# Living with a Machine:
# A Critical Focused Ethnography of Diabetes Practices in the Context of Insulin Pumps

by

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# Abstract

**Background:** Insulin pump utilization has increased significantly over the past 30 years and despite extensive research on adapting to, living with, and managing diabetes, there is a paucity of research on the enactment of diabetes in the context of insulin pumps.

**Purpose:** I aimed to explore diabetes enactment by individuals who live with Type 1 or Type 2 diabetes and use an insulin pump in Newfoundland and Labrador. Enactment comprises the iterative, interactive practices of problem-solving, decision-making, and sense-making in everyday diabetes management.

**Methods:** Qualitative focused ethnography was the design, and I drew on the analytic strategies of Fairclough's Dialectical-Relational critical discourse approach to determine dominant social discourses. Participant recruitment occurred via posters in clinics, pharmacies, the Diabetes Canada regional office and their Facebook page.

**Data Generation**: I interviewed 15 participants twice to generate 30 interviews; I also contacted four participants for an additional short post interview follow-up. As per their request, two participants were accompanied by their spouses. I used a semi-structured interview protocol which evolved with concurrent data analysis. I recorded field notes and detailed reflections immediately following each participant encounter. I examined documents such as Diabetes Canada Clinical Practice Guidelines (2018), insulin pump brochures and manuals, and diabetes artifacts such as insulin pumps. I generated data from August 2018 to February 2020.

**Data Analysis:** All interviews were transcribed verbatim, and I listened to interviews multiple times. Data analysis was managed in Quirkos©. I completed an inductive thematic analysis of data along with an analysis of discursive and social practices. I ensured rigour through verification strategies such as methodological congruency, maximum variation and theoretical sampling, concurrent data generation and analysis, multiple data sources, serial interviewing with participants, reflexive journaling, as well as regular debriefing with my supervisor and through co-supervising a BScN After-Degree Honors student who analyzed part of my dataset.

**Results/findings:** Of the 15 participants, nine were female, six were male, most were married (*n*=12), and the average age was 47 years. The average length of time living with diabetes was 27 years (range 3 – 42 years). The average length of time using an insulin pump was 10 years (range: 2 weeks – 18 years).

Four themes emerged. 1: *The insulin pump is the best way forward for diabetes management*. Participants acknowledged the pump as superior to injections and viewed returning to injections as a step backward in management. 2: *Working like a pancreas: Maintaining homeostasis from the outside*. Participants manipulated their pump and bodies to mimic the function of their pancreas. 3: *The constancy of surveillance*. Participants constantly monitored their blood glucose either subjectively through attention to body cues or objectively using technology and negotiated with others' attempts to offer advice or to provide surveillance. 3: *Living in predictable unpredictability* where all participants prepared, to some degree, to mitigate fluctuations of blood glucose. As a result of hegemonic practices, influenced by neoliberal ideologies of self-management, participants discursively constructed themselves as 'good' self-managers.

**Implications:** Diabetes enactment exists in networks involving multiple actors, of which the individual living with diabetes is one. Successful diabetes management continues to be measured by meeting glycemic targets; the dominant knowledge is biomedical. Participants utilized experiential knowledge but simultaneously evoked a sense of deviance. Diabetes management through a network lens broadens the view of self-management and subsequently self-management support. Nursing education, research, policy, and practice changes are needed to legitimize expert knowledge and promote a practice-network approach to diabetes management.

**Conclusion:** Self-management and person-centered care need reconceptualizing as currently the emphasis remains on the dominance of biomedical assumptions in meeting diabetes management goals. Continued *centering* of the person leads to blame, shame, and stigma. Further evolution using a praxiographic approach, highlighting the existence of practice-networks, is warranted.

# Preface

This thesis is the original work of Renee Crossman. The research project, of which this thesis is a part, received ethics approval from the University of Alberta, Research Ethics Board, *How do People with Insulin Pumps Enact Diabetes*?, Pro00081587, as well as Memorial University of Newfoundland, Health Research Ethics Board, HREB#2018.113.

# Dedication

In loving memory of my father,

Arch Drover

*"My father gave me the greatest gift anyone could give another person: He believed in me."*
*Jim Valvano*

# Acknowledgements

I have been extremely fortunate to have been surrounded with the most wonderful people throughout my doctoral studies. I am forever grateful for my entourage of mentors, colleagues, family, and friends. First and foremost, I wish to extend sincere thanks to the participants who made this study a reality with their generous sharing of knowledge.

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Thank you to my mom and my sister, who are both the strongest women I know. Mom, thank you for your endearing support throughout all of my life. Your bravery, dedication, and fiery spirit inspire me each and every day to be the best that I can possibly be and to make a difference where I can.

Last but not least, to my husband Doug, our sons, their families, and our grandchildren. Our sons and their children are our greatest gifts. Doug, your love and support never cease to amaze me. This dissertation was only possible because I have you by my side.

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# Chapter 1: Introduction

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*Imagine that it is late at night, and you are preparing for bed at the end of a long and tiring day. You live with Type 1 diabetes and use an insulin pump that is in essence your lifeline, always attached to your body and some article of clothing. As you do every night, you check your blood sugar for the last time, and you see that it is low at 3.0 mmol/L. This worries you, as the last time it was this low before bed, even after drinking juice at 11 pm, you woke at 3 am drenched in sweat, shaking, and uncoordinated as you tried to consume warm orange juice left on your nightstand. Right now, you are in desperate need of sleep but need to deal with this low blood sugar first. You need to be careful as you want to rapidly correct the low blood sugar so you can go to bed but eating too much too quickly can cause a high blood sugar which leaves you feeling physically sick and like a failure at managing your diabetes. So, you forego the much-needed sleep, in favor of trying to delicately correct your blood sugar so that you can be sure that you will wake up in the morning.*

*You begrudgingly trek to the kitchen and pour some juice and sip while berating yourself for not checking your sugar before now. Checking your blood sugar again, you see it is even lower. So now you have some Skittles. As the sugar crunches in your teeth that you just brushed (and now need to do it again), you again berate yourself for checking your sugar so late. Finally, your sugar is 6.8 mmol/L, and you are now feeling comfortable enough to go to bed. But you still worry. Did I overeat? Will I have a high blood sugar in the morning? Perhaps I should set the alarm for 3 am to check. Yes, I will do that. You sigh, and head to bed for the few precious hours of sleep before the alarm goes off at 3 am.*

*As a person living with Type 1 diabetes, this is what you do tonight and every time in your life that the situation calls for it. You do what you need to do, not only to stay alive, but also* *to stay within the learned parameters to stay well. Diabetes is not just something that you have, it is something that you live with, you experience, you feel, and you 'do'; it is something you enact every day.*

This is one of my stories about living with diabetes. The ideas framed in this story- the never-ending work, worry, and mandatory routines and practices – have intrigued me for many years. I have wondered why some people seem to struggle more than others. I perceive the impact of insulin pump marketing as promoting a "normal life". What is meant by normal? Does being different inherently imply deficiency or deviance? Throughout my life, I have experienced shifts in approaches to diabetes management support by health care providers, but I am aware there is always a tension in our power and expertise-based relationships. I have challenged myself to explore how diabetes, a fundamentally physiological disorder of the pancreas, is discursively constructed by those living with the condition, health care providers, and the larger society.

This dissertation reflects my learning journey as a doctoral student and my unique contribution to the body of knowledge around self-management and the constitutively entangled nature of networks of diabetes practices. I have lived with diabetes for 16 years and this research represents my challenge to the notion that diabetes self-management involves distinct, separate knowledges (i.e., biomedical, psychosocial, experiential) but that all knowledges mutually constitute each other and are inseparable in diabetes management practices. Subsequently, this research also represents my challenge to continued measurement of successful diabetes self-management with narrow *outcome* measures such as HgbA1c, to the (often) neglect of other *processes* in self-management, namely the everyday practices of those who live with diabetes.

In this dissertation, I start in Chapter 1 by providing a broad outline and introduction to diabetes management and insulin pump therapy. I develop these ideas further in my literature review in Chapter 2. My goal here is to assess the state of knowledge around adapting to, living with, and managing diabetes and determine the gaps for which my research could potentially address. In Chapter 3, I describe in detail the research design and research strategies I used to answer my research questions. I outline how I addressed ethical safety and ethical challenges to my participants and how I iteratively ensured I was on the right track in my research and thus could identify potential threats to rigor as the qualitative research process unfolded.

In chapters 4 - 7, I present my findings. I have structured and presented my analytic themes to show the genealogical flow of practices from when the participants first obtained and learned to use the pump, to their intricate manipulation of the pump's features to mimic the function of their pancreas, to how they incorporated the pump into their general diabetes practices of monitoring and planning for, as well as mitigating glucose fluctuations. I have endeavoured to link my findings to the literature throughout these four chapters as identifying dominant and counter discourses was my primary goal. Then, in Chapter 8, I conclude by considering a range of recommendations for nursing and diabetes management practice, policy, education, and research. First, I introduce you, the Reader, to the world of diabetes and using an insulin pump to manage.

## Approaches to Diabetes Management

Diabetes is a rapidly growing global health phenomenon with a significant proportion of the world's population either diagnosed with this disease or at risk (World Health Organization, 2016). While there is a significant body of literature acknowledging diabetes as a physiological entity with management aimed at delaying or preventing the onset and severity of physiological complications (Collins et al., 2009; Lippa & Klein, 2008; Nathan, 2014; Norris et al., 2002), clinicians and researchers have historically and increasingly acknowledged the social constructions of illness (Arduser, 2017; Bury, 1991; Conrad & Barker, 2010; Stevens, 2020; Wellard, 1998). These constructions profoundly impact and shape how diabetes is perceived and managed by individuals living with the disease, health care providers, and society in general. The focus on physiology is important, but the intricacies of living a life with diabetes extend beyond the physiology of the condition.

Currently, diabetes care is framed by contemporary notions of self-management that are based on philosophies of person-centered care, including the principles of empowerment and patient activation, autonomy and self-determinism, and self-care agency (Arduser, 2017; Epstein & Street, 2011; Slater, 2006; Tucker, 2012). In person-centered care, the focus is on mutual decision-making and the importance of context and culture instead of adherence with prescribed regimens (Cheng et al., 2018; Holmstrom & Roing, 2010; Mead & Bower, 2000; Ratner et al., 2017; Slater, 2006; Teunissen et al., 2019). Current recommendations for diabetes self-management support include a focus on psychosocial issues and not just biomedical dimensions of disease (American Diabetes Association, 2018; Diabetes Canada, 2018; Romeo & Abrahamson, 2015; Sabourin & Pursley, 2013; Young-Hyman et al., 2016). Despite these claims, there are tensions between the ideal practice(s) of blending the psychosocial and biomedical dimensions and the reality of living with and managing diabetes. Along with clinical experience, health care providers base their practice and recommendations on best available evidence (American Diabetes Association, 2018; Diabetes Canada 2018; McCrea, 2017) which is mostly informed by large-scale data that focuses on the short as well as long term effects of variations in blood glucose and subsequent risk of acute and chronic physiological complications (Nathan, 2014; Rodriguez-Gutierrez, 2019).

Ideally, individuals living with diabetes should keep blood glucose levels within certain parameters, eat certain foods, exercise regularly, monitor blood glucose, and sustain good relationships with their health care providers and attend numerous appointments with a range of health care providers (American Diabetes Association, 2018; Diabetes Canada 2018; McCrea, 2017). Increasingly, with the acknowledgement of diabetes as a complex and multidimensional condition (Arduser, 2017; Graber et al., 2010; Mol, 2008), there is an understanding that these ideal best practices are not consistently achievable for many people because of numerous individual and sociocultural factors (Hill-Briggs et al., 2021; Paterson, 2001a).

### ***The Newfoundland and Labrador (NL) Context***

In Canada, 29% of the population live with diabetes which includes Type 1 (diagnosed) and Type 2 (both diagnosed and undiagnosed) as well as prediabetes and this is expected to rise to 32% by 2030 (Diabetes Canada, 2020a). Prediabetes is a condition where blood glucose is slightly elevated higher than normal, but not high enough for a diagnosis of Type 2 diabetes (Diabetes Canada, 2020a). In NL specifically, diabetes prevalence is higher than the national numbers with 33% of the population living with either Type 1 or Type 2 (diagnosed and undiagnosed) diabetes as well as prediabetes which is estimated to increase to 37% by 2029 (Diabetes Canada, 2020b). Additionally, the median age in NL is 45.7 years, which is higher than the national average, overweight and obesity rates in adults is 39%, 22% of adults smoke, and the majority of people do not eat enough fruits or vegetables and are physically inactive, and there is a higher rural population than the national average (Diabetes Canada, 2020b). As a result, individuals living in NL are at high risk for developing Type 2 diabetes, as well as limited access to diabetes management education and support due to geographical challenges.

### ***Insulin Pump Therapy***

Advances in diabetes research and technology have led to the widespread use of Continuous Subcutaneous Insulin Infusion (CSII) or insulin pumps (McCrea, 2017). Those who utilize this technology to manage their diabetes must meet minimal expected self-management behaviours such as checking blood glucose, counting carbohydrates, and effectively use the pump to administer both basal (insulin infused constantly throughout the day) and bolus infusions (intermittent insulin to correspond with rises in blood glucose) (Groat et al., 2017; Haddadi et al., 2020; Wilmot et al., 2014). Individuals with insulin pumps problem solve and make decisions daily and often on a moment-to-moment basis within the context of living a life with diabetes. Given the inherent physical and psychological risks with using an insulin pump (Ejaz & Wilson, 2013; Shulman et al., 2012; Payk et al., 2017), problem-solving and decision-making are critical aspects of self-management. If ideal best practices are not achievable, what is it that people with insulin pumps are doing in the context of living their diabetes? What are insulin pumps are doing? How do people with insulin pumps learn the intricacies of self-management practices that suit them in the context of their personal, social, and health related contexts? Additionally, what are the normative assumptions that support or inhibit self-management practices?

## **Adapting to and Living with Diabetes**

Adapting to, managing, and living with diabetes are well represented in both historical and contemporary research literature utilizing a variety of methodologies across numerous disciplines. Major concepts explored include change to identity or sense of self, self-efficacy, adaptive processes, and individual uptake of self-management practices (Bury, 1991; Brahim, 2019; Charmaz, 1983, 1995; Hernandez, 1996; Johannsen et al., 2009; Lin et al., 2017; Oftedal, 2014; Paterson et al., 1999).

Since the early 1980s, researchers have explored the impact of chronic illness on identity. Charmaz (1983, 1995) described how a person may become lost in the context of a newly onset chronic illness diagnosis and Bury (1991) contributed to the understanding that people incur a biographical disruption following such a diagnosis. As a result of this initial and ongoing disruption to self, the individual tries to normalize the illness in terms of explanation and legitimization as much as possible such that there is limited assault to identity or sense of self (Bury, 1991). Such experiences are "…not only influenced by the social context in which the person lives, but by the nature of the symptoms, and their perception by self and others" (Bury, 1991, p. 454). The terms 'lost', and 'disruption' signify that the person is no longer the 'same' as they once were. Chronic illness adds new dimensions to the way life is experienced and therefore, a journey begins for the person that involves a process of normalization both to self and others; of becoming someone different, yet at the same time still the same.

Researchers continue to explore the impact of diabetes on a person's sense of self or identity. Johansson et al. (2009) acknowledge that despite being diagnosed with diabetes, people want to be the same person as before. Similarly, Olshansky et al. (2008) found the process of living with and managing diabetes was one of 'normalizing' lifestyle changes to minimize the changes to self or identity. More recently, Brahim (2019) calls for increased focus in research and practice on the social embeddedness of the 'self' in self-management, acknowledging the impact of diabetes management on sense of self.

Using a grounded theory approach, Hernandez (1996) characterized adapting to and living with diabetes as a staged integration process characterized by the merging of the personal self with the diabetes self where individuals developed lifeways that either facilitated or inhibited the integration process. These lifeways included an ongoing negotiation of "…selected aspects of diabetes and the diabetes regimen into the life and lifestyle of the individual, while maintaining a focus on the art of living" (Hernandez, 1996, p. 49). Within this process of integration, the style of living often deviated from rules, guidelines, and proposed regimens for diabetes care. That is, people devised strategies and methods to integrate diabetes to fit their life regardless of guidelines and regimens. Similarly, Audulv et al. (2009) suggest that self-management is an ongoing process of negotiation between various perspectives such as social needs and medical needs. This negotiation is ongoing throughout life and is not a one-time process or accomplishment. Paterson et al. (1999) goes further in describing living with diabetes as a transformational experience where the adaptation to and living with diabetes was characterized not as a sequential process, but as infinitely cyclical. These authors suggested that rather than utilizing the concept of transformation in diabetes as the peak of adaptation to illness, it should be used to understand the essential experiential processes of living with diabetes.

Individuals diagnosed with diabetes need to find a place for it in their lives. Diabetes must be integrated into the life of the person in the context of their past, present, and future lives (Due-Christensen et al., 2018). In a recent meta-analysis, Due-Christensen et al. (2018) identified five constructs associated with adaptation to a diagnosis of Type 1 diabetes in adulthood. These constructs are disruption, constructing a personal view of diabetes, reconstructing a view of self, learning to live with diabetes, and behavioral adaptations. These authors suggest that negotiating through these constructs demonstrates the conflict between a sense of self and the idealized view of how diabetes can be managed, and such perceptions may be "…. unwittingly reinforced by HCPs by setting unrealistic goals for people with T1D…" (Due-Christensen et al., 2018, p.255). This can lead to individuals lacking confidence in their ability to self-manage their disease, yet in this study, the intricacies of the learning to live with and the behavioral adaptations are still poorly described. While these authors focused on those with newly onset Type 1 diabetes, others have acknowledged the ongoing, dynamic process of adaptation and living with diabetes that occurs over the adult lifespan (Ingadottir & Halldorsdottir, 2008; Karas-Montez & Karner, 2005; Kneck et al., 2012; Mol 2002, 2008; Paterson, 2001b; Paterson et al., 1998; Thorne et al., 2003; Youngson et al., 2015).

The process of adapting to diabetes is ongoing throughout the lives of individuals as they consistently negotiate and renegotiate life with this disease. There is no endpoint of mastery, cut-off adaptation point, or a transformative point of peak adaptation (Paterson et al., 1999). As Paterson (2001b) theorizes, living with chronic illness involves ongoing shifting perspectives where illness and wellness shift from background and foreground, depending on current contextual factors in the life of the person with the disease. Within this continual, dynamic process of adaptation to and living with, a person with diabetes engages in practices in relation to managing this disease and integrating it into their life. For those who use insulin pumps, this process of continual adaptation and living with includes a delicate balance of problem-solving and decision-making, which may mean the difference between life and death (or disability). Within the boundaries drawn by this level of critical awareness, there is a life that is lived in the many interrelated contextual factors that impact the disease but are often considered outside of it.

## Practices, Networks, and Enacting Diabetes

Mol (2002) suggests that ‘doing disease’ opens several avenues for exploration in that diseases are enacted differently in different contexts and relations and thus practices. According to Nicolini (2017) practices are spatially and temporally dispersed patterns of doings and sayings that have a history, a social constituency as well as a normative dimension. Practices are performed by a social group on a regular basis so that they are kept in existence. Continued patterns of practices result in a normative sense in that there is a right and a wrong way of doing things (Nicolini, 2017).

While different enactments may be recognizable as stemming from one disease, ontologically they can be very different, occurring in different places, spaces, and time. Therefore, diabetes comes to exist in the various practices of doing diabetes and these practices depend on the contextual and relational factors within which they occur. As such, one may ask, ‘how is diabetes *done*? not with the expectation of seeking one practice or a few, but with the expectation of exploring multiple practices that are ontologically different, yet hang together. Diabetes becomes more than one but less than many (Mol, 2002). While different, such practices evoke the recognition of diabetes, and they are related through many intersecting and shifting networks.

Mol (2010) and Mol and Law (2004) suggest that a body is both enacted and acted upon, and the boundaries between the body and the outside world become blurred. Through a network lens, diabetes practices become more than what is done with or to the body but includes many other actors. According to Lower (2006), an actor is both a human and non-human entity that possesses the ability to perform action and that the ability to act does not reside in the actor but located in the relationships between the actors. Subsequently, when actors work together networks are established, which represent “…collections of actors that form, align, and entangle with each other for the purposes of accomplishing actions or tasks” (Booth et al., 2016, p. 111).

Sociomateriality is a relational and performative approach to studying phenomena and has been considered an “…onto-epistemology…” (Hultin, 2019, p.93) where knowledge is a process which cannot be separated from the practices performed to enact it. Knowledge is not obtained at a distance, but from direct material interaction and engagement with the world. As such, this approach is not concerned with a ‘being ontology’ or a world that ***is***, but a ‘becoming ontology’ or a world that is always and continuously ***in the making*** through relations of practices by various actors in networks. Sociomateriality is a blending of the social (meanings and symbols, desires, fears, cultural discourses, etc.) and the material (referring to all things in our lives whether physical or non-physical, e.g., technology or anything occurring naturally) (Oliveira de Moura & Bispo, 2019). Also known as a practice-based perspective, sociomateriality can assist researchers to think about the often-messy entanglement of human and non-human actors in everyday phenomena.

## Problem Statement

Although there is an increased focus in research and practice on the psychosocial issues related to diabetes, there is a paucity of literature that explores the minutiae of moment-to-moment problem-solving, decision-making, and overall sense-making in the context of everyday life with individuals who have diabetes, and more importantly for this dissertation, those living with insulin pumps. It remains unclear how diabetes practices both influence and are influenced by the contexts of the current person-centered care landscape of diabetes self-management support.

To support individuals living with diabetes to self-manage, it is imperative that health care providers have a better understanding of diabetes practices by those living with the disease (Hood & Duke, 2015). To do this, a critical approach was appropriate to investigate and question the status quo of diabetes self-management practices wherein the following questions were explored: What are the practices of individuals with insulin pumps? What is the rationale for and meaning of these practices? How do these practices represent the status quo in diabetes management?

## Research Questions

The research question guiding this study was: *how do individuals who live with diabetes and use an insulin pump enact diabetes?* Subsumed within this question was: *through which arrangements is diabetes enacted by individuals who use an insulin pump?*

## Significance of the Study

The overall goal of this research was to explore and begin to understand how people with insulin pumps enact diabetes against the backdrop of the current landscape of diabetes self-management within person-centered care. The results of this study may help to increase awareness by both individuals living with diabetes as well as health care providers of the contextual influences on diabetes practices and the subsequent impact on self-management. Kumagai et al. (2009) used patient narratives to teach patient-centered care to medical students and, enhance understanding of living with illness from the patient's perspective to challenge students' preconceived assumptions and beliefs. Similarly, the findings of this research add to a body of knowledge that challenges taken for granted notions and assumptions related to diabetes self-management practices, adding to nursing disciplinary knowledge, and ultimately clinical practice efforts to assist people to live with this disease.

## Insulin Pumps in Canada

In the next few sections, I will describe the technology of insulin pumps and continuous glucose monitoring systems. I have included a glossary of terms (Table 1.1) to help guide the Reader through the pragmatics of what pumps look like and how they are manipulated by the user. The first times in the findings chapters I use these terms, I have provided a link so the Reader can easily return to this glossary.

***Table 1.1: Insulin Pump Therapy: Glossary***

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| **Insulin Pump** | A mechanical device that is used to administer insulin. It is available from several companies including, but not limited to – Medtronic, Insulet (Omnipod pump) and Tandem Diabetes (the t:slim pump). It can be tethered to the body via a tube which connects the pump to the insertion site on the body or tubeless, as with the Omnipod (Minimed 670G (Medtronic) System User Guide, 2017; Omnipod User Guide, 2017; T:slim Insulin Pump User Guide, 2011). |
| **Basal Insulin** | The amount of insulin that is delivered each hour via the pump (Minimed 670G (Medtronic) System User Guide, 2017; Omnipod User Guide, 2017; T:slim Insulin Pump User Guide, 2012; Wilmot et al., 2014). |
| **Bolus Insulin** | The amount of insulin that is delivered during times of ingesting food (Minimed 670G (Medtronic) System User Guide, 2017). This is based on individualized **carbohydrate-insulin ratios,** which is the amount of insulin required per grams of carbohydrate. For example, if the ratio is 1 unit of insulin per 15 grams of carbohydrate, then the individual would require 3 units of insulin per 45 grams of carbohydrates (Minimed 670G (Medtronic) System User Guide, 2017; Omnipod User Guide, 2017; T:slim Insulin Pump User Guide, 2012; Wilmot et al., 2014). |
| **Correction Bolus** | The amount of insulin that is delivered when blood glucose is above target range (Minimed 670G (Medtronic) System User Guide, 2017). It is based on individualized insulin **sensitivity factor**, which is how much blood glucose will drop with 1 unit of insulin (Minimed 670G (Medtronic) System User Guide, 2017; Omnipod User Guide, 2017; T:slim Insulin Pump User Guide, 2012). |
| **Active Insulin ('insulin on board')** | Most insulins taking through a pump have a duration of action of approximately 4 hours. The active insulin (also known as 'insulin on board') is the amount of insulin that the pump calculates as left in the body at a certain time following the delivery of a bolus (Minimed 670G (Medtronic) System User Guide, 2017; Omnipod User Guide, 2017; T:slim Insulin Pump User Guide, 2012 ). |
| **Basal Checking** | Periodically, pump users will check their basal rates. The basal rate is supposed to keep blood glucose level in usual life conditions for the individual. As such, individuals are called upon to check these rates. And to do so, they will skip a meal and check their blood glucose every hour to assess changes over a 4–6-hour period (Minimed 670G (Medtronic) System User Guide, 2017; Omnipod User Guide, 2017; T:slim Insulin Pump User Guide, 2012; Wilmot et al., 2014). |
| **Extended Bolus** | An extended bolus is a bolus of insulin that is taken over a period – i.e., all the insulin dose is not delivered at once (Minimed 670G (Medtronic) System User Guide, 2017; Omnipod User Guide, 2017; T:slim Insulin Pump User Guide, 2012; Wilmot et al., 2014). Types of extended boluses include the ***dual bolus*** and ***square bolus***. |
| **Dual Bolus** | A dual bolus is one that is taken in two waves – so much of the insulin dose is taken right away and the rest is delivered over time such as 2-4 hours (Minimed 670G (Medtronic) System User Guide, 2017). This is beneficial for meals that have a high fat or protein content as fat and protein will increase blood glucose later then carbohydrates (El-Hussein et al., 2018). The ingestion of carbohydrates will affect blood glucose almost immediately, however fat and protein will cause delayed increase in blood glucose. If the bolus is taken over time, this 'extended' insulin bolus will help with the delayed increase in blood glucose. |

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|---|---|
| | With the Omnipod and t:slim systems, the term dual wave is not utilized, only '**extended bolus'** (Omnipod User Guide, 2017; T:slim Insulin Pump User Guide, 2012). |
| **Square Bolus** | A square bolus is a type of extended bolus like the dual wave bolus. The difference is that with a square bolus, the entire dose of insulin is delivered over time such as 2-4 hours. This type of bolus is recommended for periods of 'grazing' or ingesting foods over time, such as at social events (Minimed 670G (Medtronic) System User Guide, 2017). With the Omnipod and t:slim systems, the term square wave is not utilized, only '**extended bolus**' (Omnipod User Guide, 2017; T:slim Insulin Pump User Guide, 2012). |
| **Infusion Set** | An infusion set is a device that connects from the pump to the body. It includes a small cannula which is inserted under the skin and remains there for 72 hours. The cannula is attached to a tube which is connected to the pump (Minimed 670G (Medtronic) System User Guide, 2017; T:slim Insulin Pump User Guide, 2012).<br>***Note:*** for the Omnipod system there is no infusion set – there is a Pod which contains insulin and is placed on the skin. A cannula is inserted under the skin from the Pod and the infusion of insulin is controlled remotely with a PDM (Personal Diabetes Manager) (With the Omnipod system, the term dual wave is not utilized, only 'extended bolus' (Omnipod User Guide, 2017). |
| **Temporary Basal** | This is a basal setting which is more or less of the usual basal rate (Minimed 670G (Medtronic) System User Guide, 2017; Omnipod User Guide, 2017; T:slim Insulin Pump User Guide, 2012). For example, during periods of exercise when blood glucose may fall, the person may set a basal rate of 80% of the usual rate to decrease the chance of hypoglycemia. In instances where there may be higher than normal blood glucose, such as during illness, the person may increase the basal rate to 130 - 150% of the usual rate (Wilmot et al., 2014). |
| **Suspend** | This is the ability to suspend/stop insulin delivery from the pump for an amount of time. This can be done in times of hypoglycemia or before or during exercise or activity which will cause a decrease in blood glucose (Minimed 670G (Medtronic) System User Guide, 2017; Omnipod User Guide, 2017; T:slim Insulin Pump User Guide, 2012). |
| **Continuous Glucose Monitoring (CGM)** | Technology that includes a sensor and transmitter that reads interstitial glucose. This information is either sent to a pump, a receiver, or a phone (Dexcom Canada, 2021; Park & Le, 2018). |
| **Sensor** | A small device that includes a needle which is inserted under the skin and retracts to leave a small piece of wire (Dexcom Canada 2021; Minimed 670G (Medtronic) System User Guide, 2017). |
| **Transmitter** | A sensor attaches to a transmitter which through Bluetooth technology transmit glucose readings to either a pump, receiver, or phone (Minimed 670G (Medtronic) System User Guide, 2017). |
| **Dexcom** | A type of CGM system. Interfaces with and readings show up on the screen of the Tandem t:slim X2 pump model. Can be used with an external receiver or the glucose readings can be seen on a smartphone using the Dexcom app (Dexcom Canada, 2021). |
| **Freestyle Libre = Flash Monitoring System** | This is not a CGM but involves the placement of a small device on the body (usually arm). It is left in place for up to 14 days and a meter is used to scan the device to read glucose levels. It is different than the CGM in that blood glucose readings are not checked automatically and sent to a device but using a meter; individuals swipe the meter past the sensor on their skin |

| | |
|---|---|
| | (there is no pricking of the skin to obtain a blood sample) and obtain the reading on the meter (Al-Hayek et al., 2019) |
| **Carbohydrate counting (carb counting)** | The process of counting the number of carbohydrates in food to match food intake with appropriate amount of insulin (Woolley, 2019) |

### *Medtronic Insulin Pumps*

Medtronic began making medical devices in 1949 with the development of the first battery operated pacemaker and the first insulin pump was commercially available in 1983 (Medtronic, 2021). Since then, there have been several different versions of the pump with increasing ability to deliver minute dosages of insulin which can be tailored to an individual's unique insulin needs. Medtronic has developed and continues to redesign CGM devices and technology that links to their insulin pump. The premise of CGM is that there is a thin wire inserted under the skin and this stays in place for seven to ten days so that interstitial blood glucose readings are detected automatically sent to a device (insulin pump, receiver, or smart phone depending on the CGM) (Guardian Sensor (3) User Guide, 2021; Dexcom G6 User Guide, 2021).

The thin wire is attached to a sensor, which is then attached to a transmitter. Using Bluetooth technology, the sensor detects an interstitial blood glucose reading and then the transmitter sends this information to either the pump or another device, such as a cell phone. The CGM takes an interstitial reading every five minutes. This provides more information about glucose trends than a random finger blood glucose check; there is the ability to visualize trends in blood glucose patterns throughout the day. While the CGM measures interstitial glucose as opposed to capillary blood glucose, with advances in research and development, CGM readings are becoming increasingly accurate and close to blood glucose readings, resulting in claims that insulin intake can be based on CGM values (Dexcom.com, 2021).

**Figure 1.1:** ***Medtronic Insulin Pumps***

Medtronic Pump 670G model, shown with Enlite CGM transmitter with Blood Glucose value Displayed on Pump Screen, as well as linked Contour Next Blood Glucose Meter (CGM)

Medtronic Pump 630

https://www.medtronic.com/content/dam/medtronic-com/us-en/newsroom/media-resources/media-kits/diabetes-management/images/minimed-670g-lowres.jpg.thumb.319.319.png

https://www.medtronicdiabetes.com/products/minimed-630g-insulin-pump-system

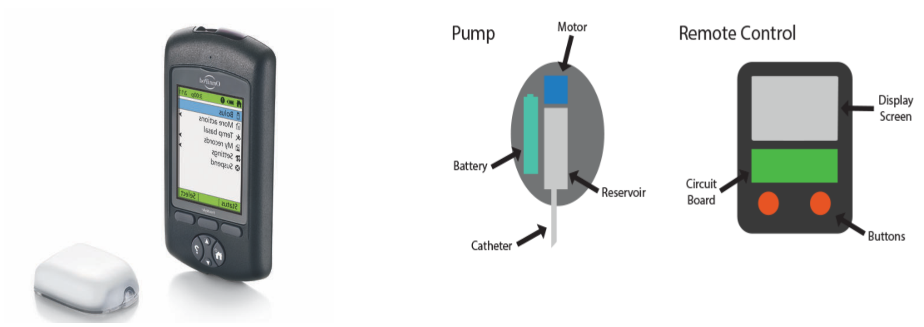
Medtronic pumps are smaller than a deck of cards and, as seen in Figure 1.1, a tube is required to connect the pump to an infusion site under the skin in subcutaneous tissue; there is a cannula and tube attaching the person to the pump and this tubing is usually around 58.4 cms (23 inches) long to allow for movement and attaching/clipping the pump to clothing. Currently Medtronic offers two types of pumps, the 640 and 670G. Both are very similar in terms of reservoir capacity, the ability to micro-dose, etc. as described below, however the 670G, when used with the Enlite continuous glucose monitoring (CGM) system has the capacity for ‘auto mode’ which means the ability to adjust basal insulin delivery depending on the blood glucose level as detected by the CGM. In theory, this sounds magnificent and beyond the wildest dreams for a person living with diabetes – almost a pancreas! However, this technology is not without issue and even with the 640 model which is able to suspend insulin delivery when a low blood glucose is detected by the CGM, the CGM value is not always accurate, and this results in higher than wanted blood glucose.

Medtronic recommends the person using this pump should change the infusion site every 72 hours to ensure correct absorption of insulin and avoidance of the development of lipodystrophy or the development of scar tissue (Minimed 670G (Medtronic) User Guide, 2017). The Medtronic pumps are waterproof (submersion of 3.6 meters for up to 24 hours), include an integrated CGM which will automatically suspend insulin delivery when a low blood glucose is detected, includes an LED backlit screen, is able to deliver micro doses of insulin of 0.025 units, includes the integration of a blood glucose meter (Contour Next), and the insulin reservoir can hold 300 units (or 3 mls) of insulin. The Medtronic pumps usually cost around CAD $7200.

### ***The Omnipod Insulin Pump System***

The Omnipod insulin delivery system consists of a Pod which is a small device (called a ‘patch pump ’as shown in Figure 1.2), about a third of the size of a deck of cards, and about 2.5 cm thick that is stuck on the skin. This Pod holds the insulin, which is infused through the cannula under the skin in the subcutaneous tissue. This pump does not rely on tubes but uses Bluetooth technology to control the infusion of insulin with a PDM – or Personal Diabetes Manager. This device is approximately the size of a Blackberry phone and twice as thick and it allows the user to control the Pod attached to the skin. Basal rates are programmed into the PDM and because of inputting the amount of carbohydrates, based on carbohydrate to insulin ratios, a recommended bolus amount of insulin is suggested on the pump screen. Additionally, and different to other pumps where there is manual insertion of the infusion set, after adhering the Pod to the skin and with the press of a button of the PDM, a cannula, automatically inserts itself under the skin.

**Figure 1.2: *Omnipod 'Patch-Pump' System***



https://www.myomnipod.com/en-ca/home https://www.diabetes.co.uk/insulin/how-insulin-pumps-work.html

*The Omnipod 'Patch-Pump' System* is a product of Insulet Corporation, which was founded in 2000. It was the first Omnipod pump made available in the US in 2005 (Zisser, 2010). As with the Medtronic pump, the infusion device or Pod must be changed every 72 hours (Omnipod, 2017). Unlike Medtronic however, there is no ability for CGM information to be sent to the pump, i.e., there is no CGM integration. If users of the Omnipod pump system choose to use CGM, it is a separate system. For example, Dexcom can be used, and the information sent to a Dexcom receiver (another small, hand-held device to be carried) or the information can be sent directly to a smart phone via a Dexcom app.

There are some other key differences to the Medtronic pumps. The smallest bolus for the Omnipod pump is 0.05 units, which is not as small as either of the Medtronic pumps (0.025 units), and this has implications for micro-dosing and thus the ability to fine-tune individual insulin requirements. The reservoir in the Omnipod only holds 200 units of insulin which can be problematic for some individuals who require more than this amount of insulin within the 72-hour period; if they chose this pump, they would have to change it more often than the 72-hour recommendation. Therefore, while the Omnipod itself is tubeless, the user must carry the Pod (or 'patch') stuck to their skin, the PDM device to program basal and to take boluses, as well as if they choose to use CGM such as the Dexcom a separate device (either the Dexcom receiver or cell phone) must be carried to display the blood glucose level. This system costs approximately CAD$6500 for the PDM.

### ***The Tandem T-Slim Insulin Pump***

The Tandem T-Slim is the one of the newest types of insulin pumps available in Canada. The company was founded in 2006 in San Diego, California and the first commercially available insulin pump was released in 2011 (tandemdiabetes.com, 2020). This pump is approximately the same size as the Medtronic pump however it is not as thick and has a touch screen. Recently, in 2016 the newly redeveloped t: slim X2 can interface with the Dexcom CGM and thus the results of the CGM will show on the t: slim screen and there is no need for individuals who use the Dexcom to carry another device (i.e., the receiver) or have the results visible on a smartphone via the app. Like the other pumps, the infusion set must be changed every 72 hours and like the Medtronic it has a tube. Like Medtronic, with the ability to integrate CGM technology (specifically Dexcom), this pump can suspend insulin delivery when a low blood glucose is predicted with the CGM, and this information is sent to the pump. The insulin reservoir holds 300 units of insulin, is water resistant although the company recommends that individuals can splash in water, but not dive or swim (Waltzing the Dragon.com, 2020). While the bolus dose can be the same as the Omnipod (0.05 units), the basal rate in the t:slim has a minimum rate of 0.1 units per hour, which is larger than both the Omnipod (0.05 units) and the Medtronic pump (0.025 units). Lacking the ability for micro dosing, the Tandem t:slim does not have the same capacity has the other pumps (especially Medtronic) for highly individualized insulin dosing.

**Figure 1.3:** ***Tandem t:slim Insulin Pump***

https://bionicwookiee.com/2018/08/09/tandem-cannulae-and-upgrades/

## Conclusion

In this chapter I have provided the contextual background and rationale for my study of diabetes practices by individuals who use an insulin pump in NL. I have outlined the research questions as well as the significance of the study. To provide further context for the following chapters, I have included a brief overview of three insulin pump systems which were utilized by the participants in the study. To further understanding of insulin pump technology I have included a glossary, which I will refer to throughout this dissertation by using hyperlinks. In the next chapter I will present the literature review that framed this study.

# Chapter 2: Literature Review

# Chapter 2: Literature Review

The purpose of this chapter is to provide context for this study. I will discuss how diabetes is more than a physiological disorder and will describe approaches to understanding the social construction of illness. I will then discuss insulin pump therapy, self-management, as well as person-centered care. I will also review how I conceptualized enactment, practices, and networks in relation to insulin pump therapy for this study. Ultimately, I will discuss tensions inherent in historical and contemporary research literature in relation to diabetes self-management as well as support.

## Diabetes: Not Just a Metabolic Disorder

Physiologically, diabetes is a disease of metabolic dysfunction where either the pancreas does not produce any insulin at all (Type 1), does not produce enough insulin for bodily needs and/or there is resistance of cell receptors to insulin (Type 2) (Burchum & Rosenthal, 2019). Therefore, the focus on biomedical and physiological approaches to managing diabetes is not only warranted but is essential to remain alive. However, this biomedical focus is only one piece of diabetes management, which occurs in the contextual intricacies of life (Ferzacca, 2000). Diabetes simultaneously involves and impacts all aspects of the person's life, including work, school, holidays, sickness, sadness, happiness, etc. For the person living with diabetes, a state of heightened vigilance and bio-psychosocial self-awareness is warranted because of the need for constant monitoring of blood glucose, bodily awareness and responsiveness, and overall management of the disease. Indeed, there are few chronic illnesses that require such a heightened state of bodily surveillance and awareness, and this requirement increases for those using insulin pump therapy (Fairchild, 2015).

## Insulin Pump Therapy

There are many medications and therapies utilized to manage diabetes, but for Type 1, the only treatment is the injection of exogenous insulin. Insulin is currently only available parenterally and cannot be taken orally as it is destroyed by gastric enzymes (Burchum & Rosenthal, 2019). Since insulin became commercially available in the early 1920s (Allen, 2003), ongoing research and development have culminated in the widespread use of Continuous Subcutaneous Insulin Infusion (CSII), or insulin pumps. Globally, more than 1 million people living with diabetes use an insulin pump and this has increased from 130,000 people in 2002 (McCrea, 2017). Type 2 diabetes may be treated with oral medications (Burchum & Rosenthal, 2019) however, increasingly, more individuals living with Type 2 diabetes are using insulin and many who require intensive insulin therapy utilize an insulin pump (Dicembrini et al., 2019; Farid et al., 2013; Ghazanfar et al., 2016; Reznik et al., 2014).

In the 1960s the first insulin pump was developed and was based on the idea of a closed loop system, where an intravenous (IV) catheter was inserted to measure blood glucose and then respond by automatically injecting insulin in a catheter placed in subcutaneous tissue (Ejaz & Wilson, 2013). These first pumps were exceptionally large and cumbersome and there was an increased risk of infection with the indwelling IV catheters. Since the 1960s, there has been significant research and development with open loop systems, where the insulin pump is attached to subcutaneous tissue and insulin is delivered from the pump to the tissue via plastic tubing. With a pump, some insulin is delivered every hour (basal insulin) and more insulin is injected (bolus insulin) to counter the effects of rising blood glucose with the ingestion of food, the occurrence of stressful events, and so forth (Bode et al., 2002; Ejaz & Wilson, 2013; McAdams & Rizvi, 2016). The individual checks their blood glucose and enters this value in the pump.

Then, based on program details related to individualized carbohydrate-insulin ratios, and the current life events of the individual (stress, sickness, etc.) an amount of insulin to be taken will be displayed on the pump screen based on previously inputted individualized parameters (Bode et al., 2002; Ejaz & Wilson, 2013; McAdams & Rizvi, 2016). There is continued research and development on a closed loop system once again, most notably in the development of an artificial pancreas (Benhamou & Reznik, 2020; Ejaz & Wilson, 2013).

From a disease perspective, individuals who have an elevated glycosylated haemoglobin or HgbA1c (which measures the average blood glucose over a period of approximately 120 days) (El-Hussein et al., 2018), hypoglycaemia unawareness, recurrent or unpredictable hypoglycaemia, nocturnal hypoglycaemia, as well as other issues that may present difficult glycemic management may be suitable for pump therapy (McCrea, 2017). Regardless of the physiological need for a pump, an individual must be highly motivated and willing to engage in self-management practices such as checking blood glucose levels several times a day, attending diabetes appointments with health care providers, and willing to learn insulin pharmacokinetics, pharmacodynamics, and pump technology, as well as carbohydrate counting (McAdams & Rizvi, 2016; Bode, Tamborlane & Davidson, 2002; Didangelos & Iliadis, 2011; McCrea, 2017). While an insulin pump is considered an advancement in diabetes self-management, using it requires an enhanced level of self-monitoring and vigilance, effectively increasing the type as well as frequency of diabetes practices.

## Self-Care, Self-Management, and Self-Monitoring

A consensual definition of self-care has not been reached and many definitions exist (Jones et al., 2011; Jaarsma et al., 2020; Wilkinson & Whitehead, 2009). Omisakin and Ncama (2011) define self-care as individual responsibilities for healthy lifestyle behaviors needed for human development and functioning as well as the activities required to care for health conditions. Similarly, Kennedy et al. (2007) propose that self-care includes actions by individuals for a healthy lifestyle to meet their social, emotional, and psychological needs, to care for chronic conditions, and to prevent illness. Other definitions include processes that permit people to take initiative, responsibility, and function effectively to develop their own potential for health (Norris, 1979), and activities that individuals participate in to live productively (Agthoven & Plomp, 1989). Further, Kickbusch (1989) described self-care as a social behavior and human agency required to engage in this behavior is subject to boundaries through structures that are both enabling as well as constraining and meaning is established within wider social structures such as the health care systems and people themselves. Inherent in these definitions are practices based on the notions of a self-governing, autonomous being as well as normative definitions of health.

Self-care involves activities such as monitoring, assessing, and supporting life processes, therapeutic and corrective self-care, prevention of disease, and specifying health needs and care requirements (Norris, 1979). Self-care can be divided into three areas: symptom-related self-care for acute problems, symptom related care for chronic problems, and asymptomatic related care involving alteration of lifestyle and risk factors (Green & Moore, 1980). Within the context of living a life with diabetes, these activities of self-care constitute self-management practices.

Self-care and self-management are often used interchangeably or synonymously in the literature, yet there are differences. Self-care is a broad concept denoting any activity involved in the care of the self. Self-management is embedded within self-care and includes partnering with others (health care providers, family, communities, health care systems, etc.) in holistic self-care of chronic diseases (Lorig & Holman, 2003; Omisakin & Ncama, 2011; Wilkinson & Whitehead, 2009). Also inherent in self-management is self-monitoring that is composed of two components: awareness of bodily symptoms, sensations, etc., and measurements, recordings, and observations that provide information for independent action (Wilde & Garvin, 2007).

More recently, Jones et al. (2020) expanded the differences between self-care and self-management in terms of the nature and breadth of networks as well as the intended outcomes. They suggest that self-care involves a broad network of individuals which includes the person, and perhaps family members, friends, health care providers, and communities and the resulting outcome is prevention or maintenance. Self-management involves a more focused network of individuals of peers, family, friends, coordination of community resources, and the healthcare provider is a key collaborator (Jones et al., 2020). The resulting outcome is coping or controlling. As with previous literature, self-management exists within the more expansive concept of self-care.

Within current conceptualizations of self-management (SM), there is an increasing focus on education, practice, and research regarding self-management support (SMS). Articulated as a "…commitment to fostering a culture that creates structures, enacts policies, and offers services to reduce the impact of chronic conditions and support people's SM behaviors" (Mills et al., 2017, p. 945), SMS includes a collaborative, partnering, person-centered approach to assist people to cope with chronic illness and self-manage within their daily lives (Beck et al., 2017; Klinkner et al., 2017). Mills et al. (2017) suggest that current SMS initiatives have been hampered by several issues such as inattention to underserved and disadvantaged populations, a lack of integration between health, personal, and social domains, as well as an overemphasis on personal responsibility for health. These authors suggest an integrative framework for the provision of SMS, inclusive of the contextual factors impacting an individual's ability to self-manage. Similarly, Beck et al. (2017) and Klinkner et al. (2017) outline that person-centered approaches to SMS are imperative, highlighting the central importance of the inclusion of individual needs, priorities, values, and goals in self-management planning.

## ‘Doing’ Diabetes: A Process of Enactment

Individuals living with diabetes engage in ongoing daily monitoring of blood glucose and corresponding responses related to medication administration, eating patterns, and activity levels. During periods of acute problems, such as high or low blood glucose, they monitor and adjust their medication regimen and other (diet/activity/life events) accordingly. In general, those living with diabetes consistently practice alteration of lifestyle factors and risk mitigation. With insulin pumps in particular, individuals monitor blood glucose frequently throughout the day, monitor the device itself, respond to bodily cues (i.e., symptoms of high and low blood glucose), as well as modify their lifestyle beyond the physiological management of diabetes such as choosing which clothes to wear to attach the pump (Didangelos & Iliadis, 2011; Payk et al., 2017; Shetty & Wolpert, 2010; Todres et al., 2010).

The minimal expected self-management behaviors for those using an insulin pump to achieve glycemic control and meet targets include counting carbohydrates at least three times per day, delivering insulin boluses at least three times per day, and checking blood glucose at least four times per day (Groat et al., 2017). In their study of self-management behaviors in adults with Type 1 diabetes who use an insulin pump, Groat et al. (2017) determined significant variability in self-management behaviors and that they do not always match recommendations of health care providers. These authors call for further research into the motives and beliefs of self-management decisions to inform self-management education. More broadly, self-management education is one aspect of providing contextually relevant, person-centered SMS for people with diabetes (Beck et al., 2017; Klinkner et al., 2017; Mills et al., 2017). Thus, more than beliefs and motives are necessary, research that explores self-management practices or the 'doing' of diabetes, from motives to action, is warranted.

Diabetes practices involve daily, often moment to moment problem-solving, decision-making, and in doing so, sense-making. Decision-making in chronic disease happens in real-world contexts that are meaningful and familiar to individuals and thus is not a rational, linear process (Reigel et al., 2013). Individuals living with diabetes utilize several pieces of information (guidelines, current objective as well as subjective data, past experiences, etc.) in tailoring decision-making to their unique, individual needs at any given point in time (Jull et al., 2016; Paterson at al., 2002; Thorne et al., 2003). Decision-making and problem-solving are interconnected (Bratzke et al., 2015) and problem-solving in chronic disease includes disease-specific knowledge interfaced with past and current experiential knowledge (Hill-Briggs, 2003). A result of, and implicated in both decision-making and problem-solving, Mamykina et al. (2015) propose that sense-making in diabetes management involves the iterative processes of perceiving new knowledge, developing inferences that inform the selection of actions, and daily practices in response to new information. Sense-making involves the continual assimilation and integration of current and past knowledge to revise and refine practices. Ultimately, the interactive, iterative processes of decision-making, problem-solving, and sense-making in diabetes care are personally constructed, change over time and in various situations, are complex, and based on continually changing knowledge (Paterson et al., 2001).

As an example of interrelated diabetes practices, in treating a low blood glucose the individual with diabetes must solve a problem; the low blood glucose must come up to prevent further problems such as disorientation, fainting, and coma (Burchum & Rosenthal, 2019). There are guidelines to aid with this problem solving, such as those listed by Diabetes Canada (2018), where depending on how low a blood glucose is, the individual should treat with a certain number of fast-acting carbohydrates. In the face of solving this problem, the person must decide on a course of action, based on contextual factors. Questions the person must pose include inquiries such as how much insulin is 'active? That is, how much insulin remains in the body after the last dose of insulin? How long ago was the last injection? This requires mathematical calculations or a review of insulin pump information. Other questions the individual needs to ask include, what activities have I been doing, or do I plan to do now? How much stress/excitement/nervousness/anxiety/happiness do I have now or will encounter soon? What has worked for me in the past? Given these factors, how many carbohydrates should I need right now? All these questions contribute to a process of sense-making, or development of tacit knowledge as an individual living with diabetes. Although influenced by guidelines and recommendations, individual and contextual factors come together in the making sense of individual disease.

All these problem-solving, decision-making and sense-making practices occur in the life of an individual living with diabetes every day and essentially self-management guidelines provide just one source of information in these processes. These practices may be so mundane, so commonplace, and so every-day, that they remain invisible as diabetes management. According to Nicolini (2017) practices are "…open and spatially, temporally dispersed sets of doings and sayings organized by common understandings, teleology (ends and tasks), and rules" (p. 21). Additionally, practices may be conceptualized as regimes of mediated object-oriented performance of organized doings and sayings, which have a history, social constituency, as well as a normative dimension (Nicolini, 2012, 2017). Practices only exist to the extent that they are reproduced and are made possible because of material and discursive resources. Therefore, foregrounding the practices in exploring diabetes is not simply about what is ‘done’ or the actions, but is also about the collective social and material influences mediating the execution of those practices. Foregrounding practices attends to both what is said and done, but also more importantly, examines the rationale/background as well as the meaning of those practices as well as their embeddedness within networks or groups of practices and actors.

As social actors, individuals living with diabetes engage in various self-management practices, which vary and shift depending on past and current individual and contextual factors. Approaching this exploration of diabetes enactment by foregrounding the practices includes attention to networks and as a result, the places, spaces, and time where diabetes exists. According to Mol and Law (2004), bodies are acted upon as well as enacted and thus boundaries between within and outside the body become blurred. A focus on networks includes attending to more than the body (and other bodies), to include how sociality and materiality both influence and are influenced by the body. Therefore, as Mol (2010) suggests, actors within networks never act alone in that they are afforded their ability to act by other actors in a network. For example, for those living with diabetes who use an insulin pump, the practice of taking bolus insulin depends on the interconnectedness of the person and the pump. To take the bolus, the pump must be present, be functional, have previously pre-set insulin-carbohydrate ratios, and the person must be able to manipulate it. Both actors (person and pump) are assembled in the practice of taking insulin through a pump. Ultimately through a network lens, diabetes enactment may be considered an ‘assemblage’ or an entanglement of people, places, institutions, artifacts, discourses, values, beliefs, knowledges, etc. in time (Buse et al., 2018).

As Hunt and May (2017) articulate, with the increasing emphasis in chronic illness care on self-management, the burden of care and the work involved has shifted from the health care provider to the individual living with the disease. In those with insulin pumps, the outcomes of this work are evident in the many benefits as well as challenges of this therapy.

## Benefits and Challenges of Insulin Pump Therapy

While insulin pumps provide flexibility for people with diabetes with respect to diet, sleeping, exercise, and general eating patterns, they often require more work in terms of monitoring and vigilance then conventional therapy with multiple daily injections (Pouwer & Hermanns, 2009; Reidy et al., 2018; Saarinen at al., 2014). Physiologically, benefits of insulin pumps include lowered HgbA1c levels and blood glucose in general, less blood glucose variability, along with a lowered incidence of hypoglycemic episodes (Bode et al., 2002; Ejaz & Wilson, 2013; Fairchild, 2015, Garmo et al., 2013). However, there is a higher risk of diabetic ketoacidosis (DKA) for individuals who use an insulin pump (especially for those with Type 1 who have no endogenous insulin at all), as only rapid acting insulin is utilized, and individuals do not take any intermediate or long-acting insulin (Ejaz & Wilson, 2013). Thus, in the event of pump failure or lack of insulin delivery, the risk of DKA is greater for those who use an insulin pump as compared to those who use multiple daily injections (and use long-acting insulin) and can happen within a very short time frame. In the lack of prompt and appropriate treatment, DKA can be fatal (Burchum & Rosenthal, 2019). This risk places an increased level of vigilance on people who utilize an insulin pump.

From a lifestyle perspective, there are several benefits with insulin pumps. The use of insulin pump therapy has been associated with increased self-esteem, decreased stress, as well as better mood (Ghazanfar et al., 2016). Additionally, insulin pump therapy leads to a greater sense of diabetes control, enhanced flexibility, and freedom with respect to activity, sleeping, and eating patterns, more convenience, and greater independence (Barnard & Skinner, 2007; Grose et al., 2017; Hood & Duke, 2015; Ritholz et al., 2007; Saarinen et al., 2014).

Despite physiological and lifestyle benefits, insulin pump usage may increase the care burden in many ways (Fairchild, 2015). Using an insulin pump requires an enhanced level of vigilance and monitoring. The average cost of a pump is approximately CAD$6500 -$7000 and several Canadian provinces provide coverage for pumps until approximately age 25, with Ontario, Alberta, Yukon, Northwest Territories, and Nunavut providing provincial coverage for pumps for people of all ages (Diabetes Canada, 2021). Across Canada, all individuals who use a pump pay approximately $1400 - $4900 annually out of pocket and in NL, individuals may incur slightly more cost on average, paying $1000 - $6300 (Diabetes Canada, 2020). As such, cost may present a barrier for some, and in addition to the increased monitoring and vigilance, intensive education is needed to learn pump technology and mechanics which may not be available in all areas of the country. Therefore, accessibility may be an issue because of the cost of the pump and the requirement for enhanced education/support.

As a result of the increased risk of DKA, those who use insulin pumps must assess their glucose often throughout the day (Diabetes Canada 2018; McCrea, 2017) and travelling with several back up supplies if pump failure is necessary and can be cumbersome (Barnard & Skinner, 2008; MacNeil & Fredericks, 2015). The use of insulin pumps has been described as both a ‘shackle and a lifeline’, creating daily tensions in users from feeling subjected to empowered, dependent to autonomous, routinized to flexible, burdened to relieved, and stigmatized to normalized (Garmo et al., 2013). For some, insulin pumps are a visual reminder to self and a symbol to others of evidence of diabetes (Barnard & Skinner, 2007; Grose et al., 2017). Other drawbacks of the pump include preparing and planning for the event of pump failure, fashion challenges, skin and subcutaneous tissue discomfort and pain, as well as intimacy issues (Barnard & Skinner, 2007; Grose et al., 2017; Hood & Duke, 2015; Ritholz et al., 2007).

Several researchers have investigated the impact on psychosocial factors and quality of life in those with insulin pumps with mixed results (Barnard, Lloyd & Skinner, 2007; Didangelos & Iliadis, 2011; Grose et al., 2017; Payk et al., 2017; Shaban et al., 2017; Todres et al., 2010). Pouwer and Hermanns (2009) acknowledge that one of the goals of diabetes treatment is to enhance quality of life, yet in several studies with insulin pumps various measures of quality of life have been utilized and therefore it is difficult to draw conclusions. Nevertheless, Ritholz et al. (2007) and Shetty and Wolpert (2010) found quality of life in those using insulin pumps to be related to HgbA1c measures and patient expectations. Those with higher HgbA1c were found to have lower scores on quality of life associated with utilizing insulin pumps. These authors also found that those with higher HgbA1c viewed the pump as a miraculous cure for their diabetes, in that they expected it to make their lives easier but were disappointed to find that it was more work than their previous regimen. Conversely, Shaban et al. (2017) found that using a pump was unrelated to a change in HgbA1c but was associated with a decrease in diabetes distress (the emotional burden, stress, and worry associated with the demands of diabetes management) as well as fear of hypoglycaemia. The authors suggested that the individual may place greater value on decreasing the onerous nature of the daily management of diabetes as opposed to optimizing glucose control (Shaban et al., 2017). In living life with diabetes, the individual may place more value on decreasing the burden of management, rather than obtaining prescribed control or clinical outcomes of diabetes.

## Continuous Glucose Monitoring

With the increasingly widespread use of insulin pumps, there has been an associated increase in research, development, and utilization of continuous glucose monitoring (CGM) as well as flash monitoring systems (Slattery & Choudhary, 2017). Conventional blood glucose monitoring using capillary blood testing with a meter provides a ‘snapshot in time’ glucose level but these newer monitoring systems provide more information of glucose patterns. With CGM there is an indwelling cannula which rests in the subcutaneous tissue attached to a sensor which sends interstitial glucose readings sent to an external device every 4-10 minutes (Slattery & Choudhary, 2017). CGM also can alarm which alerts the wearer of blood glucose fluctuations outside of target range. Like CGM, flash monitoring includes a small cannula that rests in the subcutaneous tissue attached to a sensor. Unlike CGM however, there is no continuous reading of glucose values as the wearer must swipe the external device past the sensor for a reading. Additionally, there are no alarms with flash monitoring.

Both these systems offer the wearer increased surveillance ability without additional frequently painful finger sticks and increased knowledge in relation to blood glucose values and patterns. These benefits provide enhanced reconnaissance for planning practices to mitigate blood glucose fluctuations which ultimately leads to improved blood glucose stability as well as lowered HgbA1c (Brown et al., 2019; Park, & Le, 2018), however there are also limitations. Wearers often experience surveillance fatigue in that they experience too much information about their blood glucose which ultimately places the processes as well as outcomes of their diabetes practices on display (Sorgard et al., 2019). Like insulin pumps, wearing a sensor on one’s body can increase the visibility of diabetes to self as well as others and alarms can draw unwanted attention to the individual, furthering the increased visibility (Lawton et al., 2018).

Other barriers include that sensors may be painful to insert, the systems are not covered by all insurance companies and thus they can be quite costly, as well as that there is an expected slight difference between capillary blood glucose value and the CGM/flash monitoring which measures interstitial glucose as a result of the ‘lag time’ between the rate of change of blood glucose and interstitial glucose (i.e., when blood glucose is rising of falling, there may be a 4-10 minute delay of accuracy in CGM readings)  (Sorgard et al., 2019; Tumminia et al., 2015; Slattery & Choudhary, 2017). CGM readings are intended to be very close to blood glucose values, but they may not be exact. Users should expect CGM values to be within 20% of the meter value when the meter value is 4.5 mmol/L and higher (Dexcom, 2021). This slight difference along with the ability to visualize trends rise and fall, can prompt the individual to act too quickly either taking extra insulin or eating to mitigate changes in trends which can precipitate hypo/hyperglycemia (Tumminia et al., 2015).

## Increasing Use of Technology and Poorer Biomedical Outcomes

From an epidemiological perspective, there is an increasing trend in the incidence and prevalence of diabetes globally, nationally, and locally (WHO, 2020). There has also been a substantial increase in the number of people with diabetes who utilize insulin pump therapy in the self-management of their disease (McCrea, 2017). Yet, regardless of advances in diabetes research and technology, globally, people with diabetes are not meeting HgbA1c targets (McKnight et al., 2014). What is happening? Despite increasing efforts to enhance self-management support within a philosophy of person-centered care, there is limited knowledge of how diabetes is self-managed or practiced in the complexities of everyday life (Due-Christensen et al., 2018). Diabetes research and clinical practice needs to focus on the practical knowledge of diabetes, rather than mainly on the technical (Paterson et al., 1999). In drawing attention to the rhetoric of agency in diabetes care, Arduser (2017) suggests an increased focus on the ‘work’ associated with diabetes. Arduser (2017) questions the linearity of the acquisition of agency in diabetes management - first a person must acquire specialized knowledge (episteme) and then the skill (techne) can be practiced. Primacy in evidenced-based practice is given to epistemic knowledge (Arduser, 2017) and there is limited information of the dynamic interplay between evidenced-based guidelines and subsequent recommendations and the tacit knowledge in the everyday decision-making, problem-solving, and sense-making in diabetes self-management. Using glycemic targets as measures of successful self-management presents only one view of a complex picture.

### ***Limitations of the Biomedical Model in Understanding Diabetes Practices***

Since the 1970s health care policy makers, researchers, and practitioners have articulated that health is not merely the absence of disease and includes influencing factors such as lifestyle and environment (Engel, 1989; Lalonde, 1974). Engel (1989) described the biomedical model as becoming our folk model in Western health care, one that represents our culturally specific views about health and health care. Engel (1989) further outlined how the reductionistic, dualistic biomedical model evolved from the Enlightenment, with a focus on predictability and clear ‘factual’ markers of alteration in human anatomy. Drawing on Engel’s work, Hewa and Hetherington (1995) posit that the biomedical model in essence alienates the human spirit from the context of health and illness.

Despite current attention placed on incorporating psychosocial and spiritual issues in diabetes self-management support, the success of diabetes education, behaviour and lifestyle change is overwhelmingly measured with changes in biomedical markers measuring glycemic targets (Furler et al., 2008; Krug, 2016; Lippa & Klein, 2008; Parsian & Dunning, 2009;

Unantenne et al., 2013). Ferzacca (2000, 2012) suggests diabetes care practices are developed within the context of culture and that this cultural milieu is representative of the dominance of the biomedical model. Researchers and clinicians need to focus on the embodied life with diabetes in the context in which it is lived and the practicalities of everyday life (Gomersall et al., 2012; Nagelkerk et al., 2006). Therefore, research that questions how individuals with diabetes take up, resist, or conform to normative knowledge(s) is warranted.

Storni (2013, 2015) suggests that a focus on the biomedical model is not enough in research and practice related to diabetes and there is a need to enhance diversity of diabetes knowledge. Basnyat (2011) and Bury (2002) acknowledge that attention to cultural contexts is required to understand how people construct health and thus practices to maintain and/or restore it. Diabetes and subsequent self-management practices are as socially constructed as much as they are a physiological disease and response. Given its' contextual influences, one cannot study behaviour related to illness or self-management practices outside of the context in which it occurs (Maller, 2015).

## Social Constructions of Illness

The meaning of illness is deeply woven into the fabric of society. Such meanings impact "…the way illness is experienced, how the illness is depicted, the social response to the illness, and what policies are created concerning the illness" (Conrad & Barker, 2010, p. S69). Wellard (1998) contends that there is an overwhelming focus on biomedical approaches to illness, which emphasize key societal health-related values of individualization and normalization. In Western societies we value individualization, holding in high regard individual interests over collective interests. With these values, however, comes an obligation, the need to demonstrate responsibility for individual actions and conform to expectations of society (Galvin, 2002;

Wellard, 1998). There is a moral imperative to live a healthy life, and this is expressed by health authorities, media, and by the general public (Ljungdalh, 2013). In diabetes, there is an expectation to conform to standards (i.e., blood glucose and HgbA1c, diet, and activity parameters) as set by health care systems and society in general, which may or may not be realistically achievable for individuals.

For chronic illness in general, the individual feels pressure to conform to be ‘normal’ in the sense that diabetes is outside the ‘norm’ as this relates to the moral imperative to be ‘healthy’. To practice otherwise can be viewed as unmotivated, ignorant, in denial, unaware, useless, or careless (Ljungdalh, 2013). Diabetes practices have been associated with moral discourse of ‘good and bad’ and poor self-management has been related to lack of understanding and other issues related to personal responsibility.

Normalization as described above is a measure of defining the boundaries between health and illness. Once thought of as linear (Wellard, 1998), the chronic illness trajectory has been acknowledged as a shifting pattern of attention to illness and wellness (Paterson, 2001b). Individuals living with diabetes structure the personal meaning of their disease and management decisions within the context of home and family life and their responsibilities (Asbring, 2001; Mendenhall et al., 2016). Similarly, Townsend et al. (2006) discussed the moral work of diabetes management and that people often describe what they ‘should’ do to manage in the context of how this management affects their families. For example, individuals will more so consider how diabetes affected family meals (content and timing) as opposed to how the meal affected their blood glucose (Townsend et al., 2006). Thus, diabetes practices are not solely the domain of the individual but are situated in social relationships.

The meaning of illness, rooted in societal norms, impacts the experience of illness as well as the social response to it (Conrad & Barker, 2010). Despite this, the care of illness is entrenched within a biomedical model that favors the mechanics and physiology of disease and there is a need to explore disease within the context of the chronic illness experience (Paterson et al., 2006) as the medical experience is social and needs to be understood in this context (Martin & Peterson, 2009). Yet, consistent with neoliberal notions of health and illness, people may be blamed for their diabetes and choice of practices (Barnett & Bagshaw, 2020; Crawshaw, 2012; Deering, 2016; Galvin 2002) with limited attention to sociocultural contexts. This has implications for the provision of diabetes self-management support and leads to tensions in patient-provider relationships.

Many health care providers focus foremost on the disease, while people with diabetes focus more on the life with the disease and not just on the disease itself (Jallinoja et al., 2007). McDonald et al., (1999) argue the mandate of nurses in diabetes care is to increase patient and family knowledge of appropriate lifestyle modifications to ensure blood glucose remained within parameters to delay or prevent complications; this was their ‘job’. Similarly, Gillibrand et al. (2004) found that nurses felt maintaining the health and well-being of patients with diabetes was integral to their scope and performing physical monitoring tasks were the most important aspect of diabetes care. As offered most recently by Duprez et al. (2020), nurses frequently align their perceptions of successful self-management support with biomedical glycemic markers which often leads to disillusionment and ethical conflicts for the nurse, and blame for the person living with diabetes.

People living with diabetes are often blamed and blame themselves for their illness as well as for lack of control stemming from poor management. Barriers to diabetes management have been regarded as the result of the patient more so than the system (Jansink et al., 2010) and often, it is the patients that are perceived as ‘unwilling’ to change (Abdulhadi et al., 2013; Jallinoja et al., 2007). This has implications for discourse related to and implementation of health promotion models and education in diabetes care, and subsequently how people with diabetes self-manage. The different foci for health care providers and individuals with diabetes may potentially lead to a dichotomous sense of caring for the physical aspects of the disease and the everyday practicalities of living with diabetes.

## Moral Discourse in Diabetes Self-Management Practices

Discourses linking the maintenance of a healthy body with self-worth are prevalent with diabetes as good management is assumed to be within personal control (Miewald, 1997). Self-management behaviors in chronic illness have been associated with moral discourse of ‘good and bad’ and poor self-management has been related to lack of understanding and other issues related to personal responsibility. Chronic illness clashes with notions of the ‘good’ citizen as health and illness are set up as measures of personal responsibility (Ferzacca, 2012; Galvin, 2002; Mol, 2002).

Since the 1970s, there has been a rise in health promotion discourse along with a rise of personal responsibility for health (Galvin, 2002). Health has become the ideal value in society, and people are personally responsible for maintaining and enhancing their health (Crawford, 2006; Crawshaw, 2012; Snelling 2012). Responsibility for self and health is an aspect of neoliberal rationality emphasizing the role of the individual who has the freedom to choose from available resources with the aim of self-discipline to achieve the idealized health state (Barnett & Bagshaw, 2020). To assist people with diabetes to achieve this idealized health state, self-management support is framed within the philosophy of person-centered care, which includes a focus on empowerment, self-care agency, and the patient-provider collaboration. Despite increasing attention to the values of autonomy and self-determinism within these areas, there are questionable tensions with their expression in self-management practices by individuals living with the disease and validation by those who support them. In the next sections I will explore and examine person-centered care including the inherent principles of empowerment, autonomy and self-determinism, and self-care agency, as well as the evolution of the patient-provider relationship.

## Person-Centered Care

Acknowledging patients as unique living beings and as ‘people’ first, Epstein and Street (2011) suggest that patient-centered care refers to knowing patients as persons in their social worlds, listening to and respecting them, as well as honoring their wishes. This has implications for the relationship between patient and provider and includes mutual decision-making, sharing of power, and collaborative development of diabetes self-management goals. As Mead and Bower (2000) found, there are five aspects of provider-patient relationships that are considered patient centered. These include a focus on the biopsychosocial perspective, the ‘patient’ as a person, sharing of power and responsibility, focusing on the therapeutic alliance, and considering the doctor/provider as a person. A person-centered perspective includes more than the biomedical model of disease with a focus on the collaborative nature of the interaction between provider and patient as people first.

In a review addressing the beneficial outcomes of a person-centered approach, Michie et al. (2003) acknowledged that patient-centered care could be divided into two categories of provider behaviors: taking the patient’s perspective (eliciting the patient’s beliefs and responding to them) and ‘activating’ the patient (the patient actively taking control). Activating the patient was considered more effective in fostering good physical outcomes, although there was no difference between the two styles with respect to patient adherence. These authors further contend that the patient activation style may encourage patients to develop their own goals and plans for achieving them. Similarly, Hibbard and Mahoney (2010) articulate that increasing patient activation can positively influence an individual's self-concept, which is conceptualized as integral to successful implementation of self-management strategies.

Weinger et al. (2016) and Romeo and Abrahamson (2015) argue that the person must be at the center of diabetes care with a focus on psychosocial issues and health and wellness to identify and understand the key challenges and mitigating factors in a person's life with diabetes. Likewise, Tucker (2012) acknowledges how managing hyperglycemia in Type 2 diabetes requires person-centered care to address context-specific factors affecting a person's ability to manage their disease. Person-centered care has been associated with improvements in diet, self-care practices, as well as quality of life, but not with improvements in HgbA1c (Cheng et al., 2018; Ratner et al., 2017; Williams et al., 2016). While person-centered care does result in enhanced diabetes self-care practices, sustained self-management support over time within the philosophy of person-centered care is warranted to exert an effect on glycemic control (Cheng et al., 2018; Williams et al., 2016).

The implementation of person-centered care in contemporary diabetes self-management support is not without issue. Given its focus on individualizing care, a person-centered approach seems to be at odds with an evidenced-informed approach, which tends to focus on populations (Epstein & Street, 2011). An evidenced-informed approach is what frames key guidelines and recommendations in diabetes care (American Diabetes Association, 2018; Diabetes Canada, 2018). Bolster and Manias (2010) posit that despite a patient-centered philosophy, what nurses say and what they do can be different considering sociocultural contexts and organizational climates. Similarly, Sharp et al. (2017) articulate how nurses are constrained in the implementation of patient-centered care due to organizational constraints including a focus on efficiency. Despite espousing person-centered care as a philosophy within which to frame self-management support, it is difficult to articulate in practice.

### ***Empowerment***

Funnell and Anderson (2004) argue that a regimen cannot be prescribed into the life of the individual with diabetes. A person living with diabetes is required to critically think, make decisions, and solve problems throughout life. Therefore, attending to a prescribed regimen is theoretically not possible for most people with diabetes. Patients are in control of their day-to-day management and therefore a plan needs to fit with the patient's goals. Health care providers must consider that people living with diabetes have the right and responsibility to manage their diabetes that is best suited within the context and culture of their lives (Funnell & Anderson, 2004).

Empowerment is not a tool or a technique but is an overall vision of care that should guide each clinical encounter (Funnell & Anderson, 2004; Kennedy et al., 2007). Empowerment is a person-centered collaborative approach tailored to match the fundamental aspects of diabetes self-care and is defined as helping patients to discover and develop their own capacity or agency to be responsible for one's life (Funnell & Anderson, 2004). One of the fundamental principles of empowerment is that only 2% of diabetes care occurs in clinical encounters with providers and people are responsible for the other 98% (Anderson & Funnell, 2010). Therefore, patients need to be empowered to enhance their capacity or agency to make their own diabetes care decisions.

There are problems with the way that empowerment is employed in diabetes care (Anderson & Funnell, 2010). It is not about how compliant people are with prescribed regimens, yet this is how empowerment gets translated in care. Empowerment does not fit with how many health care providers are educated within the traditional or biomedical model of care (Funnell & Anderson, 2004). Despite a focus on enhancing agency, the experiential knowledge of people with diabetes is often undervalued. Paterson (2001a) theorizes that empowerment was/is a myth as health care providers contradicted the stated goal of empowerment in interactions with clients. In this study, participants felt that providers frequently discounted their experiential knowledge. Unfortunately, researchers continue to find similar results, as Storni (2013) also reported that lay knowledge is sometimes thought of as inferior, with biomedical knowledge being the normative knowledge in diabetes care. Problematically, self-care and empowerment remain embedded in the biomedical discourse of diabetes (Storni, 2015) with continued measurement of success based primarily on meeting glycemic targets (Duprez et al., 2020; Westen et al., 2019; Williams et al., 2016).

### *Autonomy and Self-Determinism*

Referring to the ability to be self-governing or to self-rule, autonomy is a core concept of self-determinism or the ability to determine self-governing actions (Lam, 2014; Tengland, 2016; Williamson, 2014). Gibert et al. (2017) suggest that patient activation may lead to decreased autonomy for some patients. This may be so if health care providers adopt a narrow view of what it means to respect autonomy (i.e., autonomous only in the ability to follow guidelines and plans) and if patient activation requires patients to behave in way(s) that corresponds with a value they may not hold, such as the meaning of good health. To be autonomous and self-determining involves the ability to make choices and Mol (2008) submits that choice may be a problematic concept in diabetes practices. People living with diabetes are presented with a myriad of choices regarding testing blood glucose, how to deliver insulin, different types of insulin and oral medications, etc. These choices occur in the life of people with diabetes and contextual factors may prevent people from attending to these choices and in many ways, contextual factors create more choices. Mol (2008) contends that a life with diabetes is not as simple in that correct choices made at certain points will not inevitably lead to optimal control.

Howard and Ceci (2013) problematized the concept of choice in their review of health coaching for chronic illness management. Health coaching is more than training physical bodies, but also includes the interplay between knowledge, skills, competencies, and social relations. In contemporary health care, health coaching focuses on empowering individuals to "…identify how they can use health information to achieve their goals to best manage their illness…" (Howard & Ceci, 2013, p. 225) in the quest for good outcomes. This quest inherently fosters juxtaposed allegiances for people with chronic illness: their commitment to quality of life and obligations for disease management and the desire to live well with a chronic illness, which may not represent the same things. Choices people make that affect their health, also affect their social relations as well as relations with the health care system (Howard & Ceci, 2013) signifying the interconnectedness and contextuality of choices within chronic illness. Diabetes does not exist in isolation, but in the context of life. Choices made with respect to managing diabetes and the agency involved in making such choices affect other aspects of life. Choices enable and constrain agency and agency enables and constrains choices.

### ***Self-Care Agency***

Arduser (2017) defines self-care agency as the actions that a person with diabetes takes outside of the clinical encounter in the daily management to control blood glucose levels. These actions include problem-solving, decision-making, and sense-making in the context of living a life within moral discourses and expectations of what it means to stay ‘well’ as a person with diabetes (Hunt & May, 2017; Jull et al., 2016). According to Arduser (2017), this work involves plasticity, liminality, and multiplicity. People with diabetes engage in bodily plasticity as they constantly manipulate their bodies and the technologies they use (such as insulin pumps, blood glucose meters, and CGM) to make their bodies function ‘normally’ in the absence of endogenous insulin. In essence, people with diabetes take on the practices of an internal organ, the pancreas. This bodily plasticity is rhetorical in that people with diabetes constantly shift identities and subjectivities in relation to diverse social situations (Arduser, 2017). Thus, diabetes practices are shifted and shaped dependent upon numerous contextual factors.

Arduser (2017) uses the term liminality to describe a state of ‘between’ that characterizes the state of the work of diabetes. The practices undertaken by people living with diabetes such as checking blood glucose, adjusting pump settings, monitoring eating patterns are part of an ongoing process of existing not ‘here or there’, signifying a continuous attempt to avoid complications and live a meaningful life. Individuals living with diabetes consistently live between various places and spaces of health and well-being.

Inclusive of the concepts of plasticity and liminality, the nature of chronic illness such as diabetes lends itself to multiplicity (Arduser, 2017). Drawing on Mol (2002), the enacted practices of diabetes are multiple and produce different realities (Arduser, 2017). Mol (2002) argues that in the practice, or in the doing, a disease may be many as various practices evoke different, yet often recognizable to each other, diseases. Mol (2002) and Mol and Law (1994; 2004) acknowledge that disease is multiple, in that it exists in many spaces and places and not solely in the biomedical patterns and markers assigned to it. Diabetes does not only exist in the evaluation of glycemic targets. Yet, problematically, Wilson et al. (2006) found that biomedical markers, such as glycosylated hemoglobin (or HgbA1c), were a key criterion in nurses trusting patients as agents of self-care. Self-care agency was thus equated to physiological outcomes. Further, Broom and Whittaker (2004) found that a moral discourse of control within patient-provider relationships decreases the agency needed for self-management. Within this discourse, participants acknowledged feeling like disobedient children when they stepped outside of prescribed regimens which decreased their sense of agency. Thus, while conceptually, scholars continue to rely on the centrality of self-care agency, the practices of self-management support would frequently appear to undermine the actions and decisions of pump users. Therefore, research is needed to explore how people living with insulin pumps enact this self-care agency and how perceived and unperceived social structures highlight some discourses and silence others.

In sum, the principles of empowerment, autonomy and self-determinism, and self-care agency are fostered within a person-centered care approach to diabetes self-management. A focus on these principles has not always been evident in the patient-provider relationship and in the following section, I briefly outline the historical evolution of the patient-provider relationship from notions of compliance to patient activation.

### *Evolution of the Patient/Provider Relationship*

Collaboration, mutual decision-making, and equality are increasingly recognized as key to providing support for diabetes self-management practices, but this has not always been the case. Compliance can be defined as the extent to which patients follow prescribed regimens (Chatterjee, 2006; Poupoulos, 2015) and as such, is a paradigm that coincides with the biomedical model and limited expressions of agency in diabetes practices (Arduser, 2017). There has been (and continues to be) research about compliance, most notably with chronic diseases where as many as 50% of patients are deemed to be ‘non-compliant’ (Cameron, 1996; Chatterjee, 2006, Cohen et al., 2012; Wilson & Symphoria, 2016). Rationale provided for the importance of compliance is related to issues of ‘diabetes control’ in terms of numbers (lowered glucose leads to lowered risk of physical complications) and benefits for the health care systems such as lowered costs (Chatterjee, 2006; Collins et al., 2009; Murphy & Canales, 2001). A lack of compliance was/is more so associated with the results of an individual’s self-management practices rather than the practices themselves. Indeed, Greene (2004) suggests that the use of the term ‘non-compliant’ corresponded with a rise in the questioning of medical authority and neoliberalism and as such, a means to shift the blame for treatment failure to the patient.

Envisioned as different from compliance, adherence emphasizes patient and clinician collaboration in decisions, rather than conveying obedience to a prescribed regimen (Chatterjee, 2006). In this manner, people living with diabetes are more involved with decision making in the development of self-management plans. Schwartz et al. (2017) suggest that to enhance adherence within a person-centered care approach, health care providers should focus less time on talking about disease management with the assumption that patients lack understanding but focus more on what is happening in the patient’s life. This may have better results in terms of fostering a sense of agency and thus positively affecting an individual’s self-management strategies than a narrow focus on adherence (Schwartz et al., 2017). Similarly, Agard et al. (2016) argue that adherence goals and outcomes for people with diabetes need to be adapted in the context of what is considered desirable and realistic for the individual.

Fundamentally different than both compliance and adherence and focusing on the consultation process rather than a specific patient behavior, concordance is about shared decision-making and in essence a sharing of power (Weiss & Britton, 2009). Concordance can lead to a more empowered patient because if their feelings have been discussed and respected there is a greater likelihood that the patient will follow the prescribed regimen (Poupoulos, 2015). Bell et al. (2007) suggest that concordance is more than compliance or adherence and does not refer to a patient's medicine-taking or regimen-following behavior, but to the nature of the interaction between provider and patient. It is based on the notion that patient and provider are equals. This sense of equality is a main value in the philosophy of patient-centered care (Epstein & Street, 2011; Slater, 2006; Williams et al., 2016).

Despite the increasing emphasis on collaboration and mutual decision making, the outcomes of when patients do not agree with and follow prescribed regimens are articulated in terms of a lack of control evidenced by biomedical markers such as blood glucose readings and HgbA1c values (Chatterjee, 2006; Funnell & Anderson, 2004; Lippa & Klein, 2008; Norris et al., 2002; Poupoulos, 2015). There is limited discussion of the person's everyday life in such measurements, and this limits self-care agency. Ingadottir and Hallsdorsdittir (2008) suggest that strict adherence or compliance to a prescribed regimen threatens autonomy and self-determinism of the individual. Thorne et al. (2000) describe this as simultaneously required to be self-reliant and compliant at the same time. This can limit ability to engage in sense-making as well as appropriate critical thinking and decision making in self-care. Effectively, people live 'in-between' these fundamental assumptions and the expected outcomes of health care providers.

The notion of strategic non-compliance, or not following a prescribed regimen or set of guidelines is in many ways a legitimate act of self-care in diabetes self-management (Anderson et al., 2017). However, when people challenge the normative discourse related to health and illness with respect to diabetes self-care, they are often labeled as non-compliant (Ferzacca, 2000). Karlsen and Bru (2002) outline how less active coping strategies (less frequent monitoring for example) could possibly indicate a lack of taking responsibility for diabetes. Thus, when challenging dominant discourse and conceptualizations of what people with diabetes should do, the act of not 'doing' is considered a lack of responsibility for disease. In developing expertise in self-management, people with diabetes will often 'let go' and not self-manage (Aujoulet et al., 2008; Paterson & Thorne, 2000). This actual process of 'letting go' of management is very much an act of self-care, as it represents a high level of decision-making, problem-solving, and critical thinking in how 'best' to manage diabetes in a certain time with a given set of circumstances. For those with insulin pumps, how individuals manage their diabetes in balance within a quality of life perspective may involve 'letting go' at times. The decision to have dessert or not, to immediately treat (or not) a high or low blood glucose, or the decision to be aggressive in management, all depend on contextual factors within the context of learned and developed tacit knowledge.

## Tensions Inherent in the Current Landscape of Diabetes Self-Management Practices

Current diabetes education, self-management support, and subsequent self-management practices are situated between contemporary and historical remnants of the evolution of models of compliance, adherence, and concordance, and the current philosophy of person-centered care. This evolution has affected self-management support that frames the expectations of what people with insulin pumps 'should do'. There are dynamic tensions in this landscape. Firstly, although conventional literature espouses that diabetes care is more than biomedicine, and that it should include psychosocial issues and be person-centered, the success of education, support, and self-management practices still are overwhelmingly measured with biomedical markers which are utilized as a proxy for 'good' diabetes self-management practices. This inherently creates a dichotomy between the disease and life with the disease and a hierarchy of knowledge. Are life and disease different entities? In the enactment of diabetes, which knowledge(s) are needed? How are different knowledges used for different aims and purposes?

Secondly, although the philosophy of person-centered care and the focus on empowerment and self-care agency are currently key frames within which diabetes self-management practices and support for such practices occur, there is still much that is unknown. It is not clear how the assumed key values of autonomy and self-determinism embedded within the aforementioned frames inform the everyday practices of navigating life with this disease which comprise the enactment of diabetes. For those with insulin pumps, this enactment inclusive of the practices of decision-making, problem-solving, and sense-making, may be so commonplace that it is invisible to self and others. To enhance the clarity of the philosophy of person-centered care, such that providers are better situated to tailor diabetes self-management support and people with diabetes are valued for their expert contributions to health care relationships, exploration of the practices comprising the enactment of diabetes is warranted.

## Conclusion

In conclusion, the current state of knowledge in diabetes self-management research and in research exploring quality of life for people living with insulin pumps is very early in its development. Thus far, most research has focused on adapting to, living with, or overall management of diabetes in general. While there has been research focusing on psychosocial issues in diabetes self-management and self-management support, there remains a significant gap of in understanding how diabetes is lived moment-to-moment and the decision-making, problem-solving, and sense-making practices by those using insulin pumps. This gap is what I intended my dissertation research to address.

In the following chapter I will outline the methods employed to explore and examine diabetes enactment by a sample of individuals living with either Type 1 or Type 2 diabetes and who use a pump to manage. Fittingly, I utilized qualitative focused ethnography (FE) drawing on strategies of critical discourse analysis (CDA) to frame my research. As a person living with diabetes and who uses a pump, these methods afforded my exploration into a phenomenon where I am so deeply familiar with my own but remain outside of the experience of others. These methods provided an opportunity to explore the diabetes practices of others and simultaneously examine my own; a necessary process as I occupied the space of insider-outsider in this research.

# Chapter 3: Methods

# Chapter 3: Methods

In the previous chapter, I presented the literature to outline the rationale for my study. In this chapter, I will now present the methods I employed to answer the research question. Specifically, I will discuss focused ethnography and critical discourse analysis as well as strategies for ensuring rigour throughout the study. I will also include a discussion on reflexivity as well as positionality and how these concepts relate specifically to this research study.

## Research Question

The aim of this research was to explore diabetes practices from the perspective of people living with diabetes who use insulin pumps. In this exploration I sought not only a description of what individuals were 'doing' in the context of diabetes self-management, but also how the intricate relationships and resources align or collide in this process of enactment. Specifically, the initial research question guiding my study was: *How do people with Type 1 diabetes who utilize insulin pumps enact diabetes?* Subsumed within this question is, *through which arrangements do people with insulin pumps enact diabetes?* During the study, this research question shifted to include not only individuals living with Type 1 diabetes, but also those with Type 2 who use an insulin pump. This expansion was informed by a continued review and engagement with the literature as well as my initial analysis, after which the focus of the study was more clearly highlighted. The type of diabetes (either Type 1 or Type 2) was not the primary focus; it was the practices in relation to diabetes self-management by those who use insulin pumps. As such, the pragmatic decision was made to also include those with Type 2 diabetes who use insulin pumps to enhance maximum variation in the phenomenon under study.

## Research Design

A qualitative approach was appropriate to answer these research questions as it would enable me as the researcher to explore and illuminate the social world which both constructs and reflects the construction of health and illness (Morse & Field, 1995). Using a critical lens, I employed focused ethnography as the method to explore how people with insulin pumps enact diabetes and the arrangements they make to do so.

### *Focused Ethnography*

Ethnographic approaches have evolved over the past 30 years and researchers are increasingly studying cultures of which they are part, or of which they have intimate knowledge. Ethnography is well suited to health and nursing research in that the focus is on the everyday interactions and wider cultural systems through the emphasis on context (Savage, 2006). Focused ethnography is an evolutionary approach within the ethnographic research tradition (Higginbottom et al., 2013). Key attributes of focused ethnography that provided the guidance for this research included: the researcher forms a part of the cultural group under study; the research deals with a distinct problem in a specific context within a sub-cultural group; the privileging of one method of data collection (in this case, experiential interviews), and the intensity of the data collection period (Barton, 2008; Cruz & Higginbottom, 2013; Knoblauch, 2005; Pink & Morgan, 2013; Wall, 2015).

### *Conceptual Framework*

To approach this research from a critical lens, I drew on the principles of Critical Social Theory. Mahon and McPherson (2014) outlined the four tenets of critical social theory integral to health research and which formed the philosophical underpinnings of this research: knowledge is not value-neutral; all social interactions involve power dynamics which shape experiences and are central areas for inquiry; power dynamics influence decisions about what knowledge is relevant, which questions are worthy of pursuit, and whose voices count; and language is the driving force behind the acquisition and dissemination of knowledge. Specifically, I drew on principles related to power/knowledge, the importance of context, and the primacy of discourse in the creation, maintenance, and evolution of diabetes self-management practices.

Boutain (1999) argues that language does not merely represent reality, but that it constitutes reality meaning that language is "…understood as being developed by people to understand the world and the world is simultaneously understood in language" (p. 3). Discourse, or language in use, involves practices through which texts are produced and consumed and contribute to the constitution of social worlds (Jorgensen & Philips, 2002). Critical social theory acknowledges that all discourse is social and social structures and interactions both produce and sustain discourse (McCloskey, 2008). In this research, I considered that the language relevant to diabetes self-management practices both produce and sustain such practices.

Power is dispersed throughout social relations and can produce and sustain behaviors and thoughts in the form of ideologies (Allen & Hardin, 2001; McCloskey, 2008; van Dijk, 1993). Drawing on the work of Foucault (Gordon, 1980), Fairclough (2013), and Mills (1997) power is not a static, oppressive entity but is fluid and productive. As a result of shifting power within social relations, what comes to be considered knowledge depends on the contextual influences of the time period. A critical approach attempts to make explicit power relationships, as they frequently remain hidden and become taken for granted ways of going about the world (Meyer, 2001). In this research, I explored the arrangements that people with insulin pumps make to enact diabetes, and the power relationships inherent in doing so.

Critical social theory has been described as an approach for critiquing existing conditions (Wilson-Thomas, 1995). In this manner, critical theory is important to nursing research because nurses need to be conscious of the constraints operating on both nurses and clients and thus affecting care practices. Sumner (2004) acknowledged that critical theory allows researchers to question extant norms, meanings, and ritualistic practices of a culture. As such, it permits the in depth questioning and exploration of the status quo. Drawing on critical theory therefore permitted my exploration into why/how diabetes practices are the way they are and the ability to question this status quo, including how those living with diabetes potentially resist, contest, conform to, or contraindicate the status quo.

I drew on Fairclough's Critical Discourse Analysis to guide the analytical process to augment the inextricable links between context, practice, and language. Fairclough occupies a specific middle range position in CDA, and his work has been termed a Dialectical-Relational Approach (Lin, 2014). He presents a systematic framework for the investigation of how discourse is mediated by broader societal implications (Meyer, 2001; Smith, 2007). Fairclough's model is three-dimensional and involves the investigation and the interplay between texts, discursive practices, and social practices (Jorgensen & Phillips, 2001). The relationships between texts and social practices are mediated through discursive practices that include the production, reproduction, and consumption of texts, and that discourse contributes to social relations and systems of knowledge and meaning (Jorgensen & Phillips, 2002; Smith, 2007). This was important to the exploration of diabetes self-management practices, as people with diabetes exist in networks (Mol, 2008) of people, places, and spaces. Self-management practices are influenced by a myriad of enabling and constraining factors within social, cultural, and historical contexts. Discourse plays a key role in how these practices are created, sustained, and how they evolve.

Therefore, an ethnographic approach with discourse analysis where the interrelationships between context, language, and practices are highlighted was warranted.

### *Setting*

As Hammersley and Atkinson (2007) note, ethnography occurs in the everyday life of people, wherever that occurs. As such, the setting for this research was anywhere that diabetes self-management practices took place. Pragmatically, the setting included anywhere in rural or urban Newfoundland; however, the majority of my 15 primary participants were from a city in Eastern NL and surrounding geographical areas. Interviews and observations took place in informants' homes, offices, my office at work, as well as via telephone.

### *Sample Selection*

My purposive sampling started with a focus on adults who lived with diabetes and employed an insulin pump to manage their blood glucose. I sought participants who were adults (over the age of 18 years), living with Type 1 or Type 2 diabetes who utilized an insulin pump, could read, and speak English (as this is my only language), and were able to speak of day-to-day diabetes care practices (please see Appendix A for Participant Information Letter and Consent Form). Time since diagnosis or since beginning to use the pump was not predetermined at the outset of the study, as I sought variation in the phenomenon.

After several initial interviews, it became clear that significant others (family members/friends) were considered integral to diabetes self-management practices. As a result, I made the decision to amend the study protocol to include this group of secondary participants so that if the participant wished, we could include family members/friends in the interviews. Two participants availed of this, as they considered their self-management practices a 'team' approach and it was not possible to discuss their management without the inclusion of their ‘team’ members.

Despite this amendment, the focus of the study was still on the participants themselves, however separate inclusion criteria were developed for family members/friends as well as a separate Participant Information Letter and Informed Consent Form (Appendix B). This was methodologically and theoretically congruent because diabetes self-management practices exist in inextricably linked networks of people, spaces, and places (Mol, 2008). The inclusion criteria for family members/friends were:

**Inclusion Criteria (Family Members/Friends).**

1. Adults (at least 18 years old)
2. Requested to participate by family member/friend who has Type 1 or Type 2 Diabetes and uses an insulin pump
3. The ability to read and speak English
4. Willing to discuss day-to-day practices diabetes care practices

**Sampling Strategies.** I employed several forms of purposive sampling to ensure information rich data in this study. In doing so, I considered the strategies that would allow me to ensure as possible the best quality of rich data in both breadth/variation and depth to enhance the rigour (Patton, 2002). As is common in ethnographic approaches, I utilized maximum variation purposive sampling to recruit participants (Jarvis et al., 2017; Roberts, 2009) who have knowledge of the phenomenon under question (Sandelowski, 1995).

Casting a wide net of recruitment posters in diverse geographic areas (urban and rural) afforded the opportunity to recruit people not only living in different areas, but with potentially varying access to supports for diabetes self-management practices and thus plausibly different experiences. I sought demographic and geographic variation, but more importantly phenomenon variation (Sandelowski, 1995). As described throughout the literature review, diabetes enactment is an ongoing process of negotiation and renegotiation with contextual factors in the person's life. Given there is no end point of mastery or a cut-off adaptation point (Paterson et al., 1999) in the exploration of diabetes enactment by those with insulin pumps, it was imperative to seek a wide variation of experiences with insulin pumps. For example, I deliberately sought participants who could speak to deciding not to wear their pumps at times (e.g., during exercise) or who were very aware they chose not to disclose their truths to their health care providers (HCP), even if they themselves understood the HCP perspective through their own health professional designation. Ultimately, maximum variation sampling enhanced the adequacy and appropriateness of the sample in terms of rich knowledge of the topic under exploration which, in turn, helped support the rigour of the study (Morse et al., 2002).

I used snowball or network sampling by asking participants to recommend other potential individuals who might be interested in participating (Richards & Morse, 2007). Four participants were recruited in this manner. To enhance the richness of the data and the quality of the data analysis, I also employed theoretical sampling (Morse & Field, 1995; Richards & Morse, 2007). In theoretical sampling, the selection of participants is guided by the emerging descriptive and theoretical analysis which is continually modified by data obtained from the next data collection event (Richards & Morse, 2007). In this study, as I employed concurrent data collection and analysis, theoretical sampling was utilized within the participant group to guide the emerging analysis. Questions and avenues for exploration were guided by the analysis of data from previous interviews and documents to further explore emerging themes and nuances in the data to question and probe deeper to enhance the richness of the data. For example, within the initial interviews and subsequent analysis, consistent monitoring, and planning for blood glucose fluctuations (either through manually checking with a glucometer, or visualizing readings from a Freestyle Libre meter or Continuous Glucose Monitoring (CGM) system) was highlighted and as such, I began to probe deeper into these practices with further initial as well as second interviews.

Throughout, I remained open to the exploration of negative cases. As described by Richards & Morse (2007), negative cases are examples of experiences that are contrary to the emerging data analysis and that provide new dimensions of exploration. Within the process of building rich data and as described later in the analysis section, attention to negative cases assisted in building the theoretical aspects of this study (Morse, 2015b). Further, in CDA, instances of negative cases can be conceptualized and understood as counter-discourses against dominant discourses, thus allowing for further exploration of power and ideology (Fairclough, 2013; Luke, 1995-1996; Meyer, 2001).

**Sample Size.** With maximum variation sampling, researchers usually decide on appropriate sample size based on which variations to focus on that will assist to achieve analytic redundancy or theoretical saturation (Sandelowski, 1995). As Morse (2000) outlined, the determination of sample size in this study could not be definitively stated at the outset. However, there were factors that I considered in estimating the sample size such as the quality of the data, the scope of the study, the amount of useful information from each participant, and the qualitative method and study design employed (Morse, 2000). My intent was to probe deeply so I required fewer participants than if I intended to conduct one-off interviews. In the end, a total of 15 participants was a pragmatic decision based on the two interview per participant plan, knowledge of the number of informants for a similar ethnographic study addressing self-management in individuals with Type 1 diabetes, as well as the possibilities for recruitment in the NL setting. Ultimately, I ceased data collection with participant 15 (plus two extra family members), as it was at this point that no new concepts emerged and there was enough thick, rich data to answer the research questions.

**Participant Recruitment.** After ethical approval in both Alberta and NL (see Appendix C), I placed recruitment posters in family practice clinics, the regional diabetes education clinic, the regional office of Diabetes Canada as well as drugstores, supermarkets, and various other community gathering locations such as malls and art theatres in a city in eastern NL as well as surrounding areas. Additionally, the regional office of Diabetes Canada placed the poster on their web as well as Facebook pages and I also shared the poster on my own Facebook page. If interested in the study, participants were invited to contact me via email or telephone.

When contacted, I explained the study, assessed eligibility as well as obtained preliminary verbal consent. Information about the study as well as consent forms were sent to participants via email and a mutually convenient time and location was determined to meet to review the information about the study, review and obtain written informed consent, and engage in the first interview.

### ***Participant Characteristics***

There were 15 participants included in this study to reach analytic redundancy; please refer to Table 3.1 for a demographic profile of the participants. Most of the sample identified as female (*n*=9), and the mean age was 47.3 years (range: 26 – 75 years). Most (*n*=14) participants indicated they had a significant other (*n*=14) with the majority of those indicating that they lived in a household with others. Most participants resided in an urban area (*n* = 11), and all participants indicated that they were currently working or had previously worked and now were retired. In addition, all participants described having some form of post-secondary education, with *n* = 6 identifying as current or former registered nurses.

Most participants lived with diabetes for a significant length of time (average 27 years, range: 3 – 42 years) as well as used an insulin pump for several years (average 10 years, range: 2 weeks – 18 years). The majority of the participants lived with Type 1 diabetes (*n* = 11), and they used different types of insulin pumps, with most using Medtronic (*n* = 11), Omnipod (*n* = 3), and Tandem t:slim (*n*=1). All the participants experienced some form of diabetes education throughout the years, however only eight (*n*= 8) participants currently sought and received regular education and support from diabetes specialists (i.e., dietitian, certified diabetes educator, internist, endocrinologist).

**Table 3.1:** ***Participants' Demographic Profile***

| **Characteristics** | | **Value** |
|---|---|---|
| **Gender** | Female | *n* = 9 |
| | Male | *n* = 6 |
| **Age** | | 47.3 years |
| | Range: | 26 – 75 years |
| **Residence** | Urban | *n* = 1 |
| | Rural | *n* = 14 |
| **Diabetes Type** | Type 1 | *n* = 11 |
| | Type 2 | *n* = 4 |
| **Length of Time Since Diagnosis** | | 27 years |
| | Range | 3 – 42 years |
| **Length of Time Using Pump** | | 10 years |
| | Range = | 2 weeks – 18 years |
| **Type of Pump** | Medtronic | *n* = 11 |
| | Omnipod | *n* = 3 |
| | Tandem t:slim | *n* = 1 |
| **Household Status** | Lives with others: | *n* = 13 |
| | Lives alone: | *n* = 2 |

### *Generation of Data*

My primary form of data were the two experiential semi-structured interviews conducted with each participant (*n*= 30). I also accessed diabetes resources as they were discussed in participant interviews. As I will discuss in this section, while I had included focused observations in the study protocol, most participants were reticent to do this and therefore there was only one example of this strategy utilized in the study.

**Interviews.** Interviews are a key data generation tool utilized in ethnography (Foley, 2002; Groenkjaer, 2002; Hammersley, 2006; Hammersley & Atkinson, 2007; Roberts, 2009). I employed a semi-structured interview format (Hammersley & Atkinson, 2007). The initial interview protocol was developed from my understanding of the literature and my own professional nursing and personal experiences as a person living with diabetes who uses a pump. Over the course of the project, the interview questions evolved as a result of analysis of the concurrently generated data.

Prior to commencing participant recruitment, I engaged in a self-interview, where I was asked the same/similar questions that I asked the informants in the study. This was a key aspect of this study as it assisted in highlighting my stance prior to beginning data generation. Further, as I went back and listened repeatedly, this self-interview served to help me identify some of the assumptions I held at the outset of the study but did not see until later. These assumptions no doubt formed the basis of some of my thinking during initial data collection and analysis. As will be described in the section on reflexivity, I would not be aware of some of these assumptions had I not began with this self-interview. In focused ethnography, the researcher often begins with a specific topic area or problem-focus (Cruz & Higginbottom, 2013; Knoblauch, 2005; Wall, 2015) and in CDA, the stance of the researcher is made known at the outset of the research (Fairclough, 2013; van Dijk, 1993). To demonstrate researcher reflexivity and clarity of interpretations, a self-interview was an integral beginning piece of this work.

I conducted two interviews with each participant; some participants (*n*=4) were contacted further via email or telephone for a short follow-up of items discussed in the interviews. In the first interview, my goal was to establish trust and rapport with the participants having disclosed that I also lived with diabetes and a pump. I initially focused on understanding their diabetes diagnosis story and then descriptive information pertaining to diabetes self-management practices. The topics of the first interview included a description of usual/typical day living with diabetes, factors involved in diabetes related decisions, as well as questions related to considerations of dependence and independence with diabetes practices (please see Appendix D for the interview protocol). Second interviews were sought to augment the richness and comprehensiveness of the data, to verify my interpretations, and to continue exploring key ideas and concepts. During the second interviews, questions were generated from the data obtained from that person's initial interview as well as other interviews and document or other artifact analysis to add to the emerging analysis. For example, questions during the second interviews included those in relation to monitoring and planning practices to mitigate blood glucose fluctuations.

As acknowledged by Read (2018), using serial interviews provided for the development of greater trust and rapport with participants and thus more candid discussions about diabetes self-management practices. For example, during a first interview the participant acknowledged being very reticent to divulge living with diabetes to others, however they indicated several times in this interview that they were 'not sure why'. In the second interview with this participant, this issue was further discussed and more clarification of the rationale for not telling others was provided. Had I not conducted a second interview this idea would have remained under-explored with this participant and others in the study. Further, having more than one interview afforded the opportunity to explore concepts and avenues that were highlighted by other participants and as such, I was able to incrementally build on previous data and in doing so, was able to explore variations in the data (Read, 2018). Additionally, second (and any subsequent) interview questions included probes and questions related to dominant self-management practices, ideologies, and knowledge(s).

Both the first and second interviews were audio-recorded. Any follow-up telephone conversations were not recorded, but detailed notes were taken and any information in email format was kept. With each participant, I began the first interview and sometimes the initial contact phone call/email with the fact that I live with Type 1 diabetes, and I also use an insulin pump. Divulging this information had both advantages and disadvantages which I will describe further in the section on reflexivity. While I felt strongly that this contributed to the development of rapport with participants, had I not divulged this information, the discussion may have been significantly different. Interactions are different with different people who may, for the participants, demonstrate a perceived similar level of understanding. While knowing that I have diabetes no doubt led to a perhaps more candid discussion, at times it led to a discussion where it was assumed that I ‘knew” what the participant meant in their dialogue. Both the participant and I often shared a common language and as such, a seemingly shared tacit understanding on the phenomena being discussed. To maximize these advantages and mitigate the disadvantages, I kept a reflective journal throughout the study as well as engaged in critical, reflective discussion with my supervisor regarding my assumptions and interpretations of the data. Over time, I became accustomed to asking participants to explain not what something meant (such as carbohydrate counting or bolusing insulin prior to a meal), but what it meant *specifically for them* i.e. I explored *their* specific practices with respect to that particular phenomenon.

At the end of each interview, I wrote debriefing notes. I started by providing the overall ‘picture’ of the participant and their main messages. I reflected on the flow of the conversation and my own interviewing skills. When I started interviewing, I regularly reviewed my transcripts with my supervisor to imagine alternative ways of questioning and following up with probes. This critical reflection allowed me to refine my interviewing skills in determining opportunities for deeper probing, how my questioning influenced participant’s answers, as well as identifying concepts for further exploration in subsequent interviews.

**Observations.** Participant observation is a key data generation method in ethnographic studies (Foley, 2002; Groenkjaer, 2002; Hammersley, 2006; Hammersley & Atkinson, 2007; Roberts, 2009). Roberts (2009) outlines that the researcher is the main tool of data generation and in focused ethnography, the researcher forms part of the sub-culture under study (Knoblauch, 2005; Wall, 2015). As a person with Type 1 diabetes who uses an insulin pump, I formed part of the sub-culture of interest in this study and therefore I was a participant observer.

In an ethnographic study, the type of observation that is utilized depends on the purpose and aim of the research (Hammersley & Atkinson, 2007). The goal of using observation in this study was to explore and examine the interplay between what informants divulge in their interviews and what they do. Part of this research was to examine the normative assumptions and practices associated with diabetes self-management in those with diabetes who use an insulin pump. As outlined by Draper (2015) ethnography is “…concerned with taken-for-granted things, things that are so “automatic’ that we perhaps fail to realize their effect on our individual and societal or collective experience” (p. 38). Specifically, in this research, I aimed to explore taken for granted notions and assumptions in everyday diabetes self-management practices. The exploration of diabetes enactment included focusing on those activities that have become so mundane, so ‘everyday’, that they may be so automatic that their purpose and meaning are unrecognized.

While I planned to engage in focused observations outside of the interviews and most participants (*n*=12) agreed to the possibility in signing the consent form, all except one participant were reticent to meeting outside the interview. Therefore, my observations in this study took place during the interviews except for one instance where I had the opportunity to watch a participant change her Omnipod infusion site. I observed diabetes self-management practices during interviews (e.g., checking blood sugars) and these observations were recorded in detail in my field notes as well as reflection journal. Questions I addressed included: Did the informant wear a continuous glucose sensor, and did it alarm for a high or low sugar? How did they respond to any alarms? Did my CGM alarm and how did I respond? What was the ensuing conversation after any response? Did the informant check his or her pump? Did the informant assess their blood sugar during the interview? Did I?

In these observations, I was looking to explore instances of problem solving and decision making in the context of everyday happenings, such as within a conversation with another. In many of the interviews, there were beverages or food involved as the participant often had a coffee or snack during the interview. Both my field notes as well as reflective journaling formed part of the textual analysis, as well as analysis of discursive and social practices.

**Documents and Artifacts.** Documents and other artifacts contribute useful pieces of data in ethnographic research (Carspecken, 1996; Hammersley & Atkinson, 2007). In this research I analyzed formal and informal documents as they were identified as important by the participants in diabetes self-management practices. Formal documents included guidelines such as those by Diabetes Canada for diabetes management as well as documents related to carbohydrate counting. Informal documents included other sources of information used by participants such as Internet websites or blogs, advice from friends, You Tube videos, and pump brochures and online advertising. Throughout the interviews I asked the participant questions related to these documents and how they were used in decision-making and problem solving in self-managing their diabetes. These data were recorded as field notes and along with the documents, formed part of the textual analysis.

Hammersley & Atkinson (2007) describe material artifacts as integral to ethnographic work as such artifacts are "…integral to the organization of social life" (p.137). In this study of diabetes self-management practices, material artifacts included food scales, measuring cups, small plastic bags to hold candies, blood glucose meters, insulin delivery systems (needles, syringes, insulin pens, insulin pumps), continuous glucose monitoring (CGM) systems, as well as any food items (such as jellybeans) to mitigate a low blood sugar. During the analysis I considered how these artifacts were utilized (or not) by the participants in their day-to-day often moment-to-moment decision-making and problem-solving self-management practices. For example, the use of measuring tools (scales, measuring cups, etc.) or not, formed part of the foundation for a line of inquiry and interpretation regarding how participants both conformed to as well as resisted aspects of diabetes self-management guidelines. In this manner, considering how participants utilized or did not utilize material artifacts was integral to my interpretations with respect to intersecting, competing, and dominant discourses as well as ideologies.

**Data Management and Software.** Interview recordings were immediately transcribed verbatim by a professional transcriptionist who had signed an Oath of Confidentiality. Any files sent electronically were password protected. I reviewed the transcripts by reading and listening to the recording to de-identify personal information and clean the data to ensure accuracy. All field notes were initially hand-written and then typed. Data remained confidential and locked in my office. All field notes and interview transcripts were de-identified and stored using codes only (as applicable – i.e., interview transcripts) and computers and memory drives were encrypted as per University of Alberta standards. I used Quirkos$^{TM}$ to manage data and thematic analysis of the text level, as will be discussed in the following section.

### ***Data Analysis***

**Critical Discourse Analysis in Ethnographies.** This research was a focused ethnography study drawing on elements and strategies of critical discourse analysis. Both ethnography and critical discourse analysis have evolved and combining elements of each allows for an in-depth exploration of phenomena in context-sensitive research (Krzyanowski, 2011). Critical discourse analysis focuses not only on interaction; but is focused more broadly on the structures influencing interaction. As such, focus extends to the context (or various influences) on interaction. Similarly, ethnography includes a focus on more than the context but to the social integration and interaction that forms part of that context. More than observation, ethnographic analysis involves an increased focus on language utilized within contexts as well as more experiential data of interviews, focus groups, group discussions, and considers other texts such as policy documents (Krzyanowski, 2011).

Critical discourse analysis is well suited to ethnographic data analysis (Cook, 2005; De Melo Resende, 2012; Liu et al., 2014; McCabe & Holmes, 2014). Galasinski (2011) argued that discourse analysis is a crucial complement to ethnographic study and that it is a vital tool in understanding how people create the social reality in which they live. Spencer (1994) concurred that ethnography is intricately involved with discourse concerns as the responses to interview questions, the content of informal conversations, and how observations and field notes are interpreted, can be viewed as accounts of social worlds. Fitch (1998) affirmed that primacy is afforded to the interactions between context and language when blending ethnographic approaches and discourse analysis, rather than either alone.

Based on the central tenets of critical social theory as outlined by Mahon and McPherson (2014), CDA can allow in-depth analysis of the role of language in the acquisition and dissemination of knowledge claims. Fairclough's Dialectical-Relational Approach (Fairclough, 2013; Jorgensen & Phillips, 2002) provided a systematic model to explore and examine the interactions between texts, discursive practices, and social practices. It was the synergistic effect of combining both focused ethnography and CDA that allowed for in-depth exploration of context and social interaction. Together, ethnography and CDA afforded the opportunity for the dual focus on context and language; a duality that is integral in exploring how people with insulin pumps enact diabetes.

**Strategies of Critical Discourse Analysis.** While described in two sections of this chapter, data generation and analysis occurred concurrently in this study, which is in keeping with inductive qualitative ethnographic work (Baillie, 1995; Hammersley & Atkinson, 2007; Robinson, 2013; Schensul, Schensul & LeCompte, 1999). I drew on Fairclough's Dialectical-Relational three-dimensional model: textual analysis, analysis of discursive practices, and analysis of social practices (Fairclough, 2013; Jorgensen & Phillips, 2002). Discourse analysis is concerned with various semiotic modalities and is an element of social processes that are dialectically related to others (Fairclough, 2013).

There is a back and forth between the levels of analysis in Fairclough's model in forming connections between discourse and practices. In a sense, I was moving back and forth in a hermeneutic process from the parts to the whole to understand what was going on in the text and how it related to the wider social context of its creation and use. This hermeneutic process or movement back and forth from data to analysis and back to data in search of what is meaningful to the participants is central to ethnography (Hammersley & Atkinson, 2007), further linking critical discourse analysis and ethnography.

A meaningful act or piece of text is represented by symbols (usually linguistics) that are used by the actor. Such symbols are socially constituted, and their use assumes that others in the same cultural groups understand the meanings (Fairclough, 2013). For example, in discussions of diabetes, logbooks of foods ingested or lab values of HgbA1c are linguistic symbols understood by people with diabetes, quite possibly their family, and their health care providers. In many cases within the interviews, we discussed the HgbA1c value and as a person with diabetes I did not explore with the participants the numerical value of the target HgbA1c as, but by virtue of living with diabetes I am aware of the HgbA1c target as set by contemporary guidelines. As such, the participants and I understood this symbol because we are members of the same sub-cultural group.

In the following sections I outline the thematic analysis techniques that I used to comprehend, reduce, and sort data, and identify patterns that will help to illuminate how diabetes was enacted by the participants Concurrently, I also explored both discursive practices as well as social practices. Although Fairclough's approach is presented as a set of levels, this does not represent hierarchical leveling of the data and analysis, but of the interplay between texts and the contexts that were essential in the creation, maintenance, and possibly change of these texts (Fairclough, 2013). While I describe each aspect of the analysis in separate sections, this is to illuminate the distinct processes within each section. There was so much overlap that the analysis of discursive practices and social practices were concurrent, iterative processes within thematic analysis of texts. In essence, the thematic analysis of the texts assisted me to understand, comprehend, and sort data to identify key practices, expectations, and norms. The concurrent analysis of discursive practices and social practices allowed me to explore the interplay between the texts and the contextual factors involved in the production and reproduction of the analyzed texts and consider various discourses, instances of power, ideologies, and hegemonic practices.

During this study and specifically during the beginning stages of analysis, I became co-supervisor of Ms. Jessica Gonzalez, a nursing student in the BScN After Degree – Honors Program at the Faculty of Nursing, University of Alberta who was interested in the possibility of conducting a focused analysis of my dataset. In our preliminary meetings, and during her proposal development which coincided with my initial and preliminary analysis, we decided that Ms. Gonzalez[1] would conduct a focused analysis of the language practices (such as metaphors, similes, and hyperboles, etc.) that were utilized by the participants as they expressed their day-to-day, often moment-to-moment self-management practices within the context of how they viewed diabetes as one aspect of their self-identity. The use of these language practices was integral to the overall diabetes enactment by the participants and as such an in-depth, focused exploration was warranted.

Ms. Gonzalez also lives with diabetes however she does not use an insulin pump. In our discussions and meetings regarding her data analysis, we have shared understandings and assumptions of our engagement with the data and in this manner, we have both grown with respect to our stance as individuals living with diabetes as well as researchers. In the role of co-

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[1] Ms. Gonzalez completed a focused analysis using my study data to explore the language practices such as metaphors, humor, similes, and rhetorical questions. As a co-supervisor for this project, I assisted Ms. Gonzalez from proposal development to analysis and final report. Ms. Gonzalez was not a co-investigator in my research and was not involved in any stage of the study from proposal development to findings/implications. My involvement with Ms. Gonzalez' project however, influenced my conceptualizations of the importance of language practices in diabetes management of these participants.

supervisor of this project based on the data from this study, I have more in-depth reflection than I originally anticipated as I have assisted Ms. Gonzalez in her interpretation of the data. Specifically, I had to make my assumptions and interpretations known and explain how I came to the conclusions that I did. In addition, I had to explain tacit understanding as a result of using an insulin pump myself, which resulted in some of the terminology of the pump unexplored with the participants. For example, I did not follow up on what a bolus or basal rate was. Ms. Gonzalez was instrumental in challenging my assumptions and interpretations of the data, and, while her research objective was tangential to my research questions, our mutual work was beneficial in helping both of us reflect on our own diabetes journeys and how these experiences informed our interpretations. Ms. Gonzalez' research report abstract can be found in Appendix E.

**Thematic Analysis.** The unit of analysis in this research was any meaningful text. While texts can refer to anything that is written or spoken (such as interview transcripts, field notes, any documents) as well as any images (Fairclough, 2013; Jorgensen & Philips, 2002), in this study, texts were the interview transcripts, various Diabetes Canada guidelines, pump brochures and websites, as well as images and my own fieldnotes, memos, and personal journey.

Data analysis according to Fairclough's CDA begins with an analysis of the text and is concerned with the minutiae; how a text is formed and the particular vocabulary and style that is used (Smith, 2007). This can be either highly detailed at the semantic level or conducted at a more thematic level, depending on the aim of the research (Fairclough, 2013; Smith, 2007). In this study, I analyzed texts from a thematic level and as such the focus was not on the lexical style of the text, but more an exploration of the diverse discourses in the texts.

In completing the thematic analysis, I followed the techniques in the process as outlined by Braun and Clarke (2006). Similar to other discourse analyses, thematic analysis in this research was at a latent level (inclusive of underlying ideas, conceptualizations, and ideologies) rather than a semantic level (not looking beyond surface meanings in the text) (Braun & Clarke, 2006; Taylor et al., 2012). The phases of this analysis were as follows:

***Familiarizing Yourself With your Data.*** In this first step, when I received the transcript from my transcriptionist I listened and cleaned the transcripts and then read and re-read them to consider initial ideas (Braun & Clarke, 2006). Richards and Morse (2007) describe this process as "getting inside the data" (p. 135) in that I considered the meaning and implications of the texts as I read and re-read the text several times.

***Generating Initial Codes.*** In this step I began to code notable features (such as words and phrases) in the data (Braun & Clarke, 2006). Beginning with the lowest level of abstraction, I used descriptive, topic, and analytic coding. According to Richards and Morse (2007), almost all qualitative methodologies utilize some form of *descriptive coding*. This coding involved little interpretation and the identification of descriptive codes was reliant on my research question. I identified descriptive codes (such as diagnosis, pump, infusion set, food, glucometer, continuous glucose monitoring, low blood glucose) related to diabetes self-management practices in the context of everyday life. I created memos and notes throughout this process and utilized the software program Quirkos ™ to manage data analysis.

Richards and Morse (2007) outline *topic coding* as 'coding up' from descriptive coding. In all projects, researchers must be able to access data by topic and topic coding involves creating categories of descriptive codes. This is analytic as it includes creating a category, reflecting on where it belongs amongst various ideas, and how data begin to fit together. Here, I focused on creating categories of the descriptive codes such as 'treating hypoglycemia'. I sought both commonalities and differences among the data within each category that needed further exploration. Reflecting on the notes, memos, and initial descriptive codes created, I began to piece together the codes into topics.

As I coded for more categories, the process became more analytic with the purpose of making, illustrating, and developing categories theoretically (Richards & Morse, 2007). The purpose of *analytic coding* was to alert me to new themes, explore and develop new categories or concepts, and pursue comparisons. As I looked at topic codes and categories, I began to piece together themes that ran through the data. For example, I began to visualize a theme which included managing hypoglycemia within the data set.

***Searching for Themes.*** In this step, I compiled categories into possible themes and gathered relevant data for each theme. This phase involved sorting the various categories identified into potential themes and organizing all the relevant codes within those themes (Braun & Clarke, 2007). Acknowledged as theme-ing, Richards and Morse (2007) articulate that coding to develop themes may occur at any of the processes of coding and means more than a topic or category. For example, as I began to piece together bits of data in relation to managing hypoglycemia, I began to see how practices fit together in monitoring for, preparing and planning for, identifying, and mitigating hypoglycemia.

Morse (2015a) postulates that identifying themes is an interpretive process and a theme may run through the entire interview or data set and may not be easily segmented from the text. “The meaning of the theme, and some of the indicators of that theme, may be inferred, interpreted or signaled, rather than be directly present” (Morse, 2015a, p. 1317). Braun and Clarke (2006) similarly suggest that a theme captures something important about the data in relation to the research question and represents a patterned meaning within the data set. Given the research question, the theoretical lens framing this study, and as I drew on strategies of critical discourse analysis, the identification of themes and meaning did not only involve the data set, but consideration was given to contextual influences on the data as a whole and as coded segments. This was further explored during my analysis of discursive as well as social practices.

***Reviewing Themes.*** In this step, I reviewed the themes identified with the data codes and categories within each theme to assess the 'fit' (Braun & Clarke, 2006). If the categories 'fit' with the identified theme, I then considered the validity of the theme with respect to each data set. In essence, this review of the themes was to assess the fit of the thematic map created for the entire data set. This process was an iterative one and I moved back and forth between codes, categories, and identified themes. At the outset, I had seven themes and incrementally, with each draft of my results, I narrowed the thematic map to include five themes. As I continued to engage with the data, as well as discuss the themes with my supervisor and peers, I realized that two of them did not fit and that they were not themes themselves, but that the ideas fit with other themes. Therefore, I narrowed the number of themes to three, but eventually moved back to four themes as I continued to engage with the data, explore the 'fittingness' of the themes, and shape the thematic map.

***Defining and Naming Themes.*** This step begins when the researcher feels that he/she has a satisfactory thematic map of the data (Braun & Clarke, 2006). Richards and Morse (2007) describe conceptualizing and abstracting as inherent to qualitative research. In conceptualizing, my goal was to move categories to concepts and then build frameworks of concepts that map the data. Doing abstraction involves moving 'up' from the data for the most part (Richard & Morse, 2007). At this point, I now further defined and refined themes and considered the 'story' of each theme, the overlap between themes (if any), and how each theme was related to the overall goal of the research. For example, I had included a theme about the use (or not) of resources by the participants. As I continued to engage with the data and move back and forth repeatedly between the various codes, categories, and themes it became clear that 'resources' was not a theme unto itelf, but rather formed part of a complex matrix of practices within other themes. Had I not continued my ongoing movement back and forth, I would not have realized this.

**Analysis of Discursive Practices.** At this level, I analyzed the practices involved in the production and the consumption of the texts. This included an analysis of how people produce, reproduce, and interpret a given text to make visible discursive practices; where the text originated, the text itself, how the text was received, etc. (McCloskey, 2008). There are three major ways in which semiosis relates to other elements of social practices and social events: as a facet of action, in the representation of aspects of the world, and in the constitution of identities (Fairclough, 2013). These effects are significant to this study as I considered how everyday diabetes self-management practices contributed to the subject position of the participants, how such practices influenced social relationships, and how they contributed to wider systems of knowledge and beliefs related to diabetes care. Corresponding to these processes are three discourse-analytical categories including genre, discourse, and style (Fairclough, 2013). Genres are semiotic ways of acting and interpreting, such as how we interact with different people at different times. Discourses are semiotic ways of representing aspects of the world which can be identified with different positions or perspectives of different social actors, and styles are identities or 'ways of being' such as a nurse or a person with diabetes (Fairclough, 2013).

Smith (2007) outlines that analysis of discursive practices involves the rules pertaining to the development and use of the text. McCloskey (2008) notes that this level in Fairclough's critical discourse analysis addresses the structure, function of the words, additional discourses drawn upon (or interdiscursivity), the consistency of the message, the assumptions that are made, the references to other texts (or intertextuality), and how the clauses and sentences are linked together.

As I reviewed my data and engaged in thematic analysis, I examined configurations of genres, discourses, and styles, which are collectively considered orders of discourse (Fairclough, 2013). Any instance of discursive practice can be interpreted in terms of how it relates to existing orders of discourses and discourse(s) pertaining to diabetes self-management practices, and the implicit and explicit rules with various discourses, etc. I considered the genres utilized and styles drawn upon. Questions I posed included: How do people with insulin pumps act and interact with different people and in different social settings? What are the different styles? How does the style of a 'person living with diabetes' interplay with other ways of being and doing in social life?

As a result of the foundational thematic and discursive practice analysis, I identified four separate, yet interrelated themes – the *insulin pump is the best way forward* in diabetes self-management, using a pump to manage diabetes involves *working like a pancreas: maintaining homeostasis from the outside*, that *constant surveillance is a necessity*, and that despite the best monitoring and planning, *living with diabetes is predictably unpredictable*. Within each of these themes there were various intersecting and often competing discourses and these four themes as listed emerged as a result of discourses which became dominant while others were silenced or at the very least quieted. As suggested by Fairclough (1985), these discursive struggles represent ideological-discursive formations (IDF) as these ongoing struggles inevitably resulted in one discourse being dominant over the others in this study, in this point in time in the lives of the participants.

**Analysis of Social Practices.** As previously outlined, Fairclough's CDA approach explores the interplay between texts, discursive practices, and social practices. In his Dialectical-Relational Model, the interrelationships between structures and events are explored through the analysis of texts (any written word, images, etc.), discursive practices (or the interaction of orders of discourse) and social practices (discourses are situated within various social, historical, and cultural contexts) (Fairclough, 2013). Smith (2007) outlines this level of analysis as the broadest level and includes an analysis of the social context where the text is produced which allows for the linking of power and ideology that is taking place. Social practices have a strong bearing on how the text is created, distributed, and received. Analysis is aimed at examining power and ideology that dominate a given sociocultural context that are seen to affect the identities and institutions mentioned in the texts. The researcher is interested in how people and events are represented (or not) in the texts and which of the components included are given greater prominence or salience (McCloskey, 2008).

I identified and explored instances of power and ideology in the social construction of diabetes self-management as expressed through diabetes practices of the participants. In their accounts, participants took up health care provider's management recommendations and as a result of individual contextual factors, molded the recommendations and made them their own. In their telling of massaging recommendations to fit within their lives, many participants evoked a sense of empowerment yet deviance, at the same time. Recommendations were described as necessary, however in making them their own, there was ample concern that this would not be considered 'appropriate' self-management. Here, a juxtaposition was highlighted in that to be autonomous in self-management risked being constructed by society, as well as by self, as deviant.

In keeping with the interactive analysis amongst these three processes, I addressed the analysis from the discursive practice level by bringing this forward to consider where such practices are in relation to a broader societal level. I questioned how the data related to current societal and health care discourse regarding diabetes self-management practices. For example, I considered how the data from this study fit with current, contemporary knowledge of patient centered care, autonomy, and empowerment in diabetes self-management. Additionally, I also considered how the findings from this analysis augmented or challenged both historical and current conceptualizations of good, competent diabetes self-management practices.

**Data Saturation/Analytic Redundancy.** In qualitative work, concluding data generation is often dependent upon the redundancy of information or ‘saturation’ (Cleary et al., 2014). Morse (2015b) describes saturation as the “…building of rich data within the process of inquiry…” (p. 587) and this includes attention to scope and replication. Scope refers to the comprehensiveness of the data and replication refers to data from several participants that have essential characteristics in common (Morse, 2015b). Focused ethnography studies like mine have utilized data saturation or redundancy of information to indicate when enough information had been generated from participants (Hales et al., 2016; Oster et al., 2014). While saturation fits with focused ethnographic work, it is questionable in CDA. As the purpose of CDA is often cited as bringing to light taken for granted, often hegemonic, assumptions and practices, the practice of data saturation is not utilized (Fairclough, 2013; McCloskey, 2008; van Djik, 1993).

In this research I sought richness and comprehensiveness of data as well as replication (Morse 2015b) at the level of thematic analysis of texts in exploring the patterns and strategies employed by individuals daily in the practice of self-managing their diabetes. I further facilitated this through sampling adequacy (large enough sample for replication to occur) as well as sampling appropriateness (participants were experts in the phenomenon of interest) (Morse, 2015b). In the process of building rigour throughout a CDA study, detailed descriptions of discourses should be provided and linkages to other works and knowledge of the subject area such that it is convincing to the reader (Crowe, 2005) and in the analysis I provide rich detailed descriptions with associated linkages to other works.

I ceased to recruit participants after participant 15 at a point where no new data was forthcoming in the thematic analysis of texts. I ceased data generation at a point where there was enough data to "…build a comprehensive and convincing theory" (Morse, 1995, p.148), in the sense of abstracting, conceptualising and theorizing concepts grounded in the data. Data generation provided the base from which deeper probing and exploring occurred in the context of examining normative assumptions. While I considered attention to scope and replication in the development of rich description as a measure to cease data generation, I do acknowledge that exploring the data from a CDA perspective is always partial and provisionary. The analysis that I present in this study is but one point in time, based on the experiences of both the participants and I in data generation, as well as the influence of my experiential knowledge in my interpretations.

### ***Rigour: Verification***

Rigour in research alludes to how 'good' the study is; it pertains to quality. In this study, measures to enhance rigour were implemented throughout the research process incrementally to ensure that the outcome was credible and trustworthy. I used verification strategies as outlined by Morse et al. (2002) to develop and demonstrate rigour. In qualitative research, verification refers to the "…mechanisms used during the research process to incrementally contribute to ensuring reliability and validity, and thus, the rigour of a study" (Morse et al., 2002, p. 17). These mechanisms were threaded throughout this research process, such that any errors could be identified and corrected before they were built into the process, which could have undermined the analysis. Verification processes are inherent in a variety of aspects of research and involves the responsiveness of the researcher to the research process as it unfolds as well as attention to researcher reflexivity. Throughout, I remained responsive and attentive to this research process and any changes to the study design were made, as necessary. In the following sections I will outline specific verification strategies central to this study.

**Methodological Coherence.** Methodological coherence includes attention to congruence between the research question and the methodological components (Morse et al., 2002). Questions I asked included: does the question match the method, does the method match the data as well as the analytic procedures? In essence, this strategy called on me to consider the 'fit' of the research process steps with one another. The enactment of diabetes by people who use insulin pumps was well suited to focused ethnographic research as I focused on a specific problem within a sub-cultural group of which I am a member (Knoblauch 2005; Wall 2015). From a CDA perspective, the analysis of text can include data from any written or verbal sources such as notes from observations, interviews, documents, or images and other media sources (Fairclough, 2013: McCloskey, 2008; Meyer, 2001; Smith, 2007). Fittingly, I had chosen the methods of interviews, participant observations, and document/artifact review and analysis. These were appropriate means to explore the phenomenon of interest utilizing focused ethnography and CDA and thus to provide answers to the research questions. As previously discussed, most participants who had consented to focused observations were eventually reticent to be observed outside of the interview setting. As a result, most data for this study were generated from interviews as well as documents. In considering this aspect of verification, despite the lack of focused observations as proposed, the methods were still congruent with the overarching design of focused ethnography in that one method, the experiential interview, was still privileged (Barton, 2008; Cruz & Higginbottom, 2013).

**Appropriateness of the Sample.** The appropriateness of the sample relates to whether the participants best represent the phenomenon under study or have knowledge of the topic (Morse et al., 2002). Aspects of the sample to consider here included sampling adequacy that was evidenced by analytic redundancy (Morse et al., 2002). At the outset of the research design process, I planned to involve 15-25 participants in this study as well as documents and other artifacts. This was a pragmatic decision based on several factors as outlined previously and the resulting number of participants depended on the richness of the data and data saturation. Therefore, 15 participants were included in the study, after which no new ideas or concepts emerged in response to initial as well as follow-up interview questions. At the point, with 15 participants and 30 interviews, I realized I was engaging with variations of the same ideas and concepts in diabetes self-management practices, and I felt that I had enough data to provide rich, thick description in answering my research question.

In addition to sampling adequacy, I addressed negative cases in my data during analysis. These cases were instances that can be described as somewhat different to data from most of the sample (Mayan, 2001). In discourse analysis, these negative cases presented counter-discourses to the dominant discourse(s), and it is necessary in considering analysis of discursive and social practices (Fairclough, 2013). For example, most participants expressed a deep desire to be prepared to mitigate blood glucose fluctuations such as hypoglycemia, and they carried food items on their person or within very quick access (i.e., in a vehicle). For two participants, this desire to be as prepared was not as great and they did not carry food items on their person or in their car. Further, attention to negative cases provided the necessary impetus for further exploration with bolusing insulin prior to meals. Current recommendations for the types of insulin used in pumps indicate that insulin should be taken prior to the meal and in some cases, at least 10-15 minutes prior (Burchum & Rosenthal, 2019). During an interview, a participant acknowledged bolusing *after* instead of *prior* to the meal, which provided an avenue for further exploration. In further interviews I discovered that several (*n*=5, or one third of the sample) did not bolus prior to meals. As such, attention to negative cases permitted the exploration of practices that I might have initially thought was idiosyncratic and might not have been considered.

Additionally, in attending to rigour in CDA, Crowe (2005) further acknowledges that the discourse analysis researcher needs to consider whether sufficient resources have been sampled and whether there is detailed description of the methods, data generation, and analytic processes such that the reader can follow and understand the context. In this study, I believe I have sampled sufficient resources and have provided detailed descriptions of data generation and analytic processes.

**Concurrent Data Generation and Analysis**. This is a hallmark of qualitative inquiry and is an iterative process where the researcher moves back and forth between what is known and what further knowledge is needed (Morse et al., 2002). It is a process of pacing and being flexible in the process of discovery. I moved back and forth between data generation and analysis of text, discursive practices, and social practices in understanding the parts and the whole of the data.

Specifically, focused ethnography has been criticized for abbreviated time spent in the field (Knoblauch, 2005). Hammersley (2006) suggests a major concern with ethnographic approaches in general is too little time in the field and too little immersion. In the case of focused ethnography, it is far more difficult to become immersed in a setting where there are no geographic boundaries, in that each participant lived in distinct circumstances. The only way to mitigate inability to be physically present and to ‘hangout’ as advised in classic ethnography, was to ensure I was well immersed in the participant accounts and stories. Scheduling two interviews for each participant was an effective way to ensure I was continually thinking about that participant’s story as unique and in comparison, to the stories of others. My data generation started with my first interview on August 23, 2018 and concluded with my last interview on February 27, 2020.

Time in the field was prolonged because of issues with recruitment and follow up as well as the inevitable issues with transportation during NL winter months. After the initial interviews with five participants, I paused to engage in preliminary analysis to reflect on my findings and to practice abstracting or ‘thinking up’ from my data while learning the genre of qualitative research reporting. This pause afforded the opportunity to identify and consider further avenues of exploration with subsequent participants. Hammersley (2006) further outlined that the ability of the researcher to delineate the context may be limited as the context includes not only local happenings, but that these can be related to wider social and political contexts as well (Hammersley, 2006). Considering this, the addition of critical discourse analysis, in particular Fairclough’s three-dimensional model, was an appropriate method to include wider social contexts related to the data in this study.

**Theoretical Thinking and Theory Development.** It is imperative that as ideas emerge they are reconfirmed in new data that must then be reconfirmed in data already collected (Morse et al., 2002). This signifies the iterative, back and forth process of theoretical thinking and testing ideas. It is not about tidying up and ‘verifying’ the phenomenon one is trying to explore. It is about being open and flexible to the ideas as they emerge. It was about considering the assumptions that I made as a researcher. This was of importance for me as a person living with diabetes researching diabetes from a critical perspective. While I made my stance known, it was critical to pause at various checkpoints throughout the study to consider the assumptions and conceptualizations that I was making in this process. To accomplish this, I engaged in active reflexivity and kept a journal. Regular meetings with my supervisor and then with BSc Honors (After Degree) student Ms. Jessica Gonzalez gave me plenty of opportunity to reflect on my assumptions and interpretations.

A specific threat to rigour related to ethnographic approaches is the possibility of becoming too familiar with the setting to the extent of overlooking important things (Baillie, 1995). As a nurse researcher living with Type 1 diabetes who utilizes an insulin pump, there was the possibility of role conflict and over-identification with participants possibly resulting in overlooking data. For example, during one interview with a participant who was having trouble affording her pump supplies, I discussed how some pump companies will have ‘sales’ and ‘special pricing’. I had not realized that I had done this until after I listened to the recording. While I do not think this was out of bounds in a conversation between two individuals who lived with diabetes and used a pump, it was however something that made me pause and consider how slippery at times the roles may be – nurse, researcher, person with diabetes, pump user. Further, in some interviews the participant became tearful, and I found myself feeling so deeply for what they were telling me. This was no doubt related to the fact that I, as a person with diabetes, had experienced some of the more negative aspects of stigma and I ‘felt’ this very deeply when participants divulged these experiences.

To mitigate over-identification as well as encourage my emotional safety, I had questions for myself after each data generation event as well as analysis for my reflective journal. I also engaged in a self-interview prior to commencing data generation and in addition, I debriefed with my supervisor and committee. I met with my supervisor at least every two weeks during the project and weekly at this stage of my research and these meetings were integral to my considerations of the intermingling of my roles as well as how these roles affected the research and, in turn, how it affected me. These questions and debriefing sessions encouraged me to pause and consider the interactions I had and any effect on the ensuing data as I discussed potential or actual over-identification with my supervisor as a means of peer review.

Discourse analysis approaches have been increasingly utilized in nursing research (Traynor, 2006), however a main critique of this utilization is the underreporting of the philosophical and theoretical underpinnings of work presented (Beedholm et al., 2014; Cheek, 2004; Meyer, 2001; Smith, 2007). Therefore, a key component of addressing rigour in CDA research is to clearly articulate the theoretical and philosophical underpinnings, including how CDA fits with focused ethnography, which I have completed both here in this methods chapter as well as in the literature review chapter.

Approaches drawing on critical social theory where the stance of the researcher is explicit at the outset of the research may be critiqued in that the researcher interprets the findings in what they are expecting to find (Smith, 2007). However, as Smith (2007) articulates, this is one of the main understandings of critical discourse analysis; any text can be understood in several ways and the understanding and interpretation that I present here is partial and provisionary. The findings I present from this study are not static but are based on my engagement with the data given my experiences and knowledge at this point in time. Subsequently, at other points in my life or the lives of the participants, what is discussed and interpreted may change. Additionally, Stevenson (2004) highlighted several factors that allow confidence in discourse analysis approaches including negative case analysis and coherence with other works; both of which I have addressed throughout this study.

Theory development involves a deliberate movement between the micro perspective of the data and macro conceptual/theoretical thinking (Morse et al., 2002). Drawing on Fairclough's CDA assisted with this as I moved back and forth between the textual data, the practices in the production and consumption of the texts, and wider social practices impacting both. Linkages between the discourse and the findings needed to be adequately described and supported, plausible, and related to existing knowledge on the subject (Crowe, 2004). As an example, I explored the fit of my experiences and data from this study with Mol's work (1998, 2002, 2008) and Mol and Law (2004) related to diabetes and chronic disease practices in general. I also considered the fit of this research with Nicolini's (2012) notion of a 'practice' as well as other literature and works in relation to decision making and problem solving in the context of living with chronic disease.

## Reflexivity

Qualitative inquiry is a process of discovery that calls for the researcher to be open minded, flexible, reflexive, and responsive to what is happening within the research process. To be responsive and flexible, a researcher must be reflexive. Especially in focused ethnography and CDA, it is integral that the researcher is reflexive as the researcher is often part of the group under study (Cruz & Higginbottom, 2013) and the stance of the researcher is known (Fairclough, 2013; McCloskey, 2008). Jootun et al. (2009) discuss how reflexivity can enhance transparency of qualitative research and thus improve demonstration of quality. Likewise, Darawsheh (2014) and Bradbury-Jones (2007) affirm that it is through researcher reflexivity that transparency and credibility, and thus rigour, are enhanced.

Throughout this research, I remained reflexive and included checkpoints or ‘stops’ where I frequently considered my positionality in relation to the participants, the setting, the data, the topic, my interpretations, and the research process in general. I am a person living with Type 1 diabetes and I am a nurse. As a researcher, I occupied the ‘space between’ (Carroll, 2009; Corbin Dwyer et al., 2009) where I am neither insider, nor outsider. I live with diabetes and use a pump; therefore, I am an insider, yet as I knew from previous interactions with others who live with diabetes as well as my engagement with the literature, diabetes self-management is so individualized that while I was an insider as part of a collective group, I was at the same time, an outsider. As a group, our experiences while similar, were quite different. As I iteratively engaged with the data, I increasingly came to understand how constitutively entangled I was in both the data generation and analysis because as the researcher, I formed part of the assemblages under study (Hultin, 2019).

Co-supervising Ms. Gonzalez was also instrumental in my reflexivity during this study. As she completed her own analysis based on my data set from this study, she often asked questions as well as offered her interpretations of my interactions during the interviews. These questions both affirmed as well as challenged my thinking in that at times, Ms. Gonzalez’ interpretations were quite different than mine. For example, during one of the interviews her interpretation was that the participant was ‘avoiding’ certain topics and that I was educating the participant. I did not feel this way at all; my own interpretations did not reflect this. As I went back to the transcript and considered my own positionality over and over, I also considered how I philosophically approached this work and that during these moments, the participant and I were interacting as two individuals with diabetes and indeed were sharing, while at the same time co-constructing knowledge in the interview setting.

This space in-between afforded me great insight into diabetes self-management practices, yet sometimes left me with too little space to theoretically explore this phenomenon. For example, the in-group jargon in relation to pump usage such as bolus, basal, correction, temp basal, 'fictitious insulin', rage bolus, etc. I did not follow up on some of these initially as these concepts were entirely familiar to me. Through conversations with my supervisor, these issues were highlighted and as a result explained throughout the analysis. In my reflective journal and in frequent conversations with my supervisor, committee, as well as Ms. Gonzalez, where I brought forward issues related to my positionality, my assumptions were brought to light, challenged, as well as at times reinforced within the considerations of their impact on this research. Indeed, as Pillow (2003) articulated, these interactions with others were instrumental in my self-reflexivity as my reflections could not be limited to looking inward, but also, I needed to consider how I was viewed by others. These ongoing inter-subjective interactions provided the necessary foundation for my self-reflexivity.

## Ethical Considerations

Prior to beginning this research, I submitted an ethics application to the University of Alberta Research Ethics Board and received approval in May 2018 (HREB Pro00081587). As this research was conducted in Newfoundland and Labrador, I also submitted an application to the Health Research Ethics Board at Memorial University of Newfoundland and received approval in July 2018 (HREB# 2018.113). Please see Appendices C for ethics certificates. As discussed previously, some changes to the research protocol were made and each change was approved as amendments to the ethics approval at both the University of Alberta as well as

Memorial University of Newfoundland. Four amendments were approved as changes to the research protocol as indicated below:

- *Amendment 1:* To widen the geographical area to all of NL and include the possibility of telephone interviews.
- *Amendment 2:* To share the recruitment poster as posted on the regional Diabetes Canada Facebook page on my own Facebook page.
- *Amendment 3:* The inclusion of individuals living with Type 2 diabetes who use a pump.
- *Amendment 4:* The addition of Ms. Jessica Gonzalez (U of A nursing honors student) as a research team member as well as to include (at the request of participants) family members/friends during the interviews. All participants were informed either through email or during interviews that Ms. Gonzalez was a member of the research team and as such, would have access to the data.

The focus of the study was still on the participants and their self-management practices, however as these practices exist within networks the participants identified family members and friends and as integral actors within their networks. Therefore, I submitted the amendment to include others in the interviews at the request of the participant. Separate Participant Information Letters and Informed Consent were created for family members/friends as well as these documents were modified for participants (please see Appendices A and B).

The Tri-Council Policy Statement 2 (TCPS2) articulates respect for human dignity as an overarching theme in conducting research involving human beings (2018). Inherent in this overarching theme are three core principles, respect for persons, concern for welfare, and justice (TCPS2, 2018). As a nurse researcher, I also considered the nursing values and ethical considerations in the Canadian Nurses Association Code of Ethics (Canadian Nurses Association, 2017). These fit within the TCPS2 (2018) respect for human dignity and include promoting and respecting informed decision-making, honouring dignity, maintaining privacy and confidentiality, promoting justice, and being accountable.

Respect for persons includes a deep respect for the value of all human beings and their autonomy (TCPS2, 2018). Inherent in this respect was obtaining free and informed consent, which was completed prior to commencement of the research (see Appendices A and B). I obtained informed consent for both the interviews as well as any observations and participants had the opportunity to complete one or the other or both. I did not approach individuals directly about the research; I placed recruitment posters in various places as previously outlined. Participants provided written consent prior to this research and additionally, I sought ongoing process consent for the second interviews and/or focused observations. Participants had the right to answer or not any questions during the interviews and as well the right to not share any documents, material artefacts, and/or engage in focused observations. They also had the right to withdraw from this study at any stage and to not have any of the interview data utilized in the research. No participant requested a pause in the interview or withdrew from the study.

To safeguard confidentiality and privacy, I kept de-identified data in a locked cabinet in a locked office as well as on encrypted flash drives. As per HREB guidelines at the University of Alberta (2016), I will keep data for a minimum of five years. After this, a decision will be made to keep the data or not for potential secondary analysis.

Concern for welfare includes considering the impact of the research on individuals (TCPS2, 2018). Prior to conducting this research, I considered the potential benefits (such as the increasing awareness as outlined in the significance of the research) but also the risk for harm in that increasing awareness may potentially lead to questions related to diabetes self-management and/or diabetes distress. I ensured participants were aware that in the context of this research I was acting in the capacity of neither a registered nurse nor as an educator. As such, if any issues arose during the conduct of this research where participants asked for help, I had to be knowledgeable of services available to persons to deal with any questions and/or distress (diabetes or otherwise) such as those at the Regional Diabetes Education Centre. There were no participants who expressed distress where they required assistance during the course of the study.

Justice refers to the fair and equal treatment of all individuals involved in the research (TCPS 2, 2018). All participants were asked similar demographic questions at the beginning of each interview, and interviews were similar in length. All participants were provided with the same introductory email/phone call when I was contacted about their participation in the study, and I provided the study information to all participants in the same manner. I also considered notions of power imbalances that may potentially occur, and I responded to these imbalances within the research process. I specifically acknowledged my role in generating data and the impact it may have had on the responses to questions and discussion of the participants. I also considered the effect of such discussion(s) on me as a researcher. This was not to acknowledge power as an oppressive entity, but to articulate knowledge development in the shift of power from researcher and informant in a back and forth process in the co-construction of knowledge.

## Conclusion

Focused ethnography is an applied qualitative research method to explore specific phenomena within a cultural group of which the researcher is a member. As I live with diabetes and use an insulin pump and specified a problem for exploration at the outset of the research, focused ethnography was a well-suited design for this study. CDA is a strategy through which I could highlight the inextricable links between context and language as I explored diabetes practices. In this chapter, I described how I used the CDA methods embedded in my FE study to explore participants' practices and, how participants took up, resisted, conformed, or accepted various practices. In essence, the blending of focused ethnography and critical discourse analysis provided the opportunity to not only explore practices, but to delve into their meaning and to question their status quo. In the following four chapters, I will present my analytic themes.

# Chapter 4: The Pump is the Best Way Forward in Management

# Chapter 4: The Pump is the Best Way Forward in Management

> *It's changed my life completely. I can eat just about anything at all, now, and not suffer. I sort of fit it into my lifestyle, and the pump sort of fitted into my lifestyle, and like I said, the pump right now is – it lets me live just normal; you know. I can do what I want to do… [Part. 8]*

Throughout this interrelated thematic and critical discourse analysis, I have identified four themes that reflect participants' dominant discourses – 1) *The Pump is the Best Way Forward* in diabetes management, 2) using the pump features to mimic the function of the pancreas involves *Working like a Pancreas: Maintaining Homeostasis from the Outside,* 3) managing well means always knowing blood glucose levels and patterns necessitating *The Constancy of Surveillance*, and 4) that despite the best laid plans and intentions, managing diabetes means *Living in Predictable Unpredictability*. Please see Table 4.1 for an overview of each of the themes, including the intersecting and competing discourses, as well as counter-discourses that I utilized to develop the themes.

Guided by a sociomaterial lens, I present these findings to demonstrate the temporal, spatial, and relational flow of practices in the accounts of these participants. As I analyzed participants' accounts of their practices, I came to understand the flow of practices with decision-making in first obtaining a pump, then learning how to use it and problem solving common and unanticipated issues, as well as integrating the pump's features in one's everyday life. Following this, I turn to the decision-making, problem-solving, and contingency planning practices involved in monitoring, planning, and executing strategies to maintain stability of blood glucose in the context of an already full life.

Within each of the themes, tacit knowledge development, or sense-making continues to evolve as participants integrate various sources of information in creating their individualized experiential knowledge and practical expertise. As Introna (2019) suggests, through a sociomaterial approach, I was able to decenter sense-making in that sense is always already given and made simultaneously. The participants' practices existed in networks with various social and material actors and what was *sensible* for them emerged through their ongoing, interrelated practices.

While I present these themes in four separate chapters, practices described in one theme invariably are linked and related to the practices in the other themes. Additionally, to follow the actors and trace practices, I consider both symmetry (human and non-human actors contributing equally to heterogeneous networks of practices) as well as imbrication (that human and technological elements are inseparable) (Latour, 2005; Oliveira de Moura & Bispo, 2019). I focus my gaze on the agency of the actors in the network and consider the agentic capacity of both human and non-human actors to understand how agency flows throughout the practices, i.e., how various actors *are conditioned* to act and additionally, how *they condition other actors* to act.

These themes are very much dialectical as well as relational. Discourse and social actions both influence and are influenced by other discourse and social actions. Discourses are relational in that discourse and social actions exist in networks (Fairclough, 2013). For example, knowledge of their pump's features is essential to participants' surveillance practices as well as practices of planning, preparing, and managing blood glucose fluctuations. This knowledge, however, does not exist in a vacuum. As suggested by Nicolini (2009), in presenting these themes, I follow a process of 'zooming in' and 'zooming out' as I review local practices in a certain time and space with particular actors, to extrapolate connections and associations with other practices elsewhere.

I utilize colloquial expressions as well as memes in this analysis to highlight the network of practices as told by the participants. My use of these linguistic devices is to draw attention to the socially constructed nature of diabetes practices to situate these practices in the quagmire of everyday life. Living with diabetes and practices using a pump to manage does not happen in a laboratory-controlled setting; it happens in everyday life in all its ever-evolving contexts. As a result, and as these participants shared with me, guidelines and any recommendations for management are transformed to fit each person's unique circumstances and needs.

In this first analysis chapter, I present the theme; *The Insulin Pump: The Best Way Forward* where I focus on two key areas of practices; those involved with first obtaining and learning how to use a pump which ultimately led to practices to incrementally develop trust in this technology. To begin to follow the practices, I entered this inquiry at the point where participants first obtained an insulin pump. For many, this was after living with diabetes for several years and using injections to manage. As such, much of their discourse centered on the comparison of taking injections to using the pump. While the pump was new, living with diabetes was not. Therefore, the practices in this theme of first obtaining the pump, learning its features, and beginning to trust it were related to former practices of taking injections. Please see Table 4.2 for a review of sub-themes for in this chapter.

In moving through this temporal, spatial, and relational flow of practices when first using the pump, I draw on Pols (2017), Pols and Willems (2010), as well as Orlikowski (2007) in how humans and technology come together through practices that influence the construction of identities of and the relations between person and technology. In what follows, I present how a practice-based approach through a sociomaterial lens decenters the human subject to highlight the mutually constitutive nature of self and pump. Specifically, I invite the Reader to consider how pumps can both *tame* expected practices as well as *unleash* new possibilities for individuals living with diabetes who use insulin pumps. As suggested by Pols (2017), this taming and unleashing creates heuristic practices which, in this study, assisted the participants to integrate and shape new practices with former ones, creating similar yet different practices.

**Table 4.1:** *Diabetes Enactment Themes – Competing and Intersecting Discourses*

| | Living with Diabetes | | | |
|---|---|---|---|---|
| **Theme** | **1) The insulin pump is the best way forward for diabetes management** | **2) Working like a pancreas: Maintaining homeostasis from the outside** | **3) Constant surveillance is necessary to self-manage well** | **4) Living in predictable unpredictability** |
| **Description of Theme** | Decision-making & problem-solving practices WHEN FIRST obtaining a pump: Using & trusting pump with their life. Despite challenges, using pump was the best way forward in diabetes management & provided more lifestyle freedom & flexibility & better glycemic stability than injections. | Decision-making & problem-solving practices in using the features of the pump to mimic the function of the pancreas in maintaining glucose stability. | Decision-making, problem-solving, contingency planning, & sense-making in monitoring diabetes management – surveillance of body cues, blood glucose values and patterns, and the presence of any physical complications. Negotiating relationships with others as they volunteer or impose surveillance. | Decision-making, problem-solving, contingency planning, and sense-making in planning & preparing to manage hypo- and hyperglycemia. Diabetes management practices are ingrained & are *almost* second nature but not quite. |
| **Competing & Intersecting Discourses** | 1) Injections may be more freeing than pump<br>2) Pump both increases & decreases visibility of diabetes<br>3) Pump assists with a 'better' life with diabetes, but also creates more work | 1) Meticulousness with counting carbohydrates and/or guesstimation<br>2) How & when to use pump features (basal and bolus)<br>3) Type & amount of foods consumed<br>4) Pump maintenance (how & when to change infusion sets/changing battery/assessing for & managing pump malfunction) | 1) Self-surveillance (attending to body cues, checking blood glucose with glucometer, Freestyle Libre, & monitoring CGM patterns, monitoring for physical complications)<br>2) Surveillance **by** Others (welcomed, unwanted, educating others)<br>3) Surveillance **of** Others (compare and contrast with others who live with & who do not live with diabetes)<br>4) Fear and worry as impetus for surveillance | 1) Unrealistic expectation of trying to maintain stable blood glucose<br>2) Planning – carrying food, pump, & other diabetes supplies<br>3) Managing hypoglycemia & hyperglycemia once it occurs<br>4) Diabetes is second nature but not natural |

| **Theme** *(Continued)* | **1) The insulin pump is the best way forward for diabetes management** | **2) Working like a pancreas: Maintaining homeostasis from the outside** | **3) Constant surveillance is necessary to self-manage well** | **4) Living in predictable unpredictability** |
|---|---|---|---|---|
| **Counter-Discourses** | 1) Pump is much less work than injections<br>2) Injections provide more freedom than the insulin pump | 1) Consistently weighing & measuring in carbohydrate counting<br>2) Using pump features ***exactly*** like guidelines and recommendations<br>3) Changing infusion set ***exactly*** as recommended | 1) Reticence to know blood glucose value; not checking often<br>2) Surveillance provides too much data about diabetes management<br>3) Living with diabetes enhances overall health promotion & disease prevention | 1) Not carrying rescue food on person<br>2) Carrying minimal pump and/or other diabetes supplies |
| Key Interpretations | Diabetes management with a pump is better than with injections, despite challenges. Pump is not a 'life saver' – but a tool for management. Practices based on previous practices of living with diabetes and using injections as well as how 'good' management was equated with glucose stability.<br>Many actors involved – person, pump, HCP, pump brochures, Diabetes Canada Clinical Practice Guidelines (2018), syringes, needles, You Tube Videos, etc. | Guidelines and recommendations for using an insulin pump are one piece of information in creating individualized management practices. Participants highly value and regularly draw on experiential knowledge in their practices, but measure success in biomedical markers of glycemic stability – i.e., predominantly biomedical knowledge<br>Primacy of knowledge required continues to be vertically aligned as well as a focus on the 'who' i.e. the person living with diabetes is afforded primacy as the dominant actor in the network. | To self-manage well, consistent knowledge of blood glucose is required. Managing competently means always monitoring. A 'good, competent' manager consistently monitors & is a **disciplined** manager. | Living with diabetes means living with a consistent level of unpredictability & therefore always planning and preparing to mitigate any glucose fluctuations. A good self-manager is **disciplined** in planning and thus is always ready to intervene. |

**Table 4.2:** ***The Pump is the Way Forward in Management - Theme and Sub-themes***

| Theme | Theme Description (brief) | Sub-themes | Sub-themes Description |
|---|---|---|---|
| **1. The Pump is the Way Forward in Management** | The pump represents enhanced freedom and flexibility over injections and was worth any challenge despite any hardships (financial or otherwise). | 1.1The Insulin Pump? Yes Please? | Where participants imagine, plan, and apply for a pump. |
| | | 1.2 The Pump is Great! But Can I Afford it? | Considering the financial implications – starting and ongoing costs that may not be covered by insurance. |
| | | 1.3 The Land of Never-Ending Learning | Initial and ongoing learning with respect to using the pump's features to manage diabetes. |
| | | 1.4 Finding the Perfect Fit - Recommendations from Health Care Providers | Relationships with health care providers in learning to use the pump. Participants molded recommendations from health care providers into their unique contexts; often portrayed as deviance. |
| | | 1.5 Getting my Life Back – Let Freedom Reign! ☺ | Using the pump means more freedom and flexibility with types of food and eating patterns. |
| | | 1.6 Pump Forward: Inject Back | After using the pump, returning to injections represented going backward in management, and a loss of 'control', as measured through the freedom and flexibility from the pump. |
| | | 1.7 Pumps Don't Do the Thinking…But They *Do* Something | Participants had high expectations of the pump; their lives were perceived as 'better' and more 'normal' with a pump – but it was crushing realization that the pump was just another tool for management. The pump, however, demonstrates agency. |
| | | 1.8 The Pump Promise | Pumps are marketed as making life so much better and normal for those living with diabetes. However, they are more work to learn about and to maintain. |
| | | 1.9 Can I Trust the Pump with My Life? | Practices to increasingly build trust in the pump to maintain glucose stability, such as checking blood glucose frequently. Participants struggled with who or what was doing the managing – them or the pump? |

## The Insulin Pump? Yes, Please!!!!

There are many decisions to make, problems to be solved, and other aspects of life to be considered, aligned, and refined repeatedly in living with diabetes. It is not easy, although individuals with diabetes may present as though it is ‘no big deal’. This may be considered a mechanism to deal with the incurable aspect of the disease, a defense mechanism of sorts, and/or it may be a result of practices that are so ingrained, so ‘everyday’, that individuals with diabetes and others see this as simply an everyday occurrence (Heaton et al., 2016). As Latour (2005) claims, powerful assemblages such as those in diabetes management may be considered ‘black boxes’ in that they occur unnoticed; they are opaque to outsiders and often to insiders as well. The practices are hegemonic as they have become a matter of indifference, and are treated as matters of fact, rather than matters of concern (Fenwick, 2014).

For most of the participants in this study the pump was seen as a savior and provided the ability to approximate ‘normal’ again. It afforded a level of freedom and flexibility in life that simply did not exist with injections. However, the pump represented a visual reminder of diabetes and another aspect of diabetes to learn, to deal with, to manipulate - all to live and to *live well*. The pump was anthropomorphized to some extent by all participants and was seen as both friend and foe, often on a moment-to-moment basis and it involved conscious and habituated work. Pumps are marketed as a promise of ‘life changing savior technology’ to self-manage diabetes and this is how participants interpreted the marketing messages, yet, in the end the participants in my study regarded their pump as yet another tool in the arsenal of diabetes management. Nevertheless, the pump was more than some ‘thing’; it was *life*. How pumps were perceived and valued shifted back and forth as an intimate part of the participants and as existing outside of them. It was both essential and non-essential all at the same time.

## Pump Characteristics

There are five kinds of pumps currently available in Canada, manufactured by four different companies. There are the Medtronic pumps, which includes two versions –1). the 630G and 2). 670G model; 3). the Omnipod pump; 4). the Tandem t:slim pump, as well as the; 5). Ypsomed pump (Waltzing the Dragon, 2020). Choosing a pump is not a simple decision. Given the diverse features of each pump and rationale for wanting to utilize an insulin pump along with consideration of lifestyle, individuals need to comprehend the various features that they may or may not need. For example, features may include whether or not the pump is tubed (Medtronic versions, Tandem t:slim, Ypsomed) or tubeless (Omnipod); the ruggedness of the pump in terms of it being waterproof, water resistant, or not at all; if the pump has an integrated continuous glucose monitoring (CGM) system that can potentially modulate insulin administration; how large or small the basal rates can be; how large or small boluses can be; the existence of diverse bolus types (dual, square) which are all important in facilitating micro-dosing; the size of the insulin reservoir (i.e. the amount of insulin that can be held in the reservoir/pump); as well as any insurance coverage. In this study participants either used a Medtronic pump (*n*=11), the Omnipod pump (*n*=3), or the Tandem T-Slim pump (*n*=1).

Thinking through these choices requires extensive knowledge of one's own diabetes needs. Perhaps the choice can be equated with choosing a new smart phone. When one is choosing, it is likely one will have an idea of texting and data needs, and need for answering service, caller identification, and so on. Yet, the number of additional features, and the power of persuasive advertising can make the choice more complex than ever anticipated. Unlike purchasing a new cell phone however, this purchase is far more expensive and is one that individuals depend on to keep them alive. As a result, participants in this study all described extensive decision-making practices involving various networks of actors as they first acquired and learned how to use and eventually trusted their pump.

### ***May*** ***I use a Pump to Manage?***

Choosing a pump was not a decision made solely by participants as a physician's prescription for a medical device was required. Whether or not an individual was an appropriate candidate to use an insulin pump was ultimately the physician's determination. As such, when first considering an insulin pump, the human actors included the potential user as well as a physician. Other non-human actors necessary include those in current and former networks such as glucometers, foods, exercise, and resulting lab values, etc. such as HgbA1c and blood glucose values. Additionally, to adopt the technology the potential user must place value on the pump – greater value than injections can provide (Pols & Moser, 2009). Some other necessary material requirements to consider by both the provider and individual were an appropriate cognitive ability and manual dexterity to manipulate the pump. In the following quote, despite asking for a pump, Participant 7 was instructed to carry on managing with pens even though he could not achieve his target blood glucose with prefilled insulin pens:

> *So, I went in, and I was still taking insulin … and I was two years, back and forth with Dr. [Name]. And the first time I went in, 'Nope, you don't need the pump. You can take your insulin [with pens]; you can get this under control'.*
> *[Part.7]*

Conversely, in the following example, Participant 15 was encouraged to use a pump because he was considered an ideal candidate, however he was hesitant, as he did not want a device continually attached to him. His health care provider actively encouraged him to consider a pump to assist with managing his diabetes and improve his HgbA1c. In the example above and this one below, the health care provider (physician) was the dominant actor and gatekeeper to obtaining the pump:

> *I had known about the pump for maybe five or six years 'cause the endocrinologist would bring it up – diabetes clinic would bring it up, saying, you know, 'You would be a good candidate for the pump', and just the thought and the idea of being attached to a system or the tubing, and being obvious, and it seemed very cumbersome to me, and that deterred me from switching to the pump earlier.* *[Part.15]*

Despite whoever initiated the idea, the use of the insulin pump for many was dependent on the ability to afford it. In NL, the insulin pump and supplies are covered by the provincial medical care plan for individuals up to age 25 and this coverage has been expanded but is dependent on an income assessment (Government of Newfoundland and Labrador, 2021). In the following example, an individual living with diabetes for 36 years did not fall into any category eligible to receive financial assistance with a pump purchase. While she could have claimed the expense as a deduction when she filed her income tax, she still had to purchase the pump, using her money up front, creating potential financial hardship. Despite this, she chose to purchase it as she wanted to continue to manage as well as she could for as long as she could. For her, the pump afforded greater glucose stability, which she equated with 'managing well'. What is notable is her introduction to the topic; her perception that children and people with newly diagnosed diabetes should be prioritized by governmental funding marginalises and undermines her sense of value in long term effective self-management. Here, Participant 6 struggled with advocating for others (children and teenagers) while advocating for herself. As suggested by Armstrong et al., (2012), individuals living with diabetes often struggle as they strive to portray their authority and reliability in self-management, while simultaneously supporting the needs of others.

> *I'm almost embarrassed to say this…. It upset me that – not that children were covered or that teenagers were covered, or that up to 24 [years of age] was covered, but it bothered me that the government could see the value in a pump for a person [newly diagnosed] with type 1 diabetes [up to 24 years of age], who would have diabetes for their lifetime, but did not look at the person*

> *who'd already had diabetes for thirty odd years, and someone who's worked hard to try, at least, to keep things on even keel [to manage well for over thirty years], and we're [the government] not gonna do anything to help them out, and that made me angry, and I thought I was missing out on something… but I ended up buying my pump. I had to pay for it out of my pocket – it was like a little car payment, it was $8,200…it was a huge investment when I finally decided to get my pump, but I felt angry that here I was, someone who'd had diabetes for 36 years, and type 1, and didn't fall into any category that received some sort of assistance [from the government coverage] with it.*
> *[Part. 6]*

In sum, acquiring an insulin pump does not simply involve going to a store and purchasing it; there are many considerations that are dependent on extensive collaboration with health care providers, who are essentially the gatekeepers to both acquiring a pump as well as education in relation to using it. In NL, insulin pumps are medical equipment prescriptions ordered by physicians and currently physicians are the only health care provider with the ability to prescribe pumps. Therefore, the decision to obtain a pump involves collaboration between the individual, the physician, as well as insurance and pump companies. As a result, the decision to first obtain the pump involves a network of various actors of which the individual living with diabetes is one.

### The Pump is Great! But Can I Afford it?

While it may be difficult to ascertain the cost of insulin pumps in Canada through cursory internet searching as one will be directed to contact the respective pump companies, my own experience with the cost of the insulin pump itself has been in the CAD $6300 (Omnipod) to $7200 (Medtronic) range. I also use Dexcom CGM and both the start-up as well as ongoing costs included CAD $299 per month for the sensors as well as an additional $299 every three months for a transmitter. I am fortunate to have private insurance coverage, so my out-of-pocket costs for my new Omnipod pump in 2020 was $1280 out of the total cost of $6300. This is not the case for many individuals, including some of the participants in this study. There is an equity gradient associated with the insulin pump (Grip et al., 2019), and as such, the many benefits of perceived freedom and flexibility in lifestyle and less variability and enhanced stability of blood glucose (Fairchild, 2015; Garmo et al., 2013; Reidy et al., 2018) are only able to be realized by those who can afford it or who fall into a category for assistance with cost via insurance, government grants, benefits, or tax credits.

As a result of the inability to afford the pump, the freedom and flexibility that is marketed by pump companies and certainly presented by most participants in this study, is unattainable by some individuals. In addition to the cost of the pump and associated supplies, ‘other’ diabetes supplies such test strips are approximately CAD $89.99 per box of 100 strips, a glucagon kit is $100, and there are also the needles, syringes, batteries, alcohol swabs, and insulin which are also costly. The ability to manage diabetes using a pump was highly dependent upon the ability to afford it, thus money and insurance companies become actors in the decision-making practices of obtaining a pump.

Obtaining health or life insurance may be restricted when one has diabetes as a result of the increased risk of cardiovascular events as well as infections as demonstrated by the Diabetes Complications and Control Trial (Nathan, 2014). However, this does not take into account that such physical complications are more likely with sustained hyperglycemia, which can be pre-empted with management grounded in best practice consensus based clinical guidelines and recommendations. In a recent review of global trends in diabetes complications, Harding et al. (2019) found that the rates of myocardial infarction, stroke, and amputation are decreasing among individual living with diabetes in higher income countries. The authors attributed this decline to improved pharmacotherapy for both diabetes and cardiac disease as well as enhanced prevention measures and medical care. Conversely, Gregg (2019) suggested that after a small decline in diabetes physical complications from 2010-2015, there has been since 2015, an upswing due to growing gaps in the ability to access promotion and prevention care by vulnerable populations. As such, the rationale for the development of physical complications is not a straightforward cause and effect scenario between a diagnosis of diabetes and complications – there are many other factors involved.

Yet, through their discourse, the participants in this study, health care providers, and insurance and pump companies constructed a direct cause and effect relationship between diabetes and physical complications. As suggested by Orlikowski and Scott (2015) discourse does not exist outside of material production such as speech, email, documents, etc. and thus material-discursive practices are performative in that they represent an ongoing, dynamic, relational enactment of the world. Here, the participants' discourse is reflective of previous material-discursive practices as a result of research and subsequent discourse regarding how optimal self-management behaviors lead to glycemic stability, and decreased risk for physical complications (Beck et al., 2017; Ellis et al., 2017; Grady & Gough, 2014).

In the following example, the participant recounted how she initially suspected she may have had diabetes as she recognized many of the symptoms. However, prior to seeing a health care provider and obtaining a diagnosis, she debated if obtaining health insurance was strategic as the costs of a pre-existing condition such as diabetes would be exorbitant and insurance premiums out of reach. In this manner, previous knowledge about insurance coverage for those living with diabetes prompted her agency:

> *…now, we didn't have any insurance … and I said, '[husband], I think I might be diabetic, I'm thinking, and I think we should get insurance for me and you and the three children, before I go and look for a diagnosis 'cause if not, I will have had a pre-existing condition.'*
>
> *[Part. 13]*

A prevailing socially normative perception is that diabetes equates to many health complications and possibly early deaths, and from an insurance perspective this represents significant risk (Browne et al., 2013; Potter et al., 2015). The example below illustrates how diabetes is constructed as an extremely high-risk disease. The agency of the user in both obtaining a pump and affording supplies (or the capacity to act) is made possible (or not) through the agency of insurance companies:

> *I was diabetic, and then, you know, and I'd always never had an issue [with supplies] 'because I was always on my dad's insurance, growing up. So, then I started applying, like, you know, through Blue Cross and through Great West Life, like, independently, on my own, and it kept coming back, like, I was denied because I had a pre-existing disease [Part. 4]*

The participants in this study weighed the financial hardships and risk against the potential physiological as well as lifestyle benefits of the pump. Overall, the acquisition and use of a pump required more work than insulin injections, but the utopic dreams of more freedom and flexibility and a life as 'normal' as possible when living with diabetes was a goal that several participants could not let go. There was extensive initial and ongoing learning when using a pump to manage their diabetes and for some participants, this presented more work than they had ever imagined. As participants told me about their initial as well as ongoing learning about the pump and how they tried to incorporate these specific practices into their already established practices, they demonstrated taming of and by the pump (Pols, 2016). The word taming here reflects how technology may be used for either meeting the goals of the designer as well as the user. The dynamic relations between user and technology determines whether goals are met and/or exceeded (Pols, 2016). Participants told me they used the pump to align with their conceptualizations of good diabetes self-management (taming by the pump, goal of the manufacturer), as well as how they utilized the pump to meet their own individual goals (taming of the pump, goal of the user), which were often quite different from the manufacturers' intended goals.

## The Land of Never-Ending Learning

Many participants described their experiences in first learning about the insulin pump and in this section, I outline how practice networks were expanded to include other actors such as health care providers as well as the pump and associated supplies. Despite having lived with diabetes for several years and thus had developed skills around monitoring blood glucose, diet, and exercise, many were taken back by the amount of pump education, both upfront initially (when first using a pump) as well as ongoing learning, especially in relation to troubleshooting oriented to ensuring they could use the pump effectively and efficiently as designed. In this study, the participants did not consider injections or glucometers as 'technology' which they had adopted and adapted in their diabetes management – but they considered the pump as not just technology – but *new technology* and in many ways, a vastly different method of diabetes management. As the following example highlights, diabetes itself is constructed as a full-time job (managing food, exercise, and blood sugar testing) and when learning about, and using the pump (a new technology/method of management) is added to that full time job, the work involved becomes overwhelming and can be an impediment to learning how to use all the pumps' features well.

> *Factor in everyday life, like I said, two young kids, full time job, doing my masters [degree], and then, plus, managing diabetes – 'cause I'll put the pump separate for a second – 'cause managing diabetes in itself is a whole job, per se, and now you have an insulin pump where you've got increased education, increased skills that you're required to know and do. It's not as simple as syringes. Syringe, you draw it, you inject it, and you're good. Not that you're good, but it's a simple procedure. With an insulin pump, its how many carbs is in this? If you don't know, you're guesstimating how many carbs, um, and maybe you're right /maybe you're wrong. Are you gonna go high or are you*

> *gonna go low, right? Is the infusion set working, or is that malfunctioning?*
> *[Part. 1]*

When first acquiring the pump, participants attended formal learning sessions with health care providers and/or pump company representatives to learn the basic features of the insulin pump. These sessions were helpful, providing a foundation for the development of continued and ongoing experiential knowledge of body, diabetes, and pump. In the following example, the participant discussed her first education session about the basics of using the pump. Some features such as the dual/extended and/or square bolus features were not learned immediately, as these were considered too complex and not required for foundational knowledge. Therefore, the pump and its features were the driver of some of the educational content, thus demonstrating agency:

> *… but basically, it was one afternoon we put an infusion set in, filled with saline, kinda used a couple of features – the main features on the pump and just practiced it, like, in a couple of hours. Now, once we actually got on the pump, and gradually, over time, we kinda learned other features, 'cause you got options like different boluses – so, dual wave and square wave bolus. That wasn't learned right at the beginning – too complicated, too much…*
> *[Part. 1]*

Initial pump education has evolved over time. Twenty years ago, as in the following example, to be pump-educated, individuals would be admitted to hospital. They would begin using their insulin pump within a controlled environment and under supervision (Farkas-Hirsch & Levandoski, 1988). While this has benefits, it is not 'real' and there is still extensive learning to do at home in the context of everyday life. Now, individuals receive pump education either at diabetes clinics or in their homes. As such, there is a shift from a paternalistic approach to initial pump education in that pump users have more autonomy in learning to use the pump in their life contexts. Yet this autonomy is bound by other actors in the network. For example, the availability of pump brochures, You Tube videos as well as health care providers are still required for individuals to learn the features of the pump. Additionally, participants' merits in attempting to enhance their autonomy are judged according to guidelines and recommendations from pump companies and Diabetes Canada, which may or may not be conducive to the home life or values and beliefs of the user. Participant 12, below, like others, found it difficult both to assimilate all the information and to voice their preferences (such as whether breakfast/lunch is eaten) when these were counter to the advised practices of consuming three meals per day (Diabetes Canada, 2021):

> *Well, back in my day, when I got it twenty years ago, we had to be admitted to the hospital for a week. ... There was two beds allotted – two patients a week coming in, and you came in on Monday morning, and you were here 'til Friday, and they went over everything with you, well, and even as much as worked out your basal rate and your bolus and your carb ratio, and they had you do certain things, and everything was, you know, controlled environment, to get you the basics, which is very hard to do at home, and put yourself in a controlled – even to check your basal rates, you know, like the thing it's, 'Go home and do – ', but how do you do that? And how do I say, 'I'm not having my lunch today' and 'I'm not having my supper tomorrow.'* *[Part. 12]*

Continuing education was necessary to extend one's understanding of the various features of the pump and how to interface these features in everyday life. In the following example, the participant explained how working with diabetes educators helped him learn how to use his pump to deal with the 'dawn phenomenon' which occurs when blood glucose rises physiologically during the early morning hours because of usual body processes (El-Hussein et al., 2018). Not all individuals with diabetes experience a sharp increase in blood glucose during this period, but some do and require more insulin to compensate for this rise.

> *... management of it [diabetes], you know dawn phenomenon usually knocks my sugars a little bit out of whack, so working with the diabetes education, bringing it down, so things are going fairly well.* *[Part. 5]*

Participants continued to learn how to troubleshoot issues with the pump and for this they sought the assistance of health care providers. In the following example, health care providers were useful in troubleshooting technical issues with the pump and insulin delivery, providing the necessary support to assist in carrying on with diabetes management in everyday life. Here, there are other actors – for example, scar tissue which impacts the agency of the pump as well as the participant. The scarring prevents the agency of the pump to deliver insulin, and also enhances the agency of the participant in attempting to solve the problem, who in turn increases the agency of the health care provider to assist with problem-solving:

> *And that's why – 'cause I was asking – 'cause I goes to [name], the nurse practitioner down at [place] – and where I've been having issues with the insulin flow. I was asking her about it – Is it scar tissue? Is the cannula too long?... [Part. 7]*

For the most part, interactions with health care providers were helpful in enhancing the participants' ability to self-manage, yet in many ways, were influenced by a continued dominance of the biomedical model in successful diabetes management. As well, former practices and the ensuing knowledge creation of paternalistic norms continued to dominate some of the interactions with health care providers and participants considered these interactions as both enabling as well as constraining in their diabetes management practices.

### Finding the Perfect Fit – Recommendations from Health Care Providers

For the most part, assistance from health care providers was welcomed by participants as dependable comfort and accurate assistance with the enormous task of living life with diabetes. However, participants still expressed the desire to be their 'own person' and individualize guidelines and recommendations into their lives, yet as they told me, they struggled to exert their autonomy. Some participants perceived health care providers had gone above and beyond to help, especially when questions arose during the night when first using a pump. In the following extract, the perceived support was invaluable to increasing comfort with using the pump and the development of experiential knowledge to cope with various insulin and malfunction scenarios:

> *There were times when I called [diabetes nurse] at night, and I felt terrible doing it, but, you know, she was such a gentle person, and said, 'If you're at all concerned, call me. I can talk to you; it's okay…* *[Part. 13]*

The assistance of health care providers in ongoing education was not always considered the best and most immediate knowledge needed to deal with problems. Often, participants recounted centering their agency or affording primacy to their experiential knowledge over that of health care providers. Using experiential knowledge was often preferred at first and then changes made were fine-tuned with the assistance of 'nit-picking' health care providers who reviewed and refined the alteration, as generally these changes were self-initiated prior to seeing health care providers. In this example, a change in exercise/activity routine because of a broken foot prompted changes to pump settings and, given the participants' experiential knowledge of living with diabetes and using a pump for many years, he adjusted the basal rate settings as he felt were required. He then sought the help of health care providers to fine-tune the changes. In this manner, the participant valued his knowledge in making the changes over the health care providers' knowledge and believed the power for making changes rested with himself first, exerting his independence and autonomy but also prioritizing and centering of his agency, which then was validated by the health care provider:

> *I broke my foot, so then I was off it, so I wasn't as active, and my sugars started shooting up, so whenever it used to be a 5 [mmol/L] and a 6 [mmol/L], now it was like a 10[mmol/L] and 11 [mmol/L], so that really impacted me, so I kinda got frustrated – not so much panicked but just like, okay, so I'm gonna have to do something now. I'm gonna have to change my bolus or my basal rate because I need to get more insulin, or I'm just gonna be continuously high all the time. So, as soon as I did that [changed the basal rate], I was fine again, so I found just knowing more about how your body reacts to stuff, then it makes it easier to change it. So, after that, then I set up an appointment with*

> *the girls at [diabetes education centre], and they said, 'Yeah, your sugars are pretty good', so they said, 'Now we just want to nit-pick', right, so it's not something that I was overly concerned with when it was high. I just needed to know how to fix it.* *[Part. 14]*

Participants continued to learn about the pump using pump manuals and guides which assisted with practical issues such as changing pump infusion sites after the initial insulin pump education. Information from these manuals and guides was synthesized with knowledge created by interacting with health care providers. The health care provider was accessed if there was something that required clarity after reviewing it in the pump guide. As such, the health care provider was seen as a 'back-up' to what could be ascertained by the participant. In the following example, Participant 10 had been using the pump for only three weeks and, like other participants who had used their pump for years, she preferred to watch You Tube videos, read the pump information brochure, and then contact the nurse as a back-up. Learning was expanded to include other actors such as brochures and videos which were preferred especially for very task-oriented practices, such as learning to change infusion sets:

> *…when I put my site in the other day, I did use the brochure because it was pretty – like, it was one page – step one, two, three, four, five – and I just made sure that I was doing it right, so put it out. That's it, or I use my nurse. Like, if it's something I really don't know or not sure, I'll just call the nurse, and they'll answer questions, you know.* *[Part. 10]*

Generally, health care providers encouraged the incorporation of experiential knowledge, however there were times they did not, and participants felt they had to withhold truths about their practices to be perceived as managing well. Despite acknowledging the need for individualization, enhanced autonomy, and collaborative decision-making in diabetes education and self-management support (Diabetes Canada Clinical Practice Guidelines, 2018), participants experienced 'provider knows best'. At times, deviance as divergence from recommendations was apparent in the participant's accounts of how they negotiated individualized self-management plans.

Participants often felt frustrated and wanted to 'take a stand' in managing their own diabetes. In the following example, the need to assert oneself is highlighted and is described as 'going against' the health care provider recommendations. The health care provider eventually conceded but clearly would rather the participant continued to manage the way that was recommended to her by the health care provider. It was a struggle between two knowledges – one experiential, and one based on analysis of large-scale population data. In the end, the participant did what she felt was right for her (based on her experiences) but had to explain and plead her case to the health care provider, who noted the participant would feel better if she allowed the provider to guide the changes in the future. The participant struggled to assert autonomy and her agency was constrained by direction from the health care provider. In this example, while from a network perspective, all social and material actors are mutually constituted in creating knowledge (Hultin, 2019), primacy remained with the human actors and in this case, the health care provider, which distressed the participant. While Participant 2 described in great detail the value of her own knowledge based on previous management practices, now, she prioritized the agency of the knowledge of the health care provider over of her own:

> *So, okay, the information she was giving me, and little changes that we were making, I mean, it just wasn't being done quick enough, but I'd make the changes, and then, of course, I'd be still high – running high and, you know, I've never experienced this before. So, I said, 'We need to make bigger changes, quicker', so then, you know, we're discussing my exercise program and what not, and she said – you know, talks about food – and she says, 'Well, every single morsel of food that you need to put into your mouth, you need to take insulin for', and I said, 'No, if I'm eating a banana and I'm going for a 25 K run, I do not need insulin. That banana is going into my body. I only need that for energy to run. You know, if I take insulin, I'm going low.' 'Oh no, that's*

> *not the way it works', and, you know,* ***I didn't say it to her, of course****, but I'm looking at her and saying, 'You're not a runner; you're not a diabetic; that is the way it works for me.'* *[Part. 2]*

Using an insulin pump to manage diabetes calls on the individual to check blood glucose at least four times per day if using a manual blood glucose meter (Diabetes Canada, 2018). However, in dealing with health care providers some participants expressed reticence in checking blood glucose as they feared being over 10 mmol/L; the subsequent questions oriented to working out why their glucose was raised could be difficult to answer. As described here, if one does not check one's blood glucose, one cannot know – which means there is no perceived blame. However, this does limit the participant's ability to individualise pump settings. In this example, the participant balanced the risks of not knowing his blood glucose values against the likelihood that knowing his glucose would engender feelings of inadequate management:

> *Well, that's the reason why I don't want to check it – because I know it's gonna be over 10 - and I don't wanna them, you know, when I go the diabetic nurse – 'cause they look at all my trends - and they say, 'Well, what happened here?', and it's like, 'What happened here?', and if I don't check, then they're never gonna find out, so I've done that before.* *[Part. 14]*

At times, when participants felt inadequate or that their experiential knowledge was discounted by their health care professional, they attempted to avoid disclosing their management practices and results when meeting with health care providers. Often, participants told me how they either did not disclose or deliberately obscured the truth to defend their authority and reliability as good managers. As suggested by Allen et al. (2011) and Lawn et al. (2011), lying to health care providers was a means of defending what may be perceived as non-compliance which in turn preserved perceived autonomy. When experiential knowledge was perceived to be discounted, participants appear to acquiesce to provider advice even though they have decided to reject that advice:

> *Probably the only thing I questioned was one time at the diabetic clinic, that they recognized that I was taking off my pump at the gym. I still don't know how they could tell that I was taking off my pump, completely, as opposed to going into suspend, and they're like, 'Well, you know, you should be wearing your pump and just decreasing it or eat prior to, but never undo your pump for more than hour.', and I'll be at the gym sometimes an hour and a half, two hours, but again, it was just a way for me to mitigate that low, and I just find sometimes it's a little bit difficult to work out with a pump, especially if you're doing things upside [down]– it keeps falling out, so it's how to keep your pump safe and attached to you while you're doing some different manoeuvres, and sometimes it's just if you're running it's just banging against your leg in your pocket, so it's just easier to take it off and leave it in the locker, and then reattach, 'cause it accomplishes both. I told them my rationale, and they were like, 'Well, you know, try to find a way to secure your pump.' I just said, 'Okay', but knowing full well that the pumps coming off when I want the pump to come off.* *[Part. 15]*

Despite some challenges to developing a good working relationship, health care providers provided essential support and encouragement. As seen in the following example, Participant 6 was quite discouraged by her HgbA1c value, despite having significant stress in her life. She was very upset when conversing with her physician, such that the physician took her pen and changed the HgbA1c value on the report. Both human actors here were provided the capacity to act or have agency as a result of the HgbA1c, representing the dominance of the biomedical model in approaches to diabetes management:

> *[Dr. Name] was our pump clinic specialist here, and [name] – I have found, over the years, that doctors always made me feel guilty, questioning why your blood sugar is 16, here, you know. Because I have diabetes and I'm not perfect, and there's ups and downs and, you know, and I'll never forget, I was so, so upset one day at the pump clinic when my A1C was 8.1, and I was so upset, and I had been struggling. My mum had been dying – you know, she had been really unwell and I was really struggling, and the diabetes kinda was not in as good a place as it had been, and I had gone from an A1C of 6.3 up to in the 8's, and I so wanted it to be under - You know, even 8, you know, and when Dr [name] showed me the A1C, I almost cried. Like, immediately, my eyes welled up with tears 'cause it just felt like failure, right, and she said 'what did you want to be? What would you like to be?', and I said, '7.9', so she took her pen and she crossed off the 8.1 and she wrote 7.9, 'there you go' {laughs}, and it was such a silly little thing, and it didn't change anything, except how I felt at*

> *that moment in time about the diabetes and about how she felt about me, and my perception of being at fault, and…* *[Part. 6]*

For the participants in this study, their self-esteem, self-worth, as well as their perception of how well they were self-managing was most often in relation to their HgbA1c level. While some participants tolerated a higher than target HgbA1c (i.e., > 7%), many participants were quite upset with a higher than optimal value and felt guilty and blamed themselves. They all realized that diabetes occurs in an already full life, however benchmarked their success predominantly with the numerical value of the HgbA1c test. This is problematic, especially as living with diabetes is such a complex, multifactorial process. Yet, good self-management continues to be equated with optimal HgbA1c values (Advani, 2020; Duprez et al., 2020; Ellis et al., 2017).

The construction of an HgbA1c value of less than 7% (target) as a proxy for glucose control and thus ‘good’ management began in the 1960s and was solidified with the landmark Diabetes Complications and Control Trial (DCCT) in 1993 (Advani, 2020). Despite advances in research and technology as well as proposed new metrics such as the time in range, participants in this study as well as their health care providers continued to reference the HgbA1c as an indicator of successful self-management. Participants discussed examples of ‘shocked’ or surprised health care providers when participants demonstrated optimal biomedical markers such as an HgbA1c less than 7% even though they were not following recommended practices or targets. As described here, the physician was incredibly surprised to see an optimal, recommended, on target HgbA1c value – and so was the participant. As Ellis et al. (2017) found, both nurses and those living with diabetes find success in biomedical markers of disease such as the HgbA1c level and equate it to ‘good’ management, representing appropriate mitigation of physical risks, as reflected in this participants statement, “*Um, so, actually, I was talking to Dr* *[name] yesterday, and she said my sugars were perfect – so, 6.1 is what my average [HgbA1c value] is now. So, she's like, 'I'm shocked.' It's just like, 'me too' (laughs)" [Part. 14]*

With increasing insulin pump as well as CGM utilization, researchers are beginning to investigate 'time in range' as another marker of glycemic stability, as an alternative to HgbA1C. Time in range is "…an intuitive metric that denotes the proportion of time that a person's glucose level is within a desired target range…" (Advani, 2020, p.242). As a result of the increased CGM use, time in range is becoming more accessible for use in assessing glycemic stability as well as overall management in those living with diabetes. As Rodriguez (2019) explains, using HgbA1c provides only a partial picture as it is a measurement of glycemic stability over eight-twelve weeks and does not account for fluctuations of glucose, just the average glucose measurements. Time in range is inversely associated with HgbA1c as the higher the time spent in range, the lower the HgbA1c value, yet limitations remain with the HgbA1c value alone due to the inability to represent acute glycemic excursions (Wright, 2020). Additionally, the HgbA1c value may be affected by anemia, iron deficiency, pregnancy, and hepatic disease and can vary amongst different racial and ethnic groups (Wright, 2020). Wide glucose variability is implicated in the development of complications especially cardiovascular events more so than the HgbA1c level and using this level only as a proxy for glucose control and thus good management does not provide the whole picture (Advani, 2020; Rodriguez-Gutierrez, 2019; Wright, 2020).

In summary, all participants provided accounts of interactions with health care providers when first acquiring and learning about the pump. As noted above, at times recommendations and advice from health care providers were welcomed, sought after, and significantly enhanced the participant's ability to manage. There were instances however of participants feeling that their experiential knowledge was inconsequential, and they struggled for autonomy. Despite this and any other hurdles in acquiring the pump and learning to use it effectively, participants viewed the insulin pump as increasing the potential for freedom and normalcy, so any challenge in obtaining a pump was 'worth it'.

### Getting my Life Back – Let Freedom Reign! ☺

Participants discussed how they desired the pump because of its functionality in assisting with glucose stability but more importantly because of the enhanced freedom and flexibility with eating and activity patterns that was not attainable with injections (Pols & Moser, 2009). They spoke of this freedom and flexibility, yet most considered the pump required more work and thinking than did injections. The decision to choose the pump over injections went beyond 'better control' of blood sugars; for most, it was more about lifestyle – it was about what they considered to be getting their life back and feeling normal.  For others, along with lifestyle, it was to gain better control of diabetes. As such, the choice for a pump included a two-pronged rationale – to assist with the biomedical nature of diabetes and the day-to-day living-with aspect:

> *My haemoglobin A1C level was good, so it wasn't to gain better control, per se, of my diabetes, but I liked the flexibility – the flexibility that, you know, especially being a [health care provider], that I could be on third break [at work], and if I'm on – taking syringes, then my Humulin R is gonna wear off at 12:00 … – I don't get to go to my lunch until 3, so what am I doing for that three hours? Do I take insulin? Do I cover off? So, the flexibility with eating times is probably my biggest incentive, and it was probably almost always… my biggest barrier with diabetes was eating and wanting to eat more, so I think the flexibility was a little bit better, especially if I wanted to eat at 8:00 at night and have a pizza, I could. I didn't have to be on that restricted diet.*
>
> *[Part. 1]*

A typical response when discussing how the pump changed their lives was that the pump represented the ability to 'live life as one sees fit to do so'. As seen below, the pump allows Participant 8 a regular life and decreases his worry about food and a regimented lifestyle. The pump 'helps' support his lifestyle as he can eat as his schedule demands, and the 'pump does the rest'. Unknowingly, in this extract Participant 8 describes the agency of the pump in his diabetes management practices:

> *It gives me a regular life. We travel a lot, so I don't have to worry about time things [for eating] or anything like that, you know, and it gives me a very regular life. I eat what I want to eat; I count carbs, and let the pump know the carbs, and it does all the rest, and it usually keeps me very close within [blood glucose target range]... [Part. 8]*

Participants explained that benefits included fewer injections (or 'pokes') such that they felt 'pumping' was a way forward in their management. However, they quickly (and continuously) realized that despite the many benefits, the pump itself did not manage diabetes; they felt that they remained in control of management, not the pump. This represents individual responsibility for health in that the person self-manages, not any other actors such as the pump, glucometer, health care provider etc. Thus far, I have demonstrated that there are many actors in obtaining and beginning to use a pump of which the individual living with diabetes is one. Ultimately, the participants did not see this nor did I at first, as we both centered the human subject and continued to perpetuate the ideology of individualism in self-management in our discourse. As participants told me, their decision not only to obtain the pump but how to use it, was highly influenced by marketing of the pump and the promise to make life with diabetes so much 'better' as a result of fewer injections and enhanced discreetness with management.

### ***Fewer Pokes: Experiencing a Better Life while Avoiding Complications***

Switching to the pump meant one insulin injection every three days as opposed to having to take up to six insulin injections per day (not counting blood glucose pokes). This provided relief and transformed daily life, perceived to make diabetes management easier for some participants. In the following example, Participant 9 was delighted to be able to dispense with six needles per day but more than anything, she felt as though she had regained control over her life

– she was no longer controlled by her diabetes as represented by insulin injections. Here, the pump both *tamed the user* and *was tamed by the user* (Pols, 2016). The participant used the pump to meet her goals (to take less injections, thereby increasing control over her life) and thus tamed the pump/technology. Additionally, she (as the user) was tamed by the pump (her feelings of control over her diabetes aligned with self-efficacy within self-management education and support as a result of using the pump) (Morrison & Weston, 2013; Ndjaboue et al., 2020; Pols, 2016).

> *When I went to the pump – and I'm gonna say this – it was, oh my God, I got my life back…[said with emphasis and smiling] My challenge, my restriction was when I was on six needles a day – that was my restriction – every morning getting up and, you know, having to do what I had to do, and then take night time insulin at suppertime because I wasn't getting enough, and going – you know, having 176 units of insulin in my body, and had to ensure that it was there because my sugars were still high. However, when I changed over to the pump, I had a great relief.* *[Part. 9]*

The pump was perceived as allowing for a better quality of life, a life that is not encumbered by injections, even though these still occur, and the only actual automated process is the administration of the insulin- not glucose testing, or carbohydrate counting. For most participants, the practice of taking injections was equated to their diabetes as 'always in sight' or in the foreground. As Paterson (2001) theorized, aspects of living with a chronic disease that brings the disease to the front of consciousness such as taking injections continually highlights the ongoing, ever-present nature of the disease. With the pump, participants could actively place the disease in the background between boluses, allowing for some reprieve of 'always managing' and thus the perception of less work and more control over life.

The pump also offered a better social experience, where the practice of taking insulin before a meal could be shifted to the background, thus enhancing discreetness. In this next example, Participant 11 described how he would have to excuse himself to go take his injection in the washroom if he were eating in a restaurant. With the pump, he did not have to do this. In this manner, the pump provided a higher quality social experience and freedom from the anxiety stimulated by aligning eating with insulin injections. The value of the pump here, however, was more than the functionality in glucose stability, but more for the social experiences, which was more highly valued in this instance.

> *Better quality of life. The thing is, like, say, for example, if you went out to a restaurant, if I was going to order something, I would have to time it, right, okay, so it's gonna be hopefully twenty minutes before I get supper, so as you know, you should take your insulin twenty minutes beforehand, and okay, so I gotta go the washroom, and washrooms are not very sanitary, so you have to deal with the sanitary piece, and then you have to do your injection, and then you got your insulin on you, and you have to be carrying that in a restaurant…*
> *[Part. 11]*

The historical nature of associating a regimented lifestyle with good diabetes management influenced participants' perceptions of the pump's benefits of allowing for some degree of variation and freedom from normally rigid recommendations. As this participant explained, the choice of the pump was based both on discussions with others who already used/owned the pump and the fact that the pump afforded a less regimented and restricted lifestyle because she was able to 'cheat', meaning that she did not have to eat at certain times. In using the word 'cheat' here, this participant acknowledged that using a pump allows the wearer to deviate from the normative expectations of what people with diabetes and who manage with injections, should eat. In turn, continued use of language signifying deviance from normative expectations creates stigma and blame for those living with diabetes (Banasiak et al., 2020; Dickinson et al., 2020). In this manner, the pump increases freedom and flexibility, but almost all participants constructed this freedom as deviance or divergence from normal, standard diabetes expected practices:

> *Talking to others who were on the pump, and who said, 'Hey, you know, this is great. You can cheat if you want, and it's so individual to you, it's not like a doctor saying, so much NPH [insulin] and so much regular [insulin] or whatever. You control it.'* *[Part. 13]*

Not all participants spoke about switching from injections to pump for lifestyle reasons. The use of insulin pump therapy has been found to improve HgbA1c with less glucose variability and fewer episodes of hypoglycemia (Edem et al., 2018; Pickup, 2019). As Participant 6 explained, the choice to switch to the pump was predominantly to prevent and/or delay diabetes complications.

> *Absolutely, and, I mean, was in my thirties – I was 36, I think, when I got my pump. So, you know, please God, I'm not gonna {laughs} be leaving this earth anytime soon, so I need to have the best available way to manage my diabetes, and so I can continue on living a normal – what is normal? – life, you know. I don't want to have a heart attack; I don't want to lose my kidneys; I don't want to lose my eyesight or, you know, my feet, so I do what I can do to keep things as well as I can…* *[Part. 6]*

Pump practices designed to prevent future physiological complications indicate temporality in that practices now are meant to influence future practices in various spaces and places (Nicolini, 2009). In addition to any lifestyle or physiological benefits of the pump, some participants described how using the pump could in some ways shift the visibility of diabetes. While the presence of the pump on the body may be a visual reminder to self and perhaps depending on where it is worn to others of the presence of diabetes, the ability to hide the pump added to the ability to be discreet in public adding to the sense of normalcy for some participants.

### ***The Pump: Shifting Diabetes Visibility***

The addition of the pump to manage diabetes can increase the visibility of disease to self and others due to its very presence attached to the body, forcing wearers to constantly be aware of their bodies and thus their illness (Mol, 2009). Yet, pumps may be intentionally or unintentionally hidden from view such that while they may be 'felt', their presence is unseen.

Often, diabetes is hidden to prevent associated stigma with a perceived lifestyle management disease, one that may be perceived as self-inflicted (Gurkan & Bahar, 2020; Jeong, 2021; Nishio & Chujo, 2017). The participants perceived the intentional invisibility of the pump as a representative of diabetes as useful in the context of avoiding or mitigating negative or critical comments from others. These comments would often spur feelings of inadequacy or poor self-management, so the pump could be hidden to avoid these situations:

> *I hate – I don't – I don't like any questions – 'What's that? – like, what is that?' – and I've gotten that – like, 'What's in your pocket? Is that pager or is that a cell phone or something?' It's like, 'No', so , and some people have seen – you know, not on my belt – but have seen it, and asked, like, 'What is it?' kinda thing, right, so it's more so people just don't know what it is, and kinda ignorant about it.* *[Part. 14]*

Different pumps can offer different levels of public discreetness and thus invisibility. The tubeless pump – the Omnipod - provided much more opportunity for discreetness and invisibility. Participants reflected they were more aware of a tubed pump because the tube was an ever-present concern for catching and dislodging. Without tubing, diabetes could be made even more invisible to others at will and to the self even if only for a short amount of time. As Participant 1 described, the ability to 'hide' the pump from sight provided reprieve from the never-ending consciousness of their daily self-management:

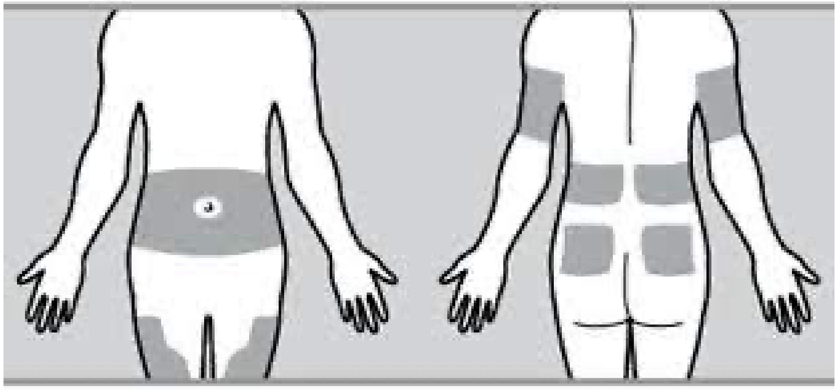
> *I don't feel it as strongly [that diabetes is visible] as I did when I was on my tube pump because that tube pump was always on me, so I felt like there was something hanging off me, whether it was in my bra, whether it was in my pants pockets, it was always there. Whereas now, like, when I went to tubeless – like, today I have my Pod on my leg. I don't – I'm not seeing it. There's nothing hanging off my body, so I don't feel – I don't feel it as much, with my tubeless pump, as I did my tubed pump, and, I mean, with regards to – I guess, that's looking at one aspect of it – the physical aspect of it, but, I mean, the pump, for me offers me way more freedom than needles could ever. [Part. 1]*

As with other technology such as cell phones, increasingly insulin pump technology continues to be developed. Participants recounted how they made decisions to switch to another pump because of more valued features, including increased discreetness. As Participant 1 continued to explain, she was on a Medtronic pump (a tubed pump), and she had switched to Omnipod (a tubeless pump). The ability to have a pump and not be tethered to it by way of a tube was enormously beneficial for this participant and represented a new layer of freedom and flexibility in life.

> *…but the Omni Pod … The biggest thing was that it's tubeless. So, I'm here sitting … with you right now with my infusion set on, but my pump is … [nearby]. My insulin pump is not on me. I'm not eating, so I don't have to take a bolus; I don't have to carry it with me. It still administers my basal rate, so that freedom alone has been life changing.* *[Part. 1]*

As she continued to discuss, when using a tethered or tubed pump, there are a limited number of bodily areas to place the pump (see Figure 4.2). Pumps must be placed in the same areas on the body where one would administer a subcutaneous injection (Burchum & Rosenthal, 2019). It is difficult to place a tubed in the arm as the tubing can get tangled or the tubing may not be long enough to facilitate easy attachment of the pump to an article of clothing. As such, not all body surfaces/areas can be used and the available sites with continued use may necessitate the placement of the pump infusion site in unfamiliar places because of scarring. Thus, the subcutaneous insertion sites as well as pump tubing also exert agency in conditioning participants both in pump site placement as well as choice of pump.

**Figure 4.2:** ***Recommended Sites for Pump Insertion.***



From https://images.app.goo.gl/XyDsinuucMdHVqx47

In summary, the pump offers more freedom and flexibility from previously rigid injection regimens which offered participants as sense of normality and freedom to live daily life as they wanted. The pump could be worn openly or hidden, depending on the individuals need for privacy, comfort, and to protect the pump. Now, I will turn to how participants divulged that returning to injections was a step backward in self-management, yet they acknowledged that pumps do not do the thinking – they perceived that it was just a tool for management.

### Pump Forward: Inject Back

Participants felt that an insulin pump was the best way ‘forward’ in their diabetes management and most believed they could never go ‘back’ to insulin injections because they would lose the lifestyle freedom and flexibility as well as blood glucose control. As such, this value was important in learning to use as well as incrementally develop trust in the pump (Pols & Moser, 2009). In the following example Participant 2 did not want to use injections even if the pump's infusion sets really hurt to insert as she could never again become accustomed to the inevitable pain of frequent injections. She perceived the pain of inserting the pumps infusion sites to be much less than frequent injections:

> *I have taken it [pump infusion set] out and I went back on injections for a couple of days, but I've realized that I can't go back to injections. Even for a couple of days, it was torture ..., I find, even the insulin being injected, stings. If it's anything – you know, if it's a unit plus – if it's, like, .5 of a unit, its fine, I don't feel it, but if I hit one unit plus, it stings, and it's just like you gotta almost clench to get the insulin in because it hurts.* *[Part. 2]*

For many participants, going back to injections represented a loss of diabetes control (or glucose stability), which was portrayed as the epitome of self-management. There is a considerable number of decision-making practices when switching from the pump to injections. To return to injections, the individual must decide how much insulin to take via injection. The general rule of thumb for the amount of insulin per day using a pump or Total Daily Dose (TDD) is that 50% should be taken via basal (or the total amount of insulin taken in 24 hours – infusing so much per hour) and the other 50% should be bolus insulin or the amount of insulin taken to match food intake (Alberta Health Services, 2017). When returning to injections the basal insulin represents the amount of long-acting insulin to be taken and the bolus dose represents the rapid-acting insulin to be taken with meals. Like beginning to use the pump, going back to injections requires that current and former pump practices are used as a baseline to create and engage in the now 'new' practices of using insulin injections again. Participants were often frustrated in having to go back to injections with most frustration stemming from the inability to administer the insulin frequently enough. Here, Participant 4 described how this left her "drove" (a NL term for extreme frustration) at her high glucose:

> *I'm a busy person, in general. Like, just with my lifestyle, I just can't - you know, I know that the minute that I go back on needles, I'm gonna lose that control. There were two days when I was waiting for my (sighs) - when my pump broke and I was waiting for the loaner [pump]one to come, it was two*

> *days, and my blood sugars – I was drove the two days 'cause I didn't have any long acting insulin in my house 'cause I haven't used it in forever, so I was giving myself a couple of units of NoVo rapid [rapid acting insulin] every few hours, but I woke up in the morning and my sugar was 20 [mmol/L], and I'd given insulin, well, 6 hours prior. I should have woken up in the middle of the night to give my insulin, realistically, but it was like, no, I should be fine, and oh, some frustrated those two days, and now I know, if I was on long-acting insulin, it'd be fine, but it's just inconvenient.* *[Part. 4]*

Despite perceiving that returning to insulin injections would represent a step 'backward' in management, there was a sentiment that in some ways, injections could be more 'free' and 'discreet' than the pump in some specific circumstances. The in-between time of injections was seen as freedom, as opposed to the ever-present insulin pump. Therefore, the notion of freedom was very much dependent upon the context and perceptions in relation to the pump and its benefits for diabetes management, which changed depending on how well the pump was perceived to manage blood glucose and provide the ability to live life as desired. These perceptions changed day-to-day and often, moment-to-moment. Many participants experienced significant lifestyle and glycemic control benefits of pump although they also told me that they came to realize it was still only a tool for management.

### Pumps Don't Do the Thinking…But They ***Do*** Something

Freedom was generally framed by participants as the primary benefit of a pump to self-manage diabetes. Most benefits were in relation to enhanced flexibility in eating and the ability to have less of a routinized, restricted, and regimented life:

> *…sometimes I eat breakfast, sometimes I don't, depending on what's on the go, but the luxury of having a pump is that I don't have to if I don't want to. I don't have to have a mid-morning snack, per se, anymore. I'm not on that strict diet/strict schedule. [I] try to check my sugars, so, again, mid-morning, and again before lunch, and sometimes I don't get to lunch until 2:00. There's been times I haven't got [to leave work area] until 3:00 to have my lunch, but I know that I'm getting my basal rate, and I don't – my insulin is not wearing off, right, so know I'm still getting my insulin.* *[Part. 1]*

Despite the freedom and flexibility associated with meal content, timing, and planning, participants acknowledged that **thinking** still needed to happen for carbohydrate counting to calculate insulin requirements, regardless of using the pump or injections. Participants counted carbohydrates and inputted this information into the pump. Then based on the pre-programmed insulin to carbohydrate ratios, an amount of insulin to be bolused is displayed on the pump screen. Prior to taking the insulin bolus, many participants mentally calculated the amount of insulin, even though the pump had already calculated it. Sometimes participants recognized this as a hangover from their habits pre-pump and sometimes it was framed as 'backup' checks that the pump was accurate. Furthermore, as in the following example, to maximize the benefits of the pump, daily life routines still need to be somewhat consistent. Hence, while there are many benefits of the pump, the participants considered it still as *just a tool* for obtaining insulin. In this manner, they continued to center themselves as the dominant actor in their self-management practices. While the individual living with diabetes needs to think (i.e. exert agency) – pumps also have agency in conditioning the capacity for agency of the user, but this was not recognized by the participants in their accounts, despite their acknowledgment that the pump *'tells'* them the amount of insulin to be infused:

> *I punch it [carbohydrate amount] into my meter, and it tells me what I've eaten, but in the background, I still do the math in my head, anyway and this is 8 ½ years later 'cause that's what I used to do before, so it wasn't much different. I would say it's easier to get more precise, but again, the rest of your life has to be fairly consistent, as well, 'cause if that part's not, then no tool is gonna help you.* *[Part. 5]*

Another perceived benefit of the pump was that it reduced participants' work in relation to recording carbohydrates intake prior to taking insulin. At times, especially when learning to carbohydrate count, individuals with diabetes record their blood glucose and the amount of insulin they take for a certain number of carbohydrates in logbooks, as Participant 11 told me, *"before I was on the pump, I used to check the sugars and write them down, but now when I'm on the pump, it reads it automatically from the glucometer to the pump…". [Part. 11].* There are blood glucose meters that link with the pump, so when the glucose is checked with a meter, this value automatically displays on the pump, thus decreasing the work associated with manually recording carbohydrates and then entering this value in the pump. For instance, the Contour™ blood glucose meter transmits the glucose value immediately to the screen of a Medtronic pump.

In sum, insulin pumps enhanced the degree and kind of freedom and flexibility in the participant's lives by moving from consuming the correct number of carbohydrates (food) to match the amount of insulin injected, to matching the insulin to what is eaten. Even though participants understood the pump's abilities in administering basal and bolus insulin, well engrained habits of maintaining a consistent schedule of waking and eating, instilled while on injections were kept or eliminated depending on the participants' needs. In the end though, participants felt more comfortable mentally calculating appropriate insulin doses to check the accuracy of the pump because, ultimately, they perceived the pump as only a tool which cannot do the diabetes thinking for them. Despite this, participants described how the pump is marketed and promised to be so much more than simply a tool for management; it is meant to be life changing.

### The Pump Promise

The pump is marketed to make life with diabetes so much better and in many ways, more "normal" as can be seen in Figure 4.1 below. This infers that diabetes is outside the realm of what society considers to be normal – i.e., having diabetes is not normal; it is unnatural and socially different. Omnipod testimonials (myomnipod.com 2020), describe the Omnipod tubeless pump as allowing for an unobtrusive, discreet way to manage diabetes and go about usual, everyday activities such as driving kids to soccer practice, commuting, working, playing sports, and gardening. Most pump advertising promises a life that is so much ‘better’; a life that is not controlled by diabetes, but the other way around. As Mol (2008) suggests, advertising such as those by pump companies, position individuals living with diabetes as consumers and attempts to target the wants of consumers. Specifically, in Figure 4.1 below, the pictures show smiling, happy individuals engaged in activities *in spite of* their diabetes. These activities may be more difficult to do when using injections, but pumps make them so much easier because of the pumps’ features where taking more or less insulin to compensate for potential blood glucose fluctuations is *much easier*. And who would not want that?

**Figure 4.1:** ***Life with a Pump***

From: https://shorturl.at/jobJK

As suggested by Pols and Willems (2010) any promise of new technology, whether perceived as good or bad, is likely to be erroneous; "…public promises in the short term always overrate the practical possibilities of technologies, whereas in the long term they are usually completely wrong." (p. 485). As participants told me, what they envisioned as something to make their lives so much easier, in many ways created more hardship – financial as well as the unanticipated work involved. As a result of tinkering, or trying, adjusting, and trying again (Fenwick, 2010; Pols, 2016) the participants in this study incorporated and adapted the pump into their already established diabetes management practices. Participants created, adapted, revised, and accepted the goals that the pump could offer them.

In a life that includes sticking needles into your body multiple times a day and trying to adhere to an unforgiving regimen to facilitate matching insulin doses with restricted food intake, the freedom and flexibility afforded by the pump is both marketed as and seen by participants, as the *Promised Land*. It is exactly what people with diabetes who rely on injections long for. *"It was – when your first get it, or when it's presented to you, too, sometimes it makes you think, like, here you go; it's the BE ALL-END ALL, right? but it's not…" [Part. 12].* Pump marketing captures buyers by promising to make life with diabetes so much 'better' and so much easier for individuals with diabetes. While the pump supports more flexibility and some freedom in management, it can be a crashing reality to realize that it is simply another tool for management. It does not replace the human element, active thinking, and work that diabetes requires or that the pump itself requires, and was not perceived as an active agent in diabetes management:

> *I think that's how it got dressed up when pumps first came around, but I think that's a slippery slope to go on, because we still have a chronic disease, you know what I mean? It's just another way to give insulin. [Part. 3]*

As Mol (2008) offers in the marketization of health, objects that bring the promise of a life unencumbered by the demands of disease hold great promise for individuals with chronic diseases such as diabetes. Pump marketing effectively enhances consumerism in people living with diabetes with the promise of a 'better' life; one that is unencumbered by injections and thus perceived to be healthier. In considering individuals living with diabetes as customers "…the language of the market makes it possible to say that patients are entitled to value for money, and that health care should follow patient demand…" (Mol, 2008, p. 16). However, this choice to manage using a pump is deeply woven into socially constructed notions of health and thus is constrained; choice is dependent on several contextual factors and does not simply represent autonomy. The choice of using a pump to manage was based on an appeal for something so much 'better' than what participants already had – a life free from endless daily injections. However, participants were somewhat disappointed in the amount of work to learn about and use a pump. Additionally, obtaining the pump is financially out of reach for some individuals, thus creating a hierarchy of those who can manage 'well' and be 'healthier' and those who cannot.

While all participants discussed the many benefits of the insulin pump, some participants acknowledged that with the newer types of insulin available, they have considered switching back to injections. The decision balances the flexibility of the pump with extra pump maintenance and the social visibility of the pump versus the ease of injections and freedom from any equipment between injections. In this example both the 'glorification' of the pump is highlighted as well as its visibility to self and others, thus the participant weighs the benefits of the pump with the discreetness of injections:

> *…it [pump] was very much glorified, right, when I first went on it, and maybe, initially, I might have been a bit awestruck over it, and, but, certainly, in the long term, … there's certainly days now when I think, gee, with these newer insulins out, perhaps going back to QID [four times a day] will be something I'd entertain, right, 'cause you know you're getting it [insulin]; you don't have something on you all the time; you can be a little bit more free with what you wear and where the pump's gonna be and, you know, you're not thinking, 'oh gee, I want to wear a tank top tomorrow. Do I really want to put this pump in my arm?* *[Part. 3]*

The pump presented a unique challenge that some participants had not anticipated. Participants now need to make decisions about which clothes to wear that will easily allow attaching the pump securely to their clothing (Didangelos & Iliadis, 2011; Payk et al., 2017). For a few participants, this was not in any way an issue that required more than a moment's consideration. For many of the women participants however, issues around clothing that could simultaneously keep a pump secure and hidden was more important. These women perceived gendered disparity when comparing the design of men and women's clothing, particularly in terms of the adequacy of pockets. Here, the network is extended to included articles of clothing as actors in diabetes management practices. Clothing exerts agency and conditions individuals to act as it will either facilitate wearing of the pump (i.e. clipping it to a waistband of pants) as well as hiding of the pump as deemed necessary or constrain the ability to take bolus insulin doses (depending on where the pump is placed, there may be no discreet, socially acceptable way of retrieving it, such as clipped to a bra). Participant 2 described how it is easier to 'wear' pump during colder months when she wears mostly pants and therefore can clip her pump to her waistband, however had to navigate challenges in pump placement when it came to wearing dresses in the summer as many styles do not have either belts or pockets deep enough to safely stow the pump:

> *And then, lifestyle wise, I mean, I certainly do [find a difference with the pump], and you don't have to carry around bottles of insulin and needles on a daily basis, you know, or pens in your purse all the time. I keep mine attached, normally – first starting out, I had a couple of different things. I used to clip it on, you know, the side of my pants or whatever, but then summer came- you know, summer was here and I'm wearing dresses, or where am I gonna put it now?* *[Part. 2]*

Thus far, I have described the decisions involved in choosing and acquiring a pump, and the required adjustments to practice networks from the habits acquired while using insulin injections. Participants found the process of acquiring a pump more complicated than expected and went through extensive consultations with physicians and diabetes educators to decide if the pump was appropriate. The pump provides the promise of a life that is far freer and more flexible than was ever possible on injections, even though that freedom is bounded by the ever-present need to self-manage and the perception of the pump as simply a tool for management.

Nevertheless, the participants in this study perceived the pump as marketed as a 'savior' for those with diabetes who currently manage with injections and for many of them, they were somewhat disappointed with the amount of work that still needed to be done when using a pump. Using a pump did not absolve participants from active diabetes management practices as many of them initially thought, but many practices were different than those used for insulin injections. While there are possible problems with injections (such as a broken insulin pen, or blunt needles), the ramifications for potential problems with insulin pumps are perhaps greater in that most individuals have many needles and other pens as they are not as costly as the pump. As a result, participants' practices in using a pump included learning how to manage any mechanical problems that may occur.

## Stay Tuned: We are Experiencing Technical (and Other) Difficulties

Despite the myriad of benefits that participants perceived were associated with the pump, there were instances of largely unexpected challenges such as having to do more work than with injections and the very practical inconveniences of wearing the pump. As suggested by Pols and Willems (2010) as well as Pols (2017), in addition to the insulin pump serving to assist the user to meet their individual goals and align their practices with normative self-management expectations based on the ideologies of individualism and responsibility for health (taming), pumps also *unleash their users* as well as are *unleashed by their users*. The challenges to using a pump as described by the participants in this study align with unexpected outcomes, or troubles (how the technology unleashes and is unleashed by the user) that may occur when adopting/adapting new technology (Orlikowski, 2007; Pols, 2017). Using the pump calls for some re-alignment of actors and thus networks and practices. In addition to any perceived benefits, there were unexpected practices including monitoring for and managing potential problems of pump function.

As Participant 6 explained, contrary to her expectations, she did not realize how bulky the pump would be to wear. Additionally, as the insulin pump only contains rapid acting insulin, if it is dislodged and/or insulin delivery is interrupted for any reason, the risk of DKA is higher than with long-acting insulin injections (Flores et al., 2020; Minimed 670G (Medtronic) User Guide, 2017). She did not have this issue with the increased risk of DKA when she used injections but now she must ensure the pump site does not become dislodged:

> *…the worst thing I found about the pump was having to just have it on me. I was bulkier than I kinda pictured it being, and I thought it was gonna be less trouble to just carry around, and then if you're wearing something where you don't have pockets or, you know, that sort of thing bothered me a bit. I was worried about it in bed. I was so afraid I'd pull it out, which I did a, a few times over the years, and I'd had diabetes for 36 years and never ever had any idea how nasty ketoacidosis could be until I got my pump and have had it a few times. I've woke up in the morning, and the pump has been dislodged or the infusion set has been dislodged and, you know, I never had that issue [with injections]. [Part. 6]*

Most participants needed to monitor and plan for as well as navigate incidences of the pump's mechanical failure. In my own experience, I have had 'motor failure' as well as 'button failure' on my pump. With the motor failure, I was awakened at 5 am to an alarm indicating this failure and there was no insulin delivery. I had a higher than usual glucose and had to take an insulin injection to bring down the high blood glucose as well as call the pump company technical support line. A new pump was sent to me later that day, however in the interim I had to manually take injections of rapid insulin several times that day.

Participants reported experiences remarkably like mine. In the following example while the process appears clear; once discovered as broken, the individual must call the pump company, decide on plan of action, and wait to receive the replacement. Here the practice changes in what Latour (2005) would call dis-rupturing where networks and practices that were so familiar become unfamiliar and adjustments or tinkering (Fenwick, 2014) must be made. In the interim, they must use a back-up pump or return to injections. This is where the work becomes less familiar for people who have not used insulin injections for a long time, if at all. In the following example, Participant 1 reflects that she *now* knows how to manage a pump failure and return to injections is smoother now than when it first happened, after learning how to transition into injection-based management:

> *Um, that was the fourth – third or fourth malfunction in two years. Now, a pump is supposed to be good – Medtronic guarantees their pumps for four years but that was the third malfunction in two years. At this point, I know what to do. The back-up plan I'm comfortable with. I know how to calculate my insulin dosages. I actually have a backup pump at home – my old Medtronic pump. So, it wasn't anxiety provoking, that I wasn't sure what to do; it was more of a nuisance than anything that I had to call Medtronic; I had to be couriered in, then I had to be home; I have to work, so, you know, it was more of a nuisance to my daily life, at that point.*
>
> *[Part. 1]*

Inevitably, pumps break down. Participants clearly recalled the most inconvenient times for pump failure which often meant disruption or premature ending of social activities, particularly if the person is out of their home environment. As explained in the example below, Participant 14 was on a long-distance run and with the heat, humidity, and sweating the pump became very wet and stopped functioning. Despite knowing this, he proceeded with his family to have a celebratory lunch, which inevitably increased his blood glucose. After the social celebration, the family returned home and tried creative methods to 'fix' the pump. Interestingly, this participant was the only one who described starting with an insulin pump immediately, rather than relying on needles initially. As such, he feared potentially having to use injections. Fortunately, his father also lived with diabetes and used an insulin pump, so he had a backup pump. In this context, the ‘team’ included his mother in working out how to manage the situation and his father as the resource:

> *Halfway through [long-distance run], my pump just died – like, completely just shut off. I went with everyone – like, mom, dad, my sister –we had a whole thing after [the run] ‘cause we always do – we always do something, and I was like, ‘What’s going on?’ [in reference to pump not working], and she’s [mom] like, ‘We’ll have to go home.’ So, after we ate, we went back [home] – and this is after having Cora’s, so all kinds of fruits and smoothies and stuff, so I knew my sugar was gonna be high, and we took it [pump] out, took it off, and I think it was wet, so we tried drying it out with a hairdryer, and that wasn’t working, and, luckily, dad had a back-up pump, so I used his back up pump, and I think we managed to get mine fixed, after. I think it just needed to dry out ‘cause it was so wet, and I was kinda freaking out – like, ‘I’m gonna have to use needles. I don’t know how to use those needles.’ Mom’s like, ‘we’ll figure it out.’” [Part. 14]*

Even in the absence of a complete pump malfunction, an essential aspect of using the pump includes paying attention to minor mechanical issues such as replacement of the battery, which if done promptly, should not interfere with the programming or insulin flow, but is still another practice in diabetes management using a pump:

> *I’d watch the battery, right, and I would change it before the life of the battery was up because they said, if you don’t change it within a couple of minutes or whatever, it’s gonna shut down, and you’ll have to reset everything. Now, I will tell you, too, I find, with the battery, when the batter life gets to half - and I’ve told Medtronic that - the power of the pump is not the same as it is with a fresh battery. [Part. 12]*

Pump company representatives also provided essential support which at times, was provided outside of usual office hours and for one participant, included ensuring that he had the supplies that he needed during a snowstorm. Despite not being able to help, this pump company representative, in the following example, acted as a liaison with another person with diabetes so that the participant could obtain the necessary supplies during a severe weather event which impacted his ability to manage. This situation highlights the interconnectedness of human and other actors in diabetes management networks (Vassilev et al., 2013). In this case, the pump company representative was one actor who interacted with another (the person with pump supplies), to help the participant obtain other pieces of his management network – pump supplies. To do this, the pump representative, another person, the participant, pump supplies, vehicles, gasoline, and so forth were involved and related in these networks of practices of decision-making and problem-solving in managing his diabetes:

> *…so I reached out to the Omnipod rep, and said, 'Is there any way I can get some pods off you until mine arrive?', and she said, 'I'm actually leaving the province tomorrow morning', and 'I'm not sure how I'm gonna get them to you.' 'Cause I was working that evening and I wasn't getting off 'til 10:30, and I didn't have time, and she lives out of town, and we wouldn't have time to get out there, and, of course, she was coming in at 4:30 in the morning, and so it was a bit – the timing was a bit off, but she said, 'I'll check with [airport] security and see if there's somehow I can leave them there at the airport for you.', but anyway, she managed to contact another person who's on the Omnipod,, and I didn't know who she was, and she offered to meet me to give me some pods. So, out of the goodness of her heart, she gave me four of her pods, and my pods finally arrived yesterday, and so I contacted the lady today and said, 'My pods arrived. I can give them back – give back the pods to you again', so, but yeah, so that was a little bit unnerving….*
>
> *[Part. 15]*

In addition to the initial and ongoing learning of the many features of the pump, participants also developed their own experiential expertise as they used the pump and began to incrementally trust it. I will now turn to perceptions and experiences of developing trust in the pump's ability to function as an external pancreas and parallel to this as a result of ongoing practices in beginning to learn about and manage diabetes using a pump.

## Can I Trust the Pump with My Life?

In this section, I will focus on two critical concepts: control and trust. In their pump education and self-management support, participants learned how to care for self, manage primarily on their own, and to take and maintain control. The term control is deeply ingrained in the very fabric of diabetes self-management. The absence of control or the absence of working toward control may be considered socially deviant as a fundamental social norm in Western society is adult independent self-care (Ljungdalh, 2013; Modarresi et al., 2020). It appeared that some participants had strongly internalized this norm of independence in that they felt they were giving up diabetes control provided by injections or pens and allowing a machine – the pump - to take over. Some participants were concerned about who or what was doing the managing; is allowing a machine to infuse insulin ***self***-managing? Historically and currently, self-management is based on neoliberal rationality emphasizes individual responsibility for health (Barnett & Bagshaw; Crawford, 2006) and centers the human subject. As a result, the participants in this study had some difficulties and uncertainties when first using the pump as to 'who' or 'what' was doing the managing. As I traced the temporal, spatial, and relational flow of practices, it became clear to me that the question is not either the 'who' or the 'what' but the 'how'. In foregrounding the practices that exist in networks, I was able to shift my focus away from who or what was managing to begin to decenter the human subject to focus on the 'how'. It was at times admittedly difficult for me to do this as I am deeply entangled within the assemblages that I am analyzing and interpreting. As a person living with diabetes, my interpretative gaze shifted in this analysis, yet I found it difficult to decenter myself as the dominant actor in my own diabetes management practices.

Despite their initial as well as ongoing sentiments about who or what is doing the managing when using a pump, this concern did not extend to other mechanical tools for diabetes management such as a glucose meter, which does the glucose reading. For these participants, the pump was different than the meter. For many, the sting of the injection was equated with managing, as there was empiric evidence of insulin being injected into flesh. But with the pump, if it is working well, the individual does not feel the insulin infuse through the in situ subcutaneous infusion set. Additionally, a glucose meter is outside of the body, it does not rest *on* and *in* the body as a pump does. As Kiran (2017) articulates, technological mediation both enables and constrains our relations to the world becoming tangled in our habits and norms. Beginning to use an insulin pump changes how individuals relate to the world as ‘living with’ and ‘managing’ diabetes changes and this takes time to assimilate in already well-established normative practices associated with good self-management. Wearing technology attached to one’s body is different than injections and also from checking blood glucose through a meter. For these participants, education but more importantly experience through continuous engagement with other actors in their networks of practice with living with and using the pump was key to showing how this machine could be integrated into their lives and needs and that it could be trusted to do its job.

Participants constructed the pump as a piece of technology that was another step between themselves and receiving insulin. The pump as technology was perceived as administering the insulin despite the participant inputting carbohydrate numbers and thus also being involved in the insulin bolus. The following quote exemplifies this concept; as this participant explained, with an injection she was in control but with the pump, the lack of empirical evidence (unable to see, hear, or feel the insulin administration) meant she *felt* as if she was not self-managing. As outlined by Hultin and Mahring (2017) from a sociomaterial practice-based perspective, actors are always shifting subject positions and are making sense as well as being made sense of. What participants considered as sensible for them during certain practices depended on previous as well as anticipated future practices. As such, the participants initially struggled with the concept of who or what was doing the managing, as they perceived it always needed to be *them*, not a *machine*.

Here, we see the remnants of ideologic practices of self-management based on individual responsibility for health where there is vertical alignment of actors with the human subject at the top of this alignment (Andrews & Duff, 2019). Additionally, as suggested by Orlikowski (2007), we need to decenter the human subject and focus our gaze on the inseparability of the social and material, of humans and technology in determining how individuals adopt, learn about, and use the insulin pump to manage diabetes.

> *First – and that was hard at the beginning because, um, like I said, it was this thing –when I gave myself a needle, I knew I was getting that insulin. I gave it, I knew it was there, I seen it go in, I drew it up, I knew it was going in. With the pump, I'm pushing in numbers like a calculator, and pushing saying, yes, go, start, um, but I don't see nothing happening; I don't feel it go in. I'm not really sure, is this thing actually working? What about if the tubing malfunctions? What about – you know, it's all the 'what ifs' so that was very daunting, I guess, in the beginning – that this thing was actually working.*
> *[Part. 1]*

Notions of control and how it is achieved through constructed practices of self-management may potentially stimulate anxiety and fear in those who consider moving to an insulin pump represents a 'passing of the torch' to their pump. Most participants who had taken injections for several years before starting the pump were very comfortable in their former self-management practices. I heard stories about 'checking' to ensure the pump was working and doing what it was supposed to from all participants, particularly when initially using the pump. To gain this trust, frequent manual checking of blood glucose was completed to validate the function of the pump and thus trust it to perform appropriately: "*I think, when I first had the pump, yeah, the biggest thing was double, double, double, triple checking my blood sugars…" [Part. 13]*

Trusting a machine with your life was not taken lightly for the participants in this study and for some there was extensive background work in developing trust in the pump. Along with more frequent blood glucose checks, trust was also enhanced because of individuals' confidence in the pump technology research and development. According to Fenwick (2014), evidence-informed practice assumes an ideal of control, which was threaded through the participants' accounts as they integrated the new pump technology into their established self-management practices:

> *Maybe it's wrong to look at it this way … I guess it's my rationale, too, is there's so much research gone into it, I'm hoping, and I'm paying big dollars for this research, and it's approved. Anyway, they've approved it all; it's all been approved, and so much research, and what's the odds, right? And I say, you know, this is better for me. Now, at the same time, if I put too much thought into it [what could go wrong in terms of pump malfunction], I probably wouldn't wear it.* *[Part. 12]*

Incrementally and eventually, participants trusted their pump such that it became an extension of self. Participants discussed giving names to the pump, calling it names out of anger, and becoming attached to the machine though which they received insulin. Regular use of wearable technology may lead to changes in human embodiment, sense of self, as well as modes of seeing and operating in the world (Lupton, 2013b). Therefore, as in the case of several participants in this study, over time wearing a pump to manage diabetes generated a shift from a sense of the *individual using the pump* to manage, to a sense of a *togetherness with the pump* in management. In many ways, the pump became such an intricate part of their very being and, as in the following example, the pump became an expression of personality. As suggested by Pols and Moser (2009) individuals develop affective relations with technology such that it is assigned personality attributes by the user.

> *My pump, like, honest, I have so many different colours [of pump cases], and it's starting to get sunny now, and I'm thinking, I should put a yellow on because it's really sunny out, and it's like, right, in October, I'll probably put an orange one on for Halloween, so Christmas it might be a red or green one, so it definitely kind of – let's coordinate it with whatever celebration's going on, whatever holiday is going on.* *[Part. 1]*

The activities of pumps can sometimes be unpredictable which can sometimes make it seem like an individual (Pols & Moser, 2009). Thus participants sometimes anthropomorphized their pumps which was manifested by talking to it either in a familial way or as a target of ire:

> *I don't – I haven't given it a name, although I've called it names (laughs), so yeah, sometimes, you know, I talk to my pump (laughs), and I know I'm not – I talk to a lot of people with diabetes – I know I'm not the only one. Some people actually give it names, but like I said, I usually call it names, more so, but yeah, sometimes when my sugar is either high or low, or I just don't want to be bothered with it, well, I talk to it, like, 'What are you beeping for now?' (laughs).* *[Part. 1]*

Additionally, the alarms created stress for the participants, and they became tired of hearing the sounds and alarms of a machine, representing a reminder of living with diabetes as well as using a pump – another aspect to consider in an already full life (Shivers et al., 2013). Most participants revealed that in times of daily interruptions/disruptions with beeping or malfunctioning, cursing the pump could relieve frustration as if it were a person as this participant told me*, "I've cursed on the bloody thing, you know, you know, beep, beep, beep, beep. [sing-song tone]. Sometimes, 'What the ffff – do you want now?', you know…" [Part. 13]*

In sum, trusting the pump was crucial to developing a sense of comfort with the pump as a tool for delivering insulin. However, many participants were anxious as they developed trust in their pump system. In their accounts, participants checked to make sure the pump was 'working' and how they 'knew' they were getting their insulin when they were on injections and now with the pump, they were not so sure. Being immersed for several years in the notion of self-management and diabetes control created stress for participants as they felt they had passed control to a machine and thus were not effectively ‘self-managing’ especially when first using the pump. These practices of ‘making sure’ the pump was working stemmed from ideological expressions of self-management based on individual responsibility for health and disease. However, in incrementally building trust, participants came to rely on their pump as more than a tool as in many ways it was considered an integral aspect of themselves. Through this trust and perhaps unknowingly, participants began to incrementally create a horizontal alignment between themselves and the pump (Andrews & Duff, 2019) where the pump was more than just a tool for management, but an important actant in diabetes management practices.

## Conclusion

In this chapter, I have started to trace the temporal, relational, and spatial flow of practices as participants first obtained and learned how to use their insulin pump. The pump was valued in terms of its functionality to aid with supporting glucose stability but more importantly for the comfort, freedom, and flexibility in eating and activity patterns. This genealogical tracing of the flow of practices and following the actants afforded the ability to begin to understand how sociomaterial entanglements contributed to subject positions and therefore the emergence of knowledges. A sociomaterial lens also facilitated understanding of the development of *sensible* practices, or how the participants began to make sense of their diabetes practices as they first began to use their pump (Hulin & Mahring, 2017). Various actors were involved in first obtaining, learning to use, and incrementally begin to trust a pump including the user, the pump, pump supplies, glucometers, health care providers, institutions such as insurance companies, pump companies, Diabetes Canada, as well as pump and other diabetes supplies, etc.

Most participants in this study had lived for years with the notion of self-management and its requirement to take ownership of their diabetes and many had difficulty becoming comfortable with the idea of the pump ‘doing its job’ independent of the individual. They perceived difficulty as they were not the only agentic actant in their network of practices. As a result of ideologies of individualization and responsibility for health upon which much of self-management education and support rests, some participants felt at times they personally were not taking responsibility for their diabetes as the pump injects the insulin rather than the individual injecting themselves. The pump represented more than a mechanical device for managing diabetes as on many occasions, participants anthropomorphized the pump such that it became either a partner or a direct extension of themselves.

In the next chapter, *working like a pancreas: maintaining homeostasis from the outside*, I will focus on one of the greatest features of the pump as told by the participants; its ability to mimic the pancreas in that it provided a basal infusion of insulin, the ability to bolus for meals, correct with extra insulin boluses, and change the rate of basal infusion depending on circumstances. This added to the perceived values of freedom and flexibility and indeed in many ways, normalcy, but depended on considerable thinking, planning, learning, decision-making, and problem-solving practices.

# Chapter 5: Working Like a Pancreas: Maintaining Homeostasis from the Outside

## Chapter 5: Working Like a Pancreas: Maintaining Homeostasis from the Outside

In this chapter I present the theme of *working like a pancreas: maintaining homeostasis from the outside.* As I traced the temporality of the participants' diabetes management practices, I determined the practices I present here are pertinent *once* the individual has a basic understanding of their pump and use it regularly. When learning how to work with a pump, participants' point of reference was primarily their past practices with injections, as well as the health care providers and pump company representatives who provided initial pump education. While the pump can be used to mimic the pancreas' functions, it is still not an organic pancreas, and the user must engage in numerous practices to emulate the internal homeostatic feedback mechanism of insulin-glucose balance. As experience grows, reference points are increasingly dependent on one's own experiential knowledge developed in past and current practices rather than the current knowledge and information provided by others.

In following the temporality, spatiality, and relationality of practices and actors in this chapter, I could see how practices in everyday operating of the pump depended on and were related to those as the participants first learned about and began to incrementally trust their pump. Additionally, participants took increased liberties based on knowledge they developed through their practices as they increasingly used their pump. As such, they increasingly made sense of using the pump to manage. This sense-making occurred as a result of the agency of both the person and the pump, as well as other actors such as food, scales, infusion sets etc. For example, to make sense of how and when to take an insulin bolus was dependent on the participants' knowledge of, and ability to count, carbohydrates as well as the function of the pump to suggest a bolus dose based on preprogrammed insulin-carbohydrate ratios, etc. There were multiple actors in this sense-making, all exerting and displaying agency (Hultin & Mahring, 2017). As suggested by Introna (2019), sense is always made and given at the same time, of which the human actor is only one part. Thus, the practice of sense-making from a sociomaterial lens decenters the human actor and thus continuously refigures possibilities for actors to act and become enacted in many ways.

In this theme, intersecting and competing discourses centered on the decision-making and problem-solving practices to decide *how*, *when, and why* to administer different insulin bolus methods, count, and measure carbohydrates, consider protein and fat, change basal infusion settings, correct hyperglycemia, as well ensure uninterrupted insulin delivery through the routine of changing infusion sets. Participants integrated biomedical and experiential knowledge in their moment-by-moment decision-making and problem-solving practices. It was clear that participants highly valued their experiential expertise, yet overwhelmingly discursively constructed themselves as ‘good’ managers in how closely they followed guidelines and recommendations and were able to meet expected glycemic targets, or biomedical markers of disease.

Before I start to explore and describe these practices, I would like to set the context of many of these practices as a very intimate aspect of self and often, largely hidden from public view. For many individuals, including myself, diabetes and ensuing management practices are such an intimate, private aspect of life. Often, we do not want to share this private aspect of ourselves with others. Living with diabetes can be seen as non-normal or unnatural, conjuring up images of a ‘less than ideal’ citizen, feelings of embarrassment and shame, and for these reasons, diabetes practices are often intentionally hidden (Hood & Drake, 2015; Stuckey & Peyrot, 2020; Walker & Litchman, 2020). While taking injections also places diabetes on display, using a pump enhances this display, as the pump is *always there*. Additionally, unlike injections, the pump features afford the user the opportunity to mimic the function of the pancreas. Therefore, not only is the pump a constant visible reminder of an intimate aspect of self, but the pump also represents an individual’s ability to demonstrate their prowess of thinking and acting like a pancreas. The sub-theme, *My Pump: Pseudo-Pancreas???* describes the challenges my participants spoke about in revealing and responding to those who are ignorant of, misinformed or otherwise discriminatory in the face of diabetes. Personal experiences of stigma, overtime, shape each individual’s openness to disclosing their diabetes but more significantly, strongly shapes their identity as a form of deviance. Please note that in this section regarding diabetes privacy and intimacy, I have chosen quotes from Participants 1 and 5 as these participants were very articulate and thus provided the richest quotes for this section. Please see table 5.1 for an overview of the theme and sub-themes.

**Table 5.1:** ***Working Like a Pancreas: Maintaining Homeostasis from the Outside Theme and Sub-themes***

| **Theme** | **Theme Description (brief)** | **Sub-themes** | **Sub-themes Description** |
|---|---|---|---|
| **2. Working Like A Pancreas: Maintaining Homeostasis from the Outside** | Employing their basic learning, participants used the pump to mimic the function of their pancreas. *How* they used the pump was informed by information from pump company representatives, health care providers, and their past practices with injections. Participants took up, accepted, modified, or resisted recommendations, depending on their unique contexts. While all recommendations did not fit all the time, when they were resisted or modified, participants portrayed this as deviance as opposed to individualization. | 2.1 My Pump: My Pseudo-Pancreas??? | The pump enhances visibility of an invisible disease; and may place practices on display for others to see. Participants were reticent to disclose any practice that was not exactly like the recommendations. |
| | | 2.2 Tinkering with the Rules to Manipulate the Pump | Participants took up recommendations and guidelines as 'rules' in that not following recommendations was not individualization – but deviance. |
| | | 2.3 Negotiating Food Intake and Delivery | Participants individualized weighing and measuring foods, carbohydrate counting, when and how to take bolus insulin for meals and to change basal insulin rates, as well as the consumption of 'sweets'; or 'junk' foods. Instead of presenting as individualization, they presented their practices as what they '***should not do'***. |
| | | 2.4 Changing my Lifeline Over and Over and Over | Participants differed in following recommendations for how often as well as time during the day to change pump infusion sets presented as doing it incorrectly as opposed to individualization. |

## My Pump: My Pseudo-Pancreas???

Diabetes is an intimate part of a person as physiologically it is about the functioning (or lack of) an internal organ. Using an insulin pump may create more visibility in a disease that is mainly invisible and as such, often places this intimacy on display. As suggested by Farrington (2016), wearable diabetes technology "…can signal the presence of diabetes to others (through visibility or audible alarms) while simultaneously reminding the wearer of their own disorder." (p. 566). While there is no cure for diabetes, there is management, which involves daily manipulation of an external 'organ' mimicking the pancreas.

Individuals with diabetes must **be** the pancreas; they must **think** and **act** in a similar way to the pancreas' functions and the participants in this study used the insulin pump as a tool to assist with thinking and acting like the pancreas. They must be able to anticipate the impact of anything and everything that would alter blood glucose and be ready to respond as the pancreas would. This is exhausting work that never stops. Acting on behalf of the pancreas continually reaffirms how constitutively entangled the individual and the pump are, so sharing these intimate practices with others may become uncomfortable in certain contexts (Orlikowski & Scott, 2007). As suggested by Arduser, (2017), individuals with diabetes consistently engage in rhetorical plasticity as they manipulate their bodies to do certain things and act in certain ways, i.e., act like a pancreas. As the following example highlights, it is difficult to explain to others (who do not have diabetes) the struggles of manipulating an organ or the interplay between human and technology to achieve this:

> *I don't want to tell another person that, 'Look, this is not my fault' or 'Yeah, my sugars are 10 [mmol/L] today' and I don't know why. Maybe I'm getting a cold that I don't know about yet, but my insulin dosage – I'm not the same insulin dosage I was on yesterday, and yesterday I was 5 [mmol/L] all day, and today I'm 10 [mmol/L] and I don't know why, that's it, and, like, one day in the lunch room, I was, uh, testing my sugars in my work bag, and, like I said, I'm kinda*

> *pretty private about it, but I had a colleague at the table, yell out across the table, 'What's your sugars?', and, honestly, I didn't want to tell the colleague what my sugars were. That day I was running high. I was busy at work – really, really busy. It was a very stressful day – very stressful day –and my sugars, I think, were running in the teens, and they were all day – all day – for whatever reason. Maybe it was stress. I can't remember if I was coming down, I was sick, whatever it was, they were running high all day, and then this colleague yells out, 'What's your sugars?', and, you know what, I wanted to say, 'I don't want to – I don't have to tell you what my sugars are. Why – that's not even appropriate for you to be asking, first of all. That's private information' (laughs), right, but then I would be considered rude, saying such a thing, right?* *[Part. 1]*

Structurally, this account reflects the elements of a story – the moral of the story or foretelling of the punch line comes first, along with a self-reflection on why she resists having to engage in the practices she subsequently describes. As she recounted the story, her non-verbal behaviour and facial expressions exemplified her words in denoting her frustration with her practices on 'display'. Interestingly it is apparent that while this participant clearly identified her colleague as being socially inappropriate by asking about her glucose level in a very public manner, the participant ultimately framed herself as the deviant social actor because it may be socially impolite not to respond to a query that superficially looks as though it is intended to be supportive. There is a 'spoiled identity' of diabetes in that anything less than an idealized health states is constructed as a form of deviance from the normal (Broom & Whittaker, 2004).

### ***Pseudo-Pancreas Equates to Deviancy***

There are several reasons why individuals living with diabetes may position themselves as the deviant social actor on many occasions. Firstly, diabetes is often represented as a self-induced disease by those lacking self-discipline and therefore individuals living with diabetes confront a society where they are seen as not normal, as well as blamed for their disease. Stigma ensues both for having the disease (assumed to self-inflicted) as well as for management, especially for taking injections which are misconstrued with having a drug problem, also viewed as stigmatizing and marginalizing (Abdoli et al., 2018; Broom & Whittaker, 2004; Browne et al., 2013; Browne et al., 2014; Stuckey et al., 2014).

In some cases, diabetes was so private and intimate that it was not revealed to many people at all. As Pihlaskari et al. (2020) suggest, there are generally three methods of disclosing diabetes to others: *open disclosure*; where the individual actively tells others, *disclosure hesitancy;* where the individual is reticent to tell others about their diabetes, and *passive disclosure;* where diabetes is indirectly disclosed by others or though activities associated with diabetes such as taking insulin or checking blood glucose. Open disclosure was often perceived as necessary for maintaining safety especially in the event of hypoglycemia, to create external support systems. Disclosure hesitancy was related to a lack of trust in others and not wanting to be perceived as different or inferior to others. Further, individuals were hesitant because they did not want to endure negative comments about their disease or how they should or should not manage it.

As described in this next example, some participants were extremely reticent to discuss living with diabetes and demonstrate management practices in public. There are several factors that may influence diabetes disclosure including the practical aspects of management (i.e., the requirement to take an insulin bolus at this very moment, regardless of social context), but more importantly the anticipated response from the recipient (Kaushansky et al., 2016). Most participants experienced instances of being made to feel different at some point in their lives because of their diabetes and as such, they kept their diabetes practices hidden from view of others to avoid criticism or negative judgments:

> *For some reason, I developed a concern to tell people I was a diabetic. I don't know why. Nobody ever gave me any reason to, and even to this day, I don't broadcast that I am, and I probably should be more vocal about it because I have had lows and such, but I've been, I'm gonna say, lucky that I've been able*

> *to manage on my own. However, it came to the point that I couldn't – you know, very few people, even in my work, are aware that I'm a diabetic, so – if somebody came out and asked me, I'd tell 'em. Like, I have nothing to hide, but, uh, you know, that conversation usually never comes up very often, or the question never comes up very often in a conversation. However, I, uh – I never ever push forward to bring it up. I don't even know – I don't even think my boss knows, but the _____[colleagues] at my site know, and, uh, I'm gonna say maybe two or three others are aware.* *[Part. 5]*

In the second interview, this same participant revealed to me that this reticence to divulge living with diabetes was a result of other experiences with being made to feel awkward and different. As Walker and Litchman (2020) suggest, disclosing that one lives with diabetes opens up avenues for two-pronged judgment by others – judged both for getting the disease as well as judged in management. In this following quote, hiding diabetes was intentional and although in the first interview (noted earlier), the participant said he was not sure why he was so reticent to divulge that he lived with diabetes, in the second interview more clarity was provided to explain how he developed the notion that diabetes rendered the individual socially deficient.

I did not probe further into the rationale for this disclosure hesitancy during this interview. Individuals living with diabetes often talk about their illness as they feel is situationally appropriate (Ploeg et al., 2017). However, in our follow-up, as seen below, this participant felt that it was situationally appropriate to talk about his reticence to be open:

> *Yeah, I used to be very open. I've had diabetes for thirty years, and I used to be very open; never ever hid it from anybody. Everybody I knew, that was usually one of the first things that I ever told anybody. It actually happened at work, where this new employee came on, and they were – I would call it rather belligerent with the way they spoke about diabetes, which made me feel, I would say, inadequate, and from that point on, I just kinda – it opened my eyes that not everybody's gonna treat you the same, so, to everybody here, I'm just a person, can be moody at times, absolutely, but I don't share it with people because I don't know if they really need to know.* *[Part. 5]*

Other participants acknowledged that disclosing diabetes to others meant having to navigate comments about how diabetes should be managed by those who do not have diabetes.

As suggested by Stuckey et al., (2014), a lack of understanding by others who do not live with diabetes may lead to those living with diabetes to feel criticized and blamed for their disease because of personal shortcomings. Unsolicited advice, represented as "the food police" in the following example, was often interpreted as offensive.

> *So, I've never been ashamed or anything of telling someone that I have diabetes. My – if I'm concealing it, the reason behind that is that sometimes I don't want the food police – if I'm eating something that according to them, I shouldn't be eating, but really, I can be. If I'm gonna get criticized for eating something, then sometimes I like to keep it discreet because, honestly, I don't want to feel like – I don't want to have to defend my choices today.*
>
> *[Part. 1]*

### *Making the "Right" Choice: An Outdated Belief?*

An ongoing practice of diabetes is to defend the choices that were informed by the individual's experiential knowledge of managing diabetes by varying the delivery modes of insulin via their pump. In contrast to biomedical knowledge, current guidelines, and recommendations, as well as historical traditions of managing diabetes, experiential knowledge may not be perceived by others as appropriate or the 'right' way. In a recent systematic review of perceptions regarding self-management support, Franklin et al. (2018) determined that both health care providers and individuals living with diabetes considered self-management as an individual's responsibility with the goal of making the 'right' choices to meet glycemic targets. Further, health care providers provided information to "…foster adherence and convince patients to make the 'right' choices." (Franklin et al., 2018, p. 95). It appeared that many of the issues I found here seemed related to old fashioned "Insulin-Dependent Diabetes Mellitus (IDDM)" social knowledge and beliefs – particularly those related to insulin injections and food planning approach to diet (in contrast to carbohydrate counting) that are no longer pertinent to the context of continuous insulin infusions (American Diabetes Association, 2020).

As the participants told me, and as I have also personally experienced, it would seem as though societal knowledge of living with diabetes has stood still; has not kept up with current recommendations and guidelines based on therapies such as insulin pump technologies. Research, as demonstrated by Franklin et al. (2018), continues to prioritize the biomedical model and stringent models of self-responsibility, control, and self-discipline spilling over to society in general and impacting perceptions of how diabetes should be managed. As shown in Figure 5.1 and through the quote below, participants in this study navigated numerous comments about whether they were *permitted* or not to eat certain foods.

**Figure 5.1:** ***Can You Eat That??? (Meme)***

From: shorturl.at/koNX9

There were times when sharing diabetes was appropriate, such as requesting someone to "champion" them, or keep an eye out when the individual with diabetes knows that the situation may render them vulnerable to hypoglycemia and passing out. Participants found it relieving to be able to talk with someone else with diabetes. Enhanced social support networks, especially those who also live with diabetes are instrumental in assisting those with insulin pumps to not only adjust to the new technology, but also to continuously adapt (Reidy et al., 2019). As explained here, Participant 1 was hailed in public with the address, “Podder” which is an in-group jargon for people who wear the OmniPod. Although the participant was ‘singled out’ amongst a crowd, it was considered appropriate as it was someone else with diabetes; someone who ‘got it’.

> *So, it’s not that – I don’t – if I do hide, it’s not that I’m ashamed to have diabetes; it’s more to avoid some of those questions, some of those criticisms and judgements, right, or I’ve had people say ‘What’s your sugars?’, you know, if they see that I’m on a pump. That’s a very personal thing that I don’t really want to be sharing with people. So, it really depends, but now I’ve also – like, we went on a trip in December, and I was walking down back to the – we were on a cruise, and I was walking back to the cruise ship, and I hear someone yell out behind me, ‘You’re a Podder!’, ha, so I turned around, and her son was also on Omni Pod, and it was – even though it was her son, it was that kinda connection, so there’s good things about it, as well.* *[Part. 1]*

In the above quote, Participant 1 recounts her interaction with another individual who uses the same type of pump, and she perceived the communication to be non-threatening and thus non-stigmatizing. Individuals living with diabetes experience less stigma when interacting with others who also live with diabetes, especially those who use the same or similar management methods (Schabert et al., 2013).

In sum, participants acknowledged that diabetes was ‘second nature’ and using the pump enhanced freedom and flexibility, but in many ways enhanced the work needed to employ the pump to its’ full potential in emulating the function of the pancreas. In the following sections I will describe participants’ day-to-day, often moment-to-moment practices in using the many features of their pumps.

**Tinkering with the Rules to Manipulate the Pump**

To achieve an enhanced sense of ‘normalcy’ denoted by perceived increased freedom and flexibility, there were many pump features to consider in the everyday, often moment-to-moment manipulation of their artificial pancreas. Participants provided detailed and vivid accounts of knowing and using the pump's features to mimic the function of an internal organ. Information about the pump's features was integrated with experiential knowledge of how they individualized the features for their own needs. In tracing the flow of practices from first beginning to learn about and use the pump, participants told me about their trial and error in bridging the gap between 'knowing about' and 'effective use' of the pump for them. Here, they spoke of tensions as they continued to bridge their expectations with their practices. As suggested by Reidy et al. (2018), while the pump allows for increased freedom and flexibility, these desired values are bounded by an ongoing disruption in activities necessitating continuous adjustments – the pump represents both a panacea and a tool for management.

In their accounts, participants knew how to employ various pump features to mimic the pancreas' output of insulin as well as the mechanical upkeep of the pump and supplies (i.e., changing infusion sets, replacement of pump batteries, associated CGM technology, etc.). In addition, participants also explained nutritional knowledge of carbohydrate counting and consideration of fat and protein content of meals, as well as knowledge of overall diabetes self-management guidelines such as those provided by Diabetes Canada (2018) for optimal blood glucose target range, activities to meet this target range, and the subsequent ability to delay or prevent physiological complications.

Often, participants spoke of learning and following 'guidelines' as set forth by various organizations and institutions and filtered through health care providers and others as "recommendations". Participants reported they interpreted these recommendations based on guidelines as 'rules.' All participants used guidelines and recommendations as benchmarks on which to base the success of their practices, yet they endeavored to individualize and make the ‘rules’ their own. In all interviews, participants spoke about living a life with diabetes that included following a set of ‘rules’ that were adapted, integrated, and interpreted within the individual contextual circumstances. Within these practices of individualizing rules into their lives, the language and talk used to describe these practices at times, manifested deviance from the rules. Yet, in other circumstances there was a resigned acceptance that these rules reflect ‘the way life is with diabetes’.

In a quest for autonomous practice in diabetes self-management, participants tinkered with the ‘rules’; they massaged and molded them into a life. Drawing on Mol (2002), tinkering is used in this sense as I attempt to capture how participants engage in diabetes practices over and over again. They take up, resist, accept, and revise various knowledges over and over as they develop and engage in their diabetes practices. In this study, participants discussed their diabetes practices not as end goals to be obtained, but as ongoing processes. As Mol (2002) offers, this “doing good does not follow on finding out about it, but is a matter of, indeed, doing. Of trying, tinkering, struggling, failing, and trying again” (p. 177). Further, in this study, tinkering was about how the participants continually adjusted their practices to allow for contingent negotiations and required improvisations (Fenwick, 2014). However, as they searched for autonomy, participants invariably found themselves feeling and acting as socially deviant from expectations and thus their search for autonomy and expertise was in the context of adhering to rules with variable success; always based on trying/tinkering.

As I considered how these participants fit guidelines and recommendations that they perceived as rules into their lives, I questioned: what are rules, principles, and guidelines and how do they influence diabetes management? How are these similar and/or different? Rules are generally instructions that tell you what you are allowed to do and what you are not allowed to do; a statement telling people what they should do to achieve success or a benefit of some kind; the normal state of affairs; and influences or restricts your actions in a way that is not good for you. A principle on the other hand, is a general belief about the way in which you should behave, which influences your behavior and/or adherence to a moral code. Finally, a guideline is something that can be used to help you plan your actions or to form an opinion about something (Collins Dictionary Online, 2021).

Diabetes Canada (2018) has published a set of guidelines for managing diabetes. Items within the guidelines include targets for and monitoring glycemic control, nutrition therapy, management of hypoglycemia, diabetes and driving, diabetes and mental health and many other chapters that include guidelines for overall management of diabetes. As noted above, guidelines are meant to aid in planning actions and/or to form an opinion. As participants discussed their management, they referenced these guidelines and others as well as how health care providers presented guidelines as simply guidelines to be individualized.

However, in their accounts, participants not only employed the guidelines to assist their management but used them as a benchmark to judge the success of their management. While it is beneficial for participants to know about these guidelines, especially so during the first months after a diagnosis of diabetes, it becomes problematic when individuals must be autonomous decision makers and problem solvers, yet they perceive their ability to self-manage hinges on their adherence to guidelines which may not fit within their individual contexts. As suggested by Vallis (2015), self-management requires different outcomes, not just those defined by glycemic control, i.e., biomedical markers of disease. There is an urgent and critical need to consider that diabetes occurs in the context of a very full, busy life of which diabetes is only one aspect. Diabetes practices take place in a variety of spaces and places with multiple actors. Therefore, health care providers must increasingly shift their gaze to focus on the lives of individuals with diabetes, as the psychosocial issues of living with and managing diabetes are just as important as the biomedical ones (Vallis et al., 2016).

In the following sections I will discuss the participants' accounts of how they utilized the features of their pump to assist with diabetes management. In their accounts of practices, they blended biomedical knowledge with experiential knowledge including the pumps' many features in individualizing guidelines and recommendations. Specifically, participants told me about negotiating food intake and insulin delivery, counting carbohydrates, as well as considering the impact of protein and fat in blood glucose. They also revealed their practices with maintaining the efficacy of the pump as they discussed changing infusion sets, changing basal insulin infusion rates, as well as the perceived easy ability to take extra insulin for a higher than optimal blood glucose when using a pump (correction dose).

## Negotiating Food Intake and Insulin Delivery

Participants all learned to count carbohydrates and then to match the amount of insulin with the amount of carbohydrates ingested. The ability to count carbohydrates is a learned skill; one that is taught through diabetes education and then revised and refined through experience. A number of books and guidelines are used for this purpose (for example, see Diabetes Canada, 2018, 'carb counting made easy' available at https://www.diabetes.ca/managing-my-diabetes/webinars/carb-counting-made-easy). The amount of carbohydrates is clearly written on the packaging of some food items. However, for other foods, individuals need to determine the amount of carbohydrates. For example, half of a medium size banana has approximately 15 grams of carbohydrates (Diabetes Canada, 2018). To be more precise in carbohydrate counting, Diabetes Canada (2018) guidelines suggest that individuals weigh their food and then, based on the weight and the type of food, calculate the precise number of carbohydrates. For example, in the past I have used a Salter™ scale, where you can place an apple on the scale, type in that it is an apple, and the exact amount of carbohydrates will display on the scale. Additionally, individuals are taught to measure food-using items such as measuring cups and the information provided on packaging (Diabetes Canada, 2018). For example, there is information about the number of carbohydrates in ½ cup in a box/bag of rice.

Balancing nutritional intake with insulin delivery was a significant aspect of decision making and problem-solving practices when managing diabetes with a pump for these participants. The ability to make decisions and solve problems was highly contingent on various contextual factors and centered on the key aspects of eating patterns, types of foods eaten, weighing, and measuring foods, and taking boluses of insulin for food intake.

One of the perceived benefits of the pump across the participants in the study included the ability to eat what they preferred even when this was not eating healthily or well. This was perceived as being ‘normal’ and like others who have no dietary restrictions. As suggested by Pols (2016) this is an example of technology unleashing their users, or the ability for technology to lead to unexpected, unanticipated consequences. As Pols (2016) and Pols and Willems (2014) outline, while this ‘unleashing’ includes new and unexpected possibilities, this can also be a source of disappointment. The pump is not going to extend the possibilities to eat a diet that is not considered appropriate for the general population.

In this next example, the desire to eat to eat more junk foods is more easily satisfied when one has a pump rather than injections because the individual can take extended boluses to account for the increased fat in fast foods. From a sociomaterial lens, the participant enables the agency of the pump as an actor to support unhealthy food choices. As this participant explained, the pump afforded the ability to eat more take-out food, but this should not necessarily be considered a benefit of the pump as its indiscriminate use can propagate unhealthy choices. As a result, the agency of the pump in this instance, may be disappointing and the freedom and flexibility of the pump is bounded by recommendations for everyone, not only individuals living with diabetes.

> *I was [happy with the pump], and kind of in a negative way, I was happy 'cause I love take out, and I realized quickly that I could accommodate for take-out, easier, with pump… You know what I mean? Like, maybe I'm having take-out a little bit too much, when really the average Canadian shouldn't have it that much in one week. Take out the diabetes – that doesn't even matter – you know, a Canadian shouldn't have it that much, and here I had it on holidays, three times in one week. Like, what was I thinking, for my little old heart, you know? So, I think sometimes being on pump gives us a false sense of some – of 'normalcy' – air quotes [Part. 3]*

While all Canadians should eat well according to Canada's Food Guide (Government of Canada, 2021), the consequences for other individuals who depend on food intake for disease management (such as celiac disease) are neither immediate and nor do they pose such complex issues for decision making. Inaccuracies in weighing food items mean that the number of carbs is ill matched with the amount of insulin administered, which can lead to hypoglycemia, a life-threatening situation, or hyperglycemia which has longer term ramifications. The primary tool for preventing this mismatch is measuring and weighing food items.

### ***Weighing…Wait, What?????? You Can't be Serious????***

The concept of a 'diabetic diet' which was based on episodic insulin injections is outdated and these rules are especially irrelevant for anyone using rapid insulin, which includes anyone who uses a pump because it facilitates close alignment of insulin and intake through carbohydrate counting. While the insulin pump can offer more flexibility than injections in eating patterns, following a routine meal plan has been historically promoted as integral for diabetes management, regardless of treatment modality (Grinvalsky & Nathan, 1983). This advocacy for routine in meal planning and food consumption is still prevalent today, despite the ability to match insulin with carbohydrates consumed (Brazeau et al., 2013).

When beginning to carbohydrate count, individuals learn to weigh and measure foods to calculate the number of carbohydrates in each food portion consumed (Diabetes Canada 2018). This number is then entered in the pump, which already has the personalized insulin/carbohydrate ratios. The pump then provides the wearer with a recommended insulin intake. There is a flow of agency between individual and pump. In theory, this process is quite reasonable and provides a basis for deciding insulin intake. However not all foods come with exact guidelines for carbohydrate amounts and 'carb counting' is not an exact science. More problematic is that different sized foods have different amounts of carbohydrates, and it is extremely difficult to judge and count the actual amount of carbohydrates in a meal. It is not a simple 'input/output' mechanism. Therefore, adding food as another actor in the practice of carbohydrate counting makes each practice somewhat unfamiliar (although related) to the previous one. While the participant draws on previous practices, there is no way to exactly determine the accuracy of current, in the moment carbohydrate counting. As Participant 1 explained, precise 'carb counting' can be extremely challenging:

> *…if you're eating an apple, I mean, there's no nutritional panel on an apple, right. You think, oh this apple is probably – and I'll say a mid-sized apple. What's a mid-size, right? My mid-size and your mid-size are two different things. It's all about perception. So a mid-size apple is 20 carbs, so take 20 carbs, but maybe it was a little bit smaller than I anticipated, or a little bit bigger than what they were calling a mid-size apple, and that's gonna affect my blood glucose levels, right. Or if you're going to someone's house and eating something, and sauces are a killer. How much is in a sauce? I barely – rarely, I should say, eat pizza, not because I don't like it; because, depending on where you're getting it from, the pizza sauce is gonna wreak havoc. I'm either going low, or my sugars is in the 20's 'cause I don't know how much sugar they got in the sauce.* *[Part. 1]*

Weighing and measuring food was still recommended by health care providers even for participants who had used a pump for years (most of the participants had used the pump for at least 8 years). The purpose of continuing to measure is to guard against the tendency to "guestimate" and to under or over count carbohydrates, weights, or portion sizes. As Reiterer et al. (2018) acknowledge, precise carbohydrate counting leads to less glucose variability. The participants in this study indicated this practice of measuring despite years of carbohydrate counting experience was also considered a socially expected aspect of managing diabetes. In the following example, the participant resisted any suggestions to weigh food because they perceived it as both too much work and largely unnecessary compared to their preferred practiced of visual guesstimation which has always worked:

> *That's what my diabetic people – they're like, 'Do you have a scale?' Like, no, I'm not measuring –weighing food. You know, that's too much work. I just wanna look and just guesstimate, so most of the time I just guess from what I think is in it to what it says on the box. I don't think I've ever weighed anything, and she's [dietician] always on me – 'You should weigh this. Like, you should get a scale.' 'Nooo, no'. [Part. 14]*

For some, the notion of having to weigh food before eating it was absurd, to the point where it was even funny, *"'Cause it's stupid. (laughs) Like, who does that? (laughs) Are you crazy?" [Part. 15].* Yet, in discussing the rationale for not weighing food, participants were resigned to the possibility that the lack of precise measurement may lead to complications later in life.

> *Like, what else [do I have to do?]and to do all the measuring and the weights, and I just find it's just way too – it doesn't work for my lifestyle. Like, I – if it means it takes a year off my life, in the long run, then, you know, it's gonna take a year off my life, in the long run. I'm at that stage. [Part. 15]*

It was clear that in the context of carbohydrate counting, at times Participant 15 would refer to the guidelines on packages, and then, based on previous experience in carbohydrate counting, other food items were ‘guesstimated’. This was not an arbitrary guess – it was based on many years of examining foods, determining the carbohydrate amount, entering that into the pump and learning how effectively they matched their carbohydrates to their nutritional consumption. While guesstimating was not as precise as direct measurement it mostly worked:

> *I’m typically looking – first of all, I always look on the package – so, is it gonna tell me how much – how many carbs is in what I’m gonna eat, or an approximate? And if it’s something homemade, it’s just a judgement, so I’m looking at, okay, the palm of my hand, typically if its rice, would have such and such carbs, and then try and extrapolate that, but am I measuring and weighing? No. Unless it’s something specific out of a package and I know the exact amount, then that’s the only time I would enter a precise amount of carbs into my pump; otherwise, everything’s a guesstimate.* *[Part. 15]*

As suggested by Roversi et al. (2020), most carbohydrate counting errors are with large meals, in particular the evening meal. Unfortunately, carbohydrate counting occurs in an extraordinarily complex and challenging full life with diabetes and other things make take precedence. In their accounts, participants felt ‘compelled’ to weigh and measure because of recommendations from others, notably health care providers. Yet, Meade and Rushton (2016) argue that consistent over or under counting of carbohydrates may not adversely affect overall glycemic control as measured by HgbA1c but can lead to in-the-moment hypo and hyperglycemia at times. Additionally, Reiterer et al. (2018) suggest that while random carbohydrate counting may lead to increased glucose variability, systemic biases in the estimates is not expected to affect the overall control (as measured with HgbA1c) since glucose variability is usually implicitly accounted for in other therapy settings such as increased basal and correction doses. The features of the insulin pump make it conducive to mitigating in-the-moment glucose variability, thus minimizing the effects of any glucose fluctuations.

Judgments were made by some participants who also discussed ‘knowing’ what a certain number of carbohydrates ‘looked like’ in the absence of directly weighing or measuring. In the following example, Participant 13 described her experiential knowledge in 'knowing' what 40 grams 'looks like' during a supper meal. Based on her previous practices of eating her evening meal and taking an insulin bolus, she felt comfortable to be less meticulous in weighing and measuring her food. This demonstrates the spatiality and relationality of her diabetes practices, as she depends on knowledge developed in previous practices to assist with her problem-solving and decision-making in the moment. She describes how, at various times, she has weighed and measured, often in response to upcoming diabetes clinic visits, but she is too busy living her life to be encumbered with a strict routine of weighing and measuring. She described the risks of guesstimating as 'Russian roulette', acknowledging the benefits of precise carbohydrate counting but balancing this with her ability to live her life as she wants. In this scale, freedom and flexibility outweighs the risk of possible later complications.

> *Say I'm having 40 grams of carbohydrate. Now, if I actually sat down – and periodically I have when I've been going back to the girls at the clinic. I would say, 'Okay, that much', and I've weighed. I got all the scales, and I got the charts that say, you know, half an apple is this much and, you know, ten grapes, this, that – it's a load of bullshit. I'm too busy living and enjoying healthy living, knock on wood (laughs) You know? And there are times, I think, ooooh, I'm playing Russian roulette here, but I haven't got a bang on the head yet, so that's good. I'm not afraid.* *[Part. 13]*

Waiting for a "bang on the head" which signals the presence of long-term complications does not ensure those complications can be halted. Most participants in this study described themselves as "not meticulous" in weighing and measuring carbohydrates although there were instances of enhanced detail and preciseness. In the following extract, Participant 3 described in detail measuring and counting practices for a breakfast:

> *…I eat my breakfast from a measuring cup because I carbohydrate count, so I had Greek yogurt in a measuring cup – ¾ of a cup – and then I had two tablespoons of peanut butter, so I made sure that was all correctly counted.*
> *[Part. 3]*

Factors affecting variability in whether individuals are meticulous in measuring their carbohydrates were more impacted by past experiences with self-management compared to contemporary recommendations.

Participants also described varying degrees to how they bolused for food intake, with some preferring to take their insulin bolus prior to, during, or after a meal despite current recommendations that insulin should always be administered 5-10 minutes prior to eating. In their accounts, participants described what 'worked' and not necessarily what they 'should do'. As a person with diabetes who uses a pump, I had known that there may be differences with these practices, yet I was struck by the amount of variation in my sample of 15 people. I was also intrigued by participants' rationales in terms of their perceived level of experiential knowledge. Despite advocating for their expertise, they framed their experiential expertise in cloaks of mysteriousness and deviousness.

Many participants explained their various insulin bolus patterns that were outside the recommendations given to them. These accounts generally contained defiant words, and their body language and tone of voice were further indications of their perceived defiance of guidelines and recommendations. As suggested by Overseen (2020), individuals either use an active, passive, or antagonistic approach to using medical technology in diabetes self-management. *Active users* emphasize the importance of information and control to manage their condition, focusing on maximizing outcomes and wellbeing; *passive users* delegated much of the disease-related tasks onto the device as much as possible, rather than using the technology as a method of increased control; and *antagonistic users* are characterized by practices which include conflicts, ruptures, and breakdowns in the technology. Antagonistic users would often sabotage, misuse, or harm their technologies, by ignoring alarms, neglecting to replace vital equipment, or by throwing it at the wall in frustration.

Based on the accounts of the participants in this study, I would suggest from a sociomaterial lens that individuals consistently move back and forth between these different types of technology users. The participants consistently interacted with their pumps and engaged in various practices were that were *sensible* for them at the time. Yet at times their tone (loud, clear voice, sitting up straight with maintained eye contact, etc.) and words used to tell me what worked for them was best, were betrayed by a following sentence or two where they whispered, cast their eyes down, and told me that they do something but they know they 'should not'. Therefore, participants were active users attempting to maximize wellbeing and passive users depending on the functionality of their pump to inject insulin*, at the same time*. From a network approach of multiple actors, it is impossible to create siloed categories of how the participants in this study interacted with their pump. As Pols (2016) articulates, technology becomes something in its use; meaning and sense consistently changes with practices and as such, it is possible for categories to appear and vanish within moments of each other.

### ***To Bolus or Not to Bolus? When is the Question!***

Rapid acting insulins such as NovoRapid (insulin aspart) or Humlog (insulin lispro) are used in insulin pumps (Burchum & Rosenthal, 2019). The insulins have a fast onset (usually 10-15 minutes), peak (approximately 2 hours), and duration of action (approximately 4 hours) (Burchum and Rosenthal, 2019). As suggested by Slattery et al. (2017) the optimal time to inject insulin pre-prandially is 15-20 minutes prior to the meal to match the onset of the insulin with the onset of a predictive rise in blood glucose. These authors also suggest that delaying or taking a bolus midway through or after a meal could possibly lead to hypoglycemia as the pharmacokinetics of the insulin is not matched to the concomitant rise on blood glucose following the ingestion of carbohydrates. However, these authors also advocate that there are individual circumstances where exceptions to taking the bolus dose may apply.

In a large scale, international, multi-country study, researchers determined that physicians would often provide quite different advice for bolus insulin doses based on the exact same data set of glycemic values (Nimri et al., 2018). Therefore, one should question – if physicians provide different advice based on the same data set, how can we not expect individuals living with diabetes to do the same? Diabetes management practices exists in networks of actors, of which the individual living with diabetes is one. Therefore, it makes sense to consider as networks and practices shift and shape (and are shifted and shaped by) various actors, the timing and amount of insulin boluses would vary. However, in their accounts, participants described these variations as deviousness.

> *I find I do better if I take it, you know, a little bit before I eat. If I'm preparing my meal, unless I'm already a bit low, I'll give my insulin, you know, ten or fifteen minutes – maybe twenty minutes, even, before I'm ready to eat it, because I know I'm gonna be high by the time – if I take my insulin when I sit down, or if I'm eating and I bolus, I'm already lost; I'm already gonna be too high, you know.* *[Part. 6]*

The participants who described taking insulin boluses prior to the meal as per current recommendations did so specifically to maintain a stable blood glucose and to prevent hyperglycemia. They felt this approach worked for them and did not attribute the practice to either the insulin pharmacology or the best practice recommendation. It simply worked to manage their blood glucose:

> *I find if I bolus a few minutes before I eat – like ten minutes before I eat – I get a better blood sugar than if I bolus when I – just as I'm sitting down, and that's what they're saying, now, you shouldn't be doing anyway.* *[Part. 12]*

The rationale for bolusing during or after the meal is grounded in the knowledge that one cannot know in advance, exactly what one will eat. If there are 80 grams of carbohydrates on the plate and the appropriate, matching amount of insulin is taken, the individual must then eat the whole plate of food, even if they are satiated half-way through the meal. They are obliged to eat everything on the plate to prevent a low blood glucose caused by not having sufficient carbs to use up the amount of insulin. Therefore, not taking the bolus prior to the meal is a means of preventing hypo- or hyperglycemia, but more importantly, it is a calculated decision:

> *During. So, I know. You look at what the recommendations, and again, people say, 'Oh, you have to bolus', you know. I'm on the fast acting or Humalog, so 'Oh, you have to bolus right before you eat', but, honestly, I don't know how much I'm gonna eat, so if I'm sitting down with a plate of food, I'm not gonna take eighty carbs because I know there's eighty carbs on that plate. I'm gonna wait 'cause I might only want to eat forty of those. If I take my insulin right before, and I take eighty, then I'm forced to eat eighty carbs. I'm forced to eat all that plate, when in actual fact, I may only want to eat a half.*
>
> *[Part. 1]*

Having diabetes, using an insulin pump, and carbohydrate counting calls on individuals to 'know' exactly how much they will eat prior to starting a meal. This can be problematic as while individuals can count the carbohydrates precisely, there is no precise measurement of hunger or feelings of satiety. Yet, an implicit assumption of the guidelines and recommendations is that individuals with diabetes can and should have this knowledge to manage effectively (Ellis et al., 2017).

> *Because, a lot of times, I don't know – it depends on how hungry I am, I may go back for seconds, so I may eat more or less than what I anticipated I was gonna eat, so I find afterwards gives me probably more accuracy…*
>
> *[Part. 15]*

The decision to take an insulin bolus before meal was also based on considerations of the pump placement. In the following example, Participant 1 stored the pump in her bra which meant there was no discreet - or even what she considered to be a socially acceptable - manner of accessing her pump when eating at work or in a restaurant. As a result, she would begin eating and then excuse herself mid-way through the meal to go to the washroom to access her pump and take her bolus. She acknowledged that this may increase risk of hyperglycemia and was prepared to correct this as needed but this possibility was not as important as her need to be socially appropriate:

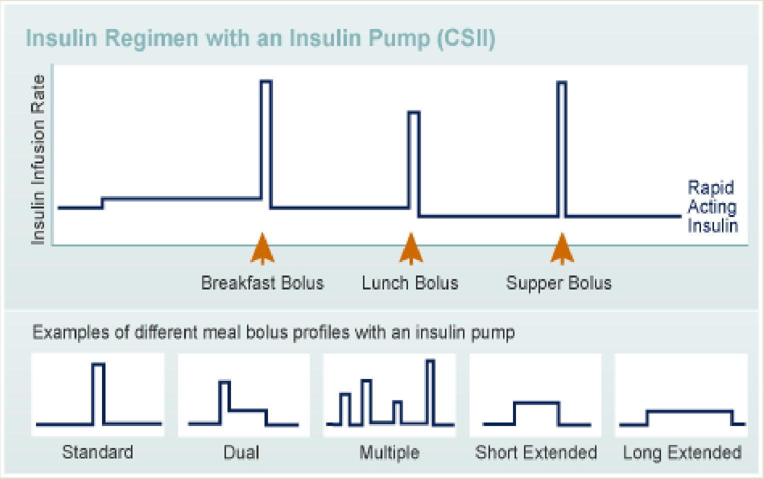
> *If I was at work, if I was out eating somewhere, outside, in a restaurant, am I gonna take that pump out of my bra, at the table? Absolutely not. So, what I would find is that I would eat, and twenty minutes or so later, I'd excuse myself to go to the washroom, and then I'd go in there and take my insulin. So, in actual fact, I mean, I'm taking my insulin twenty or so minutes after I'm eating, so, obviously, my sugars is after increasing, and I'm gonna pay the consequences of that after, and do those corrections for a couple of hours, after.* *[Part. 1]*

In addition to deciding when to take insulin boluses, participants also had to consider how to take the bolus as the pump offers the ability to take insulin over longer periods of time, rather than all at once. In this manner, the pump provides extra means to mimic the pancreas, beyond anything afforded by injections.

### ***Navigating Bolus Waves: Dual/Extended, Square/Extended, or Straight-up???***

The pump provides more ways for obtaining insulin than injections. When an individual takes an injection of insulin with a syringe, the entire dose is injected at once. As shown in Figure 5.2, there are several options for infusing bolus insulin through pumps. The full dose can be taken all at once (same as injections), the dose can be split and some proportion of the dose taken now and the rest extended over a certain period of time (*dual bolus* with Medtronic pumps and *extended bolus* with Omnipod and Tandem pumps), and the full dose can be extended over a period of time (*square bolus* with Medtronic pumps and simply *extended bolus* with Omnipod and Tandem) – three hours for example.

**Figure 5.2:** ***Bolus Insulin Injections***



(https://bit.ly/33wN23L)

Dealing with meals with higher fat and/or protein content can be accomplished through using the dual or extended bolus feature of the pump. This works for meals higher in fat as well as protein as they both break down slower than carbohydrates and impact blood sugar later. (El-Hussein et al., 2018). As suggested by Fortin et al. (2017) the major concern with meal planning and carbohydrate counting is the ability to estimate the amount of fat in a meal as well as difficulty with meals that are unpredictable such as those in restaurants or that occur over an extended period.

Over time, one becomes accustomed to using the various features of the pump to mimic how the pancreas would function in response to eating patterns. Despite this growing knowledge, participants found they still needed educated guessing to decide when and how to use the extended bolus feature; participants considered this as one of the greatest benefits of the pump in terms of physiologically matching the pancreas' insulin function:

> *I guess I've been doing it so many years that it doesn't torment me at all. I use my dual wave basal on my pump, and it is a guessing game, I know that, but*

> *I'm ever diligent with double checking my blood sugars and then doing my corrections....* [Part. 13]

Participants needed extensive education to learn how to use the extended bolus features of the pump. As in the following example, this education generally occurs with the dietician and was appreciated especially because the focus was on how long to set the extended bolus. If the bolus is set too short (i.e., an hour), this will possibly lead to hypoglycemia or too long (i.e., more than 3-4 hours) it may result in hyperglycemia and ultimately will not be effective in maintaining target glucose.

Despite the increasing use of insulin pumps, there are inconclusive studies with respect to recommendations for the use of diverse bolus types and the recommendation is that their use is based on individual needs and requirements (Heineman, 2009). In the example below, this participant learned how to program a dual bolus prior to eating fatty foods which prevented episodes of hypoglycemia that resulted in rebound hyperglycemia after the hypoglycemia was treated. If the dual/extended bolus is not taken appropriately, i.e., not take over a long enough period, the individual might experience hypoglycemia as essentially the bolus is too high for the types of foods consumed.

> *… when I started on the pump, [dietitian] then had me reading all the nutritional labels and the fat content, and I was doing - I'll dual a bolus – and I still dual a bolus. Like, if I'm eating fatty stuff, I'll dual a bolus, and I finds that excellent because before [dietitian] showed me about the dual bolus, I was taking – dialing up say, okay I'm gonna eat 50 carbs, but if there's more fat in that food, which I was start – [dietician], she taught it to me – on the fattier foods, when I dual a bolus – before I was dualing a bolus, I used to run low then, right, because I was taking insulin, and then I'd go over in the cupboard and start eating, and then I drove my sugar the other way…* [Part. 7]

The square bolus could be used to extend the entire bolus over a certain period, especially if eating would be ongoing for several hours. As in the following example, one must have the mind set to do this – it requires preparation prior to an event as well as the *a priori* knowledge of the number of carbohydrates one will consume during a given time. Many people may not be able to estimate potential intake prior to a social event but most individuals do not need to exactly decide at the outset the amount of carbohydrates they will consume at the event. It seems, therefore, that individuals who use these features of the pump must have quite possibly, an unattainable knowledge base.

> *That's what [diabetes educator] was telling me – if you're going to, like, a wine or a cocktail thing, and you're picking, or a buffet, that kinda thing, but I've never done square. I guess you gotta get the mindset to do it…*
>
> *[Part. 7]*

Despite the many types of boluses available, not everyone used them. As illustrated in the following example, individuals not only learned to trust the pump, but needed to develop trust in the various types of bolus methods. Fear of hypoglycemia often leads to under-bolusing (or taking less insulin than needed) which may lead to hyperglycemia (Jones et al., 2014; Stuckey et al., 2014). As a result of this fear of hypoglycemia, some participants never learned to trust the various bolus types and appeared to use the pump in the same way they would employ an insulin injection or pen:

> *I never use the Square [bolus] never used it. I didn't because I couldn't trust it – I was afraid of it – that's what it was – that function that was in my pump. If I want to take insulin now, I took it. If I take it, and I eat, I dunno, a dish of ice cream in five minutes or ten minutes, I will shoot up for that.*
>
> *[Part. 9]*

In sum, one of the primary features of the insulin pump is its ability to deliver insulin at different doses and times. Extended bolusing refers to programming insulin doses over a certain period to adequately account for the kind of carbohydrate and the presence of protein and fat. Nevertheless, despite extensive education to determine the insulin effect or the effect of different types of food and which bolus pattern might work, some participants were reluctant to change the patterns they had learned prior to the pump and directly control insulin rates rather than trusting the technology. Depending on the context, participants also described examples where they effectively change the basal infusion rate of the pump to manage contextual changes in their lives, much the same as a pancreas would.

### ***Change the Basal? Don't Mind if I Do!***

Another feature of the insulin pump that participants described was the ability to turn the basal rate up or down depending on activity or other issues such as illness. During times of illness, because of physiological changes in the body, blood glucose may run higher and as such, there may be a need for increased insulin (El-Hussein et al., 2018). As the following example illuminates, the pump facilitates the ability to take additional insulin without extra injections to compensate for activity or illness:

> *I did once [used the temporary basal feature], when I was sick, yeah, I had bronchitis, and even though I wasn't taking much in [food] -- I was unwell, and it was a nasty infection-- and my sugars were up a bit, but it only went – the highest I had it was 110 [increased basal rate to 110% of the usual hourly infusion rate], yeah.* *[Part. 6]*

It took time to learn *how* to use temporary and different basal rates and *when* to use them (Heineman, 2009). Even when shown, without practice, neither trust nor comfort nor ease of use could develop. This could change when there was opportunity to see the difference manipulating basal rates could make. As Participant 4 explained, their knowledge of changing the basal rates was learned from others at Diabetes Camp, which they attended as a camp counsellor as well as a nurse on another occasion:

> *I didn't really touch my basals much, honestly, until I went to diabetes camp a couple of years – working at diabetes camp, I should say, and the kids, we'd always put them on temporary basals because they're out running around and stuff, and honestly, it never really occurred to me that I could and I knew the pump had the feature, but I just never used it until I was at camp and we were*

> *doing it for the kids, and I was like, oh, this is handy. Like, why don't I adjust these?* [Part. 4]

This knowledge of using temporary basal rates was interfaced with experiential knowledge of the body, sleep, and responses to blood glucose levels at night. Participant 4 continued to explain how she integrated information about current blood glucose, effects of going to sleep, and use of a temporary basal to reduce the basal insulin infusion. This was done to receive less basal insulin and thus to prevent hypoglycemia during the night:

> *If I'm low or on the lower side, going to bed, if I'm 5 [mmol/L], I'll put a temporary basal on at 80% of my regular, and I use that feature a lot on my pump, and I learned it from camp, pretty much. I suppose I was taught about it, but I never utilized it until I started working with these diabetes educators and other nurses, up to camp, who were doing it for their kids …* [Part. 4]

In cases of hyperglycemia, the pump allows for extra insulin to be taken as needed without having to take another injection. As many participants described, the pump enhanced the ability to effortlessly take extra insulin and thus correct a higher than optimal blood glucose.

**Correcting that Glucose.** There are times when blood glucose is elevated above target range (generally considered above 10.0 mmol/L) (Diabetes Canada, 2018). This may be a result of a lower than required insulin bolus or the glucose may be elevated for other physiological reasons such as activity, hormones, stress, or illness, etc. A correction (an extra single bolus of insulin) may be taken quite easily with the pump and this creates peace of mind and comfort that hyperglycemia can be addressed somewhat effortlessly.

> *I think the pump has given me the peace of mind that I can correct, and that if I do – if I hold steady with my carb counts, or "eyeballing," as the expression goes, I'm okay.* [Part. 13]

In the following examples, participants took extra insulin through the pump because their blood glucose was high. To take more than the recommended correction insulin amount, they had to manually input a number of carbohydrates that they were ‘not really eating’, to take more insulin. While pump guidelines recommend taking an injection of insulin if a correction from the pump does not appear to be working (Minimed 670G (Medtronic) User Guide, 2017; Omnipod User Guide 2017), i.e., bringing down a higher than optimal blood glucose, these participants made the decision to take more insulin through the pump. In this manner, they overrode the pump to take more insulin that they felt was necessary: “*No, I’ll keep trying through the pump, but I will give what they call fictitious insulin”. [Part. 11]* Here, ‘fictitious insulin’ is how more insulin is taken than would have been recommended for a correction or bolus dose with a meal. This term is more accurately described as ‘fictitious carbohydrates’, as while the actual amount of insulin is delivered, the inputted carbohydrates are not eaten. This decision making and problem solving is based on past experiences with taking the usual recommended correction or bolus dose within certain contexts. Participants learned when the recommended dose based on the pump settings would not work in certain instances. This can be considered a dangerous phenomenon – or alternatively, enhanced valuing the past experiential knowledge in certain circumstances over the knowledge from information on the pump’s display screen. *“I know, I’ve done it too where you override –I’m like, override, so I’m 5 units as opposed to 1.5 or something” (laughs). [Part. 10]*

Thus far I have discussed how participants employed the many features of their pump to mimic the function of their pancreas. The practices in this manipulation included weighing food and deciding when and how to take bolus insulin doses. Additionally, participants changed basal settings depending on factors such as exercise, illness, and stress and they used the pump to take extra insulin as required. Throughout this discussion, there are many actors including the individual, the pump, foods, scales, etc. All these actors exert agency and affect the agency of other actors. For example, when taking an extended bolus, the number of carbohydrates is an actor that influences the individual who inputs this number into the pump. The pump will then suggest an amount of insulin to be taken. In all their accounts of practices, the success of the practice depended on the agency of many actors, not only the participant.

In addition to how and when to take an insulin bolus, participants also talked about carbohydrate counting and other aspects of food intake such as specialty diets (e.g., the keto diet) as well as how and why they ingested sugary or 'sweet' foods. Participants described trial and error in attempting to employ current recommendations until they find the one that mediates safety as per recommendations and fit with their daily activities.

### ***Count your Carbohydrates…But That's Not All….***

An aspect of diabetes self-management education is individual nutrition counseling where individuals initially learn about the number of carbohydrates that they should take per day based on their size, age, stress, and activity level etc. According to the American Diabetes Association (2020), there is no 'one size fits all' approach when it comes to meal planning with individuals living with diabetes and as such, health care providers should be non-judgmental about food choices.

At times, participants perceived the suggested number of carbohydrates did 'not work' for them and they sought other options for carbohydrate intake. In the case below, the individual chose to trial a ketogenic diet to restrict carbohydrate intake and thus insulin intake. There is inconclusive evidence about the benefits and risks of an extremely low carbohydrate, increased fat diet for those living with diabetes, and therefore current guidelines do not recommend a ketogenic diet (American Diabetes Association, 2020; Diabetes Canada, 2020; Turton et al., 2018). In this example the keto diet worked for a short time, nevertheless Participant 5 acknowledged he was not accounting for the high amount of protein in his insulin dosing as well. Despite explicit recommendations that people with diabetes should use caution with this approach, he felt comfortable in trying it for a short time.

> *…so, one of the things that I've done, I'm gonna say, since May or June of this year was I read Doctor Bernstein's book on the diabetic diet and I can't remember what it was called – Managing Diabetes or something – and it was about focusing on the keto diet, and managing your sugars by – I'd say, mostly by what you eat and how much you eat. So, I would say I'm midway there – I'm probably a little better than midway. …my carbs that I eat, per day, are around sixty. You know, I'm 190 pound guy, I'm gonna say I'm – I won't say I'm very active, but active and yeah, that's really what I eat in a day. When I actually – before I started it, I started tightly measuring my carbs because, with the pump, you measure per meal but not the total day and then what my doctor had told me was, based on my size, I should be eating around 200-225 carbs a day. I was like, wow, that's a lot, and when I actually checked it out, I struggled eating 150 [grams of carbs] but when I started being in tighter control, no, I didn't really need them [carbs] but I have a lot more energy, eating a lot less, and just focusing on eating when I need to. Things are going well. [Part. 5]*

After trialing this diet for some time, in our second interview, Participant 5 expressed how this diet did not work for him as it was difficult to account for the high amount of protein in this diet. He did not alter his eating patterns and stop the ketogenic diet to adhere to the recommendations; it was because he discovered that it did not work for him:

> *And no, I've – didn't do well on the keto because I kept having lows or having highs. I'd go from doing okay to going high, and then dropping really low. The problem is – I actually had a problem is I never really measured or took insulin or bolused for proteins. [Part. 5]*

I reviewed Dr. Bernstein's book, a physician who was originally an engineer and upon receiving a diagnosis of diabetes and struggling to manage, used a very low carbohydrate diet (30 grams per day), which assisted him to achieve optimal glucose levels (Dolson, 2019). After discovering that a low carbohydrate diet can assist to achieve blood glucose stability, Dr. Bernstein became a physician and subsequently an endocrinologist. Notwithstanding Dr.

Bernstein’s notoriety, an extremely low carbohydrate diet is not in keeping with current recommendations that at least 45% of the daily food intake should be in the form of carbohydrates to supply enough energy to the body per day, especially the brain (American Diabetes Association, 2020; Diabetes Canada, 2018). Despite these recommendations for carbohydrate intake, the participant felt that the number of individualized recommended carbohydrates per day did not work for him, and he felt comfortable to trial a diet outside of the recommendations. He was willing to seek and utilize other sources of knowledge.

In carbohydrate counting, individuals subtract the fiber from the amount of carbohydrates to obtain the net carbohydrates per meal/food (Diabetes Canada, 2018). If there are 25 grams of carbohydrates and 3 grams of fiber, the individual should take the appropriate insulin for 22 grams of carbohydrates. However, in some circumstances as in the following example, this is not possible. As Participant 9 revealed, she discovered challenges in calculating the effect of fibre and net carbohydrates through repeated instances of hyperglycemia as she was consistently taking insufficient insulin. In other words, fiber means less insulin is required.

> *I can’t even take the fibre from the carbs and give me the net. My body won’t let me do that, never did. So, I don’t do the net, never did. I can’t do it. My body won’t let me do it.* *[Part. 9]*

In spite of this participant’s adamant body language and tone of voice, the words she chose, ‘her body wouldn’t let her’ seemed to absolve her of rejecting the recommendations as it was her body, not ‘her’, that kept her from meeting the recommendations. In this manner, she was theoretically okay with the recommendations and kept trying to employ them, but in the end, it was ‘her body’ that would not allow it.

### *Live the Sweet Life…but Live it Quietly*

Individuals living with diabetes, as with other Canadians, should eat according to Eating Well with Canada's Food Guide (Government of Canada, 2021). This includes eating a variety of foods – vegetables, fruits, grains, dairy, etc. and in the context of sitting with others to enjoy food. Yet, there is still a social assumption that people with diabetes should not consume sweets or junk food such as pizza. These assumptions represent historical remnants of very restricted eating patterns when individuals established weekly food guides and every component of each meal and snack was predetermined and measured to fit the insulin regimen. Often, little in the way of sweets or treats were included. Yet, as Participant 9 explained, individuals living with diabetes do eat sweets and junk food, but their accounts reflect deliberate risk management as well as indications of deviance. In the following exchange when I asked Participant 9 about eating sweets, she lowered her voice, laughed, and asked if she could lie as she considered that it is not socially acceptable for her to eat sweets. She explained that while she does eat sweets, it is done so in the context and consideration of other foods, for example, when she will eat the dessert and how much she will have. She told me she will eat sweets and junk food foods in her home. In this manner, she balances what she considers to be socially acceptable eating patterns based on current or former recommendations with what she feels is right for her:

> *Can I lie? I'd be lying if I said, no, I'm not eating that, and that's not true. If I went out for dinner, I don't eat dessert. We went to [restaurant] the other day, and I had two pieces of fish and chips, and then we ordered turtle cheesecake to take home. I can't eat turtle cheesecake now [during the meal]. Two pieces of fish and chips, I'm already up to 14 or 15 [mmol/L] in my sugar by the time it starts digesting. So anyway, that evening I got into the cheesecake.*
>
> *[Part. 9]*

Eating certain foods such as pizza can be considered a 'food risk' when managing diabetes. As Participant 1 explained, there is no magic way to ascertain the exact amount of carbohydrates and fat in a slice of pizza and what works at one point in time may not work in another. In addition, despite knowing that her blood glucose is higher than target, she will still eat and deal with the consequences later simply because she is ‘human’ and, like everyone else, desires to eat certain foods at certain times.

> *So, food risks, for sure, 100%, all the time. Do I go out and eat things that I don’t know what the exact carbs is, that know that’s gonna put my sugars up high? 100% I do. I’m human. I’m not perfect. Yeah, so, I mean, I eat pizzas – that’s one of those big things, so my husband loves pizza, and he’s asked me before, ‘Why don’t you eat pizzas?’ ‘Cause pizza’s one of those foods that I don’t know what – does the sauce have this many carbs? So, I’ll go and eat one slice of pizza, and I’ll take thirty carbs, and I could be four [mmol/L], and then I’ll go to another place and I’ll say, you know, thirty carbs last time put me at [4 mmol/L], I should be good. I’ll take thirty carbs and I go up to twenty-four [mmol/L]. I don’t know. So, I do eat pizza, knowing that I don’t know what the end result is gonna be like, right, or maybe sometimes – the other day I was – my sugars were twelve [mmol/L]. I was really hungry. Should I have waited ‘til they come down a little bit? Probably, but I was hungry, so I ate and I bolused, and I went up before I came back down. Right, my sugars went up before it came back down, so yeah, 100%, with food, you know, I eat stuff I’m not supposed to eat, you know, according to the rules, right, but I eat stuff that I’m not supposed to eat or is not great for blood sugar, but at the end of the day, I’m human, and I have a life, and, you know, that’s it.*
>
> *[Part. 1]*

In summary, using an insulin pump was not simply a matter of attaching the pump and diabetes was automatically managed. There were many features of the insulin pump and regardless of how much they learned about them, participants consistently integrated this learning with current contextual factors and past experiences to make decisions about how to use the pump features. Decision-making and problem-solving were not simply matters of knowing about the pump but fitting the pump’s features into real life. Participants considered the many ways to take insulin in the form of various bolus types: dual, extended, or square as well as how the pump provided information of the amount of insulin that was still in the body after a bolus (the ‘active insulin’ or ‘insulin on board’). In addition, participants found that the ability to respond to contextual changes such as increased or decreased activity as well as illness through changing basal settings as well as taking extra insulin doses to correct hyperglycemia excellent tools in their diabetes management.

In the next section I will discuss how participants integrated pump guidelines and recommendations with other information such as insurance coverage as well as current contexts in deciding the most appropriate time to change their insulin infusion set.

## Changing My Lifeline – Over and Over and Over…

Pump infusion sites must be changed regularly – every 72 hours (Minimed 670G (Medtronic) User Guide, 2017; Omnipod User Guide, 2017). In addition, recommendations for best practices in site changes includes that the infusion set should be changed earlier in the day rather than later, especially not before late evening and/or just before bed (Minimed 670G (Medtronic) User Guide, 2017; Omnipod User Guide 2017). The rationale is that if the infusion site is changed earlier in the day, it is easier for the person to notice issues with the infusion or that they have not received any insulin because they are awake and can monitor body cues that might indicate hyperglycemia, as well as check blood glucose manually using a meter or monitor CGM readings.

Participants told me that they changed their pump infusion sets at varying times of the day. In our interviews, they constructed this decision and practice as deviance – something that they knew could be dangerous for an obvious reason- checking the patency of the infusion set – but which works for them in the way they choose to do it. In the following example, the participant felt changing the site was best completed just after the evening shower. While this participant did acknowledge the rationale for changing the site in the morning, they felt changing the site fit better after having a shower because they were clean rather than following the dictum that **it should be** completed in the morning.

> *I like changing it after a shower in the evening, and I know that's probably not the best time to change it, but I like changing it when just, it's all cleaned around where I'm gonna give myself the shot kinda thing, right. It's either first thing in the morning, out of the shower, or the last thing at night, out of the shower, unless I need insulin in the middle of the day and I got three units of insulin, so I only have like an hour and a half left to do it, then I'm kinda like, screw it, okay, I'll just do it now and get it over with.* *[Part. 14]*

Despite Participant 14 acknowledging changing the insertion site when it was conducive to his needs, he also berates himself for not changing it in the morning, stating that it is **'terrible'** the way that he does it – although it works for him. It was clear to me there was an internal struggle of sorts – the need to be independent and complete this practice as fits best in life, yet this practice was inconsistent with the best practice recommendation. Here, Participant 14 centers his human agency and does not consider the agency of other material actors (comfort, feeling if cleanliness after a shower, etc.) in the practice of changing his infusion set. In so doing, he constructs a vertical alignment of actors and knowledge (Andrews & Duff, 2019), but also problematically, of blame as well.

> *I should [change infusion set in the morning]. I don't normally. **I should, but I rarely do it, and I know that's terrible, but it is what it is**. I guess, like, the reason – I get the reasoning behind it. It's like you should always do it first thing in the morning, so that if something happens at 10:00, then you have the rest of your day. If you do it at 9, you have an hour, and then you're going to bed, and then you're asleep, then something happens, then you're – you know, then something happens, something ha – like, I dunno**, I'm fine with doing it the way** I am.* *[Part. 14]*

Sometimes participants changed the pump site before the evening meal with the rationale that if the pump site is not working and there is an interruption of insulin, this will be known as blood glucose will increase prior to going to bed. The decision to not change the site in the morning was often linked to wanting to avoid having to manipulate the pump and change it during work hours.

> *I always change around supper hour. I don't change in the morning because, if I'm going to work, and the system fails, well I gotta fool around with it at work. I don't change after supper because it could affect me two or three hours out and I don't like that, so usually around 4:30/5:00, so then if I have my supper, well I know I'm taking carbs, so if it's alright an hour or so after and I'll check it, and if it's fine, well it's working. If my sugars shoot up, high, and I ate a normal supper, I know there's trouble, right?* *[Part. 11]*

Changing the pump earlier in the day increases the chances that infusion malfunctions may mean no insulin is administered. As the insulin pump only has rapid acting insulin, in the absence of any insulin delivery through the pump, blood glucose can increase rapidly, and this can be physiologically dangerous and possibly precipitate DKA. Despite this risk, participants in this study delayed changing the infusion site beyond the recommended 72 hours, during the evening, and before bed. Participants varied in their rationale for going beyond the 72 hours between infusion site changes. Commonly, the rationale was related to a stable blood glucose, as is illustrated in the quote below.

> *Well, last night I was supposed to change – that was my third day – and I said to [wife], 'I'm waiting until tomorrow to do this now.' I said, 'We've been having really good sugars on that side there, and it was the last – it was the fifth – the fifth on the right side, and now we gotta go to the left', I said, So I'm gonna wait 'til tomorrow morning', and so I did that. ... but it's always three – usually three days, and then we know, and then it'll get fouled up, and then we'll go to the fourth day, but not very often.* *[Part. 8]*

Conversely, there were accounts of always changing the infusion set within the recommended timeframe. Vigilance with changing the infusion set was heightened as this participant developed cellulitis when she previously left an infusion site in place for longer than the recommended 72 hours. This past experience influenced current decisions with respect to changing the site rather than the current recommendations from the pump company:

> *And when I went to see [diabetes educator name], I think it was, anyway, she gave me an antibiotic ointment, and it was scary. It was the first time – first and only time – and thereafter, I make sure it's [changing the infusion set] every three days, and now the pump will beep and say it's three days since you had your infusion and whatever, since your infusion change. Now, it might not only be another half a day – I know that. It reminds me, but maybe tomorrow morning it'll be when it's gonna change. So, from that, that site now is still tender. If I lean in over the counter, I think, oooh, my needle's not there, but that spot is tender.* *[Part. 13]*

Many participants discussed financial considerations in changing the pump infusion set as well as issues in relation to the site itself. In the following examples, participants know how much longer they can leave the infusion site in place to mitigate the cost of the supplies. Cues to change the site included unstable blood glucose as well as itchiness at the infusion site. According to Messer et al. (2018) itchiness at the infusion site is a common problem, especially when sites are left longer than the recommended 72 hours. As a result of many other factors such as time to change, privacy, insurance coverage etc., individuals living with diabetes and using pumps tolerate the discomfort of skin irritations as a result of diabetes devices, as they place higher value on the freedom and flexibility, rather than skin discomfort (Berg et al., 2018).

> *… it's [infusion set change] usually about 4 or 5 days I can get out of 'em – about 5 – yeah, and if my sugars are starting to go wonky [higher than expected] or sometimes I find my sites that they start to get itchy, and I'm like, 'okay, now it's time to change it'.* *[Part. 4]*

As a result of inadequate or no insurance coverage, hardship was evident not only in obtaining the pump but in managing according to recommendations when using the pump. Financial stressors related to diabetes such as the inability to purchase supplies can lead to diabetes distress which can in turn impact diabetes management practices (Tanenbaum et al., 2016). As with first obtaining the pump, insurance coverage is also an actor exerting agency in changing infusion sets. Having insurance coverage affects the individual's ability to change the infusion set as recommended. Thus, insurance coverage is agentic in that it affords the individual the capacity to act.

As explained below, as a result of lack of insurance coverage, supplies may be used that are not optimal and at times, expired. This creates a risk in that the appropriate amount of insulin may not be received, possibly precipitating hyperglycemia and resulting in DKA. Here Participant 4 relied on stored supplies from several years ago that she received as a result of the government's pump coverage program for those under the age of 25 years. This participant perceived a difference between using expired infusion sets (which they considered to be okay) as opposed to using expired insulin (which was not okay). As such, there was a boundary across which this participant, although financially stressed in management, would not cross:

> *I'm really going through that right now, so, luckily, I have a good stockpile of supplies 'cause when I was off the pump, when I was younger, they still sent me supplies 'cause the government program, you know, provides you when you're under 25, so I have a good stockpile at home and, like, there's nothing majorly expired, and, I mean, infusion sets [may be expired]. [But] I'm not using expired insulin, but the…* *[Part. 4]*

Some participants also used their CGMs for longer than the recommended number of days. Some participants used them for up to 14 days (approximately nine days more than the recommended number of days for some CGM such as Enlite™ which is integrated with Medtronic pumps) because they had insufficient insurance or had to pay out of pocket. This enhances the risk of developing scar tissue in the sensor insertion site leading to the possibility of false readings. Participants voiced frustration about the lack of coverage in general for people with diabetes who are attempting to intensely manage their illness.

> *I have insurance, but they never covered sensors, so, and it's only now that I started at [place] back in [month], that they covered the Medtronic sensor, so I started the sensor about two years ago, so all that expense was out of pocket, so what I was finding, even though they recommend that you change every five*

> *days, I was probably changing mine – I was getting close – maybe almost twelve to fourteen days because it was so much money out of pocket that I'm trying to get every ounce that I could before it actually falls off my body type thing, so and that leads to more skin irritation because the adhesive's on that spot for longer period of time, and so you run into a few issues like that, but I saw the benefit of having CGM and I wanted it, but cost is a huge factor, and being able to keep on it on the long term basis, and it's unfortunate that, you know, more insurances don't cover it, the government doesn't cover it. Nobody wants to cover diabetic supplies for some reason, even though it can prevent a lot of long-term expenditures on the healthcare system if people were more cognitive of what their sugars are and knew what their sugars are – and could control their sugars, better, which you can with CGM.* *[Part. 15]*

In sum, participants all recounted pump guidelines and recommendations with respect to changing their pump infusion sets, yet they all deviated somewhat from these expectations. They changed their infusion sets as often as their individual lives would allow consider the time needed for changing as well as the cost of the supplies. While their practices worked for them in their particular contexts, participants also berated and condemned their practices as they were 'not what they were supposed to do'. In this manner, there is a divide between what one should do and what one is able to do, leading to a sense of not managing well enough – of not following guidelines and recommendations as they are written.

## Conclusion

In this chapter, I have discussed the many features of the pump which make it conducible to mimicking the actions of the pancreas, such that those who use a pump can emulate an internal homeostatic feedback mechanism from the outside of their bodies. As participants told me, negotiating food intake and insulin delivery were significant practices associated with using the pump to manage diabetes. Specifically, participants discussed the implicit necessity of weighing and measuring food to figure out the amount of carbohydrates, timing of boluses, as well as other aspects of food considerations such as how to calculate net carbohydrate intake, other diets such as the keto diet, and the place of eating 'sweets' in diabetes management practices. In addition, participants revealed how they integrated pump guidelines and recommendations with their experiential ability in making decisions and solving problems about how often and the time of day to change their pump infusion sets.

Throughout the day-to-day and minute-to-minute using the pump in their diabetes management, participants had to continually engage in the practice of monitoring; in a never-ending cycle of attending to and watching out; of vigilance expressed through surveillance practices. In the following chapter, I will turn to these monitoring practices as they represent the third theme in this analysis: *The Constancy of Surveillance*.

# Chapter 6: The Constancy of Surveillance

# Chapter 6: The Constancy of Surveillance

To self-manage well, participants described a *life of constant surveillance* especially in relation to blood glucose, the third theme in this analysis. Participants monitored their blood glucose as a means of always knowing their diabetes management status (i.e., through knowing their blood glucose values and hence proxies for management status) through various practices such as attending to body cues, manual blood glucose checks with a meter, and monitoring blood glucose readings from a Continuous Glucose Monitoring (CGM) system or through flash monitoring such as with a Freestyle Libre™. Participants' discourse included ***who*** performed the surveillance and the meaning of 'surveillance by others' on diabetes practices. For instance, participants often requested and welcomed surveillance by others. However, there were times when participants did not request this type of surveillance; they perceived it negatively which led to feelings of blame, shame, stigma, and marginalization. Participants made sense of their practices in that to be a competent manager it is imperative to engage in surveillance.

In the previous two chapters I outlined the *local* practices of beginning to learn about and use a pump, as well as increasingly blend the pumps' features within individualized practices of everyday diabetes management. As I traced the flow of diabetes practices in this sample of participants, I turned my attention to surveillance practices, which I conceptualized as more *global* diabetes practices. As suggested by Nicolini (2009), I am switching my lens back and forth between practices; in essence, I was 'zooming in' and 'zooming out' between the local and the global. I have previously outlined practices that were central and specific to the use of the pump and the practices that I present in this chapter as well as the next, are more expansive in that the pump, while still an actor, shifts in importance and at times, is afforded less agency. Yet, to engage in surveillance practices, the participants relied on knowledge developed and meaning created through previous practices of learning about and using the pump to now engage in surveillance practices in different places over time, denoting the rationality, temporality, as well as the spatiality of practices (Hultin, 2019).

Throughout this theme, discourses included how enhanced surveillance was necessary to validate good management, yet too much surveillance could lead to feelings of inadequacy when blood glucose values were not within target range. Fittingly, participants described a range of 'always needing to know' to 'I don't always want to know' especially when there was a possibility of visualizing a blood glucose value outside of optimal range which could spur feelings of inadequacy and poor management. As they drew from ideologic expectations for self-management, participants actively investigated the reasons behind their experiences of blood glucose fluctuations that inevitably started with themselves in that they always questioned first what **they** did to cause the high or low glucose, rather than considering any other contextual/environmental factors. As such, participants continued to center themselves within their practices, vertically aligning actors, and creating hierarchical agencies (Andrews & Duff, 2019).

All participants maintained a constant state of vigilance in their diabetes practices. As described by Meyer and Lavin (2005) in relation to nursing, vigilance is the careful art of always 'watching out'. Similarly, participants in this study expressed an ongoing necessity to 'watch out' in managing their diabetes. The ongoing monitoring, checking, measuring, listening, responding, and attending was prevalent in all interview data as surveillance practices. Whereas vigilance refers to the art of watching out, surveillance practices are conceptualized as those which execute this vigilance. Participants' accounts were indicative of their constitutive entanglement with technologies – they monitored their diabetes status through the relations between their bodies and their technologies such as glucometers, Freestyle Libre™, as well as CGM systems to surveil blood glucose values and patterns as proxies for good management as well as for the presence of physical complications. In this manner, the participants quantified their bodies and in doing so created surveillant assemblages of various sociomaterial actors (Haggerty & Ericson, 2000; Lupton, 2013b). Practice networks became more expansive with actors such as physical and emotional hypoglycemia symptoms, blood glucose meters, CGM systems, shifting in and out of importance and thus with more or less agency, depending on the practice.

Decisions made and problems solved depended upon heightened awareness as a result of practices that extended from those to promote self-awareness, to include monitoring from family and friends, coworkers, health care providers, and the general public. Additionally, participants surveilled others especially as they assessed their own diabetes practices in contrast to others living with diabetes. They also compared and contrasted their health promotive and preventative practices with others who did not live with diabetes. In this manner, participants manifested their expertise by demonstrating the importance of their experiential knowledge in diabetes self-management. Surveillance was constant and affected every facet of management. While this was so, the frequency and intensity of surveillance practices were different at distinct periods in life as well as strongly dependent on the context – for example, during and after a hypoglycemic event, during exercise, or an important celebration. Surveillance was more or less welcomed depending on who was doing the surveilling, and whether or not the participants self-initiated it. Please see Table 6.1 for an overview of the theme and sub-themes.

**Table 6.1*: The Constancy of Surveillance Theme and Sub-themes***

| **Theme** | **Theme Description (brief)** | **Sub-themes** | **Sub-themes Description** |
|---|---|---|---|
| **3. The Constancy of Surveillance** | Surveillance was necessary for good management. Participants surveilled themselves through attention to body cues or through technology. The main target of self-surveillance was blood glucose, and a stable glucose was a proxy for good diabetes management.<br>Others often surveilled the participants' practices which either enhanced perceived safety and security, or led to blame, shame, and stigma. Participants also surveilled others and perpetuated ideologies of self-responsibility for health. | 3.1 Self-surveillance | Participants surveilled themselves – mainly their blood glucose through attention to body cues, checking blood glucose with a glucometer, or monitoring CGM or Freestyle Libre values and patterns. They also surveilled for potential physical complications. This was necessary to manage well. They actively investigated glucose fluctuations (beginning with what they did or did not do) and demonstrated self-blame and guilt with fluctuations, especially hyperglycemia. |
| | | 3.2 Surveillance ***by*** Others | Others (family, friends, co-workers, general public) surveilled participants. Participants either requested (for enhanced safety and security) or was unwelcomed, leading to blame, shame, and stigma. Participants responded by educating others about diabetes management using the pump. |
| | | 3.3 Surveillance ***of*** Others (Us versus Them) | Participants surveilled others (with or without diabetes) and compared their diabetes management and general health promotive practices to others; presented themselves as 'good' managers as a result of their practices as well as in better health, generally. |
| | | 3.4 I Worry, Therefore I Surveil | Participants surveilled because they worried about physical complications, glucose fluctuations (mostly hypoglycemia and loss of bodily control), as well as getting older or sick and not able to care for 'self' (loss of 'self-control' and thus self-management). |

### Self-Surveillance

Self-surveillance practices included paying attention to body cues and monitoring blood glucose with a glucometer, a Freestyle Libre, or with a CGM such as a Dexcom. This surveillance provided information about current in-the-moment blood glucose levels and patterns over time. With this information, participants felt better able to solve problems and make decisions in the midst of current and future contexts. Participants revealed how diabetes was an ever-present concern without relief and their vigilance needed to match this persistence:

> *Absolutely, it is on my mind from the moment I wake up to the moment I go to sleep, and even when I'm sleeping. It's something that I have to be in the know of, knowledgeable of and competent of, every minute of every day. If I let it go or let it slide, it can go in either direction – high or low – which could mean in a lot of trouble. So yeah, I'd be a fool to say that it's not a major part of my life and it's not a lot of work 'cause it absolutely is. If I wanna exercise, if I wanna eat, if I wanna laze on the couch, well how that's gonna impact my sugars, right?* *[Part. 5]*

Many participants expressed the intensity of surveillance and the impact on daily life. While surveillance practices moved back and forth in importance depending on immediate contextual factors (i.e. risk for hypoglycemia) and longer-term factors (i.e. complications as a result of prolonged and consistent hyperglycemia) and general feelings of illness associated with both, it provided the background reconnaissance for everyday activities such as eating:

> *…it's a constant invasion of your day-to-day life, and I don't know if 'invasion' is the right word, but it's something that you're consciously aware of, day in and day out. From the time you're awake to the time you go to bed, it's a constant, so you're constantly checking your sugar; you're constantly adjusting your sugar; you're having to think about, 'okay, if I eat that now, then that means I got to take another bolus now', so it's all encompassing.*
> *[Part. 15]*

Diabetes represented an extra layer of attention, focus, thinking, and work in the day. In the following example, this participant always had diabetes on her mind and had to make time for it, in the midst of full-time work and caring for her family with two small children. And while diabetes was always there, sometimes it 'took a back seat'. As Patterson (2002) acknowledged, there is back and forth movement of illness and wellness in the background and foreground, depending on various contextual factors. Throughout this analysis, all participants experienced instances when their diabetes took precedence over everything and other times, they could effectively place it in the background. In this example, the participant had to make time for diabetes, and this was especially so when there is an issue such as hypoglycemia. Here, the surveillance is so mundane that it often becomes second nature, a subconscious awareness:

> *It's something that never leaves my mind; it's always there. I have to make time for it, especially having two young kids. Sometimes I put – I have to make time for my diabetes. Sometimes they [children] get put ahead of that, and it [diabetes] becomes, like I said, second nature... [Part. 1]*

For many participants diabetes was 'always there' and infused in every facet of life, however it was possible to maintain some boundaries so that diabetes was kept in the periphery to not consume too much of life and attention. Most participants referred to diabetes self-management as *work*, although Participant 14 perceived that he could mitigate the pervasiveness of his diabetes by not seeing it as work but as *routine life*:

> *I try not to look at it as work. Like, it's not – yeah, it's more like a lifestyle than work. I try and, you know, make it as like a – something that I just gotta do, as opposed to something that I've got to work at. So, if its work, then it's something that you actually gotta think about, and continuously, like, on your mind, but if it's – you know, for me, it's just there. It's been – it's more like a – I dunno, it's like a – in a way, it's work, but, for me, I try not to let it take over my life. [Part. 14]*

As suggested by Corbin and Strauss (1985) and Townsend (2011), individuals living with chronic illness work to manage the illness and integrate it into their lives. There are three types of work in managing a chronic illness: *illness related work* which involves symptom management, crisis prevention, and regimen work; *everyday life work* which includes daily tasks in life such as housekeeping, paid work, shopping, and activities such as eating; and *biographical or identity work* which is the continual renegotiation of life with chronic illness (Corbin & Strauss, 1985; Klimmek & Wenzel, 2012; Townsend, 2011).

In this study, the majority of participants referred to their diabetes management as 'work' in terms of the illness-related practices of monitoring blood glucose, using the pump efficiently and effectively, and planning and preparing for crisis intervention (mitigating blood glucose fluctuations). In addition, participants referenced how diabetes, the pump, and associated practices were a 'part' of them (identity work), and that diabetes factored into many life decisions such as which clothing to wear (everyday work). There were times, however, as with the above example, diabetes was so ingrained that it was possible to create boundaries where the management practices were not considered as 'work', but as a natural aspect of everyday life. This, in turn gave a sense of freedom and flexibility in not having to consider the all-encompassing nature of diabetes practices and thus provided some sense of 'normalcy'.

In sum, with respect to self-surveillance, the main domain of attention was blood glucose, surveilled as attention to body cues which represented shifts (i.e. low or high blood glucose) and objective measurement of blood glucose through a glucose meter (where a blood sample is checked), a Freestyle Libre, and/or a CGM system. As many participants told me, they always needed to be 'in the know' about their blood glucose such that they could make appropriate decisions. Knowing blood glucose values and trends was imperative to their ability to be seen by self as well as others as taking responsibility and thus a competent, effective self-manager (Duprez et al., 2020; Ellis et al., 2017).

### ***Internal Blood Glucose Surveillance: Attending to the Body***

In the absence of diabetes, the secretion of both insulin (to decrease blood glucose) and glucagon (to increase blood glucose) takes place internally by the pancreas and liver, respectively, in a feedback loop (El-Hussein et al., 2018). When blood glucose is low, insulin secretion decreases/stops, and glucagon is secreted. When blood glucose is high, insulin is secreted, and glucagon decreases/stops. In a person living with diabetes, this internal feedback mechanism does not work and thus the individual must manipulate this externally.

Knowing and listening to the body was a significant aspect of self-surveillance and formed a primary basis of diabetes practices. All participants experienced enhanced awareness of and response to cues from the body related primarily to hypoglycemia. Hypoglycemia is defined as a blood glucose of less than 4.0 mmol/L and the severity (mild, moderate, or severe) depends on the symptoms (Diabetes Canada Clinical Guidelines, 2018). With mild hypoglycemia, autonomic symptoms are present such as shaking and sweating, and the individual is able to self-treat. In moderate hypoglycemia, both autonomic as well as neuroglycopenic (symptoms as a result of the brain's lack of glucose such as confusion, tiredness, drowsiness) are present and the individual can still self-treat. With severe hypoglycemia, the individual requires the aid of another person to treat, unconsciousness may occur, and typically the blood glucose value is less than 2.7 mmol/L (Diabetes Canada, 2018).

Participants felt a range of hypoglycemia signs and symptoms; some were typical i.e., those that are taught during diabetes education classes such as sweating and shaking, and others which are not so easily recognized as hypoglycemia such as crying, numbness and tingling, agitation, frustration, and feeling 'funny'. Most participants in the sample ($n = 8$) reported that the experience of most combinations of hypoglycemia symptoms included anxiety which many described as panic. The participants' experiences were not 'textbook' and their classification of mild, moderate, or severe hypoglycemia was based on whether the combination of symptoms was typical or atypical for them (i.e. *not* whether symptoms were autonomic or neuroglycopenic as per Diabetes Canada (2018), but the *combination* of the symptoms) and whether or not the symptoms interfered with activities as opposed to the ability to treat.

**Table 6.2:** ***Symptoms of Hypoglycemia***

| **Hypoglycemic Symptom** | **Exemplary Quote** |
|---|---|
| Shaking | *"…if I'm 2.8 where I'm **shaking** and sweaty, and I'm like, okay, cramming everything in very quickly." [Part. 15]* |
| Sweating and freezing | *"Like, I've woken up in a cold – when you wake up when you're low, **you're soaked**, but you're **freezing at the same time**. It's a weird feeling. So then I usually stumble out to the kitchen, and just open the fridge or open the cupboard and eat, literally, whatever, I can see in front of me. Like, you're just ravenous…" [Part. 4]* |
| Heart pounding | *"…I realized that **my heart was pounding** out of my chest…" [Part. 3]* |
| Numbness of tongue, lips | *"My **tongue gets tingly; my lips get tingly**, and that's when – I'm at my worst." [Part. 5]* |
| Slurred speech | *"so it was kinda, like, 'I looove you – 'like, that **slurred type of speech**" [Part. 1]* |
| Dizzy, agitated, lightheaded | *"… dizzy, agitated (laughs). **Agitated, dizzy**, sometimes I'll sweat**, lightheaded**." [Part. 10]* |
| Feeling tired, frustrated, anxious | *"…**tired feeling and a little bit frustrated**…you feel nervous…" [Part. 11]* |
| Crying, emotional | *"So I'm sitting on the bumper of my car, drinking my juice **and crying**… I can laugh at it now, but at that time, because my blood sugar was low, and, you know, we get emotional sometimes like that" [Part. 2]* |
| Feeling 'funny' | *"**If I felt funny during the night**, and most of the times it woke me. I would get up then and take my sugar, and I may have to come out here [kitchen] and eat everything ahead of me in order to bring it up…" [Part. 9]* |
| Feeling 'loopy' | *"**I get very loopy**. So, most of the time it's in the middle of the night, and I'd break out in, like, these cold sweats…It's like very hard to explain. It's loopy – that's the only way I can think of it – I know I'm low – like, I can feel myself low, so then I check my sugar and it's always like 2 or 3[mmol/L], or 3 or 4 [mmol/L]…[ Part. 14]* |
| 'Drowning in slow motion' | *"…when you're in that moment where I feel like I'm just **drowning in slow motion**, in a low, and you know you're in trouble and you know you need help, but you can't ask for it…" [Part. 6]* |

| | |
|---|---|
| Becoming quiet | *"…starts behaving like … not the sharpest knife in the drawer – that kinda thing – and quiet 'cause [name]'s* ***not generally very quiet****…" [Part. 8 Partner]* |

Regardless of symptomology, the experience of hypoglycemia was unique and universal at the same time. As suggested by Mol (2002), this is indicative of the multiplicity of disease as participants all described varying experiences of combinations of hypoglycemia symptoms (unique), yet all recognized the experience as hypoglycemia (universal). Ontologically, these realities of disease all hang together in a recognition of 'diabetes' and the experience of a 'low' (all participants used in-group jargon for describing hypoglycemia as a 'low'). All participants described hypoglycemia symptoms and individual experiences depended on the immediate context and the associated meaning. In Table 6.2, common physical, cognitive, and emotional signs and symptoms are listed with accompanying exemplary quotes.

Throughout the course of their lives with diabetes, participants in this study developed a strong bodily sense related to various blood sugar levels. Over time, they were able to categorize hypoglycemia symptoms as 'regular, usual or typical' symptoms while others denoted something more sinister and prompted more direct, immediate action to raise the blood glucose. Here, in the practice of experiencing hypoglycemia, actors included the various symptoms in Table 6.2, as well as the meaning of the both the individual as well as combinations of symptoms. Agency shifted between symptoms with atypical symptoms afforded the most agency in the network:

> *I've got a few common symptoms – I always have – and I can usually tell how bad it's gonna be just by the symptoms I have. If my tongue starts going numb, that's it, I'm in real trouble…* *[Part. 5]*

With numerous experiences of blood sugar fluctuations, the symptoms and thus experience of hypoglycemia changes. Participants experienced changing symptoms of low blood sugar depending on how long they have had lived with diabetes. Awareness of these changes was integral to hypoglycemia management as lack of consideration can prove fatal. As individuals living with diabetes manage ‘well’ i.e. keep blood glucose within recommended parameters, there is still a risk for hypoglycemia. Unfortunately, with more experiences of hypoglycemia, a phenomenon called ‘hypoglycemia unawareness’ may occur in that the individual no longer experiences the usual symptoms when their blood glucose drops (Diabetes Canada, 2018). This presents another level of vigilance; what one perceives body cues to mean and the subsequent treatment decisions, may change over time. How participants made sense within their practices of attending to their bodies changed depending on the actors (i.e. the symptoms of hypoglycemia). What was sensible to do next (i.e. treat the low blood glucose or wait) was dependent upon knowledge developed in past and current practices (Hultin & Mahring, 2019; Introna, 2019).

> *When I was a youngster, yeah when I was a child, I used to always feel like I was vibrating inside, and that was my low – first sign of my lows was I was shaking, and it wasn’t that you could see it, but I could feel it on the inside, and as I’ve gotten older, if I have trouble concentrating, I know I’m getting low. I gotta check.* *[Part. 6]*

While attending to body cues signifying hypoglycemia was paramount in relation to immediate contexts and consequences, participants also paid attention to body cues indicating hyperglycemia. Ultimately, there was a consistent level of awareness of body cues as participants consciously navigated an internal physiological feedback system from the outside. As these participants demonstrated, there were also typical symptoms and feelings of hyperglycemia that also must be addressed. The two participants below differed in their perception of discrete physical symptoms versus broader cognitive and bodily sensations, signifying that there are individual (unique) symptoms interpreted as recognition of hyperglycemia (universal):

> *…if my sugar is up high like that, my eyesight is blurred – I wouldn't be able to see across the room, but I know right away what it is, and if it goes the other way [low], I'm sweating and shaking.* *[Part. 7]*

> *If you're laggy [extremely tired], you know, you're tired, your sugars are going up. If you feel fine, your sugars are good, right…* *[Part. 11]*

Participants differed in how they responded to and listened to their bodies. Some were stricter and more regimented than others, while some pushed their bodies to the extreme in terms of skirting low blood glucose. The following participant was quite regimented in maintaining awareness of their body cues and need to respond, *"Yeah, so I always put that [body cues of high or low blood glucose] as a priority, and everything else can wait…" [Part. 5].* Some participants responded emphatically when asked if there was ever a time where they did not listen or respond to body cues in that they would **never do such a thing**, as this participant stated, *"**No,** I've **always** addressed it. **I've never been to the point where I haven't addressed it** because I don't know what'll happen." [Part. 2].*

During the interviews, I always disclosed that I lived with diabetes, and I also used a pump. In many instances and, as I described in the Methods chapter, this was beneficial because I could see the participants visibly relax and smile as they shared their experiences. Conversely, there were also instances where I felt surveilled and 'measured up'. In the examples above, I had been asking about times where a low blood glucose may have been ignored for even a few minutes. I had indicated that I briefly ignored symptoms for a short time if I was in the middle of something perceived to be important. In answer to this, these participants were quite strong in their responses of *'always'* attending to a low blood glucose which effectively made me feel like I was not managing well enough and that I had somehow 'messed' up not only with my management; that I had been less than a competent self-manager.

While some participants would halt all activities to address body cues and downward blood glucose trends, other participants attempted to pre-empt hypoglycemia through proactive food intake, although valued activities sometimes meant that diabetes was a secondary consideration. The following participant desired to continue with normal activities such as running in the midst of experiencing a low blood sugar. Interestingly, this is one of the participants who quite defiantly said that they **always** addressed a low blood glucose, however for many other participants as well as me, it did not seem prudent to run for eight kilometers without quick access to food in case of hypoglycemia. As such, what one considers to be *appropriate, competent management* is based on experiential knowledge of and the meaning developed within extensive surveillance practices over the years. As Introna (2019) suggests, while the human actor makes sense of practices, they are also always and already arranged to do so as a result of subject positioning. Within networks, subject positions are afforded through the agentic capacities of the actors; a subject becomes positioned through a process of iterative enactment that presupposes the subject and the practices they describe (Hultin, 2019). As such, participants in this study were positioned as a result of their practices. In this next example, the participant needed to both correct a slightly high blood glucose with insulin but also needed to ensure there were enough carbohydrates ingested to sustain an extended run. As a result of this practice, she positioned herself as one who could 'push through' and not let diabetes interfere with her plans, but at the same time positioned herself as cautious in that she planned to monitor her blood glucose:

> *I was out for a 27 K, so I did a loop of 15 K. I was a bit high when I checked it before I left and I bolused for that, did a correction for that; I ate the banana and I left; I got 7 K in and at that point I was 8 kilometers from my car, and I started to feel low. Now I had sugar in my pocket, so I ate that, but I suffered for the next 8 K to get back to my car, and when I got back to my car, my blood sugar was 3.1[mmol/L].* *[Part. 2]*

Listening to this participant describe how close they were to hypoglycemic danger was uncomfortable. Severe hypoglycemia is when individuals require the assistance of others to treat the low blood glucose, unconsciousness may occur, and the glucose value is typically below 2.8 mmol/L (Diabetes Canada, 2018). In the example above, the participant's glucose value was close to 2.8 mmol/L which caused me to pause and reflect on my own experiences with hypoglycemia and how, with a value just below 3.1 mmol/L, I have experienced symptoms such as tingling lips, a numb tongue, and intense panic. I found myself comparing my experiences to those of this participant and wondering if we both we managed 'well'. It was in this moment, as well as other times in this study, that I realized how implicated we all are in perceptions of 'good' and 'bad' management and thus how we perpetuate dominant discourses of how to manage the 'right way'.

Throughout this research as well as my own diabetes management practices, I have come to engage in certain practices that seem 'right' to me. In this case, based on listening to the other participants, as well as reflecting on my own practices, to run several kilometers with a low blood glucose did not seem like a 'right' practice. As suggested by Nicolini (2012) practices have a normative aspect in that there is a sense that emerges from performing practices over and over in that there is a 'right' and 'wrong' way of doing them. The social constitution of a practice is when a social group performs the practice regularly such that it becomes legitimized (Nicolini, 2012). Therefore, practices do not become legitimized and normalized by themselves, it is through individuals who take up, perform, resist, recreate, and revise the practices. In this case here and in other instances throughout this research, the participants and I provided a social constituency as well as normativity to diabetes management practices which ultimately impacted our interpretations of the best management practices.

Treating a low blood glucose was dependent on place but also other individuals. Many participants choose to delay treating a low blood glucose when in public and with other people, to avoid drawing attention to themselves. The experience of a low blood glucose in public spaces heightens the difference between self and others in that the practices associated with detecting and mitigating hypoglycemia may be perceived as unnatural or non-normal (Walker & Litchman, 2020). In this instance, agency was afforded to other human actors in this network, which influenced the participants' capacity to act; although not the participant, human actors were centered and vertically aligned (Andrews and Duff, 2019). Often participants recounted how they did not want the attention, nor did they feel that that the practices of experiencing and treating hypoglycemia were socially acceptable:

> *Yes, 'cause I would never do that [over treat] – if I was in public – you know, I've been low before in public, and someone's been talking to me, and I've held out to go treat because I've been talking to someone, and I can feel the sweat trickle down my back (laughs), and I'm like, okay, just five more minutes and I'll go treat it. Versus, if I'm home, I don't wait for that, or if I was in public, I'm not gonna sit down and eat a box of bars in public. I'll try to be more discreet I guess, about it, so people aren't, I guess, recognizing that I'm low, and they're not asking me questions, and 'Are you okay?', 'Do you need this?', 'Do you need that?'* *[Part. 1]*

The awareness of body cues in relation to hypoglycemia and hyperglycemia formed only one group of actors in a network of blood glucose surveillance practices. All participants checked blood glucose either manually with a blood glucose meter, a Freestyle Libre™, visualized CGM readings, or a combination of these. Both the awareness of body cues (symptoms) and the blood glucose levels (signs) generated a knowledge base that, together with environmental and other factors (context), as well as guidelines and recommendations, provided a basis for problem solving and decision-making practices in managing diabetes.

### ***Enhancing Body Knowledge: External Blood Glucose Surveillance***

Participants manually assessed blood glucose using a glucometer and test strips as well as through the Freestyle Libre, which, as described previously, is a patch that is worn on the arm and a meter scans the patch to determine the level of blood glucose. These patches are worn for two weeks and while they are marketed to eliminate painful finger pricks (Freestyle, 2021), many participants deliberately checked their blood glucose manually on occasion to validate Freestyle readings. Other participants wore a CGM such as the Dexcom. As with the Freestyle Libre ™ and depending on the type of CGM, participants manually checked their glucose on occasion to validate the CGM readings or because of the requirement to 'calibrate' the CGM (which depends on the type of CGM i.e. Dexcom G6 requires no calibration) (Dexcom, 2021) or because they routinely wished to assure themselves that the interstitial CGM reading was consistent with the blood glucose reading.

Networks became more expansive and other actors were added within surveillance practices. Blood glucose meters, test strips, blood, manual dexterity, CGM systems, Freestyle Libre systems, etc. were added to the surveillance of blood glucose. Here, participants expanded their interactions with technologies in their diabetes management practices. As Pols and Moser (2009) suggest, technologies can be understood as prescribing roles and relations between different actors, and I came to understand how technologies such as glucometers and CGM machines create relations with each other as well as human actors. A blood glucose value on a CGM device is agentic as it affords agency of the human actor who may validate the glucose value with a glucometer; thus, the human actor leads to agency of the glucometer. In turn the resulting value on the glucometer entices agency of the human actor to either take insulin (value indicating hyperglycemia), eat (value indicating hypoglycemia), or do nothing (value indicating normoglycemia). Whether checking blood glucose was done manually through pricking a finger and testing the blood with a meter, or though the visualization of readings using a Freestyle Libre™ or CGM, participants routinized these practices in developing their personal diabetes knowledge base.

**Creating Routine Surveillance**. The daily routine usually began with either a manual check of blood glucose using a glucometer, a scan with the Freestyle Libre, or a quick glance of CGM readings. For many participants, this check was the priority before getting out of bed: *"…when I get up, I'll check my blood sugar - before my feet touch the floor, I check my blood sugar…" [Part. 13]* Most participants tried to create habitual practices to ensure they could always respond quickly to blood glucose fluctuations. The pump itself provided necessary information in determining the correct amount of bolus insulin as participants embedded surveillance of the '*active insulin*' feature of their pump into routinized practices. Additionally, the participants were surveilled by the pump, as information about overall insulin use, number of boluses per day, time since last bolus, as well as patterns of blood glucose values entered prior to boluses were retained within the pump's memory (Medtronic, 2017; Omnipod 2017). This information could be uploaded by the participant to computer software associated with the specific pump, which could also be viewed by health care providers.

The decision to upload as well as enable health care providers to view this information was determined through past and current practices of interacting with health care providers as well as the desire to surveil one's own pump practices. As such, the pump demonstrated agency in surveillance practices as uploaded information potentially provided the basis for action(s) by other actors including the individual and health care provider.

**Active Insulin: 'Insulin on Board'.** In addition to manually checking blood glucose with a meter and monitoring readings on either a Freestyle Libre™ or CGM, participants also surveilled the pump and used a feature of the pump to enhance glucose monitoring practices. The pump facilitates a stable blood glucose level but the ability to balance rebound highs and lows is dependent on the individual's knowledge of how much insulin is active. Most insulins used in pumps have a duration of action of approximately four hours. A feature of the pump displays this pharmacokinetic information as the amount of *active insulin* and the amount of insulin required for boluses for food or corrections (extra insulin taken for blood glucose above target range) are calculated by the pump based on this information. Without knowledge of active insulin, it is possible to take too much insulin with a bolus or to correct a glucose imbalance (resulting in hypoglycemia) or too little (resulting in hyperglycemia). The *active insulin* feature provides extensive information and is an added means of surveillance when regulating blood glucose. In this manner, the insulin pump assisted the participant to decrease variability in their blood glucose levels toward recommended parameters:

> *Yup, and another thing too with the needles, like say if I got up in the middle of the night, and say my sugars were up to twenty, well I wouldn't mind giving myself extra insulin, but I wouldn't know what was active, and I wouldn't know if I was over shooting, so I could end up in the morning with a low because I might have taken too much, or I might have not taken enough…*
>
> *[Part. 11]*

Many participants considered the 'active insulin' feature of the pump as an essential aspect of information that contributed to their knowledge about how to maintain stable blood glucose levels. They integrated this with their experiential knowledge of manual blood glucose monitoring as well as Freestyle Libre™ and/or CGM readings.

### ***Finger Pokes: Manually Checking Blood Glucose***

Many participants welcomed and performed frequent manual checking of blood glucose describing it is as comforting to ‘always know’. For individuals with insulin pumps, Diabetes Canada (2018) recommends testing ‘frequently’ throughout the day. Enhanced ‘knowing’ blood glucose facilitated their ability to make decisions that ultimately supported feeling and managing ‘well’. Even those who utilized CGM validated CGM readings with manual glucose tests to verify readings and thus make management decisions. Despite the benefits of a CGM system in providing increased knowledge of glucose trends, the participants (as well as I) regarded the information from CGM as somewhat extra information about glucose values ‘all of the time’. I still validate my CGM most of the time prior to taking an insulin bolus as a result of an ingrained habit, but more so to enhance my trust in yet another ‘machine’. The manual checking of blood glucose using a glucometer is the gold standard of information in making diabetes management decisions (Diabetes Canada, 2018). While there have been technological advancements for blood glucose surveillance, for these participants, manually checking is still the most trusted source of blood glucose information, *“I want to know what my sugars are all the time” (Part. 8)* and participants manually tested their blood glucose frequently:

> *Some days it could be as high as thirty times a day, depending on what I’ve done or what has happened or whatever. Other times it’s probably –the lowest would be six or seven –that would be my lowest…the thing with checking your sugar, with me, is that I always want to know where I was. I always wanted to be at target. To be comfortable, I need to know. I couldn’t go all day and not check my sugar.* *[Part. 9]*

Some participants did not want to know their glucose level all of the time and thus did not check as often as recommended by contemporary Diabetes Canada (2018) guidelines. While they saw value in the rationale for more frequent checking in that more information would aid in problem solving and making management decisions, they did not want to ‘see’ any high readings, which would prompt questions from their diabetes care team leading to feelings of guilt, failure, and not managing 'well'. Knowing that one's blood glucose value is not in the target range is difficult and may lead diabetes distress including feelings of self-guilt, self-blame, and fear of 'being out of control' (Abdoli et al., 2018; Archer, 2014, Liu et al, 2017; Seo & Song, 2018; Schabert et al., 2013; Vallis et al., 2016). In this manner, the blood glucose value is agentic in that it influences the action, or rather the decision for inaction (i.e. not check blood glucose) for some participants. As Pols and Moser (2009) suggest, individuals develop affective relations with technologies and here, those relations may be perceived as negative; as putting one's 'transgressions' or less than ideal management decisions on display. Common decisions made by most people in society, such as eating more at a meal than one normally consumes, could, for these participants, generate anxiety about control and consequently, their self-management image, as this participant explained:

> *If I have a big meal, no, screw that, I don't want to see, like, a 20 [mmol/L] – I'll wait. Sometimes I should check it [glucose] more often than this, and I talked to … she's my diabetic doctor – and she said, 'Why wouldn't you want to know?' I said, 'Well, I'm afraid.' She said, 'but at least you'll know for next time.' I said 'Yeah, you're right, but kinda want to be this – I want to have my sugars always nice looking, as opposed to seeing all these highs.'*
> *[Part. 14]*

While all participants monitored their blood glucose frequently, various activities such as exercise and subsequent incidents of hypoglycemia precipitated more frequent blood glucose surveillance. This increase in surveillance practices was attributed to the anticipation of greater fluctuations in blood glucose and the need to respond accordingly:

> *Then, depending on what workout I have to do, I'll test before I go do my workout, with my snack, and test when I get back in the evening from my workout, and test before bed… [Part. 2]*

Participants frequently checked their blood glucose during episodes of hypoglycemia, especially after treatment and waiting for blood glucose to rise. Ultimately, participants described the experience of a low blood sugar as terrible, one of the worst feelings in the world, and associated at times with panic because hypoglycemia is a potential threat to life, as explained by this participant, *"It almost – I say that it's the worst feeling in the world…because in that moment, you feel like you are going to die…" [Part. 1]* As such, participants frequently assessed their blood glucose to be certain that it was rising. This participant's response was typical, *"I would test oh, I would say 8, 10 times until I'm comfortable, then I'm actually rising…" [Part. 5]*

In sum, technological advancements have transformed the ability to monitor blood glucose in the past ten years. In addition to manual finger sticks and using a glucometer, individuals can now utilize a Freestyle Libre™ or CGM to identify blood glucose patterns. While this information does not replace manual blood glucose testing, it certainly adds to and augments the knowledge utilized for decision-making and problem-solving practices.

### ***Keeping Up: Using Enhanced Tech Surveillance***

Insulin pump as well as CGM and Freestyle Libre ™ advertising promises effortless blood glucose tracking, but certainty about one's safety was usually found only in consciously viewing blood glucose levels. Knowing blood glucose patterns and trends provided essential knowledge to predict the effect of certain foods, drinks, activities, emotions, and contexts. The ability to watch levels change and the magnitude and speed of change facilitated short and longer-term problem solving and decision-making practices:

> *It's something [blood glucose] I'm extremely interested to know, for many reasons. How does certain things, whether its food, drinks, or situations, impact my sugar? and is it [blood glucose] starting to rise? Is it not? Is this*

> *something I can avoid? How can I approach it differently? It's just a tool to really learn about how things impact you.* *[Part. 5]*

The many benefits of having a CGM included always knowing blood glucose levels at any given moment. This was helpful and reassuring from a safety perspective, but also in terms of reinforcement of a 'job well done'; and the ability to do it 'well'. As a society, we have become increasingly concerned with self-tracking; using technologies to monitor several aspects of our sociomaterial lives from heart rate, respiratory rate, calories consumed, steps taken, as well as our emotions (Lupton, 2013a, 2013b; Lomborg et al., 2018; Pols et al., 2019). Diabetes monitoring practices which include CGM enable individuals to both look backward as well as forward in ensuring that their management practices lead them in the 'right' directions (Pols et al., 2019). That is, using enhanced monitoring technology affords the individual the ability to increasingly engage in normative diabetes practices, driven by biomedical values as measures of self-management success (Pickersgill, 2019; Pols et al., 2019). Self-tracking through using CGM is a method of enhancing diabetes 'control' which was conceptualized as the epitome of 'good self-management' as Participant 6 illustrated:

> *I did for a while [used CGM], and that was the thing that first convinced me I wanted a pump over multiple daily injections – because I wanted to have that continuous information coming in, so I knew I was great all the time (laughs), right? …but I did find it reassuring 'cause I've always walked a lot, and I would just take out my pump and look, and if I had my double arrows going down [impending low blood glucose] (laughs), I'd have a couple of [jellybeans](laughs)… I love that… I need that reassurance, or I need that information, that feedback that tells me 'You're doing great. Good job. Yeah, that was the right thing to do.* *[Part. 6]*

Using enhanced technology such as a CGM was not without issues. As an added measure of surveillance, CGM provided another layer of security, safety, and protection, and the positive reinforcement of 'doing things well'. But it could become another intrusion and something very inconvenient; a disruption in usual activities (Lomborg et al., 2018). As Participant 7 acknowledged, CGM can even interrupt sleep and impact other members of the household:

> *… not that I don't like it [CGM]. Just, I guess I never had it long enough to get used to it, and I had that [CGM]on, and all of a sudden, 'beep, beep, beep', sugar's going up, 'beep, beep, beep', sugars are going up, 'beep, beep, beep' Like, it's … if my pump vibrates and I got 50 units left, like, either I'm up or [wife] is digging me in the ribs, like, 'Turn that off' or 'Fix that' or 'Go and do something with that', and you get up… [Part. 7]*

For safety measures, CGM systems have alarms that alert the wearer when blood glucose moves out of target range; either too high or too low. When this happened, the alarms could lead to anxiety, fatigue, and frustration with all of the sounds and constant reminders of a fluctuating glucose (Mian et al., 2019; Shivers et al., 2013). As Participant 7 explained, *"…first when I got the pump, I had the – the pump sensor was talking to one another, and that would drive ya around the bend." [Part. 7]* The alarms could be worrying as a constant reminder of always trying to stay in a particular range; of always trying to reach a target. The outcomes of not 'being in range' meant increasing the risk for complications as well as the risk of being perceived as 'not trying', representing poor management. As Participant 3 claimed, *"…alarm fatigue is huge with CGM" [part 3],* and as a result, it was clear that many participants were not using CGM as recommended by manufacturers. This technology is meant to increase understanding of trends and patterns over time and is not intended to facilitate quick fixes of moment-to-moment blood glucose levels. For some, the enhanced amount of information generated by CGM was too much - more than they felt they needed to make decisions. For Participant 12, it became a nuisance and, in some ways, incongruent with her long-standing, personalized routine:

> *It's another friggin' thing stuck in my abdomen. It's another beep saying, watch, watch, watch, do this, watch!' I thought, Christ, I don't want it, no. I found it – it was helpful, yet it was a nuisance because I know my routine now, very well, you know. [Part. 12]*

Despite being considered immensely helpful and an augmentation to information provided by manual blood glucose testing, some participants referred to CGM in a deviant manner because a machine is actually performing the work of 'testing' the blood glucose. For example, while Participant 3 described the many benefits of using CGM, at the same time she referred to herself as a *'cheat'* for doing so *"I'm not regimented, no, but I wear a sensor, so I'm a bit of a cheat that way, hey, so I'll glance at it (laughs). I'll glance at it and see where I am…" [Part. 3]*. This participant berated herself for being dependent on CGM when she experienced hypoglycemia during a period when she was not wearing her sensor and CGM. The CGM served as peace of mind and comfort. Similar to learning how to use and trust the pump, the question of ***who*** or ***what*** is doing the managing surfaces as a result of ideologies of self-responsibility for health (Barnett & Bagshaw, 2020; Crawford, 2006). Here, the impact of historical interpretations of 'self-managing well' as centering the human subject is manifested in the context of having an external device (the CGM) monitor blood glucose and the individual does not manually check with a meter. In the following excerpt appropriate self-management is typically regarded as 'doing it yourself' rather than having a device 'do it for you'.

> *…it was running through my mind, gee, I should really have on my sensor, and then that irritated me because I was thinking, that's really expensive, and I shouldn't be dependent on a machine, but you know, it's a comfort, and my husband's about to go out of town, so you know, having that on is a greater sense of comfort when he's not around… [Part. 3]*

To realize the benefits of the increased blood glucose information, individuals must be patient in watching the trends and not respond too quickly (Sorgard et al., 2019). As this participant explained, learning how to interpret and utilize the patterns and trends is paramount not only to diabetes management decisions but also more importantly, to self-worth. In the extract below, she overreacted to her CGM readings by aggressively increasing a bolus insulin dose (a diabetes in-group jargon of 'rage bolusing') or by eating excessively, neither of which was ultimately useful, and both undermined her confidence in her own self-management:

> *"…for me at first … I sabotaged myself watching those arrows. I was either rage bolusing, which I never rage bolused before, or I'd see the arrows going down, and I'd be piling the food back into me, thinking I was going low, when really I was just about to stabilize…"* *[Part. 3]*

Surveillance practices formed a basis to make decisions which would affect future management, but also provided a foundation for back-tracking investigation during unanticipated blood sugar fluctuations (Pols et al., 2019). The participants described surveillance as a means of discovery in determining the context and rationale for hypoglycemia and hyperglycemia episodes. Interestingly, this detective work inevitably began with considering **self-induced** shifts in blood glucose first, and then attention was paid to other factors such as pump malfunction and associated issues such as kinked infusion tubing, as well as various contextual factors such as exercise, stress, fluctuating hormones, and the weather – whatever each individual perceived as relevant to their situation.

### *Person Living with Diabetes = Honorary Detective* ☺

In their surveillance practices, participants needed to understand trends and patterns in their blood glucose and in the process, they began their investigation with questions about what 'they did' to influence fluctuations. Participants began with questioning themselves and what they, themselves, did 'wrong' or did not do 'appropriately', as opposed to first considering any contextual factors which may have affected blood glucose. In doing so, they discursively prioritized the 'self' in self-management and the responsibility for their disease and management, centering the human actor, thus creating a hierarchy of responsibility:

> *Occasionally, I mean, I can be in the teens and think, 'what the hell'? What did I eat?, and not quite be able to figure it out, but for the most part, if I'm high, I*

> *know it's because I ate – I can figure out, oh, for cripes sake, I forgot to bolus, or I guessed at carb, right? If it's something homemade and you guess at it, and I so don't want to be high, that I guess more than it's worth, sometimes, and I end up being low, so, ugh.* *[Part. 6]*

After they considered their own actions and what they did or did not do in terms of carbohydrate counting and matching with insulin, participants then examined the pump and associated infusion set for potential problems. Their investigation of was stepwise and hierarchical, beginning with self:

> *Well, I back track on, first of all, what I ate, what I did, and then any other previous experiences that I had. You know, 29 years, I've had a lot of experiences – good ones and bad ones – throughout my diabetes. One of the first things that I checked is … I'm on the Medtronic 630, and the issue that I had – I use the 'Quick Sets" [type of infusion set] – and when they turn on and click, I had wondered – but it actually wasn't clicked, so nothing was actually getting in and, you know, my leg was wet. So when I woke up in the morning and my sugar was at 18 or something, so always check the site to make sure that there's nothing there; it's not tender or anything else; not pooling or anything, but, for the life of me, I couldn't figure out anything…*
>
> *[Part. 5]*

After investigating to determine the cause of fluctuations in blood glucose, participants often described themselves as 'stupid,' 'hard on themselves,' 'guilty,' and potentially causing complications. For these participants, their sense of self was highly dependent on their ability to discern the rationale for blood glucose fluctuations, and they could not, they became upset and perceived they were unable to self-manage well and thus were not "…good enough…" (Archer, 2014, p.102). The following table 6.3 highlights some of the comments that participants used in reference to themselves in the day-to-day management.

**Table 6.3:** ***The Fallout of Perceived Mismanagement***

| **Experience** | **Typical Quotes** |
|---|---|
| No good | ***I never feel like I'm doing good*** *– well, not, like, never feel that way…[ Part. 10]* |
| Being 'stupid' and self-inflicting complications | *I was poorly controlled, you know. I look back at it; it was* ***all me just being stupid,*** *but I experienced some complications … yeah, at one time I thought I was invincible, and, yeah, whatever they say about diabetes, it doesn't pertain to me. … then diabetes turned around and kicked me in the ass, and, you know, what everybody says is actually true, and follow it – follow it and manage it. That's the worst thing I have with it – unfortunately,* ***self-inflicted.*** *[Part. 5]* |
| Being stupid and over treating a low blood glucose | *Yeah, and then you get up, if it [low blood glucose] happens in the wee hours of the morning, and you get up the next morning and you're 12 [mmol/L] or 14 [mmol/L], and you think,* ***holy shit, how stupid was I last night****? I should have just only had that much, and go to bed, sweat, be wet, whatever, and then feel cold because, when you have a low, you're really sweaty – I am. [Part. 13]* |
| I must be a slow learner | *Oh, I know, I do this [over treat hypoglycemia] all the time, and it really upsets me 'cause, like I said, I should have learned this by now,* ***but I'm a very slow learner****. [Part. 8]* |
| Blood glucose high? No 'slack' for me | *I'm more upset when I'm high than when I'm low. When I'm low, I cut myself slack, and I might get, you know, very temporarily upset with myself, but I treat it and I move on, and at least I'm not high. That's in my mind – at least I'm not high. [Part. 6]* |

Often, confirmation of managing well lay in the HbA1C result. In this next example, the participant berated herself because of her higher than target HbA1C level even though it was an acceptable value given her age (Diabetes Canada Clinical Practice Guidelines, 2018). The target optimal HbA1C level was so ingrained that anything outside of those parameters, regardless of other factors such as age and context, were not considered in the domain of managing well. The numerical value of the HgbA1c constituted ideologic representations of successful diabetes management:

> *I think I'm hard on myself. My A1C is usually hovering near 8, and, you know, I'm well. Like, NAME [diabetes nurse educator], she's a positive person – 'You don't have diabetic neuropathy or retinopathy; you have no [complications] – none, none, none, none, none, none, and if you're being so hard on yourself about that A1C, what for?' I'm 70, you know, and, you know, a lot of people will say, 'Well, if your blood sugar is ten or lower – ', but that's still quite high. My aim is between 4[mmol//L] and 7.5 [mmol/L]. [Part. 13]*

In summary, while constant surveillance practices rested primarily with blood glucose monitoring, it extended to other aspects of management that give meaning to the blood glucose monitoring. Pols et al. (2019) suggest that numbers are normative and enable the categorization of 'good' or 'bad' diabetes management. However, 'good' is determined by an individuals' preferences within particular contexts. As such, *normatively*, the participants in this study acknowledged good/bad management as a result of enhanced technological monitoring of their blood glucose, however *individually* there was often 'good' in some blood glucose values that were higher than normal, especially after treating hypoglycemia. For these participants, the notion of 'good/bad' blood glucose values and patterns as a result of enhanced technological surveillance was determined through the meaning (or sense-making) developed in the performativity of practices. What was sensible for the participants in their determination of good or bad was both constructed and contested within their practices (Hultin & Mahring, 2017; Introna, 2019). Nevertheless, surveillance practices using CGM created knowledge of blood glucose that often meant one is doing a 'good job' in diabetes management and thus on track to prevent or delay any future physiological complications. As participants described, surveillance also included paying attention to other aspects of management including keeping a close eye on their feet.

### ***Expanding Surveillance: Keeping Tabs on Everything***

Surveillance extended from checking and monitoring blood glucose to careful watching out for potential complications, especially in relation to feet. Participants were keenly aware of the risks for physical complications, especially in relation to the risk of infection and potential loss of lower limbs. They devoted extensive worry about the risks of complications and there was much fear as this participant described, *"I'm frightened to death – I'm frightened to death." [Part. 8].* Much of what has been described in terms of diabetes complications relates to physical complications. This was illuminated in several landmark studies especially the Diabetes Control and Complications Trial (DCCT) followed by The Epidemiology of Diabetes Interventions and Complications (EDIC) study (Nathan, 2014). However, recently researchers have suggested that with increased pharmacotherapy and preventative care, the incidence of diabetes related physical complications have decreased (Harding et al., 2019) and research about the importance of psychosocial issues/complications such as diabetes distress (Fisher et al., 2019; Vallis, 2012) has increased. Despite this, current research that continues to focus on physical complications (Beeney & Fynes-Clinton, 2018) was at the forefront of the participants' mind and they talked at length about preventing physical complications. As a result of historical and contemporary literature as well as social constructions of diabetes, general societal knowledge of physical complications (rather than others such as diabetes distress or anxiety) remained dominant and pervasive through my participants' accounts. Therefore, they worried about and engaged in, active care and surveillance practices to prevent foot/lower limb complications:

> *And I don't have any issues with my feet. When I do my – when I cut my toenails, I'm checking the pulses in my feet and making sure everything is rounded and there's no excessive skin or cracks – yeah, it's a big deal.*
> *[Part. 6]*

Other participants, including myself, described more frequent preventative practices. For example, I never wear the same pair of shoes throughout the workday. I keep several pairs in my office and change them approximately four times throughout the day. Participants in the study often manifested panic associated with injury and breaks to the skin on their feet. In the example below, Participant 4 exerted significant time and energy on the risk for lower limb complications, illustrated in her account of a heel blister. As I listened, I found myself echoing the same anxiety about my feet:

> *A couple of months ago – the boots I usually wear, I gotta get the leather fixed on the inside – there's like a hard spot – I went for a walk, and I came home and I had a big blister on the back of my heel, and that just sent me [upset her]. '…**that's it, I'm done, my foot's gone' (laughs). It was like 0 to 100**. Just, like a normal little blister on my heel, and I said, 'this is how it starts'. This isn't gonna heal, and I was really focused on it for a few days. I said 'okay, like, it's fine', but I was so paranoid over just this little blister, and it was – the color changed, I remember. I guess it was like a blood blister. It was really dark the next day, and I thought 'it's going necrotic, that's it, like, my foot's gone' (laughs). …any nick I'm just you know, hyper focused on it. [Part. 4]*

All participants discussed surveillance practices as a means of enhancing their awareness of and thus responsibility for their diabetes status. In their constant attempts to take responsibility for their health through surveillance practices, the participants produced, reproduced, and sustained healthism discourse based on neoliberal rationality (Lupton, 2013a). As Crawshaw (2012) and Barnett & Bagshaw (2020) suggest, health is an ideal value in society, and it is an individual's responsibility to aim for self-discipline to achieve this ideal value. In this study, participants internalized a neoliberal rationality in terms of their sense of self-responsibility which was manifested in their constant surveillance practices.

In the next section, I will describe surveillance by others. In their accounts of a constant state of vigilance, participants revealed how surveillance practices were also accomplished by others such as family members, friends, and by members of the general public. The perceived meaning of this ‘surveillance by others’ depended on whether participants actively sought this outside surveillance, or if it was imposed without their consent. Further, it was more welcomed in times of great physical danger such as an extremely low blood glucose where help was needed to correct the hypoglycemia.

### Surveillance by Others

Family members, friends, coworkers, health care providers, and members of the general public were implicated in surveillance. Participants experienced a ‘felt’ surveillance from others, defined as “…a heightened awareness of being seen” (Lucherini, 2016, p. 259) which contributed to their self-surveillance practices as well as how they placed these practices on display. This ‘felt’ surveillance created normative diabetes management practices contributing to conceptualizations of ‘good’ diabetes management (Lucherini, 2016).

#### *Welcomed Attention*

Often, others provided an increased sense of safety for the participants, especially for assistance with managing hypoglycemia. This participant considered the symptoms of low blood glucose very scary and even scarier was the inability to be able to treat. She explained how her husband detected her low blood glucose in the middle of the night based on her speech patterns (e.g. nonsensical, mumbling) and sweating. As a result of his surveillance, he responded with getting her something to raise her blood glucose and removing her from physical danger:

> *We’ve been together for 19 years, so he turned over and I can – he said that he touched me, and I was full of sweat, so he knew right then and there something was wrong, and I mean, [he] tested my sugars – like I wasn’t even with it actually. When I kind of came to, he was giving me sugar water or something…*
> *[Part. 1]*

Similarly, in this next example, the participant did not wake up for work, which was not her typical routine. Her mother was unable to arouse her and responded by providing treatment with juice and maple syrup:

> *…She tried to wake me up and I wouldn't wake up, so – she said I was talking, but it [speech] didn't make sense, and I can remember like trying to but nothing coherent, and [I was] you know, dazed. I didn't remember until she had told me, an hour later. So, she checked my blood sugar, and it was 1[mmol/L] … so she like shoved juice in my mouth and maple syrup and just, you know, did what she could…* *[Part. 4]*

These examples demonstrate the need for help when a person living with diabetes cannot help themselves. As the people who were assisting were close family members, they no doubt understood the physical necessity to intervene in these situations. In times such as these, a loss of autonomy and independence may be perceived as the individual must rely on others to intervene to live.

The concept of autonomy situated within current conceptualizations of self-management emphasizes ideologies of self-responsibility to achieve 'good' diabetes management (Barnett & Bagshaw, 2020). In a network approach, the survival of the participants in these examples were dependent on the interrelated agencies of various actors. The slurred speech as well as the inability to rouse were agentic material actors in that they afforded agency to the human actors (husband, mother) to intervene. The choice of food items (sugar water, juice, and maple syrup) was selected to rapidly increase blood glucose, thus the food items transferred agency to the body and in particular, blood. Therefore, in flattening the ontology (Hultin, 2019) in diabetes management, a network approach also flattens the responsibility for management. This has implications for notions of self-blame, stigma, and marginalization in diabetes practices.

The Dexcom (CGM) can be synchronized with more than one person's smart phone. This introduces the possibility of remote surveillance by others and while this may be welcomed, it may also be perceived as potentially eroding another layer of independence and increasing vulnerability. Yet, the very act of asking someone to engage in this surveillance may be felt as an act of independence and autonomy, thus decreasing vulnerability. Enhancing the network may increase perceptions of conventional notions of autonomy and independence. In this example, Participant 10 experienced a hypoglycemic episode where she had to call the ambulance. Since then, her husband has worried so they synchronized Dexcom readings to his smart phone so that he could monitor her sugars as well:

> *…he's like, 'I'm following you on that Dexcom!' (laughs) So sometimes I'll get, a call, and he will say, 'You're 2.5 [mmol/L]. Where are you?!' (laughs) I say 'I'm eating candy', you know, so yeah, they worry… [Part. 10]*

She continued to describe not responding to CGM low glucose alarms at night, but her husband does hear it and prompts her to respond. In this example, as well as others where participants requested surveillance by others, they were actively creating safety networks in managing their diabetes. Knowing that her husband will also hear the alarms provides comfort for sleep in that the alarm will be heard and someone will respond. I experience this as well. My husband in a light sleeper and I am not; knowing that he will hear my alarms adds to my network of practices that I employ to keep me safe through the night. In doing so, my husband supported conventional perceptions of my autonomy in diabetes management and increased my agency as a human actor for self-care (Lee et al., 2019).

> *I've even changed the sound different times, so it will be like a new sound, and I sleep through anything, and plus you're low, so I think that, you know, luckily it goes off, so he will respond to it, and he'll ask, 'Do you know you're low?'… [Part. 10]*

Surveillance not only extended to spouses/partners, but to others as well. At times, the participants asked others to 'watch out' for them. Here, Participant 12 openly disclosed her diabetes to maintain her safety (Pihlaskari, 2020). As she described, she welcomed the extension of surveillance from her husband to her neighbors who spontaneously offered to keep an eye out for her:

> *My neighbors knew I was diabetic; I was in the house by myself. If my lights didn't go off over the front of the house by 9:00 in the morning, then I'd get knock on the door to see if I was okay. That gave me independence because I knew that somebody was looking. I didn't ask. They had mentioned it to me.*
> *[Part. 12]*

Requesting the surveillance by others is a means of enhancing networks or arrangements to keep oneself safe. The participants in this study (and I) created surveillant 'assemblages' of people, places, objects; "…a multiplicity of heterogenous objects, whose unity comes solely from the fact that these items function together, that they "work" as a functional entity" (Haggerty & Ericson, 2000, p. 608). These assemblages are fluid and boundaries between and within them shift depending on individual contextual/environmental factors. For example, more surveillance may be requested at night as opposed to during the day, or during activities that may result in blood glucose fluctuations such as imbibing alcohol or during exercise. In essence, the participants and I revealed how our surveillance practices were both local (by us) as well as global (by others) (Nicolini, 2009).

Most participants felt supported by others in their diabetes management which included both visible and invisible emotional, psychological, and practical support from family, friends, health care providers, and so forth. As Participant 3 explained, she is independent in the actions for managing her diabetes but dependent on the support of others. In this manner, she presented herself as an autonomous, competent manager of her own diabetes, yet had a back-up when/if needed and chosen, especially in the ongoing emotional and psychological support necessary to sustain a life of never-ending surveillance. Here, she both centers herself as the dominant actor however acknowledges the importance of other human actors in her network of practices:

> *I've always considered –I am independent, yeah, despite my earlier comments [about having help from husband in counting carbohydrates], I believe I'm fairly independent, and I – I know that my husband and my parents would say the same, but I am dependent on their support, so I'm – I'm independent in the actions. Like, my husband would never check my blood sugar for me, or, you know, put in a pump site … he doesn't feel that he is involved in my diabetes care, even though he is, you know? Like, he's a huge factor in – in how supported I am, and, certainly, I look at other people sometimes, and I think, if I didn't have him, I would be lost, so, you know, but…. I can do it without him too.* *[Part. 3]*

In this section, I have described how participants actively and intentionally created safety networks of various actors to ensure their safety in specific contexts. Intimate partners or family members made natural support systems and participants selectively chose others to keep watch through active surveillance. It was rare to hear of a person allowing another to keep watch without invitation, although this did occur on occasion. Generally, surveillance from others without express invitation was taken up by participants as stigmatizing such that they actively hid both the process as well as the results of their diabetes practices (for example checking their blood glucose values). Participants responded to unwanted surveillance by others through educating them about their practices to increase others' awareness, but most importantly to maintain their image as competent self-managers in that their practices were 'right' for their individual management.

### *Unwanted, Intrusive Scrutiny*

The very act of requesting help in surveillance can increase independence and decrease vulnerability. As Patterson & Thorne (2000) theorize, the act of letting go in managing diabetes is a means of 'hanging on' in continuing to manage well. However, there are boundaries that may be crossed in terms of surveillance, effectively turning it into an unwanted, intrusive act that can increase feelings of vulnerability. For example, some participants discussed forms of surveillance by others, such as colleagues watching and commenting on blood glucose testing, personality changes, behaviors, and eating patterns- including types of foods chosen. During these experiences, participants often felt offended and interpreted this unwanted surveillance as rude and stigmatizing.

**Figure 6.1*: Eating Pie and Living with Diabetes Meme***

From: https://bit.ly/3sA3Guu

As in Figure 6.1, participants countered myths with respect to causes and cures for diabetes, which included social expectations about what ‘they’ are ‘permitted’ to eat. Colloquially, as discussed in Chapter 5, participants referred to individuals in the general public who monitor and scrutinize their practices as the ‘*diabetes police’*. In the example below, over time, these comments about what others felt this participant was permitted to eat or not to eat led to feelings of being different, objectified, and isolated:

> *...I’ve had people bring in cupcakes, and go around the lunchroom table and literally, in front of everyone at work say ‘You can't have any because you're a diabetic. We can’t give the diabetic cupcakes…* *[Part. 1]*

Often, participants negatively perceived the surveillance by others, especially when it was not requested and the undertone was that the participant was not doing what they 'should', or they 'should' be doing better. Experiencing this unwanted surveillance, participants sometimes responded with prevarication to assert their autonomy and independence, centering themselves as the dominant agentic actor in this network:

> *I find co-workers are probably the worst, back when I was checking my sugar [manually with a meter], they'd say, 'What's your sugar?' or 'you're a diabetic, aren't you? You shouldn't be eating that. There's a lot of sugar in that. Are you sure you should be eating that?', so a lot of these questions kinda put you on the spot where you wanna say, 'Mind your own business. This is my life, and I'll control it how I see fit. I'm managing my diabetes; you don't have to worry about it.' There are times when, you know, if my sugar is a little bit high, I would lie and say, 'No, it's in normal range – its 5.6 [mmol/L]', even though it could be at 13.6 [mmol/L], so, but I find my colleagues are probably the worst for asking those invasive questions.* *[Part. 15]*

There were times when the participants in this study were profoundly affected by surveillance and judgment, such that they contemplated risking their health to avoid being perceived as 'not taking care of' themselves. In the following example, Participant 6 thought about being admitted to hospital if she experienced any complications in relation to diabetes. Despite living with diabetes for over 40 years and doing what she considered to be a 'good job', she felt that health care providers would not recognize all her years of hard work if she developed a physical complication.

> *The few times that I have had ketoacidosis, I've dealt with it myself; I haven't gone to the emerg. You go to the emerg, and you've spent most of your life doing a great job with your diabetes, and the first thing somebody says or writes on your chart is 'noncompliant'.* ***[whispering***]*I'd die in my bed. 'No, I'm not going' ...you don't get a pat on the back for doing well, but you'll get a finger in your face when you start using up hospital time and resources, and you become a burden of diabetes (laughs). I think to myself, in the end, it's not gonna matter how hard and how well I've done for so many years. It's gonna come down to some nurse who doesn't know me saying, 'another fucking diabetic.'* *[Part. 6]*

Unfortunately, as a result of ideologic expectations of good diabetes management based on self-responsibility for health, individuals living with diabetes may engage in practices that while intended to increase safety, may be harmful to their overall health (Ploeg et al., 2017). Here, Participant 6 felt that maintaining her dignity and presentation as a ‘good’ manager by not going to the hospital if she experienced DKA was a measure of upholding emotional safety. She felt strongly about the possibility of being viewed as ‘non-compliant’ or not caring for herself and disclosed that she would rather treat her own ketoacidosis (DKA) at home for as long as she could as a result of not wanting to be labelled, possibility risking physical harm.

In addition to feeling watched, judged, and criticized for not managing well enough, some participants experienced criticism from their health care provider for being <u>excessively</u> controlling and maintaining an unreasonably austere regime as is evident in the following example. In recognition of the impact of language on diabetes practices by those living with the disease, health care providers are increasingly incorporating self-management support strategies with other contextual (or ‘life’) factors in mind (Speight et al., 2021). Here the diabetes educator encouraged Participant 5 to ‘relax ’and ‘take it easy’ a little:

> *So tight [self-management] that the diabetes educator says I need to relax and give myself some credit instead of beating up on myself, but things are improving – much better – much, much better, so sugars are more in range, and things are just, all in all, going a lot better.* *[Part. 5]*

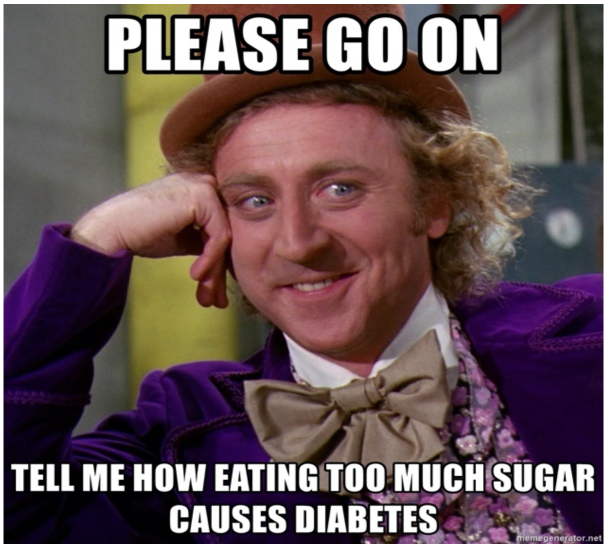
So far, I have described how participants engaged in the art of careful, continuous ‘watching out’ or vigilance in managing their diabetes. This vigilance was expressed as surveillance practices which included self-surveillance as well as monitoring by others. Participants surveilled their blood glucose, either through manually checking with a blood glucose meter, scanning with a Freestyle Libre™, monitoring CGM readings, and attending to body cues indicating if blood glucose was high or low. They also surveilled for physical complications such as the presence or potential for any problems with the feet. Additionally, participants endured surveillance from others, which they described as either a means of safety and security or an intrusion leading to feelings of stigma and isolation.

As I have discussed thus far, surveillance practices included various actors in many networks. In many of their accounts, participants centered themselves as the dominant actor and that they were in charge of their self-management, i.e., that it was *their responsibility* (and theirs alone) for the outcomes of their diabetes management practices. At the same time, participants also recounted the importance of other actors (technologies such as glucometers, CGM systems) as well as their emotions, experiences of hypoglycemia symptoms, test strips, food items, other human actors, and so forth, in the success of their management practices. Here, I came to understand that while a network approach lay underneath their accounts, participants were entrenched in dominant ideologies of self-responsibility for health (Barnett & Bagshaw, 2020). In their accounts of responding to this ever-present level of surveillance from others, participants educated others to increase awareness of diabetes management practices, but more so for preservation of their self-worth and image as a competent self-manager.

### ***Responding to (Endless) Scrutiny***

In living with diabetes, using the pump, and creating practices that became so mundane that they were second nature, participants needed to educate others about these practices. Participants often felt judged, criticized, or simply regarded as not doing a ‘good job’ of management. To mitigate the impact of such comments and criticism from others, participants educated others.

**Figure 6.2*: Please Tell me How to Manage My Diabetes Meme***



From: https://bit.ly/3lWbcNz

There are many misconceptions and myths about the cause of diabetes (as in Figure 6.2) as well as its management and participants countered these myths and misconceptions by explaining how they managed. Educating others about management practices occurred quite frequently and was generally considered as something that just needed to be done, as participants realized that there may be limited understanding among those who do not live with diabetes or have a family member with it. Yet, educating others became a mechanism whereby participants defended their choices in management to uphold their pride and dignity. This became vexing and tiring for some and was also a source of frustration at times. As in the following example, there were times where the thought of discussing diabetes was just so tiring that it was bothersome:

> *So, and this happens, at, like I said, my place of work. I've had people misinterpreting the pump a lot of times, misinterpret the pump as Weight Watchers – thought it was a little device that I'm putting in my points for Weight Watchers – so many times, right – and, honestly, sometimes I just let people believe whatever they believe because* ***I just couldn't be bothered anymore****...It gets tiring. It's very tiring, very frustrating, and I'm usually – I'm*

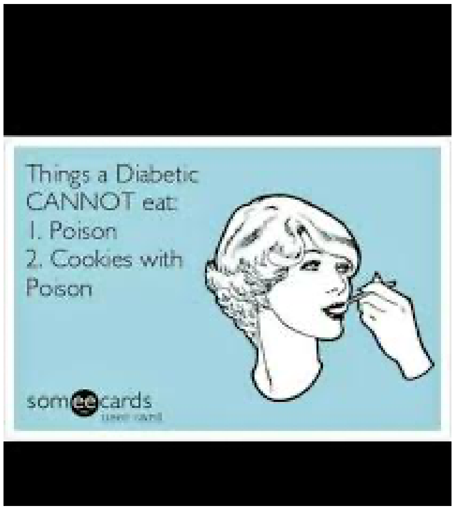
> *very pro-education. Like, I want to educate people and make them understand, but sometimes I just want to be left alone…* [Part.1]

Often, participants felt compelled to educate others specifically about how insulin taken through pump is matched with the amount of carbohydrates in foods eaten and while the pump does not work exactly like a pancreas, the user manipulates the pump to mimic the pancreas. This is not automatic; it also depends on the individual. In this manner, educating others both promoted the awareness and understanding of practices while at the same time created sameness between the participant and others without diabetes:

> *… it's okay to treat yourself, and the way I say it to people, like it's no different from me to have a piece of cake or a chocolate bar than it is for you who is nondiabetic because the thing is, what you do – and I explain to them – you prick your finger, check your sugars – and I show 'em with the pump – okay, so I say, for argument's sake, say my sugars were six [mmol/L]. Every chocolate bar – I use a chocolate bar, for example – got the carb count on it, so I just put I the fictitious carbs to show 'em on the pump, so for this amount, based on my sugar level and my ratio of insulin to sugars, this is what I will need. So, technically, I can have it, and an hour or so down the road, my sugars should be fine, but the thing is, I said, me versus you – but I said, not even you because the fat content in that bar or whatever, it's gonna kill you just as well it is me, right, but it's a higher likelihood of me, with diabetes, because your blood vessels are smaller than a normal person's, right, to have a heart attack or a stroke, but like I said, it's no different for me because, as long as I take insulin to offset that, but I say, the thing is moderation. Don't be at – like, don't go to work every day and have a big chocolate bar, right? It's the same if you want a bowl of ice cream.* [Part. 11]

There are many actors in the above network including foods such as cake, chocolate bars, the pump, blood glucose value, the individual, a glucometer, and other human actors such as co-workers. As suggested by Stuckey and Peyrot (2020), individuals living with diabetes often want to be the 'same as others' and in using this account of actors in the network, in the quote above, Participant 11 aligns his eating practices with that of others in that 'moderation' is required by everyone. Participants often found that education regarding food items such as cakes and other 'sweets' was necessary to portray that they were in 'control'.

**Figure 6.3:** ***Things I Definitely Cannot Eat Meme***



From: https://bit.ly/3dbyQSw

Others often based comments and questions on outdated information about older types of insulin, therefore participants educated others about the advancements of insulin and how different, newer insulins work. It was not risking one's life if one ate something that may be considered 'sweet' and people with diabetes can in fact 'eat sugar'. As in Figure 6.3, the consumption of 'sweet' or sugary foods is not poison for individuals living with diabetes, although the participants in this study often perceived others believed this:

> *Oh, when I – now I go, and I guess it is a good line or an excuse, 'Well', I said, 'That is the one advantage of an insulin pump', and I said, 'Diabetes is not like it used to be. Insulins have changed." I said, 'Now we have fast acting, so it counteracts', and I said, 'We bolus for what we eat', and 'We can eat sugar like anybody else today because it's come that far', but they think – people still think it's taboo to eat anything sweet, cakes or anything.* *[Part. 12]*

Unfortunately, all too often, the questions and comments from others spurred feelings of inadequacy; of not managing well enough. In this next example, autonomy was expressed in the responses to others about individual diabetes management. However, the questions were not well received as they were perceived as an attack on the participant's autonomy. Here, questions were raised about food choices and Participant 15 attempted to educate in the midst of feelings of inadequacy:

> *Typically, I'll revert back to and explain the pump – like, you know, 'The pump's very flexible. It gives me a lot better flexibility of what I can eat and when I can eat. You know, I just have to account for it and give myself additional insulin if there's something that I want to eat', so I'll typically spin it that I'm still in control; I know what I'm doing, fuck off. (laughs) but, essentially, and I have told people 'It's none of your business'. If I'm in a bad mood, I will be up front and say, 'Mind your own business.' [Part. 15]*

In spite of frustration with perceived negative comments and continually educating individuals as a means of defending their choices in diabetes management, participants also indicated that it is 'okay' for people not to understand diabetes in the same way as those who live with it. This was compared to how the participants in this study may not know about cancer or other sorts of diseases. "*And too, you know, I mean, I wouldn't know a lot about diabetes if I wasn't a diabetic. It's like any other medical condition, I don't know enough about it". [Part. 2]*

Participants acknowledged the difference between a lack of knowledge by those that do not live with diabetes and are simply inquisitive versus those who, despite not living with the disease, profess to 'know' exactly what should be done to manage well. Neither the participants - nor I - were exempt from surveilling others and as we talked, the participants often compared and contrasted themselves to others and especially compared their management to that of others also living with diabetes.

### Surveillance of Others (Us versus Them)

Participants often compared their diabetes practices to those of others who also live with diabetes. In addition, they also compared their practices to those who do not live with diabetes and concluded that they engaged in more health promotive behaviors because of their diabetes self-management. According to this participant, once one has knowledge about management, one should be able to do well and if not, there is a problem. *The day-to- day, like, 'cause once you're educated in it, if you can't handle it, well there's something wrong. [Part. 7].* Therefore, once one 'knows' about one's diabetes, one should be able to manage it and this participant described himself as 'well able' to manage diabetes in comparison to others. As he continued, if people who live with diabetes *care*, they should be able to manage it, however, he also acknowledged that the worry and the general day-to-day practices are different than others without diabetes. But at the end of the day, he constructed diabetes as a *disability* that **must** be managed. As suggested by Lucherini (2020), diabetes "…straddles and ultimately confounds the dichotomy between abled and disabled…" (p. 3) and individuals often move between acknowledging the hardships and life constraints of the condition and the benefits of an enhanced awareness of the body.

> *Right now, I know people that is diabetic, and they're just ignorant to the fact. They don't care. So, if you care, you can manage it, right, but at the end of the day, it's still a disability, it don't matter how you looks at it. It's something out of the norm. That's something that someone else haven't got to worry about. Like, the normal person, they haven't got to worry about checking their sugar or watching what they're eating or counting what they're eating, or figuring – how come I feels off? Like, they haven't got to worry about that stuff.*
> *[Part. 7]*

In the following example, the health care provider was incredulous about the frequency and intensity of the participant's practices. In this exchange, both Participant 7 as well as the health care provider created binary thinking (good/bad) between people with diabetes who manage well and those who do not. As suggested by Pols et al., (2019), normativity is created in numbers and here the frequency of blood glucose testing as evidenced by the number of test strips used per week creates a norm and sets a divide between those who manage 'well' and those who do not:

> *And he [physician] said, 'You are doing all that?', and I looked at him, and I said, 'Really?' I said 'You really think I'm doing that?', and he said, 'I imagine*

> *yes 'cause 'he said, '75% of the diabetics don't put this much thought into it.' I said, 'Well, that's – that other 25% care about themselves; those other 75% don't care', and he said, 'Really?' I said, 'Well, I go through 100 test strips in about a week'. I said, 'I might get maybe a little over a week, but usually Saturday to Saturday, I got 100 test strips done.' He said, 'You prick your finger that much?' I said, 'Well, between home and work, yes.' I said 'Well, in order to take the insulin, I gotta check my sugar.' I always have'. He said, 'Well, everyone doesn't do that'. I said, 'Well, like I just told you' I said, 'If you're not doing that, you got – I shouldn't say don't care – but you haven't got the inquisitive to care.' [Part. 7]*

Participants acknowledged that people with diabetes **'***must'* do certain things, there is no relenting with oneself. Here, Participant 11 claimed that there is 'either control or no control' with no in-between and *'good control'* is solely the result of *'good management'*:

> *I think what happens with people, and I guess people like to say brittle diabetes, but I don't really go along with that. Like, you have controlled, or you have uncontrolled, but I think the thing is with the diabetes, too, is if you are going to have your insulin, make sure you're having your supper within twenty minutes or so. Don't take your insulin, and two hours down the road decide, oh my God, I feels awful. My sugars must be down my boots.' Have your insulin and eat your supper, right… [Part. 11]*

Participants also compared their health promotion practices with others who do not live with diabetes. The following excerpt challenges conventional societal thinking that those with diabetes are far less healthy than people who do not live with diabetes. Here, Participant 11 highlights a benefit of living with diabetes; those living with diabetes engaging in more health promotive behavior than those who do not. As suggested by Stuckey et al. (2014) and Walker & Litchman (2020), the acknowledgement of positive outcomes as a result of living with diabetes may be conceptualized as a means of resiliency and positive coping skills.

> *Yeah, and these people [without diabetes] are not [engaging in the same level of promotive and preventative health activities], and they're not on precautionary medications, so they're probably at higher risk. …in the long term part of it, I guess you're living a healthier lifestyle than the person who is not because, well the thing is, like, you're being checked, your blood pressure's being checked, and, as you know, hypertension is the silent killer because if it*

> *goes unnoticed, then people have strokes and heart attacks. You're getting your A1C's checked; you're getting your triglycerides checked, and, you know, you're getting all this stuff checked, right – your CBC's and stuff – and so if there's issues, it's being picked up on. Whereas most people don't even go to see a doctor once a year.* *[Part. 11]*

Participants also compared the cost of managing diabetes to other health issues such as addiction. In this following example, an addiction is perceived to have started as a lifestyle choice, while with a diabetes diagnosis and especially Type 1 Diabetes, there was no choice. Yet, medications for addiction are covered by a provincial medical care plan more so than medications and pump supplies for diabetes management. This is unjust and unfair:

> *… at the recovery center where methadone and suboxone is covered. Is that not a lifestyle choice? It's an addiction, but you know, it started with a lifestyle choice. Did it snowball? Yes. Is their addiction not under their control? Yes, but it did start out as a lifestyle choice, but yet they're [government] willing to cover and pay hundreds of thousands of putting people through treatment that 80% of the time never cure or fix their problem, but there's so much money for that, but for diabetes or something out of my control that I'm doing my best to control, there's still no help for that. Yeah, it's expected to be paid out of pocket.* *[Part. 15]*

In sum, as participants compared themselves to other individuals also living with diabetes as well as those who do not, they perpetuated discourses of the meaning of good, competent diabetes self-management. Participants professed what they were doing well in comparison to others, thereby presenting themselves as not only having expertise in their individualized management, but in management of diabetes in general.

As described thus far, vigilance and subsequent surveillance practices were born out of a consistent level of worry; for some participants, this was worry and concern about diabetes in general, the inevitability (or not) of developing physical complications, the fear of fluctuating blood glucose, as well as an ever-present concern of being perceived by others as 'not managing well'.

## I Worry, Therefore I Surveil

Worry and fear provided impetus for vigilance as demonstrated through surveillance practices as well as planning and preparing for the unpredictable nature of diabetes. Participants worried about the technology (i.e. the pump itself), acute and long-term complications, hypoglycemia, and growing older and losing the ability for self-management. Considered aspects of diabetes distress (Vallis et al., 2016), I found fear and worry as actors in the network of participants' surveillant assemblages and ensuing practices. At the core of self-management practices is the drive to always be better and strive to have control (Duprez et al., 2020; Ellis et al., 2017). Participants recounted how they feared loss of this imposed expectation of control and not being able to self-manage which they identified as an impetus for their practices (Stuckey et al., 2014).

As described in the example below, there is no choice really in living or not living a restricted life as the acute and chronic complications of diabetes always need to be close to mind and factor into all decisions. Despite advances in technology such as the pump, and the freedom and flexibility it offers, most participants still created some sort of a routinized life. For many individuals, creating routines decreased their sense of spontaneity but at the same time afforded a level of comfort and security in their diabetes management practices (Lucherini, 2020). As Mol (2008) suggests, choices presented are not truly autonomous choices, as choices are always made within the confines of other contextual factors. Here, participants are convinced that a routinized lifestyle will help prevent fluctuations in blood glucose which will 'pay off' later in preventing diabetes related physical complications. Further, worry and concern should factor into all decisions that are made with the goal of not only *delaying* but *preventing* chronic complications, hence acknowledging that physical complications may well be inevitable despite all the worry and surveillance:

> *Well, the thing is, if you don't have a strict lifestyle, you're gonna end up with complications. Having diabetes in itself is hard, right. It affects you physically, and it affects you psychologically, but if you go off course, you're gonna end up with highs, and you're gonna end up with long term complications, quicker than you normally would, right, so you got no other choice, basically.*
> *[Part. 11]*

### *Fear of Complications*

Fear of complications related to diabetes, such as lower limb amputations, blindness, and cardiovascular disease was paramount for many participants. This fear was heightened by personal experiences, but also by others' accounts of diabetes complications. As such, general discourse of what diabetes is and what it may lead to permeated much of the participants' talk. In the following example, Participant 6's personal and nursing professional experiences heightened her concern for complications in relation to her feet:

> *Yeah, I'm very worried about my feet. The places I've worked have been areas where the patient population is largely folks with diabetes, you know, vascular surgery, like I say, where everybody is losing their feet and their legs, and I've – and now I'm seeing so many people with diabetes losing their eyesight, right, so… [Part. 6]*

Others played a role in increasing fear of diabetes complications. Participants were informed of others who had experienced diabetes-related complications and this information created a significant worry about fluctuating glucose. I too, have been the recipient of questions and statements of 'fact' about my own diabetes. For example, I have been told that I "actually" have a much shorter lifespan than other individuals as a result of living with diabetes. Instances such as these perpetuate hegemonic ideas that living with diabetes is always 'bad', people living with diabetes are always 'sick', and inevitably they will develop complications. Examples like this leave me feeling stigmatized and as a result, a want or need to ‘prove’ myself to others as the ‘good diabetic’ and when I feel I am not doing my best at my management I really do not want to tell others. Similarly, in this excerpt, there is great concern for the risk of complications in the moment. Although physical complications as a result of diabetes do not happen to everyone with diabetes (Harding et al., 2019; Nathan, 2014), as a result of being reminded ‘what may happen’, fear and anxiety ensue (Stuckey et al., 2014):

> *…you’re reminded by the public everyday of their aunt, uncle who had diabetes, who had their leg amputated, who went blind, etc., etc., insert a diabetes complication, so you’re reminded of all the things that could go wrong, and then, when your sugars are not on target, you’re thinking, if – if your sugars are 14 [mmol/L], you’re thinking, my sugars are 14 [mmol/L]right now; there’s too much blood glucose in my blood, this is causing – this is damaging my kidneys at this moment; this is damaging my eyes; this is damaging whatever organ because it can affect everything, so it’s very stressful, and you want to get it down. It’s almost anxiety provoking that you need to get this down, right away. I don’t want to wait a half an hour for my insulin to start working; I don’t wanna wait that hour for it to kick in; I want this down, now (laughs), right now. I don’t want to wait another minute, but it doesn’t work like that, so it’s frustrating, too…* *[Part. 1]*

An aspect of diabetes self-management includes attending many appointments with a range of health care providers. Keeping on top of appointments was driven by fear of complications. As Participant 11 described, he needed to be strict in routine and keep appointments with health care providers to be proactive in preventing physical complications related to diabetes, and thus increase his competence in good management.

> *… the long-term complications from bad control, so you’re thinking, okay, well, am I gonna have a heart attack? Are my kidneys gonna give out? Am I gonna lose my vision? And then, on top of that, to be proactive, you got to have all these appointments, right, so, like, every month, okay, so you gotta go see this one; you gotta go see that one; you gotta go see someone else, so it’s – like I say, it’s very stringent. You gotta keep on top of it, but that’s it. If you don’t, you’re in trouble.* *[Part. 11]*

Fear of future physical complications was a significant discourse in my participants' accounts. To some extent, this worry could be minimized in the bustle of everyday demands. One fear that could never be ameliorated was extreme variation in blood glucose levels. In this study, the participants lived with diabetes for an average of 27 years and even with all of their experience in monitoring and planning for, as well as mitigating hypo and hyperglycemia, they remained fearful of extreme fluctuations in their blood glucose. This ongoing fear was in relation to the physical symptoms experienced with extremely high or low blood glucose, but also participants feared the perception of incompetent management resulting from these fluctuations. As participants told me, this fear provided the impetus for most of the surveillance practices.

### ***Overcompensating for Frightening Highs but even more Scary 'Lows'***

Throughout the findings a regular, recurring discourse has been fear of highs and even more fear of dangerous lows. As suggested by Brazeau et al. (2013), Stuckey et al. (2014) as well as Lucherini (2020), fear of hypoglycemia is common and is an actor in many diabetes practices leading to under-bolusing insulin, creating routines that stifle spontaneity, as well as comfort with higher than recommended glycemic targets. Living with diabetes does not happen outside of society; diabetes management practices are always in context. We often see and hear about diabetes, from the discussions and reminders of complications as described above, to programs on television, movies, commercials that advertise medications to enhance glucose stability and thus make life so much better to the inevitable expression when someone with diabetes develops a complication or worse, dies, is that 'they did not care for themselves'.

Just recently I watched a movie titled 'Greenland' in which the world was ending, and certain people were selected to live underground in a bunker for an extended time to survive. Unfortunately, one of the main characters lived with diabetes and was denied the right to be included in the population chosen to survive. This movie was made in 2020 and while it is fiction, represents how diabetes is socially constructed as a negative, unnatural, and non-normal way of life. This movie perpetuates the long-standing idea that those living with diabetes are not as healthy, and therefore not the ideal citizens.

So high was the fear of experiencing hypoglycemia, participants tended to run their sugars a little higher and correct, rather than risk a low blood glucose. In this example, Participant 9 kept her blood glucose at 12 or 13 mmol/L (potentially high enough to cause complications) as she feared not coming out of a low, i.e. passing out and not being able to wake up. *"… but to go down [low blood glucose], I have this fear of going and not waking up, not coming out of it – that's my fear, right"? [Part. 9].* Even after living with diabetes for many years, most participants especially still worried about hypoglycemia during the night, as Participant 11 told me: *"I guess the biggest challenge would probably be in the nighttime, as it still is today – going to bed with the uncertainty of, you know, is your sugars gonna drop out? Are you gonna wake up? and this sort of thing". [Part. 11].*

I also live with this fear. While I think that I manage quite well and strive to be perceived that way by others, I still worry. Since my diagnosis of Type 1 diabetes in my 30s, I have not had one night of carefree sleep. Despite all my monitoring and planning, the creation of surveillant assemblages, I still go to bed hoping that my glucose does not drop, my pump continues to function and infuse insulin, and that I will wake up in the morning. I also hope that my glucose remains stable and that my CGM does not alarm, prompting me to drink warm orange juice (hypoglycemia) on the nightstand because I am too tired to go to the kitchen, or either that I have to take a correction bolus (hyperglycemia) with bleary eyes. As other participants told me, this fear is ever-present to some extent, we just learn to 'live with it'.

At times, participants' fear was so great that they did not take enough insulin (i.e. under-bolused, took less than the recommended amount as per the carb ratios pre-programmed into the pump) to prevent hypoglycemia. *"I'll under bolus because I'm afraid of the lows, right, of going too low, so I'll under bolus, and then check it two hours later." [Part. 12]* Along with fear of hypo and hyperglycemia, participants also worried about growing older, becoming sick, and possibly losing the capacity for self-management.

***Growing Older? Getting Sick? What will I Do?***

Participants feared losing control from growing older and losing the ability to self-manage. They were concerned that others would not be able to manage their diabetes as well as they could; concern that is perpetuated by self-management education where people with diabetes are taught to constantly strive to manage their own diabetes. To relinquish 'control' to someone else lead to feelings of anxiety:

> *Now, one thing that came to my mind, my biggest fear is getting old and living with diabetes, yes. Who's gonna look after me if I don't know how, right? Do you know what - do you ever think about that? My God, you know, what am I gonna do when I'm about seventy -- I'm hoping to live to about eighty or plus, and I go, you know, what about if I'm living, and my eyesight a little bad or, you know, I can't think the same as I do now? Is my mind gonna be as sharp as it should be to know what I need to do or how much I should eat? Am I gonna be able to manage on my own, right? All that stuff goes through my mind 'because it is a real – and I'm very much a realist to look – and I probably look too far and probably worry too much, right, but I think that also comes with being diabetic… [Part.12]*

Ironically, in teaching and encouraging people with diabetes to be competent self-managers, health care providers, members of the general public, as well as the participants themselves have created a sense that those living with diabetes should not give any control to anyone else, even health care providers. Current conceptualizations emphasize self-responsibility for health and for these participants, this ideology was demonstrated through their fears and ensuing practices. I too, share this concern – ***no one can manage <u>my diabetes</u> as well as I can***. As a result of participants' ongoing practices to be good, competent self-managers, participants considered themselves to be the experts in their own management. This prompted considerable fear and concern/worry about giving any control to health care providers who may know diabetes management in general, but not the participants 'own' diabetes. In the following example, the possibility of being in hospital heightened this fear:

> *I do fear that if I have that broken hip or the knee replacement, that someone's gonna screw me up [blood glucose management] when I go under anesthetic. I know that my pump has to come off, and that would frighten me.*
>
> *[Part. 13]*

Ultimately, participants conceptualized surveillance practices as a necessary precursor to the inevitable planning that came with managing diabetes. Their desire to preserve their image as 'competent' self-managers was related to their abilities to surveil themselves and others, and to be motivated to plan and prepare for the inevitable blood glucose fluctuations.

## Conclusion

In this chapter I have presented the theme that constant surveillance is required in diabetes management. In their accounts, participants presented themselves as 'good, competent self-managers' as a result of this surveillance and both the processes as well as the results of their surveillance practices provided the necessary background to make decisions and solve problems in the moment as well as in the future. As I traced the flow of practices, I came to understand that surveillance represented a 'zooming out' as practices had now evolved from those local and specific to the pump, to how using the pump fit with more general diabetes management practices such as monitoring of blood glucose. Additionally, within their surveillance practices, participants engaged in local practices of attending to the body and self-monitoring blood glucose to more global practices of surveilling others and comparing themselves to others.

As Manokha (2018) suggests, diabetes surveillance practices demonstrate self-discipline and self-restraint which are conceptualized as good management. As a result of self-discipline, participants in this study actively constructed their identities as competent managers. Through these surveillance practices, participants both influenced and were influenced by power shifts. As a result of 'felt' surveillance, participants demonstrated power over themselves as they disciplined their practices and thus their bodies (Lucherini, 2016). In disciplining their bodies through surveillance, they actively placed these practices on display thus contributing to knowledge of the general public of what 'good, competent diabetes management' looks like. In turn, participants were influenced by what they felt were imposed expectations (power of others) for monitoring as well as the results of such scrutiny as they were reticent to divulge less than optimal blood glucose values.

As a result of these power shifts, the participants and I participated in both creating and perpetuating knowledge of what surveillance practices should include as well as their meaning. As a researcher I was constitutively entangled in participants' accounts as well as my interpretations, i.e. my account of their accounts (Hultin, 2019). In essence, I became an actor within the assemblage(s) under study and while I created the analysis, it also created me (Hultin, 2019; MacLeod et al., 2019).

Ultimately, surveillance practices generated knowledge that was utilized in planning and preparing for as well as mitigating fluctuations in blood glucose. Participants surveilled to enhance their knowledge for other diabetes practices which in turn influenced future surveillance practices.  In the next chapter I will explore the fourth theme; the necessity of always planning and preparing to deal with managing fluctuations in blood glucose as a result of many day-to-day and often moment-to-moment contextual factors. In fact, unpredictability was described as such a mundane, everyday phenomenon and simply a ‘part of having diabetes’, that it was expressed as *‘living in predictable unpredictability’*.

# Chapter 7: Living in Predictable Unpredictability

# Chapter 7: Living in Predictable Unpredictability

As a result of a constant state of vigilance demonstrated through surveillance practices, participants in this study navigated life as a delicate balancing act; always trying to stay within their target blood glucose range. As suggested by Arduser (2017), the practices of individuals living with diabetes occur in a space of neither ‘here nor there’ in that they continuously engage in practices designed to maintain optimal boundaries between hypoglycemia and hyperglycemia. The participants tried tirelessly to stay somewhere between ‘too little’ or ‘too much’ blood glucose and this work was relentless, never-ending, and exhausting. Extensive background planning practices went into everyday activities such as eating, sleeping, exercising, social activities such as restaurant dining, as well as any kind of travel from commuting to work to vacation. Participants always had diabetes close at mind, and this was mostly invisible to others and often, even to themselves; management practices were as routine and automatic as breathing. Yet, the mental effort and exertion put into these often unseen and hidden practices was enormous. As suggested by Burridge et al. (2015), the labour of internal, invisible diabetes work is often underestimated.

Despite the best intentions in planning and preparing, participants described how they perceived their diabetes practices as *living in predictable unpredictability,* which is the fourth theme in my analysis. Discourses here centered on preparing to prevent as well as manage any fluctuations in blood glucose and participants all carried food and other pump and diabetes supplies. The kinds and quantities of various emergency foods carried (as well as when to carry them) were quite individual and depended on experiential knowledge, comfort, and sense of competence with self-managing developed and refined through previous practices which consistently changed depending on the relations amongst networks of actors. Please see Table 7.1 for an overview of this theme and sub-themes.

In the previous chapter, I described how the participants in this study engaged in surveillance practices to monitor or keep a close watch on their diabetes management, most notably their blood glucose values. In continuing to genealogically trace the flow of the participants' diabetes practices, I came to understand that constant surveillance practices provided the background information required to enable planning and preparing to pre-empt, as well as manage blood glucose fluctuations. I continued to map the relationality, temporality, as well as spatiality of practices and thus diabetes enactment of these participants; surveillance practices were related to and based on the practices of first obtaining and using a pump as well as they influenced planning practices across different places and spaces over time. I continued to both widen and narrow my lens ('zooming in' and 'zooming' out) in tracing these practices, going back and forth between local practices and the associated meaning for participants' sense of comfort and competence in their overall diabetes management (Nicolini, 2009). In this chapter, I turn to those practices of planning and preparing for, as well as managing hypoglycemia and hyperglycemia once they occur. Specifically, I will discuss the unpredictable nature of diabetes, practices of carrying food as well as pump and other associated diabetes supplies, as well as practices to manage hypoglycemia once it occurred.

**Table 7.1*: Living in Predictable Unpredictability Theme and Sub-themes***

| Theme | Theme Description (brief) | Sub-themes | Sub-themes Description |
|---|---|---|---|
| **4) Living in Predictable Unpredictability** | Despite the best intentions and planning and preparing practices, living with diabetes inevitably meant living with expected predictability in glucose values and trends. | 4.1 Predictable Unpredictability | Despite the best intentions and planning and preparing, glucose often fluctuated, which affected participants' self-image and self-esteem. |
| | | 4.2 An Impossible Task? Maintaining Stability of Blood Glucose | Maintaining glucose stability was an impossible task; mastery was an imposed expectation – one that participants could not live up to leading to guilt and blame. Successful management was measured through biomedical markers such as HgbA1c. |
| | | 4.3 Food: The Emergency Stash | Food was often considered 'medicine' for hypoglycemia and participants created routines in eating patterns and whether they carried (and how much and type of) foods. |
| | | 4.4 Don't Leave Home Without your Lifeline!!! | Participants varied in their practices to carry extra pump and other diabetes supplies to manage potential hyperglycemia. |
| | | 4.5 Predictable Spontaneity | Participants planned for activities such as exercise and eating out; they planned to enable spontaneity as best as possible; but realized there would always be limits to their spontaneous experiences. |

## Predictable Unpredictability

In spite of the best intentions, and ensuing practices to prevent fluctuations, participants' blood glucose was often outside their target levels and while participants were not happy with this, they perceived fluctuations as an inevitable aspect of living with diabetes. As suggested by Ketchell (2016), individuals living with diabetes have a moral duty to care for oneself. This author also articulates how 'caring for oneself' in historical and current diabetes self-management practices is deeply influenced by numbers, where an optimal, target HgbA1c value is taken as proxy for caring for oneself. Further, according to Kenowitz et al. (2019) optimal HgbA1c values (or those within target range) are associated with diabetes-specific self-esteem and self-image as a competent manager. Thus, the participants in this study invariably indicated that they felt 'bad', or 'out of control' with blood glucose values that were not optimal or fluctuated from target.

Participants' practices included extensive thought and action in planning for and managing various situations and instances of potential higher or lower than the individualized optimal blood glucose targets. Hinder and Greenhalgh (2004) found that self-management as reported by a sample of 30 individuals living with diabetes was physically, mentally, emotionally, and socially demanding. These authors suggest that self-management includes the continuously interplay of influences at the micro-level (the individual), meso-level (relations with others such as friends, family, co-workers, etc.), and macro-level (policies, cultural norms, and expectations, etc.).

In this sample of participants, even with considerable time and effort, inevitably there were untoward or unplanned developments such as unexpected hypoglycemia and hyperglycemia. Being more prepared led to better 'control' which in turn enhanced the likelihood that they themselves, as well as others would perceive them as a good, competent self-manager. In their qualitative study with 27 individuals living with Type 1 diabetes using intensive insulin therapy (either pump ($n = 16$) or injections ($n = 11$)), Browne et al. (2014) found that stigma and discrimination result from perceived mismanagement of diabetes from others leading to a judgment of lack of 'control'. Through planning and preparing practices, the participants in this study added to the image of good self-management in that they could always be in control, thus perpetuating dominant ideologies of self-responsibility for diabetes management which center the human actor.

Living with diabetes in the context of everyday life inevitably leads to some blood glucose fluctuations and the pump adds other factors which impact this unpredictability. As explained below by Participant 3, using the pump adds other issues which compound the already unpredictable nature of diabetes management. As in the previous chapters, the agency of the pump and associated supplies are evident here as the kinked tubing affects the agency of the pump (specifically, its ability to deliver insulin), while the inability to deliver insulin leads to a higher than target blood glucose value, which then prompts Participant 3 to either change the infusion set or take an injection of insulin to bring down the blood glucose:

> *Well, I mean, certainly, it [diabetes] can make you feel vulnerable. I mean, you know, you can do everything – I'm using air quotes again – 'right'–but the pump adds in factors that we have no control over. You know, a kinked cannula, a tear in your tubing from a dog nibbling on it or a cat nibbling on it, overnight. Like, that stuff happens, and then you have health care providers looking at you, saying, 'What went wrong?' or 'What did you do?', and it wasn't you, you know, or maybe you had scar tissue you didn't know about. You put the site in there, and you have blood sugars that are not quite right for three days. Like, you know, I think there are certainly parts of the pump that make it [diabetes] – make you more vulnerable… [Part. 3]*

While all participants acknowledged the inevitability of fluctuating blood glucose, they endeavored tirelessly to prevent 'too much' fluctuation. What was amenable to one participant as an acceptable fluctuation, was not acceptable to another participant. According to Borovoy and Hine (2008), the assessment and mitigation of risk (in this case glucose variability) is highly contextualized and individualized and thus what may be considered acceptable risks for some individuals is not for others. Additionally, the participants acceptability of risk was influenced by knowledge developed through previous diabetes management practices, attesting to the relationality, temporality, performativity, and normativity of practices (Hultin, 2019; Nicolini, 2009; Oliveira de Moura & Bispo, 2019). In spite of the best knowledge, experience, and planning, participants perceived a loss of control when blood glucose levels were outside of their target range. Throughout this analysis, 'loss of control' may be considered an actor in diabetes practice networks. For these participants, loss of control was agentic in that it prompted agency of the participant to engage in certain practices to ensure as optimal glycemic control as possible.

Quite often, participants did not know why the same planning, preparing, and managing lead to quite different outcomes. This was difficult as participants desired to always know 'why' their blood glucose was not in target range. As Ellis et al. (2017) suggest, nurses' perceptions of 'good' self-managers are those individuals living with diabetes who strive to increase their knowledge base and mitigate risks by achieving and/or exceeding biomedical targets thereby increasing responsibility for disease management. Good self-management was the result of knowing the rationale for blood glucose fluctuations and in this sample of participants, the inability to discern rationales for hypoglycemia and hyperglycemia was frustrating.

From a sociomaterial lens, there are many actors in the network of supporting blood glucose stability. It is impossible to predict how several internal and external actors will interact in attempting to maintain normoglycemia. For example, the beginning of an infection is agentic in that it may increase blood glucose, often outside of the knowledge of the individual. At times, participants offered no discernable reasons such as forgetting to take insulin or taking too much, which led to feelings of frustration. As suggested by Baldwin and Parsh (2020), individuals living with diabetes may be critical of themselves as a result of high blood glucose levels and subsequently develop shame and guilt:

> *Most times, you know, if it's [blood glucose] high, I say, okay, well maybe I miscounted the carbs in that particular meal. I can say, yeah, okay, well you did grab that granola bar and didn't take insulin for it or whatever. You know, sometimes I can explain those, but then there's sometimes that it's just there is no rhyme or reason; it just happens. I guess, for me, what I find frustrating is, you know, what works today, in all likelihood, won't work tomorrow.* *[Part.2]*

Participants also made mistakes with carbohydrate counting or did not allow for exercise or other factors that may have affected their blood glucose levels. Different from the above example, but in keeping with Ellis et al. (2017) as well as Duprez et al. (2020) in their exploration of 'good' self-management, the ability to discern reasons for fluctuations mitigated feelings of guilt and frustration. At times participants expected fluctuations and as described in the following example, could discern the rationale, which was perceived as in 'better control' of diabetes, however still impacted self-image. Mamykina et al. (2010) suggest that the ability to offer probable causes and explanations for blood glucose fluctuations leads to a reaffirmation of competence in self-management and thus protects one's self-image as a competent self-manager.

> *I know because I overshot my insulin for lunch, and that's the reason why – because my sugars had been up a little bit in the morning because I had fasted for blood work, and then I probably overate a little and didn't calculate the sugars, right, so then by lunchtime my sugars were up a little bit, so then I probably took too much insulin, which, three or four hours down the road, showed up as a low, and also, I was overactive yesterday afternoon with work and stuff…* *[Part. 11]*

Not all changes were random. Some factors, such as hormones are predictably active at certain times. As Participant 10 explained, routine hormone changes during the menstrual cycle affected her blood glucose levels so that her usual diabetes management practices were no longer effective, and she needed to plan for changes in pump settings to maintain target blood glucose levels. As a result, living with diabetes meant not only paying attention to body cues in relation to shifting glucose levels, but also to other internal physiological mechanisms such as her menstrual cycle. Here, the network continues to expand to include other actors such as hormones associated with the menstrual cycle. As described here, while one can ‘keep these influences in mind’ it is impossible for individuals to accurately predict such influences on blood glucose. However, historical, and current research on self-management and self-management support, continue to promote the necessity of enhanced knowledge of everything that will impact blood glucose (Ellis et al., 2017). In this example, in collaboration with her diabetes team, the participant changed basal settings to attempt to mitigate the increased insulin requirement:

> *I’m pretty steady. We find now [herself and diabetes educator], with my cycle, it, like, really affects my sugars. So, like, just before my period it’s like insulin turns into water, and then afterwards I gotta change all my settings.*
> *[Part. 10]*

Along with personally navigating the predictable unpredictability of diabetes management, participants also had to do this in social contexts with other people. Others often did not understand this unpredictability and there were times, where others were incredulous about changes in blood glucose levels, leading the participants to feel incompetent. I, too, have experienced instances where I have divulged the unpredictable nature of diabetes in that I did not sleep well as my glucose was higher than usual (for unknown reasons) and I woke up with a glucometer reading of 11.4 mmol/L. I have witnessed my colleagues eyes widen and have received questions about why my glucose was so high, if I had ate anything I ‘should not have’, and if I needed anything (i.e. if I needed to sit down or proceed to the emergency room). I, like the participants in this study, realize that others who do not live with diabetes might not understand the ebb and flow of blood glucose and how difficult it is to consistently manipulate the function of the pancreas from outside the body. Others may not understand this concept of rhetorical plasticity, as individuals living with diabetes manipulate their bodies in the absence of a functional internal pancreas in various social settings (Arduser, 2017). Local practices of navigating unpredictability now become more global and on display (Nicolini, 2009). The results of these practices on display for others who may not understand, often lead to feelings of not managing well enough (Archer, 2014) and possibly enhancing feelings of blame and shame in not being able to manage as expected.

All participants planned to maintain stability of blood glucose as much as possible, given that diabetes management occurs in everyday life and as such in many contexts. In their accounts of planning and preparing, participants referred to maintaining stability in many ways as ‘chasing the elusive’ in that they engaged in exhausting work in attempting to maintain an ideal stability of blood glucose, knowing full well that it was something they could never entirely master.

## An Impossible Task? Maintaining Stability of Blood Glucose

Participants described a level of constant preparedness not only to prevent hypoglycemia and hyperglycemia, but to manage it once it occurred. It wasn’t a matter of *‘if’* it would occur; but to prevent *‘too many’* occurrences. Participants realized that it was impossible to achieve ‘mastery’ with diabetes - this was an unattainable goal. Using the term “mastery” is in reference to how the participants felt about societal expectations which in turn affected their level of planning and preparedness. Definitions of mastery include *‘power or control over something’, full command or understanding of the subject’, ‘outstanding skill or expertise’,* as well as *‘victory or superiority’* (Collins Dictionary Online, 2021). This perceived expectation of mastery was about knowing how to manage and manage well ***all of the time***. While participants felt that this was an unreasonable goal, using technology such as CGM with the pump as well as close monitoring of blood glucose levels provided the necessary background practices to create possibilities for some level of predictability (Pols et al., 2019).

Contemporary conceptualizations of self-management often acknowledge the impact of various contextual factors besides individual skill in diabetes management (Ambrosio et al., 2015; Houtum et al., 2015; Jeon et al., 2010; Vallis et al., 2016), yet researchers continue to study and provide methods for achieving *mastery* in management (Fearon-Lynch et al., 2015; McGulgan et al., 2021). All participants in this study felt this was an unrealistic goal and, in their accounts, they spoke of mastery as an imposed expectation, one that was neither realistic nor attainable: *"because you're never gonna figure it out 100% - that's impossible…" [part. 7]* As suggested by Ketchell (2016), "…neoliberal ideologies create unrealistic expectations that autonomous patients who act in accordance with a normative standard of diabetes care will achieve precise results" (p.57). These ideologies lead to feelings of blame and shame culminating in stress and anxiety as demonstrated in the excerpt below:

> *So, absolutely not, they're [blood glucose levels] not always on target. I think that's impossible – absolutely impossible. Uh, it's stressful – stressful in – I don't know if it's anxiety provoking, um, terrifying – because you think about all of the things that could occur, that could go wrong… [Part. 1]*

Planning, as Participant 1 explained, it is just something that is 'done' and not truly considered an extra step. It was routine, mundane, almost done without thinking because it was ingrained in daily life practices. These everyday mundane practices become the normative method of enacting diabetes in that such practices become the expected ways of seeing, doing, and acting in making decisions and solving problems (Nicolini, 2017). Planning to deal with problems in managing blood glucose meant participants often carried extra food and pump supplies – having 'backup for one's backup' as Participant 9 explained, *"I have a backup for my* *backup, all the time, right? But I never thought of it as being a challenge. I guess it's because I'm so used to doing it now, right?" [Part. 9]* This heightened level of preparedness was evident in many participants, but not all. As such, although planning and preparing was apparent to some extent in all participant accounts, the level or intensity of preparation varied widely amongst participants. For many participants, planning and preparing practices provided a sense of comfort and control and ultimately, a sense of freedom that they would be able to deal with and manage whatever unpredictable diabetes events may happen:

> *Yeah, I feel the same [in needing to be prepared]. I'm always kind of prepared. Like I said, I got stuff in my purse, stuff in my car, food in – my work bag food, and my book bag food, and my – you know, like I always got stuff, so, you know, I got a bit of freedom that way, yeah. [Part. 4]*

While still required to prevent and manage hypoglycemia, participants often became more complacent and comfortable with themselves as individuals living with diabetes. In the example below, when first diagnosed this participant experienced intense panic with low blood glucose but after many years and practices with hypoglycemia, this panic subsided. As a result of ongoing decision-making practices to mitigate hypoglycemia she increasingly developed her own experiential knowledge base to draw from, creating a habitual mode of practice (Mamykina et al., 2015). This participant learned how to manage hypoglycemia, and in doing so, developed a sense of trust in herself and practices routinely executed to increase blood glucose. She increasingly made sense of her experiences of hypoglycemia through her practices to mitigate them. As suggested by Introna (2019), sense is made "…not only by other human subjects, but by a whole host of other actors intra-acting with the sense-maker(s) in the very act of sense-making" (p. 750). As a result of ongoing relational practices amongst many actors (glucometer, blood glucose values, hypoglycemic symptoms, various food sources, other human actors, etc.) participants increasingly learned what was sensible from them to do during experiences of hypoglycemia (Hultin & Mahring, 2017). Here, Participant 12 continued to attempt to prevent and manage low blood glucose, but at the same time the level of panic had evolved over time:

> *I've become much better with the low. I will check my blood, and say it's – now, if I'm out walking, and I'm 3.6 [mmol/L]or 3.7[mmol/L], nothing for me to keep walking and take three or four jellybeans, and I'll say, just keep walking; just slow your pace down a little bit, and if I'm walking with my friend, I'll say, 'Yeah, we gotta slow down', and other times I might not say anything, and just pop the jellybeans 'cause I know three or four are gonna bring me back up and that, so I got really good at not [panicking] –I used to have those meltdown[s] – and the anxiety, then, made the low feel that much worse, so I kinda got myself past that, to a certain extent, 'cause I just keep going, 'Fifteen minutes, fifteen minutes – just wait your fifteen minutes', and I'd have to talk myself down, right.* *[Part. 12]*

To either prevent, delay, or manage hypoglycemia and/or hyperglycemia, participants created routines and patterns of activity and food consumption, carrying both food as well as pump and other diabetes supplies to plan for events such as exercise, social activities, and travel. This planning and preparing impacted spontaneity as well as feelings of dependency and vulnerability and participants tried to create spontaneity while trying to keep a certain amount of predictability.

### ***Staying on Course***

In preparing for and managing the inevitability of blood glucose excursions from target range, participants created routines to both prevent and manage hypoglycemia and hyperglycemia. They described the pump as marketed to allow more flexibility in eating practices (types of foods eaten and trends/patterns), however most participants created routines to aid with blood glucose stability regardless of this added flexibility. Routines enhance perceived self-efficacy with self-management (Schulman-Green et al., 2015) and in this sample of participants, the majority incorporated routinized planning in their everyday diabetes management practices.

As these participants explained, having similar breakfasts and lunches each day facilitated maintaining stable blood glucose levels. Additionally, visualizing stable blood glucose levels resulting from those routines produced a sense of emotional wellness and enhanced self-worth as a 'competent manager'. Hortensius et al. (2012) suggest that the overly positive representations of blood glucose values portrayed by glucometer advertisements do not do justice to the incredibly complicated and often difficult diabetes management practices. As a result, such advertisements create an illusion of control and competence that many participants in this study strived for but realized they could never fully meet. This had implications for their self-esteem and self-image which was clearly manifested in the happiness expressed with achieving target blood glucose values as this participant told me: *"The happiest happy time I am when I know – oh, guess what, your sugar is seven.* ***Oh, perfect!"*** *[Part. 9]* Kenowitz et al. (2019) suggest that diabetes-specific self-esteem is closely related to the HgbA1c value, indicating that this biomedical marker of disease serves as a proxy for good, competent management. To achieve this happiness and feeling of self-worth because of stable blood glucose, many participants created routine meals as such as consistent types of breakfast foods:

> *I have my breakfast every single day, and I can tell you I probably eat the same thing every day – a slice of toast with peanut butter and a cup of coffee – and I'll check my blood, say, five – and it's too funny because I go '****Yes!'*** *It's like I'll wake up and it's 5.1[mmol/L] or its 4.8 [mmol/L], and I'll be '****Yes, okay****!'*
> *[Part. 12]*

As with routine breakfasts, participants ate the same or similar lunches. This was especially beneficial as it created *a priori* knowledge throughout the work week leading to an ability to decrease thinking in the moment (at lunch time) about carbohydrate counting. As many employed readers may know, having a routine for lunches reduces the effort needed to plan and get out the door in the morning, but in living with diabetes, creating routine lunches enhances knowledge required for effective diabetes management, as well as normalizes the experience. Routine lunches contributed to a sense of freedom but when there were deviations from the norm, a corresponding increase in problem solving and critical reflection was warranted. In the following quote, Participant 10 articulates how even minor alterations to normal routine can have significant effects that require post hoc analysis to determine what changed and why. In this example, the bread produced by Dempsters® has approximately 24 grams carbohydrates per slice, while Wonderbread® has approximately 16 grams of carbohydrates. If the participant inputted the carbohydrates for the Dempsters® bread, but actually ate the other bread, she would have taken too much insulin and thus potentially experienced hypoglycemia:

> *Similar lunches. Not the same, but I'll have similar lunches. So, normally, I'll have, well, four days out of five I'll have a sandwich (laughs) on the same Dempster's bread that I have, and even that routine, so say if one day we bought Wonderbread, which is way less carbs, I'll still enter my Dempster's bread, and then I think 'How come I went low?', and I think 'Oh yeah, I had Wonderbread', but yeah, so I usually eat the same bread, and a piece of fruit and yogurt, so around the same amount every day.* *[Part. 10]*

Routines were different at home as opposed to at work. As a result of change in space and place, networks change and thus practices change as well. For Participant 14, being at home meant more flexibility with different foods and snacking. In the example below, he was able to check his blood glucose more often while at home as he perceives others scrutinize his diabetes practices when at work and thus, he is able to snack a little more freely as a result of checking and taking required insulin. While many of the actors in this practice network stayed the same during meals both at work and at home – glucometer, test strips, blood, blood glucose value, food items, pump, infusion set etc., at home there were fewer human actors as there were no co-workers. As a result, this participant felt better able to assess his blood glucose without any comments from others that were perceived as stigmatizing and marginalizing. This network of actors shifted, and so did the meaning, or sense that was created within the practice. The performativity of this practice of having lunch at home, outside of the purview of coworkers enabled the agency of this participant in that he was able to act differently (Hultin & Mahring, 2017). However, by acknowledging his ability to *'get away'* with a different routine, he alludes to the belief that although he has the pump and extra freedom and flexibility, he still needs to create and maintain diabetes management routines and to err outside of these routines may be perceived by others and felt by oneself as 'bad' or deviant. Thus, venturing outside established normative routines, designed to maintain glycemic control, could indicate poor self-management:

> *Yeah, I definitely snack. Like, I find this week was bad because I didn't have the routine. So, I'd get up at the same time; I'd have my breakfast, but I would have more breakfast when I was home. So, I would have my sausage, my eggs, my bacon, my eggs, toast. Like, if I'm working, I'm just getting a slice of toast or cereal, you know or something smaller, – so this week was just all messed up, and then I will have my lunch. I wouldn't have breakfast until 9:30/10:00, as opposed to, you know, having it at 8:00 or 7:00, probably wouldn't have a lunch because I'd have my breakfast so late, so then I would just have my supper, so I'd have two meals as opposed to three, right, and they are all off because my bolus is reading for those times of the day, right, so that's…I thought it [blood glucose]was gonna be a little bit worse than it was, but I think it's just because I was so close to home. Like, I was home all day, so I could just get away with it.* *[Part. 14]*

Creating routines with meals represented one aspect of 'staying on course'. Participants also devised routines with respect to carrying rescue foods to prevent/manage hypoglycemia, as well as pump and other supplies to manage hyperglycemia.

**Food: The Emergency Stash**

In planning to manage hypoglycemia, food becomes more than just food; it is something required to treat a medical condition, often felt as an emergency and thus food becomes medical treatment. Most participants had quick access to emergency food both to prevent as well as manage episodes of hypoglycemia. According to Maietta (2021), individuals living with diabetes engage in planning and preparing practices especially those designed to mitigate hypoglycemia such as carrying food sources to continue to perform tasks related to their identity or sense of self. In this study, the participants indicated they carried food to seamlessly manage hypoglycemia should it occur, and their other tasks (e.g. those that support their professional self-image or role image e.g. of motherhood) would not be interrupted. To ensure their ability to conduct these identity tasks, participants often had food sources in many places, as a contingency plan for having to manage low blood glucose and a typical comment was, *"And I got 'em [carbohydrate sources] in every coat pocket I put on; every purse I take; every – everything" [Part. 12].*

In contrast, in this next example, which was uncommon in this sample of people, Participant 15 ate whatever he could find at home during an episode of hypoglycemia, but if he was outside the home he would need to stop at a store as he does not carry food items on him or in his car. This represented a counter-discourse in that most participants carried some food items to prevent or treat hypoglycemia, but this participant did not. Participants' perception of risks associated with planning and preparing differed and in this instance, the participant found that carrying food sources was not necessary. In this sample, this participant's determination of risk was quite different than the other participants as well as my own. Admittedly upon further consideration, my conceptualization of my personal acceptable level of risk with my diabetes management is influenced by my past, current, and future practices which are (and have been) situated within a health care culture highly dependent on a biomedical approach to chronic illness (Borovoy & Hine, 2008). This culture is heavily steeped in moral imperatives of 'control' based on neoliberal ideologies for health (Barnett & Bagshaw, 2020; Crawshaw, 2012; Ketchell, 2016). As a result, my interpretation of this participants' practices of not choosing to carry food items on his person was different than current recommendations for individuals living with diabetes, especially those who use insulin and particularly for those who use a pump (Diabetes Canada, 2018) and also different from the majority of the participants.

> *… how I treat it depends on where I'm to and what I have accessible to me. If I'm home, then the fridge is the limit (laughs). It's whatever I can get my hands on. If I'm out and about, I'll stop into a side store and pick up, typically, a chocolate bar or some form of candy, or orange juice, something that I can get in pretty quickly so I can resume whatever it is I'm doing… [Part. 15]*

Aside from this example, most participants were extremely cautious as seen by multiple food stashes. Not being prepared to manage was taken up by most participants as incompetent self-management. In selecting their preferred foods to treat hypoglycemia, participants preferred foods that tasted good, could possibly be considered a 'treat', and additionally they preferred foods that they had become accustomed to throughout their experience of living with diabetes and treating hypoglycemia in the past.

### *Choice of Food Stash*

Participants chose a variety of foods to eat in case of a low blood glucose. There were several reasons cited for the types of foods. As explained below, Welch's Fruit Snacks® were preferred as they are versatile to carry as they are small packages, they taste good, and there are 17 grams of carbohydrates in each bag which decreases the need for precise carbohydrate counting during the hypoglycemic event. Not having to count the exact carbohydrates during a low blood glucose is an example of planning *a priori* knowledge for inevitable blood glucose fluctuations. Additionally, as I will describe later, depending on symptoms, it may be impossible to count as a primitive urge takes over and treatment includes eating to survive, regardless of the carbohydrates consumed. In using these snacks, the participant enhances her safety network in planning to treat hypoglycemia; allowing her to consider the guidelines for treatment but also absolves her from the need to count in the moment.

In this example below, the relationality of practices is highlighted in that current planning to pre-empt or mitigate hypoglycemia is based on previous practices of hypoglycemia experiences, knowledge of Diabetes Canada (2018) guidelines and recommendations, and current practices of counting carbohydrates and putting the food item(s) in a purse, car, jacket pocket, etc. Along with relationality, these practices have a temporal dimension in that the practices now (counting, planning, etc.) are designed with later practices in mind (mitigating hypoglycemia), which could happen anywhere (spatiality) (Nicolini, 2017).

> *Yes, the problem with that [Dextrose tablets] is I find, if you're nauseous, I don't like the taste of them, I do like the raspberry ones, but they're hard to get – you gotta order 'em –, I don't order them all the time. It's just…and also a bag of those Welches are 15 or 19 carbs – I can't remember what it is. Whatever it is it's exactly what you need, so I take a bag of Welches. It tastes good, I'm not nauseous from them, you know?* *[Part. 10]*

Interestingly, participants described selecting foods that they would ***not want*** to eat all of the time and in this manner, a non-preferred food could be preserved and not consumed when they did not need it. As Participant 4 explained, she selects granola bars even though she does not like them. In this manner, she creates a boundary between usual food and 'food as treatment' for hypoglycemia. Aarhus and Ballegaard (2010) postulate that individuals with chronic disease often create boundaries that exist on a continuum between integration and segmentation of the disease within everyday life. For some participants, choosing foods to treat hypoglycemia that they would not normally consume, creates a boundary, and therefore creates segmentation between life and disease. These authors further suggest that through these boundaries, individuals create order from complexity in caring for chronic diseases. For Participant 4, boundaries help her to self-manage well in that she keeps these foods for when she needs them as opposed to just wanting them and is thus a measure of self-discipline, a precursor to effective self-management (Song et al., 2010). As a result, creating this boundary is perceived to be required to effectively self-manage:

> *Well, actually, in our spare room, I have a big pack of juice boxes from Costco and, granola bars, and I have granola bars 'cause I don't really like them (laughs). Like, in normal life, it's not something I'm gonna reach for, so I had them for when I go low 'cause I won't eat them any other time, and yeah, so that's usually what I'll go with at home. [Part. 4]*

Despite the symptoms experienced, at times treating a low blood glucose was considered just that –a treat. At times, participants perceived the low blood glucose as a time to enjoy what they may have considered previously as forbidden foods. As the following examples highlight, there is some enjoyment to treating a low blood glucose. As described, there is '*free-wheeling'* meaning that the treatment is enjoyed and it is *'too bad'* when here is no need to treat low blood glucose, as there was anticipation of having a cookie to treat.

> *Oh, not at that time, no [feeling upset with self because of low blood glucose]. I'm just – like I said, I'm free wheeling, at that time. Now, it doesn't happen very often. That's the unfortunate thing (laughs). [Part. 8]*
>
> *And lots of times, I think I might be low, and I'll check, and I'm not, aww, too bad. Don't have to have – can't have that bar, and bar's not – not bars, you know, as much as a nice cookie or something really sweet. [Part. 13]*

Participants often treated hypoglycemia or risk of hypoglycemia with various foods that are high in fat such as chocolate and cookies and not necessarily the foods/carbohydrates listed in any guidelines. The juice, cookies, and chocolate bars taste good and considered treats not just by people living with diabetes. *I remember the last time that I was low, like I said, I had orange juice, so I had, like, four fruit to go's; I think I had small little Halloween chocolate bars [Part. 14]*. It is therefore conceivable that the treatment of low blood glucose is sometimes anticipated, to be able to have some types of food that people without diabetes eat so readily without concern for the resultant impact in blood glucose. As suggested by Borovoy and Hine (2008), the selection of food items by those living with diabetes includes more consideration than the impact on blood glucose. Individuals consider influences such as culture as well as the importance of certain foods in social relationships. Further, according to Benavides-Vaello and Brown (2016) the determination of 'good' and 'bad' foods for individuals living with diabetes depends on several other issues, not just the nutrient content and the resulting effect on blood glucose. The meaning(s) associated with food change(s) depended on the time, location, and the event. For Participant 13, the experience of the low blood glucose (event) potentially legitimizes the ingestion of 'taboo' foods (i.e. changes from bad to good at this point in time). Here the shift in relations among the actors (i.e. previously considered 'bad' food is now 'good' food) in this network leads to the development of knowledge and thus sense (Hultin & Mahring, 2017) about certain types of foods that would assist to increase blood glucose.

> *If I've made cookies or there's a chocolate bar in the house, I know that's all fat, but I think – I think, well, I'll take this, but I'll wait for my next low and I'll enjoy it, and I do. I enjoy a cookie, whatever it is, and I will check my sugar after I've ingested that.* *[Part. 13]*

Along with preparation to manage hypoglycemia with rescue foods and their choice of foods, participants also needed to have quick access which meant carrying food on their person or at the very least, nearby. As with other practices in planning and preparing, participants differed in their personalized need for quick access.

### *I Need that Stash NOW!!!!*

Most participants always carried food items or had quick access to emergency food items. However, as Participant 5 explained there were times when he found himself without quick access because of a lack of or an oversight in planning which typically caused panic:

> *Yes, if I don't have something – and I've had it where I've – I had it in my desk at work but I didn't have it in my jacket because I didn't restock the jacket, and I was away from my office, and I started going into a low, and it was just panic mode, so as long as I have it, I know, no matter what happens, I'll be okay, in that sense.* *[Part. 5]*

Mostly, participants expected to be able to access food in most places to treat a low blood glucose, such as at a corner store, supermarket or café, although many participants felt it necessary to carry food items on their person because they could not assume the environment or people would be able to help, such as Participant 10 who spoke about flying, *"… and on the plane, like, you gotta have your own food 'cause you can't be relying on stewardess and stuff, so I have a whole bag of food." [Part. 10]*. Even in everyday life, some participants preferred to carry their own food rather than risk having to search for it when already experiencing the effects of hypoglycemia. In doing so, self-management is maintained:

> *Yes, there's a lunch can in my locker, so there's always a few bars and stuff in that. There is – there's kitchen areas here in the facility, so, I mean, if I got stuck, I would grab a juice or something, right, but I normally don't. I usually take my own, and I usually don't have a lot of lows because I got everything timed out pretty good.* *[Part. 11]*

Only one participant in this study preferred not to carry emergency candies or other high sugar food sources in favor of purchasing them when needed. As we continued to talk, he revealed that another reason to not have food stores is that he feels he has little control over sweet foods in general. As I listened, I kept thinking how different this was from most participants and even for myself. I always carry food and have rescue foods stashed virtually everywhere. In this excerpt, the participant positions himself like others who have a 'sweet tooth' and tend to over-indulge with sugary food. Having diabetes though, means that quick access to food may be essential for survival and *in that moment,* I found myself judging this participant for not carrying food and thereby putting himself at risk. Ultimately in doing so, I perpetuated the ideology that to manage well, one must **always** be prepared and that individuals living with diabetes **must** be different than those in society who do not need to regulate their insulin but who also find it challenging to resist their sweet tooth.

In my interpretations I unknowingly perpetuated the necessity of self-discipline as a necessary precursor to 'good' diabetes management. Nantha et al. (2019) suggest that a lack of self-discipline is associated with poor restraint in food choice practices and while I am critical of this in the context of living with diabetes in everyday life, my thoughts in this moment betrayed me. Here, Participant 15 positions himself like others (who do not live with diabetes and enjoy sweets) as a result of his food choices and consumption practices (Hultin, 2019):

> *No, very rarely [carry food sources] because I'll eat them even when I'm not low. So, I have no control, especially when it comes to sweets. If there's something there, I'm gonna eat it, so, typically, if I'm home, I'm gonna eat some sort of carb that's in the house that might not typically be sweet, or juice, but do I keep candy/chocolate, anything immediately sweet, on me? No, I can't because it never lasts. When I go to get it, it's never there because I've already eaten them when I'm not low… [Part. 15]*

This was the only participant who revealed that he did not want to carry food sources and provided the rationale that he cannot 'control' himself when it came to sweets. This approach to planning can be contrasted with other participants who have food stashes 'everywhere'. As such, there was variation in what participants considered to be an acceptable level of risk. Similarly, many of the participants described the necessity of access to pump and other diabetes management supplies, however as with food sources, they differed in the number and type of supplies required, as well as the need for quick access.

### Don't Leave Home Without Your Lifeline!

In planning and preparing for day-to-day activities with diabetes, participants also carried or had access to pump and other diabetes supplies in case they had to change any aspect of their pump set up i.e., if they needed to change the infusion set if the site was blocked, or in case of a pump failure, they had access to a syringe to inject insulin. Participants planned to **always** be able to obtain insulin. No matter what happened, participants had to ensure they had the ability (either through the pump or a syringe) to self-administer insulin. Preparation for such an emergency is advocated in diabetes pump education (Minimed 670G (Medtronic) User Guide, 2017; Omnipod User Guide, 2017) and while almost all the participants in this study had emergency supplies, few had actually used them. When not needed the supplies can be actively ignored, and other than being aware of the location of the supplies and expiry dates, participants did not need to think about it until it was needed. In the following example, Participant 9 takes a 'goodie' bag of supplies with her every time she leaves her home so that she is prepared:

> *So, now I do my goodie bag. In that will be a reservoir [which holds insulin in the pump]; it will be an infusion [set]; it will be extra batteries; it will be insulin already done in the vial [reservoir]; also extra bottles [of insulin]. There probably is right now one of those syringes in there – I think there is. That is my goodie bag. That's how I make sure that when I leave here, that if anything can happen, I will be prepared.* *[Part. 9]*

Being prepared and carrying supplies did not necessarily mean the same thing to all participants. Depending on the rationale (i.e. day to day preparedness or planning for travel) participants either carried extra pumps and associated supplies, syringes, or insulin pens. Some participants used older pumps that still worked, but they had simply upgraded as a result of insurance coverage and they were able to afford another pump, or for some a travel loaner pump was requested and received (from my experience, most pump companies will supply a loaner pump for travel that must be returned when travel is complete). Pump supplies are much bulkier and difficult to carry easily, while an insulin pen (holding prefilled insulin cartridges) can easily fit in a pocket or small bag:

> *… [pharmacist] gave an extra pen, so, and I always have me pen in the fridge in the work, so I kept one at work, and I had one out here [home]. So, when I went with the pump, no, I don't carry extra [pump supplies] if something goes wrong…* *[Part. 7]*

Planning for any kind of travel with diabetes, from shopping to commuting to vacations was related to the functionality of the pump and more expansive to include the wide variety of potential diabetes challenges. The majority of participants discussed diabetes and travel which represented significant thinking and planning practices, especially for long trips outside the country. They were 'over-prepared' and took many more supplies than were needed. This created a sense of safety and security yet as Participant 9 told me, involves extensive anticipatory thinking:

> *So, when I'm getting ready to go, okay, I need this much in strips, and I need this much in the silhouettes [a type of insulin infusion set for Medtronic pumps], and I need this much in reservoirs, and I need – you know, because I'm on certain drugs – you know, the drugs that I take – so I have to take enough for to get me back in Canada. … All diabetic supplies, all that's needed, the skin preps, the everything.* *[Part. 9]*

Another participant echoed this cautious approach especially when there was potential for activities that were outside their normal range of events which have potential for the pump to fail. In this following example, the supply requirements were exceeded as a result of education i.e. individuals with insulin pumps are educated to take three times the required amount when travelling (MacNeill & Fredericks, 2015) to allow for possible problems with activities such as more frequent swimming/water activities and a change in the outside environment (heat and humidity) which impacts the ability of infusion sets to stay on the body and thus can impact insulin delivery. Interestingly, this is the same individual who does not carry emergency food items on his person when driving in the city and who said that he could simply stop at a store to get something. Yet, the change in actors which meant a change in network for management (out of country with perceived limited access to diabetes and pump supplies) called for increased preparedness:

> *I always bring – I probably double what I probably need for the trip, just because you don't know – if I'm going south, then the sensors and pod or inserts typically come off 'cause I'm sweating or in the pool, so they fall off, so I'm going through more supplies, so I tend to bring double. But even if I'm going into a non-sweaty area, you know, I don't know if it's [infusion set] gonna hook in [anything and pull out] or how much trouble am I gonna get with supplies while I'm away? So, to avoid any of that nonsense, I'll just bring extra with me 'cause it's easier. So, always – always well prepared when travel.*
> *[Part. 15]*

Commuting to work was a concern and required planning as well. Many participants kept emergency supplies at their workplace, but they also needed to carry them during commuting. As I also have a long commute to work, similar to Participant 5, I carry extra pump supplies, a syringe, as well as an extra glucometer and food in my work bag.

> *I have a bag of supplies that's kinda like a travel case of supplies in my office at work. And I always carry something extra – I carry a pack sac, computer bag, and I always have stuff in there too…* *[Part. 5]*

In summary, participants described the intensity of planning and preparing so that they could approximate somewhat 'normal' levels of spontaneity even if this were in the creation of 'predictable' spontaneity. Participants wanted to be like others or those not living with diabetes; to just be able to do whatever they wanted to do, when they wanted to do it. In their accounts of planning and preparing, participants described the ways they planned to be spontaneous while considering their need for safety.

### Predictable Spontaneity

Planning for social events, either planned or spontaneous was more complex. Participants evoked a sense of trying to be as spontaneous as possible, given their perceived need to always be prepared. Participants attempted to create 'predictable spontaneity' prior to exercise, restaurant dining, as well as other social events such as baby/bridal showers and nights out at a pub with friends.

### ***Navigating Exercise***

Exercise is an aspect of healthy living for everyone. It is also an especially important aspect of healthy living with diabetes. Individuals living with diabetes are at increased risk of cardiovascular complications such as heart disease and stroke and exercise is a key aspect of delaying or preventing cardiovascular complications (Nathan, 2014). While the rates of myocardial infarction and stroke have decreased for those living with diabetes in higher income countries, there is still an increased risk for those who experience sustained hyperglycemia (Harding et al., 2019). The participants in this study engaged in various exercise activities from walking to work, casual walks with friends and family, shoveling snow, and going to the gym. While exercise is a universal need to support health, there are more serious considerations and risks for people living with diabetes, and particularly for those using a pump. In all instances, participants prepared for possible instances of hypoglycemia and hyperglycemia during, immediately after, or up to 24 hours afterwards any increased activity. Often this meant planning to increase carbohydrate intake prior to, during, and after activities, reducing insulin intake by turning down basal rates, and ensuring the availability of emergency/rescue food and pump supplies.

As Participant 6 explained below, walking to work in the morning meant getting up a little earlier and adjusting her basal infusion down slightly so that she reduces the hourly amount of insulin she receives. With exercise, the body uses more glucose to expend increased energy (El-Hussein et al., 2018). Practices are necessary to balance insulin/food/exercise to reduce the risk of hypoglycemia. Negating planning practices for walking may necessitate treatment with high carbohydrate sources which was perceived as counter-productive to the exercise:

> *I walk back and forth to work a lot, so when I get up, first thing I do, I'll turn my pump down for an hour so that I hopefully, don't have a low when I'm walking, you know. Because if I don't get a chance to get my pump turned down an hour, [or] an hour and a half before I leave, then I'm probably gonna have a little dip 'cause [when] I wake up, usually my sugar is 5 or 6 in the mornings, so if I don't turn it down, I'm gonna end up eating frigging candy on my way to work, and what the hell is the sense of that, eh?* *[Part. 6]*

Sometimes planning for activities such as walking was experienced as completely exhausting and limiting. Diabetes and the demands of the pump adversely affects one's perceived autonomy and ability to do whatever is desired when it is desired. In the following extract, the participant tells a story of a walk with her baby in which she had forgotten to take food sources with her. This limited her walk as she could not go far from her home if she needed to treat hypoglycemia. However, her baby was asleep, and she wanted to keep on walking. Resolving the tension between wanting to be autonomous and having to be cautious in the absence of emergency supplies generally ended in limiting activities. In this story, Participant 10 had left the house briefly to visit a neighbor with her infant. She left comfortable, having checked her blood glucose which was a relatively high 9 mmol/L. As can happen, her plans and needs changed, but she was restricted from following those plans because of her diabetes:

> *Yes, it's completely exhausting (laughs). It is. Like, the other day – just for so many reasons it's just so tiring. I wish I could just do the things I want to do, when I want to do 'em, and not have to be worrying about this. Even the other day, I went for a little walk. The baby fell asleep, we had gone to our neighbor's house–literally just walk around with her [the baby]so she won't wake up, and I had to stay within a certain range because I realized I didn't have the stuff [rescue food for hypoglycemia] in the stroller –I didn't have candy or anything 'cause when we left the house I was 9 [mmol/L], and we were only going two doors up, and then, so, I was walking with her, and I was like, oh frig, I gotta stay on the street, you know what I mean?"*
> *[Part. 10]*

Participants also planned for more formalized exercise such as training for a marathon as well as taking exercise classes and working out at the gym. As explained in the following excerpt, there is extensive planning that occurs with marathon training without diabetes, so running with diabetes is even more complicated. Despite many years of planning and balancing insulin and food prior to training runs, Participant 2 still experiences inexplicable hypoglycemia and hyperglycemia at times.

> *For instance, on a long training run, I park my car so as I can do a loop, get so many kilometers, and get back to my car, test my blood sugar, refuel, drink, go again, loop back again. So, that day, whatever was going in, I was just burning it [glucose] right back off, you know, but two weeks before that, I had gone out, and my blood sugar was around 12 when I checked it, so I took a little bit of a correction, and then, during my last 5Km was feeling miserable, had no idea was going on. It was hot, it was humid, got back to the car and I was 24 [mmol/L].* *[Part. 2]*

In this sample, Participant 2 described above, was the least amendable to any idea of restrictions on her activity. She traded what others may perceive as safety for running time, carried the minimal emergency carbohydrates with her, and hoped that she could plan runs from and to her car so she can access food as needed. The second person who took more risks than was typical for the rest of the sample was the person who did not carry emergency food but expected to be able to duck into a store to purchase what he needed when he needed it. He did not carry spare pump supplies either.

These two participants demonstrated counter-discourses within the intersecting discourses of always planning and preparing. While most participants discussed varying levels of cautiousness regarding the need to carry food and some pump and/or other essential diabetes supplies, these participants appeared to be the least amenable to the dominant discourse of preparation. I found myself thinking that they should be more prepared, and I realized how I perpetuated this dominant discourse and the ideology of always being prepared. It was so common-sense and thus hegemonic to me as well as to other participants to be prepared and in many instances, over-prepared.

Researchers have found that individuals who have lived with diabetes for a number of years and have engaged in ongoing management practices may appear to push the limits of recommendations and guidelines as well as engage in experimentative practices as they become increasingly comfortable and competent with their individual management (Burridge et al., 2016; Shwartz et al., 2017). Yet, research continues to construct such experimentative practices as unhelpful to self-management, indicating a lack of self-discipline (Nantha et al., 2019). This contributes to continuing moral imperatives and dominance of neoliberal rationalities for health (Barnett & Bagshaw, 2020; Ketchell, 2016). This notion of preparedness is taught in pump and diabetes education, filtered through ideologies of how of to be a good, competent, autonomous manager. I caught myself wondering if these instances of what I, and others, considered to be a lack of necessary preparation was indeed ‘good’ management.

Planning for the immediate effect of exercise occurs both prior to and during the activity, and additionally there is a need to consider the longer-term impact of exercise on blood glucose and the subsequent requirement for insulin over a period of about 24 hours (Zaharieva et al., 2020). As Participant 12 explains, there is a need to plan for *now* and for *later*:

> *I exercised today, and I know I can burn [glucose]for up to 36 hours, and if I’m gonna dose [take insulin], when I’m having my meal, and I’m going like, yeah, okay, that’s a 60 gram meal, but I think I’ll just take 50 [grams of carbohydrates]because my body is still burning, and I’ve gone into what I call a low, that I can’t get my blood sugars up, and it’s the most horrid feeling because I’m jittery for almost sometimes two days and my blood sugars are staying around 5 [mmol/L]* *[Part. 12]*

Participants needed to plan exactly which exercises they would do at the gym. Depending on their workout, participants planned a little differently depending on whether the exercises were cardio, weights, or a combination. The trade-off is safety instead of spontaneity, but over time, participants learned how distinct kinds of exercise affected their immediate and long-term blood glucose levels and based on this experiential knowledge, could anticipate planning requirements:

> *It [planning] depends on if I'm doing cardio, weights, or a combination or both. So, before I go the gym, I'll look at – see what my sugar is. If I'm below eight [mmol/L], I will probably have a Nutrigrain® bar to bump me up a little bit to accommodate for the drop, especially if I'm doing cardio. I find, after forty minutes of cardio, I'm probably getting down to 4 to 3.5 [mmol/L]. So, if I'm anywhere below ten [mmol/L], I'm gonna dip. Sometimes I will suspend my pump for the hour that I'm doing cardio if I don't get a chance to eat before I go. If I'm just doing weights only, I typically wouldn't do anything; just keep my basal going, and I'm usually fine. Sometimes I might even have a little spike [higher blood glucose] during resistance exercise, as opposed to going low, so it depends on the activity, how much, how long, and what my sugar was prior to.* *[Part. 4]*

Along with consideration of how exercise could affect and be affected by blood glucose, participants considered the impact of social activities on glucose such as restaurant dining and other social activities with family and friends. The goal of planning and preparing was to simply to be able enjoy social activities and in many ways, participants' accounts were in relation to planning to be as spontaneous as possible. Being prepared meant that they felt safer and more in control of their diabetes management; thus, they were managing well.

### *Dining Out?*

Diabetes management just does not happen in the confines of home or personalized individual spaces. Diabetes happens everywhere, all the time. Participants described a range of social activities such as restaurant dining, bridal/baby showers, celebrations such as birthdays, and activities which included imbibing alcohol as activities that presented different challenges for people with diabetes. As the following participant explained, the necessary pre- and post-hoc analysis of diabetes management practice networks may be difficult for others to understand:

> *I have siblings, you know there's times they'll say 'Well, can you come out tonight? We're having supper.' I can't go because I'm tired. Last night I never slept well. For example, say, for argument's sake, for example, say I woke up 3:00 in the morning, my sugars were low. Alright, so I got to treat that low; I gotta try and get back to bed, get a rest, so then I gotta get up again for 5:30/6:00; I gotta go to work for eight hour shift, right, so then my sugars are probably up a bit, and they level out, so I'm tired, and because of the disease, it makes me even more tired, so then I'll go home and I'll sit on the couch, and they'll say, 'Okay, well how come you're not coming out tonight for supper with us?' or 'How come you're not coming to participate in this?' Because you know what, unlike you, I never had a good night sleep. My sugars dropped, or it was on my subconscious part of my mind, last night, because the day before I might have had a bad day with sugars, so it's hard for families to understand, or 'Why are you not going downtown to the club with us tonight?' or if you go down, 'Where are you not drinking?' and stuff, right? 'Cause it's hard. Like, people don't understand that, right?* *[Part. 11]*

Most participants were able to identify foods that were too 'dangerous' to eat because of their effects on blood sugar. While restaurant dining may be conceptualized as poor diabetes management, in their study of the social dimensions of eating and associated nutrient intake, Pachucki et al. (2018) determined that meals outside the home were associated with better scores on dietary indices for men, but not for women. In this sample of participants, those identifying as male generally described greater lengths and more in-depth practices and less adversity to eating in restaurants, although there were some exceptions and those identifying as women recounted greater stress in dining outside the home. For example, one participant indicated that the variability in carbohydrates and fats in pizza means she never attempts to eat prepared or take-out pizza. However, despite knowing of the risk some foods can pose, Participant 11, in contrast, described in vivid detail how he diligently prepared to eat Chinese food. As do many people, he loves Chinese food but where most people can worry about caloric content, MSG or salt, Participant 11, along with the other participants, must work hard to figure out how much insulin is needed. To avoid feelings of being constrained in his choices, he uses a variety of food items to balance the meal.

> *The thing is with the Chinese food is try to stay away from the battered foods, and stay away from the sauces - that's the stuff that's gonna drive your sugars [up], and obviously Chinese food is loaded with salt, so you're not gonna eat a lot of that, but like I'll choose some rice and, say, and egg roll, and a couple of chicken balls and chow Mein, and, you know beef and broccoli and that kind of stuff – but another thing, too, is don't load up your plate and go back for your second serving, and don't go for your dessert because dessert – and if you choose dessert, well, like, the buffet place …if you choose your dessert have a little bit of fruit… [Part. 11]*

Another method of managing restaurant food was to take extra preparatory insulin as another participant explained, still in reference to Chinese food. This decision was guided by knowing how certain foods affected blood glucose and the effectiveness of former pre-emptive practices. Underlying these decisions is the assumptive value that there is no reason for designating any particular type of food as inappropriate as long as sufficient mitigating strategies are employed:

> *I enjoy Chinese food and it kills me. My blood sugars just go 'voom'. You can, well, as soon as we go in [the restaurant], I'll take fifty [units of insulin] you know. I'll put in fifty units right away before I eat anything. [Part. 8]*

When dining in restaurants, participants needed to consider calories and weight control as opposed to only counting carbohydrates and considering the impact of fat and protein. I asked this question thinking about managing blood glucose in restaurants based on the expected challenges in relation to diabetes. However, this participant's answer challenged my assumption that all decisions related to food intake for a person with diabetes are driven by diabetes; there are often other issues at play. Admittedly, I did not expect this answer and in retrospect my question stemmed from dominant thinking that all food decisions by individuals with diabetes were in relation to effect on blood glucose. Both my asking as well as several responses from other participants perpetuated this hegemonic idea:

> *I probably go out maybe once, twice a week [to eat]. How do I negotiate [food intake]? Pretty much I eat whatever I want on the menu (laughs). You know, unless I'm conscious, like, about my weight, if I'm trying to restrict because – Calories, because I'm trying to watch what I'm eating in that regard, with regards to weight wise. It's never with regards to my diabetes that I'm not gonna have something.* *[Part. 15]*

Even though many participants extensively creating plans for eating out, some participants chose not to eat in restaurants to avoid the challenges of guesstimating carbohydrates and risking blood glucose going awry, as Participant 2 said, *"Yeah, I don't normally find myself in that situation [attempting to count carbohydrates at a restaurant] 'cause I don't go to restaurants like that. (laughs). If there's nothing there that I normally eat, I'm not gonna go there." [Part. 2]*. As Participant 8 also explained, over time, everyone has to decide if dining out is worth the risk:

> *And I'm really not that way, [I] don't like to adventure or anything because I don't know what it [number of carbohydrates in foods] is and things like that, and, basically, when you go to a lot of these restaurants, I don't like doing it because you just don't know what's going on. And, like I said, to go to a restaurant, I just don't know what to order anymore, and I've really gotten to the point –I'd just as soon not even go inside …* *[Part. 8]*

The consumption of food holds many meanings in many cultures. In addition to being necessary to sustain life, food consumption is a social phenomenon. Foods are consumed because of hunger, emotional needs, celebration, and simply for pleasure (Benavides-Vaello & Brown, 2016). However, in diabetes management, the consumption of food and practices associated with that consumption may lose their social meaning. For example, this participant considered food mainly in terms of numbers and impact on blood glucose, not as something delicious or pleasurable.

> *You cannot sit down and look at a plate of food, and just look at it for what it is – that it's food and it's gonna taste delicious. You're looking at – you know, I'm looking at this donut with cream and everything, and I'm looking at this –*

> *either gonna – that's a high blood sugar or that's gonna be a low blood sugar, but I'm definitely not getting [it] spot on, and if I do, it's a win, but you're not looking at food for what it is.* *[Part. 1]*

For some individuals who live with diabetes, restaurant dining is not always an enjoyable social experience because of the need for advance thinking and planning. As Participant 3 explained, many restaurants still do not have nutrition guides (or they have limited information) to help with counting carbohydrates. I have been at some restaurants, where they usually have nutrition guides, however at the time I was there the guides were being updated and not available. For that meal I made an educated guess based on my past practices of eating similar meals at other restaurants, but it muted my enjoyment of the social meal. In the following extract, counting carbohydrates can potentially erode the joy of eating and in many ways, is anxiety provoking as it is felt to take away the spontaneity of eating and creates a disruption in the dining out experience:

> *Meals like Wendy's, that I really enjoy the taste of, I do find that bolusing will ruin the experience – like, not ruin it, but will certainly take away from the enjoyment, or if it's a meal at a restaurant, where I have no idea – like Montana's or Kelsey's – or no real guide – those meals tend to cause me more angst than enjoyment.* *[Part. 3]*

In the example below, Participant 12 tries to be spontaneous in some aspects of her life, yet it causes her anguish. As offered by Lucherini (2020), diabetes management reduces one's ability to be spontaneous, however planning and preparing may increase comfort with the lack of spontaneity. Notwithstanding all her planning and preparation practices, considering what 'may happen' erodes Participant 12's sense of spontaneity, which is bothersome for her. Despite her anxiety, she pretended to be as spontaneous as her friends, but deep down, the uncertainty of her diabetes worried her:

> *And you'll never be able to just go or just do something on the spur of the moment. Even though I'm good at pretending that, yeah, let's go, right, and I'm like – at the same time, I'm a bag of nerves, and I'll push myself through it to try…* *[Part. 12]*

Social activities often included alcohol which mandated special consideration about its impact on blood glucose and the corresponding insulin demand. As Participant 6 explained below, drinking alcohol affects how the liver works. The liver works to release glucagon and the pancreas stops releasing insulin in the event of a low blood glucose (El-Hussein et al., 2018). For those living with diabetes however, while the liver produces the glucagon, exogenous glucose is required because the insulin does not get 'turned off'. If it is injected into the body, there is no switch to 'turn off' insulin in the same manner the pancreas would stop producing it. The injected insulin needs to run its pharmacokinetic course and lasts approximately four hours (fast acting insulin used in pumps). When alcohol is ingested it is metabolized by the liver and as Participant 6 explained, one must consider the liver's ability to produce glucagon and any other exercise undertaken at the same time. Here, actors to be considered include alcohol, food, exercise, as well as another organ – the liver. All of these have agency as they influence other actors in the network to act. Here, the participant places regular pop in her alcoholic drink, guided by the agency of the liver in its metabolism of alcohol and subsequent influence on the slow release of glucagon:

> *Well, first of all, its alcohol, and if anything, if you're gonna be drinking, you might actually need a little bit of sugar to accompany your alcohol. It puts a bit of load on your liver, I can only remember one time where I drank, like, alcohol – like, hard alcohol – and I actually had to put regular pop with it because we were dancing so much…* *[Part. 6]*

As participants told me, regardless of all their surveillance practices as well as attempts to plan and prepare to maintain stability of blood glucose, fluctuations inevitably occurred. All participants experienced hypoglycemia and they all described very individualized treatment practices while sharing common knowledge of Diabetes Canada Clinical Practice Guidelines (2018).

## Managing the Inevitable

All participants described measures to plan and prepare for fluctuations in blood glucose and they also discussed management of these fluctuations once they occurred. They shared many stories regarding the treatment of hypoglycemia. Like surveillance of, and planning for an experience of hypoglycemia, the treatment of these experiences varied amongst participants. Specifically, participants treated hypoglycemia with the acknowledgement of guidelines from Diabetes Canada (2018)[2] reinforced by health care providers and others; yet individualized based on context including historical, social, financial, and other factors.

The guidelines from Diabetes Canada (2018) are consensus documents based on a variety of studies indicating how long it takes to increase blood glucose with a certain type and amount of carbohydrate. Examples of 15 grams of carbohydrate include 15 grams of glucose in the form of tablets, 3 teaspoons or packets of sugar dissolved in water, 5 cubes of sugar, 150 ml of juice or regular soft drink, 6 Life Savers, 1 teaspoon of honey (Diabetes Canada, 2018). Except for the glucose tablets and Life Savers, these food sources are difficult to travel with and/or to keep on one’s person. While juice is in this table, Diabetes Canada (2018) does not recommend using juice for hypoglycemia (over the other food sources listed) as it is slower to raise blood glucose and thus symptom relief.

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[2] Current Diabetes Canada Clinical Practice Guidelines (2018) recommend that for mild to moderate hypoglycemia, individuals should treat with 15 grams of carbohydrate (specifically as glucose or sucrose tablets or solution), wait 15 minutes and retest. If at this time blood glucose levels remain < 4.0 mmol/L, the individual should retreat with another 15 grams of carbohydrate. Severe hypoglycemia with no loss of consciousness should be treated with 20 grams of carbohydrate, wait 15 minutes and if blood glucose remains < 4.0 mmol/L, retreat with 15 grams of carbohydrate. For the individual who is unconscious with no IV access, 1 mg of glucagon should be given subcutaneously or intramuscularly.

In the example below, despite that it is not recommended over other food items in the Diabetes Canada (2018) list, the decision to drink juice was based on the participant's previous knowledge and experiences of treating hypoglycemia. While the knowledge of the guidelines is present, this knowledge becomes tested and verified through practices, which then forms the predominant knowledge base for decision making and problem solving in the context of current and future episodes of hypoglycemia. Here, knowledge of blood glucose, the activity, and what has worked in the past are integrated in making decisions of how to solve the current problem of hypoglycemia, attesting to the relationality, temporality, and spatiality of practices (Hultin, 2019; Nicolini, 2009, 2017).

> *Yeah, and you know, for me it's not – it's that, you know – like testing my blood sugar that at 3.1 [mmol/L], that amount that – you know, their [Diabetes Canada] standard amount of carbohydrates wasn't gonna work for me. That was only gonna be enough to get me up to a regular level. I also had another 12 kilometers to run. So I had to take the extra, you know – two chocolate chip cookies which are 25 grams of carbs, plus the glass of juice, which was another 25 grams of carbs, so I put in 50[grams of carbs]and still went low.*
> *[Part. 2]*

The studies referenced in these Diabetes Canada Clinical Practice Guidelines (2018) are older and include those where the evaluation and treatment of hypoglycemia was either under laboratory settings, with people who were newly diagnosed with limited self-management experience or if at home, there was very little mention of the contextual factors involved in the onset and treatment of the hypoglycemia (please see Bradows et al., 1984; Gunning & Garber, 1978, and; Slama et al., 1990, as cited in Diabetes Canada Clinical Practice Guidelines 2018; Management of Hypoglycemia.) This raises the question - how realistic it is to follow these guidelines in everyday life? A tension exists as individuals discussed the '15 grams of carbohydrates' as something more than a guideline or principle – but as a rule - something that must be done and must be followed. This was inherent in participants' discussions of treating hypoglycemia; they described knowledge of how to treat according to these guidelines, but *how* they specifically treated each low blood glucose experience depended on the interaction of various actors such as symptomology, time of day, place, current and future activities, as well as past practices with hypoglycemia. As postulated by Gingras et al. (2018), increased insulin pump therapy using rapid insulins, may mean the current recommendations for the hypoglycemia treatment are no longer reasonable. In their study with 47 adults and 10 adolescents who use an insulin pump, 16 grams of carbohydrate was insufficient to treat most hypoglycemic episodes. These authors call for a review of current recommendations and guidelines to treat hypoglycemia because of increased development of diabetes technologies such as pumps, CGM, and the advent of newer types of insulins which drastically differ pharmacokinetically than their earlier counterparts. Regardless of their experiential knowledge, participants in this study described their diabetes outcomes and measures of success based on the biomedical glycemic targets as in the guidelines, not in their ability to navigate various practice networks and pull many knowledges together.

### ***Please! Please! – Make it Stop! Take it Away!***

Regardless of knowledge of the Diabetes Canada (2018) recommendations of 15 grams of carbohydrate and wait 15 minutes, test again and then re-treat of necessary, all participants did not always follow this guideline. As described here, when blood glucose is falling rapidly or continues to fall, it is not comfortable to treat with 15 grams and wait 15 minutes before retesting blood glucose. It is extremely difficult to wait out the symptoms and the consequence is that hyperglycemia may result. As suggested by Burridge et al. (2015), there is tension between *knowing* and *doing*. In my study, while there were many actors impacting the practices of treating hypoglycemia, the main agentic actor is often the combination of symptoms. These symptoms lead to agency of the individual with diabetes to consume food, also influencing the type and amount of food ingested. Often, the risk of hyperglycemia in a particular moment is not as consequential as the immediate feelings of the hypoglycemia:

> *…15 carbs in five minutes 15- and usually it's 15 – it's supposed to be 15 in 15, but I can't. …when I'm dropping, I'm dropping. I would test oh, I would say anywhere 8, 10 times, until I'm comfortable, then I'm actually rising, and then I would say, you know, even after 29 years, I still overshoot and end up high.*
> *[Part. 5]*

There is a primitive stress response that occurs with a low blood glucose. The symptoms are based upon the stress response or the fight or flight response (El-Hussein et al., 2018). Symptoms of hypoglycemia reported by this sample of participants included the physical symptoms of increased heart rate, pounding heart sensations, sweating, pallor as well as psychological symptoms of anxiety, panic, and at times, derealization (El-Hussein et al., 2018). As such and as described in the following example, there is a primitive urge to get out of danger and that includes eating/treating to feel better, rather than to increase the number on the blood glucose meter:

> *… you know, I felt a bit funny you know, and then I was like, oh God, my sugars, and sure enough, as soon as I thought, oh God, my sugars, I checked and they were 2.5 [mmol/L], so I sat down and I had a bag of candy, and then, you can't wait fifteen minutes. I felt like I was gonna –I felt really funny. I had to sit down. I felt off, so then I had another bag of candy and another one, so I had three bags of candy, so I think 'cause you get in a panic, so you're not thinking 'I'll have these fifteen carbs and wait fifteen minutes' 'cause you get in a panic… [Part. 10]*

**Table 7.2***: Making Hypoglycemia Treatment Decisions*

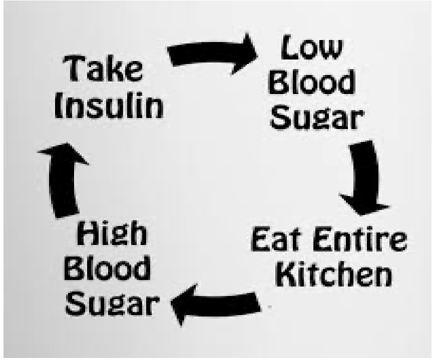
| Rationale for Treatment | Exemplary Quote |
|---|---|
| Drowning in slow motion | *…any time that I've had a nasty low, most always [over treat]. Because when you're in that moment where I feel like I'm just* ***drowning in slow motion,*** *in a low, and you know you're in trouble and you know you need help, but you can't ask for it, and, like, I stood in front of the open fridge door, one day, having a low, and ate an entire bag of grapes –a big thing of grapes. I ended up 21 [mmol/L], right?... I was just piling the grapes in and hardly chewing them – just squishing them and swallowing – and the fridge door was open, and in my mind, I can remember thinking, you should close this fridge door – you know, you need to close this fridge door – and I stood there eating grapes, hand over fist, you know. [part 6]* |
| Panic Mode; loss of control | *Try to [not overeat], but it depends on what kind of mood or what kind of state you're in. Like, I've had – I mean, I've eaten over 100 carbs, and still had nothing [no rise in glucose], and then, all of a sudden, everything shoots up. It's just that* ***panic mode where you know you're not in any control****. When you see that arrow [on CGM] is still pointing downward and you've just consumed so much, and this stuff should kick in by now, it's – yeah, it just doesn't make things feel very well. [part 5]* |
| Miserable and Crappy | *I tend to – I know they say you probably should keep to 30 carbs when treating a low. I would say I'm closer towards 60 to 80 [grams of carbs]. Do I overdo it? Probably 'cause I get that spike, and then I'm fighting to get it back down again,* ***but at the time you're just feeling so miserable and crappy, you just want to get that spike, so you're – eliminates the symptoms****, yeah. [part 15]* |
| Soaked and Weak | *Yes, that's what I mean. Like, when it says it depends on the low, it depends on the symptoms, for sure. Like,* ***if I'm soaked and weak****, I'll have more. 100% Yeah, that's right, you're not thinking, oh, I'm just gonna have 15 carbs, and then I'm gonna wait 15 minutes (laughs) You're like just get it up, get it up, get it up, and then you're like, alright, okay, you know? [part 10]* |
| Going to pass out | *Well, because, like, I just find – again, maybe just me, but when my sugars run low, I don't care if I takes 50 carbs, I wants to get my sugar back up* ***'cause it feels like you're gonna pass out****. [part 7]* |

As Table 7.2 highlights, participants needed to eliminate the symptoms and return to feeling 'normal' again. They described the experience of a low blood glucose as a time of panic, of urgency, of drowning, and in these times, their knowledge of the Diabetes Canada Guidelines (2018) for treating hypoglycemia was peripheral. While it may serve as a guidepost, the primitive survival instinct that creeps in is the paramount knowledge addressed at that point in time. Experiencing these body sensations, all participants described instances where they ate more than the recommended 15 grams of carbohydrate and were not able to wait the 15 minutes for a recheck of blood glucose.

### *I'd Rather be High*

In the moment of treating hypoglycemia participants were very willing to risk a high blood glucose and deal with it afterwards, rather than continue experiencing the hypoglycemia. Quite often, as depicted in Figure 7.1, this sets up a cycle where individuals experience low blood glucose, sometimes treat aggressively depending on various contextual factors, then have to take insulin as a result to the 'rebound' hyperglycemia, which then may lead to a low blood glucose once again.

**Figure 7.1*****: The Low, Treat, High, Repeat Cycle Meme***



From: https://bit.ly/3fpB6rM

The experience of hypoglycemia is an immediate threat. Conversely, the experience of hyperglycemia does not have the same immediacy; therefore, participants were willing to experience a higher than optimal blood glucose, especially during the night when individuals are generally tired. As explained in the following example, when low blood glucose interrupts sleep, individuals usually want to go back to bed and therefore a higher blood glucose is sought despite knowing the treatment guidelines; "*You see, I didn't [count 15 grams of carbohydrates] – I* *probably was told that but I'm just like, if I'm low, I want to go high –I want to go back to normal, so I go back to bed, yeah." [Part. 14]*

Overall, participants provided vivid detail of planning and preparation practices while realizing that they could never completely perfect this task. The physical symptoms brought on by hypoglycemia often induced panic which in turn lead participants to eat more, which then lead to hyperglycemia. As a result, as Participant 10 explained, a correction bolus is needed, which may then precipitate another episode of hypoglycemia; this was a 'constant battle':

> *That's the thing (laughs), so I had my peach, so I went to fridge then, I better have something else 'cause I figured the peach would bring me back up as soon as I ate it, but it must have been going really low, I suppose, 'cause I was 2.7 [mmol/L] after a peach. ...so I had a bottle of juice, and then once I had the bottle of juice, I came around, so then I went to do whatever after, but sometimes you treat, and it's like – you'll know this, I'm sure – then all of a sudden, it's like, oh, now you're ten [mmol/L] (laughs), so then you gotta correct, and then it's like that constant battle, right? [Part. 10]*

Deciding to treat and how to treat (i.e. the number and type of carbohydrates) depended on the extent and interpretation of hypoglycemia symptoms. As Participant 15 explained, the worse the experience of symptoms, the less attention was paid to the amount of carbohydrates ingested and the associated increased risk for rebound hyperglycemia.

> *For me, I don't get really – like, I could be 3.8 [mmol/L], 3.5[mmol/L] – typically, I'm starting to feel crappy at 3.2 [mmol/L], so I'll let it go down, let it go down, and I'm like, okay, if it's still trending down, like okay, now I'll go eat something. It won't be to the extent as if I'm 2.8 [mmol/L] where I'm shaking and sweaty, and I'm like, okay, cramming everything in very quickly. So, I find if I treat, you know, just below 4 [mmol/L], then it's a more controlled… treat… [Part. 15]*

Experiences of hypoglycemia are not the same, not even for the same participant. In this sample of participants, the practices of treating hypoglycemia included a continuous 'zooming in' and 'zooming out' as they engaged in local practices, but at the same time had to draw on previous practices and anticipate the results of the current practice to mitigate the hypoglycemia (Nicolini, 2009). As indicated below, there is a marked difference in a gradual drop in blood glucose (such as the ones experienced during the night), and the ones experienced during the day as a result of too much insulin or activity. Each may produce different symptoms and thus require different treatment responses. People living with diabetes need to understand this and use this knowledge to make decisions about their self-management treatment:

> *… it depends on the low. So, if I'm having a low –if I'm in bed and my sugar's 3.8 [mmol/L], I'll have candy or a juice box and I'll just have that, and then usually I just fall right back to sleep, but if I'm, having a low and it's an insulin low or if it's like a rapid fall – a drop, I find that you're almost, like – you're hungry, first of all – it's like hunger creeps in, and panic or something, so I'll have two bags of candy, or I'll have a bag of candy and a granola bar, or I'll have – you know, it depends on the low, that's what I find.* *[Part. 10]*

Thus far throughout this analysis, I have discussed how all participants shared stories of their knowledge of contemporary guidelines and recommendations and how they integrated this knowledge with other knowledges such as experiential expertise as well as current contextual factors. All participants described making diabetes their 'own' in their lives and this was especially evident in how they combined knowledges in the management of hypoglycemia. In their accounts of diabetes management practices, participants all created and recreated life with diabetes in that diabetes was second nature, but not natural at all.

### Diabetes Is Second Nature, But It's Not Natural

All participants discussed the 24-7 nature of diabetes; there is no time off. They talked about how diabetes is so often ingrained, that the practices become so mundane that they are not recognized as 'doing diabetes.' Diabetes management is a way of life that becomes almost invisible to those around individuals living with diabetes as well as to themselves. "*My goodness, things that I don't even think twice about, you know. It's just part of my every day. I've had* *diabetes forever". [Part. 6]* Sometimes this invisibility is intentional, and other times it is not; often participants did not recognize their diabetes management practices as they had become such an ingrained way of life. Many participants thought the pump would ease some of the burden of diabetes management and in many ways, make it easier. However, it was not that the pump took away the worry or the management but shifted some of the practices. Diabetes was still there and despite what participants thought when first using the pump and others in society currently think (or thought), the pump is one actor in diabetes management networks. It is not a pancreas, and it is not Artificial Intelligence; the pump does not solely manage diabetes; the pump and the person as well as many other actors are implicated in networks in managing diabetes. At first using the pump was overwhelming for participants, but then, like using injections to manage, using the pump became second nature:

> *Initially, it [using the pump] was a bit overwhelming because, okay, you gotta do carb counting, and you gotta make sure this is right, and you're counting your days for when you change your sites, and then you got to fill up your reservoir, but now it just comes second nature. [Part. 11]*

. While diabetes practices become so second nature, participants did not consider them a natural existence even to Participant 1, who lived with diabetes for over 30 years. Diabetes practices may become 'easier' with experiential knowledge in that the recognition of diabetes practices as requiring much effort shifts as the practices are integrated into somewhat of a 'natural' existence:

> *…it [diabetes] is second nature, but it's still not natural, if that makes sense. You kinda get used to doing it; it's not as much work anymore because that learning curve is past, but, at the end of the day, it's still a job. It's still there on your plate; it's always there; it doesn't go away, so it gets easier that way, but… [Part. 1]*

Despite living with diabetes for such a long time (or as a result of it), participants were frustrated with 'always having to manage' diabetes. As much of a part of you it becomes, it is still not an autonomic process such as breathing which generally occurs without our conscious knowledge. Participants illustrated how they always must consider diabetes, as their lives (all other decisions) revolved around it:

> *This is all I've ever known since age seven. It is what it is, and I just gotta suck it up and deal with it, but 'frustrated' is probably a better word for me, as opposed to 'burnout' because it's just a constant – you're inundated with all – like, there's – you don't get a break from it. It's – your life revolves around it.*
> *[Part. 15]*

### *Forgetting to Check BG and/or Bolus? You're Kidding Me!*

Diabetes becomes so routine and second nature that sometimes, checking blood glucose or taking insulin prior to a meal may be forgotten. How does this happen? If diabetes is so prevalent and such a part of everyday life, how is it that one can forget the very thing that sustains life? Paradoxically, in the quest to manage as best as possible and create routines etc., practices become so automatic that they may slip conscious awareness for a limited time. The automaticity of practices attests to their normativity as well as hegemonic status (Fairclough, 2013; Nicolini, 2017). Practices become hegemonic when they are based on ideological-discursive formations (IDF) that have become so 'common-sense' and thus hidden (Fairclough, 1985, 2013). In consistently engaging in diabetes practices, repetition and integration into daily life keeps them in existence (normativity) yet at the same time creates the plausibility of forgetting to do it ('common-sense' and thus hegemony).

For these participants, diabetes was second nature, but definitely 'not natural.' As participants told me, they startle when they realize they had forgotten something so important and vital for life such as checking blood glucose and/or taking insulin. According to Ketchell

(2016) forgetting to take insulin is associated with a lack of moral imperative to care for oneself, based on neoliberal rationality/ideology that caring for oneself will lead to the most optimal diabetes outcomes, but does not consider other aspects that may impact blood glucose values.

In this study, participants felt guilty when they forgot, as they were supposed to always 'know and remember'. In the following example, self-blame and guilt ensues because of not remembering to check blood glucose prior to eating. I have done this on many occasions and must admit, that I actually feel embarrassed. How could I have not checked my glucose or taken an insulin bolus? However, perhaps it is like going to work and during the commute having to wonder *if* you put on deodorant; this is a mundane, everyday occurrence that we have been taught to do since childhood. How is it then that one may forget something practiced each day? We have all done these things; missed something that has become so mundane that we forget. However, as with the following example, guilt is associated with forgetting these mundane practices in diabetes management as it is more than simply a routine; such practices are life-sustaining. To manage well, a person living with diabetes cannot 'forget' (Ketchell, 2016). The participants in this study evoked a sense of always trying to be like others, to create sameness, while coming to terms with the perceptions that they were, and will continue to be, quite different:

> *But I've got a problem, and anyway, I really get upset at myself, to think that I can get up in the morning and do a whole bunch of things and things like that, and all of a sudden, well [wife], my goodness, she'll come and she'll say, 'What's your blood sugar today?", and I says – this is unbelievable – I said, you know, I've had diabetes now, what, 30 – 40 years?, and it never even came to me to do a blood sugar in the morning, and that really upsets me, and I said I'm gonna get a big sign and put up on top of the door ---going in the kitchen, 'What is first?' I just put 'first' on it, but I'm after putting the signs there, and like I said, I'm liable to walk underneath that sign and not even look at it. … well I feel stupid. I just – you know, I says, how can I be so stunned?, and not even dawn on me – it doesn't even dawn on me –and I've had diabetes for so*

> *long, and I've been doing this regular routine for so long, and yet…*
> *[Part. 8]*

Often the routine is so established and the second nature of diabetes so ingrained, that at times there is oblivion as meals are eaten without taking a bolus dose of insulin to match the food intake. Inherent in making diabetes management so routine that it becomes second nature, participants attempt to decrease some of the burden, and they strive to decrease the enormity of the management. The concern is that individuals living with diabetes may forget to do things in creating hegemonic practices, and as such represents the downside of making diabetes so second nature. It is however problematic when individuals berate themselves and feel guilty after managing for so long, that such practices become oblivious:

> *… That's happened [forgetting to bolus with meals] to me before too. I ate my sandwich, and then I was gonna have my next thing, which would have been fruit or yogurt, and you're always thinking the carbs, right, and then I realized, oh my Jesus, I didn't even – I didn't enter anything [in the pump], you know what I mean?, 'cause I was looking through my bag, and, asking 'what am I gonna eat next'? But, I know, you're saying how do you forget I have diabetes? (laughs).* *[Part. 10]*

## Conclusion

In this chapter, I have presented the fourth theme in my analysis, *living in predictable unpredictability.* All participants acknowledged that inevitably, living with diabetes meant engaging in various practices to plan and prepare for as well mitigate blood glucose fluctuations. They all described how preventing all glucose fluctuation was unrealistic however they felt that this was an imposed expectation by others including family and friends, health care providers, as well as the general public.

I have outlined various intersecting, often competing discourses, counter-discourses, instances of power, as well as practices based on ideologies which having become so naturalized, that they are often taken up by others as well as the participants themselves as common-sense or hegemonic. For example, there were variations in the level of preparedness required with some participants being over-prepared and others carrying the bare minimum or nothing at all.

Ultimately, power was evident in how the participants engaged in planning as well as practices to mitigate blood glucose fluctuations based on what they have been educated to do and what they felt they ‘should’ do. They recounted how in the moments of managing hypoglycemia they relied on their experiential knowledge, yet they based their considerations of successful management on recommendations and guidelines from predominantly biomedical knowledge. In doing so, the participants unknowingly perpetuated the ideology of hierarchical diabetes knowledge with biomedical knowledge as best.

The participants and I influenced, and were also influenced by, the dominant conceptualizations of a ‘good, competent self-manager’. Throughout the interviews as well as during my analysis of transcripts and other documents, we perpetuated ideas of what good management means. We evoked the sense that to manage well, one must consistently plan and prepare to manage any blood glucose fluctuations as not doing so lacks self-discipline, a precursor to staying in target glucose range and thus ‘good’ self-management. We also took up and perpetuated the idea that all food planning and subsequent decision-making centers around diabetes management. While carbohydrate counting and the consideration of fat and protein is paramount in taking the appropriate amount of insulin, other factors are important as well such as weight control, social dimensions of eating, and whether one likes the food or not.

Throughout my study, the participants (and I) discursively constructed themselves/ourselves through their/our various practices as ‘good, competent self-managers’ based on ideologies of responsibility for health and thus self-management. I have highlighted the interactive and relational nature of the practice networks of decision-making, problem-solving, and sense-making practices in diabetes enactment. In the following chapter, I will review these findings in light of current conceptualizations of diabetes self-management and self-management support and conclude with recommendations for nursing education, practice, policy, and research.

# Chapter 8: Conclusions and Implications

# Chapter 8: Conclusions and Implications

My objective in this study was to explore the diabetes enactment by individuals who use an insulin pump. My rationale for this exploration stemmed from my own personal experiential knowledge as a person living with Type 1 diabetes who uses a pump, as well as a review of extant literature. Despite an extensive research-based body of literature regarding adapting to and living with chronic illness and, in particular, diabetes, there is a paucity of literature focusing on the minutiae of moment-to-moment problem-solving, decision-making, and overall sense-making in the context of everyday life by individuals who use insulin pumps. With mounting focus on psychosocial issues in diabetes self-management as well as endeavors for person-centered care as the frame for providing self-management support, it is imperative that health care providers have a better understanding of what individuals who use insulin pumps are *doing* to understand how to offer more appropriate and effective self-management support. In this chapter, I reflect on my research process and as part of this, trace my conceptual knowledge evolution as I came to appreciate the nature of a network approach in understanding diabetes practices in context. As a result of this network approach, I wonder if the combined emphasis on *self*-management with a philosophy of *person-centered* care is appropriate. This raises the question; *how* can we decenter the human actor in diabetes management models that have historically centered the ‘self’? The findings of this research make me pause and consider that we need to revisit and re-imagine whether continued attempts to incorporate patient-centered models will be futile at best, and harmful at worst. The most crucial question is whether diabetes requiring complex management involving numerous actors (human and non-human), can ever be *person-centered*?

I approached this research through a critical lens and utilized focused ethnography as the design, blending the analytic strategies of Fairclough's Dialectical-Relational Critical Discourse Analysis (Fairclough, 1985, 2013). At the outset, I knew that blending ethnography and critical discourse analysis was integral to this exploration, however in completing this research, I realized just how interrelated these approaches were in understanding how the practices of diabetes enactment exist in networks. I knew initially that I needed to foreground the practices, but I have now come to appreciate the extent to which practices contribute to the interpretation of experience and experiential knowledge in diabetes self-management.

In genealogically tracing the flow of practices, I moved from a stance where I understood biomedical knowledge and other (biopsychosocial/spiritual) knowledge(s) as separate, distinct entities that may intertwine, to a greater understanding of how several knowledges are mutually constituted and created within decision-making, problem-solving, and sense-making practices by those who use insulin pumps. The findings of this study indicate that these practices exist in networks with several actors, and as such, all knowledge(s) are both *developed and utilized* as needed *within* practices. Problematically, while the participants in this study explained how they often prioritized their experiential knowledge in their practices, overall they measured their self-management success as their abilities to meet glycemic targets and implement general diabetes management guidelines and recommendations, which are mainly based on biomedical knowledge. They continued to center themselves, the human actors, which, unfortunately may often lead to blame, shame, and guilt.

Throughout the last four chapters I have presented the four overarching themes based on my analysis of the data. In Chapter 4, *The Pump is the Way Forward in Diabetes Management,* I presented the decision-making and problem-solving practices when participants first acquired a pump and learned how to use it and incrementally began to trust it with their lives. Moving forward in Chapter 5, *Working Like a Pancreas: Maintaining Homeostasis from the Outside*, I presented participants' practices as they started to use the pump to mimic the function of their pancreas. Here, decision-making, and problem-solving centered on how to utilize the many features of the pump appropriately for their own contexts; combining information from pump companies and guidelines as well as drawing on knowledge developed through past pump practices. In Chapter 6, *The Constancy of Surveillance*, I presented the practices involved in decision-making and problem-solving with respect to monitoring diabetes management and, monitoring blood glucose levels. Here, participants' networks of actors and thus practices expanded and included more contingency planning practices and ultimately, sense-making. Finally, in Chapter 7 *Living in Predictable Unpredictability*, I presented participants' practices with respect to planning and preparing for, as well as those involved in managing hypoglycemia and hyperglycemia once they occur. Within each of these themes there were various intersecting, often competing discourses while others were silenced or at the very least quieted. I also identified counter-discourses as some participants' practices were counter to those of most participants and this was especially evident in Chapters 6 and 7, surveillance practices, as well as planning and preparing practices to mitigate blood glucose fluctuations.

My analytic process, where I drew upon the analytic strategies of CDA, lent itself well to integrating historical and contemporary literature with my findings. In this current chapter, I now focus on the importance of recognizing networks of actors in diabetes management practices and how actors, networks, practices, and discourse analysis fit together in diabetes enactment. In the following sections, I outline the concept of diabetes enactment which exists in networks of various actors, how sociomaterial assemblages within practices hang together as a result of relations created within networks, and how these networks add to the discursive construction of 'good' self-management, with a focus on neoliberalist ideologies of responsibility for health and well-being. I will also outline how these conclusions perpetuate the continued dominance of the 'self' in diabetes self-management, fueling hierarchies of knowledge, measures of success, and notions of power.

Through foregrounding the practices, the findings of this study add to understanding the complexity of diabetes self-management as practices exist in extensive networks of actors in various spaces and places, across time and which discursively constructs notions of 'good' self-management. As Vallis (2013) suggests, we need to focus on the complexity of self-management as it is not a 'one-size-fits-all' concept. Ultimately, these findings call into question current conceptualizations of diabetes *self*-management as well as the philosophy of *person-centered* care, including the concepts of autonomy and empowerment and as a result, opens avenues for re-consideration, re-thinking, and re-conceptualization. To continue to expand our thinking in these areas, I have offered recommendations for nursing research, education, policy, and practice. As suggested by Hood and Duke (2015), to enhance diabetes self-management and self-management support, ongoing research is needed to understand the everyday experiences of individuals living with diabetes and approaching diabetes self-management from a practice-based lens assists with that. These authors further theorize that individuals living with diabetes experience a tension between caring for their diabetes and living a meaningful life. My research demonstrates that boundaries between 'diabetes' and 'life' are blurred as they are constitutively entangled from a sociomaterial approach.

## Diabetes Enactment

For individuals living with diabetes, management occurs in the context of everyday life. The practices that collectively make up self-management do not exist in isolation from everything else; enacting diabetes exists in complex practice networks of various actors. The interactive and iterative practices of problem-solving, decision-making, and sense-making comprising the enactment of diabetes by the participants in this study was highly contextual, involved various intersecting and often competing discourses, and was infused with shifting power relations. Participants determined the 'best' knowledge to guide decision-making and problem-solving through shifting power relations within practices, which changed, often moment-to-moment. They took up, resisted, modified, as well as accepted current contemporary self-management guidelines and recommendations based on large-scale data from institutions such as Diabetes Canada which were filtered through health care providers, pump companies, insurance companies, as well as the general public. Participants' accounts were indicative of the constitutive nature of social constructions of 'good' diabetes self-management which center the human actor and their practices were reflective of this.

According to Mol (2002), a praxiographic study of disease is one where the researcher does not isolate the disease from the practices in which it is enacted. In this study, I have investigated diabetes enactment or how diabetes *is done*. I have come to understand practices as intricate patterns almost like the loops created through crochet. In making an afghan, loops are all made from yarn, but their color and pattern may change. One may see the individual loop sometimes, but often it may remain hidden, only visible when you hold the afghan and visualize it with intense scrutiny. Similarly, the practices that comprise diabetes enactment by the participants in this study are like the networked loops of a crocheted afghan. We know that the individual loops are there and sometimes we can see them with the naked eye, but not always. We know that the loops hang together in what we have come to know as an afghan. Each individual loop is created through the relation of several actors – yarn, crochet hook, pattern, hand dexterity, time to work on it, etc. According to Mol (2010), is not possible to precisely define actor when considering networks, but simply that an actor 'acts' and is afforded their ability to do so by what is around them. These actors of crochet (the hook, yarn, pattern, resulting loops, person, hands, hand dexterity, etc.) cannot act alone, but are interwoven in a complex array of practices that eventually become recognizable as an afghan. By itself, a crochet hook is one actor in the network as a result of being acted upon by other actors, the yarn, the hands, the person, etc. This is similar to diabetes practices.

Nicolini (2017) suggests research that foregrounds practices cannot be truly specified at the outset but must emerge through engagement with the phenomenon. At the beginning of this research I had several questions - what are diabetes practices? What is the rationale for and meaning of practices indicative of diabetes self-management? How are such practices assembled, disassembled, and reassembled? At first, these questions appeared somewhat clear and straight-forward, however I have come to understand that "…practice theory cannot be written first and operationalized later; it can only emerge through engagement with the phenomenon" (Nicolini, 2017, p. 25). Integral to my understanding, is that practices exist only in the extent that they are reproduced, that there is a right and wrong way of doing things that depend on a shared view which keeps practices together by different forms of association or sharing common elements (Nicolini, 2012, 2017).

As I moved through the various stages of this study, and especially in the analysis, my understanding of practices deepened, as my gaze shifted from centering the participant to addressing all sociomaterial actors *symmetrically*. As suggested by Oliveira de Moura & Bispo (2019) and Rees et al. (2021) symmetry is a key component of practice-based research and is the heterogeneity of human and non-human elements of a phenomenon, each with power or agency over the other. As such, I was able to shift my thinking to consider not only the agency of the participants, but how their agency was both constrained and enabled through the agency of other actors. For example, through this lens I was able to consider the agency of the pump and question – what are pumps doing? Additionally, I was able to consider the agency of other actors, such as shame and guilt and consider how they enabled or constrained agency of other actors i.e., pumps, glucometers, and the participants. Initially, I did not set out to widen my gaze in this manner, and admittedly, I held a narrow view of practices as driven by the participant. Through my immersion in the data and moving back and forth in a hermeneutic process between the thematic, discursive practice, and social practice analyses of Fairclough's CDA approach, I saw boundaries melt away and in doing so, I was able to begin to trace the relationality, spatiality, and temporality of diabetes practices as recounted by these participants.

Drawing on Mol (2002), participants' practices hung together in what we have come to know as diabetes and that the boundaries between knowing *in* diabetes (the disease) and knowing *about* diabetes (the practices) were blurred. Through a praxiographic approach it became impossible to separate biomedical knowledge from other knowledge(s) such as experiential in the enactment of diabetes. Problem-solving, decision-making, and sense-making practices all happen a result of their relations with other practices and therefore, diabetes enactment is a complex web of interrelated practices existing in intricate networks, occurring across space and time.

## Actors, Networks, and Practices

Decisions made, problems solved, and the ensuing sense-making in diabetes management are practices as they are the result of the interactions with other practices – meanings that are ascribed within practices are the result of relational performativity (Hultin & Mahring, 2019). For example, in surveilling blood glucose values and trends, participants made decisions and solved problems based on their knowledge of what has worked for them in the past as well current and future contextual information. Surveillance practices such as blood glucose monitoring were related to past and current contexts which gave rise to their meaning as well as influenced preparing and planning activities that in turn, influenced mitigating practices for high or low blood glucose.

Throughout the analysis, I have presented the many actors in diabetes practices including the person living with diabetes, family members/friends, health care providers, institutions such as Diabetes Canada, insurance companies, and pump companies, as well material artifacts such as carbohydrate counting guidelines, pump brochures and manuals, You Tube videos, various foods, scales, measuring cups, insulin, syringes, alcohol swabs, pump supplies (reservoirs, infusion sets, Pods, batteries), glucose testing and monitoring technology (glucometer, testing strips, lancets, Freestyle Libre, CGM, etc.) as well as the pump itself. All of these actors have agency at some point in time. As Sayes (2014) suggests, an actor (human or non-human) is afforded agency as it demands action from other actors. For example, an insulin pump displays information on its screen thereby contributing to the practices of the user. In this manner, the insulin pump displays agency in that it demands some action from the individual. Similarly, a glucose strip that is placed in the blood glucose meter exerts agency because its function and the result of determining the blood glucose value evokes a response (agency) from the user.

## Networks, Practices, and Critical Discourse Analysis

As I foregrounded the practices and came to understand diabetes practices as existing in networks, Fairclough's Critical Discourse Analysis (CDA) was imperative to my understanding as well as to situate the findings of this research in the context of historical and contemporary literature. As suggested by Nicolini (2017), practices are spatially and temporally dispersed sets of doings and sayings organized by common understandings and rules which have a history, social constituency, as well as a normative dimension. Practices never exist outside of their production and reproduction, and they *are* practices because of their relations with other practices. As such, practices exist in networks of people, places, spaces, objects, and time because of an entanglement of material and discursive resources (Mol, 2002, 2010; Mol & Law, 2004).

Fairclough's CDA was instrumental in highlighting the discursive and social influences on the participants' diabetes practices. As Nicolini (2017) postulates, there is a commonly understood right and wrong way of performing a practice and thus a normative dimension to practices. This normative dimension, or the right and wrong way of doing things, becomes hegemonic because of the influence of ideology. Practices become naturalized, and therefore common-sense, because of ideologic discursive formations (IDF). When an IDF becomes so naturalized that it is 'common-sense' and often hidden, resulting practices become hegemonic (Fairclough, 1985, 2013). For example, despite the many challenges of using the pump as described by participants, it was common-sense to want a tool to manage diabetes that creates more freedom and flexibility overall in terms of living a 'normal' life. Beyond this, one can extrapolate that a life of endless injections as well as fluctuating blood glucose levels is not 'normal', and an insulin pump provides some semblance of normalcy. Through analysis, I constructed themes as my interpretation of the various discourses of the participants evolved. As suggested by Orlikowski and Scott (2015) neither material phenomena or discursive practices are ontologically separate, but are *ontologically entangled*, and thus they are part of and constitute each other. These entangled material-discursive practices are performative as they configure reality, or the relational enactment of the world. In this study, four discourses emerged as dominant in the data, based on neoliberalist ideologies of self-responsibility for health as an ideal value. As a result of these ideologies constructed within dominant as well as intersecting and competing discourses, the participants and I discursively constructed and thus actively presented ourselves as ‘good’ managers.

### ***Dominant Discourses***

The identification of dominant discourses represented the outcome of discursive struggles, resulting in ideologic discursive formations (IDFs) (Fairclough, 1985), of which the participants and I played a part. Overall, this research demonstrates that diabetes enactment includes the practices of decision-making, problem-solving, and sense-making; these practices exist in networks, and that ‘good, competent, self-management’ practices are discursively conceptualized and constructed. These findings were dependent on shifting power relations which influenced understanding of ‘correct’ knowledge at the time and have implications for both individuals living with diabetes, family and friends, as well as the health care providers who support them.

The participants and I drew on other discourses as well as other texts in our conversations. *Interdiscursivity* (Fairclough, 2013) was evident as participants referred to their experiential knowledge as the most influential in their decision-making and problem solving, while at the same time referencing biomedical knowledge and glycemic targets in the measurements of success. Additionally, within their accounts as well as my interpretations of the texts (interview transcripts, my reflection journal, as well as my field notes) we referenced other texts such as Diabetes Canada (2018) Clinical Practice Guidelines, pump manuals, You Tube videos, online blogs and chatrooms, as well as carbohydrate counting guides. As such, *intertextuality* was evident in the references within texts to other texts (Fairclough, 2013). As a result of my interpretation of the data and these dominant discourses, I have come to understand that individuals living with diabetes, health care providers, participants' family, and friends, as well as the general public construct living with diabetes as a reflection of a mixture of historical as well as contemporary norms and expectations.

### ***Discursive Constructions of 'Good' Management***

In their accounts, participants engaged in practices to 'live up' to constructed 'good self-management', and they also actively created these constructions. I, too, participated in this construction as I interacted with the participants and we co-created knowledge during our interviews as well as when I engaged with the data during the analysis. Throughout, the participants and I were influenced by, and we also influenced, ideologies in the evocation of what it means to be a good, competent self-manager and the best knowledge required to accomplish this goal. As the participants and I discussed examples of practices indicating surveillance, planning, preparing, as well as mitigating blood glucose excursions, we presented the right and wrong ways of doing this in our talk, actions, and thoughts (Nicolini, 2012). For example, most participants extensively prepared to manage hypoglycemia by ensuring quick access to carbohydrate sources however, some participants did not prepare like the others and carried minimal food, if any. They explained how this is what worked for them, however for other participants and me, this was taken up as deviant. Through pump education based on

Diabetes Canada Clinical Practice Guidelines (2018) and pump manuals (Minimed 670 G (Medtronic) User Guide, 2017; Omnipod User Guide, 2017) the participants received education about the necessity of preparation to mitigate low blood glucose. Both in their telling of these practices and my interpretation of them, we constructed notions of good (following exact recommendations) or bad (not following exact recommendations).

In their descriptions of surveillance practices and those of planning and managing blood glucose variations, participant's accounts evoked a 'common sense' approach in that to be a good, competent manager, one must surveil, plan, prepare, and execute practices to maintain optimal blood glucose levels. Despite current contemporary notions of the social construction of diabetes and how so many physiological and other factors affect blood glucose (Litterbach et al., 2020; Watermeyer et al., 2020), control always reverted to the self and what was or was not done to 'control' the blood glucose. It was as if individuals with diabetes should be able to do better than the pancreas, at all times, and in all situations. Interestingly, participants also described surveilling others in comparing their own management practices to that of others living with diabetes as well as the norms and advice offered by those not living with diabetes.

Participants all described varying practices of managing blood glucose fluctuations, specifically hypoglycemia which confirms and adds to previous research by Brown et al. (2019) and Vallis et al. (2014) in that treating hypoglycemia is highly individual, contextual, and involves a complex interplay of emotional factors. My research augments previous hypoglycemia management studies in that I focused on the *relations between management practices*, most notably how agency flows between actors. The most influential knowledge during a given episode of hypoglycemia was highly contextual. For instance, the agency of several sociomaterial actors such as body symptoms, the blood glucose value, available foods, activity either during or planned for after the hypoglycemia, all influenced what was *sensible* management decisions. Knowledge, and thus sense, were consistently made and remade as a result of the performativity of practices (Hultin, 2019; Hultin & Mahring, 2017). Experiential knowledge, knowledge of current and future activity, as well as knowledge of guidelines and recommendations all came together to determine the best self-management practice(s) in this particular context. Nevertheless, participants described judging their treatment of hypoglycemia (and being judged by others) in terms of external guidelines and clinical recommendations. They often manifested shame, blame, and in their accounts, they spoke of stigmatizing and marginalization by others as a result of their diabetes practices.

Agard et al. (2016) argue that desired outcomes for individuals living with diabetes need to be adapted to what is desirable and realistic for the patient, not simply their ability to meet glycemic targets. Despite increased pleas for attention to the importance of psychosocial issues in diabetes care (Jones et al., 2014), researchers continue to find dominance of the biomedical model in self-management support. In their systematic review of patient and health care professionals' perceptions of self-management support, Franklin et al. (2018) highlight how diabetes care remains embedded with a biomedical framework and those living with diabetes are encouraged to make the 'right' choices to meet biomedical markers to achieve successful self-management. Despite Diabetes Canada (2018) articulating person centered values in their guidelines, the notion of tailoring glycemic according to the person's values and goals appears to have had minimal impact on how the participants in this study portrayed themselves as 'good' managers. While participants understood that management is individual, their accounts and discourses were of 'being caught' between two worlds – living a meaningful life and managing diabetes well. As suggested by Litterbach et al. (2020), individuals living with diabetes continue to feel compelled to meet glycemic targets to preserve their self-image and identity, even if recommendations and guidelines are incompatible with their life values and goals.

**Genres and Styles.** In their accounts of managing their diabetes using a pump, participants expressed several genres (presented themselves in various ways) as well as styles (diverse ways of being as a result of social as well as personal identities) (Fairclough, 2003). Participants presented themselves as both expert and novice in diabetes management, often within the same story. As identified by Engstrom et al. (2016) in their study of individual experiences of living with diabetes, to enhance self-management support, diabetes care needs to include individual needs and contextual factors. Similarly, Watermeyer et al. (2020) argue that health care providers need to understand the lifeworld of the patient. Despite ongoing research of the importance of the person's unique contextual factors in diabetes management (Litterbach et al., 2020) the participants in this study demonstrated a conflict between asserting their experiential knowledge and thus self-responsibility, and maintaining their ongoing need for support from others, notably health care providers.

Participants also presented themselves as both competent as well as incompetent self-managers, and they valued and used their experiential knowledge developed within their ongoing practices most often, yet their reference to whether they were managing 'well' was predominantly in relation to biomedical markers of the disease such as blood glucose levels as well as the HgbA1c value. As Vallis (2015) suggests, self-management requires a different measure of evaluation aside from biomedical markers of disease such as HgbA1c, as success measured through biomedical markers represents a narrow view of self-management and self-management support. Paterson (2001b) theorized that adaptation to chronic illness is a continual, ongoing process. My study adds to Paterson's (2001b) Shifting Perspectives Model of Chronic

Illness as the findings demonstrate that diabetes knowledge is created within the practices in an ongoing, continual process of adaptation. While illness and wellness may move back and forth between foreground and background, my study focuses on ***<u>how</u>*** they move, as a result of a flow of agency between human and non-human actors.

In their study of the emergence of health through a sociomaterial lens, Andrews and Duff (2019) suggest that practice-based approaches to health and illness "…recognise nonhuman actors and forces that variously contribute to the emergence (and expression) of specific healthy or ill bodies, by acknowledging the varying capacities each actor and force exhibits" (p. 125). The heterogeneity of human and non-human actors in diabetes management creates a horizontal alignment of actors, rather than vertical, meaning the person is one actor afforded agency and thus responsibility by other actors (Andrews & Duff, 2019). While contemporary attention to the necessity of self-responsibility in successful diabetes self-management (O'Brien et al., 2020) is at times warranted, the 'self' it is *<u>just one piece</u>* of a complex array of moving parts, and thus self-responsibility must be tempered with the knowledge that diabetes is a complex disease requiring complex management. My study extends the findings of other studies such as Watermeyer et al., (2020), where they focused on patient and health professional experiences of diabetes care and determined that diabetes management includes a complex interplay between various factors (the ***who, what,*** and ***why***) to new understandings of the ***how,*** or the constitutive relations between the various factors.

Knowing and utilizing guidelines and recommendations for self-management is not by itself problematic. However, in this study, it was problematic when, despite having extensive experiential knowledge as a foundation on which to base self-management practices, the participants judged their success on how well they employed biomedical knowledge. To be perceived as a good self-manager, adherence to guidelines and recommendations was perceived as paramount. While participants valued guidelines and recommendations from institutions such as Diabetes Canada as well as pump companies, *how* and *when* they utilized these recommendations was very dependent on whether these fit within their current context-in-the-moment. When they struggled to work with the recommendations, either unexpectedly or because experience indicated the recommended goal was incongruent with the resources and demands in the situation, it could engender self-blame and shame.

All participants universally recounted experiences of diabetes stigma, marginalization, diabetes distress (Abdoli, et al., 2018; Archer, 2014; Liu et al., 2017), and epitomized the elusive 'diabetes control'. As Rand et al. (2017) and Wardian (2017) conclude, the notion of control is inappropriate in diabetes management as there are so many moving parts (and from a practice-based approach, many actors) so the concept of control is not only outdated, but it is impossible. Shifting our gaze to foreground the practices, affords an ability to increasingly highlight diabetes complexity and shift our critical attention to words such as 'integrating', 'managing' or 'balancing' as opposed to 'control'. Despite continued research about psychosocial issues in diabetes management (Joensen et al., 2018; Vallis et al., 2016), and the elusive nature of the concept of 'control' (Rand et al., 2017), researchers continue to report measures of enhancing glycemic control (Bain et al., 2020; Tourkmani et al., 2018). Continued use of the word 'control' has implications for individuals living with diabetes. As the participants in this study recounted the ongoing predictably unpredictable nature of diabetes, they also felt blame for their inability to manage the unpredictability, or to obtain and maintain 'control'.

In our discussions about what may be considered historical remnants of diabetes practices prior to the advent of newer insulins and the pump, the participants and I talked about eating sweets, junk foods, and take out foods, among others. Historically, a diet for a person with diabetes did not include these food items and if they were consumed, it was in very small quantities. While a diet predominantly consisting of these food types is not recommended for any Canadian, social norms dictated that they are effectively taboo for individuals with diabetes – in fact, they may be considered ‘forbidden’ foods. The historical nature of practices (Nicolini, 2017) is clearly evident in how these past practices, developed long ago in the context of using insulin injections, influenced participants’ current accounts of their insulin pump practices. In discussing eating practices, when various ‘taboo’ foods arose, participants would lower their voices and laugh nervously. While they said they ate these foods, their body language and tone of voice indicated that this was not an aspect of ‘good’ diabetes self-management. Similar to Martyn-Nameth et al. (2019), in their study of hypoglycemia challenges in individuals with Type 1 diabetes, the participants in my study described a changed relationship with food in that they paid more attention to the type and number of foods (i.e., number of carbohydrates) consumed. They also perceived increased guilt in relation to the ingestion of junk foods.

The participants in my study perpetuated the idea that some foods are ‘bad’ and should not be consumed. As Pols (2017) suggests, ‘good’ is a loose concept and is related to sociocultural values inherent in the practice. What is considered ‘good’ at one point in time, may not be so in another. Participants’ connotation of ‘good’ was dependent on their perceived expectations of self and others as to what ‘good diabetes management’ meant even when, in the context of the insulin pump, these foods are much easier to manage by matching insulin to the number of carbohydrates consumed (Nimri et al., 2020). Similarly, Benavides-Vaello and Brown (2016) suggest that what individuals consider ‘good’ and ‘bad’ foods depends on sociocultural meanings assigned to them. Interestingly in some of my discussions, participants’ word choices were at odds with their body language and tone of voice as they rather defiantly told me about their intention to continue integrating cake, cookies, donuts, muffins, pizza, and Chinese food to name a few items, into their lives – yet their tone and body language signified self-perceived deviance form the expected norms that constitute 'good management'.

Dominant neoliberal ideologies of self-responsibility for health (Barnett & Bagshaw, 2020; Crawshaw, 2012; Deering, 2016) underlay why participants in this study manifested blame, shame, and guilt when their practices were not aligned with current guidelines and recommendations. Browne et al., (2013) suggest that stigma arises from several sources such as media, health care providers, family, and friends, and so forth. However, in this study both the participants and I continued to perpetuate these ideologies in our interactions. In our discourses, we demonstrated that while we valued our own experiential knowledge developed through our ongoing practices, we inherently were not managing well enough to meet current recommendations and standards. As suggested by Fisher et al. (2019) and Jones et al. (2014), diabetes distress includes the worries, fears, and concerns associated with the everyday, all-encompassing complex management of an uncertain disease. In keeping with Fisher et al. (2019), the participants in this study worried about threats of complications, possible loss of functioning, as well as access to care. These concerns and worries were manifested as ambivalence and the occupation of a liminal space (Archer, 2017) between meeting recommendations, and doing so in their own way.

### ***Power and Knowledge***

As I engaged with the data, I could not help but liken the various instances of power in this study to the waves on the sea. Power was so fluid in this study as it shifted back and forth between participant, health care providers, recommendations and guidelines, experiential knowledge, biomedical knowledge, others (family, friends, co-workers, society in general), pump companies, institutions such as insurance companies, as well as the pump itself. Drawing on the work of Foucault (Gordon, 1980) and Fairclough (1989, 2003, 2013) I understood power not as an oppressive static entity, but that it is fluid and productive. As a result of shifting power relations, what came to be considered knowledge and more specifically, the best knowledge for decision making and problem solving, was very much dependent on contextual influences. I was also very keenly aware of the shifting power relations between myself and the participants.

In this study, participants' diabetes practices were held together by a common goal of their requirement to individualize management while at the same time meet glycemic targets and in doing so, represent themselves as 'good' self-managers. For example, in making decisions to solve the problem of hypoglycemia, participants drew on their own unique experiential knowledge developed through their practices as well as knowledge of Diabetes Canada (2018) Clinical Practice Guidelines for hypoglycemia treatment, glycemic targets, and their individual contextual influential factors (example, stress, sickness, exercise, etc.) at the time. In this manner, the participants used disease-specific, as well as past and current experiential knowledge to solve problems and make decisions (Hill-Briggs, 2003). Throughout their practices with hypoglycemia, participants continued to refine their experiential knowledge in an ongoing iterative, interactive process that was personally constructed and changed over time (Paterson, Thorne, & Russell, 2001).

The participants talked of what had worked in the past which spotlighted their copious expertise, but this was consistently framed as peripheral knowledge in comparison to their clinically determined blood glucose parameters; typically, participants spoke of *'I know I am not supposed to, but….'* which I interpreted as marginalising their own experiential knowledge in favor of institutionalized clinical parameters. Paradoxically, when participants described their in-the-moment decision making and actions to treat, those same institutional guidelines and recommendations based on biomedical knowledge were peripheral to their experiential knowledge. It was clear that the participants struggled at times with asserting their autonomy, as they perceived both autonomy and empowerment to be embedded within adherence to normative expectations of 'good' management, i.e., adherence to guidelines and recommendations as well as meeting glycemic targets. In the following sections, I will review the findings of my study in the context of historical and contemporary literature with respect to autonomy, empowerment, and person-centered care within self-management.

### ***Autonomy, Empowerment, and Person-Centered Care***

The participants and I actively created a juxtaposition between autonomy in individualizing recommendations while attempting to meet glycemic targets. Ellis et al. (2017) found that health care providers expected 'good' self-managers to take responsibility for their health, which represents a moral obligation to society and one's social network. Ultimately, a 'good' self-manager will adhere to medical advice regardless of whether it is not compatible with their way of life. Autonomy refers to the ability to be self-governing or self-rule and therefore the ability to make choices (Lam, 2014; Tengland, 2016; Williamson, 2014). As Mol (2008) postulates, the ability to make choices is often constrained in diabetes practices. For the participants in this study, choices were not simple decisions, but included several knowledges as well as the inevitable unpredictability of the disease. In making decisions and solving problems, the participants made a variety of choices but their descriptions and measures of their success of their autonomous choices were measured in terms of their ability to meet glycemic targets and follow recommendations and guidelines rather than quality of life.

While health care providers provided some necessary support, encouragement, and assistance, for the most part, participants perceived this support to be framed from the overall biomedicine approach. This is why participants often felt concealing or prevaricating their actual practices was valid given the perceived discounting of their experiences by their health care providers. While some participants perceived immense support from health care providers, they embedded this support within biomedical parameters of diabetes management. For example, in an account of the health care provider changing the HgbA1c value on a report, the action by the health care provider and the account of the participant continues to frame optimal diabetes management success within biomedical markers of the disease. Other participants recounted examples of not wanting to disclose their glucose values for fear of being perceived as ‘not managing well’. Schulman-Green at al. (2015) found that individuals living with chronic illness are reticent to be honest with health care providers to avoid conflict. In my study, participants were often dishonest with their providers because they felt their experiential knowledge was inferior. While the participants in this study expressed their attempts at autonomous decision-making, problem-solving and thus sense-making, this was in the context of current recommendations and biomedical knowledge.

Historical and contemporary literature is replete with studies of how successful self-management is embedded within meeting biomedical targets (Duprez et al., 2020; Gillibrand et al., 2004; McDonald et al., 1999). In this study, I interpreted that while the participants, as well as health care providers, respect psychosocial issues and the complexities of managing diabetes, they both constitute and are constituted by ideologies of self-responsibility (Crawshaw, 2012; Deering, 2016) for health as evidenced by participants’ accounts of their practices. Participants felt health care providers *did attempt* to individualize management, however this individualization took place within larger social practices influenced by ideologies of self-responsibility.

As suggested by Vallis et al. (2016), understanding diabetes-related psychosocial outcomes for individuals living with diabetes can assist health care providers to understand the day-to-day self-management practices and thus enhance provision of self-management support. As demonstrated in this study, the importance of psychosocial issues continues to take a back seat to a biomedical approach in diabetes self-management and perceived self-management support. In this study, the concepts of autonomy and responsibility for health were at odds and require revisiting and re-conceptualization (Snelling, 2012). Murdoch et al., (2015) challenge the individualistic nature of self-management, as talk and illness related behavior are forms of social action which shift as individuals move through various discourses across time and space.

The findings of this research suggest a need to re-think the concept of autonomy in diabetes self-management. Perhaps a re-imagining of the concept of *relational autonomy* is more suited to diabetes self-management and self-management support, which '…offers the individual the opportunity to take control of his or her own life within the limitations of social, physical, and mental abilities" (Teunissen et al., 2019, p.55). I suggest however, that instead of foregrounding the human actor's authority, the concept of relational autonomy could be expanded to consider the agency of the various actors in the network of diabetes practices. As Brahim (2019) suggests, the concept of autonomy is at odds with current conceptualizations of self-management in that to be truly self-governing negates the impact of the highly contextualized nature of diabetes self-management.

### ***Empowerment***

It is impossible to live a life with diabetes where management is a prescribed regimen (Funnell & Anderson, 2004). As the participants in this study demonstrated, guidelines and recommendations are only *one part* of managing this disease in the context of everyday life. The findings of this study suggest that a tension still exists between the concept of empowerment and how it is operationalised into diabetes management practices for those living with the condition. Experiential knowledge continues to be discounted or considered inferior to biomedical knowledge and empowerment gets translated into practice as the ability to follow guidelines and recommendations and meet glycemic targets (Duprez et al., 2020; Storni, 2015; Westen et al., 2019; Williams et al., 2016).

The concept of empowerment is often at odds with the culture of health care providers as well as their training in that their purpose is to promote health and prevent disease for their patients (Funnell & Anderson, 2010; Sharp et al., 2017). Vallis (2015) suggests that we need a shift in how health care providers see themselves – not as experts, but as collaborators with patients who are experts in their individual disease. Unfortunately, when patients do not meet glycemic targets, health care providers often experience ethical conflicts as they wish to support the autonomy and thus empower the patient, yet through their education and training feel compelled to promote guidelines and recommendations to meet glycemic targets regardless of the situation of the patient. This leads to ethical conflicts for health care providers (Duprez et al., 2020). A practice-based approach to diabetes management which decenters the human actor, allows for expanded thinking of the concept of empowerment as individuals living with diabetes are both enabled and constrained by other actors in their practice networks. Therefore, empowerment does not simply rest with the person to *obtain*, or the health care provider to *enhance*, but is flattened within a practice-based approach with a focus on relations between actors.

### ***Person-Centered Care***

Contemporary self-management support for individuals living with diabetes should be situated within a person-centered approach because it prioritises experience over biometrics (Diabetes Canada, 2018). This approach acknowledges patients as ‘people’ first, knowing them in their social worlds, listening to them, and respecting their wishes (Epstein, 2011; Mead & Bower, 2006). For diabetes management in particular, the person living with the disease should be at the center of any care provided with the focus on health and wellness, not just biomedical and glycemic targets (Romeo & Abrahamson, 2015; Weinger et al., 2016). The Diabetes Canada (2018) Clinical Practice Guidelines include how person-centered care and collaborative approaches are essential in self-management education and support, yet this approach appeared to be consistently taken up by the participants in this study as primarily aimed at meeting biomedical targets. The findings from this research highlight the ongoing tension within a person-centered approach which continues to center the human actor. As a result, there is limited acknowledgement of the other actors in the networks or the ongoing flow of agency amongst them. This has implications for the continued use of person-centered care in remarkably complex disease management. I question if instead of person-*centered* care, person-*inclusive* care should be the most appropriate approach, acknowledging the complex, intricate relations between actors.

For the participants in this study, influenced by neoliberalist rationality, the ‘self’ was the dominant actor in the networks, so much so that there was blame associated with not being able to control the other actors in the network. Archer (2017) suggests when individuals experience that they are not managing 'good' enough, they manifest shame. This has implications for how self-management, within the philosophy of person-centered care, is conceptualized, promoted, taken up, resisted, or revised by individuals living with diabetes and those who support them. The 'self' in chronic disease management reflects beliefs and assumptions about the ability of individuals to manage their illness. As Thirsk and Clark (2014) suggest, the term 'self-management' implies that living with a chronic illness is an individualistic activity and that interventions to support self-management can only influence change at the individual level. The Chronic Care model, an increasingly utilized model of structuring chronic care at social, organizational, and personal levels to both prevent and treat chronic conditions specifically references the need to consider the links between these levels to optimize chronic illness care (Kadu & Stolee, 2015). These authors further suggest that this model "…provides no clear blueprint on now each component can be implemented in practice…" (p. 2). The findings of this study add to the understanding of the personal level in this model in how individuals manage diabetes on a day-to-day, moment-to-moment basis.

Ultimately, this research demonstrates that diabetes practices and knowledge remain embedded within a predominantly biomedical framework. Success of management practices are consistently measured with glycemic targets, despite the continued perceived necessity of espousing the philosophy of person-centered care to frame self-management support. There are continued tensions between embracing a person-centered care approach and what is actually done in practice by both individuals living with diabetes and those who support them. Throughout my analysis and ensuing findings, I wonder about the current emphasis on person-centered care in diabetes management and whether it is even possible to implement. Given the complexity of diabetes management practices (Burridge et al., 2016; Rand et al., 2017;

Watermeyer et al., 2020) and as demonstrated throughout this study, are we (those who live with diabetes and others who support them) chasing an elusive phenomenon we have come to know and understand as person-centered care? Person-centered care has been discussed for decades, including the evolution of the notions of compliance, adherence, concordance, as well as empowerment, autonomy, and self-determinism (Kuipers, 2019; Michie et al., 2003; Santana et al., 2018; Romeo & Anderson, 2015; Weinger et al., 2016). Further evolution is required and I question if it is time to let go of the nomenclature of 'person-centered care' and focus on relations. While the importance of the 'person' should remain in diabetes education and self-management support, the 'centering' piece is at odds with a practice-based approach and belittles the complex, intricate network of actors and thus practices and relations. As Pel et al. (2021) suggest, 'person-centered care' is taken up by patients and health care providers in many diverse ways, with the underlying concept of acknowledging the *person* in the patient. Current conceptualizations of 'person-centered care' are problematic (Moore et al., 2017), and as demonstrated in this study, may lead to blame, shame, and stigma for individuals living with diabetes and ethical conflicts for health care providers who support them.

The findings of this research indicate that diabetes management exists in networks of various actors and to enhance diabetes self-management and self-management support, a shift is required. Attention must shift from centering the human actor (as in current self-management, self-management support, and person-centered care), to a focus where the individual is just *one actor* in a network comprised of numerous actors that are held together by the relations between them. While the individual is important in diabetes practices, opening our gaze to the other actors and the flow of agency and power between them, also opens avenues to also reconsider blame, shame, and stigma in diabetes management.

## Implications

Since the 1970's self-management has been the cornerstone of diabetes education and support from health care providers (Wilkinson & Whitehead, 2009). This dominance of self-management has occurred alongside the evolution of the patient-provider relationship as well as a rise in neoliberalist notions of health and well-being culminating in the good citizen contribution to society. Continued evolution of diabetes management requires a return to focus on the 'self' in self-management, what constitutes best knowledge, articulation of power, as well as the existence of networks. Historically, the nursing contribution to chronic disease management has remained hidden and to clearly articulate nursing's role, nurses need to develop a distinctive nursing gaze (Forbes & While, 2009). To enhance this nursing gaze, I suggest recommendations for nursing research, education, policy, and practice.

### *Implications for Research*

The findings of this research indicate that diabetes practices by those who use insulin pumps exist in networks and that a re-visiting of self-management is warranted. This study represents one snapshot in time with a distinct subset of participants who live with diabetes and use an insulin pump. To add to a knowledge base about a network approach for diabetes management, further research is warranted to explore the practices of those who use injections, as well as oral medications which could provide a more extensive perspective of diabetes enactment. Topics for exploration may include whether the practices of those using injections are different or similar to the practices identified in this study.

In this study, diabetes practices represent enormous work and further research to explore the concept of diabetes work is warranted. As Corbin & Strauss (1985) articulated, chronic illness work involves three types of work – illness work, everyday life work, and biographical work. The findings of this study indicate that diabetes practices are work and this concept should be explored further, adding to a necessity of experiential knowledge in diabetes management and extending the work of Corbin and Strauss (1985) and other scholars such as Townsend (2011) on the work of chronic illness.

Further research with various populations (or other human actors) such as health care providers and family members/other support individuals of those living with diabetes about diabetes practices in the context of self-management support is also necessary. Research about the meaning of self-management and self-management support with health care providers is especially needed to re-imagine the philosophical tenets of person-centered care, including empowerment, and autonomy within a practice-based approach. Exploration is required to examine how to support the importance of the person in diabetes management but at the same time, decenter the individual and focus on the flow of agency within complex networks.

In keeping with furthering a network approach to diabetes management, future research should include person-inclusive methods such as participatory-action research with a focus on change. Research that explores diabetes practices through a variety of methods such Participatory Action Research (PAR) (example, photovoice) meant to engage in the meaning of practices are necessary to focus on emancipation and change oriented understanding and knowledge. These methods would be useful in gaining further insight into the rationale for and meaning of the practices for individuals living with diabetes.

### ***Implications for Education***

In Canada, there is an impetus to shift from a predominantly didactic teaching-learning pedagogy in nursing education to more concept-based curricula. As Funnell and Anderson (2004) and Storni (2015) suggest, health care providers, including nurses, have been traditionally educated to be the expert in the patient-provider relationship which hampers the patients' expression and articulation of experiential knowledge. With continued access to information, individuals living with chronic illness are becoming more informed and educated about their bodies and illnesses. Additionally, individuals live increasingly complex lives of which their health and wellness are but one part. Nurses need to be aware of this as well as their position in relationships with others, which has implications for both undergraduate, as well as continuing nursing education.

**Undergraduate Education.** Reconceptualizing self-management calls for a reconsideration the role of the nurse in providing self-management support. To fully engage individuals living with diabetes, I suggest a relational inquiry approach within which to educate future nurses to provide self-management support. This approach foregrounds the context and thus provides an opportunity to fully embrace a network approach. Relational inquiry in nursing involves two essential components: a relational consciousness and inquiry as a form of action (Doane & Varcoe, 2015). A relational consciousness is compatible with a network approach as it is grounded in the assumption that people are relational beings, situated in and constituted through social, cultural, political, and historical processes and communities" (Doane & Varcoe, 2015, p. 4).

Foregrounding inquiry as a method of action calls on nurses to enter situations inquiring into the relational experiences of individuals (and themselves), contexts, various knowledges, and meaningful practices (Doane & Varcoe, 2015). Stuckey et al. (2015) suggest that health care providers need to *listen to and learn from* individuals living with diabetes, indicating the importance of a relational inquiry approach. While a focus on the pathophysiology of disease and pharmacology of diabetes management is warranted, it is not enough to prepare future nurses to engage with individuals living with chronic illness and specifically, diabetes. Educators need to focus on key frames within which to provide diabetes self-management support and communication strategies and techniques such as empowering language and motivation interviewing should be taught within a Strengths-Based Nursing approach (Gottlieb, 2014).

The language that nurses and other health care providers use in collaborating with individuals living with diabetes may have empowering, positive effects or negative, stigmatizing effects that affect a person's self-management. As Anderson and Funnell (2000) suggest, compliance and adherence are dysfunctional concepts in diabetes self-management and self-management support as they denote an individual as having complete control over their diabetes. These words indicate an 'either/or' situation, whether an individual follows the recommendations or not, without enough consideration of the importance of contextual influence, or networks.

Language used in diabetes education and support should be empowering. For example, use of words such as 'control', 'diabetic', 'testing', 'allowed/not-allowed' etc. should not be used and replaced with more neutral language such as person living with diabetes (instead of diabetic) and checking (instead of testing) (Dickinson et al., 2017). When health care providers use labelling and stigmatizing language, individuals tend to hide aspects of their diabetes management, which was indicated in the findings of this study, and may be devastating in the short and long-term management and outcomes of this disease. Using outdated language such as the above terms clearly delineates a power dynamic with the health care provider having more power, discounting experiential knowledge, and inducing negative framing of a disease (Banasiak et al., 2020).

The findings of this study demonstrate that diabetes self-management and self-management support remain deeply embedded within a biomedical model, with emphasis on meeting glycemic targets. The participants all referred to themselves through words or actions as deviant when they did not meet targets or did not exactly follow recommendations but prioritized their experiential knowledge. A Strengths-Based Nursing (SBN) approach focuses on what individuals are doing well and the supports and strengths they already have rather than begin with a focus on what is ‘wrong’ or not working (Gottlieb, 2014). The critical values of SBN fit well with diabetes management and especially well with framing diabetes practices within a network approach. With the values of uniqueness, holism, embodiment, subjective reality and created meaning, as well as the inextricable links between person and environment (Gottlieb, 2013), using a SBN approach is essential for nurses to provide diabetes management support within a network approach.

Motivational interviewing (MI) is a communication style that can enhance the collaboration in the person-provider relationship, lead to enhanced problem-solving, as well as enhanced readiness for change (Luke & Richards, 2018). Health care providers and those living with diabetes need to pay attention to blood glucose values, HgbA1C values, and other biomedical markers as an aspect of overall management. Framing diabetes care and support within a network approach, does not remove biomedicine, but shifts the focus. Individuals living with diabetes need to continue with practices to promote their physical health such as checking blood glucose, monitoring diet, and eating patterns, counting carbohydrates, exercising, etc. Therefore, an aspect of diabetes education and support is assisting behavior change and lifestyle modifications, however this cannot be driven by the health care provider. To be successful, behavior change must start from within (internal motivation) and MI facilitates this with its focus on open-ended questions, reflections, and summaries (Hunt, 2011; Song et al., 2014).

As diabetes self-management does not exist in isolation, neither should the provision of self-management support. Nurses are key players in providing this support, however they are but one player. Other health care providers such as psychologists, pharmacists, social workers, dietitians, and physicians are also key team members. As Racic et al. (2017) articulate, enhancing the opportunity for undergraduate interprofessional diabetes education results in greater teamwork and enhanced knowledge of diabetes self-management support. Therefore, undergraduate curricula should focus on the integration of teams in diabetes self-management support.

To enhance self-management support for individuals living with diabetes, nurses must embrace a relational, SBN approach, beginning with their education. They should also learn about the importance of language and MI in chronic illness support within an interprofessional approach which fit well with reconceptualizing self-management as a network approach. Learning these concepts and approaches in undergraduate nursing education provide pathways for continuing education as practices nurses and should form a crucial aspect of continuing education.

**Continuing Nursing Education.** Nurses are the largest group of health care professionals in the Canadian health care system (Canadian Nurses Association, 2013). With the increased incidence and prevalence of diabetes in Canada, it is inevitable that nurses in all areas of health care will encounter and care for individuals living with diabetes. Nurses are in unique positions to mitigate the often complex, physiological, and psychosocial issues of diabetes management. Unfortunately, gaps in diabetes knowledge of practice nurses have been demonstrated since 1989 such that these knowledge deficits are consistent and long-standing (Alotaibi et al., 2016; Griffis et al., 2007; Haugstvedt et al., 2016; Hollis et al., 2014; Modic et al., 2014). Further, nurses' perceived knowledge of diabetes care is often poorly aligned with outcomes on knowledge-based test scores (Alotaibi et al., 2016; Chan & Zang, 2007; Hollis et al., 2014), indicating a lack of awareness of knowledge deficits which can negatively affect patient outcomes.

Despite the existence of knowledge gaps, deficits are not all the same for all nurses and for all diabetes management. As Alotaibi et al. (2017) found, nurses may have knowledge about procedures such as checking blood glucose, however lack knowledge in the meaning of the blood glucose in relation to the personal circumstances of the person. As such, they may not "…be aware of, or may be confused by, the underpinning theory" (p.28). Additionally, Smide & Nygren (2012) acknowledged that nurses working in different areas may have different education needs and thus tailoring education is required and suggest that knowledge gaps can be ameliorated through regular diabetes education.

As a result of these gaps and deficits, strategies to enhance knowledge are urgently needed. Previous education interventions to enhance diabetes knowledge of nurses have had modest outcomes in terms of augmenting knowledge (Manchester, 2008; Singh et al., 2020; Young, 2011). Recently, Zhou et al. (2019) found that long-term regular training was necessary to improve nurses' diabetes knowledge and attitudes. Given the rapid expansion of insulin pumps, updating nurses' knowledge of self-management in the context of pumps is warranted especially changes in relation to appropriate foods, routines, and rules that originated in the context of injections with older insulins.

Similar to the recommendations for undergraduate nursing education, continuing education for all nurses should include the concepts of a relational, SBN approach, the importance of language and MI, as well as the importance of interprofessional teams in providing self-management support.

### *Implications for Policy*

Continuing development of policies specific to nursing in providing diabetes education and management support are warranted so nurses can continue to play an active role in the continued evolution of diabetes care. Advocacy is a key component of nursing's mandate as outlined by the Canadian Nurses Association (2021) The findings from this study indicate that financial issues including insurance coverage for insulin pump and associated diabetes supplies, the transition period between adolescent and adult care, and public health messaging continue to be significantly concerning for individuals living with diabetes. From a network lens, financial issues are key actors in diabetes self-management in that their existence (or lack of) determines agency of other actors. To address these concerns and enhance self-management support, nurses must continue to advocate for change within these policies. For example, in 2017, the Canadian Government proposed changing the Disability Tax Credit to remove diabetes as a qualifying disease. However, in 2019 this legislation was reversed and, instead of the required 14 hours per week to be spent on diabetes activities, this has been reduced to ten hours. The findings of this study indicate the inability to quantify diabetes management practices in terms of hours as these practices are non-stop, every day. It is imperative that nurses continue to advocate for the all-inclusive nature of diabetes, that management is more than biomedicine or quantifiable hours per week. A network approach fosters this advocacy.

In sum, nurses have a social mandate to enhance health equity and as a result requires "…full expression of the voice of the profession, both to advance nursing practice and to unleash the profession's capacity to lead public change and systems transformation" (Duncan et al., 2015). In keeping with a network approach, nurses must continue to promote the importance of the relations between social determinants, diabetes practices and outcomes, and overall health and well-being.

### ***Implications for Practice***

As articulated by Doane & Varcoe (2015), nursing and diabetes self-management support practice is currently situated within an individualistic, decontextualized approach which focuses on individual health care providers caring for individual clients. Nurses may see themselves as individually responsible to ensure appropriate care and thus promote optimal health for their clients or patients. Within the current conceptualization of and nursing support for self-management, measures of success remain overwhelmingly within the biomedical model of disease which potentially creates ethical distress for nurses (Duprez et al., 2020; Morgan et al., 2016). Continued focus on biomedicine as well as organization barriers such as perceived time and financial constraints also creates distress for physicians (Dowell et al., 2018) and dietitians (Siopis et al., 2020) in providing diabetes self-management support.

As with nursing education, nurses in practice must focus on their communication with individuals living with diabetes. Ahola and Groop (2013) suggest that "…openness to dialogue, ability to listen attentively, providing sufficient amount of time for a patient, providing information, and giving rationale for the treatment recommendations" (p.418) are needed to enhance the relationship between the patient and provider. Nurses must also focus on the strengths of individuals living with diabetes. Litterbach et al. (2020) and Ndjaboue et al. (2020) suggest that health care providers must focus on the unique context of the person living with diabetes and a network approach expands the thinking of the unique context to focus on various actors and the relations between them in networks of practices.

Nurses can continue to enhance a network approach in diabetes management through the use of motivational interviewing within a relational inquiry as well as strengths-based approach. To fully accomplish this, nurses need to return to basics and consider nursing values in their provision of diabetes management education and support. Risjord (2010) describes how some abilities necessary to nursing may be invisible to nurses, as nurses are also implicated in socially and discursively constructed normative expectations of ‘good’ diabetes management. A return to constitutive and contextual values is imperative to embrace a network approach in the provision of diabetes management support.

*Constitutive values* are those value-judgments necessary for, or intrinsic to an activity. In an absence of constitutive values, the person is just going through the motions and *contextual values* are not required or necessary for the activity (Risjord, 2010). Nurses must consider the core nursing values which frame diabetes education and support. To practice in a network approach, it is imperative that nurses consider their core values such as providing compassionate care, promoting health and well-being, promoting and respecting informed decision-making, honoring dignity, as well as promoting autonomy and justice (Canadian Nurses Association, 2017). These values fit with a relational, SBN approach which collectively fit within a network approach. Based on these constitutive nursing values, the success of diabetes management does not rest solely on glycemic targets and following recommendations, despite current evidence that ethical issues between meeting glycemic targets and living a life with diabetes still plague nurses (Duprez et al., 2020). To mitigate these ethical conflicts, acknowledging and embracing constitutive nursing values in diabetes self-management education and support is timely. Values such as efficiency, best use of resources, etc., are important in the provision of diabetes management support but are contextual values, not core nursing disciplinary values.

## Limitations

No research is without limitations and this study was no exception. Primarily, I live with diabetes and use an insulin pump and as such, in this research I explored a phenomenon of which I am a part of. This presented unique challenges of over-identification with the participants, not following up in-group jargon and practices, as well as strongly influencing my interpretations in terms of what I 'saw' or did not 'see' in the data. Additionally, I felt challenged to provide a 'good enough' overview of diabetes practices, of which I am so deeply involved. To mitigate this, I engaged in continuous, intense reflexivity and peer review with my supervisor. In addition, I also co-supervised an undergraduate BScN Honors Student (After-Degree) which conceptually and instrumentally assisted my evaluation of how I affected the research and its impact on me. My experiences ultimately framed who I am and how I approached the research topic, design, data generation, as well as analysis. As articulated by Hultin (2019), I was already and remained entangled within the practices I was researching and it both created me, as I created it. Despite my reflexivity and acknowledgement of myself as research instrument, my positionality and experiences remained. My quest was not to change my experiences, but to be clear how they influenced this work. As I moved through the stages of this research and I constantly engaged in reflexivity, I was able to shift my gaze and expand my positionality as an individual who lives with diabetes and uses a pump, to a beginning scholar, addressing the intricacies and problems within current conceptualizations of self-management and person-centered care.

Secondly, focused ethnography (FE) privileges one method of data collection, but is data intensive. I had originally proposed to include several methods of data collection – interviews, focused observations, as well as document and artifact analysis, and the interview would be in a sense, privileged, as I would use that method to identify other avenues for exploration (opportunities for focused observations as well as which documents and artifacts to include in the analysis). All participants were reticent to be observed outside of the interview setting. As a result, there was only one focused observation outside of the interview setting which called into question the legitimacy of focused ethnography as the method. Indeed, how could an ethnographic analysis ever exclude observations? As Cruz and Higginbottom (2013) suggest, FE includes the privileging of one data collection method and in this research, I privileged the interview, with second interviews. I incorporated observations in the interviews, and I included documents and artifacts in the analysis. In doing so, this study was data intensive and as a result, I was able to provide enough rich, thick descriptions of diabetes practices from my 15 participants to inform the analysis and thus answer the research question.

Despite these limitations, this research is unique in blending focused ethnography and critical discourse analysis to explore the phenomenon of diabetes enactment by individuals who use an insulin pump. This was beneficial as I was able to focus on the intricate nature of language and context (Krzyanowski, 2011; McCabe & Holmes, 2014). Through my position of insider-outsider I was able to explore how the participants and I both influenced and were implicated in the continued construction and perpetuation of dominant ideologies and how these ideologies influenced our diabetes practices. Living with diabetes afforded a great opportunity to examine myself as implicated in these constructions and as such, I was able to glean a deeper insight into the enactment of diabetes and the discursively constructed conceptualizations of ‘good’ self-management. This study was also the first to explore diabetes practices through a sociomaterial lens, ultimately decenter the human actor, and thus enable tracing of the flow of agency and power within diabetes practice networks.

## My Research Journey

At the beginning of this research and as a result of my experiences as an individual living with Type 1 diabetes and a nurse, I believed that the biomedical model was inappropriately placed on people with diabetes practices to the exclusion of the psychosocial aspect of living with diabetes. As a result of this study, my understanding of diabetes management and support has expanded. I no longer see polarities, with biomedicine and psychosocial on opposite ends of a spectrum. I now see these as inextricably linked in a network of practices that together are diabetes management. While certainly different knowledges are prioritized differently, depending on context, they all come together in diabetes enactment.

I started this journey excessively critical of the overuse of the biomedical model in diabetes education, care, and support. I was interested in how notions such as control, and good/bad diabetes were perpetuated by society, health care providers and others. I was not prepared for how implicated individuals living with diabetes (the participants and I in this study) were in perpetuating dominant ideologies in diabetes management. As we talked and then as I engaged with the data, the participants and I discursively constructed ourselves as ‘good managers’ framed within our expectations of what good managers should be, based on ideologies of self-responsibility for health. This was not easy for me to learn; that I am both a product and a producer of the very issues influencing my critical lens. However, this learning was integral to my understanding of the socially constructive nature of discourse in the enactment of diabetes and without this sometimes startling and uncomfortable revelation, I would not have learned as much as I did. I have learned about overall research principles, focused ethnography, critical discourse analysis, but quite importantly, I have learned about myself as a researcher and the meaning of ‘researcher as instrument’. I have grown as a researcher, a nurse, and a person living with diabetes and my learnings from this study will stay with me and provide a necessary foundation for my career and I hope to continue to add to a body of management knowledge to assist those who live with diabetes as well as those who support them.

**Conclusion**

> *The alarm clock sounds, and it is 3 am, and you need to check your blood sugar. As you reach for your phone and the meter on the nightstand, you try not to open your eyes. And you are mad; you berate yourself for being so stupid last night to over-treat your blood sugar of 3.1 mmol/L. You were tired, frustrated, and just wanted to go back to bed, so you ate until you felt better – chocolate chip cookies which tasted so good! You glance at the CGM reading on your phone which is 12.4 mmol/L with an arrow indicating that it is trending up. Good grief. You reach for the meter, take out a strip, place it in the meter, take the lancet, prick your finger, and try to bring your finger to the strip. You miss and blood ends up on your bedsheets. Oh, for heaven's sake! Now you must prick your finger again, which you do and are finally able to see the reading on the meter – 13.6 mmol/L. You take a correction bolus and by now you are totally awake but need to go back to sleep as you have to get up at 6:00 am to get ready for work. And you are disappointed. Sigh. As you lie there, you remember that you have an appointment at the Diabetes Clinic this week. Immediately, you hope your HgbA1c value is below the holy grail of 7%; that all your hard work pays off. You have tried so hard to be good these last few months and you want to see good results.*

This story concludes this dissertation and highlights the type, number, and frequency of practices that comprise diabetes enactment by those who use an insulin pump. This enactment can be likened to an iceberg where there is so little of it visible, with the majority below the surface, hidden from view. Individuals living with diabetes who use an insulin pump as well as those who support them, minimize the existence of necessary practices to achieve glycemic targets. More specifically, there is contemporary consideration of contextual influences on diabetes management, however the individual living with diabetes makes choices within these contexts. There is little attention paid to the relations amongst (actors) in networks and while this may not be intentional, comprises hegemonic ways of thinking about 'good' diabetes management.

In my study, I found four themes could comprehensively describe a range of common and unique practices in insulin pump self-management. The Pump is the Way Forward in Management reflects the excited anticipation of obtaining a pump and the bureaucratic and financial requirements to authorise one. It is exciting to dream of a new world in which for all intents and purposes, one is ‘normal’ as the pump mimics the pancreas. Unfortunately, there is a sometimes ‘crushing’ realisation that the pump is simply another management tool. The theme Working Like a Pancreas: Maintaining Homeostasis from the Outside involved the practices of when participants took their initial learnings from when they first obtained a pump and in essence ‘made the pump their own’. Here, they increasingly fit the pump within their own unique contexts. Participants drew on these practices and ensuing knowledge developed in this theme in their accounts of practices in the next theme - The Constancy of Surveillance. Practices here were more global to diabetes in general, however practices and knowledge from the previous two themes were instrumental in fitting the pump within former surveillance practices using injections to create new ones inclusive of the pump and other technology such as CGM. Finally, in the fourth theme, participants recounted their practices in Living in Unpredictable Unpredictability in that while they realized mastery was impossible, they felt it was an imposed expectation as a result of practices with family, friends, other individuals living with diabetes, health care providers, who collectively were all influenced by dominant ideologies of self-responsibilities for health.

Overall, the findings of this research demonstrate the constitutive entanglement of human and non-human actors in diabetes management practices. As a result, the findings augment and enhance other research regarding the complexity of diabetes management and the complex interplay of various factors or moving parts (Rand et al., 2017; Watermeyer et al., 2020). As well, this research adds to the necessity of including and validating psychosocial issues in diabetes self-management support (Jones et al., 2014; Vallis et al., 2016).

Now, in the words of Mol (2002), what is to be done with this focus on the relations of diabetes practices? How does knowledge of *'doing'* diabetes impact self-management and self-management support within current the current philosophy of person-centered care? To continue to enhance diabetes management education and support, a network approach in nursing research, education, policy, and practice, focusing on the intricate, relations between actors and practices is warranted. As health care providers and those living with diabetes, we need to *re-think*, possibly *re-conceptualize,* but most importantly, *re-imagine* the possibilities of focusing on these networks in self-management and self-management support. We must consider - what are the possibilities for person-*inclusive* care instead of person-*centered* care? How do we let go of *centering* the person, yet keep the *importance* of the person in diabetes management practices? How do we decenter individuals and focus on the flow of agency and the relations of actors (of which the individual is one)? To continue this exploration, I suggest that we should always start with this question - where does diabetes exist? It exists in the everyday ***practices,*** not in numbers, foods, pumps, injections, or in a pancreas – but in the messy, entangled relations among them. Let's start with that.

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# Appendix A

## Participant Information Letter and Consent Form

### PARTICIPANT INFORMATION LETTER

**Title of Study:** How do People with Insulin Pumps Enact Diabetes?

**Principal Investigator:** Renee Crossman BN MHS RN, PhD Candidate, Faculty of Nursing, University of Alberta
Email: rcrossma@ualberta.ca
Phone: (709) 597-0994

**Supervisor:** Dr. Jude Spiers, PhD RN, Associate Professor, Faculty of Nursing, University of Alberta
Email: jaspiers@ualberta.ca
Phone: (780) 492 9821

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### Why am I being asked to take part in this research study?

I (Renee) invite you to be in this study because you have Type 1 or Type 2 Diabetes, are over 18 years of age and use an insulin pump. I also invite family members and /or friends that have been identified by participants as important to his/her diabetes management and who wish to take part in interviews and/or observations with the participant. I hope this study will help health care providers better understand how to support people with diabetes.

This letter gives more information about the study to help you to make an informed decision about participating. Before you decide, I will review this information with you. You should ask any questions you want. I will give you a copy of this letter to keep.

### What is the reason for doing the study?

Diabetes is a complex health issue. Much diabetes education and support has focused on the physical actions e.g., control of blood sugars. However, how diabetes impacts daily life is just as important. This study explores how people integrate diabetes into their daily lives.

### What will I be asked to do?

If you agree to be in the study, you can choose to take part in two interviews (and possibly one more) and/or be observed during routine daily activities.

1. **Interviews**

We will decide on a time and place to meet. Interviews may be in person, on the phone, or by Skype. We will talk about your activities in living with an insulin pump. Each interview will take about one hour to one hour and a half each. We will talk about different aspects of life with a pump. You can decide what you would like to discuss or not discuss. I will record these interviews so I can review them later.

2. **Observation**
   If you agree, I will accompany you during your normal daily activities, e.g. shopping or meal preparation. During this time, we will talk about how diabetes is part of these daily habits.

3. **Additional information**
   If you have important kinds of information resources that you use, we can talk about them. If you agree, you can share copies of this information. This information might include clinic guidelines, pamphlets, Internet sites, or personal diaries.

**What are the risks and discomforts?**

There are no known risks in being in this study. It is not possible to know all of the risks that may happen in a study, but I have taken all reasonable safeguards to minimize any known risks to study participants. For example, if you become tired during interviews or observations they can be paused and resumed at a later time and/or date.

**What are the benefits to me?**

There are no direct benefits from this study for you. This study may help health professionals better understand how people with Type 1 or Type 2 Diabetes who use an insulin pumps care for themselves.

**Do I have to take part in the study?**

Being in this study is your choice. If you decide to be in the study, you can change your mind and stop participating at any time. Your participation (or not) will not affect the diabetes care you receive. You do not have to answer any question(s) in the interview that you do not want to answer. You do not have to be observed. You can do just the interview, or just the observation, or both. If you opt out of the study, the information that you have already provided will be kept and used in the study, unless you ask me to not use this. If you do not want your data used in the study, please tell me this within 2 weeks after we have met for an interview and/or observation.

**Will I be paid to be in the research?**

There is no monetary gain for being in this research.

**Will my information be kept private?**

I will collect some data about your age, sex, living arrangements, and type of diabetes as well as type of pump so that I can describe the people in the study as a group. I will do everything I can to make sure this data is kept private. No data that includes your name will be released outside of the office or published. Sometimes, by law, I may have to release your information with your name so I cannot guarantee absolute privacy. However, I will make every legal effort to make sure that your information is kept private. Study data will be stored using a secured drive. Only me, my supervisor, and research team will have access to the data. At the University of Alberta, we keep data stored for a minimum of 5 years after the end of the study. I may use the data I get from this study in future research, but if I do this it will have to be approved by a Research Ethics Board.

**What if I have questions?**

If you have any questions about the research now or later, please contact the primary researcher at (709) 597-0994 or rcrossma@ualberta.ca

The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta, as well as Memorial University of Newfoundland. If you have questions about your rights or how research should be conducted, you can call (780) 492-2615 (Alberta) or (709) 777-6974 (Newfoundland). These offices are independent of the researchers.

UNIVERSITY OF ALBERTA

**Title of Study: How do people with Insulin Pumps Enact Diabetes?**

## CONSENT

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**Principal Investigator(s): Renee Crossman BN MHS RN** **Ph: (709)597-0994**
**Supervisor: Dr. Jude Spiers PhD, RN** **Ph: (780)492-9821**

| | **Yes** | **No** |
|---|---|---|
| Do you understand that you have been asked to be in a research study? | ☐ | ☐ |
| Have you read and received a copy of the attached Information Sheet? | ☐ | ☐ |
| Do you understand the benefits and risks involved in taking part in this research study? | ☐ | ☐ |
| Have you had an opportunity to ask questions and discuss this study? | ☐ | ☐ |
| Do you understand that you are free to leave the study at any time without having to give a reason? | ☐ | ☐ |
| Has the issue of confidentiality been explained to you? | ☐ | ☐ |
| Do you understand who will have access to your study records? | ☐ | ☐ |

Who explained this study to you? ______________________________

**I agree to participate in:**

☐ **YES** ☐ **NO** **Two interviews**
☐ **YES** ☐ **NO** **Observation period**
☐ **YES** ☐ **NO** **Sharing of resource information**

Signature of Project Participant: ___________________________

Printed name: ___________________________

Date: ___________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.
Signature of Investigator or Designee ______________________ Date _______

**THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT**

University of Alberta PRO# 00081587

# Appendix B

## Family/Friend Participant Information Letter and Consent

UNIVERSITY OF ALBERTA

### PARTICIPANT INFORMATION LETTER

**Title of Study:** How do People with Insulin Pumps Enact Diabetes?

**Principal Investigator:** Renee Crossman BN MHS RN, PhD Candidate, Faculty of Nursing, University of Alberta
Email: rcrossma@ualberta.ca
Phone: (709) 597-0994

**Supervisor:** Dr. Jude Spiers, PhD RN, Associate Professor, Faculty of Nursing, University of Alberta
Email: jaspiers@ualberta.ca
Phone: (780) 492 9821

---

**Why am I being asked to take part in this research study?**

I (Renee) invite you to be in this study because your loved one has Type 1 or Type 2 Diabetes, has agreed to participate in this study, and has requested that you participate in the study with him/her. I hope this study will help health care providers better understand how to support people with diabetes.

This letter gives more information about the study to help you to make an informed decision about participating. Before you decide, I will review this information with you. You should ask any questions you want. I will give you a copy of this letter to keep.

**What is the reason for doing the study?**

Diabetes is a complex health issue. Much diabetes education and support has focused on the physical actions e.g., control of blood sugars. However, how diabetes impacts daily life is just as important. This study explores how people integrate diabetes into their daily lives.

**What will I be asked to do?**

If you agree to be in the study with your loved one who has Type 1 or Type 2 Diabetes, you can choose to take part in two interviews (and possibly one more) and/or be observed during routine daily activities.

4. **Interviews**

We will decide on a time and place to meet. Interviews may be in person, on the phone, or by Skype. You, your loved one, and I will talk about activities in living with an insulin pump. Each interview will take about one hour to one hour and a half each. We will talk about different aspects of life with a pump. You can decide what you would like to discuss or not discuss. I will record these interviews so I can review them later.

5. **Observation**
   If you agree, I will accompany you and your loved one during your normal daily activities, e.g. shopping or meal preparation. During this time, we will talk about how diabetes is part of these daily habits.

6. **Additional information**
   If you have important kinds of information resources that you and/or your loved one use to help manage diabetes, we can talk about them. If you agree, you can share copies of this information. This information might include clinic guidelines, pamphlets, Internet sites, or personal diaries.

**What are the risks and discomforts?**

There are no known risks in being in this study. It is not possible to know all of the risks that may happen in a study, but I have taken all reasonable safeguards to minimize any known risks to study participants. For example, if you become tired during interviews or observations they can be paused and resumed at a later time and/or date. Additionally, being part of the study with your loved one may involve that you will find out things about your loved one's diabetes that you did not know before. Your loved one may find out things about how you feel towards their diabetes that they did not know before. This may be uncomfortable for you and/or your loved one. To minimize this risk, you and your loved one will be made aware of this on several occasions prior to being involved in the study verbally and in writing. If you do become uncomfortable, the interview or observation will be paused and resumed at a later date, or stopped altogether, whatever your preference is.

**What are the benefits to me?**

There are no direct benefits from this study for you. This study may help health professionals better understand how people with Type 1 or Type 2 Diabetes who use an insulin pumps care for themselves.

**Do I have to take part in the study?**

Being in this study is your choice. If you decide to be in the study, you can change your mind and stop participating at any time. Your participation (or not) will not affect the diabetes care your loved one receives. You do not have to answer any question(s) in the interview that you do not want to answer. You do not have to be observed. You can do just the interview, or just the observation, or both. If you opt out of the study, the information that you have already provided will be kept and used in the study, unless you ask me to not use this. If you do not want your data used in the study, please tell me this within 2 weeks after we have met for an interview and/or observation.

**Will I be paid to be in the research?**

There is no monetary gain for being in this research.

**Will my information be kept private?**

I will collect some data about your age, sex, and living arrangements so that I can describe the people in the study as a group. I will do everything I can to make sure this data is kept private. No data that includes your name will be released outside of the office or published. Sometimes, by law, I may have to release your information with your name so I cannot guarantee absolute privacy. However, I will make every legal effort to make sure that your information is kept private. Study data will be stored using a secured drive. Only my supervisor, research team members, and I will have access to the data. At the University of Alberta, we keep data stored for a minimum of 5 years after the end of the study. I may use the data I get from this study in future research, but if I do this it will have to be approved by a Research Ethics Board.

**What if I have questions?**

If you have any questions about the research now or later, please contact the primary researcher at (709) 597-0994 or rcrossma@ualberta.ca

You can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through: Research Ethics Office 709-777-6974 or email at info@hrea.ca. You can also contact the University of Alberta Research Ethics Office at 780-492-2615.

UNIVERSITY OF ALBERTA

**Title of Study: How do people with Insulin Pumps Enact Diabetes?**

**CONSENT**

**Principal Investigator(s): Renee Crossman BN MHS RN** **Ph: (709)597-0994**
**Supervisor: Dr. Jude Spiers PhD, RN** **Ph: (780)492-9821**

| | **Yes** | **No** |
|---|---|---|
| Do you understand that you have been asked to be in a research study? | ☐ | ☐ |
| Have you read and received a copy of the attached Information Sheet? | ☐ | ☐ |
| Do you understand the benefits and risks involved in taking part in this research study? | ☐ | ☐ |
| Have you had an opportunity to ask questions and discuss this study? | ☐ | ☐ |
| Do you understand that you are free to leave the study at any time without having to give a reason? | ☐ | ☐ |
| Has the issue of confidentiality been explained to you? | ☐ | ☐ |
| Do you understand who will have access to your study records? | ☐ | ☐ |

Who explained this study to you? ______________________________

**If requested by my loved one who has agreed to participate in this study, I agree to participate along with him/her in:**

| | | |
|---|---|---|
| ☐ **YES** | ☐ **NO** | **Two – three interviews** |
| ☐ **YES** | ☐ **NO** | **Observation period** |
| ☐ **YES** | ☐ **NO** | **Sharing of resource information** |

Signature of Project Participant: ___________________________

Printed name: ___________________________

Date: ___________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.
Signature of Investigator or Designee ______________________ Date ________

# Appendix C

# Ethics Certificates

# Notification of Approval

| | |
|---|---|
| Date: | May 18, 2018 |
| Study ID: | Pro00081587 |
| Principal Investigator: | Renee Crossman |
| Study Supervisor: | Judith Spiers |
| Study Title: | How do People with Insulin Pumps Enact Diabetes? |
| Approval Expiry Date: | Friday, May 17, 2019 |

Approved Consent Form:

| Approval Date | Approved Document |
|---|---|
| 5/18/2018 | Informed Consent Form |
| 5/18/2018 | Participant Information Letter |

Sponsor/Funding Agency:

| | |
|---|---|
| Canadian Nurses Foundation | 5157 |

Thank you for submitting the above study to the Research Ethics Board 1. Your application has been reviewed and approved on behalf of the committee.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Sincerely,

Anne Malena, PhD
Chair, Research Ethics Board 1

**Ethics Office**
**Suite 200, Eastern Trust Building**
**95 Bonaventure Avenue**
**St. John's, NL**
**A1B 2X5**

July 23, 2018

Dear Ms. Crossman:

**Researcher Portal File # 20190352**
**Reference # 2018.113**

**RE: "How do People with Insulin Pumps Enact Diabetes? "**

Your application was reviewed by the Health Research Ethics Board (HREB) at the meeting held on July 19, 2018 and **ethics approval** of this research study has been granted for one year effective July 19, 2018.

While this has been granted full approval, the Board suggested that the PI reconsider the language associated with "doing diabetes" as it may be confusing to some participants. Additionally, question #3 in the secondary interview document may need to be reworded as the phrasing "What do you call when your sugars are not on target?" is not entirely clear.

**This is your ethics approval only. Organizational approval may also be required**. It is your responsibility to seek the necessary organizational approval from the Regional Health Authority (RHA) or other organization as appropriate. You can refer to the HREA website for further guidance on organizational approvals.

This is to confirm that the HREB reviewed and approved or acknowledged the following documents (as indicated):

- Application, approved
- Research proposal, approved
- Email from Diabetes Canada Office (Recruitment Posters), approved
- Verbal Permission for Recruitment Posters, approved
- Introductory Script with Participants (Informed Consent Process), approved
- Introductory Email (after initial contact), approved
- Script for Participants, approved
- Participant consent form, approved
- Participant information letter, approved

# Appendix D

## Interview Protocol

Primary and secondary interviews will be sought with study participants. Questions in the first interview will be to explore daily self-management practices. Based on data from the first interview, observations, and any artifact review and analysis, secondary interview questions will be developed to explore normative assumptions and practices related to diabetes self-management.

### Primary Interview

1. Please tell me about when you were diagnosed with diabetes?
2. Please describe a usual/typical day with your diabetes? What do you strive for?
3. What are the tools, technologies, and any other resources do you utilize daily with your diabetes?
4. How do you know what to do?
5. How has life changed since you moved from injections to your insulin pump?
6. What influences decisions you make regarding your diabetes?
7. How are you independent with your diabetes? How are you dependent?

### Secondary Interview

1. Are there suggestions or recommendations from your health care provider/diabetes clinic/resources that you feel are not a good fit for you? How do you manage this?
2. How do you and your health care provider come to a mutual agreement about your diabetes?
3. What do you call when your sugars are not on target? How would you describe what you do when you are outside of your target blood sugar range? How do you think others would describe this – your health care provider, family, friends, etc.
4. How have you tailored recommendations and instructions you have received to fit with your life?
5. How do you know what to do when you are ill or have low or high blood sugars? Where did you learn this information? Please describe a situation or situations where you have dealt with high or low blood sugars and how you solved problems and made decisions in these situations.

# Appendix E

## Ms. J. Gonzalez N499 Final Report Abstract

Individuals' experiences living with diabetes continually change, and how they feel about their diabetes evolves throughout their lives. The purpose of this focused analysis research project was to explore how individuals who live with diabetes and who manage with an insulin pump use language practices to describe their experiences with diabetes, their self-identity, and threats to self-identity. The data set consisted of 30 interviews from 15 participants in Newfoundland and Labrador. I employed inductive content analysis to identify essential language practices, implied meaning in the conversation, intended audiences, and conversational consequences in the interviews. Understanding how people with diabetes express their experience provides insight into how individuals perceive their self-management practices and their self-identity with diabetes in different contexts. This, in turn, may aid nurses to identify language indicators that need to be followed up in conversation to illuminate the challenges and stigma people may face in living with their diabetes.