beside my grandmother's bedside, checking her blood sugar while she is too weak to do so, as I learn how to use my first blood glucose monitor on her and not myself. I am diagnosed a month later, a twenty-four-year-old adult. It is kind of like "drink the juice, Shelby" but not quite, a story of a still stubborn and steel magnolia who now beeps on her way down.

I am not the child you expect to see. Try googling Type 1 Diabetes. Feel lucky with the first selection. And see the children that do not look like me, an adult at diagnosis attempting to fit into the same hula hoop as the child pamphlets say I should be. Type 1 Diabetes, previously known as juvenile diabetes, is an autoimmune disorder where the body's immune system attacks the cells in the pancreas that make insulin. Most individuals will develop Type 1 diabetes as children to early adulthood though its onset can occur at any time, this type accounting for about 5% of all diagnosed cases of diabetes (Centers for Disease Control, 2015).

"You're too young." My gaze rolls up from my current task of meticulously wiping and re-wiping the area of injection for an insulin infusion, the cool plastic between my fingers and the metal needle just about to pierce. I glance at my grandmother withering away from poor control of Type 2 Diabetes, thin bones, sagging flesh, curled fingers folded into a sign of prayer. Haunted by the memories of her family members who have lost their lives to Diabetes, she holds a stifling apprehension over an inevitable responsibility of our supposed genealogy all rolled together into one comment that etches

into every crease on her forehead. I'm too young or maybe too old, or maybe not quite too young or too old. Maybe somewhere in the middle, where I'm not supposed to be—the age where I'm not supposed to have illness. An age of invincibility, illness invisibility. Beep, BEEP!

“Is there any way to turn those off?”

Unlike Type 2 Diabetes, previously known as adult-onset diabetes, which can be linked to obesity and weight gain, there is no known cause for Type 1 Diabetes and no set of concrete measures to prevent the onset of the disease (Vishwanath, 2014). Literature addresses the stigma associated with Diabetes and how Type 1 Diabetics could not have taken preventative measures to avoid onset; however, the previous naming of juvenile diabetes (or even the similarity in type numeration now) leaves much to the confusion of both the patient and society. With the lack of representation even in the pamphlets I am handed at the doctor's office coupled with stigmatized views of diabetics in general, a significant part of this journey is the acceptance of a constant beeping, of an illness that becomes part of my identity. Such a big part, that it comes before my own name.

Purpose and Objectives

My thesis is an autoethnographic study that focuses on my chronic illness experience with Type 1 Diabetes. My purpose is to highlight areas of tension, negotiation, and clashing of identities as an adult diagnosed with Type 1 Diabetes continuously coming to terms with life after diagnosis. Constant corporeal interruptions of the mechanical components of management are the tools used to monitor and manage the disease, though inadvertently disrupts the course of healing. This autoethnographic project will utilize sensory discourses and aesthetic engagement through creative writing

in order to instigate mindful action in public arenas, to disrupt the common narrative of a Type 1 diabetic, and to interrupt the usual formulations of thought when anyone (not just health care professionals, friends, or family members) encounters a patient. Utilizing the critical lens of intersectionality and applying feminist framework to Foucault's theories of bio-power and discipline, this thesis examines different intersections of power, disability, and identity negotiation of an adult Type 1 Diabetic as an Asian woman, a professional, a family member, and a friend.

The disclosure and vulnerability illustrated through the autoethnographic layering of narratives and poetry will aim to address the cyclical, exhausting, and messier sides of Diabetes that cannot compute to any given biomedical measure of wellness. The text is meant to be accessible, from the endocrinology offices to the hands of a new college roommate, to the barista responsible for making a sugar-free drink, and ultimately to reach and reassure the adult who cannot seem to make ends meet, having to sacrifice healthy food for a prescription of insulin. For they too have to explain to a doctor their choices, but sometimes the story behind the numbers that dictate our lives do not match up. Sometimes, people are not even given the opportunity to beep, and that silence is too frightening a reality to let be.

Type 1 Diabetes and Illness Identity

Current literature on Type 1 Diabetes communication focuses on the stigma attached to being seen as a diabetic, the struggle of day-to-day maintenance of a chronic illness, burn-out and, the possible negative consequences of illness identity rejection. Type 1 Diabetes is a chronic illness that “exact a substantial personal and societal health burden” (Gawlik, Elias, & Bond, 2016, p. 351). While substantial, these personal societal

health burdens are not extensively explored beyond the use of canonical and vastly biomedical methods. Vishwanath (2014) emphasizes just how strenuous and dependent on numbers Type 1 Diabetes management can be when “patients suffering from Type 1 Diabetes have to follow a lifelong regimen of regular blood glucose testing, urine testing, and insulin therapy, in addition to constantly monitoring their diet and maintaining a healthy lifestyle” (p. 516). In short, Type 1 Diabetes management is exhausting, time-consuming, and wields a large amount of emotional toll.

However, the equation of testing, insulin therapy, and healthy lifestyle leaves variables out of a full experience of illness identity for Type 1 Diabetics such as societal stigma, representation in media (or lack there of) and, body image issues to name a few. Vishwanath (2014) argues it is critical to research public stigma of Type 1 Diabetes because little is known about it and few scholars have researched or addressed this issue. While lack of awareness and knowledge is commonly attributed to the stigma surrounding Type 1 Diabetes, Vishwanath’s study found that “62% of the respondents believed that information about having juvenile diabetes should be concealed from someone” (p. 523). This public belief in concealment of the illness leads to the shame and denying of identity for many patients. Even more striking in his study was that respondents had felt that the number one person this illness should be concealed from is their physician, yet the exploratory study did not go into why this was the case. The current methods currently in use are not enough.

There is less emphasis placed on the impact of Type 1 Diabetes on adult life, when nearly half of the cases that occur in North America and Europe emerge in adulthood (Thunander et al., 2008). In a meta-synthesis of nine qualitative cases of Type

1 Diabetes in adulthood, grief and mourning of a previous lifestyle lost was a common theme across participant accounts. Literature is needed to examine this transition and experience with sudden illness identity, especially as past research highlights a major difference from a diagnosis as a child versus as an adult, “adults must adapt to diabetes in the context of a life already well established in the social world” (Due-Christensen, Zoffmann, Willaing, Hopkins, and Forbes, 2018, p. 255). This interruption, from diagnosis to its continuous disruption of daily life, can trigger psychological distress, a state where the early adaptive phase and the habits acquired during it will have monumental and long-term consequences on the patient’s beliefs and behaviors (Due-Christensen et al., 2018). Disruption and the continuous chaos for an adult reconciling a life before diagnosis with a life influenced by chronic illness needs to be explored in greater detail.

Furthermore, while Diabetes education and management programs are provided and research is put into optimizing diabetes management care, literature suggests “individuals with Type 1 Diabetes may feel poorly understood by other group members or staff who do not have diabetes themselves, and who may have limited knowledge of the broad ways in which diabetes can influence daily life, long term health and self-concept” (Colton, Olmsted, Wong, & Rodin, 2015, p. 316). First words to the health care team may be “do you have Diabetes?” or even “do you know what it’s like?” Not just the feline with injections or the grandmother with a missing limb, patients search for an understanding from their healthcare team, to anyone involved in the everyday management of the disease. Colton et al. argues that “core issues related to developing an authentic sense of self efficacy and autonomy are sometimes complex” where prescribed

meal plans and insulin therapy may be seen as being controlled rather than the patient having control. This sense of having control through acts of regulating, calculating, and measuring creates a fine line on which Diabetics tread. But then, through this meticulous and particular regulating, is there the freedom, autonomy, and control of life that adults crave? Rejection of these prescribed treatments point to a larger problem of adequate central illness identity integration. Additionally, when tethered to machines, I wonder to what extent are they tools for monitoring and calculating the trends. I attach to a new technological crutch that leaves me panicked if I do not have it, or beeps angrily, admonishing me for stepping out of its predetermined range. In fact, the jolting beeps and buzzes monitor me.

By monitoring the body, we take care of it. While taking care of the body, we hurt it. Gawlik et al. (2016) focus on appearance investment, quality of life, and metabolic control of Diabetes and found that women with Type 1 Diabetes define and measure their sense of self-worth through the importance of appearance. The researchers assert “lack of clear image-modulating strategies could result in feelings of futility for individuals with high motivational salience” (p. 352). By looking at a Type 1 Diabetic, it is not easily detected that the patient is ill without the physical manifestations of its upkeep in the form of syringes, pumps, needles and pricks. Not only is insulin a growth hormone that may lead to problems with a patient’s sense of self-image and appearance, the act of administering and maintaining care for the chronic illness (an individual’s high motivational salience) mars the body, resulting in constant issues of self-image acceptance. While protecting and preserving the body through injections and insertions, we destroy it. The scars line are thighs to our forearms, the bruises leave trails, evidence

of our hard work. We are doing as we are told, but we're admonished for showing it. It's grotesque. It's dirty. No one wants to see that.

But they should. Luyckx, Rassart, and Weets (2015) warn of the consequences of illness self-concept rejection where someone who has accepted their illness identity may feel engulfed or overwhelmed by their illness, "individuals scoring high on rejection simply reject their illness and view it as unacceptable to the self" which could lead to very detrimental and life-threatening results (p. 83). Rejecting the illness identity and all its continuous management, or even attempting to hide it can take away from the effectiveness of management. But there's more to this than just a patient unwilling to comply. There's a patient just trying to live.

Illness Narratives through the lens of Autoethnography

"You don't look like you need a sugar free latte."

And maybe I don't, I agree with the employee donning the green apron and the backwards white visor cap, seeing as some days I could use the extra syrupy sweetness that melts in my mouth topped with heavenly whipped cream. But today my blood sugar trends were looking more like the mountainous terrain than the even flats of the quad, but I still had a class to go to and be awake for. So, sugar free it would have to be.

I meet his eyes to reply, and for some reason all that surfaces beyond the rehearsed responses in my mind is light laughter and nonchalant shrugs of my shoulders. He continues to stare down at me, elbow hanging from the order booth, reflecting my shrugs and goes ahead with making my drink. That is until he begins conversing with another customer more aptly responding to his inquiries, passing my drink to another employee as she brings out the remains of the lemonade container. The neon yellow bits

of crystalized sugar slug around slowly on the bottom of its plastic cage, and I wonder vaguely if that's what my blood looks like when—

“Do you think I'll get Diabetes if I drink this whole thing?” He grins at his new audience, leaning over once more from drink window. “Do you dare me to?”

Illness narratives often have a goal to address and reduce stigma and marginalization of illness and disability. Beyond the gaze placed upon me as a frame undeserving or perhaps not needing a sugar free drink, there is the obvious humor the worker, someone who has no connection to me or my audience, has that uses a disease as the butt of a joke, a punchline used in an effort to flirt. However, while I am not completely helpless, my indignant voice remains silent. This is not the first time, nor the only time. Bochner (2000) argues that illness narratives, rather than being portrayals of pathetic and hopeless victims to a biomedical malfunction, are rather “source[s] of empowerment and a form of resistance to counter the domination and authority of canonical [biomedical] discourses” (p. 749). Diabetes as a disease worthy of ridicule can be seen from the “dia-beetus” jokes on the internet to the off-handed comments of something sweet giving them a sugary death. Lunceford (2015) further asserts that autoethnography is more than a well-told story, but a narrative that should “promote some sense of understanding that touches on humanity in ways that numbers and brief snippets of text cannot” (p. 14).

Ngunjiri, Hernandez, and Chang (2010) define autoethnography as a conscious method with a specific and intentional process that aims to analyze “the social-cultural understanding of self” which sets apart autoethnography from memoir and autobiography (p. 2). While using a theoretical lens to develop and craft stories as evocative tools,

autoethnography invites the audience into the continuous process of sense-making. While doing autoethnography, the researcher “zoom[s] into personal, bodied experiences and zoom[s] out to wider cultural concepts and frameworks” (Lunceford, 2015, p. 19; Adams, Holman Jones, and Ellis, 2015; Ellis & Bochner, 2000). Within this definition, the zooming in and zooming out is integral to what the method of inquiry can bring to the literature on illness identity. Autoethnography can thus shed light on personal bodied experiences to fully explain the disconnect over life-long regimens within chronic illnesses and the subsequent problems of adhesion to medical advice and discipline. This function of autoethnography agrees with Adams et al.’s (2015) description of how autoethnography reflects on identity, relationships, and experience to create understanding, where a researcher’s narrative becomes a contribution to the existing gaps of knowledge “while recognizing that knowledge is both *situated* and *contested*” (p. 103).

Focusing beyond the normative discourse of illness management, Tillmann-Healy (2009) describes how literature and description of illness is heavily biomedical, whereas the emotional intensity of the illness experience and daily struggle is lost:

“I don’t doubt the good intentions of physicians, therapists, and even producers of popular culture. But these sources focus on “deviant” behavior, medical diagnosis, and treatment directed towards the ultimate end: ‘cure’ of the ‘disease’” (p. 80).

The use of the word deviant behavior calls to mind rebellions, already placing autoethnography on the battleground of bruises and illness, the war on the body, but also the war of power over it. Like Bulimia, the discourse surrounding Diabetes is heavily biomedical, focusing on cause and effect paradigms that focuses on malfunctioning body

parts, “where causes are accorded more importance than experiences around fears about not being able to trust one’s body” (Ramanathan and Makoni, 2007, p. 287). In Tillmann-Healy’s account of eating disorders and being unable to trust herself and the damage that she does to her body, the same emotion resonates with the strict regimens and almost obsessive management of food, body, and insulin. Autoethnography can then shed light on how the equation isn’t always as simple as its made out to be in the doctor’s office, which only makes sense, as we continue to live our lives outside of it, day to day.

Lucherini (2016) describes Diabetes research done by a diabetic as an “inescapable autoethnography”, as a researcher who does research on diabetes, he also, unavoidably does research on himself. He asserts that as he delves into fieldwork, meticulously reading, writing, and analyzing about the disease from day to day, there was no way to turn away from his work life, or turn off the stress he had created by studying himself. He laments “although having switched off from work, [I] still have to attend to my own constantly diabetic body. I am consumed by all things diabetes” (p. 2). Indeed, having to study illness identity is on par with studying issues of race and gender, as one cannot hide these facts from day to day, as it shows clearly on one’s body. The work quickly becomes one that cannot shut off, that is constantly in a state of inquiry and remembering, whether it’s a good time to do so or not. Research then takes on the same nature as the beast. Richards (2008) also utilizes illness narrative to look closer at the discussion on chronic illness and disability, revealing her own vulnerability through her story of kidney failure. Not only is chronic illness overwhelming, Richards explains how illness vulnerability never leaves a patient: “I do not want to be seen as defective. So I fake normality” (p. 1718). The bubbling anxiety silences a patient who does not want to

be ‘seen’ as defective, who yearns to achieve ‘normalcy’ even through ‘fake’ means would only heighten a researcher’s anxiety over not being able to ‘shut if off’ and go home from a day’s work. There are no vacation days in chronic illness, no matter how desperately we try to make it look easy.

Edley and Battaglia (2016), in their collaborative autoethnography on chronic invisible illness and erasure, speak to the act of faking normalcy as imperative to become aware of as it manifests as overcompensation. Erasure was embodied in the oversimplification of a self to its illness, of an illness to its symptoms, and the dismissal of frustration and emotion that erasure may cause. Thus, overcompensation and erasure of those feelings is integral to the illness experience. The researchers explain through their own personal narratives “neither of us are good at it. We take on too many responsibilities, too many supportive roles, and try to prove that we are not ‘lacking’ due to our invisible illness” (p. 38). This adoption of many different roles and responsibilities highlights the different identities beyond my chronic illness that I hold dear. Rather than a rejection of one identity, there is a battle for power between multiple identities that demand to be equally addressed despite the complexity and intricacies of how each identity weaves into the very fabric of my appearance. And in the midst of that chaos, I continue to beep.

Research Aims

With the emphasis on the biomedical approach to symptoms of chronic illness, Type 1 Diabetes research requires a personalized look into the living experiences of those who handles Diabetes day in and day out. Thus, my journey to acceptance (and continuous re-acceptance) of my illness and identity that adds to my already complex

intersections of identities as a Filipino woman, an academic, and a professional will shed light on aspects of the Type 1 Diabetes experience that are overlooked and hard to understand unless one has the illness or knows someone who is affected by it. The aim in sharing this experience is to convey how the experience is exhaustingly cyclical—every day is diagnosis day. Every new reading, number, or test result is another confirmation of my illness that I cannot escape.

Taking my personal accounts from the past three years after my diagnosis, I bring my personal illness experience and tensions with identity to the forefront.

Autoethnography will function as a sense-making and evocative tool, but also as an evaluation of the many different identities and societal forces at play that intersect in my own illness experience as an adult-onset Type 1 Diabetic, an Asian-American, and a networked professional and scholar. The research questions I will explore will be about the intimate experience of Type 1 Diabetes and how intersectionality and acceptance of illness identity interact in conjunction with how the many facets of my identity confounds and complicates the experience.

The next chapter delves into the lenses of intersectionality, power and discipline as guiding concepts for analysis. Chapter III explains the process of evocative autoethnography and performative narratives, depicting chaotic illness experiences. Chapters IV and V weave together scenes and analysis before concluding in Chapter VI with a final narrative and chronic illness advocacy takeaways.

Interlude 1

Three years. It's been three years, and the day passes in a blink of an eye. One moment I'm making morning coffee, preparing eggs and a whole grain English muffin; the next, the cotton candied decent of the sun past the horizon catches my gaze as I prep and wash dishes, only realizing that I haven't stopped to take note. Three years and the diaversary simply passes, without a break or a reflective moment of silence, not even a 'hah-in-your-face' congratulatory ice cream cone.

Just like that, it passes.

I must have gotten used to it; the beeps mundane, the jarring loud sirens no longer causing a flinch. It's better not to be so absorbed in only the illness. Other things can and should take precedence now: working, writing, cooking, reading, researching, cleaning, living. Like maintenance of a house, I'll only start to pay attention to things when they start breaking. The importance of the house is to become a home and to live in it. Diabetes management happens only when it must, because I'm more at home in my beeping body.

CHAPTER II – THE LENSES

Intersectionality Framework

Lorde (1984) asserts that difference should be more than tolerated but “seen as a fund of necessary polarities between which our creativity can spark like a dialectic” (p. 111). It is through seeing the differences and plethora of experiences of women that can lend power to create dialogue. While the process of becoming a community of women is necessary to wield power and voice, Lorde urges feminists to recognize that community does not exist if differences are dismissed, or even denied existence. Intersectionality was conceptualized as a framework in response to the tendency in critical research to treat race and gender as two mutually exclusive subjects that did not intersect (Crenshaw, 1989). By taking a linear approach to issues such as gender discrimination and racism, Crenshaw argues that past critical and feminist works focus on and are limited to inquiry of only the privileged members of a group.

The focus on the privileged members of a specific marginalized group “creates a distorted analysis of racism and sexism because the operative conceptions of race and sex become grounded in experiences that actually represent only a subset of a much more complex phenomenon” (Crenshaw, 1989, p. 140). Navigating these “complexities of compoundness” (p. 166) places the marginalized—or the erased black woman from predominantly white feminist literature, legal practices and political implications and societal definitions of discrimination—at the forefront to illustrate the intricacies otherwise not spoken. Following Crenshaw’s coining of the term intersectionality, Hooks (1996) describes simply within theorizing and having the power to develop a feminist

framework places the communication tools in the hands of the privileged where viewpoints or even definitions may be inaccurate or distort what is really taking place.

Crenshaw (2005) examines Asian intersectionality in the case of battery, noting how cultural implications often make it hard for the Asian community to access the limited resources available, or even to meet the requirements to be helped if they get to a facility that can help. As many generations may live together, issues of privacy, opportunities to leave the home, or ability to use resources make it difficult for immigrant Asian families. The sentiment of lack of resources and cultural values against seeking help on private matters resonates with me; however, as a primarily Asian American, first generation woman born in the United States, I find my experience of intersectionality slightly tweaked.

Adapting to the words and teachings of Lao Tzu, Minh-ha (1989) adapts the proverb of knowing ignorance is strength to “knowledge for knowledge’s sake is sickness. Let her who is sick with sickness pass on the story, a gift unasked for like a huge bag of sunlight” (p. 2). Asian feminists have begun to apply intersectionality to the collisions of identity of Asian women under different power structures. As intersectionality “moves beyond single or typically favored categories of analysis to consider simultaneous interactions between different aspects of social identity [...] as well as the impact of systems and processes of oppression and domination” (Hankivsky, Cormier, and De Merich, 2009, p. 3). Indeed, being deemed a writer as one of my identities sparks a hidden glee, a covered smile and shy glance because, a writer of color involves the act of writing as luxury. Leisure is not a profession, simply a pastime, almost a guilty pleasure. Minh-ha (1989) explains it to be “permitted to a privileged few, whose

idol hours of the day can be viewed otherwise than as a bowl of rice or a loaf of bread less to share with the family” (p. 7). In examining my own intersectionality, I further examine what it means to be an Asian woman in this illness experience.

Today’s Diabetic looks a bit different from years past, technology branding management, creating new robotic tools that beep, alert, and alarm. This machinery is not merely a tool for intensive insulin therapy or continuous glucose monitoring, but is instead an integral part of the body, an added mechanical part to the self—pump therapy births cyborgs. In her cyborg manifesto, Haraway (2006) describes that modern medicine is filled with cyborgs “of couplings between organism and machine, each conceived as coded devices, in an intimacy and with a power that was not generated in the history of sexuality” (p. 292). She suggests that women of color might be a cyborg identity, a mixture of outsider identities within the multiple layers of myth, history, and biography. Here Haraway (2006) argues a woman of color writer, specifically in English, is a crucial part of the Western myth over past colonized communities where writing was the difference between primitive and civilized. However, like Lorde’s (1984) taking back the master’s tools, Haraway (2006) argues that cyborg writing is about the “power to survive [...] on the basis of seizing the tools to mark the world that marked them as other” (p. 311). I agree as I write my story from the intersection of multiple identities that mark me as a mix of organism and technology, not just for my mechanical parts, but as a face on a Type 1 Diabetes brochure that should have been there.

Applying intersectionality to an Asian woman’s experience, Im (2016) highlights the importance of analysis of intersectionality to Asian American Women’s health as it addresses cultural attributes, knowledges, and beliefs as well as specific health concerns

that affect the Asian American Women population. The literature surrounding Asian Americans and illness experience is limited, and the information collected thus far mainly focuses on the impact of race on health issues such as mental illness. Many sources attribute this lack of research to the concept of Asian Americans as the ‘model minority’ (Kim, Atkinson, & Yang, 1999; Kwan, 2000; Im, 2016; Carrera & Wei, 2017; Le, Nguyen, Pan, Maglalang, Butt, Bautista, Nitta, Barg, 2017). This concept comes from a high regard for the group’s ability and desire to perform well academically and professionally. This idea of model minority spills over into our community’s reputation with health as well. With assumptions such as Asians being the model minority with less prevalence of chronic disease, this population’s diversion of preventative testing like routine pap smears and mammograms are often overlooked. Im (2016) asserts the necessity of interventions that aim towards intercultural competency with the Asian American Woman community.

However, the study does not go beyond intercultural competency and does not touch up on the intricacies of the complex collisions of identity that happen in these intersections. Interventions are useful tools, but for what and to whom? Hankivsky (2012) remarks how one of intersectionality’s best applications is how “it leaves open the possibility of simultaneously experiencing the effects of privilege and penalty, thus challenging binary thinking which tends to place certain groups in opposition of one another” (p. 1713). Being a product of a considered model minority, having the economic status to afford the machinery and technology in order to keep my privilege and penalty at odds with one another. While I am continuously ill, I am also at a place and

ability to talk about it. Like Minh-ha, I am sick of sickness, therefore I offer my illness identity story.

Intersectionality applied as a theoretical framework to individual illness identity has been raised in more than just semantic and critical research, but also in public health literature (Bowleg, 2012; Thomas, 2012; Weber & Parra-Medina, 2003). Rooted in feminists of color scholarship, intersectionality gives a framework for understanding how multiple social identities intersect at an individual's experience at a microlevel which speaks to the pressures and complexities driven by macro structural and societal forces (Bowleg, 2012; Thomas, 2012). The lens of intersectionality as applied to public health and health disparity research outlines:

“Intersectionality is a theoretical framework for understanding how multiple social identities such as race, gender, sexual orientation, SES [social economic status], and disability intersect at the micro level of individual experience to reflect interlocking systems of privilege and oppression (i.e., racism, sexism, heterosexism, classism) at the macro social-structural level” (Bowleg, 2012, p. 1267).

Bowleg (2012) argues the framework has a major role to play “as intersectionality provides the discipline of public health with a critical, unifying interpretive and analytical framework for reframing how public health scholars conceptualize, investigate, analyze, and address disparities and social inequality in health” (p. 1267). Taking a moment to reflect and reframe not only can be placed into practice as a continual process of understanding from provider to patient, this framework can be applied to interactions

outside of a medical setting, from friends to work colleagues, down to a stranger on the bus or in a coffee shop.

Similarly, Thomas (2012) asserts that chronic illness and disability scholars should think in terms of intersectionality as it speaks to the complexities of social identity and how those identities interject into a chronic illness experience “in complex ways and have differential weighting and salience in the day-to-day lives of individuals and communities” (p. 223). Intersectionality is not used as a tool to weigh one more than the other, or to prescribe a magical take-away that can address the problems of identity in power structure; however, it can instigate a little thought in the back of the mind and provide a new lens at which we can look at a situation or an interaction with a Type 1 Diabetic.

In their study on chronic illness experience from a critical feminist perspective, Eddley and Battaglia (2016) argue that “just like race, gender, or any visible markers of identity, disability [as a cause of illness] is seen as a personal or family matter, a defining characteristic of an individual and thus, not political or societal” (p. 35). While Type 1 Diabetes literature has yet to be examined through the lens of intersectionality, Diabetes research as a whole (Type 2 mainly) has discussed the effect of race and class disparities on Diabetic control maintenance (Pilkington, Daiski, Bryant, Dinca-Panaitescu, Dinca-Panaitescu, & Raphael, 2010; Link & McKinlay, 2009; Brancati, Whelton, Kuller, Klag, 1996). Pilkington et al.’s (2010) study on persons with low income and Diabetes found “the overshadowing of diabetes self-management considerations by survival issues exemplifies the intersectionality of health and its social determinants” (p. 124). The study emphasized that daily survival and class struggles took precedence over care of diabetes

management, focusing on the complex implications of class and race had on the ability to take care of their chronic illness. While the research remains focused on non-adherence and patient-provider communication and interventions, intersectionality framework can shift the lens to a new look upon the healthcare team beyond the professionals to the support system that aids in the arduous and unrelenting maintenance of Diabetes.

As the continuous care of Diabetes holds true in any of its types, new research should focus on intersectionality or use the framework as a lens to describe the differences in illness experience. The American Diabetes Association (2014) reports that from the SEARCH for Diabetes in youth study in 2009, of the 18,436 new cases of Type 1 Diabetes in the United States, only 276 of them were Asian/Pacific Islander (p. 2034). While the number is small in comparison to the majority of patients, 276 is still larger than a classroom, can fill more than one coffee shop, can become an entire medical practice. Chun, Lipsitz, and Shin (2013) describe the misinterpretation of academia to utilize this tool solely as a way to manufacture a personalized “designer identity based on the complexities and contradictions of individual biographies, the concept of intersectionality emerged initially as a mechanism for revealing that power works in uneven and differentiated ways” (p. 922). The goal is not to simply lay out my identities and point out the intricacies in the tangled ties of skin, metal, and tubing, but to see how power and discipline disproportionally influence body, disease, and social interaction. Therefore, the underlying issues of power and discipline are integral to examining the effects of intersectionality on illness experience.

Power and Discipline as Health Management

Foucault (1979) describes disciplinary displays of power specific to modern day forms of army, prison, manufactory, and hospital in order to increase the utility of the body, the usefulness of the machine and all its parts. Through this practice of power, Foucault asserts “discipline produces subjected and practiced bodies, ‘docile’ bodies” (p. 138). When applied to regimens for Type 1 Diabetes, Foucault (1979)’s theories of exercise as a disciplinary practice link the healthy lifestyle of diet and exercise to have positive and productive effects. A body of exercise, manipulated by authority, could be molded into “a body of useful training and not of rational mechanics” (p. 155). Akin to soldiers in training, artificial movements mandated by higher authority, results in excessively artificial movements. Foucault argues in the act of discipline, exercise is imposed upon the body, but the body “spontaneously rejects” it, deeming it “incompatible” (p. 155).

Bartky (1997) applies this concept to a feminist framework, claiming that modern society’s power now works against the political axis of individualization, thus employing channels that affect the individual themselves and their bodies. Power then goes a step beyond attempting to punish or imprison the body, instead working through specific and finer channels to seek minds that might be tempted to disobey. These finer channels must have stricter control over the body’s time and movements, a channel that requires “ceaseless surveillance” and a “new knowledge of the individual”, their psychology and sociology (p. 106). Anderson (1995) critiques Foucault’s theories of power and resistance by putting Foucault’s theories into the context of Diabetes. Here he explains that unlike prison inmates, patients can and will react to the medical gaze, not simply out of

retaliation to the show of power, but because the body is subjugated and reacts to the medical gaze. He argues “the application of the gaze cannot be accepted as given, and our attention should be directed towards the process which shape patterns of interaction with health systems” (1995, p. 73). While the medical field does hold some resemblance to a prison, namely in mental hospitals and asylums, the patient provider realm does allow for some deviation under the medical gaze. The patient has the ability to reject and issues of non-compliance come into play. Balfe (2007) further asserts Foucault’s theory lacks the gendered aspect of self-image that occurs during disciplinary practices like exercise. Women and men work out disciplinary acts on the body differently, and how different contexts of material spaces and any particular audience or community might thus affect how they perform these practices (Smart, 2002).

Gastaldo (1997) applies Foucault’s concept of biopower and discipline to government implementation of health education, a link between the government and the population as a way of disciplining the individual through various health behaviors. Focusing on ‘anatomo-politics of the human body’, or viewing the human body as a machine on the micro level of power, Gastaldo (1997) asserts “focusing on individual bodies or on the social body, health professionals are entitled by scientific knowledge/power to examine, interview, and prescribe ‘healthy’ lifestyles” (p. 116). Thus the clinical gaze, past the medical community to society at large directed at a patient is considered “omnipresent and acceptable” because its primary objective is health and ultimately a disciplined, or healthy society (p. 116). These forms of discipline are the social media platforms that hashtag Diabetes on a sugary dessert, to a more individualized surveillance when a friend carefully watches every bite of food,

calculating the calories. Disciplined docile bodies subscribe to healthy lifestyle brands on twitter and watch videos of crossfit on Facebook.

Foucault's (1990) describes bio-power at play as an individual's ability to integrate into economic and social life, measured through the individual's docility and usefulness. Applied to Type 2 Diabetes management, Ferzacca (2000) defines biopower at work in a clinician's visit as a "configuration of shared values measured with medical technology and enacted in various techniques of life" (p. 30). Biopower and biomedicine are heavily intertwined in the clinical encounter, where biomedical influence is an integral component of the analysis and measurement of clinical reality. Biopower in a modern diabetic society is translated into the mechanical beeps that manage the biomedical aspects of the disease. Though the tools are seen as instruments for better management, the patient manages the disease just as the tools manage the patient. Integrations into cell phones and diabetes management specific apps add to the clutter of mechanical parts, some attached, some detached, but all creating the same kind of dependency.

I find the concepts of power and discipline as described by Foucault intriguing; however, as Anderson (1995) and Balfe (2007) critique of the missing gendered body is critical, especially under the lens of intersectionality. While grappling with the fit of the theories, I come across a mix of the two theories in the form of Frank's illness narratives as told by the wounded storyteller. Frank (1995) describes a similar story of discipline, but in the context of illness narratives, stories of the wounded storyteller. He posits four ideals of typical bodies (disciplined, mirroring, dominating, and communitive) asserting that while "ill people may not choose their bodies, as body-selves, they remain

responsible for their bodies, and they choose how to exercise this responsibility” (p. 41). Disciplined bodies’ primary concerns are those of control. Meanwhile, narratives (or anti-narratives) of chaos are the complete loss of control, an opposite to the restitution narrative where biomedicine dwells. Coupled with Foucault’s bio-power and discipline, Arthur’s ideal disciplined body deals with issues of ‘self-regimentation’ and when in a crisis of power and lack of predictability, a ‘single-minded pursuit of regimens’ separates the body from the self, reducing the body to an ‘it’ (p. 41). Thus ideal disciplined body lacks desire, it follows after regimens in pursuit of being a ‘good patient’ or for the approval of a medical team, without any regard for itself. It strives to regain predictability and create a guise of normalcy. Inevitably, the disciplined body does not love itself.

Moretti and Morsello (2017) analyze the feedback and impact of diabetes cell phone apps that aid in management through the use of reminders and interactive information recording to instigate more open conversation between doctors, patients, and caregivers. They note the positives of this addition to the regimen include increases in self-care, a creation of a new public pedagogical tool, and the possible reduction of cost of treatment by being able to send their digital charts electronically to doctors instead of going in for a visit. Still drawbacks include added responsibility placed on the patient to understand and keep up with new technology, and in fact these apps are not guaranteed to effectively enhance the patient’s quality of life. Added discipline and responsibility on the already burdened patient creates a discrepancy, adding more reprimanding power to the healthcare team should the patient be too easily overwhelmed by the added maintenance.

Meta-analysis of the impact of insulin pump therapy on a patient is measured via significant increases in glycemic control and fewer hypoglycemic outcomes (Weisberg-Benchell, Antisdel-Lomagilo, Seshadri, 2003). The measures of control and outcomes speaks to the weight of scientific numbers over lived experiences and psychological tolls of the introduction of mechanical tools to management. The American Diabetes Association follow up this meta-analysis with a qualitative study on the psychosocial factors of insulin pump therapy which focuses on emotional impacts of the insulin pump on selfcare, body image, and social acceptance (Ritholz, Smaldone, Lee, Castillo, Wolpert, Weinger, 2007). Patients describe the pump as a tool for management rather than a panacea resulted in better glycemic control. Female patients were more likely than male patients to have concerns with body image and social acceptance during insulin pump therapy control.

Tools for management are effective in improving the overall maintenance of chronic illness; however, it fails to address the maintenance of the person behind the patient and their perceived quality of life. What benefit is access to machinery and new technology if it only enhances societal disciplines and strains on our already tired and bruised bodies? The next chapter explores the process of illness narrative writing, using the multifaceted lens of intersectionality and the concepts of bio-power and discipline.

Interlude 2

Even beeps that numerate every second,

every bite,

every step out of line come

as a constant white hum of comforting white noise. A sound I want to be white, not red, not yellow. The trill of alarms follows me from one room to the next, a companion I can count on.

The beeps have my back.

I've followed the trail of mechanical cyborgs past, from the first archaic lancet to the white monitor and black zip up case, my first machinery, first clutch, first time I left the house since diagnosis, fingers wrapped around my cell phone, heading to church less than five minutes away when my mother realizes that my monitor is not with me. I leave the house naked.

"That wasn't very smart," she reprimands. "You need to carry these things with you from now on."

And sure enough that same black pouch lays on the table next to my books, untouched, still zipped. We've come a long way since then, I can go a day without thinking too much about the whereabouts of my monitor, my CGM, or my insulin pump attached to my hip. I glaze over the numbersscreen colors, a blur of Morse code and equations most could not decipher. Some days I just get it, the management, the lines, the trends, the alerts may sound but the lack of beeps reveals tantalizing respite.

Some days I remember what it's like to breathe deeply again, nothing interrupts moments. I am me. And for a brief moment of unadulterated glee, I remember what it's like to forget.

CHAPTER III: METHODOLOGY

“I’m not sure what to write about,” I exhale as I settle into the plush seat across from my thesis adviser, Kathryn, fingers clutching the blue folder specifically designated to the topic. I’m a very apprehensive person and easily fall down a rabbit hole of different paths and ideas. “Stories, poems, what about spoken word? Where do I even begin? I feel like I have so many stories to tell; how do I find the important ones?”

“Just write. Write to wherever your memory takes you, as long as you’re writing. The story you told me about in Starbucks, or you can even write about me! Remember the one time I yelled at you for your beeper going off in class?” her smile is a mixture of humor and underlining apology. I simply shake my head. It was true, that was one of my many stories of interruptions, of being misunderstood a byproduct of being part human, part machine. Normal bodies beep in silence.

“My insulin pump,” I offer, tugging the machinery by the tubing and pressing the center button, illuminating it to life. “And it wasn’t that big of a deal to me, honestly. I didn’t even think you were yelling. I thought it was called for, and I knew that if I explained, you’d understand.”

As if to agree, my pump trilled, a series of three beeps piercing the air.

“Yeah, like that.”

Many sources on autoethnography highlight the process of crafting and creating the story, the scenes, and beginning fieldwork on the self. Adams et al. (2015) describe a common strategy of beginning that process through focusing on experiences such as epiphanies, stories that cause us to “pause and reflect, [...] encourage us to explore aspects of ourselves and others” that, before this experience, we may not have had the

bravery or opportunity to do so (p. 47). Bochner and Ellis (2016) also note how structuring the narrative revolve around an epiphany or a dramatic event which have a very distinguishable quality of discerning a past self and how we view ourselves now. Stewing on that definition for a bit, I know the easy answer to this question of an illness narrative is diagnosis. That is the story we all tell sitting in a circle at support groups, the story while similar, is distinctly different from person to person. We're not cases that can easily be clustered together; however, we are alike.

I don't like easy. My story of diagnosis is a journey accompanied by a best friend and her life-saving intuition, sparked by an off-handed comment by my nurse mother about potentially having Diabetes because I wasn't feeling too well, and a blur of emergency rooms, pristine whites hallways, IV lines, confusion. The experience itself wasn't easy, but it does not feel like it can separate the me from the past and the me now. Instead, my mind travels to another memory, two weeks later. I think of little rubber ducks on blue curtains, a slip mat under my feet, salty tears under silver showerhead, curling my body into a question mark. I mourn in confusion. I do not know what died in the cartoon ridden, bubblegum pinks of my cousins' bathroom. And I am not aware until epiphany slams like an aggressive end of a phone call, hidden away in an empty office in my workplace.

I began to think of times where I hid and when I couldn't anymore. When my face of normal and healthy Asian American woman is stripped to a child trembling in fear. When I realize my body doesn't work anymore, and over that, I have no control. Bochner and Ellis (2016) describe a method of producing stories as "emotional recall" where you relive a situation in detail that you have been before, returning to the scene both

emotionally and physically (p. 168). To me that sounds like going where your mind takes you, and when possible, I try to interact with people who were there when my mask became undone, who I hid with in my workplace, who remember the confusion first hand. The who is simple: my friends who are there pre and post diagnosis, my co-workers and family still in my hometown.

I am not prepared for the caliber of these emotions that hit me or for where my mind flashes when discussing this topic. I realize I have never written about this diagnosis despite my habit to write about everything. It's harder to approach my parents about the topic and find myself skating around it, a big white insulin filled elephant. While I can protect others outside of my family with pseudonyms, my family members' identities are clear. I also find that recalling the past instead generates much more focus on the present and talk about the future: how well I'm doing now, how great it is I am in graduate school, what I'm going to do next. Talking about it is a lot harder than I thought. The dismissal of the topic, as a past unchangeable, muffles the cry of a child hidden behind plastic shower curtains. As Corey (1998) discovers, the narrative is "a literary form ideal for lives governed by silence" (p. 249).

Minge (2013) describes autoethnography as a method that "creates knowledge through relational—familial—connections, focuses on local action, and attends to sensory details" (p. 427). I wonder just how I could hit all the connections, instigate action, and provide an evocative story that performs on the page, that resonates with an audience, without feeling my own face of normalcy disintegrate further. Stories come from the body. Despite me not wanting to talk about my Diabetes, my body forces me to, announcing its presence with a resounding trill. As Frank (1995) argues, the "stories that

ill people tell come out of their bodies. The body sets in motion the need for new stories when its disease disrupts the old stories” (p. 2). Memories and their subsequent realizations highlighted through the process of writing are laced with tremendous emotional value that they suffocate and confuse me, yet still I wait till the last possible minute to arrive in front of my adviser with a fresh cup of tea that promises to be soothing.

It helps to remember what it is I want my thesis to do. Similar to how Tillmann-Healy (2009) describes her illness experience of bulimia through a “sensual text to pull you away from the abstractions and categories that fill traditional research on eating disorders and into the *experience* [...] to help you engage how bulimia *feels*” (p. 104), the pieces of performative narrative aims to draw the reader into a vulnerable embodied experience, connecting the dots of blood sugar pokes on fingertips on a trail of testing strips. Scenes focus on experiences with illness that go beyond the sudden impact of illness diagnosis and disease introduction into daily life, instead narrowing in on instances of constant monitoring and continuing moments of maintenance of a chronic illness.

My thesis consists of ten scenes of narrative and a series of four interludes to frame chapters of analysis while simultaneously being interwoven and in conversation with it. Scenes build upon one another, and while they may not be in chronological order, reveal the chaotic and reflective nature of life as a Type 1 Diabetic, one that uses medical technology to monitor it. The following chapters are organized according to the themes of communal experience of food and culture, aspects of my life introduced and valued by my Filipino family. The second chapter focuses on conversations with colleagues,

friends, and the population at large, all while being interrupted by continuous conversation with my idea of self as the mechanical guiding beeps disrupt but also aid my experience.

“I don’t know, this is a lot harder than I thought. It’s overwhelming,” I exhale, mouth hovering over a cup of vanilla mint tea. Half way through the literature review and writing phase of this project, I felt as though I had met a block, both emotionally and writing wise. Inhaling the comforting scent of the tea, I ready myself for the response from my thesis adviser.

Writing has been my method of sense-making and understanding since the fifth grade; however, one thing I had yet to creatively write about prior to graduate school was my Diabetes experience. While the diagnosis and integration of chronic illness management was a relatively new experience, my ability to log or write anything about the experience was telling of my reality’s intricacies and the sensitivity of the reality I was not sure I was ready, or fully equipped to face and articulate sufficiently.

Bearing all my scars is more than the sticky remains of infusion sets or bruises on my thighs, it is the words that people have said, the return to the scenes of where others’ words seep and manifest into my fears of stereotypes and judgements, and the brutal reality that I was the exact same way before I was diagnosed myself. It was almost too much to bear, and I couldn’t turn it off. The inability to escape the beeps and buzzers, the reminders of the vulnerability and hardship constantly recycled through my memory, revisiting and reopening scars and bruises that have yet to heal, and the constant discipline expected from me to respond to each of these accounts was suffocating.

“Do you still want to continue with this thesis then? Your wellbeing is the most important here,” Kathryn responds, words slow and deliberate.

“I can, don’t worry,” I insist, “I want to even more now.” Firm gaze and reassuring nods of my head accompany the slide of stapled piles of paper across the small table. The smell of ground coffee within the small café comforts me for what is to come, and a half-eaten blueberry muffin promises of a ‘bolus-worthy’ treat to come after.

I weigh my words and purse my lips, feeling as though the ones I had chosen did not completely convey the gravity with which I approach this thesis. This story is not mine alone, but an intersection of stories, a starting point for many more stories, someone else’s story retold. It was not just me, but it still felt incredibly isolating, almost overdramatic, like a grown adult should not feel this unhinged at the edges, fraying indefinitely. The unraveling in directions unknown taunted me, I’m used to schedules, perfection in regimens, punctuality. Perhaps the body heavily intertwined in order and control stifled the creative process, making comfort with chaos all the more unbearable. But I most definitely am not alone.

“Not just I want to,” I correct. “I have to.”

“Good,” she encourages, eyes rolling down to square up what I have given her, commenting pen posed above paper. “Are you ready?”

Langellier (1997) describes personal narrative as dependent upon the different contexts in which they are situated. While analyzing a young black girl’s same story told to different audiences, the act of telling of the story drastically changes based on the audience, her peers evoke certain performative attributes like voice inflection and sound effects that differ from she delivers the story to a white male (Gee, 1986). Here Langellier

(1997) “draws upon unequally distributed cultural resources in choosing a particular style of narrating which, in turn, establishes a context for making sense, presenting one’s identity, and valuing experience” (p. 140). My stories pick up on conversations with myself and my machinery which simultaneously occurs with my company, as we remain in public spaces where our bodies communicate conversations with our communities. The way I phrase my stories to my friends, to my family, and ultimately to my healthcare team shapes the reality, the constant illness experience and places it in a situated context that speaks to the ordering of power relations in discourse, Langellier’s (1997) politics of personal narrative.

Politics and conflicts of power play a fundamental role in personal narratives (Langellier, 1997; Corey, 1998). A conflict of power remains in the dominant discourse about Diabetes which focuses primarily on Type 2. Type 1 versus Type 2 discourses are heavily intertwined in the Type 1 Diabetes experience, even from the hospital bed I shouldn’t have this disease. One look at me and the nurse decides I’m too thin for Diabetes. One discussion with the attending physician and my age and ethnicity say I’m most probably Type 2. Never mind the high blood sugar numbers, fatigue, blurry vision or sweetness on my breath. Never mind how I struggle to go back to urgent care because something just does not feel right. Corey (1998) describes personal narratives as experiences, though practical and repeated, are not given a part in science, not considered ‘medical’ and yet “the absence of these stories has contributed to the collective destabilization and discreditation of the master narrative, of scientific knowledge” (p. 251).

While conversations with healthcare professionals and the Type 1 Diabetes community are very important to discuss and analyze, I too realize conversations are situated in the context of medical and emotional understanding that can only come with shared experience. Talks of neuropathy and ketoacidosis are thrown around as if we are not talking about pain and coma. Because those stories too are so heavily situated in the contexts, I shift focus away from the patient provider relationship to the other contexts that shape what I might bring to an appointment and under what circumstances I may do so. I focus mainly on the experience of a patient outside the comforts of a medical community that have a special level of understanding and acceptance of the beeps that the general public does not have. Therefore, I do not include those conversations in my narratives and analysis.

“I want to see more of your body performing on the page, showing on the page. Do more showing than telling,” Kathryn reminds as she sifts through once stapled papers. I’m filled with images of bleeding sheets of printer paper, bruised, holes drilled through, something a perfectionist like me would not be able to tolerate, already uneasy with the tiny coffee marks that muddy the bottom corners. Together we deconstruct and rearrange into order. It’s an uncanny, uncharacteristically warm day for winter and we make a point to go outside and work. Something hits me like warmth on my face and an eerie calm before more storm. I feel days like these are a tease, and yet I wish to hold onto it, savor it, despite how it goes against the rules of February. The idea hits me.

“Let’s not put the scenes in chronological order and make the reassembling as chaotic as it feels. Analysis will interrupt narratives, and narratives will interrupt analysis, we can braid it through the final chapters and break up one long narrative to represent

temporality, living life chronologically, but still continuously disrupted by my memories, by my beeps.” I grow more excited as I attempt to explain my thought process, hands moving up and down as my heart beat hammers. As Frank (1998) aptly notes, “the disciplined body-self is not likely to tell stories about itself; rather, its stories are told through the pursuit of the regimen” (p. 42). My focus is the continuity, the powerfulness of the regimen, the stark contrast of the beeps, not the chronological order my life is lived.

“That’s a good idea, write it down,” she responds, still flipping through the pages. “We did see the theme and importance of food, right?”

“Correct,” I agree, scribbling furiously against my note paper, hoping that my hand can keep up with the jumble of thoughts and ideas bouncing in my mind. Like a warm day in February, I want to preserve that delight and eagerness, that positivity, that want to do something despite how dreary the weather has been. I want to savor that brief moment of happiness, hopefulness, that fills the Quad with more students than there ever were on campus.

Langellier (2009) argues that performing narrative medicine is telling, reading, and writing a story constitutes the act of performing narrative medicine between physician and patient. Therefore, the process of making stories “simultaneously unmakes them in the embodied contingencies of performance” (p. 152). After deconstructing and rearranging the scenes, the performative nature of illness narrative illustrates on the page, having the story interact and invite the reader as a character. Through a disjunctured arrangement of braided narrative, cyclical and mundane experiences interrupt the natural flow of analysis, sending the conversation with the current literature in different

directions, according to the different intersections of identity and illness I explore. Frank (1998) argues that what is needed in both clinical settings and more generally in interpersonal situations, is a comfort with chaos as part of the story. Each scene interrupts layers of analysis as my beeps interrupt thought and daily activity. The very disruptive nature of the scenes performs the experience of life as mechanical diabetic, whose beeps, whistles, and alarms frazzle and confuse the patient and those around them.

Between each of these chapters is another ongoing narrative interrupted by the chapters of scenes and analysis, building another layer of the passage of time in a chronological experience of Type 1 Diabetes as a functioning adult. The next chapter dives right into the family wok, illustrating the importance of meals and food where chaos lies when eating and drinking does not rely on how hungry or thirsty I am, but is instead dictated by the ever-present beeps.

Interlude 3

Never mind, I remember now, again, as the pots bubble over and the oven timer notifies a pre-heat. Terror thrashes, a cold sweat sliding down my neck, mouth slacking and parting slightly, the shakes start in my line of vision before they reach the pads of my fingertips.

Dread cripples from within,

flashes,

trembles.

Something is coming for me.

I'm not alone but tunnel vision

leaves out

anything

but the

kitchen floor;

my roommate is chattering about her day at the table behind me, the chicken is sizzling in the pan, the rice cooker dings, and I look up from my cutting board—the knife falls. My knees buckle and my fingers curl over the curve of the kitchen counter, the whistling sound of a plane crashing berates my ears.

Not now, not now, not now, not now

CHAPTER IV: BEEPS BETWEEN BITES

Stir Fry

Do you eat to live or live to eat? Well, both. Technically. Typically. Food gives the body sustenance, energy, it is the very fuel to our well-oiled machine. Between carb counting and calorie hunting, between measured meal plans and that 20th bowl of stir fry that week, I have to say I fall under the category of eat to live. From the suburbs of Virginia with restaurant weeks and foodie hits, with our fingers always searching for a new yelp find, and our shopping runs best completed with dinner rests—food is always an occasion, a social outing, a way of life. And yet, food is measured in bowls of rice as a serving size, not knowing the exact number of carbs, no food scales, silver measuring cups, precision or math.

We live to eat. Food is family. Food is love. Holidays are a magical time of *tupig* rolled on banana leaves over an open fire, where *lechon* shares the table with turkeys and ham. Pot roast and pies sharing the same table as *lumpia* and *kare-kare*. From Halloween to New Years is the hardest time for a carb counting, meal substituting, calorie calculating Diabetic. How do I look up the carbs in a Filipino dish online? Are the numbers accurate when every family has a unique way of cooking it? Where do I begin? Is it worth it to begin? Just as I start to weigh this out, to sift through the information that the internet had to provide—"hey, fish and stir fry are on the counter." A pointed look in supposed subtlety, I stare at the main dishes on the table, then to the food on the counter, then on to the hopeful grins on the faces of my family. They want to help, but I can see just fine.

As a young Filipino girl setting the table for holiday festivals, food is the source of gathering, from the preparation in the early hours, of rhythmic chops and divvied

chores, the women of the family report to duty in the kitchen. Company comes to a boil and reoccurring stories of the past and missed anecdotes of the present come up in steam above the smell of soups and names of dishes I struggle to pronounce with my American tongue awkwardly situated on my Pinay face. Food is the reason for occasion, why people gather for midnight dinner. They say it's a holiday, a Catholic religious celebration of a birthday, but the food is what brings the family members together at the table after hours of preparation. Recipes pass down from mouth to mouth, hand to hand, not a single pen in sight, until the soup tastes just right. If I look in confusion at their instructions in only half a language I understand, the women in the family all smile in playful satisfaction. "You come here; you learn."

The rituals of holidays are a cultural aspect of life lived in illness. Websites dedicated to the Diabetic life highlight paths to survival through this period, carb counts of common holiday foods from candies on Halloween to drop sugar cookies on Christmas (Beyond Type 1, 2018). There are sources for slices of apple or pumpkin pie, but what about the holiday traditions of other ethnicities who celebrate the same holidays but in slightly different ways? The failure to represent my struggles, to offer resources to a community while small still exists. Just as Crenshaw (1989) describes the erasure of the black woman from predominant white discourse, the erasure of the face of a Filipina woman with cultural context to the food I eat, to the time I treasure, depict an erasure of culture lost in the disciplined body.

Here a younger version of me learns the tradition and the value of food consumed with family. No matter what, no matter where we may be in the world or in our lives, holidays are time we must be home, surrounded by our own flesh and blood. When we

grow our families with children, of new hands to teach and new mouths to articulate the traditions of our family, I come to love the holiday that pushes bodies closer together in the heat of a kitchen, of eggroll assembly lines, and mindless chatter in mixed languages.

Food is an offering of love. Preparing a plate for an elder is how we show respect, and no one eats until the plate for the dead is presented to the altar. Discipline with food exists before illness disrupts, but its power increases tenfold over an ill body.

Surveillance increases. A casserole dish holding baked fish is my family's way of including me in the tradition, of saving a seat for me at the table, of wishing me long and healthy life. While prepared in the best intentions, the separation, branding me as the Diabetic in my own familial community fills my esophagus with swallowed back words of contempt and dismay. I cannot accept their act of love when it separates me from them.

Food betrays me.

The first years are the hardest, when tears cling to eye lashes, poorly stifling a groan, breath hitching for a breath of freedom to eat something more than brown rice and chopped zucchini, bits of pork and baby bok choy, broccoli and grilled brussel sprouts. With blinding precision, silverware morphs into measuring cups, a calming meal graciously prepared as I arrive looks nothing like home. After dodging meals and snacks of cookies and pies, napoleon cakes and strawberry crepes, I realize stir fry looks like shackles, and I cry.

"It's just like medicine," I whine, wiping desperately at the water on my cheeks. My parents watch in deafening silence. It's been a while since they've seen their fully-

grown daughter throw a tantrum. “I can’t tell the difference between this and insulin. I don’t like food anymore. I don’t like anything anymore!”

Frank (1995) outlines the body’s problems with illness, pointing to the body’s innate desire as an insatiable want for more. Ill bodies in particular are more likely to cease desiring in the form of resignation and indifference to mundane acts, like eating or buying new shoes. Frank (1995) explains “the narrative tension is whether lost desire will be regained [...] this plot of desire lost and regained informs all lives at various points, but illness demands reflection on cycles of when the body is lacking and when the body produces desire” (p. 38-39). Often the ill body can regain desire as disease offers an opportunity for reflection on how to be a body producing desire.

Poor parents that only want to help stare with wide-eyes, dumbfounded. How can they understand the body’s problems with illness? Dread and panic overflow onto shaking hands as I detest a life sentence of stir fry and brown rice, a verdict unfairly pressed upon a child where an adult once sat. This time the shaking is not hypoglycemia. Anger feels foreign, clawing through my veins like hunger pains, pulse raising, cheeks flushing. I push the eight unit shot away from me in resentment. At least for an hour, I could appeal the verdict, right before I knew my blood sugar would plummet. Even my rebellions must fall on schedule.

Rebellions signify a loss of power, a discontent with the forces over my body, discontent with my body—I separate from it. Resent it. As Frank (1995) describes, the disciplined body does not love itself, especially if for a culturally immersed Asian American woman, food is a sign of love and affection. I feel unworthy of the love and attention afforded to me by food. And yet, I stress the tension of my family’s hopes, how

they reflect and retry to appease the body's need for healthier options. As the storyteller, I narrate the people most commonly around me: their silence, their unspoken guilt, thousands of words in their eyes that echo a bit of my pain. Frank (1995) states "The ill person is immersed in suffering that is both wholly individual—my pain is mine alone—but also shared: the ill person sees others around her [...] she sees others who are pained by her pain" (p. 36). I still grudgingly deny. Why should I feed it if I don't love it? I come to resent my body, and through that I resent food, all in the process of sticking to regimen. Regardless, the regimen continues, forcing me to eat at the times I am allotted, a bratty child stuck at the table until I finish my supper.

Can You Eat That?

I'm just trying to eat.

Lunchtime regulars swarm the taco bar, the waft of grilled meat and corn tortillas hits our faces as we file into line. Stomach grumbles, exhaustion heavy on my steps, hanging low on my shoulders, body simply following the smell of chili powder and coriander. As I come straight from a long morning of appointments and work meetings, I desperately need my three chicken tacos, chips and queso. I sit at a communal table with my family across and next to even more families, ripping apart the foil wrapping and digging my hands into the brown paper bag of chips. The tortillas crumble under my fingertips, almost tasting the salt on my tongue when—

"Ahem." Wide eyes dart from side to side, wondering what I had done wrong. I reach further into the bag of chips when it chirps again, the clearing of throat, the click of the tongue, my mother's "think, can you eat that?" without words. How dare I dive into a meal without an injection of insulin, a standard of fifteen minutes to allow it to absorb, to

carb count the worth of the chips as they crumble, crumble, smaller still. As Foucault (1979) describes an obsession with a world of ‘small bodies, small movements, small actions’, discipline strikes in an effort to organize and regulate, a mechanism of power. For a moment, I see a nurse in dark scrubs entering a sterile environment, a prescribed order scribbled on loose paper, a whispered reminder while surrounding my arm with silicon and Velcro straps. But under this guise, I can’t help but retaliate. Pulling the sodium filled snack out of the bag, looking at my mother defiantly, cheeky smile and full set of teeth chomp down. Twenty-four-years-old, and yes, I can eat that.

Regimens and reminders of the regimen come as second nature to my mother, a nurse by practice, a caregiver by nature. She’s gentle and quiet in the context of a public setting, but her insisting of healthy eating spurs on another one of my mini-rebellions. There is no guarantee that the patient is a prisoner to the medial gaze. Anderson (1993) asserts unlike Foucault’s described inmates, patients are not confined physically and forcibly to the space of the medical gaze. While some people may seek medical transaction, say in the case of a broken ankle, they expect to become the subject of the gaze. While I may take medical advice seriously, context surrounds the operation and productivity of these acts of discipline. Anderson argues: “this is an interaction between socially positioned bodies, bodies capable of collusion, appropriation, inactivity, or subversion. This is not simply a play on power and its counter-resistance. Bodies which have prior social position engage with and are engaged by the gaze” (p. 76). More than a call to discipline and reprimand for bad behavior, my position as an adult with desires and cravings, as any other socially situated pre-illness body reacts to the discipline placed upon me.

I laugh, shaking my head and reaching for my bag of supplies. I know she doesn't mean it as anything but a gentle reminder, wordless secrecy ringing with underlying worry. A mother's heart never changes. Little red pouch with golden tassel accents surfaces from beneath the table, climbing from my lap to the table top, a container of 10 insulin syringes, extra fine needles on the tip. I pull off the orange safety cover and draw out the prescribed amount of insulin according to scribbles on piece of loose-leaf paper, equations and ranges of insulin muddle in smudged lead and creased folds. Animated conversation continues as if the needles and test strips were commonplace, as if the walls of our home surround the table we occupy, deliberating on our plans for the afternoon, getting home, doing errands, grocery lists and chores when I hear it—the quiet scoff of disgust.

I look to my parents to see if they hear it, but they make no sign of a sound out of place. Apprehension curls my fingers into waves of anxiety that crash with dread on shores of my own exposed and bruised belly. Hunched over the edge of the table, hidden behind my mother, I hadn't expected anyone to see, and I wonder momentarily if it's all just in my head. Dosing in a public restaurant, the mere idea on the drive over, fills my entire body with trepidation. I imagine the whole thing—widening eyes, whispers of contempt, looks of disdain. Would it be better to dose in my car, hiding like an addict, submerged in the shame of my malfunctioning body? My gaze turns to my upturned t-shirt, needle embeds into red flesh, the guilty weapon surrounded by cold hands, a loosening grip. I yank the syringe out too fast, swift, stammering motions causing blood to ooze and dot my white-t-shirt. Instead of reaching for a napkin or an alcohol wipe for

the exposed wound, I mumble the words “I’m so sorry.” To whom I am sorry, I had no idea.

How do you let an unintended, possibly imagined audience know that a needle is responsible for saving my life? Their condemnatory glances and glares, their disapproving whispers I can hear despite their lack of presence. My chaotic story “traces the edges of a wound that can only be told around. Words suggest its rawness, but the wound is so much of the body, its insults, agonies, and losses that words necessarily fail” (Frank, 1993, p. 98). Scenes of a jury too high above me I cannot face bombard me. Apologizing is all I can think to do, however that deferring action is not how my body responds, inflicting more of a wound to match the psychological toll of a stranger’s judging gaze, or even just my perception of it.

My position as an Asian woman intensifies the experience, where the stereotype of a model minority distorts my pushback on power and counter-resistance, a misleading myth of economic, educational, and professional success while simultaneously passive to political issues of equality and acts of authority (Cho, 1997; Crenshaw, 1989). Cho (1997) originally applies this stereotype to unpack how sexual violence against Asian women internalizes and manifests in popular culture, creating a sense of normality in the submission to power and the gaze of others. Not only am I subjected to this gaze, I am to expect it and be submissive to it. The heaviness of the perceived gaze is so strong, it brings about an act of violence on myself, inflicting more of a wound than the injection itself, handing in my submission to shame.

Dodging into empty offices or pretending I felt no hunger as a cookie from the last meeting is presented to me, I wonder why salads suffice. Every prick of pain to

myself that causes even an ounce of discomfort for them comes back to wound me once more. They who cannot be named. They who I cannot catch fast enough when they direct their judging gaze onto me. They who do not exist in “today’s world”. They who inevitably and irrevocably do.

Comparing the two interjections into my life story event, of my mundane activity of eating lunch, the power dynamic difference between my familiar mother and the unnamed ‘they’. With my mother, rebellion takes the form of movements, Foucault (1979) posits that actions of discipline have a correlation of body and gesture. Disciplinary control is more than teaching and imposing productive gestures but includes the positioning of the body to improve efficiency and speed. Disciplinary activity “must be punctuated and sustained by injunctions...the order does not need to be explained or formulated, it must trigger off the required behavior and that is enough” (p. 167). Foucault’s likening of the disciplined body to a machine which fires when ordered speaks to the dehumanization of the human body that Frank (1995) discusses of the separation of body-self, body becoming a productive ‘it’. While one disciplinary act results in cheeky rebellions and comfort increase, the other results in immediate deference, even without knowing the power source. I mare the body in surprise, a bloody punishment for the unproductive.

“Did you say something?” my father asks, folding the edges of the brown paper bag, creating a bowl to eat out of. I find myself smiling. The walls of our kitchen are redrawn, I exhale, muffling the sounds of shame. My mother passes the queso container closer to me, raising a brow.

“No, it’s nothing,” I point with my plastic fork to the still wrapped taco in her red wired bin. “Are you gonna eat that?”

Our Usual

“So, our usual?”

I smile from ear to ear as I shuffle into the familiar wooden benches of our favorite restaurant, fingers running over the metal chopsticks as my eyes rake over the nostalgic spread of cool kimchi, sautéed brussel sprouts, pickled radishes, and a freshly scooped bowl of rice. I can’t remember being so excited for vegetables.

“Half and half, mild tofu soup with an order of barbequed ribs?” I respond, shooting with little finger guns. Right on point. “Is this rice—?”

“—Multi-grain? Yep. It’s pretty good too. I tried some of it.”

I shoot my best friend a playfully appalled look, scandalized as my hand hovers over the heat of an untouched dome of rice, shielding it from its attacker.

“It’s 48 grams right there,” Connie insists with an equally playful roll of her eyes. “I was just trying to shave it down to 45. You can thank me later.” After the waitress comes and takes our order, Connie’s quick to lean forward over the table, placing some sprouts over my rice. “So, how are things? Have you been good?”

I rub the back of my neck and shrug, fingers resting over the tangle of metal and plastic at my side. “Things...are the same. Like always,” I assure, placing some of her favorite side dishes over her rice as well. “You?”

“As good as things can be in medical school,” she shrugs. “But really, are you sure things have been good?”

I glance up to find eyes narrowed, lips pursed, and if I could see them beneath the table, I'm sure her hands would've been on her hips, her foot tapping against the floor. I just know what that means.

In comparison to family bonds or spontaneous interactions, friendships have a unique voluntary and 'horizontal' nature, a seemingly balance of power where both individuals are equal based off "mutual affection and reciprocity of liking" (Finke, 2016, Hartup & Stevens, 1997). However, that balance tips when including the ill self. In a seemingly equal footing, how does the presence of chronic illness and dependence play out between two Asian American females of higher education? While my relationship with my parents are a clearly "vertical" dyadic relationship which results from a difference in age, family position, and level of control over the relationship (Finke, 2016), my friend and I finish each other's sentences, relate on another level, and can even match our struggles through higher education. I would say the act of pushing for further information would not be an imbalance of status or exercise of disciplinary power. It is implied that she is asking about my health, and despite our closeness, we do not address this directly and instead resort to vague questions like "how are things"?

While 'things' can refer to many different issues like quality of life in graduate school, romantic endeavors, or relations with my family, 'things' also mean my body. My body, the thing, a nuisance and an indicator of my well-being. And just as she indirectly asks about the wellness of my body, I respond in the same manner, indirectly and incomplete. Discussing illness as an Asian woman can oftentimes be difficult. As Le and colleagues (2015) investigate the experience of Asian Americans through cancer journeys. The authors speak extensively about how patients see physical concerns of the

most importance but speak little of the emotional toll on the body and how cancer patients in general keep the gruesome details to themselves in order to spare their family's emotional distress.

Through Lorde's (1980) account of breast cancer and mastectomy, she notes how women handle crisis, either through 'business-as-usual' sentiments to muffle her pain or through a vehement denial of feelings of pain at all in her quest to avoid being seen as a helpless victim. 'Things' can also inevitably mean my mechanical parts that beep despite my claims to normalcy, similar to how Lorde (1980) views her prosthesis: "the warrior's painstaking examination of yet another weapon, unwanted but useful" (p. 1). Fear of being an emotional burden presents itself as I deflect my answer, and I use another 'thing', my insulin pump, to distract me from thinking too deeply about her question. Still, due to our close relationship, she feels empowered enough to push.

"It's been a bit more difficult this semester," I confess, taking the time to punch in the 48 grams into my metal box attached at the hip, eyes glued to that rather than her knowing gaze.

"You didn't tell me that," her tone changes and I hear her stop chewing, placing her chopsticks against the table once again.

"Yeah, I don't know," I do know, but I'm struggling, scrambling at the last minute to find the right words to say that won't have her so—

"I'm worried."

Ah, damn.

“I should come visit you more often. I’ll make a point of that next semester,” she declares, reaching forward to press a hand over my shoulder. I flinch away from the contact.

“But you’re busy too.” I insist, not out of anger or resentment, but out of worry of my own. Everyone has their own problems. I don’t want to add to anyone else’s. “Year three hasn’t been easy for you too. Don’t worry, it’s not so bad anymore and I’ve actually been looking into getting a dog!”

Her eyes brighten at the prospect, she’s appeased by pictures on Facebook of puppies in training. “This will be good for you,” she agrees. She can read my uneasiness with the subject as if it were written across my cell phone screen. “I just feel uneasy with you by yourself all the time. I know you can handle yourself well; it just would make me feel better if I can come visit you next year. We’ll get work done together just like old times. It’ll actually help me. I can’t focus in the library anymore.”

A sigh of relief I didn’t know I was holding. Or maybe a sigh of gratitude I couldn’t hold back. “Okay, so our usual?”

The tension between a good situation for and a level of comfort for her speaks to the emotional burden and toll placed on friendships as they tackle the chaotic narrative together. Le et al. (2015) highlight the need for more emotional support for Asian Americans especially with the cultural context of holding their emotional distress in; however, despite the similar cultural understanding, there is a desire simultaneously to be comforted as support people suffer emotional trauma from the illness experience as well. Indeed, this friend in particular has seen many of the ups and downs of my Diabetes, having known me pre-diagnosis, and plays a proactive role in my maintenance.

A friend taking on an additional role as caretaker disrupts the equal footing and balance of power that creates the horizontal structure of friendship. As Foucault (1979) mentions, acts of discipline can be seen in the small actions, in this case her playful regulation of my carb intake. I play along as I shield my food, but since the imbalance is not large, retaliation and refusal of actions of power do not emerge. Even in relations of little power imbalance, acts of discipline can be met with gratitude instead of resistance. Perhaps this may be because she hears me, articulating the difficulty of my chaotic experience in the words I did not say. Moreover, she does not challenge this difficulty, drawing the nuances in my tone and mannerisms. Moving beyond speech, a friend can identify the chaos narrative that lies in the lacking: “chaos is what can never be told; it is the hole in telling” (Frank, 1995, p. 101-102). If I hold my breath, she exhales.

Installation

Thanksgiving finds me on my first trial of a CGM. Promises of better control and better management become mantras as the nurse makes the first insertion. I’m not sure if I should look at the needle, look away...of course, I’ll look at the needle. It’s nothing new. The way her fingers wind around the sensor and expertly pull of the tabs while simultaneously prepping the skin for insertion intrigues me. This seems like a procedure to be done in hospitals, by professionals, and yet the trial is so I can have a monitor of my own. “Are you ready?”

A stab. Sharp. I grunt at the piercing of skin as she inspects for blood, well, blood out of place. Her hands move with a precision I don’t think I could perform on my own. Exhale. I didn’t remember holding the inhale, and she has the gray plastic transmitter between her fingers, sliding it into the plastic cradle, and snapping it into position. The

site protrudes from my body like a hidden growth, a mass whose white bandaging encloses the eye, the iris the transmitter. I rub my fingertips over the smooth plastic, acquainting my new appendage.

My attachment grows more each second, especially when the screen comes to life! Calibrating...it's calibrating! Like a child with a new toy on Christmas morning, I'm apprehensive, jittery, bouncing on the balls of my feet, taking quick steps in place. I should be running to keep up. Two beeps is high. Three beeps is low. White is the color of perfection. The promises of tighter control place different dishes on my tongue, the ability to experiment acknowledges my need to try. I want one, not just for the week. To do this I need to do well in the trial, I have to prove my performance is better with it. After one week, I'll return to the doctor's office again to examine the trends, see how different foods affect blood sugar in real time, and make adjustments to my management plan based off the black box as it sits nestled carefully, cradled in my hands.

This monitor is the most magical thing I've ever laid eyes on and I can't rip my eyes from the tricolor screen of reds, yellows, and whites. What number was my score now? Click. What was my Diabetes number now? Click. How am I doing now? Click. Enamored with an instant gratification report card, I could see the blood sugar rollercoaster reacting, continuing, a moving entity with whom I interact. Hi Diabetes, how are you doing today? Managing Diabetes is expecting a reply back, the dips and valleys beeping into a language I could now understand.

Better control, better management, better discipline. To aid in the wounded body's productivity is the introduction of the continuous glucose monitor, where even the name insinuates losing a sense of time. Continuous monitoring, continuous insulin IV,

continuous management to become the most productive cyborg of a woman. At first glance, the conversation may appear to be with the certified Diabetes educator, but the nurse is not a voice in this conversation but a surrogate, a voice of the monitor. Foucault (1979) describes body-object articulation as discipline having control over the body and the object that the body manipulates, posing for example a soldier's gun. He describes a "meticulous meshing" of body and object in what he calls "the instrumental coding of the body" (p. 153). A master's pet's pet, I converse with my CGM as I would a dog, barking orders of silence, enacting it as my own tool of discipline and yet it disciplines me. Through the pain of insertion, I am initiated into the world of beeps. Foucault (1979) describes the body as a passive force, making the body's object passive still, but I argue it is a force that enacts upon me as much as I enact upon the gazes I receive.

Control and chaos exist on opposite ends of the spectrum, so a promise of greater control is an attribute of a restitution story; the constant battle for control is the chronically ill person's narrative. Frank argues "chaos feeds on the sense that no one is in control" so how could an object whisper promises of control when it is the body that controls it? Medicine and technology offer patients tighter tools for management only after they display need, in my case, after a loss of consciousness at work after a particularly bad case of hypoglycemia. There my body tells stories of "being swept along [...] by life's fundamental contingency" (Frank, 1995, p. 102). Biomedicine and technology tell their own story, finding my experience not inevitable but preventable, through magical tools that cannot fail, that watch even when the body is no longer watching.

Despite the heightened surveillance, my fascination with the tool envelops a desire from the body, a desire a disciplined body sheds. Therefore, my misplaced self, separated from the body that lacks the ability to love food, suddenly falls in love again. Technology instigates a body's desire to be under a continuous medical gaze voluntarily, as if the continuous glucose monitor is my friend.

BEEP BEEP, you're too high. Better check me.

BEEP BEEP BEEP. What did you do?

Overbearing worry manifests itself into a machine and becomes an entity I yell at to "shut up already, I'm coming!" The monitor grades me continuously, a machine meant to address the chronic nature of my disease. It collects colored evidence of not only the food I consume, but any variable in the equation is blatantly and glaringly obvious to decipher. Diabetes days are colored maps of hills and valleys or white calming plains. Patterns and trends enter the conversation of maintenance, but kick convenience out of the room. Peace of mind comes at a noisy price. Beeps into the middle of the night as vibrations and sirens begin the days when I never sleep a full night.

I desperately wish to be rewarded for good behavior as intensive insulin therapy leaves my body unpredictable. If discipline yields punishment for rebellion, my body prays for reward, hoping for stability. Looking to a lover with hopes of a restitution narrative, I look upon the tool with affection and tenderness. Le et al. (2017) describe a trait of Asian Americans to shy away from invasive procedures, however insulin pumps and CGMs invade the body every few days. I remember my contempt for the tools when I first heard of them, hoping I never got 'so bad' as to develop a need for continuous

treatment, but my mind quickly changes as the improvements of infusion sets and sensors provide.

Note the lack of a hyphenated interruption, thoughts and words are given a chance to complete. In previous scenes, hyphens denote a surprise: surprise judgement, surprise discipline. Surprise unhinges me and my narrative, taking the scene off its track and eliminating any sense of control. My beeping tools are promises to eliminate the surprise yet providing real time surveillance of the illness that uproots plans and throws them in a direction unseen, shifting responsibility to the patient. I live with one eye on the monitor and one eye on the road, like this a crash is inevitable. Control becomes an elusive reward, an incentive dangling. Responsibility denotes power back into the hands of Foucault's passive body, yet I do not feel empowered.

At least I have the beeps. As Lorde (1984) argues, "the master's tools can never dismantle the master's house", it can only result in a temporary game, but for those who are not privileged enough, for those who rely on master as their only source of support, they do not even enter the game. They do not have access or power as I do to utilize the beeps, to accept and manipulate medicine, to manipulate disease as it enters into my body, and I collide with my own privilege. If I'm already living a recurring nightmare, what about the ones who cannot afford insulin? The impoverished Diabetic becomes a pawn, a mere playing piece in the temporary game.

Inhale. Exhale. The process of inhaling and exhaling repeat as I stifle the 'feelings', the emotions my body expresses. While I grow accustomed to beeps and alarms, my body reacts the same with blood and bruises, scabs and crimson trails. Inhaling can be silent, a passive acceptance of come what may attitude, an

acknowledgement of chaos. Yet only others, something or someone can help me exhale, to release the pent-up distress and disarray. As breathing is wordless, the exhale follows, and maybe someone can hear the subtle sigh of release.

In the meantime, one beep is always better than none.

Interlude 4

I gaze wistfully at the pristine piles of journal articles and books on the kitchen table I long to return to, laptop a dark screen, sleeping as I agonize over approaching peril. It's coming on fast, nails digging nervously into crimson freckled peeling skin, plastic tubing caught between fumbling fingers—a harsh tug, maybe I could be free. Novocain injected numbness enlarges my tongue,

t o o b i g , no room,

ob stru ction to antidote

whERE?

Volume slides down to mute, I'm still here, aware of that stupid stubbornness but still unwilling to take a pause. I shouldn't have to take a pause. I need that juice.

Meek and small, I whisper instructions, pleads for help. Jittery hands clasp together to hide the tremors, terribly, shaking hands like shaking heads I imagine will follow. My own head falls; I shouldn't have waited that long. I know better. Bashful smile accompanies my request for sustenance, looking at the floor, a child waiting for reprimands on bad behavior. "Sorry, could you go into the fridge and pour some juice for me?" Barely able to lift my hands, my legs a lulling desire to sit on the floor, but that would only instigate panic. I mumble something along the lines of "not to worry" as she passes a cup of mango juice into my hands. I don't dare to look in her eyes as my own sting.

If I don't drink this juice, if I don't drink every single juice can and candy in this damn house, all of it, right now, I'll die. I promiSEE yoU IlldIe

CHAPTER V: ALERT AND ALARM

Take Care of Yourself.

Of all the things to neglect with selfcare, this is perhaps the easiest to accomplish.

While I re-inject infusion sets every three days, tying the strings of flimsy fabric around my neck and covering my nose and mouth against the brisk winter air stifles more, grabs more attention than the robot beeps. A cotton shackle hangs loosely around my ears so strikingly different from the full faces of yawning mouths and free, yet stuffy noses. Daunting, so glaringly protruding, these surgical masks with ties at the back or easier elastics with patterns on the front. Mickey Mouse is my favorite; sunny yellow is my normal. Like someone carefully expecting rain and remembering to take an umbrella, my mask expects germs and flu season, stands out in its pale-yellow disposition among the seas of black and white.

Slowly, tug by tug, I slide the cloth down, and all my other efforts to avoid the flu, the common cold, or any other winter ailment is void. Somehow, as soon as I lower the fabric from my nose, past my lips, snug at the chin, I inhale fresh, chill air and in return voluntarily lower my own defenses, willingly dropping my barrier. I allow preventable illness to infiltrate the foolproof wall, as if this piece of fabric could be more of a shield than skin and constant sprays of Lysol.

In. Out. Breathe. BEEP.

When gauging a gray face mask against another physical manifestation of disease we may think there is not much difference. Ties of string, tangles of white, are tethered to the body, signifying its presence. It lacks the subtlety of embodied evidence for crimson dots on fingers are often overlooked. I find that the face mask, a signal of sickness

riddled with visions of sterile surgeons, white hospitals, and unspeakable gravity of a situation—it attacks my sense of normalcy. No matter how mundane, how cartoonish the pattern, how common the usage for other things other than illness (dust storms and pollution, to name a few), the mask stands out, an indicator of inadequacy. It calls me out on my lie.

Normality is not me; I am not well.

A mask over a mask of normality, as Richards (2008) states we fake normality in our struggle to not seem defective. We discipline the body to be more productive, and as Richards explains, we are careful with who we tell our story to. In essence, I do not wish for anyone, the stranger on the bus, the barista at the coffee house, or the new acquaintance at the party to know, without my prompting, that I have an illness. In this way, I can enact power upon my disruption by choosing when and where my illness manifests, on what days I pull my pump out of my pocket, or not.

Guilt infiltrates as I “allow” myself to lower my mask, to gamble with fate. How is it that my mask is more of a marker of illness identity than my pump? Its discipline tuts with beeps of disagreement, making its presence known all the same. I cannot stuff a sound into my pocket the same way I can wind tubing and shove it into my pants.

Whether or not the mask is on, I cannot hide.

Edley and Battaglia (2016) warn of the dangers of overcompensation and the importance of saying “no” and letting go. I fear the mask is my overcompensation, an overdoing of discipline, my extra bit of maintenance in hopes of demonstrating how I do everything I can to prevent further illness despite my lowered immune system. In an effort to escape defective, I make maintenance visible. Perhaps by playing the part of the

“good” patient with the disciplined body, others may more readily accept the times when my body is. By highlighting my effort, I highlight my defectiveness despite it. I take the mask off. Am I still fooling anybody?

“Are you sick?” they ask, concern oozing from their tone.

“Are you contagious?” I hear.

“It’s just a precaution,” I assure.

“I’m looking for attention,” they hear, I fear the thoughts that fill to the brims of their eyes and spill out, spelling disdain.

“That’s good, take care of yourself,” they respond.

Foucault’s (1993) ‘technologies of the self’ delve into the Christian ideology of disciplinary aspects having a distinct moral quality, creating feelings of positivity or even superiority. Foucault argues this notion originates from an administrative self-examination, building upon elements of the Christian spirituality, a disciple’s obedience to a master and contemplation of God. Growing up Roman Catholic, I recognize these technologies of the self as they apply to my understanding of chronic illness maintenance. Here the act of power remains in the societal space, but the spoken words do not match the conversation in my head. Similar to the ever-present medical gaze when enacting insulin injections in a public restaurant, the effect of unsaid words illuminates how society view illness, a something to be cared for in private, behind closed doors, out of the healthy master’s sight. The master’s tool of shame works silently but effectively as I dip my head in guilt. Am I a good patient or an overreacting hypochondriac? I can never win.

‘They’ fill different questions in my head, calling on self-reflection when “take care of yourself” implies you should take care of yourself, a moral meaning behind an act of discipline, a scolding. However, within that discipline is another side, one that beeps to another tune of self-reflection, could a patient be too good they are bad? The morality of the action lies in a continuum, searching for an accepted sweet spot.

As Balfe (2007) finds, all respondents to their study on Type 1 Diabetics of college age have a concern about the “right” practices of healthy eating and exercise (p. 140). Wearing a mask, eating lunch, engaging in exercise, these disciplinary acts on the body are under the scrutiny of those who witness it. Eating healthily constructs a more positive self; however, wearing my mask my mask can be interpreted on either side of morality. Type 1 Diabetic women specifically found an ambiguous meaning to their disciplinary practices despite a desire to engage in them, specifying that “individual practices often have multiple moral meanings that cannot easily be integrated” (Balfe, 2007, p. 137). While men emphasized a wish to not stand out, to be looked upon as meticulous sportsmen, women highlight how social settings inhibit them from accommodating both discipline and social practices, creating ambivalence. According to differences in desired gendered aspects of self, the positivity meter shifts along the continuum. As a woman, as an Asian, and as a functional member of professional society, I find my ambiguity multiplies, compounds, leaking from my expressions until I try to articulate into words, but by then it falls on deaf ears. It is too late. The story vanishes behind the mask.

My lips spread across my face, tugging against teeth in what I imagine is a convincing smile. Company moves along. I submerge in my recurrent beeps and

machines, dip in blood and cover with clothes, shove in pockets, and hide from view.
Take care of yourself.

“I’m trying,” I want to scream, but there’s no one left to hear.

Too late.

The car doesn’t slow. There’s no way we can go back, they reason, looking at the road. The vibrant hues of redorangeyellow frame the pavement of our journey. Funny how something dying can look so captivating, so compelling, can be more moving than my immediate need for this car to turn around. How far have we gotten from home already? Thirty minutes? The seat belt tangles my tongue.

“Shit! I’m sorry guys,” the prelude to the upcoming statement hangs heavy, deafening, I break conversation, eyes turning from the road ahead to the passenger seat. I fiddle with my thumbs and curl fingers around the smooth fabric and metal zippers of the insulated case that wasn’t here. Taking counted breaths, I glance down at my empty machinery, out of gas, out of fuel. I meet the expectant gazes upon me. “We need to go back.”

A pregnant pause, the silence suffocating, I look around at the full car. I didn’t mean to. I didn’t think this would happen. I don’t know why it’s happening. This is the last thing I want to happen. “I’m so sorry,” I repeat, a breathless and monotone recording, apology tired, automated, and rehearsed. It’s hard to read the faces of the people sitting around me if they won’t look at me, their eyes still fixated on the autumn scenery. We prepare for my blood sugar to fall with juice boxes and prepped lunch boxes, but I didn’t remember to prepare for this.

Frank (1995) discusses the narrative force of a story that originates from a sense of “genesis” where a clear lineation of how a story comes to be creates a sense of comfort. A series of interruptions leading from one to another gathers stability as “interruptions are assimilated into a stable pattern of memory” (p.108). However, Frank argues a clear lineation and showcase of linear force is not a chaos narrative, or anti-narrative, as chaos takes on no clear genesis. There is no cause and effect here, just a multiplicity of problems that are difficult to sort through and order into the chronological. This loss of temporality festers into a feeling of dread, an unsurmountable fear of the unknown where prevention and proactiveness are ineffective. Certainly, the lack of preparedness can be a cause, but a linear explanation to the dread of impending punishment oversimplifies the situation.

With Diabetes, it is almost impossible to keep track of all the things that can affect blood sugar levels, and even more so to anticipate technical difficulties before they occur. Issues of contingency resurface, separating me from my friends, emphasizing my inability to keep my body working. They do not see me, as if I am not there, but things that aren't there, like my blood glucose meter, I can almost feel and touch its absence. Apology after apology, the rehearsal feels inauthentic, relating back to Foucault's (1993) technology of the self and its Christian origins. As a Catholic, we are taught to go to penance, to confess our sins in an authentic way and pray for repentance. On the same token, God will absolve any sins and forgive us, as long as we truly mean the words we say and attempt to never sin again. The repetition of the same apology creates this tension of being seen as inauthentic when the apology is very real, but to my own ears, I doubt myself.

“It’s alright, don’t worry!” The exuberance behind the driver’s words definitely sounds rehearsed. “We’ll just head back, grab her insulin, and then get back on the road! There’ll still be some day light left!”

It’s my turn to look out at the falling leaves, crumpled masses, fluttering to the ground in soundless waves until the trees are bare. I dread the looks on my friends’ faces. The truth behind their high-pitched voices and bright laughs, their downcast eyes train on their phones and the corners of their mouths flatten, brows furrow at exasperated sighs from the weight of the words they dare not say with their mouths. Pity veils disappointment. ‘Aren’t you old enough to know better than this?’

I wonder if the trees ever feel as bare as I do.

Friendships in the context of chronic illness describes a dual function of the relationship, similar to how female patients may experience a dual morality from disciplinary acts. Helgeson and colleagues (2014) describe how in comparison to relationships between the family, where a clear hierarchy of exists, the realm of social circles on equal and voluntary footing may result in a detraction of care for maintenance in pursuit of sociability. Birditt and Antonucci (2008) argue that negative experiences with friendship can have a positive and productive effect on management, forcing the patient to be less dependent and avoids reinforcing sickness behaviors. Again, productivity and healthy normalcy is the dominant narrative, and restoration of health builds into the restitution narrative and erases the chaotic narrative, the one my body and thoughts spell out painfully, bit by bit.

Critique of Foucault’s approach of knowledge equating to power and empowering a physician’s medical gaze is unilateral and does not include how the body is subject to

perception (Anderson, 1995). The body experiences touch, smell, taste, and time, along with its visual cues. The visual manifestation of disease is not the only way the body experiences illness. Like the changing seasons and the dying of trees, its colorful artistry notifies others of an oncoming winter, placing a temporal and linear string of causality: the leaves fall and then the trees die. And with time, spring comes again. In contrast, Anderson (1995) claims “disease is an entity whose existence is confirmed through processes of social interaction. Its character emerges and is transformed” (p. 77). If repeated apologies begin to fall on deaf ears, true hearing of the disease is lost. What is expected is a causal “if I had prepared for this, the interruption would not happen”, but what is erased is the idea that preparation, a clear linear explanation, a sense of stability in the chaos is never guaranteed. To expect the unexpected you must expect it, but no one ever says how. They may postulate on what they may do if confronted with the same situation, but in telling me so, only erases what I experience, yelling over my pleas for help with an “I told you so”.

My apologies for my shortcomings are rehearsed, but they are not inauthentic simply because a part of me agrees with them. A part of me wishes I have a claim to normalcy, a hope for the restitution narrative to occur for me as well. Having twenty-three years of life on the side of normalcy predisposes me to the very same judgements I have when entering this chaotic journey: “All of us on the outside of some chaos want assurances that if we fell in, we could get out. But the chaos narrative is beyond such bargaining; there is no way out” (Frank, 1995, p. 102). Perhaps the best way to remedy this situation is to demonstrate for the healthy community an understanding of their role

in the chaotic narrative before they understand from a base of shared experience, before it's too late.

Tethered

“I’m sorry, can you repeat that?” I hiss incredulously, mystified, tightening my grasp over my cell phone. There’s a bookshelf straight ahead and if emotions could present itself physically, there would already be a gaping and burnt hole through mahogany.

“The insurance wasn’t verified, and we’ll have to ask for another authorization from your insurance—”

“—but you said that I could get this in three days!” I interject, panic settling into every open crevice of my heightened tone. My hands wave above my head as if acting like a displeased customer ready to send in a complaint would have any kind of positive effect over the phone. “Do you even know what this is like? Do you have Diabetes? I don’t have a week! I’m on my last infusion set! What do you expect me to do until then?”

Options are rattled off in my ear, but I can’t seem to hear them as my own thoughts of inadequacy wade and eventually drown out all outside noise. Perhaps this is an avoidable situation. Despite the fact that I had called two weeks earlier to ensure a smooth ordering process, maybe if I had been more attentive, or called earlier, this would have never happened. How am I supposed to take care of myself? A multitude of things should be better. I could have kept my cool and not screamed at the customer service representative. But as a novice to all of this myself, I am at a loss.

As a perfectionist and a planner, I rely on time, on the order of temporality. But I find the very clock I depend on that dictates my acts of discipline from when I eat, attend

class, do work, and complete chores fails me. My expected productivity lowers and any effort to make up for that loss only compounds the losses. Despite my attempts to plan ahead, it is not enough. Despite my visions of a put-together adult, I do not pull through. This is the reality of my chaotic illness and the source of unraveling. To do something the same way multiple times, one would expect the same results, but sometimes, given the different variables of the day to day, the very same action results in a plethora of different reactions. But the unraveling does not occur there. It is when we open the door from our private spacing and invite the perspectives of the people around us do we really know fear and anxiety.

Arthur (1995) describes fear of reentry as a dread that the harm and difficulties the wounded storyteller faces will be met with trivialization, a nightmare of “reentering a world that cannot imagine, and does not want to imagine, that dissolution” (p. 107). My anger surfaces as administrative mishaps of a health insurance company do not take into account that I am not just a paying customer, but a person with an illness heavily dependent on their product. The nightmare becomes real as nothing I say or do impacts the situation. Why does a medical equipment seller have to get repeat authorization for an illness that is not going away? It’s chronic. The difficulty in renewing my order confirms my fears that echos in other stories of chaos. The nightmare has only just begun.

Contemplation storms in my head, am I too aggressive? Am I playing the dramatic sick role too much? Arthur’s own experience with chemotherapy highlights how he both loves and hates the hospital; he finds comfort in having a place there. No one questions the patient in the hospital; however, when one is chronically ill and exists the first few weeks of diagnosis, questions of control and rejection of sick role is expected.

Triumph with the help of biomedicine, the core of a restitution narrative, silences the chaotic tale for it situates in the sick role for longer than apparently needed, even perhaps at a secondary gain. Arthur likens it to a broken clock that is technically right two times a day and overlooks the premise that actions can occur without purpose. I have no reason to get angry at a person over a phone, I see no gain in the added stress and anxiety that threatens my productivity. I see no motive, only loss.

“I’m sorry ma’am there’s nothing we can do” is the last thing I want to hear.

Angrily I prod at the glass screen and drag to end call, unsatisfied with the lack of slamming that action accomplishes, before exiting the office. I’m convinced ‘distressed’ is scribbled across my forehead as I make way to my desk, avoiding eye contact with any that pass me until my supervisor and mentor happens to pass by. There is no way to avoid Meredith when she is fully equipped with a large smile and a question of lunch preferences. I take one look at her: salt and pepper hair framing a beaming smile, kind, animated eyes, hands folding comfortably over her stomach. Motherly figure in the office witnesses my most unprofessional moment.

She takes one step closer, and it creeps up my throat, builds into burning in my eyes, a helpless plea for guidance pooling at the brims. I burst into tears, sobbing so hard everyone on the east side of the floor could hear it.

Clearly baffled by such a response to a question like “so Chinese or Peruvian?”, Meredith steps inside an empty office and ushers me in, offering a tissue as she attempts to sift through my disarray. The amount of words I try to articulate are lengthier and faster than what my mouth can keep up with. Explanations should happen, but my mouth

opens, and closes, and opens again in an effort to formulate all the thoughts and concerns spinning around in my head when—

Beep beep beep!

This is not the first time my tongue ties and I struggle to put words to a feeling that will not subside, crashing over me with Diabetes' wave like force. The experience disorients me from the life I knew before this disease enters my body and I fumble like a child learning to walk, my first words are that of indignation. Arthur insists the chaotic body has no voice, "muteness begins in the body [...] at least in the sense of articulating his feelings in a way that gains the recognition from others" (1995, 109). It is only from a place of reflection outside of the chaos can one find it and pay witness to its distress.

Floundering hands tug out my insulin pump by the tubing. As the cold metal attached by translucent string lays useless in my open hands, it alerts me of another occlusion alarm.

Stop,

body blocks infusion!

Stop!

Reinsert.

On my last infusion set of the week, a shaky sigh marks the realization of how uselessly defective I am without this machine. I tremble from within. We often say we cannot live without our phones, we need to check the latest updates on our feeds and be able to communicate with our families and loved ones. But realizing you could die without your cellphone seems far-fetched, over dramatic, and a concept I could not wrap my brain around and comprehend, much less articulate to someone else. But she waits,

slowly patting my back, coaxing the jumbled words out and reeling some semblance of coherent thought in.

Lorde (1980) describes her chaos with cancer as “the bee that was never meant to fly” where science dictates she was meant to die (p. 13). Noticing my own mortality and dependency on a box of cool, unfeeling metal is similar to her experience, “carrying death around in my body like a condemnation, but I do live. The bee flies” (p. 13). This dependency denotes the power, of its curling grip around me like tangles of tubing circling my waist as I sleep. Almost as if I owe medicine, I owe discipline my right to live. I owe a life of prescribed productivity. And when I cannot meet those demands, I submerge into chaos once more, punishment for failure.

The heavy contradictions of who I am manifests into awkward, sputtering silence. Tongue ties and dizzying disruptions of alerts leaves me unable to tell my story to someone I am quite comfortable with, I do not know how to start, I do not know to express the gravity for fear of judgement, for fear of coherence. Words that I rely on so comfortably which illustrate more for me than colored ink abandons me. As Frank narrates the chaotic body “cannot tell enough of its own story to formulate its needs and ask for help; often it cannot even accept help when it is offered” (p. 110). I agree as I am notorious for claiming “I am fine” when I am anything but, holding onto the last remnants of normality of a life that is no longer mine. Arthur instead calls for the healthy to bear witness to the chaotic story, to see the patient’s testimony in our silent tear-stained faces. Chaos can only be transcended after it is acknowledged.

While I am denied by the durable equipment representative, Meredith waits to listen, a surprising turn given the power dynamic between us. Disease emerges through

interactions, through social positing which places the one with voice in a space to ‘see’ disease and perhaps provide relief (Anderson, 1995, p. 77). Meredith waits for me, at my own pace, she does not accuse. She does not judge. In fact, she says nothing at all, simply remaining a presence beside my chaotic body. She does not deny me, as Frank (1995) warns against when encountering a chaotic narrative, for denying a person only denies them proper care. She does not rush moving on or push me out of my despair, she simply notices and acknowledges the cries for help that do not articulate into words but bubbles over the surface into the corners of my eyes. She tolerates my chaos.

“If I don’t get the materials I need, this thing won’t function,” I begin, looking disdainfully at the machinery I once loved. “And if this doesn’t function, I have to switch to injections again. That’s more than six times a day, eight most days. Maybe even once an hour—I just, I just can’t.” The thought struggles to process, a life of needles upon needles, lack of appetite and avoidance of food, tiny pricks that start my days and follow me into my sleep, the minutes of coaxing to mentally prepare to fight the intrinsic notion that I should not be hurting myself. It is a part of my life I refuse to go back to, but I stand trapped between two nightmares. Here I face a bigger, more immediate problem: the dependency on something I couldn’t even properly order supplies for has ultimately yanked apart my carefully drawn up seams of a dependable, working adult. My self undone.

Out of Sight

“So, if I go blind, do you think I’d still be able to do this with you?” I joke, leaning over the wire metal table in a whisper between friends. It is one of our favorite games: people watching while giving a story to each person or group as they walk by. My

friend shares the same kind of humor that I do, that somehow, in some dark kind of twisted way, everyone's lives intertwine in some convoluted, evil plot towards world domination and total destruction. Typical coffee conversations. But the aim of the game is to narrate the lives of those around us, so the sudden switch of topic has Rachel responding with raised brows and even more preposterous laughter.

“What? Why would you go blind?” Rachel scoffs, shrugging her shoulders.

“I don't know,” I do know, and the knowledge requires another sip off the foam of my latte. Taking a proverbial swig, I too shrug my shoulders. Of what I'm so nonchalant about, I have no idea. “It's just a possibility. Like it could happen.”

“To anyone,” she points out.

As Frank (1995) argues, chaotic stories can only be told from the outside or when given enough reflective space. My friend and I take on the narrator role as a game, interpreting chaos from the easily visible, a common occurrence of ill-humored fun until the questions and narrations collide with the narrators. The game ends; the joke is over. Suddenly, this is not fun anymore. Particular to the chaotic story is its erasure, its disqualification, and how hard it is for others to hear it. Frank emphasizes the challenge of encountering a chaotic narrative and not steering the narrator away from her feelings. Comprehending a chaotic story is difficult when both discipline and disease interrupt it, taking away from its linear progression and disorienting the audience. Moreover, a sense of anxiety fills the audience when the notion that it could happen to them consumes. Even imagining what the disruption might feel like makes it harder to accept the chaos story, especially when there is an easier restorative narrative available.

This game is horrible and in bad taste, and I acknowledge my continuing presence in it. Hooks (1996) asserts “the privileged act of naming often affords those in power access to modes of communication and enables them to project an interpretation, a definition, a description of their work and actions, that may not be accurate, that may obscure what is really taking place” (p. 62). A game between two women having the power, the audacity to attribute a lifestory to other people while a mode of entertainment is consequently an act of power. An act of power enacted upon as two Asian females reinterpreted and thrown back as we enjoy leisurely activities as coffee and dessert. We’re here. We made it.

It’s only after I glimpse chaos and attempt to narrate the story of myself that her gaze suddenly falls upon me. As chaos stories don’t follow a linear temporality, ambivalence for the root cause in the story corresponds to an unclear prospect of future (Frank, 1995). Between women glimpsing another woman, and noting signs of her own chaos, I see how quickly Rachel diverts. She refuses to imagine, especially if the core or butt of our joke would then be me.

Her eyes narrowing in on a mother pushing a gray stroller while her other toddler circles around them, clad in multiple layers of every blue shade possible, and a puffy, white coat that barely zips up, and a hood that covers his little eyes. “Like, what if she went blind? What if she is blind? And everyone’s saying she should be watching her other kid, but she’s actually blind. And then, they’re like, what right does she have to raise two kids?”

“That’s mean. What if she’s having a bad day?” I ask, adding onto her supposed conversation, a scenario that only plays out in our heads. “What if just yesterday she went

to the doctor and they told her that she was slowly having leaks in the veins of her eyes? What if they told her she was going blind and she was worried that she wouldn't be able to see her children, watch them grow up? What if—"

"Whoa, that's getting too serious," she tuts, eyes moving from the mother across the street to rest on me, a steady, unrelenting gaze that calls for yet another swig of my coffee.

"And I'm serious," I reply, the porcelain of the coffee cup meeting the wire frame of the table with a subtle clang. I'm finished with it. "What if one day I can't play this game with you anymore?"

"I mean, even if you did go blind, you could just stay in my basement with me or something," she offers, the corners of her lips curving upward, a light laugh on her lips.

"Thanks," I scoff, "Glad that's settled."

The question is a what-if, an inquiry of future, a possible reality and yet as a Diabetic, I find myself learning how to focus on the present, or else my own mental health would suffer. While we exercise the utmost discipline upon our bodies, it is not out of choice, as we hope for an acknowledgement that management is not easy, is not perfect, and cannot be measured in our syringes or insulin pumps. We have variables that may aid in our journey to avoid complications of this disease, but there is no guarantee. Compliance is not a cure.

However, the moment we start to entertain ideas of the future, social arenas and the audience we choose to entertain with challenge our ideologies as Rachel challenges my body's ability to succumb to disease and go blind. Shame and blame shift away from biomedicine when "society prefers medical diagnoses that admit treatment, not social

diagnoses that require massive change in the premises of what the social body includes as part of itself” (Frank, 1995, p. 113). When social situations might confront a Diabetic with unhealthy food choices, a female Diabetic respondent explains they eat certain foods because they live on a contingency (Balfe, 2007). Why stop what you want to do today, out of fear tomorrow? Modern society focuses on resolving the chaotic story with biomedicine, with technology that disciplines the undisciplined body, but at what cost do the interruptions cause? I am not the only one who hears the beeps in my story, whose words are cut short by jarring jolts of noise, and we cannot turn them off. But they do stop, after three beeps or a loud siren from a CGM, the beeps halt after I click on the okay button, after I acknowledge its existence. The chaos isn’t forever, but it will come back.

Interlude 5

BEEP BEEP BEEP!

I'm downing the last of the large cup full of juice as my CGM goes off 10 minutes later, still wiping at the juice stains that streak down from the corners of my mouth and over my chin. I laugh as I resume cooking dinner with a very inconspicuous wipe of my cheeks, reassuming the role of Mama in our unspoken game of house. "Ah, shut up!" I call at the little black box resembling a first generation ipod from across the room, brandishing my spatula around, expecting my youngest child to talk back to me. "Behave!"

It beeps as it should, in ten-minute intervals until the arrows on the display finally indicate a safe upward trend. That is until, it's two beeps instead of three. But two, I can handle a little more discreetly than three.

"Are you good?" my roommate asks hesitantly, though she's seen this before. Not just with me, a relief within itself.

"Oh yeah," I nod, wrinkling my nose affectionately at the younger. "I'm good."

The oven timer goes off, the only dings and beeps I've been waiting to hear. Dinner's ready.

CHAPTER VI: BEEPS BEYOND, BEEPS SHARED

BEEP BEEP BEEP!

Your day starts before it has become day, nighttime grogginess still clinging to your lashes as you reach out to silence the alarm. What time is it?

3:32 AM.

And you can't silence it. It's not that type of alarm. You curse under your breath, shaking your head at the intrusion on sleep.

BEEP BEEP BEEP.

You don't need to turn around to know what time is shining on your phone display. 3:47 AM. But this time you wake up in a panic, the apples of your cheeks buzz and your hands are shaking, and you wonder for a brief moment if you just read your own time of death. You inhale as if sugar is component of oxygen, and don't exhale until the lingering of immediate death leaves your body. Ketoacidosis be damned, hypoglycemia can kill in 45 minutes...or something.

4:09 AM. You've made a grave mistake. Your eyes dart frantically between candy wrappers and emptied bags, chips, half open apple juice cans, and smarty dust trickles from your hands like the fairy dust from your dream that suddenly doesn't sound too bad now. The panic subsides like the tide retreating from shore, and you sigh, an incoming high blood sugar inevitable before there's even light outside. Nice.

BEEP BEEP!

The perfect alarm clock sounds five hours after your past alarm, the sun is out but the grogginess clings even tighter than before, causing you to squint in the natural sunlight, eyes burning from the past surge of sugar or the lack of sleep, maybe both you

reason, as you check your blood sugar without even looking down. Hmm, really ought to change that lancet. As you've predicted, you forgot to give insulin for the extra food you had in your terror striking morning and are left with a hazy brain fog that will take 2 hours minimum to subside. You smile at the number that reflects back at you, like a warm greeting might bring you better results.

Ah, no this one is your fault.

BEEP BEEP!

The interludes follow a frame of a chronological story, of how I experience life in a forward motion, and the brief glimpses of a restorative health narrative. The interludes tell a story of continuation evidenced by the continuation of studies, the flow of a day, the repeated occurrence of a diagnosis anniversary, a continuation of a wound left unhealed, yet swept under the proverbial kitchen rug. "I'm good" or I'm as good as I can be. However, analysis surrounds chapters four and five for they are the stories of mute illness, of a silenced body.

Intersectionality framework illuminates how the body is displayed publicly to the communities of which my multiple identities reside, tearing open the wounds of chaos. The conflicts of intersectionality thus "primarily concerns the way things work rather than who people are" (Chun, Lipsitz, Shin, 2013, p. 923). The body acts as the map, the surface upon which my identities collide, Diabetes the center of the collision. I enact my identities through my interactions with others, and as my illness becomes a part of my identity, it lives through my interactions as well. The body, more than a mere medium for illness, becomes the main storyteller of the disease and narrates how it messily intertwines with all my other identities as daughter, as friend, as Filipino-American, and

as a woman. The way I view my body and present it to others changes throughout the course of disease, from my upturned shirts and raw maintenance in front of my family to my instruction and education of close friends who are filled with questions at the sight of a large syringe. But as the scenes change and the terrain of my body change along with it, evidence of my illness cycles the way I cycle infusion sets around my body, attempting to avoid stiff scabbing in attempt to promote healing. Chronic illness never ends, but it changes with the ebb and flow of life's tides.

Common themes of disruption, destruction and silence throughout the narratives of the past two chapters include a focus on repetition, repetition of management, repetition of beeps, repetition of discipline, repetition of wounds. It's an unsettling *déjà vu* where similar beginnings result in different endings. It's in Hook's experience of repetitive discipline for speaking out of line, for being drawn to theory from a young age. In terms of other-relatedness, Frank (1995) describes the body as 'monadic'—ultimate, indivisible, and alone—which contributes to its struggles to find support for its pain and suffering. This creates a 'feedback loop' where "where chaos stories erect a wall around the teller that prevents her from being assisted or comforted, and the less assistance and comfort she experiences, the more she may feel compelled to breach that wall" (Frank, 1995, p. 102-103). Wounded storytellers repeat because we are trying to break down a barrier. I repeat 'I beep' at every introduction not because no one knows, but so they don't forget.

Beeps frame the narratives by which I live, disrupting the ordered temporality of a possible restitution story, the dominant discourse of Diabetes care. Diabetes is discipline and power's dream, the disease entering the body and demanding we fill a timetable with

medicine, food and exercise all to restore the productivity of our body. But this equation of control for a disease isn't so easy, and just as the restorative narrative manifests in the interludes, I suffer and hurt through the trying cycles of the chaotic. Time goes on, but the chaos never truly ends. It begins again, seemingly just where it left off.

And yet, I am told, time and time again, that there are things I can do, more strategies I can use to discipline my body, to have control. From a sideways glance of 'can you eat that?' to the whispering of a miracle cure in a spoonful of cinnamon or a bite of bitter melon, any Diabetic, regardless of the type, should be able to restore their own health by themselves—the patient drives the car and sits behind the wheel. I would like to emphasize that there are times when this is true, and the biomedical community has proof of this. To minimize risks of complications, patients with Type 1 Diabetes need to engage in physical activity and healthy eating habits (Toljamo and Hentisen, 2001; Balfe, 2007). And while previous research points to the difficulty of adhering to such a strict and disciplined lifestyle (Balfe, 2007; Vishwanath, 2016), interactions with health care teams, friends, family, colleagues, even the good Samaritan on the street undermine our actions. We are not disciplined enough. Machinery is added to our body so that we can and will adhere to the beeps: "Modernist medicine has regarded suffering as a puzzle to be 'controlled' if not eradicated" (Frank, 1995, p. 146). We have no choice as our stories of struggle disappear.

Aspects of model minority translate into model Diabetic patient, one who seamlessly integrates technology, pricks, blood and insulin into everyday life. A model patient, a disease conquered, another narrative of the ill body is a warrior on a quest. The Quest Narrative (Frank, 1995) suggests as Lorde (1980) does with her stories as a female

warrior against breast cancer that I the model patient have come out of this experience better than I have before. Conquering Diabetes and becoming a model cyborg patient should result in a stronger, more cohesive patient more in tune with her natural body as well its ever-present beeps. However, as past literature notes, the Asian American community is quick to internalize the emotional distress. As an adult at diagnosis, my identity as an Asian American breaks down further still, beyond a first generation Filipina woman is piecing together an incomplete puzzle of my language and culture. Through my relational experiences, my identities that I hold dear become lenses for interpretation of the new identity, the type 1 Diabetic. I am neither here nor there, neither robot nor human, straddling the line between Asian and American, the intersection grows larger still with the addition of an adult Diabetic. I am a perfectionist that attempts to keep control in ways that I can, but I still dip my salty chips in queso because I am learning to embrace the chaos with the control. Regardless of the tools I have, I am still sick. There is no way to compensate for that.

The American Diabetes Association (2018) recommends a glycated hemoglobin (A1C), or average blood sugar over a span of 3 months, of below 7% to prevent or slow complications, the report card of tight control to a Diabetic. However, during all of these stories of chaos, I simultaneously reach the tight control goal. My HbA1C remains below 7%, yet stories of chaos still remain, their narration silenced, emotional distress internalized. If this is the main restitutive story, why do my claims to chaos disintegrate into the daily drops of blood I shed? Looking closer at the guidelines, the statistics of occurrence of complications for those who remain with tight control still “start” or have “already started” issues with the eyes, kidneys, or nerves. Despite our best efforts,

normalization is not in our horizon. Control is not a cure. Our chronic illness story can never be restitutive. We need to acknowledge the contingency of chaos.

But remaining in eternal chaos is not in my story either. I still exist and live in the temporality of the story, and our lives go on past diagnosis, but like a sense of *déjà vu*, our diagnosis day repeats and repeats as we constantly adjust to this story. Of importance to note is the age of my own disease, only three years old, perhaps my quest is yet to be seen, my transformation in the making. Frank (1995) warns however that just as chaos is not constant, neither is transformation: “The phoenix does not mourn what lies in its ashes; the serpent does not mourn its old skin. Even when lives as a quest, always returns to mourning” (p. 136). I return to mourning for my past healthy self, and I mourn for the possibility of others. As I gaze into the faces of my baby cousins who whisper “*Ah-tay* CJ is a robot”, I see the fascination in their eyes and I pat their heads, one by one, praying that they never come to understand what it means to become one, praying they never feel the cool metal penetrate their skin.

Therefore, I do not claim to experience a major change in self, to take part in a journey and transformation as apparent in quest stories, but I do bring testimony to my own chaos. And after I allot myself the room to acknowledge chaos, only then can I write about it. As I take back the time snatched away from me in the midst of chaos, only then can I advocate for myself and others. Only then can we both heal.

A Call to Advocacy

The change that a testimony of chaos calls for is “not reorganization of ‘service delivery’ or enhanced ‘communication skills’ among physicians” but implies a change to social ethic (p. 145). Narrative ethics implies a moral component to illness stories, a face

to blame, a structure to change; however, while I do believe there needs to be a change in how we view disease, its effect on the body, and the erasure of the body's stories into symptoms on a medical chart, I do not see this thesis addressing whether or not I blame the actions of myself or other people, nor do I categorize the interactions with others and myself. My story is not a moral justification for actions as one cannot truly enter the same space of illness without a shared experience. In the last narrative of the fifth chapter, my judgement game is one I invent and partake in from a healthy person's perspective, and as disease enters the body, I still play.

Intersectionality as applied to women's health and feminism, Hankivsky (2012) notes one of the common criticisms of intersectionality as applied to the health sector, resides in research, and how the framework can be applied in practice. Often practitioners may see how the framework allows providers to see a patient as multifaceted within many different systems of power, however there are so many identities and imbalances of power that the framework may seem inapplicable to practical research design. However, Havinsky explains that the framework is not meant to be prescriptive on the ground, but rather instigate an "intersectionality shift [which] encourages researchers to reflect on the complexity of their own social locations" (p. 1715). The framework can caution not to fall back on familiar, often assumed categories, and to approach practice in a more open-ended way. Applying intersectionality to a testimony enables a process of healing, of bearing witness to the chaos, of noting the different areas of the wound that tear, that hurt. Hooks (1996) describes the process in her interaction with another black woman, describing the testimony to chaos:

“Holding my hands, standing body to body, eye to eye, allowed me to share empathetically the warmth of that healing. She wanted me to bare witness, to hear again both the naming of her pain and the power that emerged when she felt the hurt go away” (p. 73-74).

Hooks previously describes a tension between the acts of discussion and perceived action, where talking about the matters that hurt us was seen as cyclical act, as not producing anything productive. Though here she argues that discussion wasn't even an option, much like the silenced body in chaos, the stories were always silent. But in order to begin small acts, we have to start by communicating why it is the chaos debilitates.

My own positionality as a researcher to tell this story places me in no realm of ability to judge the moral character of one patient to the next. In fact, that is what this thesis warns against. In these stories, we never know if we're the protagonist or antagonist, but that doesn't matter—the suffering and pain does. Frank (1995) argues “the moral imperative of narrative ethics is perpetual self-reflection on the sort of person that one's story is shaping one into” (p.158) and to attempt to change continuously towards what is found to be “good”. I do not wish to add to the rhetoric of what constitutes a “good” or “bad” Diabetic or “good” or “bad” interaction in my story. My argument is that beyond the “good” and the “bad” stories, we must acknowledge the beeping, the disruptions, the chaotic story that begs to be heard before we decide the moral reasoning behind it. If we first look at how we talk to each other, how ‘I’ talk to ‘them’ and ‘they’ talk to me and reflect on that process, we can begin to tackle the larger issues of morality and biomedical culture.

Minge (2013) describes “mindful action” as a cyclical process that mirrors autoethnographic work where cultivating mindful action happens when one acts, reconsiders, and then mindfully acts from that reconsideration. The goal is to start a ripple effect of mindful action that resonates with not only the physician, but with family, friends, colleagues, down to the coffeehouse barista, so they too are forced to think mindfully about the chaotic contingency of chronic illness, of disruptive beeps, and their previously unknown relationship to disease without having it enter the body. As it disrupts me, it disrupts you.

Thus, I address you, dear reader. Through second person narrative, I invite you into my body and sit with illness as I do. As Langellier (2009) prescribes, co-construct the story with me, enter into the scene as you would interpret and evaluate it, improvise how you would respond, and allow yourself the space to imagine the chaos. When your hands and vision shake, when words nearly fall off the page, when you can almost feel the stabbing injection over, and over, and over, I invite you into conversation with me. With you, I share the chaos. With you, I share my beeps.

At Least It's Not

At least it's not cancer, you say.

But then why are you calling me at home, at 9 o'clock at night, on my personal cell phone when you could have just sent an email. Dinner is half eaten on my plate and I do not have the energy to stand, what do you mean I have to live on multiple injections per day? What do you mean other medicines won't work? Doc, if it's not really bad news, in comparison to other bad news, couldn't it wait until tomorrow?

Things could be worse, you say. My grandmother has Diabetes and I give insulin injections to my cat. I understand what it's like, don't worry, it's not that bad.

If it's not that bad, then why does it interrupt my daily life? Sure, things could be worse. Nights continuously interrupted by beeps, tangled wires, and stolen moments can become common place. You can tell me everything my Diabetes is not, but will you listen to what Diabetes is? Diabetes is more than insulin injections, infusions and bruises, hardened stomachs and battered thighs we hide because you can't bear to see the pointed metallic tip of a needle too close to your food when we don't have a choice. I'd never be able to, you say. I sigh, I wish we had a choice. If we don't do it, we die.

Those words are so sweet, you say, just got dia-bee-tus. You post bags of Halloween candy and Christmas cookies hashtag Diabetes. It's all innocuous good fun; jokes are only humorous when you're not the punchline.

At least it's not cancer, you say.

I say, I wish you'd think about that, for just a second longer. Those two things are not comparable, but pain and suffering feel the same. Illness, I wouldn't wish it on anyone.

Embrace instead, I plead, don't speak. Just listen to me talk. I exist still within this wounded body.

Say at least there's tomorrow.

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