

Type-1 Diabetes, Gender and Technology
Exploring Lived Experiences

by

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Abstract

This thesis explores the experiences of women living with type-1 diabetes who use diabetes technology in Ontario. The thesis also looks at the Diabetes Online Community (DOC) and how women use the DOC to interact with other type-1 diabetics, access information and blog about their experiences of type-1 diabetes. The research methodology consisted of 9 in-depth interviews with women who have type-1 diabetes who use some type of diabetes technology: insulin pump, Continuous Glucose Monitor (CGM), and/or applications. The study found that the presence of the body is heightened in the presence of technological diabetes devices. Participants described how the body was rendered more present with the insulin pump and Continuous Glucose Monitor (CGM), compared to other diabetes regimens. Participants faced a number of challenges after diagnosis that ranged from dealing with stigma, to the mental health implications associated with type-1 diabetes management. The goal of good diabetes control is woven throughout participants' narratives. However, good diabetes control is elusive.

Chapter 1

1.1 Introduction

This research is not about the physiology of type-1 diabetes (T1D), rather, it is an attempt to look at the experiences of type-1 diabetics who use technology in the form of insulin pumps, continuous glucose monitors (CGM) and other forms of technology. I argue that the topic of the use and consumption of technology is an inherently gendered discussion and as such, I focus on women's relationship to technology in the context of type-1 diabetes. This introductory chapter is a discussion of the methods and theoretical perspectives used in the completion of this research. Additionally, I outline the objectives and the research questions that framed the research.

I did this research as an insider to the world of living with type-1 diabetes in the technological age, as I have had type-1 diabetes for over 14 years and I have been using an insulin pump and CGM for over three years. I am struck by the reality that a century ago, diabetes was untreatable, until the discovery of insulin in 1922, an advancement that allowed life after diabetes. Diabetes is much more than a story of insulin. As a subject position, the type-1 diabetic who uses technology on a constant and continual basis to better manage chronic disease is doing something that was impossible even a decade ago. Technology, then, is the building block of the contemporary diabetic subjectivity. Diabetes has largely become a matter of numbers, measurements, devices, and technological malfunction with the goal to live longer and healthier than ever before.

However, social science research has yet to comment on the relationship between diabetes, technology and gender.

I am a person who is drawn to understanding the world through asking people about their experiences. As a feminist, I am particularly interested in the ways in which gender affects individuals' lived experiences. While I am an insider of sorts to this research topic, I approach this project with a genuine curiosity about how notions of technology and illness were playing out in particular ways in women's lives. Feminists have long questioned the historic exclusion of women from the creation and use of technology. I am interested in the relationship that type-1 diabetic women have with technology when it is used in such an intimate and urgent way to treat and live with their type-1 diabetes.

1.2 Literature Review

The following literature review draws on three bodies of scholarly work: discussions of social science perspectives on diabetes, 'cyborg' feminism, and writings on phenomenological embodiment. Anthropological and sociological perspectives on living with diabetes reveal that the relation between the self and body is altered by diabetes, bringing the status of the body and the self into question. The 'cyborg' is an important concept used to describe the proliferation of technology and its incorporation into human life in the twentieth century. However, the concept of the cyborg may be too removed from everyday experience to be useful. The concept of the 'posthuman' as presented by Kim Toffoletti (2007) provides inroads to talk about people that may 'be cyborgs' without identifying as such. The concept of the posthuman reconciles how the presence of technology can be subtle yet ubiquitous in our lives. Finally, Maurice

Merleau-Ponty's (1945/2012) approaches to phenomenology and specifically embodiment provide the conceptual framework to speak of the body as the locus of experience. For disability theorists, this means speaking about the disabled or diseased body as agentic and full of intentionality. That is to say that the disabled body is not a passive object but rather the location of experience.

1.2.1 Anthropological and Sociological Perspectives on Diabetes

This thesis looks at aspects of diabetes that have yet to be addressed in much of the current anthropological research on diabetes, such as gender. By focusing on type-1 diabetes (T1D), this research explored the unique experiences of women with T1D and in particular, women who use technology in the intensive management of their disease. Both the type of diabetes and a women-focused research question are rare within the anthropological and sociological literature on diabetes. My research therefore placed both type-1 diabetes and a gendered analytical lens at the core of the study, asking women about their experiences of chronic disease, identity and technology.

The current lack of anthropological research on T1D might be attributed to multiple factors. Given that T1D represents only ten percent of all diabetes cases (CDA, 2010), and given the increase in type-2 diabetes (T2D) globally (WHO, 2011), there has been much more focus on T2D. T2D has become a global phenomenon that brings together a web of biological, demographic, social and behavioural factors and therefore has been a ripe site for social research (Ferzacca, 2012). In contrast, the lack of social factors in the onset of T1D has placed it firmly in the jurisdiction of medical, rather than social, research.

A few social science studies of diabetes do explicitly address gender and gender relations. In their study of the personal narratives of Mexican Americans with T2D,

Mendenhall and colleagues (2010) suggest that discussions of diabetes become an idiom through which people express social suffering. The individual-level analysis reveals how diabetes achieves social, rather than strictly medical, significance among Mexican Americans seeking medical treatment for their T2D. Participants told of personal accounts of stress, from child abuse to migration, in the idiom of diabetes. The authors argue that diabetes is a platform in which the disorder of the social lives of participants is mirrored in the disorder of their diabetes. The narratives they examined were gendered, to the extent that men and women often located the sources of disorder in respective public and private spheres. However, after migration to the United States, it appeared that when gender roles were transgressed, this also became a source of disorder and thus a contributor to participants' diabetes narratives. Mendenhall and colleagues signal the importance of narratives in unpacking the meaning of diabetes for people who live with it. Furthermore, these narratives are gendered and shaped by issues of citizenship, as well as social and economic conditions. The understanding of gender here is limited to conceptualizing gender as women being relegated to the private sphere of the home and men being concerned with the public sphere and paid employment. This simplistic dualism fails to capture the ways in which gender is embodied and performed, beyond a simple matter of what type of activities men and women engage in.

In one of the few social science studies that addresses type-1 diabetes specifically, Paterson and colleagues (1999) explore the nature of the experience of chronic disease through their study of type-1 diabetics' experiences of self-management in Canada. Their research participants subscribed to the perspective of viewing chronic disease as something that enhances the quality and meaning of life rather than being a burden for

individuals. Participants described a transformation in which they differentiated between self and body as a way to better face the challenges in good self-management of their T1D. Differentiation of the self involved believing and acting as though the individual was the primary agent of the outcome of the innumerable decisions that are made in self-management. There was a conscious effort to see the self as the subject rather than the object of the disease as a way to ensure that challenges of management did not affect self-integrity and self-esteem. While this study did consider the experiences of type-1 diabetics, a gender analysis was absent from it.

In sum, social science research on diabetes has focused primarily on type-2 diabetes given the larger proportion of diabetics with type-2 diabetes. It appears that there are few experiential studies of type-1 diabetes and of those, there is little focus on gendered aspects of living with type-1 diabetes. The past research approached the experience of living with diabetes from a Cartesian paradigm, speaking about the mind and body separately.

1.2.2 Cyborgs: No Longer the Stuff of Sci-Fi

Donna Haraway's (1991) theory is crucial to any discussion of gender and the embodied experience of technology. My research explores the extent to which participants perceived their gender identity as being changed by the significant presence of technology in the form of insulin pumps, CGM and other forms of diabetes technology in their daily lives. Haraway's focus on the potential relationship between femaleness and technology as empowering led me to question whether the mastery of technology can result in women's empowerment. In the context of type-1 diabetes, I question whether the mastery of diabetes technology in the form of insulin pumps, CGM and other forms of

diabetes technology produce anxiety or empowerment for women living as diabetic 'cyborgs,' that is, humans who live with the daily presence of technology.

Within feminist theory, the concept of 'cyborg' is most closely associated with Donna Haraway and her 'Cyborg Manifesto' in which she begins to think about the significance of the cyborg as a political and intellectual allegory about the world at the end of the twentieth century (Bell, 2007). For Haraway, the cyborg, a hybrid of both machine and organism, is a social reality as well as a political fiction (Haraway, 1991). It is a social reality because technology was becoming increasingly sophisticated in the late twentieth century and more common in individuals' lives. The cyborg figure is a political fiction because it is a critique that takes the form of a character to defy the idea of the 'woman as goddess' in radical feminism. Goddess feminist liberation is conceived as emphasizing and celebrating women's reproductive role in a way that links women with the biological, as opposed to the technological. For radical feminists, the military industrial complex is inherently oppressive because it is built and maintained by patriarchal institutions. Technological power, for radical feminists, is inherently problematic. In this way, neither the goddess ideal nor radical feminists associate women with technology. In contrast, the idea of the cyborg offers us the possibility to re-imagine our social and bodily reality, a reality in which power is not rooted in biological differences but rather in the power of technology. The cyborg world is concerned with imposing total control in the world through quantification, mechanization and technology to end the appropriation of women's bodies as workers and reproducers. This is to say that technology can accomplish the labour traditionally done by women such as

housework and producing children in new ways as technology continues to develop and evolve.

For Haraway (1991), the cyborg exists at the crossroads of the distinction between the organic and the mechanical, a distinction that she argues pervades Western culture. Haraway encourages feminists to seize the cyborg as a tool by which to overcome the traditional association of women with the natural, the antithesis of the mechanical, and to challenging the othering they experience as a result of such essentializing notions. For Haraway, the machine is not a dominating or threatening force but rather a vehicle with which women can begin to complicate the equation of the body with femaleness and to question feminisms that reify that equation. Female embodiment of nature seemed at one time to be a given - organic and necessary, but Haraway pushes feminists to challenge the current assumptions about machines as inherently masculinist and harmful. Cyborgs are the vehicles by which women can transgress the boundaries that maintain their exploitation in the marketplace and in the home. There continues to be work to be done to critically evaluate how the cyborg can help in challenging the domination of women's bodies by the military-industrial complex and by technology (Bell, 2007).

Kim Toffoletti (2007), who writes nearly two decades after Haraway's "A Cyborg Manifesto," argues that the figure of the cyborg pervades daily life in the twenty-first century in ways that were not previously conceivable. Toffoletti uses the term 'posthuman' to describe this age in which the status of the body and the self are ambiguous in the technological era. For Toffoletti, we need a theory of subjectivity for our posthuman age of biotechnologies, information networks and virtual reality. The condition of posthuman subjectivity is more than technology's penetration of the human

body. It consists of bodily transformations and augmentations that come about through engagements with technologies that muddle ideas of a natural human essence.

The body and embodiment have constituted an important subject of second wave feminist thought and thus are a logical starting point for feminists who wish to contribute to the theoretical foundations of posthuman subjectivity. The posthuman space is one where the distinctions between self and other or between body and machine can no longer be sustained. This understanding of posthuman suggests that posthuman identity is constantly in flux; furthermore, the images of posthuman bodies may be rejected by those who are indeed posthuman. The concept of posthuman addresses the two problematic outcomes that have come out of postmodernist and feminist accounts of the cyborg. The posthuman concept can challenge both the flight from the natural body that is associated with embracing the cyborg (Braidotti, 1994), and the exclusion of women's experiences from cyborg theorizing, a domain created and controlled primarily by men (Cohen Shabot, 2006).

Within Toffoletti's posthuman age, the cyborg figure represents women's interaction with technology. Haraway's cyborg represents the optimism of alliances between feminists and emergent technologies and it operates as a figure through which women can re-imagine the self in a technological age. Toffoletti argues that the posthuman landscape does not presume that technology is inherently good or bad for women; rather, she views it as a means through which bodies and identities can be changed outside of our current views of the self and the Other. Feminist criticism of the gendering of technology and the historical exclusion of women from its design and

application point to how the dominant culture constrains posthuman subjectivities because of persistent gender inequalities.

At best, the cyborg offers a means through which women can reconfigure cyborg subjectivity not as a question of gender difference but as being enhanced through the integration of technological power. At its worst, the cyborg is an exclusionary and oppressive creature borne from the parents of Western culture that reproduces systems of sexism, racism and classism. Yet the cyborg is not a metaphor. It is a reality that is here and amongst us, because humans today do embody technologies. Perhaps, the cyborg in the flesh is more mundane than Haraway's liberatory vision and more complex than Toffoletti's description of posthumans. By studying the experiences of women who use insulin pumps and other forms of diabetes technology, I interrogate the impact of technology on participants' perceptions of identity, and whether the idea of the cyborg is useful either to those who use technology in this way, or to researchers in describing women's relationship to technology.

1.2.3 (Dis)abled Perspectives on Embodiment

The third body of literature this research engages is that of the phenomenological study of embodiment, as most extensively elaborated by Maurice Merleau-Ponty (1945/2012), and its application in the fields of anthropology, sociology and disability studies. This research builds on the idea that (dis)abled embodiment provides the language and conceptual framework to talk about experiences of the world through participants' diabetic and technologically enhanced bodies. Embodiment articulates experiencing the world from the point of view of the person being in the body. By relating personal accounts of living as an embodied self, this research reaffirms that

participants' bodies affect the ways they exist in the world. My purpose in this section is to locate key points of Merleau-Ponty's philosophy in order to better understand the literature on disability and embodiment. Merleau-Ponty challenges the mechanistic, dualistic Cartesian view of the mind and body as separate and distinct, by arguing for an understanding of body as agentive and the basis of human subjectivity (Crossley, 1995). For Merleau-Ponty, the body-subject is already situated in a historical order yet decentred in a dualistic world. That is to say that the body-subject does not fit into the Cartesian arrangement of experience and as a result, the body-subject is not understood as the thinking self that is a disembodied subject.

Two central elements of Merleau-Ponty's theory of embodiment are his understanding of both perception and the mind as part of the body, not separate from it. In its simplest form, perception is an embodied experience. Merleau-Ponty's theory challenges the Cartesian approach to perception that is predicated on the assumption that the mind is a distinct entity that exists within the body. For Merleau-Ponty, Descartes' explanation of perception as the mind transforming physical objects through mental judgment was unsatisfactory for explaining the role of the body. Cartesians argue that we see in our minds rather than with our eyes. Merleau-Ponty argues that there is no duplication of the outer world inside the mind as a distinct representation. Rather, perception happens *in the world* where the perception of the object occurs between the body and the object. There is a single perceivable order to the world (Merleau-Ponty 1945/2012). The body-subject perceives the world as it is and in relation to itself rather than the mind perceiving and creating an internal representation of the external physical world.

Perception can be understood as sensations that hold meaning for the body-subject. The sensations that comprise perception belong to the body as a sentient being (Crossley, 1995). The body-subject as a visible seer demonstrates that we perceive from somewhere and therefore all knowledge is situated. Perception is based in behavior as acquired cultural habit-based conduct that is manifested in ways of looking, listening and touching. The body-subject actively applies the perceptual schemas (or behaviors) that render the things that we see and hear immediately meaningful. Perception is thus the active relation of the body to its world and the body embodying meaning and ideas. The body-subject becomes the perspective from which we understand and construct our world. In this way, an account of the body is critical when speaking about experiences of living with type-1 diabetes, because, as phenomenologists argue, it is the medium through which we experience the world.

Along with his discussions of perception, the body as having a form of consciousness is critical to Merleau-Ponty's theories on embodiment (Romdenh-Romluc, 2011). To be a 'self' is to be a living being in the world through the vehicle of the body, and the self and body are single elements of human beings that participate in their world (Matthews 2002). For Merleau-Ponty, to think of the body as simply an object like any other in our world fails to fully address the complexity of experience generally (Romdenh-Romluc, 2011). Merleau-Ponty's theories of bodily consciousness develop

through his psychological analysis of Schneider, a WWI veteran with significant brain damage (Merleau-Ponty 1945/2012)¹.

Through analyzing Schneider's disability, Merleau-Ponty develops an alternative view of the body (Romdenh-Romluc, 2011). Schneider is unable to move a part of his body when he is asked to by researchers. In order for Schneider to move a part of his body, he must either look at it or begin moving his whole body and eventually isolate the movement to the part in question. He can, however, perform day-to-day tasks with ease. For Merleau-Ponty, Schneider lacks some sort of bodily knowledge that others have in being able to move his body and understand the body through the situation and context it is located in. Merleau-Ponty asserts that even though Schneider can understand the command to raise his arm, he fails to do so when asked by psychologists, therefore there must be an alternate account of action than one based on the idea of the mind controlling the body. In this way, Schneider is sort of negative case to demonstrate Merleau-Ponty's point about bodily action. In the absence of brain injury, the body can move without conscious thought to guide and control the body. The body has knowledge and intelligence that is absent from Cartesian accounts of the self/body. The bodily self acts in the context of the environment that it finds itself in, engaging in intentional acts rather than brute physical reactions.

Merleau-Ponty's theories of embodiment, in conjunction with works by Michel Foucault and Pierre Bourdieu, have been critical to locating the body as a subject of study

¹ It is important to note that the conclusions Merleau-Ponty made are inconsistent with modern psychological practice and so we must be cautious of the validity of the interpretations Merleau-Ponty made.

and a theoretical problem within anthropology (Csordas, 1999). The body has been reconfigured in such a way that revises biological essentialism, collapses dualisms and highlights the ambiguity of the borders of the corporeal self. Embodiment as a theoretical perspective provides a critique of the enduring dualities of mind and body, subject and object, and distinctions between body and embodiment. When using the phenomenological approach to embodiment, it requires a focus on the body as both a source of representation and the source of being-in-the-world. The focus of the phenomenological approach to embodiment is “neither behaviour or essence *per se*, but [it is] about the experience and subjectivity, and understanding these is a function of interpreting action in different modes and expression in different idioms” (Csordas 1999, p. 184). Embodiment focuses on the ways in which the embodied self is shaped by social interaction so as to produce novel bodies that merit further investigation (Katz & Csordas, 2003). As such, embodiment provides the theoretical framework to look at bodies as the location of experience rather than an object that has a disease like type-1 diabetes.

Paterson and Hughes (1999) argue that a phenomenological approach to embodied agency may shed light on the role of the body within disability studies. The disability movement has drawn attention to the ways in which ableist norms and practices work to exclude people with impairments from mainstream society. The social model of disability hinges on the distinction between physical impairment and socially produced disablement. Paterson and Hughes argue that this social view of disability and current poststructuralist theories of disability take the body as an abstract, self-existing and socially removed individual. The identity and cultural meanings of the postmodern body are passively determined by discourses of power. This understanding of the body depoliticizes issues

of disability by refusing to see the body as agentive in the determination of identity and meaning. The social origin of impairment emphasizes the relationship between impairment and social structures. This reifies the binary opposition of the social and the biological that typify the Cartesian subject.

Within the discipline of disability studies, the 'body' often is not represented as a sense of bodiliness but rather as an object devoid of intentionality and embodied subjectivity. A phenomenological approach to impairment highlights the ways in which the impaired body is simultaneously a cultural phenomenon and a biological fact (Paterson & Hughes, 1999). Additionally, phenomenology can overcome the tendency of disability studies to focus on the macro-level analysis of disability by locating the disabled body as the medium with which everyday reality is experienced and created. The phenomenological body emphasizes lived experience and the sensation of the subjective body lends itself to reflecting on how impairment is both culturally constructed and biologically rooted.

Citing Drew Leder (1990), Paterson and Hughes (1999) argue that the healthy body disappears from our everyday experiences. The body is brought forth in consciousness during experiences of disease and pain. When the body is in pain, the body becomes unceasingly present in a dysfunctional manner. Leder calls this phenomenon *dysappearance*. Phenomenology gives us the language to talk about pain as a lived and embodied experience or a way of *being in the world*. Unlike the social model of disability, Leder's model integrates the physical experiences of disability into issues of political and social structures that shape the experience of being disabled. Applying Leder's dysappearance to disability, Paterson and Hughes argue that the continual

confrontation of the social and physical inaccessibility that people with disabilities face is a confrontation with oneself. The confrontation occurs when the norms that reflect the carnal information of the nondisabled result in the exclusion of the disabled. The exclusionary practices are social constructs that operate on the basis of non-conforming physicality. In this way, the experience of disability is simultaneously physical and social, while being rooted in the body.

Perhaps the most convincing element of Paterson and Hughes' argument lies in the incongruous experience of embodiment of the disabled. The disabled body dys-appears as the consequence of interacting with other nondisabled bodies. That is to say that the impaired body is shocked into recognition by the oppressions of everyday life of an ableist world as a state of being *alien* in the world (Paterson & Hughes, 1999). From the phenomenological perspective, the world becomes embodied through the projects that make it what it is. However, when any body is excluded from contributing to world projects, there is a sense of dislocation and discomfort that makes the body more present and consequently dys-appear. In a world that is filled with projects that reflect the embodied experiences of the able-bodied, disabled bodies dys-appear because of the discomfort that arises in confronting the social and physical world that excludes non-conforming bodies.

Andrea Vick's (2013) study of the embodied experiences of women with episodic disability challenges the meaning and construction of categories of disability. The shifting embodiment of relapsing and remitting multiple sclerosis (MS) is experienced in unconvincing ways across different contexts of Vick's participants' lives. That is to say that shifting embodiment of episodic disability challenges cultural understandings of

what constitutes a legitimate experience of disability and those who experience MS are not understood as having really having a disability. Episodic disabilities are characterized by fluctuating periods of illness and wellness that negatively affect a person's quality of life. Vick conducted her doctoral research with three women with multiple sclerosis to investigate the ways in which episodic disability is experientially understood, socially constructed and politically recognized.

Like Paterson and Hughes, Vick argues that the social model of disability has been effective in transforming the understanding of disability into a form of socio-political oppression. However, the social model of disability has been inadequate in addressing more complex forms of disabled embodiment. The modernist divide of impairment as biological abnormalities, and disability as the social construction that excludes disabled people, is experientially porous for Vick. That is to say that experiences of disability and impairment cannot be understood as a static experience that we attribute to those living with MS or other episodic disabilities. As such, embodying disability can change from one social environment to the next, from person to person or throughout one's life living with an episodic disability. Although MS and T1D are not comparable experiences in and of themselves, the occasional invisibility and periods of relative health of MS sufferers speaks to some of the experiences of T1D participants in this study.

From a phenomenological perspective, an in-between embodiment speaks to the permeability of moving back and forth between embodied states of health and illness. Such individuals threaten classificatory systems by remaining neither properly well or sick, and existing between the statuses of able and disabled (Vick, 2013). For those with episodic disabilities, the ambiguity of living in-between augments the complexity of

bodily experience and cultural constructions of what rightfully constitutes a disabled body. Borrowing the notion of fluid embodiment from queer scholarship, Vick notes that bodies do not simply correspond with pre-given and fixed identities. Those living with episodic illness unsettle hegemonic constructions of disability because they possess the ability to be sometimes healthy and sometimes disabled. The incongruous embodiment of those with episodic disability is a legitimate carnal template that more effectively reflects the malleability and fluidity of particular experiences of disability.

The first theme of Vick's analysis concerns the tension that arises around a woman's appearance of wellness and the cultural unfamiliarity that arises with episodic disability. In the absence of obvious and consistent markers of disability, women with episodic disabilities are doubted and their ability to define their own reality is denied. Vick argues that "society is not culturally attuned to the diverse embodiment of disability, how disabilities that fluctuate make an appearance in commonplace ways" (2013, p. 182) such as needing to sit down when speaking to others. When participants told others about their symptoms such as overwhelming fatigue or muscle soreness, their claims were doubted. The able-bodied often seek recognition of their normalness while those with episodic disability seek recognition that they are sometimes not. The second theme of Vick's analysis addresses participants' description of the ways in which their normal-looking bodies outwardly perform able-bodied expectations such as regular physical exercise. These performances challenge what plausibly and performatively counts as disability (183). Vick argues that the reality that her participants look well and function fairly well often challenges the monolithic notion of what it is to be disabled.

Vick argues that persons with episodic disabilities are experientially and discursively discredited in public policies. One of the participants describes the disapproving reactions she receives from other commuters when she uses an accessible elevator at public transit stations. The same participant attempted to qualify for accessible transit but she did not have the adaptive devices of a more visible disability. Consequently, she was not considered as sufficiently disabled to qualify for the service. This participant's body materially and discursively exists outside of bureaucratic parameters developed by her city's public transit system (Vick, 2013). Her subjective experience of pain and fatigue is institutionally contested and thereby denies her accessible services. Defining disability can be deeply problematic to the extent that there are fluid disabilities that resist permanent categorization. The shifting embodiment of persons with episodic disabilities is rendered an experiential impossibility in such policies. Participants' ambiguous status excludes them from policy as either properly healthy or properly disabled and these individuals remain on the fringe of the populace as absent citizens.

Vick argues that her participants' accounts reveal that health, illness, ability and disability exist as a continuum of experience as opposed to static subjectivities. Unlike other forms of more visible disabilities, the embodiment of persons with episodic disabilities is contingent on how they feel rather than others' perception of their bodies. This requires a new approach to disabled embodiment that Vick suggests will challenge the category of disability. Lived bodily experiences are informed and impacted by societal structures, relationships and practices, and need to form the basis for embodied politics. Such an approach requires that fluid embodiment be placed at the center of conceptions of disability and that static representations of disability be challenged. For

Vick, the exclusion of persons with episodic disabilities from the cultural construction of disability has a profound impact on the political rights that they can access.

Speaking about the performance of disability as fluid creates a theoretical language and expands the discussion of disability to include those people that do not look like they live with a disability. In the context of type-1 diabetes, rapid swings in blood glucose levels may go undetected by others but they may be debilitating for those experiencing those changes. Furthermore, that same person that experiences that debilitating episode may feel well within hours. These rapid changes challenge the understanding of disability as a static state. Diabetics may move in and out of states of illness or malaise multiple times a day. The language of episodic disability fits the continually changing character of living with type-1 diabetes. Additionally, Vick's concept of fluid performances of disability when objects like canes are present lends itself to the way in which an insulin pump or other forms of diabetes technology signals type-1 diabetes. Without the presence of the insulin pump, there is no outward sign of type-1 diabetes.

In sum, phenomenological approaches allow us to challenge the dualistic Cartesian representation of experience and in particular, that of the mind/body, suggesting that we experience the world through a sentient body. In the context of disability or illness, embodiment suggests that the body and the feeling of the body is just as important as the social and political structures that shape the experience of living with a disability or illness in our society. Those who experience episodic disability, with frequent changes from wellness to illness, challenge cultural understandings of what disability looks like, and societal ideas about disability often exclude the experiences of episodic disability. In

this way, those who do not fit into the cultural understanding are often unable to access the care and services that they require.

1.3 Methods

1.3.1 Methodology and epistemology

The methods that I used in my research were not feminist in and of themselves, rather, my epistemological and methodological position is a feminist one. The link between theory and methods in the realm of feminist research is explicit, in that the principle of feminist research is a commitment to the empowerment of women and other oppressed people (Hesse-Biber et al., 2004). My research continues this tradition by interviewing women about the ways they create meaning around the use of the insulin pump and other forms of diabetes technology. By asking diabetic women about their experience with diabetes technology, this study reveals the knowledge that these women have of being in dual worlds, the world of women and the world of technology-- something that is often associated with men and male bodies.

The 'standpoint perspective' encourages researchers to start from women's everyday experiences while looking for the gaps that occur when women try to fit their lives into the dominant culture's ways of conceptualizing women's situations (Hesse-Biber, 2012). I conducted nine open-ended interviews with diabetic women using insulin pumps, CGM and other forms of diabetes technology. The focus of those interviews was a discussion of the women's everyday experiences living with multiple forms of diabetes technology.

Given that this study is an exploratory study, I believe that nine was a satisfactory number of participants. I had hoped to access ten participants during a month-long recruitment period. I was concerned that locating a larger pool of potential participants

with type-1 diabetes might be a significant challenge because I was unsure as to the number of type-1 diabetics that would openly disclose their illness. Alternatively, diabetes research is often done through medical institutions. Conducting research through diabetes doctors' offices such as the Ottawa Hospital, a teaching hospital, would have required additional approval from the Ottawa Health Science Network Research Ethics Board. I felt that I could access a smaller pool of participants more efficiently through the Internet and speak to participants from across the province in an attempt to bring a range of experiences into the fold.

1.3.2 Sampling Strategies

The target population for my research was adult women who have T1D and use an insulin pump, CGM and other forms of diabetes technology. I initially sought participants in the Ottawa region for in-person interviews. I was also prepared to conduct interviews with participants throughout Ontario with the use of Skype and the telephone for interviews. Due to the wide range of women who experience this disease, my participants were different ages, classes, 'races' and ethnicities. My sample was composed of women who have had T1D and have used different forms of diabetes technology for varying amounts of time. This time range is another factor that affected participants' experiences of T1D and diabetes technology. I do not know the demographic composition of women using insulin pumps in the Ottawa area and throughout Ontario. Therefore, I cannot say with confidence that the sample was heterogeneous or representative of the population of women who use insulin pumps and other forms of diabetes technology. However, to my knowledge, little information exists on this topic and therefore the knowledge gained, even if exploratory, compensates for any lack of representativeness I was able to obtain in my study.

The goal of this research was to understand the meanings that some women with T1D that use technology attribute to their social situation, rather than making generalizations about the wider population of diabetics. As such, a small sample size was justifiable. The population in my study is small and difficult to locate, so nonprobability sampling was appropriate. I anticipated a small sample of volunteer female participants who were interested in discussing and exploring their everyday experiences living with an insulin pump and other forms of diabetes technology.

In the first phase of the research, I employed a convenience sampling technique. Convenience sampling creates a research sample that is selected for ease of access. It is a technique that is best used when the population is unknown or when the researcher is exploring an unknown setting (David & Sutton, 2011). For my research, I recruited through Connected in Motion (CIM), an organization of type-1 diabetics in Canada that focuses on active living and peer support to encourage a community of self-managed, active type-1 diabetics. I chose Connected in Motion because of its popularity among adult type-1 diabetics and CIM's focus on active self-management. I developed a poster that was adapted into a status post on CIM's Facebook page. I responded to interested participants with a standard letter by email. The letter contained a brief description of the research project and my contact information. CIM posted information about my study twice in a two-week period. Immediately after the posts, I received emails from potential participants. The first post produced five viable participants that resulted in interviews. The second post resulted in four viable participants that also resulted in interviews. I was skeptical that having Connected in Motion (CIM) post on my behalf a third time would be effective in recruiting more participants. Additionally, data produced from the

interviews were being repeated by participants after the sixth interview. I had received additional inquiries from interested type-1 diabetics but I was contacted after the month-long recruitment period and I decided to decline more interviews. This decision was made in order to remain on schedule, and because the data already obtained was sufficient for the scope of the study.

1.3.3 In-Depth Interviewing

I conducted in-depth interviews with nine women who have an insulin pump, and/or use CGM and other forms of diabetes technology. In-depth interviews are most useful when focused around a particular issue and used to gain rich information about the topic (Hesse-Biber & Leavy, 2006). In-depth interviews are an opportunity to allow the experiences of participants to shine through. To gain the rich data needed for a full description of the meaning of insulin pumps, CGM and other forms of diabetes technology for women, I used a semi-structured interview approach. Semi-structured interviews guide the conversation through a similar set of questions that are asked in each interview. However, there is a degree of liberty given to participants to speak about what is important to them during the interview process (Hesse-Biber & Leavy, 2006). As such, the interview format helps to guide participants in their discussion of certain topics of interest at the same time as it allows participants the opportunity and flexibility to expand upon and explore the meaning that the topic holds for them and for their everyday life.

The interviews were conducted over a month-long period in April 2014. I interviewed participants once individually in a single session. The interviews lasted about 30 to 90 minutes and covered questions about the participant's sense of identity as a female diabetic who uses an insulin pump, CGM or other forms of diabetes technology. Two local interviews in the Ottawa area took place in a coffee shop. I also conducted

seven Skype and telephone interviews with those I could not access in person. The primary objective of the interview questions was to explore how participants live day-to-day with type-1 diabetes with particular attention given to participants' use of technology (see Appendix 1 for Interview Guide). The age of diagnosis was an important aspect that I wanted to address, so I developed slightly different questions for participants that were diagnosed as children and those that were diagnosed as adults. This was done in an attempt to capture how living with diabetes from a young age can affect attitudes towards type-1 diabetes and to capture how being diagnosed has changed over the years. Another issue that I wanted to focus on was how type-1 diabetes affected participants' sense of self and whether being a woman had an effect on type-1 diabetes management. Finally, the last theme of the interviews had to do with how technology figured in the daily management of type-1 diabetes. Specifically, I wanted to explore how wearing and using technology in an intensive manner might affect participants' feelings about their bodies.

1.3.4 Data Coding

Participants were assigned pseudonyms by the most popular baby name for the year of their birth. If that pseudonym was the name of another participant, the next most popular name was used. For the coding portion of the project, I used an Excel spreadsheet to create and organize my codebook. The transcripts were coded in three stages: open coding, systematic coding and refinement of the systematic codes. The initial phase of coding began with an inductive approach in which the codes were generated from the interview transcripts. In this phase, I generated the codes either to describe or summarize. However, I occasionally coded with participants' own words, or *in vivo*, during the first phase of coding. Once all of the transcripts had been coded, I proceeded onto the second phase of coding. In the second phase, my objective was to create systematic codes to

organize the codes generated from the open coding phase. Systematic coding involves going through a text to identify emerging themes that the researcher can find (David & Sutton, 2011). I treated the open and *in vivo* codes as the text to be analyzed for emergent themes. The systematic codes grouped together similar ideas at the second level. By grouping similar experiences or ideas together, I saw the most commonly shared issues and how often participants talked about those issues. The last phase of coding involved refining the systematic codes and grouping them into higher-level categories. See Appendix 2 for a flowchart of important themes that emerged during the coding phases.

1.3.5 Participant Demographics

Participants recruited for the study were female or female-identified. All participants who were ultimately interviewed were cisgendered (i.e., their gender corresponded to their biological sex). No participants identified as gender non-conforming and several participants cited biological processes of menstruation and pregnancy as signifiers of womanhood.

Participants in the sample were relatively ethnically similar. Seven participants identified as being white with references to European and Canadian ancestry. One participant identified as being Jewish from both sides of her family. One participant identified as being a Canadian of Cantonese decent. Given that type-1 diabetes does not have a higher genetic propensity amongst particular ethnic groups in Canada (Canadian Diabetes Association [CDA], 2008), the ethnic makeup of the sample is not representative of the breadth of the larger type-1 diabetes population.

Participants' ages ranged from 24 to 46 years old with an average of age of 33 years old. There was considerable difference in age of diagnosis and the amount of time

living with type-1 diabetes. This appears to be a significant factor that affects experiences of living with type-1 diabetes. The most recent diagnosis was in 2012, such that the participant had lived with type-1 diabetes for only two years. One participant had lived with type-1 diabetes for 36 years, the longest period of all participants. Two participants were diagnosed with type-1 diabetes as very young children, both at the age of 3. Three participants were diagnosed as children at ages 5, 7, and 11 years old respectively. Only one participant was diagnosed as a teenager, at the age of 16. Three participants were diagnosed as adults: one participant at the age of 21 and two participants at the age of 28. The initiation of type-1 diabetes generally occurs before the age of 30 and often peaks around the age of puberty. However, adult-onset type-1 diabetes may represent over 50% of all type-1 diabetes cases (Borchers, Uibo & Gershwin, 2010).

All nine participants had type-1 diabetes although their use of different forms of diabetes technology varied (see Table 1.1). At the time of the interviews, eight participants were using an insulin pump and all insulin pump users were participating in the Ontario Assistive Devices Program (ADP) that covers the cost of the insulin pump and supplies (see Chapter 2 for more on the ADP). One participant, Crystal, was not using an insulin pump because her endocrinologist determined that it was not necessary. Five participants said they used Continuous Glucose Monitoring (CGM) and of those CGM users, three participants revealed that they used CGM on occasion and two participants described using CGM on a daily basis. Two participants used applications on their cellular phones to look up nutritional information, and to log blood glucose readings and other information regarding their management. The interviews also revealed that participants turned to the Internet and the Diabetes Online Community (DOC) to seek out

information and support for living well with type-1 diabetes (see Chapter 4 for a more extensive discussion of the DOC). Technology should be conceived as both the devices such as the insulin pump and CGM, but also in terms of everyday technology that most people use such as the Internet and cellular phone applications. Technology as described by participants is both material and immaterial, and these different types of technology have a profound impact on the way that participants live with their type-1 diabetes.

Type of Technology	
Devices	
CGM	5
Insulin Pump	8
Glucometer	9
Other	
Apps	2
DOC	8

Table 1.1 Number of Participants Using Different Types of Technology

Participants were engaged in a range of different occupations, although there are some interesting similarities to be noted. Three participants worked for non-profit organizations. Of those working in the non-profit sector, two participants worked for diabetes-specific organizations. Two participants worked in healthcare-related fields. Two participants were at the time of the research outside of the paid labour force, one identifying as a homemaker and the other as unemployed. One participant who was diagnosed as a child noted that her experiences of living with diabetes affected her choice of a healthcare related and service-oriented position:

All of these weird skills, being an advocate for yourself and I see the job I ended up in. Would I be a social worker if I didn't have diabetes? No. Obviously my experiences have formed who I am. (Rebecca, diagnosed at age 5)

Those participants that were diagnosed as adults did not comment on the relationship between the choice of career and type-1 diabetes. Overall, eight participants held or

currently hold service jobs. The occupational characteristics of the participants reflect larger trends in women's participation in Canada's labour force.

In Paid Labour Force	
Occupation	
Non-profit	3
Healthcare affiliated profession	2
Childcare	2
Not in Paid Labour Force	
Homemaker	1
Unemployed	1
Total	9

Table 1.2 Number of Women in Different Occupation Categories

1.4 Outline of the Thesis

The thesis is divided into five chapters, including this introductory chapter. This first chapter has outlined the methods used and the theoretical perspectives that informed the research. The second chapter presents the economic, medical and political context of insulin pump usage for type-1 diabetics in Ontario and provides an analysis of the complex institutional responses to diabetes care in the province in which the participants live. Chapter Three presents emergent themes from data collection on the challenges with living with type-1 diabetes and provides an analysis of the findings by drawing connections to the literature discussed in the introductory chapter. The fourth chapter addresses strategies that participants have developed to better live with type-1 diabetes, with particular attention given to exploring the role of the Diabetes Online Community (DOC) in participants' narratives of living with type-1 diabetes. The thesis concludes with a summary of the findings and provides a perspective on the intersection of diabetes,

technology and women that can help to guide future research on the experiences of those living with type-1 diabetes.

Chapter 2: Living with Diabetes in Ontario

Introduction

In order to understand the meaning of using an insulin pump, CGM and other forms of technology, it is important to consider the medical, political and economic contexts in which participants live with their diabetes. Certain aspects of diabetes are experienced in the context of the doctor's office or filling out forms to qualify for provincial subsidies to pay for supplies. This chapter attempts to describe the landscape in which diabetes management exists. The first section of the chapter is devoted to understanding the medical definition of the various types of diabetes, the treatment of type-1 diabetes and the role of various devices in diabetes management. This section also addresses the significant costs of the medication and devices that are critical to diabetes management. The second section outlines some of the most important aspects of type-1 diabetes management as defined by the Canadian Diabetes Association's *2008 Clinical Practice Guidelines for the Prevention and Management of Diabetes*. The final section of the chapter focuses on Ontario and the recent expansion of provincial coverage of insulin pumps for adult diabetics, the first jurisdiction to do so in Canada.

2.1 Understanding Diabetes: Definition and Treatment

Diabetes is a chronic, sometimes debilitating and fatal disease in which the body cannot produce or cannot properly use the insulin it produces. Insulin is a hormone that regulates blood sugar (WHO, 2011). This lack of insulin leads to increased glucose levels that can damage organs, blood vessels and nerves. Nearly 374 million people globally have diabetes and diabetes is projected to become the seventh leading cause of death by the end of the next decade (WHO, 2011). In the same period, the Canadian Diabetes

Association predicts that one in three Canadians will be affected by diabetes and prediabetes, by 2020 (Canadian Diabetes Association [CDA], 2011a). Given the growing importance of diabetes, it is necessary to distinguish the various types of the disease and to highlight the unique challenges of living with type-1 diabetes.

Type-1 diabetes (T1D) is an autoimmune disease that occurs when the pancreas no longer produces any insulin. T1D often develops in childhood and adolescence and represents approximately ten percent of all diabetes cases. There is no cure for T1D and it is treated with lifelong insulin injections and attention to glucose levels (Canadian Diabetes Association [CDA], 2009). Type-2 diabetes (T2D) occurs when the pancreas does not produce enough insulin to meet the body's need or the body cannot properly respond to the insulin it produces. Although T2D was previously typically seen in adults, the number of children and adolescents developing the disease is on the rise. Treatment of T2D includes careful attention to diet and exercise, diabetes medication and/or insulin (Canadian Diabetes Association [CDA], 2011a). The term prediabetes refers to a patient that experiences elevated blood glucose levels below the diagnostic threshold for T2D (Canadian Diabetes Association [CDA], 2009). Impaired glucose tolerance (IGT) and impaired fasting glycaemia (IFG) comprise the two intermediate conditions associated with prediabetes, transitioning from normality to T2D (WHO, 2011). Gestational diabetes occurs when the first recognition of diabetes occurs in pregnancy and symptoms are similar to T2D. Diagnosis of gestational diabetes usually occurs through routine blood screening rather than the reporting of symptoms (World Health Organization [WHO], 2011).

Insulin is a key component of treatment for all type-1 diabetics and some type-2 and gestational diabetics. Insulin can be administered in one of three ways: syringes, insulin pens, and continuous subcutaneous insulin infusion (CSII) or insulin pumps. Insulin pens generally contain 3 milliliters of insulin and the patient must attach a needle, prime the pen, dial the dose, insert the needle and depress the plunger to receive the dose. The pen offers many advantages over a syringe such as increased portability, compliance with intensive insulin regimens and ease of use. Insulin pens contain a cartridge of insulin that stays in the pen and require that a small disposable needle be placed in the pen for injections. Compared with syringes that require diabetics to draw from a vial of insulin, insulin pens are more streamlined and more discrete as they look like actual pens for writing (see Figure 2.1 for a comparison between syringes and insulin pens). Greater adherence to insulin therapy and better health outcomes have been observed in studies comparing insulin pens to syringes. Patients prefer the insulin pen because it is more discreet to use in public and pens are thought to increase quality of life for patients who use pens compared to those who use syringes (Selam, 2010).



Figure 2.1: Insulin syringes are used once per injection and diabetics may have up to ten injections a day (left)(BD, 2014) and insulin pens increase portability and discretion when injecting insulin (right) (Institute for Safe Medication Practices [ISMP], 2011)

The primary advantage of the insulin pump (Figure 2.2) is that it can be programmed to better replicate the insulin patterns of healthy individuals and lessen the burden of administering insulin. More recently, insulin pumps allow for the programming of multiple basal (base) rates throughout the day and the ability to calculate appropriate mealtime insulin doses. Multiple dosage profiles can also be created for close management during physical exercise and sick days, events that can make normal glucose levels difficult to achieve. Large amounts of data regarding insulin doses and blood glucose (BG) readings are compiled by the pump. This aids diabetics to make better everyday decisions and more informed clinical decisions with doctors and nurses. Compared with Multiple Daily Injections (MDI) with either a syringe or insulin pen, insulin pump therapy in the treatment of T1D offers the advantages of better BG control, reduced daily insulin dose, elimination of daily injections, and more flexibility around food and exercise (Selam, 2010).



Figure 2.2: Two of the three brands of insulin pumps covered under Ontario's Assistive Devices Program (ADP), Animas Ping (left) (Hoskins, 2013a) and Medtronic Minimed (right) (Medtronic Canada, 2013)

Another significant technological development for people with diabetes is the continuous glucose monitor (CGM), that is, a sensor that is worn to give “real-time” readings, data and sound alarms when glucose levels are excessively high or low. CGM can augment insulin pump therapy by communicating with the insulin pump if the alarms are ignored and potentially avoiding cases of prolonged hypoglycemia (low blood

glucose caused by an excess of insulin) (Vazeou, 2011). CGM has been shown to improve glycemic control in adults, with less conclusive evidence for children with T1D. CGM offers improvements in the quality of life of diabetics through less anxiety over blood glucose and gives patients the ability to gain tighter glycemic control with greater safety.

The sustained presence of technology in the lives of diabetics creates a relationship of dependence on technology that is critical in normalizing the daily experiences of diabetics. The idea of the cyborg draws out questions of the boundaries between the self as a viable subject, the event of disease and the on-going interaction with technology in the lives of diabetics. The idea of the diabetic cyborg offers the opportunity to investigate to what extent technology becomes an element of one's subjectivity, particularly when one's life circumstances are constrained by a disease such as T1D. Technology may contribute to the formation of different medicalized subjectivities that have different constraints and possibilities than those of diabetics that do not use insulin pump therapy.

2.2 Medical Guidelines for Type-1 Diabetes

In the introductory section of the *Canadian Diabetes Association 2008 Guidelines*, there is considerable emphasis on the problem of poor patient compliance with evidence-based recommended management regimes, and how diabetes and its complications contribute to the cost of primary care and are a strain on emergency room waiting times. The portion of patients that are diabetic in acute care is estimated at 10 percent, with a trend of increased hospitalization due to diabetes complications that have gone unchecked over a five-year period. Despite increasing evidence about the importance of

managing diabetes effectively, it is clear that people with diabetes do not have access to appropriate care, education and management required for lowering the risk of complications. Effective diabetes care involves an interdisciplinary team to provide care that includes physicians, nurses, diabetes educators and pharmacists to work with the individual with diabetes. However, a high level of self-management is required for this approach to be effective, and this signals a need for a paradigm shift from an acute care model to chronic disease management (Canadian Diabetes Association [CDA], 2008). The *CDA 2008 Guidelines* are evidence-based recommendations that are intended as a reference tool to translate the best available evidence into practice. The intent of these guidelines is therefore to provide government officials with the evidence they need when rationalizing access to healthcare so that outcomes are maximized for people with diabetes. It is interesting to note that there is an emphasis on the importance of self-management and furthermore, that any clinical practice is only rendered effective through a high degree of self-management by diabetics.

For the treatment of T1D, the *CDA 2008 Guidelines* suggest that CSII (insulin pump) therapy is a safe and effective method of intensive insulin therapy for selected patients and may provide some advantages over other methods of intensive therapy (syringes and insulin pens) particularly for those individuals with higher average blood glucose levels. In determining a patient's insulin regimen, the treatment should be tailored to the individual's lifestyle, diet, age, general health, motivation, ability for self-management and with the special consideration of financial and social aspects. The Diabetes Control and Complications Trial (DCCT) conclusively demonstrated that the intensive treatment of T1D significantly delays the onset and slows progression of

complications. Low blood glucose (hypoglycaemia) is the most common side effect of intensive insulin therapy in the treatment of T1D. However, better self-management, appropriate glycemic targets, self-monitoring of blood glucose (SMBG), and regular consultation with doctors may lessen the frequency of hypoglycemia in intensive insulin therapy. Again, self-management is emphasized and is required in intensive insulin therapy. The best treatment appears to rely on the patient to provide adequate self-management to meet clinical guidelines. There is an underwhelming endorsement of CSII or insulin pump therapy that is particularly interesting when the intention of the *CDA 2008 Guidelines* is to inform professionals involved in the rationing of healthcare in Canada and by extension, the rationing of provincial healthcare money in insulin pump therapy.

CSII is thought to reduce the frequency and duration of hypoglycemic (low blood glucose) events, lead to greater glycemic control, and reduce the number of diabetic ketoacidosis episodes (Scuffham & Carr, 2003), which were identified in the *CDA 2008 Guidelines* as factors that lead to complications from diabetes. Although there are greater benefits and improved quality of life from CSII compared with MDI, there are greater costs associated with CSII. In their model, Scuffham and Carr used quality-adjusted life years (QALYs, which quantify the burden of disease on the lives of patients) to assess patients that used CSII and MDI for a period of twelve months. Over an eight-year period (the expected life of an insulin pump) a patient on CSII cost twice as much as a patient on MDI to the United Kingdom's National Health Service (NHS). However, those patients on CSII gained 0.48 QALYs over those on MDI, primarily gained through an improvement in quality of life rather than reduced mortality. In all of the cases studied,

only 0.2 percent of CSII cases were cost-saving whereas all CSII resulted in an increase of QALYs. The greatest cost-savings occurred with individuals that had multiple hypoglycemic (low blood glucose) episodes that required hospitalization. CSII is the least economically viable in cases where diabetes is well controlled with few hypoglycemic events.

Scuffham and Carr warn that these results may be somewhat misleading because CSII requires greater patient education and self-management than MDI. As a result, patients using CSII already have better glycemic control, thus a reduction in episodes of high and low glucose is less likely among CSII than MDI users to begin with and the cost-effectiveness in reducing hospitalization is therefore not apparent in CSII groups. QALY is a measure of disease burden that focuses on the quality and quantity of life lived. In this way, an intervention, such as CSII can be measured in QALYs to determine how many QALY years can be added to a diabetic's life when adding CSII to their diabetes management. The most significant positive outcome associated with CSII was the QALYs gained through CSII. The costs per QALYs from CSII are at the lower end of the QALYs scale. In this study, the most significant benefit of CSII appears to be improvement in the quality of life rather than observable financial gains by the NHS. However, the authors did note that a limitation of their study is that they did not look at the cost-effectiveness of CSII in higher productivity, less time off work because of poor glycemic control, or better quality of life which would lower the cost per QALY, thus making CSII more attractive.

Insulin pumps have not been evaluated under the Canadian Drug Review (CDR) (Canadian Diabetes Association [CDA], 2012b), but the agency responsible for the CDR,

Canadian Agency for Drugs and Technologies in Health (CADTH) has completed a Health Technology Assessment (HTA) on insulin pump therapy. CADTH HTAs are comprehensive assessments of health care technologies that examine high quality bodies of evidence that determine clinical effectiveness, cost-effectiveness, the impact on patient health, and the impact on the health care system (Canadian Agency for Drugs and Technologies in Health [CADTH], 2012). In their report on insulin pumps, the HTA focused on meta-analysis to assess clinical and cost effectiveness rather than conducting primary research. The report suggests that their meta-analysis shows that only two studies demonstrated statistically significant decreases in average glyceic levels (or hbA1C) and several noted no difference with CSII over MDI (Banerjee & Farrah, 2008). Hypoglycemia (low blood glucose) events did not differ significantly in most studies. Although results varied, there was a slight improvement of quality of life for patients on CSII as compared to patients on MDI. In addition to the Scuffham & Carr (2003) study, HTA evaluated two other similar cost-effectiveness studies of insulin pumps that demonstrated better glyceic control, fewer complications, improvements in quality of life and QALYs and good value for the QALYs gained with CSII over MDI. The report concludes that the improvements to average glyceic levels are modest and improvements of quality of life tend to be conflicting. Screening processes are emphasized because motivated patients are less likely to discontinue use of CSII, thus making any investment in CSII more beneficial (13). Much like the results of the meta-analysis, CADTH does not have a very clear position on CSII as it relates to provincial formularies. The medical evidence does not build a strong case for the clinical effectiveness of CSII over MDI.

2.3 Ontario's Involvement In Insulin Pump Therapy

Diabetics may incur significant costs in the treatment of their diabetes and these costs may determine which treatments they use and their compliance to them. The Canadian Diabetes Association (CDA) suggests that fifty seven percent of Canadians with diabetes do not comply with their prescribed therapy because of out-of-pocket expenses associated with medication, devices and other fees (Canadian Diabetes Association [CDA], 2012). The CDA focuses on the out-of-pocket expenses that diabetics incur and have developed a composite study to follow changes in coverage in T1D management and differences between jurisdictions. Since 2001, the CDA has used a simulation named “Janet,” a 22 year-old type 1 diabetic who does not take any additional medications and does not have any complications from T1D. Janet lives alone and has an annual income of less than \$15 000 and relies on government assistance (CDA, 2003). In the past, “Janet” and many people with type-1 diabetes in Ontario faced very high out-of-pocket costs, well beyond the threshold established by provincial and federal health organizations. However, CDA notes a significant drop off in out-of-pocket expenditures by people with T1D on MDI from 2005 to 2011 because of an expansion of provincial coverage of diabetes supplies (Canadian Diabetes Association [CDA], 2011a).

Despite increased coverage, in January 2012, the CDA noted that Canadians with T1D using an insulin pump incur far higher costs than those that do not use a pump as well as compared with those who have type-2 diabetes. In many jurisdictions, the out-of-pocket expenses incurred with insulin pump therapy make it inaccessible to low-income Canadians despite the therapeutic advantage of pumps (Canadian Diabetes Association [CDA], 2012a). In *The Burden of Out-of-Pocket Costs for Canadians with Diabetes*, the composite case Janet was altered so that she used an insulin pump rather than MDI and

her out-of-pockets costs were calculated at three income levels (\$15 000, \$43 000 and \$75 000). When the out-of-pocket costs are averaged across the provinces, people with T1D pay more than three percent of their annual income for diabetes management. Individuals using insulin pump therapy pay two to six times the three percent threshold when costs are averaged across provinces. The Kirby and Romanow Commission established that Canadians that pay more than 3% of their annual income or \$1 500 per year on medication should qualify for catastrophic drug coverage (Canadian Diabetes Association [CDA], 2012a). These statistics suggest that patients that use insulin pump therapy exceed the Kirby Commission's threshold of out-of-pocket costs for Canadians and therefore bear considerably more costs than those individuals on MDI and non-diabetics.

In the case of Ontario, publicly funded insulin pump therapy came about through advocacy and the passing of Private Member's Bill 55-*An Act to Amend the Health Insurance Act* which proposes to cover the cost of insulin pump therapy under the Ontario Health Insurance Plan (Canadian Diabetes Association [CDA], 2005). In 2006, the insulin pump and supplies program was established for children (age 18 and under) and Ontario became the first Canadian jurisdiction to fully fund insulin pump therapy. In 2008, the insulin pump and supplies program was extended to adults with T1D (Auditor General of Ontario [ADGO], 2010). The program is run as a part of the Assistive Device Program (ADP) through the Ministry of Health and Long Term Care in Ontario. The program covers the cost of the pump (around \$7 000) and an annual grant of \$2 400 to help pay for supplies (Canadian Diabetes Association [CDA], 2011b). Adult eligibility for the program is based on the patient being on the basal/bolus intensive insulin regime

for one year, the ability to self-assess and monitor through blood glucose tests and other facets of diabetes self-management, and clear demonstration of commitment to long-term care through the Diabetes Education Program (Assistive Devices Program [ADP], 2012). In addition to those eligibility criteria, the patient must be able to demonstrate either improved quality of life, improved average blood glucose levels (which must be conducted at least twice annually), a reduction in hypoglycemic (low blood glucose) events, a reduction in the number of diabetic ketoacidosis (very high blood glucose) episodes, or the management of dawn phenomenon (morning time glucose rises) to qualify for the annual grant to cover the cost of supplies.

Although this program is designed to fully reimburse the costs associated with insulin pump therapy, there are additional criteria which prescribing physicians and diabetes educators are given by ADP to screen for future clients of the insulin pump program. Above and beyond the skills required of intensive insulin therapy, patients must have sufficient financial means to pay for the portion of the costs not covered under ADP. This financial criterion may be a result of cases where patients break or lose the pump or they use more supplies than are covered by the grant. Regardless of the rationale behind the implementation of that particular criterion, it transforms a program designed to make insulin pump therapy accessible to all type-1 diabetics in Ontario into one that is not universally accessible, especially for those who do not qualify for other provincial funding or those without private insurance. It appears that this additional criterion tends to exclude those diabetics that are without supplemental insurance and perhaps do not have sufficient financial means to afford expenses associated with insulin pump therapy,

and these are the very people who have been shown to be less likely to use insulin pump therapy.

The question of inequitable access is quite apparent in Canada when it comes to public funding of insulin pump therapy. Based on the composite study of “Janet,” there is full coverage for insulin pump therapy in the Northwest Territories (Canadian Diabetes Association [CDA], 2011c), Nunavut (Canadian Diabetes Association [CDA], 2011d), Ontario (Canadian Diabetes Association [CDA], 2011b), the Yukon (Canadian Diabetes Association [CDA], 2011e) and under the Non-Insured Health Benefit (NIHB). “Janet” would have provincial funding for insulin pump therapy until she was twenty-five in Newfoundland and Labrador (Canadian Diabetes Association [CDA], 2011f) and Saskatchewan (Canadian Diabetes Association [CDA], 2011g). As Janet demonstrates, diabetics who use insulin pump therapy cannot count on the ability to secure provincial funding and thus are subject to several factors such as geographic location, salary, and private insurance that determine their access to CSII, rather than medical necessity.

Conclusion

Using technology in the management of type-1 diabetes occurs through the interaction of several medical, economic, and political structures. To have access to technology such as insulin pumps is a challenge in and of itself, let alone the challenges of living with these devices on an on-going and necessary manner. However, the way in which programs like the Assistive Devices Program (ADP) operate, excludes the individuals that may need the financial assistance the most. That is not to say that the ADP is not a major step forward in increasing access to technologies that improve clinical outcomes and increase quality of life of insulin pump users. By locating the

experiences of participants, we can better understand the meaning and specificity of using technology in the management of T1D. In this chapter, I described Ontario's attempt to subsidize insulin pump therapy for adult type-1 diabetics. However, we will see in the next chapter that the financial burden of type-1 diabetes goes beyond the cost of insulin pump therapy and that the financial aspect is a major stress in the lives of participants.

Chapter Three: Challenges

Introduction

The challenges of living with type-1 diabetes can be at best tedious, and at worst, overwhelming. Despite this, participants articulated that they live *successfully* with their diabetes. This chapter begins to investigate some of the most significant challenges that participants discussed during the interviews. The chapter is composed of four sections. The first section focuses on four challenges that participants spoke about in the interview process. The first challenge relates to the period immediately after diagnosis, when participants adjusted to their new life with type-1 diabetes. The second challenge is the cost of type-1 diabetes technology and its impact on access to that technology. Thirdly, I discuss the challenge of being a woman with type-1 diabetes, with regard to two themes: wearing diabetes technology, and menstruation and pregnancy. Finally, the fourth challenge is the experience of negotiating a difficult relationship with healthcare providers. Each participant identified and coped with her own unique set of challenges in her own way. The diversity of experience points to the importance of creating a complex representation of all types of diabetes and type-1 diabetes in particular. The narratives of participants provide us with a glance into the inner world of participants as they confront the challenges of living with type-1 diabetes in a technological age.

The subsequent sections describe the common challenges identified by participants in living with type-1 diabetes that both men and women may face on a daily basis. Additionally, participants identified particular challenges that arose from being *women* with type-1 diabetes and using diabetes technology on a daily and intensive

manner. Chapter four will discuss participants' coping strategies to overcome some of the challenges identified during interviews.

3.1 Diagnosis

The period after diagnosis can be a challenge as participants adjust to their lives with type-1 diabetes. Participants that were diagnosed as children had difficulty recalling their emotional state at the time of diagnosis. Child-diagnosed participants were more likely to discuss facts and events that were corroborated by parents and siblings. For these reasons, the diagnosis stories of adult-diagnosed participants revealed more information about the experience of being diagnosed with type-1 diabetes and are therefore the focus of this section. The most clear and descriptive accounts of participants' experiences of diagnosis came from participants that were diagnosed as adults or as adolescents. Some of the major challenges of adult-diagnosed participants were centered on adjusting to a new reality of living with type-1 diabetes. Unlike the child-diagnosed participants, there was a significant 'before and after' diabetes paradigm.

Elizabeth was diagnosed two years ago just after a move to a Northern Ontario city for a job opportunity and she describes how type-1 diabetes fit into her life:

Um, well the timing kind of worked out interesting because it happened the same time that I moved to a new city, I feel like I associate my adult life with [type-1 diabetes]. So, when talking about like being at school or growing up and that kind of stuff, it's all like I'll make a joke and I'll say pre-diabetes so like my entire life before it, but ya, it's very connected. (Elizabeth, diagnosed at age 21)

For Elizabeth, her life became organized around the event of her diagnosis. Given that the treatment of diabetes (the first dose of insulin) results in a dramatic change after diagnosis, it is clearly bound in time. The change in symptoms, treatment response and satisfaction with care can alter patients' construction of illness, but life circumstances are

also important influences in illness explanation narratives (Hunt et al., 1989). Elizabeth's understanding of her diagnosis is partially oriented around a significant move and career change and her understanding of her health is integrated into her life experience.

For another participant, Crystal, her type-1 diagnosis occurred at the age of 28 and marked a significant change in her working life as she decided to walk away from her dream job as a journalist. This suggests that the demands of diabetes management may have been too great, especially so soon after diagnosis, as a busy video journalist. The physical demands of carrying equipment, the odd schedule and high levels of stress can be serious challenges when living with diabetes. Given her age, it took approximately a year to determine that she had type-1 diabetes rather than type-2 diabetes. This participant revealed that the possibility of having type-2 diabetes was very difficult to deal with given the stigma around type-2 diabetes. Lifestyle changes such as weight loss and exercise are recognized to improve glucose control. Type-2 diabetes can be also prevented with lifestyle choices, and health care providers can sometimes treat poorly those patients that do not comply with these difficult lifestyle changes. These social attitudes may lead patients to blame themselves for developing type-2 diabetes and they face high levels of stigmatization, especially given its association with obesity, for which people are typically seen as blameworthy in Canadian society (Teixeira & Budd, 2010). After receiving an initial diagnosis of type-2 diabetes after seeing a doctor in a walk-in clinic, Crystal revealed that:

I kind of didn't understand what was happening because, amongst all my friends, I'm the health freak, I'm the one that always makes time for physical activity, I'm the one that watches her diet. So it didn't make any sense to me and I kind of felt like, you know, maybe I wasn't healthy enough, even though I'm the most healthy person out of most people, but [laughs] it was really a kind of bizarre experience.

Crystal was very active before her diagnosis and already developed the habit of writing everything down regarding the impact of exercise on her body and the food she ate in a cellular phone application. Crystal described herself as being a “Type A Personality” and this made the transition after diagnosis of recording blood glucose levels, exercise and what she ate an easier task than if she were less oriented toward recording these events.

After diagnosis, type-1 diabetics experience a honeymoon period, which is characterized by good glycemic control and low insulin requirements, followed by the need for more intensive management to meet glycemic requirements (Canadian Diabetes Association [CDA], 2008). This period occurs once insulin therapy has started and some natural insulin production is temporarily restored. Honeymoon periods increase in duration for older individuals at the age of diagnosis (Daneman, 2006). Several participants discussed the experience of the honeymoon period as both a relief, and a challenge once the honeymoon period ended. Megan described how during the period after her diagnosis at the age of 16, she could not fathom the phenomenon of “diabetes burnout” that she had read about in the Diabetes Online Community (DOC) because diabetes management was easy and relatively uncomplicated during that time. Megan describes “having perfect blood sugars without even trying” and maintaining a very good average glycemic level. However, two years later, things changed quite dramatically:

But then, probably I was going to university, I think it was, all of the sudden my insulin needs went up a lot more. I think, my doctors saying, I think I had finally dropped off of the honeymoon period. It was then that I had more extremes like lower lows and higher highs. And everything became more finicky and took more thought. Exercising was harder because I would go low. And just it was just my insulin needs going up that complicated everything (Megan, diagnosed at 16).

Thereafter, the demands of management became much greater and Megan experienced the onset of some mental health issues during this period.

Although the honeymoon period often makes management easier for type-1 diabetics, for one participant, it became an obstacle to accessing an insulin pump. For Crystal, her recent adult diagnosis means that she is still in her honeymoon phase and as a result, she requires less insulin, especially since she is so active. Her endocrinologist advised against Crystal starting the pump given these considerations. Crystal tried CGM for a week and she came to discover that she was experiencing the ‘dawn phenomenon.’ The dawn phenomenon refers to an increase in growth hormone that occurs after someone falls asleep. This release of the growth hormone triggers insulin resistance and an increase of glucose from the liver in the morning, lasting from four to twelve hours (King, 2014). This spike in blood glucose is undesirable as high glucose can result in diabetes complications. Crystal explained:

So in that sense, once I found [the dawn phenomenon] out through my CGM trial, it made me want the pump so much more because I would be able to tweak that, right? Because if that is happening every night, that’s scary.

Despite the inconvenience of wearing a pump, Crystal explained that she would be willing to wear it in order to tighten her blood glucose levels and by extension, lessen the likelihood of complications.

The main challenges of living with type-1 diabetes centre on adapting to constantly changing variables in the pursuit of maintaining control. The diagnosis can bring about changes in life plans such as ending a career. For example, diabetics are often excluded from safety-sensitive positions like police officers, firefighters, train engineers and conductors, commercial pilots and cabin crew to name a few. With an adult diagnosis

comes the stigma associated with diabetes as a preventable disease that happens because people do not take adequate care of themselves. This leads to self-blame and guilt and it is part of a wider culture in which individuals are held accountable for their state of health. In the context of type-1 diabetes, gaining control becomes more difficult as more time passes after diagnosis and the honeymoon phase comes to an end. At this time, many events like the dawn phenomenon begin and the reality of management sets in.

The language of control and management places a premium on holding the individual responsible for health outcomes. Being diagnosed with “diabetes” is often seen as a personal failure to eat healthy, exercise or to take care of oneself. Our culture does not often distinguish between the different types of diabetes. Participants must contend with these cultural attitudes towards diabetes, which is why I believe that the language of control and management become so important in participants’ narratives. In order to counter the idea that diabetics lack self-control, quantifying and measuring become an imperative to be met despite the impossibility of always being in control. We can see that the challenges of diabetes are very difficult to navigate all of the time. Failure to control stigmatizes the individual as lacking the proper discipline and character to overcome the perception of diabetics as being ‘out of control.’

3.2 The Cost of Type 1 Diabetes

The *New York Times* chronicled the cost of living with type-1 diabetes in early April 2014 (Rosenthal, 2014). The article sent shockwaves across the Diabetes Online Community (DOC), reactions of both gratitude for shining a light on the extraordinary expense of technology in the treatment of type-1 diabetes, and frustration because it was felt that the article described changes in insulin and CGM technology as minor and

insignificant, rather than substantial. The article focused on the cost of type-1 diabetes in the United States, where there is limited government coverage of diabetes technology or clinical care. In Canada, access to specialists is covered by the provincial formularies but there is an inconsistent approach to covering the cost of devices and medications that are essential for type-1 diabetics. Although the costs of the insulin pump have been greatly reduced since the introduction of the Assistive Device Program (ADP) in Ontario, participants almost universally commented that the cost of medication and devices remained a significant issue. In this section, the challenges of paying for access to the best care for type-1 diabetes will be explored.

The overriding concern of participants that used CGM was the high cost of wearing the technology. CGM is not covered under the ADP, but it is occasionally covered by private insurance either partially or entirely. For example, the Dexcom Continuous Glucose Monitoring System had been recently released in Canada in the fall of 2013. Dexcom consists of three separate elements (see Figure 3.1). The first element (left) is the Dexcom receiver. The receiver is a one-time purchase at a cost of \$800 (all prices were quoted in December 2013). The second element (center) is the transmitter that communicates with the receiver and is connected to the sensor. One receiver lasts approximately six months and costs \$700. The sensor is pictured with the insertion device (right) and is worn on the skin with a fine wire that is inserted in the skin to reach the subcutaneous fluid. The sensors are approved for seven days of use by Health Canada. Each sensor costs \$84 dollars. A year of continuous wear would therefore cost the user \$5 768 per year plus the initial \$800 for the receiver. In addition to Dexcom, Medtronic has a CGM that is approved by Health Canada and their devices are very similar in price.

Animas (the Canadian distributor of Dexcom) and Medtronic have CGM–integrated pumps, thus eliminating the need for a separate receiver and slightly reducing the cost.



Figure 3.1 Dexcom Continuous Glucose Monitor, US model shown (Javanmardi et al., 2013)

The cost of CGM can be significant, if not entirely inaccessible, a concern widely expressed by participants that used CGM. As previously discussed, Crystal benefitted from her CGM trial that revealed the dawn phenomenon that had gone undetected. Despite the clear advantage that CGM would provide in her management, Crystal was very upfront about how the cost of CGM made it inaccessible to her:

I did do a CGM trial for a week and the information I got from that was just amazing. And I'm trying to figure how as an unemployed person how I'm supposed to afford CGM [laughs] but I feel that would be the most instrumental, like when I had that CGM, I felt so free because I could see when things were getting bad and I could correct them before I would go too low.

The cost of CGM also affected other participants that were employed. Several participants commented that they did not receive insurance coverage through their jobs

that would cover the cost of the CGM. Angela commented, “there's no getting around the fact that diabetes is a really expensive disease and you know, I work in the non-profit sector and I have coverage but it's not fantastic.” There were several times in which participants commented that their type of occupation, whether it be in the non-profit sector or in childcare, often did not provide adequate insurance coverage for the costs of their type-1 diabetes. This lack of coverage in the occupations of participants reflects an undervaluing of these types of work, and women are overrepresented in these fields. Thus, effective diabetes care may be more difficult to access for some women given the low pay in many female-dominated occupations (as well as being difficult to access for low income individuals in general).

Several participants commented on how paying for devices was made even more difficult to justify when the devices were poorly designed. In particular, Medtronic’s previous version of their CGM was uncomfortable to insert and wear. Megan had insurance coverage for her CGM but explains how she used CGM:

I use it once in a while. If I'm having trouble with my blood sugars, I will wear CGM for a few days to figure things out. I just find, like, either I put them in and then I get alarms like in the next few hours because it didn't go in properly or there was too much blood and it cancelled it out. I've just had so many problems with it, where it falls out, it's not accurate enough, I just couldn't afford to keep buying new ones to replace the other ones all the time. I don't know, I haven't tried the new ones that came out, I haven't gotten around to it yet.

It would appear that despite the benefit of using CGM, there are many factors that go into the ongoing decision making processes surrounding diabetes management with different forms of technology. Furthermore, Megan’s experience with a previous CGM makes her hesitant to try the newer technology.

Wearing the CGM can be a challenge in and of itself as insertion and the adhesives needed to keep it attached to the body can cause a whole range of problems.

Michelle described how the newer generation of CGM has become easier to wear:

It's too expensive to wear all the time and it really is annoying [laughs], its function and what it does is fascinating, um and is great but it's also, I don't know if it's a me issue but that thing, I don't know, there's like 20 bandages to make it stick. They've gotten smaller but and this last one was really, because I just took it out a little while ago, was really good. I only had 1 bandaid on top whereas before it's one one one one [slapping noise] and my skin does not like it at all, I don't care what one you use, I, I'm on fire when you, that sucker comes out, I'm just flaming red. But, for the first time in my life, at the [endocrinologist], the nurse that I see also has diabetes herself, so which was interesting. I had great service, I had no issues but was actually interesting to talk to someone similar in age with the same issues and she always wore it in her leg whereas nobody ever put the sensor in my leg, and so she put it in my leg, well I put it in my leg as she guided me through it. Wow, I can handle this in my leg, this is ok, it's nice not to be in my stomach for once.

Three of the four participants that wear CGM on a long-term basis described their CGM use as “on and off,” citing the cost as one of the principal reasons for inconsistent use.

Rebecca explained that she uses a loyalty program at a major national pharmacy to accumulate points that can be then put towards the purchase of sensors. She uses the sensors on an ad hoc basis until she has enough points to purchase another box. Cost is a key concern when using CGM for participants. It becomes a matter of determining how often to wear or replace the sensor, measured against the advantage of wearing CGM and getting real-time information about glucose readings.

The ADP greatly lessens the burden of paying for an insulin pump and supplies for adults in Ontario. The objective of the ADP is to cover most of the cost of purchase of an insulin pump and a year's worth of supplies. The annual grant is paid out in four equal payments. However, if insulin pump users purchase supplies from the insulin pump companies, they are required to pay the amount in full at the time they order, typically for a year's worth of supplies, which may be financially challenging. Melissa started on her insulin pump in October 2013 and she has found that with the insulin pump she has more control than she has ever experienced in the past. However, Melissa described how faulty

infusion sites are costly inconveniences, since problems may result in prematurely changing the site, and wasting supplies. Melissa revealed:

Anytime that I've put it in sort of the infusion site in my backside, it's either I don't feel it and it's amazing or there's lots of blood and [laughs] it's like 20 dollars a pop for the infusion sets which is, see that to me kills me, the price of it, cause it's not all paid for right away and it's ya... The cost for sure is what's infuriating.

Changing her infusion site before the three-day interval needs to be weighed against the running tally of how much each infusion set, reservoir and other supplies cost.

The cost of type-1 diabetes is significant. Undoubtedly, the cost of type-1 diabetes is more significant in other jurisdictions that do not offer the Assistive Devices Program (ADP) as the *New York Times* article describes. Despite the relatively generous support that participants receive as residents of Ontario, cost still remains one of the most common concerns raised by participants. Currently, the cost associated with Continuous Glucose Monitoring (CGM) is so high that it is not very accessible without insurance coverage. This was made apparent when employed participants described using the CGM less frequently because of the cost associated with using it. The ADP is intended to heavily subsidize the cost of insulin therapy but in practice, the structure of the program means that users face significant out-of-pocket expenses on a daily basis when making decisions about how often to change devices.

These are microdecisions, made every day, multiple times a day, even with the financial support of the ADP. The cost associated with diabetes technology points to the ways in which participants experience technology and their embodied awareness of the technology. The mental tasks of remembering and managing the costs of physically wearing the technology suggest that it is simultaneously a physical and mental experience. The technology of insulin pumps and Continuous Glucose Monitors (CGM) are worth the

cost. Participants were clear that these forms of technology improve their lives. However, the challenges of the cost and frustration are remembered on a daily basis when changing the infusion site or CGM sensor or dealing with faulty or poorly designed equipment. The technology is imbued with the reminder of its cost. The cost of wearing these forms of diabetes technology needs to be connected with the resources that are available to participants, given that participants worked in traditionally female occupations that are underpaid and undervalued. Participants often received inadequate insurance coverage and/or income to cover the cost of the technology. Access to technologies that have the potential to improve quality of life and facilitate better diabetes management become a gendered issue because of the gendered nature of work and associated income. In this way, the gender of participants affects the resources that they have access to and their lack of resources compromises full access to technologies like CGM.

3.3 Being A Woman with Type-1 Diabetes

The intersection of gender and type-1 diabetes lies at the heart of this study. In practice however, asking participants about gender proved to be a difficult task because the responses to questions about gender greatly differed from one another. Despite the variety of responses, one clear issue that came out of the analysis was that gender becomes the setting for several challenges that participants face in the management of their type-1 diabetes. In this section, three dimensions of what participants identified as ‘being a woman’ in the context of type-1 diabetes will be explored (see Table 3.2 for distribution of responses). The most common challenge associated with gender was the challenge of wearing diabetes technology such as insulin pumps and CGM. Issues

surrounding menstruation was another challenge that was identified by several participants as a challenge that women type-1 diabetics face. Finally, participants also raised the challenges of pregnancy and type-1 diabetes.

Challenges of “being a woman” and diabetes care	
Wearing Diabetes Technology	8
Menstruation	2
Pregnancy	3

Table 3.3 Number of women identifying particular challenges of “being a woman” with diabetes

It is important to note that gender took an essentialist form in participant narratives, where participants discussed their biological sex and gender as one and the same. During the interviews, gender was discussed in these terms as ‘being a woman’ or ‘being a man,’ that is, biologically speaking, rather than focusing on the social experiences of gender.

3.3.1 Wearing Diabetes Technology

The occasional challenge of wearing technology was expressed by all of the participants that wore insulin pumps. Wearing technology was a challenge to the extent that it is difficult to position both the infusion site and the pump in a discrete manner. In particular, participants expressed that women’s clothing is typically tighter and therefore more likely to show where participants’ pumps were being worn. The challenge of clothing was the typical response to questions about the specific challenges that women face as type-1 diabetics. Despite the shared challenge, most participants qualified the challenge of clothing as a superficial problem, as Melissa had:

I think that that is the biggest thing that comes to mind when I think specifically about being a woman and having diabetes, um and also, the, what seems to be maybe just trivial challenges, but serious challenges around like clothing choices and, especially with my pump, I've found some great ways to stash my pump when I'm wearing more summer clothes that don't have pockets, but that's something that I often think that my male friends who have diabetes don't have to think about to the same extent that I do.

And I dunno, maybe they do think about it but I like to think that I'm thinking about it more [laughs].

Rebecca also described some of the process that she goes through in managing where she wears her insulin pump with different types of clothing:

Most people don't see my pump. As a woman, all those ideas come in, where to clip it where it will be more obvious, less obvious. At a wedding, the placement of things two days ahead of time, know what outfit I was going to put it. Which dress has less square boob, where which bra clips best so I can have access to it, where my CGM not have to, the whole thing, I think you have to be fairly confident person to care but not care.

Even these trivial challenges require considerable foresight and planning. This focus on the body of women seems to be consistent with gender role expectations that women be judged in part by their physical appearance and that they maintain hyper vigilance around their bodies. This sort of policing of what the feminine body should look like suggests that participants engaged with the need to make the body look normal and homogenous (Bordo, 1993). Participants became the enforcers of these expectations by hiding and disguising their diabetic and technology-wearing bodies.

In addition to the physical object of the insulin pump, three participants described their experience around the marks that the infusion site and CGM sensors leave on the skin. One participant described her abdomen as a “war zone” from the marks left from the various devices. The feeling of having the pump attached became a source of frustration for Megan who describes how the pump made her more aware of her body, especially as she has lived with a diabetes-related eating disorder (see Chapter 4 for in-depth discussion of diabetes-related eating disorders):

There was a phase where I hated my pump because I didn't like putting the insertion set, where you have to squeeze your fat to put the set in, and I was just, I hated that

feeling and I hated the feeling of having something on my stomach. If my tubing got caught on something and I could feel it pull on my stomach.

Several participants described how they had failed to consider how the constant presence of their insulin pumps would affect their feelings towards the insulin pump and their bodies. For one participant, the design of her pump, the Omnipod (a tubeless design insulin pump, see Figure 3.2) changed the way she felt in her body with both the insulin pump on and off.



Figure 3.2 Omnipod Insulin Pump, a tubeless insulin pump (Mylife Diabetes Care)

Elizabeth describes an instance when she became detached from her Omnipod:

[I am] more aware [of my body] because [the pump] is physically attached to me. Even when you're completely naked, you're never completely naked, and when I don't have it on, so when I went tubing last summer, at the very end of the river we got to a bridge and everyone jumps off of the bridge and into the water, well the way that I had my pump was in the aerodynamic ways, so when I went into the water, it swimming off, it flew down the river. So from that point until I could get to dried land to go and put on a new one, I didn't have it on my way and it feels funny, so it definitely becomes a part of your body, to the point when you don't have it on, you can tell, it feels different. You're never naked. [laughs]

This account seems to complicate Greit Scheldeman's (2010) analysis, in which she describes insulin pumps becoming incorporated into young people's being. For Scheldeman, the pump is explicit and outside of one's corporeality when the user has not mastered and understood how the pump functions. When the user can see the pump as

part of the functioning of their body and can use it to effectively manage their diabetes, it is incorporated into the functioning of the body (Scheldeman, 2010). However, it would seem that Elizabeth is describing an on-going awareness of her insulin pump. In her description, Elizabeth points to the way in which her body is rendered more present by wearing the pump. Without the pump, Elizabeth experiences a heightened awareness of her body because her normal feeling of her body includes the insulin pump.

3.3.2 Biology: Menstruation and Pregnancy

In this section, the concept of womanhood and female biological processes that are affected by type-1 diabetes are explored in greater detail. Menstruation and pregnancy are discussed together to signal the way that menstruation often signifies sexuality and reproduction in patriarchal and heterosexual societies (Lee, 1994). In participant narratives, there appears to be a conflation between a ‘woman’ (as a social category) and ‘female’ (as a biological sex) that does not represent the complexities of either the social construct of gender or biological sex (Lorber, 1993). The distinction between biological sex and socially determined gender does not speak to the experience of several participants and as such, biological experiences come to signify what it means to be a woman with type-1 diabetes. In contrast to expectation, women did not discuss the social dimensions of being a woman who is diabetic.

Two participants narrowed in on their menstrual cycles as a key component of being a woman with type-1 diabetes. Crystal was diagnosed two years ago and she still struggles with distinguishing symptoms of her monthly cycle from the daily realities of living with type-1 diabetes:

I feel like for me, and again it’s very difficult to pinpoint as someone who is naturally anxious and has a tendency to be depressed. Trying to decipher even the “time of the

month.” I already try to work really hard, understanding my emotions but since I was diagnosed and my time of the month...I just feel like as since I’ve been diagnosed my emotions have been all over the place. Especially during those times. And I feel so out of control in terms of anger, like I would just lose my shit over the stupidest things that I know in all rational mind is nothing to be sad about. So I feel this loss of control and just based on when it happens, I feel it contributes to that time. So in that sense, I go “what is going on?” But yet again, I get to talk to my girlfriends who are type 1 and they’re like “ Oh yeah, welcome to the club!” So then I feel better.

Despite the challenge of mental health and menstruation, it becomes an experience around which other type-1 diabetic women can relate and talk about together. The ability to reach out to other type 1 diabetic women helps Crystal through the challenge of diabetes management. For Crystal, diabetes management is an on-going emotional challenge that is made more difficult when combined with what she perceived as a heightened state of emotionality during menstruation. In this way, Crystal associated the emotional difficulties of diabetes with female emotionality and felt that this is greater during menstruation.

Menstruation can make diabetes management more difficult. However, there is little research done on the effects of menstruation on glycemic control. Clinicians rely on women self-reporting fluctuations in blood sugar during their menstrual cycles (Type 1 diabetes, 2003). Michelle describes some of the changes that occur in her management during menstruation:

It has absolutely affected the monthly cycles. The two either get along beautifully or they are way on opposite ends. So I'm either running low that I'm dragging and I can never be on top of it, I'm just going to rip the whole thing out and be without it [laughs] or I can't fill it fast enough because I need more. And it's consistently inconsistent. So I don't know. So it's that whole "can we just get rid of one of you because I can't handle both of you at the same time" [laughs]. But then I do learn to recognize and it's usually a week prior ... That part of it, don't know that's a, I mean female functions probably, obviously cause some of that impact. It's, the pump is lovely, but it is a pain.

Michelle's description provides insight into another time when her diabetes is in flux. The reality that this aspect of women's diabetes management is not being researched raises questions about this relatively common and frequent event being neglected by medical research. This neglect may reflect a larger trend of corporate interests bolstering the direction of health research and care (Sobo, 2009). In the case of type-1 diabetes, there is growing focus on developing a mechanical cure in the form of a closed loop system of an insulin pump, CGM and glucose delivery system. This is a breakthrough with a much larger reach and profit margin for both health researchers and pharmaceutical companies, compared to conducting research into developing means to monitor the diabetes control needs of menstruating women.

The topic of pregnancy has not suffered the same neglect from medical researchers as menstruation has, and pregnancy has experienced a medicalization of what were once nonmedical events (Sobo, 2009). Pregnancy with type-1 diabetes requires close medical attention from long before conception through to the postpartum period (Canadian Diabetes Association [CDA], 2008). Type-1 diabetes in pregnancy is associated with several adverse outcomes such as higher risk of miscarriage, pre-eclampsia, preterm labour and delivery, delivery by C-section, and retinopathy (Institute of Health Economics [IHE], 2012). Given the complexity of pregnancy, three participants spoke of the ways in which their diabetes and pregnancy were linked. For example, Stephanie explains:

I think if anything, I've thought of [being a woman] as more challenging especially as I've got more information and just learned more about um, other woman's experiences with pregnancy and diabetes, I think that was the first like wake up call to me that this was going, it was going to be a different experience and it was going to be a very challenging experience in someday in the future it will be [laughs]. But I

think that that is the biggest thing that comes to mind when I think specifically about being a woman and having diabetes.

There seems to be a considerable difference in the challenges that diabetic women face during pregnancy. Rebecca described how she struggled to relate to a friend with a chronic illness when trying to become pregnant. Information regarding type-1 diabetes and pregnancy is hard to come by. What is available is often from doctors or the occasional blogger from the Diabetes Online Community. In her pursuit of pregnancy, Rebecca reached out to a friend with MS in the hopes of finding someone else that faced a similarly complicated pregnancy. Rebecca reveals:

Might be off topic [of women and type-1 diabetes] but I had a friend who had an early diagnosis of MS. And she and her partner wanted to get pregnant. It's not ideal but the advice was to stop your medication and restart when done breastfeeding. She asked me what do I do and I said I don't stop being diabetic. I thought someone else with a chronic disease would get, just didn't. I don't get her reality either. The pregnancy one is the tough one right now.

Speaking to another type-1 diabetic about a story of personal tragedy gave Angela enough confidence to pursue having children with her partner. Angela explains:

Actually I have always wanted children for sure but I never really, uh, considered doing something about it [laughs]. I was with my partner have been together for 14 years and I was with him for oh gosh I mean, probably 10 years before we started thinking about having kids and it was really reconnected with a friend through Facebook that um she has kids and she shared her story with me and she said 'you know, it is absolutely possible.' I never considered that it would be possible but she said that it is absolutely possible you just need to be aware about this, that and the other thing. She, uh she shared her story, it was a very heartbreaking story she told me that her first son she lost him when he was three weeks old due to congestive heart failure. Which likely was due to the diabetes um, to her diabetes that is while she was pregnant. So that, you know, that really made me very aware of how important control was.

Much like living with diabetes, pregnancy becomes a clinical experience that participants described in terms of risk and possible adverse outcomes, and with a sense of hesitation.

Despite these challenges, two participants have children and two participants are planning

to pursue pregnancy in the future. The impact of diabetes on childbearing is likely to be particularly relevant for women diabetics. Although participants may not have expressed this, it is still an important element of the gendered experience of diabetes given that most women are socialized to expect to experience pregnancy and motherhood in Canadian society.

3.2 Strained Relationships with Healthcare Providers

The nature of the relationships that participants have with their healthcare providers can have a significant impact on management, especially in the case of deciding to pursue pregnancy. Several participants commented on their good relationships with their health care providers and how that in turn helped them in the management of their type-1 diabetes. Yet, the experience of difficult relationships between participants and their healthcare providers can also cause tension and stress when accessing type-1 diabetes care.

When these relationships become strained, they can become a source of stress for participants. Rebecca felt that the information she got from wearing her CGM was empowering and helpful to better manage her type-1 diabetes, but did not feel that her healthcare providers used the CGM data in a meaningful way. Rebecca described her current struggle with her healthcare providers as centering on the issue of their expectation that she write blood glucose readings into a booklet or log with a pen, rather than simply providing them with the electronic data produced by the technology. For Rebecca, she feels that her healthcare providers have an obligation to adapt to the way the information is organized in the software that accompanies CGM. Rebecca talked about

how she sensed that she may be perceived as a difficult patient. The cooperation issue is of particular importance to Rebecca, and she explains:

This is probably my bias as a healthcare provider, like, I, you should be working with what makes sense for me. I shouldn't be providing you what's easiest for you and their critique is they have to scan through, its kind of listed as, like time and date stamped but they want to see all the lunch reading in one column... You just going to have to highlight or ask me about it.

This example demonstrates that Rebecca is aware of the gender expectations and behaviour and the consequences they may have for her. The hesitancy to challenge doctors has particular consequences for women. In one study (Chrisler & O'Hea, 2000), it was suggested that women who challenge their physicians, as Rebecca has done, are more likely to be labeled as more demanding patients or even bad patients than their male counterparts. This bias stems from assertive female patients deviating from their gender-role expectations. Given her profession, Rebecca is uniquely located to better pinpoint the problems in her relationship with her healthcare provider, while still having to negotiate having the reputation of a bad patient.

Conclusion

In this chapter, embodiment was explored from the perspective of the challenges of management, the cost of diabetes technology and the gendered dimension of living with type-1 diabetes. Participants faced a number of challenges after diagnosis that ranged from changes in life plans and dealing with the stigma associated with (type-2) diabetes, to the mental health implications as diabetes becomes harder to manage some time after diagnosis. The significant cost of wearing diabetes technology like insulin pumps and Continuous Glucose Monitors (CGM) meant that physically wearing the device would be a mental reminder of the money spent to use these life-changing medical devices. This

physical/mental state was described as an embodied awareness of the cost of diabetes technology.

Being a woman with type-1 diabetes does not change the expectations that are placed on participants. The body is implicated in femininity to the extent that being a woman entails concealing diabetes technology such as the insulin pump and Continuous Glucose Monitoring (CGM). The need to conceal the pieces of technology suggests the desire to normalize the body by hiding the equipment associated with type-1 diabetes is a way to conceal illness. The concealment or deliberate display of diabetes technology relates to Andrea Vick's (2010) discussion of episodic disability. The performance of type-1 diabetes is related to the visibility of insulin pumps and CGM. The meaning of the devices and what they represent may be limited to those that know what an insulin pump looks like and what disease it is used to manage. Nonetheless, participants want to control the objects that signal their diabetes through the concealment of devices even if few people know what those objects mean.

The way in which participants articulated their understanding of being women as diabetics focused on the body and the biological processes of women's bodies. This understanding contrasts with feminist readings of gender that see the conflation of socially determined gender with biological sex as essentialist and simplistic. However, while women did not discuss the social dimensions of gendered illness experience as I had expected they would, it is important to let participants' experiences speak and to understand that feminist readings of gender are different from participants' focus, based on their lived experiences.

The language of control came up again when participants described a loss of control during menstruation and the need for control during pregnancy. Menstruation represents a period when female emotionality is perceived to be heightened or out of control. The difficulty of diabetes management is perceived as a greater problem during menstruation because women may feel like it is more difficult to cope with the emotional challenges of management.

In the case of pregnancy, good control is important to limit complications for mother and baby. Beyond the medical need for control during pregnancy, control is an important construct in the way that type-1 diabetes is discussed. A lack of control is associated with tragedy and the responsibility for good pregnancy outcomes for diabetics is placed on the mother. Good control is associated with a healthy pregnancy and baby. To lack control is perceived as irresponsible. These pressures exist for women that are not diabetic. My point is that the personal control of a complicated disease then becomes a criterion for judgment of who is a good mother with good control, one who has a good pregnancy without complications. The female body then becomes the domain a continuum of lack of control during menstruation and needing strict control during pregnancy.

Finally, this chapter has addressed how gender expectations shape the interactions between healthcare professionals and patients and the defiance of those expectations that has negative consequences for the patients. The anxiety that arises when women challenge or demand better care from doctors can result in a tense relationship that may lead to adverse health outcomes. In the next chapter, I address the role of the Diabetes

Online Community in the experience of type-1 diabetes in the technological age, and positive aspects of wearing diabetes technology.

Chapter 4: Coping Strategies

Introduction

Technology fundamentally alters the way in which type-1 diabetes is experienced. A consideration of the role of technology in diabetes care is complex, and its discussion needs to represent the diversity among participants. Technology is not a universal experience or category and this is supported by my participants' experiences of the online world of diabetes and wearing diabetes technology. In this chapter, I discuss the Diabetes Online Community (DOC) in greater detail and the ways in which the DOC is a tool for information and support for participants. This status of technology as agentic is explored and I pose the question of how to talk about networks of diabetics in the context of the DOC. The second topic of this chapter details the benefits gained through wearing diabetes technology and the conclusion that technology can lessen the burden of successfully managing type-1 diabetes. Finally, I point to some new questions that emerge from my findings that suggest a new understanding of embodiment is needed in order to capture the complex relationships women have with their bodies, and the potential receding of the diabetic body through the use of technology.

4.1 The Diabetes Online Community (DOC)

The definition of diabetes technology changed throughout the course of the study. Initially, technology was understood as the devices such as insulin pumps, CGM and glucometers that participants interact with. However, the diabetes online community (DOC) was missing and such an omission needs to be addressed. In this section, the DOC will be explored in greater detail in order to understand how the DOC constitutes an

important tool or coping strategy to better live with type-1 diabetes as described by participants.

The early DOC was constructed in opposition to the pharmaceutical industry. This opposition stems from the exclusion of persons with diabetes as consultants in the creation of products and the extraordinary cost of type-1 diabetes. There was a progression from message boards to personal blogs used by diabetics to share their stories. A common theme of bloggers is the desire to connect with others, show how they live with diabetes successfully, and talk about their experiences beyond the medical aspects of living with diabetes (Hoskins, 2012). As the DOC continued to grow, the pharmaceutical industry reached out to bloggers. In 2009, Roche invited diabetes bloggers to their headquarters to begin a discussion about social media and Big Pharma's involvement (Sparling, 2009). The relationship between bloggers and Big Pharma continued to grow closer as diabetes bloggers were invited to write on the companies' blogs. There are concerns that the outreach efforts are thinly veiled attempts to coopt grassroots organizing. In response to this corporate encroachment on the DOC, several initiatives have been started by prominent bloggers. One example is the video movement called *You Can Do This Project*, started by Kim Vlasnik of *Texting My Pancreas* where diabetics share video logs (vlogs) that speak frankly about the ins and outs of living with diabetes (*The Battle Cry*, 2012). The DOC continues to grow and has now proliferated on multiple social media platforms like Facebook, Twitter and Instagram.

It is important to note that participants were recruited for this study through the social media outlets of Connected In Motion (a diabetes organization). Therefore, all participants interacted with the DOC in some capacity. That being said, two participants

said that they did not use the DOC to research specific issues of management. These participants used the DOC to keep in contact with other diabetics rather than as a database of ideas on how to manage type-1 diabetes. For Michelle, who was diagnosed with type-1 diabetes as a child and experienced a more recent diagnosis of Celiac Disease, conducting research on the DOC was not an option for her. Michelle explains:

That's what makes me a dinosaur [laughs] but online searching, I hate searching, tell me where to go, I will happily go there. But tell me to find it, well [laughs] no. I just find it very frustrating. It also didn't help when the celiac was diagnosed, I lived rural so Internet was bad luck. That in it of itself is not worth it. Now I'm not, not the fastest high speed, but it's better [laughs] but ya, no, it's that, I'm only as comfortable as, I mean the information on the Internet is only as good as the person that puts it in, so then how do you know what's good, what's not good.

For Michelle, the DOC cannot be trusted as a source of information and her rural location poses an obstacle to access to the Internet and the DOC. I do want to stress that the DOC still plays an important role in participants' experience, albeit to varying degrees.

One unique feature of the study is that there appears to be an unusually high number of participants who are bloggers. The DOC has not being significantly researched; it is therefore difficult to estimate the difference between the proportion of bloggers in the study versus the proportion of bloggers amongst the total population of type-1 diabetics. That being said, three of the nine participants were diabetes bloggers. This seems to be a larger proportion than what we would find in the wider population.

Kristin, a long distance runner, turned to the Internet some seven years after her adult diagnosis. For Kristin, the DOC has opened up several doors including advocacy and peer mentorship. Kristin describes the evolution of her participation since joining the DOC:

I actually, um, so like I said earlier, I was diagnosed in 2002 and until, if I remember right it was 2009, I didn't know another person with Type 1 diabetes, online or in real

life. Like I had never met someone else like me. Um, and then I sort of stumbled across that there's sort of a world of people online and uh, from there, it kinda of grew pretty quickly. I discovered that a lot of people write blogs and that sort of stuff, so I started my own blog cuz I thought that would be kinda cool. And I've been doing that now for a couple of years and that's helped me meet people and it's also helped people kind of find me, so I've had people that I don't even know approach me with questions and looking for support, so that's been kinda neat. Um, but it's trickled out beyond that. So I've had, for example, the diabetes center that I go to, they've asked me several times to kind of mentor adults who are recently diagnosed with Type 1 who aren't dealing with it particularly well, like they're struggling with it. Um, so I've done that sort of stuff. In the last year or so, I've been asked to do some presentations uh, to diabetes educators and that sort of thing, so I kind of, you know, I say yes to everything and everything kind of rolls into the next thing. So, that's kind of how it progressed.

The blog becomes a gateway into connecting even further with the community that exists offline. It appears that the DOC and Kristin's blog in particular, are seen as reputable if Kristin is given offers to mentor and speak to, and on behalf of, type-1 diabetics. Kristin was able to engage with the offline community only after spending some time and effort in the DOC, after which she was asked to speak and mentor in person.

Megan decided to start her blog in response to not finding adequate support and help from healthcare professionals when dealing with a diabetes-related eating disorder. The DOC proved to be an invaluable source of support and a wealth of information for dealing with the difficulties of management and other issues. Type-1 diabetics are at particular risk for eating disorders with some estimates suggesting that girls with type-1 diabetes are twice as likely to have an eating disorder as their peers (Jones et al., 2000). Given that people who have diabetes haven't externally imposed dietary rules that discount feelings of hunger and satiety and a general inability to integrate food habits with peers and family, there is an increase in purging and bingeing. Additionally, weight gain is experienced with the administration of artificial insulin and can lead to restricting insulin as a way to gain control over their diabetes when weight control is elusive (Starkey &

Wade, 2010). Finally, the bruising and lumps that develop from administering insulin can lead to increased levels of body dissatisfaction, a factor in the development of disordered thinking (Darbar and Mokha, 2008). Diabetics will withhold administering insulin which results in hyperglycemia (high blood glucose) and this means the body is unable to process the glucose in the body and omits it through urination (Mathieu, 2008). This results in weight loss if the hyperglycemia is maintained.

Despite this being a significant issue for women with type 1 diabetes, there is a lack of consensus on how to diagnose and treat “diabulimia” and other diabetes-related disorders (Weaver, 2012). Megan turned to the DOC to find support for living with an eating disorder in the context of type-1 diabetes, that she could not find elsewhere.

Megan explained:

I kind of tried the private counseling route at first. I’ve tried to see a psychiatrist, a psychologist and that was really not helpful at all. I just found that like any person we went to that was dealing with a health practitioner, they were very focused on my diabetes exclusively, or my mental health exclusively. They didn’t tie the two together. I think the most helpful thing I have found has been support within the diabetic community, like people with diabetes, not health practitioners. Um, it hasn’t even been the counseling I’ve got that’s helped me, it’s been just talking with other people and hearing their stories. Having the social support networks, that’s been mostly it... It’s mostly Facebook, I know there’s tons of diabetes groups out there. So specifically, type-1 groups I’m a part of. I’m part of a couple ones, some for diabetics with eating disorders, some just like you know, funny groups for diabetics, or somewhere people vent about stuff. Some advocacy groups and basically I just use it to kind of, if I see a post that I relate to, I will message that person or to publish something I felt and then they message me back. My blog has been really helpful in making good connections with people that I wouldn’t otherwise connect with. And I had other diabetics message me and even some nurses and people like that too. So not just within the diabetic community but other people working in the healthcare field. And so, pretty much between Facebook and my blog, I’ve connected with a lot of people.

Megan’s narrative shows how the DOC became a network of support for her, and subsequently, her blog became a resource for the healthcare professionals that failed

Megan in the first place. The DOC can therefore be vital in some diabetics' lives, and the sharing of their experiences is then used to support diabetics on and offline. The DOC can replace to a certain extent the support that is expected in the clinical setting. The DOC may not replace the care given by healthcare practitioners, but given the lack of services, it helped Megan and others like her share their experiences in therapeutic ways.

The DOC is a particularly valuable resource for athletes because care and advice in the clinical setting can be hard to come by when facing unique challenges surrounding participation in sports and type-1 diabetes. Kristin described how the challenge of running a long-distance race required her to turn to the Internet for ideas about how to manage her type-1 diabetes.

Um, [laughs] what's really funny is actually, I was training for a long race that um, I was just having trouble with you know, diabetes and running and it was in the winter and I was, all sorts of stuff, so I went online and I Googled if there was any other runners in the world that I could learn from and I discovered a blog that was called Canadian D Gal. It was written by a girl who lives 20 minutes off the highway from me and she was training for the same race I was training for and I thought 'oh my god, they're everywhere' [laughs]. So that's, that was the first one I found and then from hers, there was a million links from her blog to other blogs and I just kind of clicked around and found a ton of people who are like triathletes and do all kinds of cool stuff, so.

This shows that the DOC is a powerful tool to the extent that it connects diabetics together in ways that were previously difficult. *Canadian D Gal* lived very close to Kristin and was engaged in similar activities, yet they had not interacted with each other. The DOC brings type-1 diabetics together allowing the sharing of information and experiences about type-1 diabetes that is either otherwise unavailable or difficult to locate. I want to stress that the DOC is an important resource for type-1 diabetics given that the prevalence of type-1 diabetes is much lower than that of type-2 diabetes, which tends to

take up the lion's share of resources and care made available for the universal category of "diabetics."

Crystal, who was diagnosed as an adult in 2012, described how diabetes care can be alienating when trying to adapt to her life with type-1 diabetes. Crystal commented:

So when I was first diagnosed, the first thing I did was, I started a Twitter account. And that was my way of finding people who understood and I was so confused and I really feel that it saved me in a lot of respects because I didn't want to tell anyone, uh, so I was able to ask questions and get real-time responses from people who had been there without going to the hospital. And every time I went to the hospital to do these educational programs from when I was diagnosed, it was me and 5, 6 other people in a very sterile environment where most people were type-2 and over 60. So I felt really out of place and no one, you, know I just didn't feel like, I just felt really weird in that circumstances. You're in different stages of life, totally different lifestyle...

Despite the anonymity of the Internet, Crystal found information and support that helped her begin to adapt to her new reality of managing type-1 diabetes. In the time following her diagnosis, Crystal spoke about a period of "social media burnout" that occurred through constant engagement with the DOC to the point where it became overwhelming to constantly be talking about diabetes and where some members of the DOC were overly critical or negative towards Crystal's management style. However, Crystal returned to the DOC after a break, with her blog that promotes active living for type-1 diabetics.

The DOC can be an invaluable resource for type-1 diabetics, as participants' experiences reveal. Participants' experiences also demonstrate that there are limits to the DOC and that the DOC ought to be used cautiously. The DOC is a space in which type-1 diabetics can locate information that is unavailable in their doctors' offices, or that is gained through the experience of living with type-1 diabetes, and therefore beyond the knowledge base of most interdisciplinary care teams that deal with type-1 diabetes. The DOC is a form of diabetes technology that supports individuals in the management of

their type-1 diabetes. Much like insulin pumps or CGM, not all diabetics use it but for those that do engage in the DOC, it can have a profound effect on the decisions they make, the actions they take or how they feel about their type-1 diabetes.

Before the DOC, often the only time type-1 diabetics would meet one another would be at a diabetes camp for children. This limited interaction meant that type-1 diabetics were isolated in their communities often only confiding in healthcare professionals about diabetes issues. By contrast, the DOC creates a space where type-1 diabetics can interact with each other. They may participate in the DOC as those who publish on the Internet (as bloggers) or they may participate in a more passive role of reading blogs and discussion boards. The DOC is also a space for the sharing of information about diabetes beyond the bounds of the doctor's office. Diabetics are expected to take full responsibility for their health outcomes even when healthcare professionals may have little to offer as is the case with eating disorders or management when engaging in sports. The DOC becomes a space where diabetics share their experiences dealing with these complex issues that no one locally could help them with. In this way, the DOC approaches diabetes management as a grassroots, collective experience when the doctors and health professionals can no longer help, but diabetics still require productive solutions with the goal of good diabetes management.

4.2 Benefits of Wearing Diabetes Technology

Despite the challenges explored in Chapter Three, it should be stressed that wearing technology changed the way participants managed their type-1 diabetes for the better. Diabetes technology in the forms of insulin pumps, CGM and apps allowed participants to be less constrained by their type-1 diabetes, compared to when they used

Multiple Daily Injections (MDI). In this section, I will explore participants' descriptions of how technology is beneficial to their management and begin to connect these experiences with some of the ideas of subjectivity and embodiment presented in the introductory chapter. A significant benefit to wearing diabetes technology cited by participants was that they experienced some of the inconveniences of type-1 diabetes less than they would otherwise on MDI. There is no way of completely removing the labour of type-1 diabetes management, but insulin pumps seem to require less thought, they lessen the mental stress of injections, and they decrease the use of syringes, pens and insulin that is associated with injections.

The desire to have tight control of insulin levels can be quite a challenge to achieve on MDI, especially at mealtimes. Melissa described how she would take her injection before her meal and would test after eating her meal. Since the insulin did not have enough time to process the glucose from the food she just ate, Melissa's blood glucose would be high. Melissa would then inject to address the high blood glucose but this would be too much insulin. Melissa's method for avoiding high blood glucose readings after a meal, prior to having an insulin pump, was tedious and perhaps risky. This method is tedious because of the need for extra testing and an additional injection. There is the risk of giving too much insulin, which results in low blood glucose after a meal and this can lead to the need to eat or drink food even when one is not hungry. This behaviour can have an impact on type-1 diabetics' feelings towards food and increased food can result in weight gain. Melissa's experience demonstrates how each improvement in treatment and technology results in more convenience for type-1 diabetics. As she recounted:

Um but ya when I got the [insulin] pens it was awesome because it was so much more convenient because I could inject and then eat almost right away and that was fine and then I'd got into a system of testing after, like without the doctor's orders I would test afterwards and if I was starting to climb then I would give myself more and with the pump. I find its really great because sometimes if I'm going high after supper um I'll, my first inclination would be to inject whereas the pump says no like you haven't given yourself enough time to wait for those carbs to kick in and so it's like ok, I listen to the glucometer tell me like no, like you still have insulin on board and I love that because it's way way more convenient and I have less lows because again if I'm spiking after supper then it's like "oh no, quick, give me the insulin" [laughs] so it's less, I find it's way less stress.

This demonstrates that the pump's ability to store information and to do calculations prevent Melissa from taking too much insulin and avoids the stress of having high blood glucose or low blood glucose, a common side effect of tightly managed type-1 diabetes. Simple algorithms and data retrieval lessen the stress of having to remember all of these factors when making decisions about how much and when to inject insulin in addition to avoiding the uncomfortable experience of high or low glucose levels. The technological capacity of the pump supports Melissa's wellbeing by completing at least some of the micro-scale decisions, allowing Melissa to be less stressed by the minutiae of type-1 diabetes management.

Wearing technology helped several participants navigate the particular challenges of exercise. Exercise is a crucial part of healthy living for any person, but diabetes can make exercise a challenge. Given that there are no clear guidelines for adjusting insulin doses during exercise, type-1 diabetics are expected to make adjustments themselves (Franc et al. 2012). That is to say that diabetics are expected to determine dosing on a trial-and-error basis. Four participants commented on the ways in which technology made exercising easier. Kristin described how the logistics of running pushed her to move to the insulin pump:

Um, it's actually interesting because when pumps, when I first became aware of pumps, I don't know how long they've been around on the planet but when I first learned about it as an option, I immediately dismissed it. I thought I never ever want a pump [laughs]. Um, and I don't remember when I started to change my mind but I'm guessing it had to do with sports. You know, like if I was doing long distance running, I was carrying like a running belt and it would have a glucometer in it, it would have a needle in it with insulin, just in case and all sorts of other things and I remember just probably thinking it would be easier to carry less stuff. And it would also be easier to adjust insulin differently than you know committing to taking a needle and then all of a sudden it's like "well, now I can't go for a run because there's too much insulin in my body". So I don't remember the exact way that it happened but I just kinda opened up, warmed up to the idea and went to an information session and tried on one of their little sample infusion sites and thought "ya, you know what, I can do this" and it was in a couple of weeks I had a pump.

This shows that the physical presence of the pump is less intrusive than the things that are needed for injections when engaging in endurance sports, such as long distance running.

Furthermore, the pump gives Kristin more control over the insulin in her body. Greater control is achieved by reducing the amount of insulin that is released by the pump (basal or background insulin), not including insulin that is taken at meals, to lower high glucose levels (bolus insulin). On MDI, the basal or background insulin is administered once or twice daily with long-acting insulin. If someone were to exercise, the person using MDI would have to remember to reduce the basal injection, which they might need to do up to 24 hours in advance and might result in higher glucose levels in the interim period. For endurance sports, the body eventually requires insulin over the course of the exercise, and the pump is compact and easy to use, thus eliminating the need for additional things to be carried (e.g., while running). The pump lessens the physical presence of diabetes-related things to carry and manage and makes running less complicated for Kristin.

The insulin pump gave several participants the feeling of freedom because the pump allowed for less planning around the timing of insulin injections. Three participants commented on the significant difference between rigidity of their schedules with Multiple

Daily Injections (MDI) and the ability to be spontaneous with their insulin pumps.

Elizabeth described how the pump created flexibility in her life:

Um, it's a lot easier to um, not have to plan things as far in advance. So, if I want to go for a run with one of my friends, I don't have to tell her "ok you have to tell me at least 5 hours in advance because I need to shut my insulin off." I've been able to work things out a little bit differently that now I can do things um a lot closer to the actual event. Same with, like going to party or anything like that, that I don't have to plan it as far in advance and I can always make adjustments while I'm doing things a lot easier.

This shows how the pump lessens the stress associated with continually planning ahead or having to make changes to insulin, food intake or exercise. The ability to make plans with little warning may seem unremarkable to non-diabetics, but participants associated the insulin pump with regaining a sense of normalcy and ease of participation in daily life events. One participant commented that the spontaneity and flexibility that she gets from the pump would keep her from ever giving it up, regardless of the inconveniences, cost or awkwardness of wearing diabetes technology. The ability to plan less by wearing the pump is valued among participants.

Finally, the insulin pump reduces the number of the smaller, everyday sources of anxiety associated with MDI. Before the introduction of fast-acting insulin in the late 1990s, the way that diabetics used insulin in relation to food was quite different than the practice of carbohydrate counting. Diabetics were given a meal plan that required them to eat at the same time every day and to eat the same amount of carbohydrates at each meal. This meant little flexibility from day-to-day, and the amount of food needed to match the amount set out by the dietician and doctors rather than how hungry the diabetic was. Often meal plans were based around the Government of Canada's Healthy Food Guide, requiring diabetics to eat from a variety of food groups and to measure all food in order

to correctly determine the nutritional content of their food. Because the diabetic knew how many carbohydrates they were going to consume at that meal, there was a set dose of insulin to be administered with a sliding scale to correct high or low blood glucose levels. Regular insulin requires at least 30 minutes before it begins to work. In order to have the insulin processing the glucose when the diabetic is eating, it is necessary to inject the insulin 30 minutes before eating. This regimen makes sleeping in or a delayed meal at a restaurant a source of anxiety, as not following the guidelines can result in high or low blood glucose.

Today, one is more likely to see type-1 diabetics using faster acting insulin (Humalog or Novolog) that begins to work in five minutes. In Ontario, type-1 diabetics are encouraged to practice carbohydrate counting. This involves adjusting the amount of insulin to the amount of carbohydrates one is going to eat. When using the newer insulin, this means injecting or bolusing with the insulin pump before eating. What this means for diabetics is that they can choose how much food and when they would like to eat with far less planning. Carbohydrate counting is a skill that takes time to develop as one needs to remember how many carbohydrates are in different types of food. Angela described how introducing the skill of carbohydrate counting, associated with using a pump, was a welcome change to her management of her type-1 diabetes:

Ok, yeah I mean certainly my insulin pump [makes diabetes management] easier. It means, you know, less carting around the various stuff that you need when you are on syringes. You can tweak things a little more. I came by carb counting fairly naturally because I always fairly resistant against the Food Guide that my mom, when she was taking care of me, “Well, you have to have your 3 grains and however many fruit and not more. Not a penny more, not a penny less [laughs]. I was fairly resistant and carb counting was a good option for me. I mean like that I only really functionally worry about having one type of insulin in my fridge and again it does, there are setbacks that you always have to worry about. Like it failing, be prepared for when it does fail. Technology in general is great, it is great

when it works and it can be very helpful used the right way but there's also, can also cause problems if it fails or it is not used the right way. All technology.

Angela expressed how auxiliary issues of which insulin to use, how to eat, and the threat of technological failure are easier to negotiate with pumps than MDI. There is considerable energy and thought that goes into using an insulin pump. For example, Angela spoke about the learned skill of carbohydrate counting, an important skill for intensive insulin therapy in both MDI and insulin pump therapy. Since carbohydrate counting involves matching the amount of carbohydrates in a meal with the appropriate amount of insulin (Canadian Diabetes Association [CDA], 2008), the amount of carbohydrates must be determined by weighing foods and using nutritional information to calculate carbohydrate content. Healthcare providers in conjunction with patient trial and error determine insulin to carbohydrate ratios. The insulin pump is programmed to calculate the amount of insulin needed for a bolus based on the amount of carbohydrates that the user enters into the pump and their current blood glucose. The pump lessens the mental calculations associated with MDI, which are done manually by MDI users.

Conclusion

Technology has transformed the experience of living with type-1 diabetes in several profound ways. The Diabetes Online Community (DOC) is a space that has allowed for diabetics to interact in new ways that were previously impossible.

Participants described how they have turned to the DOC when they faced challenges because they could not find adequate support from healthcare professionals. This was the case for participants seeking out support for an eating disorder and accessing lifestyle-appropriate advice about exercise and type-1 diabetes. The DOC constitutes a form of technology in and of itself because diabetics are changing their management strategies

when they go to the DOC. The DOC is a tool that shapes how diabetics live with type-1 diabetes.

Participants also described the advantages of wearing diabetes technology. Using diabetes technology in the forms of insulin pumps and Continuous Glucose Monitoring (CGM) allows participants to live diabetes less. That is to say that technology lessens the labour associated with measuring, calculating and remembering associated with type-1 diabetes management. Living diabetes less was expressed as a return to normal eating and exercising. Technology facilitates a normalization of experience that is otherwise impossible. The challenges of type-1 are great even with using diabetes technology, but participants expressed how they gained a sense of freedom from the burden of type-1 diabetes with the convenience of insulin pumps, CGM and other forms of diabetes technology.

Chapter 5: Conclusion

Diabetes is changing and becoming increasingly dependent on technology, and the need to study the effects of this technology has motivated this thesis. Gender is also an important theme for analysis because it is missing from the current social science literature on diabetes. There is a substantial canon of literature on the intersection of gender and technology that produced the idea of women embracing the hybridity of humans and machines in the form of the ‘cyborg’ (Haraway, 1991). However, the cyborg does not appear to be an apt metaphor for understanding what participants in this study described. The cyborg did not fit participants’ narratives, because they maintained that their bodies were not technologically integrated. As I will discuss below, the insulin pumps and Continuous Glucose Monitor heightened their awareness of the body, rather than seamlessly integrating into it. The posthuman better captures the way participants talked about using technology in an increasing way to manage their diabetes. That is to say that the posthuman subjectivity is a technological-human hybrid whether the posthuman subject acknowledges their hybridity or not. This opens up the category of hybrids to include a range of experiences of living with technology in the context of chronic diseases like type-1 diabetes. Furthermore, as I will discuss below, participants’ narratives supported the idea that the diabetic body is the locus of experience, thus making scholarly approaches to examining embodiment a helpful perspective with which to understand the bodily experience of living with type-1 diabetes in the technological age.

The cultural construction of women as existing in opposition to technology is challenged by participants’ experiences of living with technology in an increasingly intensive manner. Participants used technology countless times every day to make better-

informed decisions about the amount of insulin they needed, what types and how much food to eat, and how and when to exercise. These decisions were based on a multitude of factors that must be considered with every action taken throughout the day. These microdecisions can have emotional and psychological costs for diabetics. Despite the ongoing challenges of type-1 diabetes management, technology seems to alleviate some of the burden of the calculating, measuring and recording of information regarding diabetes management. In this way, participants are active users of technology. They are experts in their deployment of technology, using it to best fit their lives and to live successfully with type-1 diabetes, a feat that was not previously possible before the advent of insulin pumps, Continuous Glucose Monitoring (CGM) and other forms of diabetes technology. Participants are a part of a generation of type-1 diabetics living with technology in new and more intimate ways, uncharted territory for type-1 diabetes in the technological age.

When I began this project, I had suspected that the pump might *alter* the way in which participants experienced type-1 diabetes. However, the use of terms such as “less” and “lessening” came as a surprise. The ‘lessening’ of the presence of diabetes in day to day life through the successful use of the insulin pump supports Griet Scheldeman’s (2010) findings of her study of adolescent type-1 diabetic pump users. Scheldeman argues that young people using insulin pumps live diabetes less, that is to say that the pump lessens the hassle of diabetes and gives back freedom. Objects like the insulin pump are relied upon by participants to work and act on behalf of the subject. The agency of the person who uses technology to continually inform her decisions about her diabetes may be temporarily shared with the technological tools that are so fundamental to living with type-1 diabetes in the technological age.

The pump changes the way participants conduct the daily activities of type-1 diabetes, from exercise to eating. I do not want to conclude that because participants act through the pump, it is therefore engaged in the subjectivity of people who use insulin pumps. Furthermore, participants did not talk about their forms of diabetes technology displacing their ability and responsibility to make hundreds of microdecisions about management. The pump retains its object status in the narratives of the women in this study while simultaneously being trusted to act and work. Scheldeman is not suggesting that the self completely disappears in the midst of the insulin pump. Scheldeman argues that young people may forget that they have the pump, but the 'I' intervenes in other ways through counting carbohydrates, pushing the buttons, and presence of the pump on the body. Diabetes recedes with the pump, which over time recedes too, but does not become entirely invisible.

The findings of this study suggest that the presence of the body is also heightened, in other ways, in the presence of technological diabetes devices. Participants described how the body was rendered more present with the insulin pump and Continuous Glucose Monitor (CGM), compared to using Multiple Daily Injections. I believe the reason for this lies in participants' narratives that talk about the awkwardness of wearing diabetes technology on the body and how it is incompatible with the clothing women are expected to wear. Although participants tended to rely on essentialist understandings of femininity, I would argue that all women, diabetic or not, participate in a culture that places importance on women's bodies. This emphasis means that there may be little chance for women to have their bodies mentally recede or disappear from their consciousness. Many of the cultural constructions of womanhood apply to participants' narratives. The

centrality of the body in their stories, and how it looks with technology worn on it, reflects the cultural expectation that women perform their femininity through a body that conforms to hegemonic constructions of the body as natural rather than technological.

What does this mean for a theory of embodiment? Technology makes diabetes easier but it does not make the body disappear, as Scheldeman suggests. Technology changes the bodily experience of type-1 diabetes, making the body less present, while also occasionally more present through its awkwardness and discomfort. The body is heightened in these circumstances, and we need a new theory of embodiment to capture how technology on the body simultaneously helps it recede, and brings it into focus.

Participants did not describe their embodied experiences of type-1 diabetes as an episodic fluctuation from illness to wellness, as described by Vick (2013). This may be attributed to several factors. Firstly, type-1 diabetes does not appear to relent or recede even in the presence of technology like insulin pumps. Even during periods of good glycemic control and relative health, type-1 diabetes requires constant measuring and taking of medication. The slightest miscalculation results in high or low blood glucose that can be felt in minutes. In this way, the boundary between periods of illness and wellness can be crossed multiple times a day, not constituting clear differences between these states. The threat of illness as high or low blood glucose or the complications that arise from sustained poor glucose control are always present in the embodied experience of type-1 diabetes. This is different than the episodic disability, which involves the marked contrast of experiences of those living with, for example, Multiple Sclerosis, as described by Vick. It appears that the constant changes that participants describe

constitute a more consistent embodied experience of living with type-1 diabetes without periods of remission or reprieve.

The participants' narratives of living with type-1 diabetes often point to some contradictions in regards to embodiment and in so doing, reveal that there is a great range in participants' understanding of what constitutes embodied experience. The difficulty arises when participants talk about their body and diabetes technology as separate entities that are monitored by the rational self, neatly fitting into our Cartesian understanding of experience. However, the distinction between the self, body and technology becomes unclear when we consider how the body adopts new ways of feeling with the technology being worn. Or when, despite all the correct amount of measuring and calculating of blood glucose, food and insulin, the body goes rogue and does not comply with the self or technology and this leads to poor glycemic control, for example. The narratives show that participants' experiences are often described in terms of the dominant paradigm, rather than neatly fitting into the theoretical frameworks I began with. In this way, the narratives simultaneously support and challenge cultural understandings of the self, body and technology.

Finally, it is noteworthy that access to technology is shaped by the intersection of gender and technology. The cost of using diabetes technology is significant and participants universally discussed the cost of paying for life-changing technology for their life-long illness. This is even more surprising when we consider that the Government of Ontario largely subsidizes insulin pump therapy with the Assistive Device Program (ADP). However, an insulin pump is only a part of the technological arsenal of diabetes tools. Continuous Glucose Monitoring (CGM) and glucometers are

not covered under the ADP. The cost is so significant that it is difficult to pay out-of-pocket for these devices. As a result, those using these devices can only do so with private health insurance that is provided by employers. However, participants' involvement in the paid labour force reflects women's labour patterns. Those participants that were employed were in the service industry, an industry in which women represent the majority of workers. These forms of labour are undervalued in our culture and the compensation and remuneration is not adequate. Specifically, the health insurance that participants received often did not cover the cost of CGM. Women engaging in undervalued work has an impact on the resources that they have at their disposal to pay for the devices and supplies that are critical to the management their diabetes. In this way, gender has a significant impact on the technology that participants can afford to use and access.

In closing, I would like to connect the narratives of the women in this study with the wider technological landscape of our lives. Living with type-1 diabetes has its particular challenges, but that is not to say that we cannot gain insight from their experience, into the more general, increasing presence of technology in our lives. The Diabetes Online Community (DOC) and wearing diabetes technology stand out as the two significant dimensions of technology and type-1 diabetes that have implications beyond the world of people with diabetes.

It is beyond the scope of this project to comment on the Internet beyond the DOC in any level of detail. However, the Internet was the first resource recently-diagnosed participants used to understand highly technical diagnoses from the moment they were told about having diabetes. In this way, the Internet becomes a complex place of

community, health information, and trust. The role of the Internet is expanding into areas of our lives that were previously and exclusively the domain of medical professionals. Furthermore, participants commented that the support and information obtained on the Internet often addressed problems that healthcare professionals were incapable of resolving. The DOC and the Internet have a subversive quality that can temporarily displace the authority of doctors, nurses, dieticians and social workers. The transmission of information and support beyond the purview of the medical establishment can strengthen individuals' ability to make decisions in the daily management of their chronic illness.

Future directions for this topic may involve a deeper investigation of the Diabetes Online Community (DOC), given that the DOC is an important space where the diabetes community converges in order to share stories and information. Within the DOC, there are several gendered implications that seem apparent to me at the end of this project. Firstly, participants used the DOC to reconnect with other type-1 diabetics that they had met as children at diabetes summer camps. The reconstitution of old social networks is very interesting and it would be intriguing whether women's use of the DOC as a social network differs significantly from male type-1 diabetics. Secondly, the DOC is made up of countless diabetes blogs, where individuals document their lives with diabetes in striking detail, sharing solutions to common challenges of diabetes management. It appears that women make up a substantial number of prominent diabetic bloggers in the English-speaking DOC. A point of interest may be addressing the gendered dynamics of diabetes bloggers and how individuals connect or consume the content produced in the DOC. This research suggests that the DOC is an important space for type-1 diabetics, a

space that shapes the experience of type-1 diabetes in the technological age. As such, the DOC merits further inquiry in order to better understand the social and group dynamics of living with chronic diseases like type-1 diabetes.

With regard to embodied technology, the wearing of technology on a continual basis is not only increasingly incorporated into medical treatments, from insulin pumps to pacemakers, but also becoming a common occurrence as wearable technology--for example, in the form of smart watches and fitness trackers--becomes available to the wider public. The continual presence of technology raises questions about the definition of the body versus the machine. Indeed, we may already be cyborgs, although we may not call ourselves as such. This contradictory stance, where we embody technology but continue to see it as distinct from our selves, is supported by the narratives of participants, individuals that use technology to measure, control and to mimic a healthy body but who maintain that their sense of self does not include their insulin pumps, CGM or other forms of technology. I think the unremarkable integration of technology into new parts of our lives points to the ways in which the cyborg is an everyday experience rather than a resisted or feared identity.

Appendix 1: Interview Guide

- I. Demographic
 - a. How old are you?
 - b. Where do you live?
 - c. How would you describe your ethnicity or heritage?
 - d. What is your occupation? Your educational background?

- II. Personal History
 - a. When were you diagnosed with type-1 diabetes?
 - b. Describe what happened prior to your diagnosis? What symptoms do you recall experiencing in the time leading up to your diagnosis?
 - c. Does anyone in your immediate circle have diabetes?
 - i. Did you know anything about type-1 diabetes prior to your diagnosis?
 - d. How did your family and friends react to the diagnosis?

Childhood Diagnosis

- i. What was your initial reaction?
- ii. Who was responsible for your care in the beginning?
- iii. What was it like to attend school with diabetes?
- iv. Tell me about your experiences with summer camp, sports, sleepovers, holidays
- v. Does having diabetes for a longer amount of time change your perspective on your management?

Adolescent/Adult Diagnosis

- i. What was your initial reaction?
- ii. What was the process of learning self-management like?
 1. Who supported you initially after diagnosis?
- iii. Tell me about your management style
 2. Are you primarily responsible for your care?
 3. Does your partner (or family members) get involved? How so?
- e. What positive aspects have come out of your type-1 diabetes?
 - i. Community, self-care, new perspective

III. Identity

- a. What have you learned about yourself since having type-1 diabetes?
- b. To what extent does diabetes define you as a person?
- c. Do you participate in activities that focus on diabetes awareness, fundraising or the diabetes community?

IV. Identity: Gender

- a. Have you ever felt that being a woman makes living with diabetes more difficult than a man?
- b. Are there aspects to being a woman that lend themselves to good diabetes management?

V. Social

- a. How do you talk about your diabetes with others?
 - i. How do you feel about talking about your diabetes with others? Are you hesitant to let others know you are diabetic? Who do you feel this way with? Why so?
- b. How much of diabetes do you share with others?
- c. Do you know others that have diabetes?
 - i. How do you interact with other people with diabetes?
- d. Do you think your diabetes has an impact on your social life?
 - i. If yes, in which ways?
 - ii. If no, why not?
 - iii. Does type-1 diabetes affect your romantic relationships and/or dating?
 - iv. Does type-1 diabetes affect your friendships?

VI. Changes in Technology

- a. What types of technology do you currently use in the management of your type-1 diabetes?
 - i. Glucometers, insulin pump, continuous glucose monitoring (CGM), applications, computer programs
- b. Which devices do you find the most helpful in the management of your diabetes?
- c. Which devices do you find the most inconvenient in the management of diabetes?
- d. Does using your pieces of diabetes technology affect your lifestyle?
- e. Does the presence of your diabetes technology affect you in social situations?
 - i. In the workplace, physical activities, special occasions, etc.

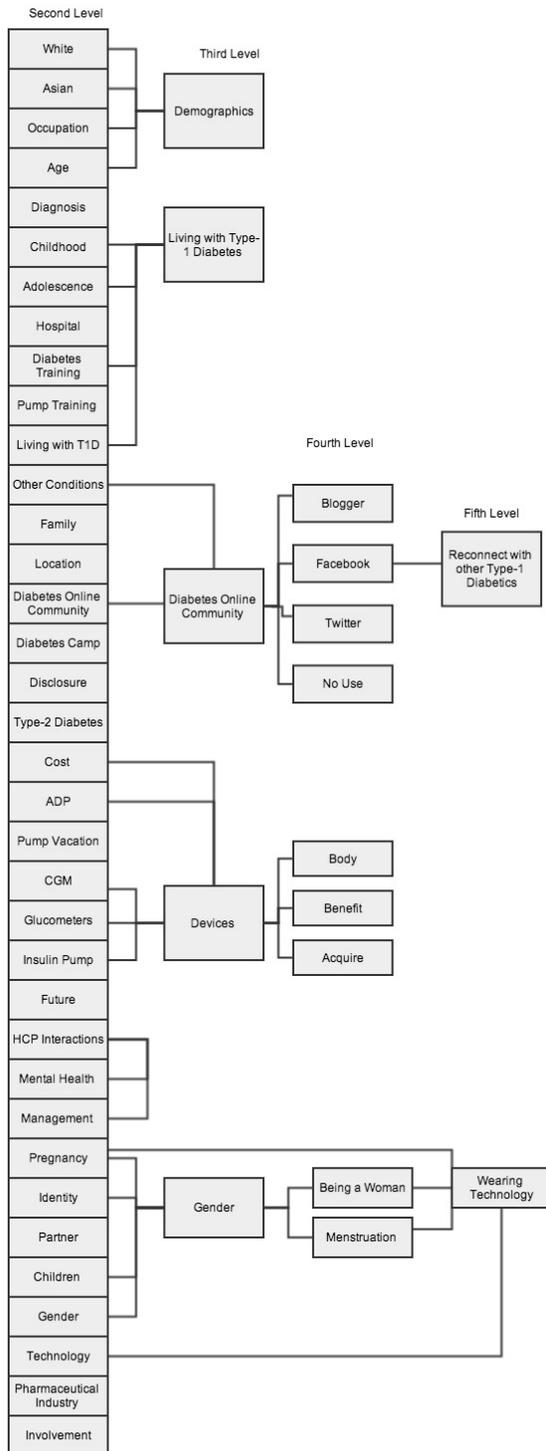
VII. Self/Body and Technology

- a. Have you experienced challenges managing your diabetes?
 - i. If yes, how did you feel in those situations?
 - ii. (Clarification) Poor management might mean: Poor glycemic control, weight control, cardiovascular complications, eyesight
- b. Does having your diabetes technology with you make you more or less aware of your diabetes?
- c. Does technology make you more or less aware of your body?
- d. Has your use of technology in your diabetes management changed over time?
 - i. If yes, how so?
 - ii. Do you experience periods of diabetes burnout? Technology burnout?

VIII. Wrapping Up

- a. Is there anything else about your thoughts or experiences that you would like to share?

Appendix 2: Thematic Coding Flowchart



References

- Assistive Devices Program (2012) *Insulin pump and supplies policy and administration manual September 2012*. Toronto: Ministry of Health and Long Term Care.
- Bailey, L. (2001) Gender shows: First-time mothers and embodied selves. *Gender & Society* 15 (1), 100-129.
- Banerjee, S. & Farrah, K. (2008) *Insulin pumps for type 1 diabetes: A clinical and cost effectiveness review*. Ottawa: Canadian Agency for Drugs and Technologies in Health/Health Technology Inquiry Service.
- Barnard, K, Lloyd, T., & Skinner, T. (2007) Systemic literature review: quality of life associated with insulin pump use in type 1 diabetes. *Diabetic Medicine* 24(6), 607-617.
- BD. (2014) *Insulin syringe size* [image] Retrieved from <http://www.bd.com/us/diabetes/page.aspx?cat=7001&id=7252>
- Bell, David. (2007) *Cyberculture theorists: Manuel Castells and Donna Haraway*. London: Routledge.
- Bernard, H. R. (2006) *Research methods in anthropology: qualitative and quantitative approaches*. Lanham, MD: Alta Mira.
- Borchers, A.T., Uibo, R. & Gershwin, M.E. (2010) The geoepidemiology of type 1 diabetes. *Autoimmunity Reviews* 9, A355-A365.
- Bordo, S. (1993) *Unbearable weight: Feminism, Western culture, and the body*. Oakland, CA: University of California Press
- Braidotti, R. (1994) *Nomadic subjects: Embodiment and sexual difference in contemporary feminism*. New York: Columbia University Press
- Canadian Agency for Drugs and Technologies in Health (2012) *About health technology assessments*. Ottawa: Canadian Agency for Drugs and Technologies in Health.
- Canadian Diabetes Association (2003) *Diabetes Progress Report 2003*. Toronto: Canadian Diabetes Association.
- Canadian Diabetes Association (2005) *Backgrounder Private Members Bill 55: An act to amend the Health Insurance Act*. Toronto: Canadian Diabetes Association.
- Canadian Diabetes Association (2008) 2008 Clinical practice guidelines for the prevention and management of diabetes in Canada. *Canadian Journal of Diabetes* 32(s1).

- Canadian Diabetes Association. (2009) *An economic tsunami: The cost of diabetes in Canada*. Toronto: Canadian Diabetes Association.
- Canadian Diabetes Association (2010) *Canada at the tipping point, charting a new path*. Toronto: Canada Diabetes Association.
- Canadian Diabetes Association (2011a) *Diabetes: Canada at a tipping point, charting a new path*. Toronto: Canadian Diabetes Association.
- Canadian Diabetes Association (2011b) *Diabetes: Canada at the tipping point: Diabetes in Ontario*. Toronto: Canadian Diabetes Association.
- Canadian Diabetes Association (2011c) *Diabetes: Canada at the tipping point: diabetes in North West Territories*. Toronto: Canadian Diabetes Association.
- Canadian Diabetes Association (2011d) *Diabetes: Canada at the tipping point: Diabetes in Nunvut*. Toronto: Canadian Diabetes Association.
- Canadian Diabetes Association (2011e) *Diabetes: Canada at the tipping point: Diabetes in Yukon*. Toronto: Canadian Diabetes Association.
- Canadian Diabetes Association (2011f) *Diabetes: Canada at the tipping point: Diabetes in Newfoundland and Labrador*. Toronto: Canadian Diabetes Association.
- Canadian Diabetes Association. (2011g) *Diabetes: Canada at the tipping point: Diabetes in Saskatchewan*. Toronto: Canadian Diabetes Association.
- Canadian Diabetes Association (2012a) *The burden of out of pocket costs for Canadians with diabetes*. Toronto: Canadian Diabetes Association.
- Canadian Diabetes Association (2012b) *In the Balance: A Renewed Vision for the Common Drug Review*. Toronto: Canadian Diabetes Association.
- Cohen Shabot, S. (2006) Grotesque bodies: A response to disembodied cyborgs. *Journal of Gender Studies* 15 (3), 223-235.
- Crossley, N. (1995) Merleau-Ponty, the elusive body and carnal sociology. *Body & Society* 1 (1), pp. 43-63.
- Csordas, T.J. (1999) The body's career in anthropology. In H. L. Moore (Ed.) *Anthropological theory today*. Cambridge, UK: Polity Press.
- Daneman, D. (2006) Type-1 diabetes. *The Lancet* 367 9513, 847-858.

Darbar, N. & Mokha, M. (2008) Population-specific concerns. Diabulimia: a body-image disorder in patients with type 1 diabetes mellitus. *International Journal of Athletic Therapy & Training* 13 4, 31-33.

David, M. & Sutton, C. D. (2011). *Social Research: An Introduction*. Los Angeles: Sage Publication.

Ferzacca, S. (2012) Diabetes and culture. *Annual Review of Anthropology* 41, 411-426.

Franc, S., Dardari, D., Biedzinski, E., Requeda, E., Canipel, L., Hochberg, G., Boucherie, B., & Charpentier, G. (2012) Type 1 diabetes: Dealing with physical activity. *Diabetes & Metabolism* 38 (5), 466-469.

Haraway, D. (1991). *Simians, cyborgs and women: the reinvention of nature*. New York: Routledge.

Hesse-Biber, S. N. & Leavy, P. (2006) *The Practice of Qualitative Research*. Thousand Oaks: Sage Publications.

Hesse-Biber, S. N. (2012) Feminist research: exploring, interrogating, and transforming the interconnections of epistemology, methodology, and method.” *The handbook of feminist theory and praxis*. Los Angeles: Sage Publications.

Hoskins, M. (2013b, Jul 3) An evolving diabetes online community [blog post] Retrieved from <http://www.diabetesmine.com/2012/07/an-evolving-diabetes-online-community.html>

Hoskins, M. (2013a, Dec 26) Choosing a new insulin pump: Decision made [image] Retrieved from <http://www.diabetesmine.com/2013/12/choosing-a-new-insulin-pump-decision-made.html>

Hunt, L.M., Jordan, B. & Irwin, S. (1989) Views of what’s wrong: Diagnoses and patients’ concepts of illness. *Social Science Medicine* 28 (9), 945-956.

Institute for Safe Medication Practices (2011) Pen injectors technology has its risks [image] Retrieved from <http://www.consumermedsafety.org/medication-safety-articles/item/361-pen-injectors-technology-has-its-risks>

Institute of Health Economics (2012). *Insulin pump therapy for type 1 diabetes*. Edmonton, AB: Institute of Health Economics.

Javanmardi, C., Jones, B., Honeywell, M., Welch, T., Johnson, A., Ward, A., Robinson, T. (2013) G4 Platinum Continuous Glucose Monitor. *US Pharmacist* 38 (9), 64-68 [image].

- Jones, J.M., Lawson, M.L., Daneman, D., Olmsted, M.P. & Rodin, G. (2000) Eating disorders in adolescent females with and without type 1 diabetes: Cross sectional study. *British Medical Journal* 320 (7249), 1563-1566.
- Katz, J. & Csordas, T.J. (2003) Phenomenological Ethnography in Sociology and anthropology. *Ethnography* 4 (3), 275-288.
- King, A. B. (2014) Reassessment of insulin dosing guidelines in continuous subcutaneous insulin infusion treated type 1 diabetes. *Current Diabetes Report* 14 (503).
- Lee, J. (1994) Menarche and the heterosexualization of the female body. *Gender & Society* 8, 343-362.
- Lorber, S. (1993) Seeing is believing: Biology as ideology. *Gender & Society* 7, 568-581.
- Mathieu, J. (2008) What is diabulimia? *Journal of the American Dietetic Association* 108 (5), 769-770.
- Matthews, E. (2002) *The philosophy of Merleau-Ponty*. Montreal: McGill-Queen's University Press.
- Medtronic Canada (2013) Pump: Potential solution [image] Retrieved from <http://www2.medtronicdiabetes.ca/Insulin-pump-potential-solution.html>
- Mendenhall, E., Seligman, R. A., Fernandez, A., & Jacobs, E. A. (2010) Speaking through diabetes: rethinking the significance of lay discourses on diabetes. *Medical Anthropology Quarterly* 24 (2), 220-239.
- Merleau-Ponty, M. (2012) *Phenomenology of perception* (D.A. Landes, Trans.) New York: Routledge. (Original work published 1945)
- Miner, K. et al. (2012) Using survey research as a qualitative method for feminist social change. *The handbook of feminist theory and praxis*. Los Angeles: Sage Publications.
- Mylife with Diabetes. The Pod—Enjoy the innovation [image] Retrieved from <http://www.mylife-diabetescare.co.uk/mylife-omnipod-the-pod.html>
- Paterson, B., Thorne, S., Crawford J. & Tarko, M. (1999) Living with diabetes as a transformational experience. *Qualitative Health Research* 9 (6), 768-802.
- Paterson, K., & Hughes, B. (1999) Disability studies and phenomenology: the carnal politics or everyday life. *Disability & Society*, 597-610.
- Romdenh-Romluc, K. (2011) *Routledge philosophy guidebook to Merleau-Ponty and Phenomenology of Perception*. London: Routledge.

Rosenthal, E. (2014, April 5) Even small medical advances can mean big jumps in bills. *New York Times*.

Scheldeman, G. (2010) Technokids? Insulin pumps incorporated in young people's bodies and lives. *Technologized Images, Technologized Bodies*. New York, NY: Berghahn Books.

Scuffman, P. and L. Carr. (2003) The cost-effectiveness of continuous subcutaneous insulin infusion compared with multiple daily injections for the management of diabetes. *Diabetic Medicine* 20, 586-593.

Selam, Jean-Louis. Evolution of diabetes insulin delivery devices. *Journal of Diabetes Science and Technology* 4.3 (2010) 505-513.

Sobo, E. (2009) *Culture and meaning in health services research*. Walnut Creek, CA: Left Coast Books.

Sparling, K. (2009, Jul 27) Roche Diabetes Summit: SUM Edition [blog post] Retrieved from http://sixuntilme.com/2009/07/roche_diabetes_summit_sum_edit.html

Starkey, K. & Wade, T. (2010) Disordered eating in girls with type 1 diabetes: Examining direction for prevention. *Clinical Psychologist* 14 1, 2-9.

Teixeira, M. E. & Budd, G. M (2010). Obesity stigma: A newly recognized barrier to comprehensive and effective type 2 diabetes management. *Journal of the American Academy of Nurse Practitioners* 22, 527-533.

The battle cry (2014) *You can do this project*. Retrieved from <http://youcandothisproject.com/about/>

The Office of the Auditor General of Ontario (2010) Assistive Devices Program. *2009 Annual Report of the Office of the Auditor General of Ontario*. Toronto: The Office of the Auditor General of Ontario

Toffoletti, K. (2007) *Cyborgs and Barbie Dolls: Feminism, Popular Culture and the Posthuman Body*. London and New York: I.B. Tauris.

Type 1 diabetes: UI researchers study the effects of menstrual cycle (2003, January 30) *Women's Health Weekly*, 31.

Vick, A. (2013) The embodied experience of episodic disability among women with Multiple Sclerosis. *Disability & Society* 28(2), 176-189.

Weaver, K. (2012) Eating disorders in people with type 1 diabetes. *Nursing Standard* 26 (43).

World Health Organization (2013). Diabetes. *Fact Sheet* 312. Geneva: World Health Organization.