

## TYPE 1 DIABETES IN OLDER ADULTHOOD

TYPE 1 DIABETES IN OLDER ADULTHOOD:  
RELATIONSHIPS WITH TECHNOLOGICAL TREATMENTS

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## ABSTRACT

The increased recognition of chronic disease (CD) has been accompanied by an era of medical technology, intended to better treat and manage CDs such as type 1 diabetes. Since the discovery of insulin in 1921, the treatment and management of type 1 diabetes has significantly improved, and witnessed innovations such as the insulin pump. Yet, as the population ages within a technological society, the implications of advancements in diabetes care and its relationship with older adults is of great concern. How do older adults identify and make use of these new technologies? How do technological advances challenge traditional life course models or expected transitions of growing old? How do older adults continue to cope and manage with a CD in their advanced years? The objective of this study was to explore how older adults with type 1 diabetes relate to management devices used in their daily routines. Five open-ended and semi-structured interviews were conducted with older adults living with type 1 diabetes (recruited through the Canadian Diabetes Association [CDA] and the Hamilton Health Sciences [HHS] Diabetes Care and Research Program [DCRP], Hamilton, Ontario). Interviews were transcribed and analyzed drawing on analytic techniques of grounded theory. Open, axial and selective coding was used in accordance to the constant comparative approach. Themes included living longer with type 1 diabetes, how type 1 diabetes challenges traditional models of aging and the lifecourse perspective, and older adults welcoming the use of technology. Overall findings suggested technology used for the daily treatment and management of type 1 diabetes may permit increases in one's quality of life (QOL), yet challenge policies and practices within healthcare settings to ensure older adults maintain independent self-management strategies.

Keywords: aging, chronic disease, technology, treatment, type 1 diabetes, older adult, diabetes community

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## **DEDICATION**

I would like to dedicate this paper to all of my T1D connections, as well as the diabetes community more broadly. Thank you for your support and understanding.

May we continue to join hands in support of diabetes research and a cure for this life-altering disease.

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## **LIST OF ALL ABBREVIATIONS AND SYMBOLS**

ADL	Activities of Daily Living
ADP	Assisted Devices Program
ANT	Actor-Network Theory
CCTN	Canadian Clinical Trial Network
CD	Chronic Disease
CDA	Canadian Diabetes Association
CDS	Canadian Diabetes Strategy
COMH	Compression of Morbidity Hypothesis
DCRP	Diabetes Care and Research Program
DfA	Design for All
DKA	Diabetic Ketoacidosis
EOMH	Expansion of Morbidity Hypothesis
HHS	Hamilton Health Sciences
IADL	Instrumental Activities of Daily Living
IDF	International Diabetes Federation
IT	Information Technology
JDRF	Juvenile Diabetes Research Foundation
LTC	Long-Term Care
NCD	Noncommunicable Diseases
QOL	Quality of Life
SCOT	Social Construction of Technology

STS	Science and Technology Studies
STU	St. Thomas University
WHO	World Health Organization

## **CHAPTER ONE: INTRODUCTION**

### **The Foundation: Statement and Direction of Current Research**

This research project is designed to explore the gaps within three broad areas of intersecting literature: gerontology, technology, and type 1 diabetes. The idea for the proposed research topic stemmed from my educational background in gerontology coupled with my personal experience of living with type 1 diabetes. While completing my Bachelor of Arts Degree in Gerontology, and sifting through various academic books, journal articles, and organizational reports, I noted that the literature neglects to mention the presence of type 1 diabetes in older adulthood. Although type 2 diabetes - a similar chronic disease (CD) - is largely associated with older adults, type 1 diabetes is not. Perhaps this neglect is due to traditional understandings of the two distinct diseases, where type 1 diabetes and type 2 diabetes were commonly diagnosed among children and adults respectively. However, with the rising sociological uptake of technology - especially for medical purposes – people with type 1 diabetes are living longer. This disconnect led me to develop the following research question and objectives for the proposed study.

#### **Research question**

- How do older adults with type 1 diabetes relate to advancements in technological treatments?

#### **Objectives**

1. Explore the experience of aging with a CD (type 1 diabetes);

2. Describe the function of technology used for daily treatment and management of type 1 diabetes;
3. Understand that older adults with type 1 diabetes use technology for daily treatment and management of the disease

The need for research to understand the relationship between older adults, type 1 diabetes and technology is pertinent as the international population is aging and life expectancy is increasing (Crimmins, 2004; Fries, 1980; Laditka & Laditka, 2000; Michel & Robine, 2004; Olshansky, Rudberg, Carnes, Cassel, & Brody, 1991). The number of older adults worldwide is expected to increase from 524 million to approximately 1.5 billion in 2010 and 2050 respectively, which is largely due to the impact of the Baby Boomers (World Health Organization [WHO] & US National Institute of Aging, 2011; Knickman & Snell, 2002). There is no doubt older adults (not just baby boomers) will influence population aging, outnumbering children under the age of five for the first time in recorded history (WHO & US National Institute of Aging, 2011). In fact, it is projected that in 2030 there will be 61 million older adults in the U.S. within the “young old” age category (66-84 years old) (Knickman & Snell, 2002, p. 850). Therefore, as the population ages, the likelihood of older adults living with type 1 diabetes is also likely to increase. This research project aims to shed light on the experiences of older adults living with type 1 diabetes and their relationship with technology used for daily treatment and management of the disease.

This paper begins with an elaboration of the journey leading up to the development of the research problem. From there, I frame my research study in the

lifecourse perspective to gain an historical understanding of type 1 diabetes. Using the lifecourse perspective, leads me to provide an overview of relevant developments in the field of diabetes, more specifically type 1 diabetes. Once an understanding of the disease is complete, I review existing literatures in the fields of gerontology, technology and type 1 diabetes to highlight the limitations, which provide support for the project at hand.

Once the research question and objectives are clear, I elaborate on the methodology used to conduct this study and explain the data collection and analysis phases. Findings will be discussed together through three corresponding themes and subthemes as they relate to current literatures. This paper will finish with the discussion of the limitations, conclusions and future directions for research.

### **Development of a Research Question – A Personal Journey**

This research project is rooted in my personal history, and can be traced back approximately six years ago to my seventeen year-old self. I was in my senior year at Fredericton High School and getting used to the idea that I would be graduating in a few short months. I was consumed with projects and essays as I was nearing the end of the fall semester. All of my hard work was translating into emotional and physical strain. I was suffering from exhaustion, and was constantly craving sugary treats. I was extremely thirsty and drinking water to the point of visiting the washroom every 30 minutes. The scariest part was my severe weight and hair loss; I was down 20 pounds in less than four weeks despite continuing my normal routine.

I had been meeting with my family physician for roughly two months but my situation was not improving. He gave me antibiotics for an infection, but it did not clear

up. He could not seem to explain the weight loss, thirst, or even my fatigue. I informed my mother about every development throughout this lengthy process, as she is a nurse. I was hoping maybe she could provide me with some sort of explanation for my symptoms. One evening, while making the trek to the kitchen for yet another snack, I happened upon a pamphlet, which was lying on the counter. My dad, who had just finished his neighborhood canvassing for the Canadian Diabetes Association (CDA), as part of their November Diabetes Awareness Campaign, had left behind one of his brochures. After perusing, I found myself reading a section, which listed the warning signs and symptoms of diabetes. As I was reading them, I noticed that the list contained every single one of my recent bodily changes. Finding the situation a bit peculiar, I mentioned it to my mom who was in the other room. She thought it was strange as well but did not make anything of it. She just simply suggested I wait until my next appointment with the doctor.

Unbeknownst to me, my life would drastically change on the dark grey, and overcast, Monday November 20, 2006 when I finally took matters into my own hands. I revisited the doctor once more and explained that my physical conditions were not improving and that I was quite frustrated. He still was not sure what to do so he said he would schedule some blood work for the following day at the local hospital. Accompanying me on this visit and quite impatient with the doctor's lack of concern, my mother asked him if he could check my blood sugar. He said his office was not equipped with a glucometer but that he could test my urine. My mom was shocked and appalled at his absent use of necessary technology and the use of seemingly archaic form of testing blood glucose. Once I handed off my sample, I heard the nurse call my doctor by name in



a panicked voice. The doctor seemed concerned and returned to tell me I needed to go to the emergency room that evening; the blood tests could not wait any longer. The urine test strip came back showing exceedingly high levels of sugar and protein. This would later be described as a state of diabetic ketoacidosis (DKA).

I remember leaving the doctor's office with my mom thinking we were headed straight to the hospital. However, she told me she wanted to go home first so we could grab a bite to eat and wait for my dad to get home from work so he could accompany us. As we headed home, my mom tried to warn me that there was a small chance I could have diabetes. "Diabetes?" I said. I had no clue what that was. I mean, I had heard the term before and knew it was some sort of disease but was not entirely sure what the word meant. She quickly changed the subject before arriving home, where she strongly encouraged me to pack some clothes in case I had to stay overnight. I did not quite understand why I would have to stay overnight but she just told me that the emergency room wait might be lengthy.

Upon arrival at the hospital, I had all of my vitals checked, including my blood glucose level, which was off the chart at 30 mmol/L. A bit confused and not sure what that meant, I turned and asked my mom what a normal reading should be. "Usually between four and seven," was her response. With a relatively calm composure, my mom tried to prepare me for the news I would soon receive. About an hour after the blood work and tests were completed (although it seemed like a lifetime) this tall man wearing dull green scrubs and a white lab coat politely told me there were high odds I had diabetes. He said they hadn't quite finished the blood work but it seemed likely, so he proceeded to

explain to me four different types of diabetes. He told me that there was a type I would have for the rest of my life, which would require me to take insulin injections; he was referring to type 1 diabetes and said it could be one possibility. He said there was another type overweight people get, referring to type 2 diabetes, but we both knew I did not fit that category. He explained the third type, gestational diabetes, sometimes occurs in pregnant women but again I did not fit that description. Lastly, he explained that there was a rare form of diabetes some people get when faced with extreme stress, and it is extinguished once the body is no longer stressed or anxious. He told me this type of diabetes diagnosis would be temporary. Reflecting on the previous two months, and the description I told the doctor about my busy school schedule, I thought for sure this would be it. I was pretty excited to think I could be leaving the hospital soon!

Unfortunately, the emergency room doctor returned a while later to deliver my fate. He apologized for being the bearer of bad news, but he told me I had type 1 diabetes and I would be put on insulin immediately. Even though I was listening to this strange doctor man, I was not quite sure what all of his words meant. I knew I was attached to beeping machines that were pumping me full of fluids but I could not fathom what it meant for my future. I was completely lost in the present; I was frozen in time while my life was a blur that continued spinning around me. By the time I finally got a room (on the maternity ward) it was almost midnight. Dad went home, but mom stayed with me. I had nurses injecting insulin into my arm every so often, but they never really told me what they were doing. I knew they were pricking my finger and testing my blood sugar hourly, even while I tried to sleep.

The next day started off with a visit from my family physician. He was in the hospital that day doing his rounds so he stopped in. He was still in shock to learn about my diagnosis and told me he could not believe it since I had not vomited nor had I not passed out on the floor. He still could not believe that he did not diagnose me himself. It was uncomfortable, but eventually he left. As the day went on I felt bad missing school and was bored out of my mind because I did not have cable television hooked up in my room yet! I eventually called some friends to tell them the news and why I was not at school. I even had a visit from my brother and his girlfriend at the end of the day. It was a little weird being the sick kid for once. I remember he gave me a hug when he walked in and I lost it; I just started bawling in his arms because I felt so lonely, confused, and isolated. I had no idea what was going on. I didn't want to be sick. I was a healthy kid!

The third day rolled around and I was told I would be seeing a dietitian and an endocrinologist. The dietitian was actually a nurse educator who worked at the local diabetes education centre. She talked to me a little bit about carbohydrates, gave me some brochures to read and told me I would see her next week. She was spewing off facts, terms, and new daily routines that I didn't understand. Next, the endocrinologist came in. I was not sure what an endocrinologist was but I was told she specialized in diabetes. She told me she was going to teach me how to give myself an insulin shot, and I would have to give it to myself in the abdomen. I just froze. All I could think of was that my life would now be paralleled with that of a drug addict, shooting up in my abdomen everyday. The idea seemed so bizarre and honestly, I felt so uncomfortable just thinking about it. She told me that the nurses in the hospital give the insulin injections in the arm because

it's less invasive for the patient. She also talked about common injection sites like the arms, upper thighs or buttocks but that insulin is ultimately absorbed 80% faster in the abdomen.

In preparation for the first injection, she told me she wanted me to do all of the work since I would be in control from now on. She showed me how this pen-like, insulin thing worked as she pretended to follow through on herself. Then, she told me to roll up my shirt, pinch my abdominal skin and inject the needle at a 90° angle. I held the pen but I hesitated for at least a good 10 seconds. “I mean, okay, I had just watched her do it, how bad could it be? Who am I kidding, of course it could be bad – it's my stomach!” I thought. I followed through and it was weird; I felt a little poke and a pinch but it wasn't too bad. Eventually she left and told me I would see her next week at the clinic too. Soon after, awaiting the delivery of yet another disgusting hospital supper, my mom told me I had some more visitors. Four of my friends had come to see me, bringing me a giant helium balloon and a stuffed turtle they created at the Build-A-Bear-Workshop store in the mall. I went for a walk with them, but found myself back in my room a little while later. After staying with me for two nights, Mom told me she was going home to get some sleep. She asked if I was okay alone. Of course I said yes, but inside I was screaming, “No, please don't leave me!” I guess I made it through the night.

I woke up to what I thought would be my third full day in the hospital. It was Thursday morning and my mom had just walked in. It was perfect timing considering I was told I would be going home that day. I was unbelievably excited. I felt bad to be leaving because my Nana had called the night before and said she was going to come visit

me. But who was I kidding – I wanted to get the heck out of that place! I got up and had a shower, and started to pack my things when my Nana arrived. She brought me a few little goodies and a pair of red striped socks with Santa faces on them. After all, Christmas was within one month! I said thank you but told her we couldn't visit long because I was going home.

As I walked out to the car with my mom, Nana, and my new bag of drugs and diabetes supplies, I was still confused. I was sent home and encouraged to take matters into my own hands. But how? How was I supposed to eat or take my shots? I didn't remember anything those ladies told me. It went in one ear and out the other. I was panicking, but my mom calmed me down. Thank God she had been beside me in those sessions absorbing all of the information so she could teach me again once reality had set in. I really was not too sure how to feel or what to expect. I was reassured that I could live a normal life soon enough, just as long as I check my blood sugar before eating, count the carbohydrates in every meal and then take insulin accordingly. I was also told that the best way to start carb counting was to measure my food. The process seemed daunting and was rather annoying but I caught on fast. I knew I had to follow these steps if I wanted to be healthy and to survive.

Since that cold and lonely November day I graduated from high school, then moved onto St. Thomas University (STU) with the goal of completing my Bachelor of Arts Degree. I continued to take good care of my health despite all of life's obstacles. I realized that acknowledging and accepting my disease would bring me the happiness and normalcy I so badly craved. In my spare time I got involved with the Juvenile Diabetes

Research Foundation (JDRF) volunteering and raising upwards of five thousand dollars for the local community walk. I became a type 1 diabetes advocate and was asked to be an ambassador for the following year.

It was not until my second year at STU that I decided to take a gerontology course, unsure of its content. I fell in love with the idea of studying aging and the process of growing old. Reading about CD and its relationship with aging confused me. Despite my searches I could not find any information in my textbooks that discussed older adults with type 1 diabetes, even though there was a plethora of material on the detrimental effects of type 2 diabetes. My quest for answers continued even well beyond my undergraduate education.

At 22 years of age I was just beginning my Master of Arts Degree in the Department of Health, Aging and Society at McMaster University. When I finalized my decision to pursue the two-year thesis option, I knew I wanted to study the relationship and connections between type 1 diabetes and older adulthood. Considering I had recently started on the insulin pump, one of the most advanced forms of treatment for type 1 diabetes, I confirmed my research question: How do older adults with type 1 diabetes relate to technological advancements in treatment? Although it might be rooted in a personal interest, this research idea was conceived when I began questioning how I would experience the aging process and older adulthood while living with a CD. I wanted to know exactly what was in store for my future. I wanted to know how other people like me lived with a CD into old age. Combining my personal interest of type 1 diabetes and my

educational interest of aging to better understand how adults age with a CD, challenges current boundaries in aging, diabetes and CD literature.

## **CHAPTER TWO: THEORETICAL PERSPECTIVE**

The lifecourse perspective is the most useful lens to frame this research project. Lifecourse is a theoretical perspective that broadly refers to human development over one's lifespan, from birth to death. "The life course refers to pathways through the age-differentiated life span, to social patterns in the timing, duration, spacing and order of events; the timing of an event may be as consequential for life experience as whether the event occurs and the degree or type of change" (Hareven, 1978, p. 21). It is a sequential intersection of life events (i.e. social, cultural, economical, historical) (Dannefer & Uhlenberg, 1999; Elder, 1998; Hareven, 1978; Hareven & Adams, 1982; Uhlenberg, 1978). Lifecourse analysis is best known by Elder and colleagues Hareven, Adams, and Uhlenberg as an historical review of one's life, while understanding that events from earlier stages influence decisions made later in life. This holistic approach to understanding aging conceptualizes life experiences as a series of cumulative life course events (e.g. trajectories) necessary to make sense of an older adult's experiences and meanings.

The lifecourse theory was born in the mid 1960s as a conceptual framework to understand development in late life (Elder, 1998). Elder's (1998) interests were concentrated on human behaviour and personal direction and their relationship with social change. Questioning aspects of child development studies, Elder (1998) noted history was a crucial component to development, yet the relationship was unclear. Elder (1998) realized children of the same historical time period and cohort had the possibility to lead



completely different lives and experience varied ranges of development, with no true pattern.

Elder (1998) understood lifecourse development as an individual experience and hence developed four different principles of his lifecourse theory. The first principle is the importance of *time and place*, noting individual lifecourses are molded by the combination of the historical time and place in which one lives. The second principle of *time* suggests the timing and order of life transitions or events impacts an individual's development. Thirdly, the principle of *linked lives* supports connections between interdependent lives as well as social and historical components in such a way as to create a “network of shared relationships” (Elder, 1998, p. 4; Grenier, 2012). Lastly, the principle of *human agency* strives on independence and believes individuals build their own life course as a result of their personal choices and actions.

Hareven and Adams (1982) expand on Elder's principles of the life course perspective when stating that timing, interaction and integration are three main features of the perspective. Timing refers to the organization of personal events or roles, while interaction refers to the connection between the individual and his or her place within a historical context (Dannefer & Uhlenberg, 1999; Hareven & Adams, 1982). Lastly, integration is the impact of earlier life events, roles or transitions on following ones; this is a cumulative perspective (Dannefer & Uhlenberg, 1999; Hareven & Adams, 1982).

The lifecourse perspective is based on the concepts of fluidity and change as transitions and trajectories are important features. Since this theory focuses on one's life as a whole, transitions - periods and stages of change overtime - are highlighted (Elder,

1998; Grenier, 2012; Hareven, 1978; Hareven & Adams, 1982). “Transitions are considered to represent anchor points to observe social changes such as family type, timing of transitions and duration of roles, and to understand the impact these changes have on personal lives and subjective states” (Grenier, 2012, p. 32). Trajectories, on the other hand, are more broad periods of change, which may incorporate several transition stages (Elder, 1998; Grenier, 2012). Trajectories tend to encapsulate an overall theme or direction within one’s lifecourse, often associated with ideas of pathways, which are dependent on both past and present events (transitions) (Elder, 1998; Grenier, 2012). For example the beginning of retirement would be a transition, while post-retirement would be a trajectory (Elder, 1998; Grenier, 2012; Hareven, 1978; Hareven & Adams, 1982).

The lifecourse perspective seems to be the best lens for understanding the experiences older adults with type 1 diabetes have as they age, especially in regards to their relationships with technology. Much of current gerontology research and literature is focused on more optimistic theories of aging, such as that of *successful aging*. *Successful aging* proposes that in order for one to experience aging in a positive manner, one must continue to be actively involved, aware and accepting of changes in all aspects of their lives: social, psychological, physical, biological (Schroots, 1996). Other theories such as the *activity theory* and *gerotranscendence* also stem from more affirmative and encouraging points of view (Schroots, 1996). The lifecourse perspective is much more broad and less restricting as it does not define one’s aging process based on a template. It does not determine an individuals’ worth by their capability to achieve, rather it makes sense of one’s life through specific decisions and chosen pathways.

Situating my current research project within the lifecourse perspective is pertinent, as a diagnosis of type 1 diabetes is a lifecourse transition that may have a severe, sometimes traumatic impact on one's life and influence their life trajectory with respect to disease treatment and self-management (Berlin, Sass, Davies, & Hains, 2002; Canadian Diabetes Association [CDA], 2008; Davison, 2003; Egede & Ellis, 2010; Goldman & MacLean, 1998). Not only does the example of diabetes fit nicely in a lifecourse approach, but it also challenges typical age-based stages or trajectories often associated with aging (see Grenier, 2012).

### **CHAPTER THREE: HISTORICAL DEVELOPMENT OF DIABETES**

This chapter will explore the historical developments of type 1 diabetes and how society came to understand, classify and treat the disease. This section will review the most salient classifications of type 1 diabetes while a more detailed account is provided in Appendix A. It will also describe the progression from original methods of type 1 diabetes treatment and management to current technology used for the daily care regimens of people with type 1 diabetes. Providing a detailed overview of the history of type 1 diabetes will aid in the comprehension of important terms and references, which may be used throughout this research study and will be necessary for understanding the social experiences of participants.

#### **Conception and Classification of the Disease**

Diabetes is a CD with a lengthy history, and an even more confusing pathology. Despite multiple understandings, the earliest descriptions and recollections of the disease date back to the Middle Ages where authors writing about the disease often described symptoms of excessive urination, thirst and wasting (Purdy, 1890); more specifically, the honey-like taste, the stickiness and the ability for the urine to attract insects were noted by Sushruta, an explorer of Ayurvedic medicine (as cited in Witters, Luciano, Williams, & Yang, 2008). *Polyuria*, a term to describe the act of excessive urination was also very commonly used during this time (Witters et al., 2008, p. 37). Sushruta also made note of the fact that this disease seemed to occur in either young children (who died promptly following diagnosis) or older, obese individuals (Witters et al., 2008). This distinction would prove to be crucial in the years to come.

The primary use of the term diabetes is also debatable. It is said that Demetrius referred to polyuria as diabetes, which is a Latin word with Greek origins meaning “a passer-through, a siphon” (Witters et al., 2008, p. 38). Although the stories may differ, the fact of the matter is that by the first century A.D. there was an understanding of term diabetes and it undoubtedly hailed from Greek origins (Bliss, 2007). The Greeks understood this disease and its excessive urination “to run through” (p. 468), and believed it to be a process in which one’s body could not use food properly (Rock, 2005). Instead of transforming nutrients into energy or fuel, the body would neglect to absorb the food, causing the body to break down and spill out into the urine, leaving a distinctive odor (Rock, 2005).

By the mid 1600s, diabetes became known as diabetes mellitus. The addition of the second word, the Latin term for honey, came when Thomas Willis, an English physician, rediscovered the ancient Greek’s discovery of the sweet smell and taste of the urine, which was present in most patients who were thought to have diabetes. Willis discovered this after sampling one of his patients’ excretions (Bliss, 2007; Purdy, 1890; Rock, 2005; Witters et al., 2008). Diabetes mellitus is the modern form of diabetes as we know it, but often times the second half of the name is dropped (Rock, 2005).

More specifically, the 1800s noticed a specific pattern in patient orientation. By 1875 it was determined that diabetes often presented itself in two fashions: in young children or in older adults (Rock, 2005). For young children, it seemed as though the onset was acute, the disease was more prominent (severe weight loss) and death typically followed shortly thereafter. However, in older adults, the onset was much slower, their

bodies were usually overweight yet they lived much longer (Rock, 2005). At this time, diabetes was still classified as a single disease, but noted that it had much harsher impacts on its younger victims (Rock, 2005).

At the turn of the century, the presence and prevalence of diabetes seemed to be most prominent amongst people who were wealthy and well nourished (Bliss, 2007). The geography of diabetes was commonly spotted in countries such as the U.S. or Germany as they were considered richer countries, and with a specific trend of the disease among Jewish people (Bliss, 2007). This understanding and presence of the disease led to a connection between diabetes and insurance. Urine tests were instituted as a common, routine procedure not only for those admitted to the hospital but also for individuals applying for life insurance (Bliss, 2007).

Around the same time period, in 1901, Eugene Opie, a student at John Hopkins University, determined a specific connection between the islets of Langerhans – floating cells within the pancreas that destroy its function - and diabetes (as cited in Bliss, 2007; Karamitsos, 2011; Pompei, 2006). This development confirmed Paul Langerhans' 1869 hypothesis that the pancreas produced an alternate secretion. Opie believed that if such secretion could be further understood through isolation it might solve the mystery of diabetes (as cited in Bliss, 2007). One year later in 1902 the term *hormone* (p. 27) was coined to describe specific chemical messengers, like adrenalin, which contribute to the control and flow of pancreatic juices (as cited in Bliss, 2007). It was at this time that the entire endocrine system was taken into consideration and understood as a vital part of the body and its functions especially for patients with diabetes. The endocrine system became

just as important as the nervous system (Bliss, 2007). By 1913, Frederick Madison Allen had published the journal article, *Studies Concerning Glycosuria and Diabetes* (p. 34), in which he highlighted that people with type 1 diabetes were sensitive to fats and proteins, in addition to carbohydrates (Bliss, 2007).

After Banting and Best's discovery of insulin in 1921, the first human insulin injections in the early 1920s once again led researchers to a new classification of diabetes (Rock, 2005). Although it was known the severity of the disease decreased with age, the importance of such information was never explored until the discovery of insulin. It was at such time that researchers, doctors and scientists noted younger patients produced little to no insulin while the older patients still produced the hormone but at various degrees – their bodies could not use insulin effectively. This led to the changing of definitions and diagnostic criteria for the disease.

In the 1950s diabetes mellitus was classified and categorized into type 1 diabetes and type 2 diabetes. More specifically, in 1959 type 1 diabetes was referred to as insulin-dependent and type 2 diabetes as non-insulin dependent (Canadian Diabetes Association [CDA], 2012; Rock, 2005). This distinction led specialists to the 1970s understanding of juvenile or type 1 diabetes as an autoimmune disease in which the patient's body attacks the pancreatic insulin-producing (beta) cells (Rock, 2005). Type 1 diabetes has similar repercussions as type 2 diabetes yet the cause is unknown (Egede & Ellis, 2010). Such discoveries finally created the pathway for an international diagnosis classification of diabetes by the WHO in 1980 (as cited in Rock, 2005).

This historical compilation of stories and facts in combination with the WHO's international definition released in the 1980s truly created the foundation which houses the most recent understandings of diabetes. After the unveiling of the WHO definitions the face of type 1 diabetes drastically changed. Type 1 diabetes became understood as an autoimmune disease in which the patient must take insulin injections simply to survive (Egede & Ellis, 2010; Juvenile Diabetes Research Foundation [JDRF], 2011; Juvenile Diabetes Research Foundation [JDRF] Canada, 2011). Genetics, acute diseases and environmental factors may have some contribution to a diagnosis of type 1 diabetes however they have yet to be determined as casual factors (Egede & Ellis, 2010; JDRF, 2011; JDRF Canada, 2011; Rock, 2005).

Aside from the classification of the disease itself, treatment and management regimens of type 1 diabetes were greatly impacted by the language and terms used to better understand the disease. As the conceptualization and classification of diabetes has drastically improved over the years, so too has the treatment and management options for people with type 1 diabetes. Let us now explore the historical development of treatments and management techniques for diabetes, which have simply been made possible due to the increasing understanding of the disease itself.

### **Original Methods of Treatment and Management**

The understandings and conceptualizations of type 1 diabetes paved the way for the introduction of technology and innovation for diabetes diagnostics, treatment and management. As the conceptualization and classification of the disease became more established since its debut in the Middle Ages, a quest for more information and an



explanation for the cause of type 1 diabetes became a fascination for many researchers, doctors and scientists. Understanding previous conceptions of polyuria, Dobson was one of the first to demonstrate that the odd yet sweet taste and smell of diabetic urine was due to abnormal levels of sugar in 1775 (as cited in Purdy, 1890). This became evident to Dobson when he evaporated the urine and was left with pure sugar crystals (Purdy, 1890). From this discovery, tests were being introduced in the early 1800s to indicate and acknowledge a presence of sugar in the urine (Bliss, 2007).

By the late 1850s, Piorry, a French doctor, shifted the focus of treatment for people with type 1 diabetes to focus on diet and food consumption (Bliss, 2007). He figured people with type 1 diabetes needed additional nourishment since such large quantities of nutrients were being spilled out in their urine. Therefore, he ordered and insisted his patients eat extravagant amounts of sugar to replace the nutrients they were losing (Bliss, 2007). Expanding on the current trend of dieting, French doctor Boucharadat started designing patient-specific diets and meal plans for people with type 1 diabetes (Bliss, 2007). He noted that patients who exercised and were active were more tolerant of carbohydrates, which led to his famous phrase, “You shall earn your bread by the sweat of your brow” (Bliss, 2007, p. 23).

All the while treating patients with diet regimes, scientists and researchers started testing their hypotheses on animal subjects. Medical history in the field of diabetes was made in 1889 at the University of Strasbourg when Joseph von Mering and Oscar Minkowski were confident that diabetes occurred when one's pancreas was removed (Bliss, 2007; Karamitsos, 2011). Testing their ideas on dog subjects, they determined that

enzymes found in the pancreas were vital for the digestion of fat. In their laboratory, they removed a dog's pancreas and noted it began urinating frequently despite the fact that it was housebroken and taken outside regularly (Bliss, 2007). Some accounts suggest Minkowski knew the dog had diabetes because flies were often attracted to its sugary, sweet urine (Bliss, 2007; Karamitsos, 2011). Pancreatic extractions on dogs were so prominent at this time that it was estimated approximately 400 researchers considered this form of treating diabetes between 1890 and 1910 (Karamitsos, 2011).

Between 1919 and 1920, just as roughly 0.5% to 2.0% of the population of developed and industrialized countries had diabetes, Dr. Frederick Allen, an American diabetologist established a name for himself (Bliss, 2007). He published his work in 1919, titled, *Total Dietary Regulation in the Treatment of Diabetes* (p. 35), which set the tone for hospital regimens (Bliss, 2007). During this time, people with type 1 diabetes admitted to hospital were placed on a liquid diet until the sugar and acidosis levels dropped. Once this was achieved, a diet measuring carbohydrate tolerance through the weighing of foods was completed. A day of fasting would occur then the patient would be placed on a fixed caloric and carbohydrate diet. This diet is most commonly understood as the starvation diet (Bliss, 2007).

The early 20<sup>th</sup> century also brought upon even greater developments to the field. During the 1920s, Drs. Frederick Banting and Charles Best started making great strides in the field of diabetes (Bliss, 2007). At the time, Dr. Frederick Banting was a practicing physician in London, Ontario who was struggling to develop a clientele (Bliss, 2007). Banting who had recently taken on a part-time job as a demonstrator in surgery and

anatomy at the University of Western Ontario, was asked to give a talk to physiology students on the topic of carbohydrate metabolism and diabetes (Bliss, 2007). After the talk, he became intrigued with this particular field of research and on November 8, 1920, approached Professor Macleod from the University of Toronto about doing research on the internal secretions of the pancreas (Bliss, 2007). Macleod promised Banting that he would assign one of his students as Banting's research assistant over the summer of 1921 while Macleod left for Europe. Charles Best, a fourth year student at the University of Toronto was enrolled in the honours physiology and biochemistry program (Bliss, 2007).

Throughout the fall of 1921, Banting and Best became landmarks in diabetes research, more specifically insulin discovery, when they confirmed the role of insulin in dogs (Bliss, 2007; Karamitsos, 2011; Pompei, 2006; Rock, 2005). They noted that injecting the dogs with insulin post removal of the pancreas, stabilized the dog and kept it alive (Karamitsos, 2011; Pompei, 2006; Rock, 2005). Banting and Best attempted to develop a medical liquid extract concoction under Macleod's directions (Bliss, 2007). The mixture consisted of slices of pancreatic tissue with salt water, which was then placed in a freezer until partially frozen. Once it had reached this stage, the solution was ground up with sand then filtered through cheesecloth to remove solid particles (Bliss, 2007). The solution was injected into dogs once it had reached normal corporal temperature. The famous duo called their extract *isletin* (p. 72) and continued refining (by adding alcohol as a component) until December 1921 (Bliss, 2007). Unhappy with their unconvincing results, Banting insisted Macleod hire J. B. Collip, an alumni of the University of Toronto who was currently employed and working at the University of

Alberta (Bliss, 2007). Collip, an active researcher on blood chemistry took a sabbatical leave to join Banting, Best and Macleod in Toronto (Bliss, 2007).

While 1921 is understood as the year insulin was discovered, the first human insulin injection was not until January of 1922 at Toronto General Hospital (Karamitsos, 2011; Pompei, 2006; Rock, 2005). On January 23, 1922, Leonard Thomson received his first injection of five cubic centimetres (millilitres) of insulin extract (prepared by Collip) (Bliss, 2007; Karamitsos, 2011; Pompei, 2006; Rock, 2005). Thompson weighed roughly 60 pounds and had most of the severe symptoms of diabetes (Karamitsos, 2011). The initial injection was successful as Thomson's sugar decreased despite having trouble with inflammation. As the months continued, Thomson received more injections of insulin, which seemed to improve his condition (Bliss, 2007; Karamitsos, 2011).

Although the trio was supposed to continue working together as a team under Macleod, Collip was often found spending time in his own lab working on his own unique extract (Bliss, 2007). Collip eventually left Toronto and Banting and Best continued their efforts throughout the spring of 1922, when they continued injecting human patients with animal insulin (beef and pork) and found it to be successful in lowering blood sugars and relieving their symptoms (Bliss, 2007). Finally, on July 3, 1922, after months of involvement with Eli Lilly and Company, the pharmaceutical giant had shipped its first batch of pork extract to the University of Toronto (Bliss, 2007). The package arrived with 10 bottles, each containing five millilitres of the extract, and was titled *Iletin* (Bliss, 2007, p. 146). The extract was later named and referred to as insulin (Bliss, 2007). This successful technique was later tested on many other human patients,

leading Banting and Best to receive the Nobel Prize for Medicine in 1923 (Karamitsos, 2011; Pompei, 2006).

Aside from insulin, alternate developments in treatment from the 1920s onward, such as the discovery of eye disease as the first complication of diabetes in 1934 by Henry Wagner and Russell Wilder, doctors at the Mayo Clinic, had began a new debate in the field of diabetes (JDRF, 2011; JDRF Canada, 2011). The question remained as to whether or not regular check-ups would alleviate such complications or if they were due to genetics (JDRF, 2011; JDRF Canada, 2011). Such controversial debates led to the serious changes in diabetes treatment regimens in 1980 after the WHO established an international definition of diabetes (Rock, 2005). The WHO stated people with type 1 diabetes should incorporate glucose levels, food (specifically carbohydrates) intake and physical activity into their daily regime including insulin injections (Rock, 2005). The WHO definition and classification of type 1 diabetes led to more technological advancements in disease treatment and management.

## **Technological Advancements and Changes in Treatment**

### **Diagnostic devices and glucose testing**

As research and testing continued in the field of diabetes, so did the development of instruments and technology to diagnose and monitor the disease. Primitive modes of blood glucose testing date back to the early 1840s when Trommer and Von Fehling both tried their hand at developing urine tests combining glucose with alkaline cupric sulphate to produce a colored substance (as cited in Clarke & Foster, 2012). By 1850, Jules Maumene had constructed the first urine reagent strip where drops of urine were placed

on a strip of sheep's wool; if the wool turned black then glucose was present (as cited in Clarke & Foster, 2012). These primitive testing ideas paved the way for Stanley Benedict who, in 1908, used a copper reagent for the purpose of testing sugar levels (as cited in Clarke & Foster, 2012). Despite a few modifications and adjustments throughout the years, the idea of using some sort of copper component in urine testing was the most prominent method for the early 1900s (Clarke & Foster, 2012).

The next development for urine testing was a dissolvable tablet. Two individuals, Compton and Treneer, at a company called Ames, created a new product called *Clinitest* in 1945 (Clarke & Foster, 2012). *Clinitest* was a copper reagent tablet formed of sodium hydroxide, citric acid, sodium carbonate and cupric sulphate. The tablet was designed to be submerged in a small tube of urine and would react immediately (Clarke & Foster, 2012). If sugar were present, the tube of urine would change color after 15 seconds. Shades of blue or green indicated less than 1% of glucose whereas yellow indicated 1% and orange determined 2% or more glucose (Clarke & Foster, 2012). It was only a few years later, when the first dry-reagent test strip was developed using litmus paper.

The litmus paper testing idea was expanded in 1956 when it became possible to measure the specific levels of sugar in the human body (Clarke & Foster, 2012; JDRF, 2011; JDRF Canada, 2011; Rock, 2005). The first urine test strip, *Clinistix*, was developed by two biochemistry researchers named Helen and Alfred Free; this milestone provided patients with the opportunity to more accurately test the amount of sugar in their urine (JDRF, 2011; JDRF Canada, 2011). Available on the market in 1957, *Clinistix* was the first “dip and read” (p. 85) urine test strip made of stiff filter paper (Clarke & Foster,

2012). Although this invention has surpassed previous versions, it remained unpredictable and led to inconsistent results. The blood glucose result in this form is highly dependent on the sensitivity of each individual strip and simply measures one's current blood glucose reading in its present renal status (Clarke & Foster, 2012). "Positive results only occur when the renal threshold for glucose is exceeded and this may vary in longstanding diabetes or pregnancy; more significantly, negative results do not distinguish between hypoglycaemia, euglycaemia and even mild hyperglycaemia" (Clarke & Foster, 2012, p. 85).

Once researchers, healthcare professionals and patients realized *Clinistix* could only yield approximate blood sugar results, Ames continued his research and successfully created one of the first blood glucose test strips concurrent with modern models (Clarke & Foster, 2012). This strip, *Dextrostix*, still a paper strip, would trap red blood cells yet would permit the sugar to pass into a dry reagent (Clarke & Foster, 2012). One minute after a drop of blood was placed on the strip the blood was wiped off. Again, the pad would change color depending on the glucose level and be compared to another color-coded glucose chart (Clarke & Foster, 2012). During roughly the same time period, a German competitor developed a product similar to the *Dextrostix* but it was called *Chemstrip BG* (Clarke & Foster, 2012). The only difference between this product and the *Dextrostix* was that this one required the patient to wipe the strip with a cotton ball, and the color pad only contained two colors – beige and blue. This allowed for more precise differentiation between glucose levels (Clarke & Foster, 2012). Soon after, Anton Clemens created a device to use in combination with the *Dextrostix* that would indicate

more specific, numeric results (Clarke & Foster, 2012). Clemens used principles of light reflection, captured by photoelectric cells to move an arrow on this instrument. The device itself had three different scales of 0-4 mmol/L, 4-10 mmol/L and 10-55 mmol/L. This measurement was the first to quantify the amount of glucose in the blood (Clarke & Foster, 2012).

The 1970s was also prominent with advancements in technological treatments for type 1 diabetes. A surgical technique to treat effects of eye disease for people with type 1 diabetes, vitrectomy, was discovered as well as understanding the impact of hormones on the effect of insulin and the entire endocrine system (JDRF, 2011; JDRF Canada, 2011). The hemoglobin (HbA1c) test, which measures an average three-month blood sugar reading, was also developed during this decade (Clarke & Foster, 2012; JDRF, 2011; JDRF Canada, 2011). It wasn't until the mid 1970s, after various upgrades and improvements to the blood glucose test strips, that the idea of self-monitoring for type 1 diabetes was considered. The idea was partially due to research reports on pregnant women with diabetes that demonstrated favorable or improved control when the disease was self-monitored (Clarke & Foster, 2012).

The 1980s brought about more treatments for type 1 diabetes including genetically engineered insulin, a connection between brain metabolism with low blood glucose levels, and the cells blood vessels are able to harden arteries as a result of diabetes (JDRF, 2011; JDRF Canada, 2011). More importantly, the *Dextrometer*, the first battery operated blood glucometer with a digital display was introduced (Clarke & Foster, 2012).



Diagnostic tools and technological treatments for type 1 diabetes have remarkably transformed from primitive measures of glucose through urine test strips, to small machines that read blood sugar levels through a small blood sample (droplet) from the finger transferred via test strip, also known as a glucometer (Karamitsos, 2011; Mol, 2000; Scheiner et al., 2009). Throughout the 1980s and 1990s glucometers drastically transformed in size and shape, as well as the speed and accuracy of producing results, in attempt to increase comfort, flexibility and accessibility for diabetes self-management (Clarke & Foster, 2012). Glucometers have become more compact in size, from original ones the size of old desktop printing calculators to a small handheld devices. Also, the amount of blood required for glucometers has also significantly reduced (Clarke & Foster, 2012). Modern glucometers require smaller droplets of blood, reducing the potential pain and discomfort while putting the patients' fingertips at ease; the size of blood samples have dropped dramatically from 20  $\mu\text{L}$  required of outdated glucometers to amounts as low as 0.3  $\mu\text{L}$  for more current devices (Clarke & Foster, 2012).

Today, glucometers are quite technical as some include features such as rubber grips, large screens, backlight displays, minimal coding of test strips and autocalibration of the device itself (Clarke & Foster, 2012). Many glucometers act as electronic logbooks with large memory databases to store and retrieve blood sugars for up to a month (Clarke & Foster, 2012). Just like any other product on the market, glucometers can be adapted to suit various audiences through their capability of connecting to video game consoles or USB ports of personal computers (Clarke & Foster, 2012). The evolution of computer technology has also assisted some companies to produce glucometers accompanied by

software, which allows the patient to upload their results and electronically send them to their physician or diabetes education centre (Clarke & Foster, 2012). The transformation of glucometers has truly demonstrated the shift from its original intended use in hospitals or healthcare settings to support the current trend of self-management and testing at home.

### **Treatment, management and support technologies**

Only one year after the discovery of insulin in 1921, production of the miracle treatment was absorbed by Eli Lilly and Company (in correlation with the University of Toronto) to begin mass production of insulin throughout North America (JDRF, 2011; JDRF Canada, 2011). A few years later, in 1924, the very first insulin syringe was designed to assist patients with self-monitoring (JDRF, 2011; JDRF Canada, 2011). The first reusable glass syringe and needle was boiled after each use, which sterilized the product and facilitated the re-sharpening of the needle with a pumice stone (JDRF, 2011; JDRF Canada, 2011; Selam, 2010).

The 1960s and 1970s proved to be two instrumental decades in the development and expansion of technological treatments for diabetes. One of the first successes was the unveiling of disposable syringes to be used with insulin vials, which would save time from boiling and re-sharpening glass syringes and needles respectively (JDRF, 2011; JDRF Canada, 2011). Albeit controversial as far as the date goes, the very first insulin pump was introduced and manufactured in the United States, during this time period (Kesavadev et al., 2010; Selam, 2010). Although it was considered a breakthrough, it was roughly the size of a standard backpack (Kesavadev et al., 2010; Selam, 2010).

As the technological support increased for the treatment and management of type 1 diabetes, so too did the social and emotional support for the disease. In 1949 Dr. Banting formed The Ontario Diabetic Association in an effort to serve and support the needs of people living with diabetes (CDA, 2012). After other provinces and territories formed their own organizations, Banting and Best figured a national organization, including all provinces and territories may better serve individual needs of their members. In 1953, Banting and Best developed the Canadian Diabetic Association, which is now recognized as the Canadian Diabetes Association (CDA) and is present in over 150 communities nationwide (CDA, 2012). The goal of the organization is to support, and advocate for people living with diabetes while also providing them with essential services such as education. Another section of this organization promotes research in the field of diabetes through developing relationships and forming community networks with volunteers, employees, and healthcare professionals (CDA, 2012).

Elaborating on the goals of the CDA, the JDRF was also formed but with a more direct focus. A mother of a child with type 1 diabetes created the first JDRF in the United States in 1970, in an effort to find more effective treatments, prevent and cure type 1 diabetes (JDRF, 2011; JDRF Canada, 2011). It was not until 1974 when Montreal parents, Mitchel Garfinkle and Krayna Golfman, created the first JDRF Canadian chapter. The focus of JDRF was and still is to focus on funding research efforts, which result in a cure (JDRF, 2011; JDRF Canada, 2011). Both the CDA and JDRF have been instrumental in promoting World Diabetes Day, celebrated on November 14<sup>th</sup> every year

in celebration of Dr. Banting's birthday. World Diabetes Day was originally declared in 2006 by the United Nations (CDA, 2012; JDRF, 2011; JDRF Canada, 2011).

Insulin administration became much easier in 1985 when Novo Nordisk introduced the very first insulin pen called NovoPen® (Selam, 2010). In an attempt to discard disposable syringes for good, insulin pens provided more precision, flexibility, portability and convenience for people with type 1 diabetes (Anderson & Redondo, 2011; Selam, 2010). Each pen contained a pre-filled insulin cartridge of which the end would connect to a small disposable needle tip for injections (Selam, 2010).

Insulin pens were seen as instrumental, especially for children, as they allowed for smaller dosing options of one or two units of insulin. However, typically the smallest dose achieved from a vial and syringe technique was five units (Selam, 2010). Needless to say, the numbers on the insulin pen were much easier and clearer to read (Selam, 2010). Not only did this allow people with type 1 diabetes to be more precise but it also provided more discreetness in public situations, which is very important in reducing stigma and misunderstanding around diabetes (Anderson & Redondo, 2011; Selam, 2010). It has been noted that some people with type 1 diabetes experience discomfort when injecting themselves, as they believe their daily routines might be confused with that of a drug addict (Anderson & Redondo, 2011; Selam, 2010). Therefore, patients have preferred insulin pens to syringes as they felt they were more socially accepted in public situations (Anderson & Redondo, 2011).

This preciseness of such techniques has also led to the creation of different devices, which deliver insulin. Original methods consisted of a syringe which drew

insulin from a vial, later transformed into insulin pens equipped with cartridges, to the most current and precise method to deliver insulin: the insulin pump (Kesavadev et al., 2010; Scheiner et al., 2009). The first portable insulin pump, MiniMed®, which was small enough to fit in one's palm, was released in 1983 by Medtronic (CDA, 2012). Throughout the 1990s more user-friendly versions of insulin pumps were introduced on the market and by 2006 Medtronic re-introduced their MiniMed® insulin pump, which was the size of a small pager (Kesavadev et al., 2010). This unveiling was crucial as the insulin pump was now more compact and convenient for patients (Kesavadev et al., 2010).

Most current insulin pumps are battery-operated devices that include a small insulin reservoir, and a “computerized control mechanism” (Selam, 2010, p. 509). The pump itself, roughly the size of a small cell phone or deck of cards, is attached to an infusion set via a thin tube. The infusion set is placed subcutaneously in the patient's skin (abdomen, arms or buttocks) and delivers a constant flow of insulin through its attached plastic cannula, which resides just under the patient's skin (subcutaneously) (Selam, 2010). The only exception to this technology is the OmniPod system, which is a small wireless insulin pump, not much bigger than a Bluetooth earpiece (Scheiner et al., 2009; Selam, 2010). This wireless patch-like pump holds the insulin reservoir while also acting as the infusion set. It is placed on the skin and contains an automated cannula insertion reducing the number of supplies needed, in comparison to a wired insulin pump (Scheiner et al., 2009; Selam, 2010).

Since the insulin pump only has one insulin reservoir, it generally uses one type of insulin: rapid-acting insulin. This form of insulin then acts as both the long- and short-acting insulin by delivering basal and bolus rates respectively (Selam, 2010). A basal rate delivers a small portion of insulin over a long period of time, mimicking normal pancreatic secretions; this ensures patients are constantly receiving insulin. The bolus rate of insulin is delivered before a snack or meal, to cover the carbohydrate consumption (Selam, 2010). The pump is unique as it provides different basal/bolus schedules or combinations to compensate for daily activity, illness or other incidents, which may change (decrease or increase) one's blood glucose levels (Selam, 2010). It can also deliver smaller amounts of insulin varying from 0.05 to 0.1 units of insulin compared to 1 unit and 5 units for insulin pens and syringes respectively (Selam, 2010).

Some of the current pumps on the market offer features to accommodate daily experiences. For example, the Animas OneTouch® Ping is a waterproof pump which allows individuals to swim up to 12 feet for 24 hours (Selam, 2010). Other pumps, like the Medtronic MiniMed® or Paradigm® are equipped with real-time continuous glucose monitors (CGMs) - sensors placed under the skin, to read blood sugar levels via tissues, sending them to the pump, and alarming the individual of abnormal readings (Scheiner et al., 2009; Selam, 2010). CGMs are unique devices as they provide blood glucose readings based on measurements of glucose amongst fluid surrounding cells, also known as interstitium (Cobelli, Renard, & Kovatchev, 2011). Most current insulin pumps and glucometers work in conjunction with computers, uploading viable information and transfiguring it into visual charts or graphs. This eliminates the need for paper logbooks

and facilitates communication between doctors and patients (Scheiner et al., 2009; Selam, 2010). Research has shown that using an insulin pump can lead to lower HbA1C levels, as a result of more precise glucose management and a reduced risk of developing complications (Scheiner et al., 2009; Selam, 2010).

The increasing advances in insulin pump technology have sparked the development of the Artificial Pancreas Project. The Artificial Pancreas Project, launched by JDRF in 2006, strives to create a “closed-loop system” (p. 72) through the combination of an insulin pump and continuous glucose monitor, which would require no effort or manual manipulation on the part of the patient (JDRF, 2011; JDRF Canada, 2011; Klonoff, 2007). Ideally, the computerized system would calculate the individual's required dosage of insulin based on blood sugar readings from the continuous glucose monitor in combination with sensing carbohydrate intake (JDRF, 2011; JDRF Canada, 2011). The system would deliver the insulin and adjust any basal or bolus settings on its own, without the assistance of the individual. The technology has yet to be perfected and the artificial pancreas has not been approved; however, human trials and research are currently being conducted across the globe (JDRF, 2011; JDRF Canada, 2011). Once the device is technologically flawless it will be considered one possible cure or at least a life-altering treatment for type 1 diabetes (JDRF, 2011; JDRF Canada, 2011; Klonoff, 2007). These innovations have changed the way patients administer their medication, offering more precise dosing options and flexibility to live a seemingly normal life (Karamitsos, 2011; Scheiner et al., 2009).

### **Biological surgeries: Transplants and implants**

Alongside specific devices used to treat and manage diabetes, the first-ever human pancreatic transplant was performed in 1966 at the University of Minnesota (CDA, 2012; JDRF, 2011; JDRF Canada, 2011). Richard Lillehei and William Kelly conducted a pancreatic and kidney transplant on a 28-year-old woman who had been living with type 1 diabetes for 19 years (CDA, 2012; JDRF, 2011; JDRF Canada, 2011).

This idea was expanded in the 1990s, which became an instrumental period for advancing research and testing on pancreatic transplants. Canadians also jumped onboard when JDRF helped launch the Edmonton Protocol conducted by Dr. James Shapiro at the University of Alberta in 1990 (JDRF Canada, 2011; JDRF, 2013; Senior, Kin, Shapiro, & Koh, 2012). The Edmonton Protocol was a name given to the research community at the University of Alberta for their successful islet transplantations, the first of which was achieved in 1999 (CDA, 2012; Senior et al., 2012).

Current understandings of insulin-producing cells, also known as beta cells, support the idea that any body, even those of people with type 1 diabetes, is physically capable of regenerating such cells (JDRF, 2011; JDRF Canada, 2011). The focuses of current biological treatments for diabetes highlight the survival, revival and regeneration of beta cells. Through research testing, it has been understood that other types of cells (i.e. liver, pancreatic alpha and stem) have the ability to be reprogrammed or develop the properties of beta cells (JDRF, 2011; JDRF Canada, 2011). It has also been determined that upon diagnosis, individuals with type 1 diabetes still house some functioning beta cells, therefore the current goal for researchers is to preserve and regenerate beta cells to



slow down the progression of the disease (JDRF, 2011; JDRF Canada, 2011). This information is pertinent for those who have a family history of diabetes, as they may be able to achieve this step before an official diagnosis (JDRF, 2011; JDRF Canada, 2011).

In some cases where people with type 1 diabetes have had the disease for a prolonged period of time, encapsulation or implantation of beta cells in the pancreas may be considered. (JDRF, 2011; JDRF Canada, 2011). The problem with this treatment option comes back to the autoimmune component of type 1 diabetes. For an individual to develop type 1 diabetes, their body would have already begun attacking their original beta cells, therefore chances are the injected cells will also be attacked and die (JDRF, 2011; JDRF Canada, 2011). Hence, if going ahead with encapsulation of beta cells, specific measures must be taken to avoid the destruction of the insulin-producing cells. The most common measure typically includes the patient taking immune-suppressing drugs, which also come with additional risks as they have a tendency to decrease the strength of one's natural immune system (JDRF, 2011; JDRF Canada, 2011).

In comparison to the procedures most recently described, the Edmonton Protocol has performed over 300 procedures on 138 individuals, since its debut in 1990 (Senior et al., 2012). Of the 138 participants, 109 (79%) had partial or full graft function meaning the procedure was relatively successful. In addition, 48% of those who had positive outcomes were also considered insulin independent, which means they no longer take insulin injections (Senior et al., 2012). Since this research began, results have increased, showing more sustainability from the procedure, fewer adverse side effects and greater long-term outcomes (Senior et al., 2012).

Aside from funding the Edmonton Protocol, JDRF Canada introduced its Canadian Clinical Trial Network (CCTN) (p. 4) in 2009 with the assistance and partnership of the Government of Canada (JDRF Canada, 2011). This network was developed in an effort to continue research and solutions to better the lives of people living with type 1 diabetes. The ultimate goal, aside from enhancing management and care of the disease is to find a cure for type 1 diabetes (JDRF Canada, 2011).

### **Canadian Programs, Policies and Initiatives**

The province of Ontario was the very first in Canada to implement an insulin pump coverage program when they introduced the Assisted Devices Program (ADP) on December 1, 2006 (Diabetes Advocacy, 2012; Canadian Diabetes Association [CDA] & Diabetes Québec, 2010). Despite meeting basic criteria including having type 1 diabetes or being Ontario resident, the coverage came with an age limit. Only individuals under the age of 18 were eligible (Diabetes Advocacy, 2012; CDA & Diabetes Québec, 2010). As the nationwide diabetes epidemic increased alongside the nationwide prevalence, other provinces such as Newfoundland and Saskatchewan also implemented similar policies in 2007 (Diabetes Advocacy, 2012; CDA & Diabetes Québec, 2010; Government of Saskatchewan, 2012a; Minister of Health Canada, 2011). Ontario set records again in 2008 when it expanded its inclusion criteria to adults as well; currently, anyone with type 1 diabetes is eligible for the ADP, regardless of their age (Diabetes Advocacy, 2012; CDA & Diabetes Québec, 2010; Ontario Ministry of Health and Long-Term Care [LTC], 2012).

At this time, I believe it is important to highlight the eligibility criteria and benefits of the Ontario ADP, as it is the most advanced program of its kind, to date, in Canada. The ADP is available to all residents of the province of Ontario who have a long-term physical disability and require specific devices to enhance their health care, quality of life (QOL), and more importantly their independence (Ontario Ministry of Health and LTC, 2012). One section of the program is specific to people with type 1 diabetes as it offers coverage for both the initial costs of the insulin pump itself, as well as monthly supplies. Eligible candidates must demonstrate a commitment to regular blood glucose monitoring, participate in an insulin pump education program and must attend a diabetes education clinic on a regular basis (Ontario Ministry of Health and LTC, 2012). Although some of the requirements may differ between children, youth and adults, there is no age discrepancy for coverage (Ontario Ministry of Health and LTC, 2012). As previously mentioned, the program allows for 100% coverage of the price of the insulin pump device itself and is paid directly to the supplier or company on behalf of the patient. As far as other coverage goes, the ADP will pay a \$2400 a year to each individual who qualifies for the program; the money is distributed in annual quarters directly to the patient (Ontario Ministry of Health and LTC, 2012). The ADP does not currently offer the same coverage to individuals with type 2 diabetes, as they believe research has not shown clear improvement results (Ontario Ministry of Health and LTC, 2012).

Since the expansion of the ADP in 2008, British Columbia, Quebec, New Brunswick, Nova Scotia, Manitoba and Nunavut have all introduced insulin pump coverage for children (Diabetes Advocacy, 2012). At the same time, Newfoundland and

Saskatchewan have both modified their criteria to include individuals up to the age of 25 (Diabetes Advocacy, 2012; CDA & Diabetes Québec, 2010; Government of Saskatchewan, 2012b). With that being said, it must be highlighted that individuals who exceed the age criteria are no longer eligible for compensation despite still having type 1 diabetes. As of June 2013, Alberta has sided with Ontario and announced a plan to implement insulin pump coverage with no age limitations (Canadian Diabetes Association [CDA], 2013a). Currently, Prince Edward Island, Yukon and North West Territories do not have any direct insulin pump coverage program in place, although minimal costs may be included through other indirect programs (Diabetes Advocacy, 2012; CDA & Diabetes Québec, 2010). Insulin pump coverage has yet to be offered to individuals living with type 2 diabetes (Diabetes Advocacy, 2012; CDA & Diabetes Québec, 2010).

It seems as though healthcare professionals and authorities are supporting the implementation and usage of such programs, like the ADP, which would place a lesser economic and financial burden on Canada's current and future healthcare systems. However the long-term benefits of such initiatives for people living with type 1 diabetes is unknown. The cost effectiveness of the program has yet to be evaluated and the broader relationship between diabetes education and policy has yet to be examined.

## **CHAPTER FOUR: LITERATURE REVIEW**

### **Introduction: Setting the Stage for Current Research**

This chapter will acknowledge the literature, as it existed prior to exploring the relationship between older adults living with type 1 diabetes and the advancements in necessary technology used for daily treatment and management of the disease. This section will provide the reader with an accurate portrayal of the current literature available in the fields of gerontology, type 1 diabetes and technology respectively. I will identify the strengths and weaknesses of what exists as well as highlight the gaps. Providing the reader with a more elaborate picture of what exists will help in clearly establishing the need for my current research. This comprehensive literature review specifically focuses on the experiences of people with type 1 diabetes. The experiences of type 2 diabetes will not be explored, aside from acknowledging the disconnect within current literature on the respective subject areas.

### **Gerontology: The Study of Outdated Aging Models**

The problem that currently exists within gerontology literature is the disconnect among increases in life expectancy, international population aging and the international prevalence of CD.

#### **Transforming aging health trends**

Aging within North America has severely transformed within the last century, as trends in mortality, life expectancy and health have greatly shifted (Crimmins, 2004; Fries, 1980; Laditka & Laditka, 2000; Michel & Robine, 2004; Olshansky et al., 1991). Since the turn of the 20<sup>th</sup> century, life expectancy at birth has risen from 47 years of age

to 73 years of age in the 1980s (Fries, 1980). Currently, life expectancy from birth is approximately 80 years of age (Crimmins, 2004; Fries, 1980; Olshansky et al., 1991). Reasons and factors contributing to this shift include declining rates of [infant] mortality, premature death, and fertility. Also, the development of advanced medical technology has led to an increase in general population health (Crimmins, 2004; Fries, 1980; Michel & Robine, 2004; Olshansky et al., 1991).

Many acute diseases of the 20<sup>th</sup> century have either been eradicated or have seen dramatic declines in prevalence. Acute infectious and parasitic diseases or illnesses of previous centuries that have largely been removed from North American societies include tuberculosis, acute rheumatic fever, smallpox, diphtheria, tetanus, poliomyelitis, and pneumococcal pneumonia (Fries, 1980; Olshansky et al., 1991). Improved lifestyles, increased medical technology (i.e. immunizations, antibiotics) and better sanitation or living conditions (i.e. improved nutrition, water sterilization, less crowded living arrangements) have all contributed to the decrease in prevalence of the aforementioned diseases (Fries, 1980; Olshansky et al., 1991). Many of these acute diseases have been replaced with a higher prevalence of CDs including type 1 diabetes and type 2 diabetes (Crimmins, 2004; Fries, 1980; Michel & Robine, 2004; Olshansky et al., 1991).

### **Prevalence of CD**

Nations across the globe are experiencing drastic increases in the prevalence of CD, internationally known as noncommunicable diseases (NCD) (CDA, 2008; World Health Organization [WHO], 2011). According to the World Health Organization (WHO) (2011), NCDs are the current leading cause of death worldwide. In leading order for

cause of death worldwide, NCDs include cardiovascular disease, cancer, respiratory disease and diabetes respectively (WHO, 2011). CDs are prolonged health-related illnesses, which exhaust medical services and resources (Chi, Lee, & Wu, 2011). More recently, CD has become the main focus for health prevention strategies and health policies in a plethora of communities worldwide (International Diabetes Federation [IDF], 2013; WHO, 2011). This phenomenon is particularly important when considering the prevalence of CDs among older adults is upwards of 70%, with the United States experiencing rates of 88% (Chi et al., 2011).

Individuals with CDs such as cerebrovascular disease, heart disease, diabetes, cancers or chronic respiratory disease often experience greater levels of disability (in comparison to the general population), which can affect patients' health on a long-term basis and require constant treatment or management (Chi et al., 2011; Crimmins, 2004; Meece, 2006). This population may also have difficulty executing self-care behaviours (Chi et al., 2011; Crimmins, 2004). CDs may hamper regular routines such as housework, shopping, cooking, transportation or managing medications and money, also known as instrumental activities of daily living (IADLs). Activities of daily living (ADLs) such as eating, bathing, dressing, and toileting may also be compromised (Crimmins, 2004).

Although we know quite a bit about older adults living with diabetes, the effort is largely directed to type 2 diabetes. Type 2 diabetes is the second leading CD among older adults, in most cases as a result of unhealthy lifestyle behaviours; poor diet and exercise are two main contributors (Chi et al., 2011; Meece, 2006). Treatment of type 2 diabetes typically consists of oral medication in combination with proper diet and exercise

regimens (Meece, 2006). In some instances, older adults may require exogenous (also known as synthetic) insulin injections if all other methods are exhausted (Meece, 2006; Tanaka & Itoh, 2011). The International Diabetes Federation (IDF) stated, in 2010, approximately 285 million adults worldwide were currently affected by diabetes (Egede & Ellis, 2010). The exponential prevalence rates of diabetes have also caused detrimental global economic strain, and in 2007 it was estimated that the United States spent roughly \$232 billion dollars on prevention and treatment of the disease.

While type 2 diabetes is extremely common within older populations, little is known about people aging with type 1 diabetes. Justifications for this tendency may be due to the fact that type 2 diabetes is typically diagnosed within older adulthood, whereas type 1 diabetes was traditionally a disease of childhood or adolescence (Egede & Ellis, 2010; Rock, 2005). However, with the aforementioned changes and increases in overall health, individuals with type 1 diabetes are living well into their adulthood (JDRF, 2011; JDRF Canada, 2011; Karamitsos, 2011; Klonoff, 2007; McGuire, Klein, & Couper, 2005; Scheiner et al., 2009; Selam, 2010). Individuals with either form of diabetes or CD in general, often require additional health care, including multiple medications and even hospital treatments (CDA & Diabetes Québec, 2010; Chi et al., 2011). With such a dramatic impact on one's lifestyle, CD places an increased strain on national medical expenditures and health care programs. It also places a large financial burden on people with type 1 diabetes, as there is a large discrepancy in out-of-pocket costs across the nation (CDA & Diabetes Québec, 2010; Chi et al., 2011).



### **Health and aging hypotheses**

The delineation from acute to CD, the increase in basic health needs and the improvement in social, cultural and environmental factors have all led to the development of a popular term used in current gerontology research literature: the compression of morbidity hypothesis (COMH). Introduced in the 1980s, this idea acknowledges the fact that basic health has improved and mortality rates from acute diseases have declined therefore populations are more likely to experience CD (Fries, 1980). Fries (1980) believed many CDs can be prevented or delayed based on personal lifestyle behaviours and attitudes; increased exercise, optimal weight and a resistance in smoking are some examples of personal choices which have been shown to postpone or eliminate a CD diagnosis. Fries (1980) suggested if individuals are educated and indulge in autonomous health-related behaviours they could delay the onset of CD into their remaining years. Therefore, individuals are compressing the state of poor health and wellbeing (morbidity) from chronic symptoms into a relatively small period of time (Barber & Pontisso, 2005; Fries, 1980).

The COMH assumes that if older adults live to advanced ages before they experience mortality there would be a limit where they can no longer continue to decline (Crimmins, 2004; Fries, 1980). This idea is also combined with an increase in the age at which chronic diagnoses occurs. With that being said, the unhealthy, morbidity state would be present into a smaller number of years, usually six to eight years, at the end of one's life (Crimmins, 2004; Fries, 1980; Laditka & Laditka, 2000; Michel & Robine, 2004). Chronic health conditions are typically diagnosed in mid to older adulthood, and

often occur simultaneously. Roughly 82% of older adults have one or more CDs, known as comorbidities (Chi et al., 2011; Crimmins, 2004; Olshansky et al., 1991).

Despite the accuracy of the decline in acute disease, researchers have been debating whether a decline in mortality produces longer years of health ending with a short span of disability (COMH) or longer consistent years of disability (expansion of morbidity) (Laditka & Laditka, 2000). Although there is some truth to Fries' (1980) COMH, it is solely based on autonomy, responsibility and choice, which are not always contributing factors to CD, especially type 1 diabetes. With that being said, I will be using an oppositional view, the expansion of morbidity hypothesis (EOMH), to extend my argument and rationale for the current research.

The EOMH contends that both individual and population health are subject to increases in chronic health conditions such as macular degeneration, dementia(s), heart disease, stroke, diabetes, diabetic retinopathy, osteoarthritis, hearing loss and other sensory impairments to name a few (Olshansky et al., 1991). Although CDs do not often pose immediate danger or death, like acute diseases, they still pose serious health risks and additional complications for patients. Cassel et al. (1990) give an example of a common complication specific to certain CDs: "Diminished vision is most often caused by glaucoma, macular degeneration, and diabetic retinopathy – all of which are age-dependent diseases" (as cited in Olshansky et al., 1991, p. 206). CDs may be perceived as more laborious, intensive, and stressful however, they are relatively manageable and in some cases, preventable (Olshansky et al., 1991).

Olshansky, Rudberg, Carnes, Cassel, and Brody (1991) argued that CDs are likely manageable today due to advances in medical technology. Advances include antibiotics or medications such as insulin, penicillin, beta-blockers, antiplatelet agents, chemotherapy and innovations designed to assist frail older adults (Laditka & Laditka, 2000; Olshansky et al., 1991). While such tools help to prolong or extend the life of a person with a CD by reducing the risk of primary complications or easing symptoms, Olshansky et al. (1991) believe the tools do not necessarily change the course of the disease itself. The specific medical technology considered by Olshansky et al. (1991) comprises imaging devices, surgical techniques, anti-aging drugs, artificial organs and transplants and antibody testing, which they believed to have an impact on the initial detection or diagnosis of a chronic, non-fatal, disease. The progression of the disease however, remains relatively stable (Olshansky et al., 1991). “An advanced warning of the presence of most nonfatal diseases of aging will allow for changes in lifestyles that may limit the disabilities and handicaps associated with having the diseases, but will not alter the underlying disease process” (Olshansky et al., 1991, p. 207). This viewpoint is extremely outdated as it does not align with current research conducted on type 1 diabetes and the usage of insulin pumps, which suggests such technology does in fact assist, and contribute to more desirable health outcomes, potentially extending one's life course (JDRF, 2011; JDRF Canada, 2011; Karamitsos, 2011; Klonoff, 2007; Scheiner et al., 2009; Selam, 2010).

The EOMH also promotes the idea that the face of aging will change dramatically as diversity, expression and individual needs may be more prominent because adults are

bringing their so-called disabilities (i.e. CD) and morbidities forward into advanced years (Laditka & Laditka, 2000; Olshansky et al., 1991). Even though the definition of aging may be changing, it is believed the rate of aging remains relatively unchanged as the goal of public health should be to increase the quality, not quantity, of adult life (Laditka & Laditka, 2000; Olshansky et al., 1991). The three most important features of this hypothesis include a post-poned age of disease onset, an increase in years between age at onset of disease and death, and an increase in age-specific disabilities in non-fatal (chronic) diseases of aging, across the board (Olshansky et al., 1991).

The EOMH debate, albeit a better fit for my current study, in comparison to its opponent (COMH), still lacks key characteristics, which reduce its reliability and validity. This outdated conception of CD is also present and consistent with Cassel et al.'s (1990) comment explained above in which they state diabetic retinopathy as being a complication of age. In fact, diabetic retinopathy is a complication of both type 1 diabetes and type 2 diabetes, and is not necessarily a product of age; diabetic retinopathy is often a result of having uncontrolled diabetes for a prolonged period of time, poor blood glucose management, high A1C tests, high blood pressure readings, high lipid levels and lower levels of hematocrit (CDA, 2008). Diabetic retinopathy screening begins at age 15 for individuals with type 1 diabetes who have had the disease for more than five years, or at diagnosis for individuals with type 2 diabetes (CDA, 2008). The progression or onset of diabetic retinopathy can be decelerated or reduced through intensive treatment and self-management behaviours such as improved glucose control (CDA, 2008).

## **Conclusions**

The relationship between CD and aging most definitely need to be reframed. Alongside the international increase in population aging the prevalence rates of CD are also on the rise, which suggests more older adults will carry CDs into their advanced years than ever before. This idea must be respected alongside the perception that humans age from the day they are born; the aging process does not simply begin at 65 years of age, but is a lifelong process (McGuire et al., 2005). Understanding both CD and aging in such broad terms will promote inclusion of all individuals within a health-related context, while conceptualizing the pathogens of illness through interdisciplinary or multidisciplinary means. “Death, dying, disease, disability, and dependency can occur at all ages, are not synonymous with aging, and should not be the focus of aging education” (McGuire et al., 2005, p. 447). This is extremely important to redefine as the relationship between older adults and diabetes is all concentrated on type 2 diabetes. Also we must take this into consideration, as the disposition of many CDs, especially type 1 diabetes, has changed dramatically over the last century.

## **Limitations of Type 1 Diabetes Research**

Although considerable research has been completed in the field of type 1 diabetes, there is one crucial problem with what we know about type 1 diabetes. Knowledge about type 1 diabetes has been largely contained to experiences of children, adolescents and youth; experiences of older adults with type 1 diabetes have not been explored.

The wealth of information known about type 1 diabetes in adolescence is outstanding. Type 1 diabetes has been linked to mental health, self-perception, identity,

self-management and QOL (Goldman & MacLean, 1998). The relationship between a diagnosis of type 1 diabetes and its impact on patient identity and self-perception has become much clearer. Relationships have been linked to self-management techniques and control of the disease, and have included gender comparisons (Gebel, 2011; Goldman & MacLean, 1998; Ockleford, Shaw, Willars, & Dixon-Woods, 2008; Olshansky et al., 1991). While the material is available, none of the research has been followed through using longitudinal research. Moreover, research on type 1 diabetes has not been linked to older adulthood.

### **Self-perception, identity and self-management**

Symbolic interactionism and identity theory are helpful in understanding the meanings and values people with type 1 diabetes derive from their disease; they are important when considering the specific roles with which patients identify as well as the social behaviours they create (Stryker, 2008). Since diabetes is a disease bound on the basis of self-management and a wide-range of relationships (e.g. healthcare workers, family, friends, coworkers) these theoretical frameworks provides additional support when making sense of such information (Stryker, 2008).

Despite the international classification of type 1 diabetes, it still creates confusion among the general population, as some fail to understand the disease beyond its traditional meaning and definition (Rock, 2005). Although the term *juvenile diabetes* has largely been replaced by *type 1 diabetes* post 1950, this type of diabetes is still largely associated with children and adolescents (Rock, 2005).

The identity development of adolescents or young adults with type 1 diabetes can be largely influenced by a multitude of factors. Glucose control, familial support and overall treatment of type 1 diabetes have been directly related to patient's identity development and management of the disease, especially amongst adolescents or young adults (Berlin et al., 2002; Esteban y Peña et al., 2010; Goldman & MacLean, 1998; Herrman, 2010; Mol, 2000; Rock, 2005). Correlations have been made between diabetes and decreased self-perceptions, anxiety and additional health risks, with patients' feelings and emotions at the time of diagnosis also considered to severely impact their self-acceptance and their acceptance of the disease (Berlin et al., 2002; Esteban y Peña et al., 2010; Goldman & MacLean, 1998; Herrman, 2010; Mol, 2000; Rock, 2005). Ockleford, Shaw, Willars and Dixon-Woods (2008) found patients could be categorized into four types of diabetic identity upon diagnosis, with the two extremes consisting of "accepters" to "resisters" (p. 30-31).

### **Diabetic temporality**

Daily experiences, treatment and management techniques of the "diabetic experience" (p.103) form an integrated system via their relationship with time (Maines, 1983). Maines (1983) discussed temporality, a linear timeline, as an objective measure of one's position, combining "physiological, emotional, social, interpersonal, technological, organizational, institutional, and personal" (p. 103) experiences. He suggested individuals with diabetes have difficulty separating the physical or physiological repercussions of the disease with their lived experience because the symptoms of either hypoglycemia or hyperglycemia create the link and blur the boundaries.

Morris (2008) expanded on Maines' (1983) discussion of temporality stating that the lived experiences of CD, specifically diabetes, disturb one's sense of past, present and future to the point of distorting their sense of freedom. People with CDs also develop a warped sense of provisional time or temporary status of being as they sometimes view themselves as being trapped in a life that is not their own (Morris, 2008). Morris' (2008) view stems from the fact that people do not choose to have type 1 diabetes therefore they may feel "clocked by what must be biologically provided" (p. 412). The altered sense of normality or regularity can also be exaggerated by technology, such as a glucometer (Mol, 2000; Morris, 2008).

The glucometer produces results with which individuals with diabetes use as a specific numerical measure of health (Clarke & Foster, 2012; Mol, 2000; Morris, 2008). Through self-management techniques, individuals with type 1 diabetes adjust and alter their treatment, management and care based solely on the numerical result produced by the glucometer (Mol, 2000). The practice of self-regulation and self-discipline however treat one's body as an object, forever tying them to such tools of measurement, which happen to be their own individual blood glucose readings (Mol, 2000).

### **Diabetes and gender disparities**

This section will focus on the experiences of individuals living with type 2 diabetes as the long-term effects of health outcomes have yet to be explored with older adults who have type 1 diabetes. When considering overall population health trends, men are more likely to endure more acute diseases like heart disease or cancer whereas women are more likely to experience CDs such as arthritis or type 2 diabetes (Olshansky et al.,



1991). Despite the high prevalence rates of diabetes among specific racial and cultural groups (Aboriginals, Hispanics, Asians, South Asians or Africans), as well as a greater occurrence in males, rates of type 1 diabetes are generally equal among Caucasian populations (CDA, 2008; CDA & Diabetes Québec, 2010; Kordonouri, Hartmann, Deiss, Wilms, & Grüters-Kieslich, 2005). Although the rates of diagnosis are practically equivalent between Caucasian genders, additional health risks and complications are typically found among females. Women with type 2 diabetes are more likely (than men) to develop high blood pressure, obesity, depression, osteoporosis, celiac disease, kidney disease, thyroiditis, multiple sclerosis and cardiovascular disease (Gebel, 2011; Kordonouri et al., 2005; Ruder, 2007). Reasoning for disparities between Caucasian genders are quite often linked to biology as women often witness a decrease in levels of good cholesterol (HDL) following a diagnosis of type 2 diabetes (Gebel, 2011). Low HDL levels combined with high triglycerides form a recipe for disaster, as they place women at greater risk for heart disease. Women with type 2 diabetes may also have lower levels of estrogen, causing their bodies to produce additional testosterone; testosterone is a known factor of kidney disease (Gebel, 2011).

Ironically, the aforementioned complications, more specifically high blood pressure and cardiovascular disease, are more prevalent in men within general [healthy] population (Gebel, 2011). Gebel (2011) argued that because of this abnormal shift, women are often subjected to less effective healthcare especially when it comes to psychological and sociological factors; one of the main reasons for such lack of care could be attributed to social perceptions. Since women in the general population typically

have lower risks of cardiovascular disease, a man may be viewed as a higher health concern. In such given scenario, women might receive less rigorous medical treatment in comparison to men (Gebel, 2011).

### **Diabetes and depression**

Along with the staggering prevalence of type 1 diabetes, rates of chronic depression are increasing, affecting approximately 340 million people across the globe (Egede & Ellis, 2010). Egede and Ellis (2010) believe diabetes and depression are intertwined as they found people with type 1 diabetes, in particularly women, were more susceptible to depression than the general population. They suggest this perhaps is a result of daily chronic stressors, noting relationship patterns of hormone imbalance, alterations in glucose function, and increased immunoinflammatory activation (Egede & Ellis, 2010).

Egede and Ellis (2010) noted the presence of depression with diabetes severely affected glycemic control, increasing HbA1c levels over four years. They also found both CDs led to higher rates of complications associated with diabetes such as diabetic retinopathy, neuropathy, functional disability, and increased risk of death. Egede and Ellis (2010) claimed it is difficult to treat both CDs simultaneously as multiple methods tend to interfere; oral medication and psychotherapy in combination with diabetic medications only improved mood, not glucose levels. The Canadian Diabetes Association (CDA) (2008) adds to the previous argument claiming poor self-care behavior, health complications, decreased QOL, and increased familial problems are potential results of the combined CDs.

Both type 1 diabetes and depression have the ability to cause psychiatric disturbances, altered autonomy or identity, low self-esteem, mood dysregulation, family dysfunction, and anxiety (Davison, 2003). Davison (2003) suggested nurses or diabetes educators should provide a comfortable environment for the individual to openly discuss concerns or problems. Healthcare providers should ask the patient how they perceive their social, sexual, educational or employment environments and follow-up appointments should be regulated (Davison, 2003). While we know this process is significant when youth are diagnosed with type 1 diabetes, it is unclear as to what the diagnostic experience may be like for someone diagnosed with type 1 diabetes in adulthood or mid-adulthood.

### **Conclusions**

Despite the fact that research on type 1 diabetes and its repercussions comes to a halt at young or mid-adulthood, the disease itself and the individuals are still animate. The ability to neglect a large population of chronically ill individuals begs the question of how individuals with type 1 diabetes age with and experience a CD across their lifecourse, especially when incorporating all of the above-mentioned relationships and trends. Understanding the experience of living with a CD across the lifecourse becomes even more intriguing when the technology used to treat and manage type 1 diabetes is considered alongside the dramatic advancements made to improve health outcomes and QOL.

## **Dispelling Myths about Older Adults and their Relationship with Technology**

### **The development of [theories of] technology**

Before critically examining the literature on older adults and their use of technology I believe it's important to take a grassroots approach, and understand how technology itself is developed as well as some theories used to explain and explore such process.

Dating back to the late nineteenth century, science and technology studies (STS) were constructed as a form of understanding relationships between science, technological development, institutional organization and health (McDonnell, Lohan, Hyde, & Porter, 2009). Since its debut, the study of science and technology has been framed through interdisciplinary means, combining aspects of both theoretical perspectives. Introductory explorations into this multifaceted relationship suggest science is the crux of innovation and technological development, while the birth of technology is viewed as a direct extension of science itself (Pinch & Bijker, 1984). STS are encapsulated in social constructivism, taking a philosophical turn in an attempt to separate technology from science using specific distinctions: science as the discovery and technology as the application of truth, respectively (McDonnell et al., 2009; Pinch & Bijker, 1984).

The consideration of technology as an artefact extends the contention that technology needs to be explored from the inside out (Pinch & Bijker, 1984). An artefact is the objectification of a technological device, implying that its success is a result of its future development (Pinch & Bijker, 1984). Pinch and Bijker (1984) believe technology is socially constructed and suggest an artefact is formed through social cultures,

determined by accessible resources. Artefacts are multidimensional objects formed through a collection of social processes, including everyday values, beliefs and behaviours; meanings, language and symbols also influence the development of an artefact (Pinch & Bijker, 1984).

Pinch and Bijker's (1984) ideas can be more broadly understood within the social construction of technology (SCOT) theory, which is one of the most common technology theories today. SCOT extends the idea of technology as an artefact and suggests that the formation and tailoring of a device to better suit a specific population is dependent on society. Therefore, the developmental process involved in the creation of a technological artefact is a result of exploration, which focused on variation and selection processes (Pinch & Bijker, 1984). This model is often visually represented by a web-like design and is used when attempting to comprehend different viewpoints, perceptions and conceptions of specific devices (Pinch and Bijker, 1984). This approach begs the question of the reasoning why some variables are accepted for the process and others are set aside (Pinch & Bijker, 1984).

The consideration of social groups affected by a particular artefact is important during the design process, as social groups attach meanings to specific objects (Pinch & Bijker, 1984). Pinch and Bijker (1984) suggest this can be a complicated process as some artefacts may be tailored to either one homogeneous social group or one heterogeneous group consisting, each of multiple subgroups. Once the most relevant social groups have been determined it is important to uncover one consistent meaning, throughout each group, which then describes the artefact. Therefore, it is crucial to have sufficient

background information to define the relevance of the artefact's meaning and function for each social group (Pinch & Bijker, 1984). Each group outlines potential problems they see with the artefact's design, followed by a review and discussion of technical requirements, solutions and moral conflicts in an effort to stabilize the artefact (Pinch & Bijker, 1984). Therefore, it is fair to claim that technology may be drastically modified before it is even rendered public. Specific devices are clearly a result of meanings and opinions to a select group of individuals.

Closure and stabilization of technology is achieved when all social groups come to a general consensus of meaning. If there are no problems, modifications are finalized and the technology takes shape (Klein & Kleinman, 2002; Pinch & Bijker, 1984). Klein and Kleinman (2002) identify two types of closure: rhetorical and redefinition. The former is when no further problems exist between social groups and the design is finalized. The latter occurs when unresolved problems between social groups are redefined in a way that they no longer pose a problem to any of the social groups. Despite either outcome, such processes question reliability and validity of moral or ethical considerations.

The final component of SCOT is the consideration of sociocultural and political contexts wherein the development of the artefact takes place (Klein & Kleinman, 2002). This idea is formed on the basis of communication, connections, and exchanges between social groups, as it encompasses relations to each individual, rules or guidelines governing interactions, and invisible discrepancies of power especially within research sites (Klein & Kleinman, 2002).

### **Governance of technology**

Fox, Ward and O'Rourke (2006) argue technology has immense implications for society through its ability to guide, control and govern. Technology acts as a form of social governance, which may be understood through examples including nuclear power, genetic engineering or modification of the food and drug safety and administration. The previously mentioned are relevant examples of governance as they pose issues in relation to health, safety, and security of the public at large (Fox, Ward, & O'Rourke, 2006).

To outline the impact of technological governance, Fox et al. (2006) use the example of pharmaceuticals, under which normal circumstances must incorporate public safety, individual freedom, human rights, as well as national, international and commercial law. Typically, pharmaceutical governance is achieved through the incorporation of governmental agencies, professional or scientific groups, and patient or consumer obedience (Fox et al., 2006). However, the introduction and widespread usage of the Internet has completely altered the type of governance offered by pharmaceutical consumption, especially in relation to the fashion in which patients obtain drugs and information. The Internet is a form of communication, which promotes and advertises health information and has completely changed the face of the pharmaceutical industry. The Internet provides patients with a more accessible way to purchase their products and has therefore become a form of authority as governments and agencies have minimal control over society's access to the World-Wide Web (Fox et al., 2006).

The actor-network theory (ANT) elaborates on the ideas of SCOT suggesting technology goes further than simply assessing the relevance of its social structures to

highlight the impact of the actor (McDonnell et al., 2009). The concept of the actor is created when authority or agency is given to any object playing a role in the social development or formation of technology (McDonnell et al., 2009).

Symon and Clegg (2005) expand on the idea of the actor through their exploration of a technological user. Given the example of information technology (IT) industry, professionals are turning to sociologists and ethnomethodology to better understand user requirements beyond direct interaction (Symon & Clegg, 2005). IT specialists are situated within the user's work environment to comprehend their technological needs. Since IT developers are constantly present, they are available to the user at all times. As a result, user representatives are constantly praising new technology to their colleagues (Symon & Clegg, 2005). Symon and Clegg (2005) argue the process of system developments and advancements are highly politicized as only specific users are involved or considered appropriate representatives.

### **Technology and older adults**

At this point I must clarify, for all intents and purposes of this research, technology may imply any sort of tangible device, behaviour, practice, belief or value that forms a crucial component to one's treatment or management of type 1 diabetes. Incorporating technology, in a broader sense, is important when it comes to older adults and their daily lives. The relationship older adults have with technology, their usage and their degree of acceptance has been a focus of gerontological research since the 1990s (Malanowski, Özcivelek, & Cabrera, 2008).



The field of gerotechnology has accepted and acknowledged many concerns older adults have with technology, including the fact that nearly one-third of the older adult population is “digitally challenged” (Malanowski et al., 2008, p. 24). Malanowski, Özcivelek and Cabrera (2008) vaguely implied the digitally challenged to be a broad group of adults who have various problems or impairments when accessing technology. Older adults are often intimidated by technology, especially if it is difficult to use due to physical impairments such as hearing or vision loss or decreased dexterity (Malanowski et al., 2008). They prefer items that are educational, and provide clear or specific instructions and are more comfortable with human interaction when in need of support, instead of an automated system (Hamilton Council on Aging, 2010). Gerotechnology has noted that older adults have many needs when it comes to technology: individual, personal environment, and social environment (Malanowski et al., 2008). Some examples of devices in each category might be hearing aids, grab bars in the bathroom, and accessible computer software respectively. All of these needs tend to fall into more comprehensive needs such as health, safety, independence, mobility and participation (Malanowski et al., 2008). With that being said, communication and accessibility are key factors when it comes to older adults and their use of technology.

Extending these ideas and understandings to the realm of healthcare is crucial when contemplating the needs of older adults. Healthcare is more complex than simple medications, treatments or services received. Fox and Ward (2006) suggest a phenomenological approach to understanding health and illness, as it establishes social, cultural and psychological components. These components explain how societies as well

as individuals come to understand health and illness with current considerations of health and technology where the responsibility is shifted to the patient or the user (Fox & Ward, 2006). I will further elaborate on the adoption and use of technology in healthcare using Fox's (2011a) explanation of boundary objects.

According to Fox (2011a) a boundary object is “a construct that has potential to improve the uptake transfer and innovation of research findings, technology and other intellectual property across the fields of social policy, organization and management and commercial and public services” (p. 70). These objects have the ability to enhance capabilities of ideas, theories or practices and extend beyond cultural limitations (Fox, 2011a). Therefore, the goals of technology primarily need to be understood by operational staff so professionals and practitioners will be more accepting of adaptation to new innovations. The success or failure of technology depends on the advantages of the product, as well as all actors involved (Fox, 2011a). This component is extremely important when considering older adults as they have an extensive history of experiencing challenges or barriers when it comes to technology.

The Design for All (DfA) concept consists of three important strategies to consider when incorporating technology into the lives of older adults: usability, adaptability and standardized interfaces (Malanowski et al., 2008). Essentially, products or services incorporating older adult users should be not only be designed specifically for an older population. Such technology should strive to target as many people as possible (sans modification), despite their age, ability or situation (Malanowski et al., 2008). This idea is similar to that of universal design or accessibility. Secondly, expanding on the first

strategy, aforementioned products should be adaptable to all users in a relatively simple manner (Malanowski et al., 2008). Thirdly, continuing with such design tactics, the products should consist of standardized interfaces or menus, so they may be accessed by people with unique needs. The DfA strives to promote an inclusive society, integrating people of all ages, races, social classes and abilities (Malanowski et al., 2008).

Fox (2011a) hit the nail on its head when he discussed boundary objects. As components that can be understood and received by actors in various settings, boundary objects establish a certain language and communication with individuals from differing physical, geographical, mental and social locations. The reception of technology is higher with boundary objects because they acknowledge social relations and power meanings (Fox, 2011a). This is essentially the same sort of design suggested by Malanowski et al. (2008).

Sparked by technology and the increasing popularity, the Internet has become an extensive forum for promoting health information and patient self-management (Fox, 2011b; Miller & Pole, 2010; Ziebland & Wyke, 2012). Fox (2011b) found one in four people who use the Internet have a CD and people living with CDs (such as diabetes) are more likely than the general population to look at health information online. This includes reading health blogs, searching health-related information, watching health videos and signing up to receive information about a specific health condition (Fox, 2011b). Social media and networking sites like Facebook are also common, especially to highlight health issues. Health issues or conditions may be recognized by users to follow their friends'

personal journeys, memorialize people who have passed (from a specific condition), fundraise for a specific cause or group, or to simply gather information (Fox, 2011b).

Blogging, in particular, is a relatively new phenomenon, which broadly focuses on patterns of self-expression, communication, and the formation of networks or communities. With that being said, many health blogs concentrate on particular diseases, illnesses or conditions and are heavy in text (opposed to audio or visual material) (Fox, 2011b; Miller & Pole, 2010; Ziebland & Wyke, 2012). Miller and Pole (2010) suggest health blogs mimic the journaling process, as authors tend to share personal experiences and stories in an effort to raise public awareness and act as a form of support for others. Blogs can also be cathartic as they often touch on the mental, physical, social and emotional aspects of living with a health condition (Miller & Pole, 2010). Similarly, reading about others' personal experiences has the tendency to impact one's decision making, sense of self or isolation, support and coping to a CD or condition (Ziebland & Wyke, 2012). Online support has gone viral because the World Wide Web is accessible around the clock; it eliminates the aspect of planning around dates, times and travel options (Ziebland & Wyke, 2012).

While such literature attempts to understand how older adults relate to technology, interactions with medical technology necessary for their survival is not discussed, only similarities, assumptions and correlations can be made. As the population itself ages within a technological society, the implications of advancements in type 1 diabetes care and its relationship with older adults is of great concern. If technology is truly adding years to the lives of people with type 1 diabetes, many more adults will be carrying their

CD with them into older adulthood. This shift challenges typical lifecourse trends and perspectives of CD diagnosis occurring within older adulthood. The trajectory of an aging person with type 1 diabetes has not been explored.

Understanding how older adults relate to the technology used to treat and manage their disease will provide a more holistic or well-rounded view of type 1 diabetes care, shedding light on particular behaviours and actions performed by the patient. This research will provide numerous practical health implications. It will give healthcare professionals a personal view and understanding of the experiences older adults face in relation to current systems and services. Expanding the knowledge database of healthcare professionals will aid in ameliorating treatment, management and education to individuals living with type 1 diabetes, as there is currently limited literature on adults with type 1 diabetes.

### **Summary and Rationale for Current Research**

Current literature has explored some very important health issues associated with diabetes. Symbolic interactionism and identity theories have shown to be valuable when uncovering relationships between people with diabetes and their self-perception, identity and self-management techniques. These theories outlined how understandings of the self, especially in relation to others (family or healthcare professionals), truly form patients' existing roles and identities. Undesirable feelings and emotions surrounding a diagnosis of type 1 diabetes can lead to negative self-perceptions, poor management techniques, depression, eating disorders, and even accelerated death. It has been noted that particular issues such as self-perception, identity and eating disorders have primarily focused on

their implications with youth or young adults. Perhaps this is due to the fact that adolescence can be a period of heightened emotion and self-direction as a result of hormone changes (Berlin et al., 2002; Davison, 2003; Goldman & MacLean, 1998; Herrman, 2010). Although, it is still troubling that we do not know if or how these issues impact older adults. Alternatively, important health complications associated with the disease, such as depression, cardiovascular problems and kidney failure, have either targeted individuals with type 2 diabetes or focused on diabetes as a general population.

Despite highlighting the importance of self-management and routine treatment techniques, individuals with any form of diabetes may often be susceptible to additional complications. Current literature predominately emphasizes the severity of type 2 diabetes complications, yet the problem lies in the application and directed target audience. There is an enormous lack of understanding when it comes to older adults with type 1 diabetes.

Although the prevalence of type 2 diabetes is on the rise among older populations, so too is the prevalence of type 1 diabetes. Individuals with type 1 diabetes are now carrying their CD into advanced adult years, primarily due to advances in medical technology; technological advancements in treatment for type 1 diabetes have improved management and QOL for people with type 1 diabetes since the discovery of insulin in 1921.

Along with advancements in technology, I have noted a stereotype or common theme within the literature. Current gerontological research suggests the majority of older adults dislike technology because of its complicated nature and numerous barriers.

However, it is evident people with type 1 diabetes rely on technology for the daily treatment and management of their disease. Therefore the relationship between older adults with type 1 diabetes and technology most certainly needs to be explored.

Literature within these intersecting fields has left serious gaps and many unanswered questions. The international population is continuing to grow alongside an international increase in the prevalence of CD. In combination with these two serious societal changes, advancements in technology have led to a rise in the uptake of devices, especially with regards to medical technology. All of these concerns provide clear support for my proposed research. The need for this project is crucial as the implications of aging with type 1 diabetes and the trajectory of an individual aging with type 1 diabetes have not been explored.

## CHAPTER FIVE: METHODOLOGY

It is extremely evident there are disconnects between aging, CD and technology research and literature. The purpose of this study was to investigate the following research question: *How do older adults with type 1 diabetes relate to technological advancements used in the daily treatment and management of the disease?* Not only was it important to conceptualize the relationship between older adults and their uptake of technology, yet comprehending how they identify with such devices was crucial. It was also imperative to explore the impact of technological advancements on traditional life course models and expected transitions of aging to further understand how older adults managed living with a CD into their advanced years.

### **Qualitative Research**

This research examined the relationship between people with type 1 diabetes and their use of technology necessary for daily treatment and management, through a qualitative framework. Qualitative research is a method of social science investigation striving to develop sociological insight (Van Den Hoonaard, 2011). Often understood as a form of action research, it is used to gain information regarding human beliefs, values, behaviours and experiences, especially in relation to an individual's decision-making process. Essentially, qualitative research is an exploratory approach to comprehending the concepts and phenomena of everyday life (Van Den Hoonaard, 2011).

The bottom-up approach of grounded theory is largely based on the notion that truthful answers are found among smaller concepts, which flourish into theoretical material (Glaser, 1992). A constructivist approach to grounded theory was used to explore



the relationship between older adults and technological advances in type 1 diabetes management (Glaser, 1992; Charmaz, 2006). It was intended to bring awareness to the needs of people with type 1 diabetes and their identification with technological devices (Klein & Kleinman, 2002). Considering the gaps within the literature, emphasis and value was placed on personal insight and first-hand experience. Therefore, the social experiences of older adults living with type 1 diabetes were explored through individual interpretations and personal accounts (Creswell, 1998).

### **Grounded Theory Methodology**

This section explains the basic methodological framework for the research and provides a detailed explanation of the processes and procedures used in this study. It will also justify the approach taken to answer the research question regarding older adults with type 1 diabetes' use of technology.

Grounded theory was introduced in the 1960s as a contemporary approach to qualitative research. Originally discovered in 1967 by Glaser and Strauss, grounded theory was designed to eliminate researcher's preconceptions of data in their field (as cited in Charmaz, 2006). The intent of grounded theory was not to test hypotheses or rely on current research assumptions but rather, to explore and discover research ideas and concepts presented within the data itself (Glaser, 1992). This specific method eliminated the concept of a guiding theory. In fact, theory is determined by the data itself because the participants are considered experts in the field; participants are the ones who are actively involved in their experiences therefore a theory is generated by first-hand information (Glaser, 1992). "The grounded theory approach is a general methodology of analysis

linked with data collection that uses a systematically applied set of methods to generative inductive theory about a substantive area” (Glaser, 1992, p. 16).

The reason grounded theory is considered reliable is because of its relationship between data collection and analysis. The researcher is responsible to begin analyzing and coding research data continually throughout the collection process (Glaser, 1992). This important procedure known as the “constant comparative method” (p. 38), allows the researcher to analyze data, construct meaningful codes, develop hypotheses and continue to test such categories or relationships on new emerging data (Glaser, 1992). Analysis then creates a bond between the researcher and his or her own data (Strauss & Corbin, 1998). Grounded theory is considered successful if it meets its four central criterion: fit, work, relevance and modifiability (Glaser, 1992). Fit refers to whether or not the categories and properties of the proposed research area coincide with their realities from the viewpoint of the subjects, practitioners and researchers. This methodology is considered effective if it appropriately outlines and explains the behaviours within the research area as suggested by the participants (Glaser, 1992). By simply achieving stages one and two, grounded theory is considered relevant. However, to be considered successful it should always be open to change and modifications especially if new data provides different concepts, properties, categories and direction (Glaser, 1992). Grounded theory must be open-minded and able to accommodate and adapt to emerging issues.

Despite the careful instructions of grounded theory, Charmaz (2006) challenged some of its core principles suggesting they were too rigid and not able to adjust to modern theoretical and methodological developments. Charmaz (2006) suggested Glaser and

Strauss (1967) ignore the valuable role and impact of the researcher or observer. She challenged the previous notion that the researcher is separate from the data and suggested theories are formed not only from the emerging data but also from the past and present experiences of the researcher. She believed the observer's interactive relationships with people, perspectives, practices and environment is relevant data, which constructs the grounded theory. Charmaz (2006) suggested meaning and theory from the data is co-constructed between both the researcher and the participant, it is not simply a profound discovery (as cited in Gibbs, 2010). Therefore any theory derived from the data is a mere interpretation of the observed because it is simply an opinion and not the actual picture or tangible experience (Charmaz, 2006). That is, it cannot claim truth status, but is a co-constructed account produced by both the researcher and the participant (Charmaz, 2006).

Despite loosely following Glaser and Straus' (1967) development of grounded theory, I believed it was important to incorporate a guiding theoretical perspective given my research topic. The lifecourse perspective was used as a framework, which provided a specific lens with which to incorporate grounded theory. At this point, the life course perspective will be used to outline the potential findings and create an expandable shell to view older adults' experiences with diabetes technology as they age.

### **Overview of Research Intentions and Expectations**

This thesis was designed to explore the various experiences and relationships of older adults living with type 1 diabetes including how older adults with type 1 diabetes related to technological treatments and management techniques. The current research

study challenged typical or expected transitions and trajectories associated with aging and aimed to explore the following:

**Research question**

- How do older adults with type 1 diabetes relate to advancements in technological treatments?

**Objectives**

1. Explore the experience of aging with a CD (type 1 diabetes);
2. Describe the function of technology used for daily treatment and management of type 1 diabetes;
3. Understand the relationship between older adults with type 1 diabetes and the technology used for daily treatment and management of the disease.

Together these objectives combined an interest in the experience of aging with CD and type 1 diabetes care. In-depth, semi-structured, qualitative interviews with older adults living with type 1 diabetes highlighted their first-hand opinions and experiences of healthcare services and systems. The results and outcomes of this research were intended to educate the general public and healthcare professionals about the lives of older adults' with type 1 diabetes, with the goal of ameliorating treatment, management and education for people living with type 1 diabetes.

After receiving ethics approval in August 2012, I began the recruitment and data collection. Knowing that I had personal connections with local diabetes organizations (e.g. Animas Canada, CDA, JDRF, Hamilton Health Sciences [HHS] Diabetes Care and Research Program [DCRP]), I started networking with them in an effort to recruit

participants. I had planned to target individuals from the Greater Hamilton Area, with most of my interviews taking place throughout the city.

Loosely following the thesis guidelines within the department of Health, Aging and Society at McMaster University, I intended to conduct and complete my interviews by the end of December 2012. Following this, I expected my literature review to be completed early in the New Year so I could begin transcribing. This would give me ample time to complete the transcription and analysis of interviews, on my own, by March 2013. I would then continue writing and tying up loose ends until mid-May 2013. Therefore I would have plenty of time to edit my paper before the oral defense in July 2013, and completing the project before its final due date of September 2013.

### **Participant Criteria**

This study included five participants from the Greater Hamilton and Toronto, Ontario regions. This geographic area was chosen due to its proximity with the researcher's location, McMaster University. Participant criteria included male and female adults over the age of 55. Each participant had a diagnosis of type 1 diabetes before the age of 45. I did not ask participants specifically about their ethnicity. Three participants were male and two were female. Ages of participants ranged from 55 to 72 years of age. More detailed demographic information of participants can be found in Table 1.

### **Recruitment**

Preliminary methods of recruitment included word of mouth and snowball sampling, which came into effect when my supervisor had distributed my contact information and study topic within her networks. This stage began in the summer of 2012.

More initial stages of recruitment began in the fall of 2012 and involved placing posters (Appendix B) in locations potentially frequented by people with type 1 diabetes. These locations were places people with type 1 diabetes may have visited on a regular basis and included health clinics, diabetes education centres, hospitals and offices of local organizations supporting people with type 1 diabetes. To be more specific, posters were placed in the waiting room at the HHS [Adult] DCRP office (4Y clinic at McMaster Children's Hospital), all hospitals belonging to HHS and circulated within various branches of CDA (i.e. Brantford, Central South Region, and Niagara Region).

The month of November 2012 was rather successful as personal connections with employees at the CDA Central South Regional Branch led to a local Hamilton support group for adults with both type 1 diabetes and type 2 diabetes. I attended one of their regular monthly meetings and delivered a presentation of my research. Posters were circulated amongst members at the meeting, and some took a few with them to pass on to acquaintances, friends and family.

Within the first two weeks of November, I established communication with my first participant, who was referred by my supervisor. A few weeks later, my second participant, a member of the support group, contacted me; we met at a coffee shop close to the McMaster University campus. After these two interviews, recruitment seemed promising but to no avail. At this time, with minimal interest from the local support group, recruitment became rather difficult. I started to think more broadly and relied on personal connections to friends, family and professionals in the field of diabetes back

home in New Brunswick. Although this raised some awareness about my project, there were no major developments through this attempt.

By December 2012, upon confirmation of my third thesis committee member, it was suggested I continue to expand my professional relationship with the clinicians at the HHS DCRP office. Within the month, I discussed my research participant criteria with the employees at the centre in hopes that they would communicate my information to their patients. This experience proved to be quite successful as I obtained two more participants using this technique.

Lastly, my fifth and final participant was retrieved through one of my committee members. The participant was a colleague with my committee member, which led to the delivery of my contact information. The colleague contacted me and confirmed interest in helping me with my research. A decision was made to complete the study with five participants due to the complexity of recruitment.

### **Sample**

The demographic background of participants (shown in Table 1) was relatively balanced with regards to the gender and marital status of participants. Trends differed amongst participants' current ages, which ranged anywhere from 55 to 72 years old; the majority of participants were in their 60s. The ages at which participants were diagnosed also varied from 5 to 36 years of age, with the majority of participants diagnosed around the age of 30.

**Table 1: Demographic Background of Participants**

<b>Participant</b>	<b>Gender</b> <i>M = Male</i> <i>F = Female</i>	<b>Current Age</b> <i>(in years)</i>	<b>Age at Diagnosis</b> <i>(in years)</i>	<b>Marital Status</b>	<b>Children</b> <i>Y = Yes</i> <i>N = No</i>
Paul	M	62	28	Married	Y
Janice	F	62	36	Married	Y
Fred	M	67	30	Married	Y
Sandra	F	55	5	Married	Y
Dalton	M	72	17	Married	N

Apart from the similarities between the majority of participants two individuals, Sandra and Dalton, maintained a more traditional diagnostic profile of type 1 diabetes as they were diagnosed at ages 5 and 17 respectively. Diagnoses at such ages are most commonly associated with type 1 diabetes and its predecessor namesake - juvenile diabetes (Diabetes Health, 2012; Rock, 2005). With that being said, these two participants were the closest to my ideal participant profile.

Nevertheless, the pattern and connection between the majority of individuals' demographic information was quite interesting. Participants Paul, Janice and Fred were currently in their 60s and were all diagnosed after the age of 25. This information reflected a more unique trend of type 1 diabetes, as patients were predominately diagnosed in childhood and adolescence. It has only been within the last few decades that the shifts in diagnostic trends have been noted across all ages (Diabetes Health, 2012; Rock, 2005). This change has been instrumental, altering the classification of the disease





from juvenile diabetes to type 1 diabetes (Diabetes Health, 2012). The reasoning for this modification is because type 1 diabetes can be diagnosed at any age and the majority of people who have type 1 diabetes are adults (Diabetes Health, 2012; Miselis, 2011).

For example, the JDRF has modified their organizational logo to eliminate the full name of Juvenile Diabetes Research Foundation to simply, the acronym JDRF (Miselis, 2011). The abbreviation was designed to acknowledge the organization's support for all individuals with type 1 diabetes, regardless of their age (Diabetes Health, 2012; Miselis, 2011). This rebranding has also changed their tag line from "dedicated to finding a cure" to "Improving lives. Curing Type 1 Diabetes", with the word curing highlighted (Miselis, 2011, p. 2) (see Figure 1). They also emphasize a T1 in navy blue, which can be found within the first two letters of the JDRF acronym (Miselis, 2011). In addition, they now refer to people with type 1 diabetes as "T1Ds" (Diabetes Health, 2012, p. 1).

Although there was some disparity between the age of participants of diagnosis and the length of time participants had been living with type 1 diabetes, one thing was for certain: individuals with type 1 diabetes are now living longer than ever before.

***Figure 1: JDRF Organizational Logo Modification (Courtesy of The Juvenile Diabetes Cure Alliance (2011))***

JDRF Old Logo	JDRF New Logo
 <p>The old logo features the acronym "JDRF" in large, bold, black letters. To the right of the acronym, the full name "Juvenile Diabetes Research Foundation International" is written in a smaller, black, sans-serif font. Below the acronym and name, the tagline "dedicated to finding a cure" is written in a smaller, italicized, black font.</p>	 <p>The new logo features the acronym "JDRF" in large, bold, blue letters. To the right of the acronym, the tagline "IMPROVING LIVES. CURING TYPE 1 DIABETES." is written in a smaller, blue, sans-serif font. The word "CURING" is highlighted in a darker shade of blue.</p>

## **Procedure**

Upon initial contact, the participants received a telephone/e-mail recruitment script (Appendix C), which reiterated the rationale for the research. Once individuals expressed desire to continue with their participation in the research study, a date, time and location for the interview was confirmed. Before the interview, individuals were given a copy of the interview guide (Appendix D) via e-mail, which contained both demographic and interview questions as well as the written (Appendix E) and verbal consent form (Appendix F). This was done to provide them with additional information, support and comfort before the interview. It also increased efficiency and smoothness for the interview.

Interview location was largely based on the preference and availability of the participant. I suggested various locations such as McMaster University, the home environment of the individual, a local coffee shop or location of individual's choice. In one instance I travelled to a rural community on the outskirts of Hamilton to meet and interview a participant at a local coffee shop. Two interviews were conducted in local coffee shops within Hamilton, while another was held at the McMaster Children's Hospital (post DCRP appointment). The final interview was held at McMaster University campus in a vacant boardroom.

On the day of the interview, participants reviewed the interview guide, signed or gave verbal consent, and were given a hard copy of the written consent form, which reminded them of their rights to refuse to answer any questions and/or to discontinue their

participation in the study at any point (see ethics Appendix E). Interviews did not commence until the participant had provided written or verbal consent.

I conducted the interviews myself as I have some previous experience interviewing older adults. Interviews were tape-recorded using a digital voice recorder and uploaded to a computer using a USB connection device. The physical interviews alongside handwritten field notes were kept safe and secure in a locked cabinet in a locked office on McMaster campus, while the digital files were in a hidden folder with password protection. The data was accessible only to myself and my supervisor, Dr. Amanda Grenier. Once the interviews were completed, participants received a thank-you letter for their participation (Appendix G) along with a personalized thank-you card and a gift card to either a local grocery store or coffee shop. All participants have the opportunity to receive a broad overview of the research study results if so desired on their consent form. All data will be destroyed three years after the study is complete as per McMaster University ethical guidelines.

### **Methodological Considerations**

At this time it is important to acknowledge my personal journey with type 1 diabetes and therefore potential connections and opinions about the current research topic. To prevent the formation of preconceived notions, I took several measures to avoid implying my experiences to those of participants. Positionality, reflexivity and bracketing were all used to ensure the reliability and validity of the research findings and interpretations of the data collected.

### **Positionality**

Insider/outsider positionality refers to the role of the researcher or principal investigator within a particular project (Greene & Thorogood, 2009). Considering it is impossible to conduct qualitative research without full objectivity or preconceived notions, the way in which investigators conduct themselves is crucial (Ahern, 1999; Elo & Kyngäs, 2008; Greene & Thorogood, 2009). The way data is collected and analyzed is truly dependent on the role of the investigator in combination with their skills and techniques (Elo & Kyngäs, 2008). Oftentimes, researchers are involved with topics stemming from personal interest, which may then become emotionally difficult or challenging to work with. “A lengthy research endeavor on an emotionally challenging topic can infuse the researcher with its inherent challenges, render continuing research an arduous endeavor and, in turn, skew the results and interpretations” (Tufford & Newman, 2010, p. 81). Positionality is pertinent for this study as it ensures my primary role as principal investigator.

### **Reflexivity**

Engaging in the process of reflexivity is important in cases of overlapping insider/outsider positionality. Reflexivity is the ability of a researcher to reflect on their experience and be able to objectify their role or involvement (Ahern, 1999; Bourdieu, 1996; Manderson, Bennett, & Andajani-Sutjahjo, 2006; Thorne, Reimer Kirkham, & O’Flynn-Magee, 2004; Tufford & Newman, 2010). Frank (1997) claims, “Reflexivity involves the realization that researchers are part of the social world that they study” (as

cited in Ahern, 1999, p. 408). Similarly, Porter (1993) extends this development saying, “This realization is the result of an honest examination of the values and interests that may impinge upon research work” (as cited in Ahern, 1999, p. 408). Reflexivity is important, as investigators must realize they are both makers and critics of knowledge (Manderson et al., 2006). Reflexivity is an extremely important process for me to follow for this research study because it provides me with the opportunity to be realistic and mindful of my dual roles. Taking field notes and keeping a journal throughout this process allows me to stay in tune with what is most important: the participants’ explanation of their social worlds.

### **Bracketing**

Bracketing is a technique, which builds off of positionality and reflexivity. Bracketing is a method used in qualitative research to protect both the researcher and the data (Tufford & Newman, 2010). Although the definitions vary, bracketing is the process whereby researchers set aside their personal connections or knowledge about the topic in question during the data collection and analysis phases, allowing the participants’ stories and experiences to take precedence (Ahern, 1999; Tufford & Newman, 2010). Essentially, the researcher should not abandon her assumptions but rather be honest about them from the very beginning (Thorne et al., 2004; Tufford & Newman, 2010). To ensure the most accurate results, bracketing must be well thought out, as its process is a “reflexive journey that entails preparation, action, evaluation, and systematic feedback about the effectiveness of the process” (Ahern, 1999, p. 408). Bracketing ensures validity

within the data (Ahern, 1999).

Despite acknowledging the connection, it is the researcher's responsibility to engage in self-reflection, and to decipher between elements belonging to her experience and those of participants (Bourdieu, 1996; Tufford & Newman, 2010). Bracketing may include the setting aside of information such as beliefs, values, thoughts, emotions, biases, preconceptions, or assumptions about the topic of research (Tufford & Newman, 2010). Some methods of bracketing and reflection include the writing of memos, notes or even research journals (Tufford & Newman, 2010). It is important for the researcher to acknowledge her personal connection to the topic, to be mindful of areas of subjectivity or role conflict, and to consider novel concepts; if there is no surprising material it could be a result of reaching saturation, or disconcertingly, it could be a sign of investigator desensitization (Ahern, 1999). However, Thorne, Reimer Kirkham, and O'Flynn-Magee (2004) suggest previous theoretical or subject knowledge may in fact be beneficial as it creates a much deeper connection with participants and may yield richer data. Therefore it is the researcher's responsibility to be carefully organized, take precautions and use their knowledge appropriately (Bourdieu, 1996).

In an effort to bracket myself within this research, I was mindful of my personal connection to type 1 diabetes and how it may affect my thoughts and opinions on the research topic. I made a conscious effort to ask for clarification and explanation of specific terms or acronyms used within diabetes nomenclature (i.e. A1C or CDA), as I did not want to hinder or skew the data. In order to receive the full experience, I made sure I

formed a generalized understanding of type 1 diabetes but always inquired about tools, terms, or practices.

### **Positionality, reflexivity and bracketing within my research**

Considering I had a personal connection to my research topic, as I have been living with type 1 diabetes for the last six years of my life, it was most important for me to maintain my role as researcher. In order to gain the most unbiased information from my participants, I did not divulge my diagnosis of type 1 diabetes willingly. However, my goal was not to deceive anyone, so if the participants asked me directly if I had type 1 diabetes, I answered truthfully; if the question did not present itself, I proceeded as if I did not have any insider positionality. Regardless of the situation, I disclosed my connection to type 1 diabetes at the end of each interview.

There were two individuals who were aware of my diagnosis before the interview had begun. To maintain outsider positionality, I used critical reflexivity techniques to focus the interview on their experiences. At any point where I felt as though the direction of the interview was changing or they were asking questions about my personal understandings, I would re-direct them to the question, re-phrase the question or ask them to further elaborate on their experiences. I made sure to politely remind them I was most interested in their life history with type 1 diabetes. I also kept a research journal as well as multiple memos or sticky notes which expressed particular feelings, emotions, thoughts, behaviours or attitudes with regards to any aspect of the research.

## **Analysis**

The analysis phase began when the digital mp3 voice interview files were transcribed using VLC media player 2.0.1, in conjunction with Microsoft Word. Each interview was transcribed manually, playing back small sections of the audio interview while typing. Participant personal identification information was not included in the transcripts. Names of participants were changed using pseudonyms created by the researcher.

Once the transcriptions were edited, I printed out a hard copy of each interview. Relying on the traditional techniques used in grounded theory analysis, the analytic process for this research loosely consisted of three main types of coding: open, axial and selective. Open coding is a preliminary form of coding where the researcher organizes data based on distinct properties, which then group together similar phenomena that are generated into specific codes (Gibbs, 2010; Glaser, 1992). For this stage, I completed an initial read-through of each interview, which acted as a preliminary form of analysis, during which I highlighted sentences or passages I found particularly interesting or relevant. Once this process was finished, I created themes and subthemes, also known as nodes. Once I established a list of nodes, I referred back to my initial research questions and created three major categories:

1. The experience of living with type 1 diabetes across the lifecourse and in advanced years.
2. Technology as a challenge to traditional lifecourse models, transitions and trajectories.



3. The relationship between older adults, identity and technology.

I colour-coded each question – yellow, orange and pink respectively. At this point, I reviewed the main arguments made in my literature review. I colour-coded and sectioned my literature review broadly, in conjunction with the abovementioned themes. I conducted a secondary read-through of my interviews, categorizing important passages into one of the three major themes, and coded them with the appropriate coloured flags. Throughout this stage I created linkages between the interviews and made note of more prominent subthemes, with specific examples and quotes from the interviews. Subthemes included the importance of type 1 diabetes identity and acceptance, CD as an interruption of life stages and the need for accessibility among type 1 diabetes management devices. This second read-through is identical to axial coding procedure, whereby the researcher creates multi-dimensional connections and relationships between codes, creating a visual axis (Gibbs, 2010; Glaser, 1992).

Lastly, I reviewed my colour-coded themes to highlight the subthemes, which were most prominent, especially in correlation with the literature. This third phase, also known as selective coding, is the process of choosing specific codes, which best describe the overall data and using them to generate one main theme or story that translates and produces an overarching theory (Gibbs, 2010; Glaser, 1992).

Charmaz (2006) expands on Glaser's (1992) perception of grounded theory, contending such methodology offers the researcher an opportunity to understand the messages portrayed without getting too broad or too specific. One of the basic principles of grounded theory is the constant-comparative approach, which allows the investigator to

understand concepts, patterns and develop basic properties of potential categories (Glaser, 1992). Using the constant comparative approach the investigator may examine a single excerpt of data (i.e. an interview or quote) and compare it to others. During this process the researcher would not only look for similarities but also differences between participants' reactions or statements on similar topics (Thorne, 2000). The constant comparative technique allowed me to stay in tune and close to the data; it provided me with the opportunity to stay in the realm of my research and refrain from adopting an outsider point of view (Charmaz, 2006). This was an extremely important habit for me to adopt as a researcher, considering my personal connection to the research topic.

Drawing on this technique allowed me to constantly compare the initial codes through each interview as well as the codes between interviews, without inserting my own personal reflections and opinions (Charmaz, 2006; Thorne, 2000). For example, I made mental notes of comments and quotes that were salient or repetitive throughout each individual interview. I was mindful of what each participant believed to be the highlights of their social experiences. I then compared how those comments and experiences transpired throughout each interview as well as how they may be similar or different to other participants. Considering aspects of a grounded theory analytic framework in combination with additional techniques such as positionality, reflexivity and bracketing, also helped me further understand and give meaning to words or phrases representative of the individual and the individual as part of a larger group (people with diabetes). These methods assisted me in keeping themes as close to the original meanings as possible (Charmaz, 2006).

Completion of the analysis phase resulted in a plethora of themes, which emerged from the data. Considering the research questions and objectives, only the three most salient themes and their corresponding subthemes on type 1 diabetes identity and acceptance, CD as an interruption of life stages and the importance of technological accessibility among type 1 diabetes tools were retained.

## **CHAPTER SIX: FINDINGS**

This chapter is designed to introduce the results and findings from the research, while incorporating relevant literature. This section combines traditional results and discussion pieces by intertwining the two to provide readers with the opportunity to relate and reflect on the relationship between the data collected and the literature in this field.

Three major themes will be discussed:

- Theme One: Living Longer with Type 1 Diabetes
- Theme Two: How Type 1 Diabetes Challenges Traditional Models of Aging and the Lifecourse Perspective
- Theme Three: Older Adults Welcome the Use of Technology

### **Theme One: Living Longer with Type 1 Diabetes**

#### **Identity and acceptance**

One of the most common and underlying subthemes for this entire research was the role of individual identity and acceptance of type 1 diabetes. The experience of a type 1 diabetes diagnosis was definitely a significant moment for most participants. Table 2 presents the details of diagnosis for the five participants. All but Sandra - who had minimal recollection due to her young age - discussed the importance of the diagnosis.

A diagnosis of type 1 diabetes can be highly emotional. The participants expressed many emotions and sentiments at the time of their diagnosis including anger, confusion, denial, disbelief, fear, relief, shock and stress. Some individuals, like Janice were not overly surprised by their initial diagnosis. Janice was adamant and knew something was wrong.

“It was based on the symptoms. Absolutely symptoms. No question. Yep, something was wrong and I knew it!” Later on in the interview, referring to the day she was diagnosed, Janice said, “And, all of a sudden something wasn’t right one day and I lost 25 pounds in three weeks. I had the blurred vision and the fronts of my legs were bleeding because I was scratching from the dry skin. I had a wicked appetite for French fries with gravy and root beer floats and that’s stuff I never ate. So I was diagnosed that day. I went to the doctor and he sent me over to the hospital and I was diagnosed right then and there.”

**Table 2: Participants’ Type 1 Diabetes Diagnostic Experiences**

<b>Participant</b>	<b>Symptoms</b>	<b>Informal Diagnosis</b>	<b>Formal Diagnosis</b>
Paul	1. Frequent urination 2. Thirst	1. Delivery room (daughter’s birth) 2. Medical test for group insurance company	1. Family doctor 2. Hospitalization (few days)
Janice	1. Blurred vision 2. Weight loss 3. Severely dry skin 4. Craving sugary & salty foods	1. Symptoms 2. Friend (RN)	1. Family doctor 2. Hospitalization (eight days) 3. BG of 19.8 mmol/L
Fred	1. Weight loss	1. Test at Shopper’s Drug Mart	1. Family doctor (eye test and insulin injection) 2. Endocrinologist * No hospitalization 3. BG of 700 mg/dl = 38.9 mmol/L
Sandra	1. Frequent urination	1. Failure of kidney pills (for dogs)	1. Hospitalization
Dalton	1. Frequent urination 2. Thirst 3. Fatigue	1. Symptoms	1. Family doctor (urine test) 2. Hospitalization (2-3 weeks)

The experience of a type 1 diabetes diagnosis differed slightly between participants. Although Paul had an inkling he may have had diabetes, his symptoms were not all that evident.

“Nothing severe. I mean, yeah maybe I was going to the bathroom a bit more than I should have been, and maybe I was a bit thirstier than normal but it wasn't anything really all that dramatic that you can put your finger on... It wasn't as dramatic of a thing and it turns out that they actually only got diagnosed when somebody took a blood sample and said, ‘Oh yeah, blood sugar's way up in Never Never Land.’”

Lastly, the diagnostic experience of Dalton seemed to be the most descriptive as he clearly explained many of the emotions and thoughts he was having. The following passage illustrated his experience well:

“Obviously the symptoms of diabetes are you get thirsty, you urinate, and at that time, even though I had a younger brother, nobody seemed to think much of it, you know? You just didn't know. I got to the point where I was really dragging me butt and finally I thought, ‘Oh, I've got to go to the doctor.’ So I went and I think it was in October or November or something like that. It was May or June when I had me mishap and it took a few weeks before you really felt some of these symptoms. Obviously your body doesn't change instantly, or at least I don't think it does. Anyway, in the doctor's office that night he said, ‘I gotta wrap on the knuckles for ya!’ And he said, ‘You got diabetes.’ And it sort of rocks you a little bit as a young person, you know it's a disease, which at the time it was considered serious ... And I didn't really know the ramifications. Anyway, it sort of upsets you psychologically, like you know. Part of it is the physical, you know? You drink, you can't get enough to drink and as it goes in, it goes out. So it's a really uncomfortable life for a while, or it was for me ... Anyway, you know. The first night I had that little shot, I could sleep for the night, which was amazing – instead of being up every 10 minutes, you know, running to the bathroom. And yeah. It's a long time. Like, actually, psychologically, the fact that you can't get enough to drink and that, I'll be honest with you, you used to think, ‘I'm gonna go drown meself in the river.’ You just want to get immersed in water.”

Just a few moments later, Dalton made another comment that resonated with me. He was reviewing his original stay in the hospital and his roommate who had developed a rare form of diabetes, which was temporary. When talking about how some forms of diabetes can suddenly disappear, he said, “I used to hope but it didn’t go away.” Keeping in mind what Dalton said while reflecting on the principles of symbolic interactionism and identity theory, help to shed light on the experiences and social worlds of individuals with type 1 diabetes. As expressed earlier, the competition between identities within a variety of social networks becomes complicated when emotion is added and self-esteem or self-perception are involved (Stryker, 2008).

According to the literature, one’s experience during diagnosis has significant implications for their future treatment, management and acceptance of type 1 diabetes (Ockleford et al., 2008). Ockleford et al. (2008) discussed two main types of individuals in relation to their diagnosis – accepters and resisters. Accepters typically had better health statuses as they tended to identify with their disease, had taken proper precautions, and were meticulous about treatment and management (Ockleford et al., 2008). Patients who accepted personal responsibility were also likely to maintain desirable health results due to their positive attitudes and behaviours. People with type 1 diabetes who described positive social support from their families, friends or workplaces seemed to have more optimistic narratives regarding their diagnoses and daily experiences (Goldman & MacLean, 1998; Ockleford et al., 2008). However, patients in all other groups faced numerous problems as a result of their neglectful identification of a diagnosis of type 1

diabetes, which truly impacted their attitudes and management behaviours; many neglected proper treatment or care (Ockleford et al., 2008).

### **Adaptation and emotion**

The relationship between a diagnosis of type 1 diabetes and disease management is also something I found during my data collection. Most participants reflected on their diagnosis and following years as significant to their connection with type 1 diabetes. There was definitely an adjustment phase for each individual; some lasted a few months while others lasted years.

The adjustment phase of type 1 diabetes was complex, as patients attempted to comprehend the disease, as well as tools and technology required for daily care. The development and adaptation to treatment and management regimens were highly emotional. For many, the knowledge could be overwhelming, which may explain why some individuals, like Fred, experienced phases of depression. This is consistent with what we know about the link between diabetes and depression (Egede & Ellis, 2010).

Fred said, “So I figured, okay, I’m diabetic, how is this going to work? I do know the first couple of years, the first year, I actually got into a depression, which I never do. I’m not an individual who, I’m not the kind of person who says, ‘Okay I’m not gonna.’ No, my makeup is I don’t get that way. That’s just not me. But I must admit, that one year, I guess it was diabetes. I figured, okay I got one guy saying I’m gonna die and another guy saying this is a long term chronic illness with all sorts of bad side effects but of course back then I was only 30.”

Janice expressed her uncertainty with diet and food consumption. She lacked confidence, as meal planning was not a focus of her initial hospitalization. She said:



“I came home from the hospital and I had no idea what I could eat - whether I could have bread or not. I remember those things. A friend of mine handed me a roll and said, ‘Eat it!’ And I was afraid to eat the dinner roll.”

Dalton discussed his fear of stigma and his phobia of being perceived as a drug addict, when he said:

“Well, one of the problems was I grew up and I came to Canada in 1963 and drugs and dope were all the things. And I was always afraid of being picked up as being a drug addict. And these were fears, you know. And I thought, oh, well even though you had a card and a tag, you know, you used to think, ‘Well, they’ll probably just lock me up if they see me doing this.’ And it was a bit of a phobia.”

Although circumstances surrounding diagnosis may have been difficult or fearful, it seems as though the experience combined with routine led all participants to adjust and slowly accept their diagnosis. Paul was a perfect example of this concept:

“They started by getting me used to the idea of giving myself an injection with just sterile water to get used to the idea of needles. Of course, the first time I just about keeled over – not quite but I felt a bit woozy after giving myself a shot of water. But since then, that’s millions of needles ago it seems. And it’s just a part of my daily routine now.”

The literature outlines how treatment options may facilitate a patient’s adaptation of numbers or numerical blood glucose results at face value, overruling and ignoring crucial physical signs and symptoms of the disease. This behaviour can be dangerous as technology (i.e. glucometers) can sometimes fail or produce inaccurate results (Mol, 2000). Mol (2000) claimed individuals with type 1 diabetes rely heavily on numerical results to determine a course of treatment or management action. Adopting numerical

results as definite may distract patients from their physical sensations, further blurring the boundaries between mind and body (Mol, 2000; Morris, 2008). Although constant monitoring may increase one's self-awareness, the reliance on numbers permits an increase in patient confidence.

An increase in confidence may lead an individual with type 1 diabetes to take more risks in their self-management responsibilities, even to the point of acting as their own personal doctor (Mol, 2000; Morris, 2008). Sandra truly expressed this idea when she claimed, "Yeah, I've fired many doctors over the years." She was referring to a point in her life when she wasn't happy with certain healthcare professionals and took it upon herself to attain the best care possible, elsewhere. Sandra was an extremely diverse case as she was not only a person with type 1 diabetes yet, a registered nurse and certified diabetes educator by profession. Sandra worked in a community health centre. When Sandra explained her health care routine she mentioned that she sees a variety of specialists (for multiple CDs) as well as her family doctor on a regular basis. However, when asked whether or not she attends a diabetes clinic or education centre, her response was unique.

"No, I do my own thing. So where my specialist is, is in [name of city], so I developed that program. And I trained her on insulin pump therapy. So I don't need to go anywhere. I'm a little bit off when it comes to those types of questions. I'm the odd ball."

It was hard for Sandra to separate her many social worlds, especially between her career and her personal health care regimens because she's constantly surrounded by diabetes.

Another commonality I noted was that most participants held on tightly to events of severe hyperglycemia and hypoglycemia, with excessive emphasis on the latter. Such experiences were quite emotional as they sparked embarrassment, fear, and in some cases guilt. This supported Maines (1983) argument that individuals with diabetes use the symptoms of such occurrences to interpret and make sense of their bodily function in past, present and future contexts. The hypoglycemic event Janice had, truly had and still has an impact on her. The event was significant as I could clearly sense her emotions when she told me about it.

“So I took my dose of 25 units of NPH going to bed and within an hour and a half I was convulsing. I could hear things but I couldn't make my body work. I couldn't talk and I had no idea the research that had been done on NPH and NPH will give you false positive readings ... that was devastating. Humiliating. Embarrassing. Because what happens to our body when ... because our bodily functions just release. So it was very embarrassing for me. It took me a while to get over that. Because they came, all of the family came to the rescue. And they had to call 9-1-1, so that was not nice.”

When reflecting on a couple of his more severe episodes of hypoglycemia, Dalton said:

“I passed out. I was working overtime. I had rush jobs. I didn't feel quite right but anyway, you didn't take much notice. I passed out and they took my driver's license away and after that, they wouldn't give it back to me until I started going to a specialist.”

Lastly, there's Sandra who also spoke intricately about one of her experiences.

“I think just luck brought me to where I am today. Yeah, luck. I don't have the best control. I have a lot of troubles with lows; unconscious lows ... We were camping up in the mountains, and that was before I had a glucometer. So I went into a severe low and my husband had to find a phone, a ranger station, to call for help. The ambulance came in and I know it was from Virginia City, wherever that is. And he said that on the way down the mountain, the ambulance pulled over. He was following with the car, and he said, ‘What's wrong?’ and they said, ‘We couldn't find her pulse. We stopped so we could see if there was a pulse.’ So that's how close to death I was.”

### **Self-management and routine**

All of the experiences described above were mentioned or hinted at throughout the five participants' interviews. The relevance of each story is that they not only impacted one's journey with type 1 diabetes but I believed they also affected or played a part in each participant's self-management, adjustment and acceptance of the disease. This idea is also supported by Maines (1983) who claimed connections between the mind and body set the stage for self-management and routine or scheduled behavioural patterns. It became evident to me that all participants engage in a fairly regular and sometimes strict routine. Examples of these routines are as follows.

Janice sheds light on her daily weekday routine:

“Because my coffee is two cups in the morning and that's it. And I get that at home before I head out. Then I'm off to the gym, then off to work in the afternoon.”

When asked about carbohydrate counting, Paul, who's routine is based around his career in the HVAC trade, replied:

“I do that on occasion. Mostly because I, what I’ve actually ended up doing in the past, is weigh everything and calculate the carbs and all the rest of that. But what I’ve gotten in the habit of doing is I will have exactly the same thing for breakfast and exactly the same thing for lunch pretty much everyday except for Friday. Well, Friday, I, yeah I always order the same thing ... The waitress just says, ‘Yeah, you want your usual?’ ‘Yeah.’ And they just, I get my usual, you know. I get a mushroom omelette with home fries, and rye toast with jam.”

Although the routines seemed complex, they definitely aided participants during the adjustment phase, as well as leading them to fully accept their diagnosis. Dalton verbalized this well when he said:

“It’s a lot of rigmarole. Like, you know. I get up in the morning and the first thing I do is have a blood test and generally take one of me long-lasting shots at that time. When I was working, of course, you had to have it all so you could get going and have breakfast and get going but all of these things you have to carry the stuff around with you – most of the time. Like, when I worked I had in me lunch pail a test meter and insulin, which I would have. But you learn to take that in your stride, right? ... Once you have it for 20 or 30 years it’s sort of like an old hat. It’s like riding a bicycle – you don’t forget to do it.”

Dalton hinted at the fact that he initially took his diagnosis as “the end of the world” and thought it would ruin the rest of his life. However, he mentioned that he believed once one lives with type 1 diabetes for a while they begin to rationalize their thoughts and realize they have opportunities. The treatment and management of type 1 diabetes becomes routinized over time and is incorporated within one’s lifecourse, rather seamlessly. Participants seemed to suggest that the disease and its management becomes

part of their identity, with which they carry forward into future transitions and trajectories of the lifecourse.

### **Education and mentorship**

As participants showed successful adjustment and acceptance for their type 1 diabetes, optimistic advice and projections for the future were discussed. Many individuals mentioned their current perceptions and understandings as a person with type 1 diabetes and their roles going forward with the disease. Many of the participants clearly stated the importance of diabetes education, mentorship to others with the disease and even empowerment used for advocacy of type 1 diabetes.

The re-occurring theme of education highlighted the importance for all newly diagnosed patients - of any age - to get involved with informational and supportive organizations for people with type 1 diabetes, such as the CDA and the JDRF. Paul who had previously been a volunteer for CDA said:

“I think the first thing that we really should be getting involved in is the CDA's growth. The CDA is an educational, primarily an educational organization. And the people that are involved in the CDA, they've got a better shot at surviving long-term with diabetes than people that isolate themselves. I think joining groups like the CDA, or CDA, or increasing the size of the CDA by getting more people into it that are active participants and that are willing to teach new diabetics about their experiences - probably it's gonna be the best thing that I would advise a new diabetic to do, is to seek out the CDA ... It's a bit overwhelming but education I think is probably the best answer for new diabetics if they don't know anybody that's diabetic or if they haven't spoken to anybody that's diabetic and has been for a number of years. Then, that would be step one.”

Fred elaborated on this idea when he shared his experience of talking to a newly diagnosed young man.

“Oh gosh. I’ve had that experience. I met him up in the clinic. Nine years ago I guess. You could tell right away he was in there because something was wrong. You could see it on his face. He was real pale and I just started talking to him. I said, ‘You look like you’re having some problems.’ And he suddenly realized I was talking to him; he was with his mom. She told me that they just discovered it and he’s like 15 or 14. So I said, ‘Wow.’ And he looked at me, some grey haired man, and I told him I’d been diabetic for 30 years. It’s not a death sentence. You’re not gonna die ... But you have to be there to know that’s what you’re thinking because when you’re 15 and that’s what you’re thinking, it doesn’t matter what you tell a 15 year-old ... It’s not a positive thing, it’s a downer and you have to cope with this crap, right? So, it’s hard Julie. I told him that he will survive and that technologies are a lot better and that if you’re disciplined you’ll have a good life.”

Janice also agreed with the idea of education when she said:

“Being diagnosed with type 1 diabetes is not the end of the world, number one. It’s extremely manageable and an excellent opportunity to be part of a team that’s very well educated and current with your teachings. So I would recommend that anyone being diagnosed is involved with the diabetes education clinic ... And life will go on. You’re gonna remain healthy, you’re gonna remain who you are and this is gonna become part of who you are. Yeah, and not to stress it too much.”

Janice also mentioned the positive influence her support group has had on her life:

“My ability to help people come to understand what type 1 diabetes or type 2 diabetes is all about; helping and learning to cope on a day-to-day basis. My adult diabetes support group that I’ve had going for 19 years – that’s a definite positive. Still helping people after all of these years. Still sitting down and being able to communicate and get messages across – preparing for surgery with the right information, literature and what to do. I don’t know, it’s just been so rewarding.”

Together, Theme One: Living Longer with Type 1 Diabetes provided insight into the social experiences of people with type 1 diabetes, particularly at the time of diagnosis. Subthemes such as identity and acceptance of the disease not only impact an individual’s

emotions but also one's adaptation of treatment and self-management routines. Additional subthemes of education and mentorship were present especially between people with type 1 diabetes who positively accepted and identified with their disease. The attitudes and behaviours possessed by people with type 1 diabetes truly pave the way for how they experience transitions and trajectories throughout their lifecourse. Theme two will elaborate on this idea and using a lifecourse perspective will explain how type 1 diabetes challenges traditional models of aging.

### **Theme Two: How Type 1 Diabetes Challenges Traditional Models of Aging and the Lifecourse Perspective**

#### **CD before middle age**

Chronic disease situates itself within traditional models of the lifecourse, as Elder (1998) suggested individuals with similar beginnings may experience completely different trajectories and pathways throughout their lives. For example, two people diagnosed with type 1 diabetes would experience similar diagnostic profiles but may differ when it comes to disease management and repercussions. Although all participants within this study maintained similar diagnostic profiles, they differed with respect to the use of technology used for self-management as well as overall health outcomes; some had additional complications or comorbidities while others did not.

Despite the situation of type 1 diabetes within traditional models of the lifecourse, understandings of CD are largely overlooked in gerontology literature. According to aging research, the COMH suggests adults do not experience chronic illness until late life. Although type 2 diabetes fits this trajectory of CD, type 1 diabetes does not. Type 1



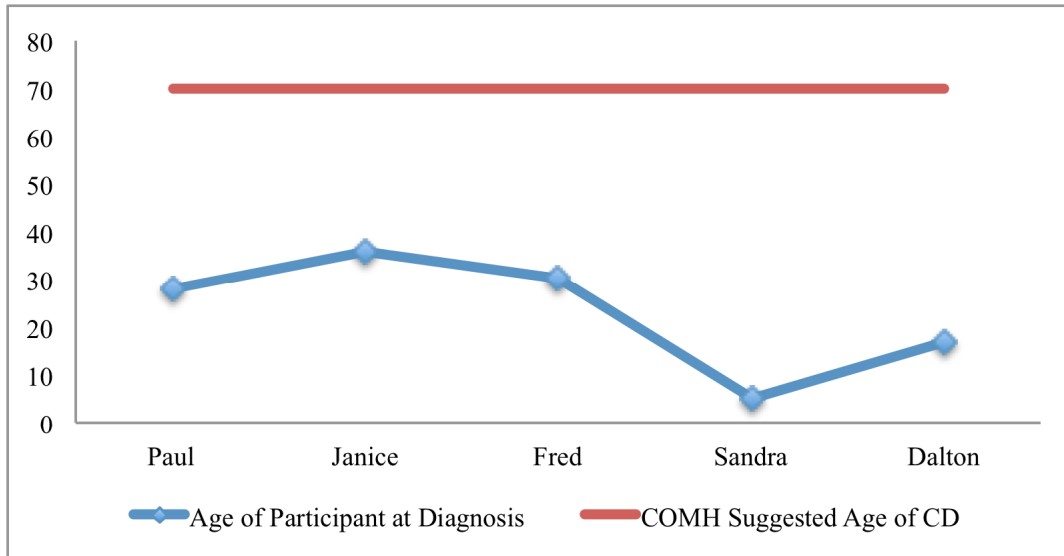
diabetes, most commonly diagnosed in children or adolescence, is not normally understood in the lifecourse trajectories or transitions of older adulthood, possibly because individuals with the disease were never expected to reach older adulthood (Bliss, 2007; Karamitsos, 2011; McGuire et al., 2005; Purdy, 1890; Rock, 2005). Yet, with current medical technology and advancements in diabetes treatment and management, individuals with type 1 diabetes are indeed living well into late life (Bliss, 2007; JDRF, 2011; JDRF Canada, 2011; Karamitsos, 2011; Klonoff, 2007; McGuire et al., 2005; Scheiner et al., 2009; Selam, 2010). Therefore this study challenges typical understandings of transitions and trajectories of aging as well as CD itself.

The trajectories of CDs diagnosed prior to adulthood, such as type 1 diabetes, are absent among current theories of aging and health. For example, the COMH suggests adults will live healthier, longer lives until older adulthood where they will be diagnosed with multiple CDs within the last few years of life (Fries, 1980). Although the EOMH increased awareness of CD in general, both the COMH and EOMH were constructed on typical age-based stages and transitions that assume individuals will only develop CDs in early to late adulthood (Laditka & Laditka, 2000; Olshansky et al., 1991). Not only is the EOMH a problem when discussing the pathways of CD in adults, but it supports misconceptual views of aging and gerontology. “The links between the widespread CDs and aging are the insidious loss of organ reserve common to both processes and the often identical factors that influence the rate of development. In preventive medicine these variables are seen as antecedents to the disease, whereas in gerontology they are markers

of age” (Fries, 1980, p. 133). CD challenges our understanding of aging by marking impairment or disease in earlier parts of the lifecourse.

Therefore, the experience of living with type 1 diabetes challenges traditional theories of aging such as the COMH because people with type 1 diabetes do not experience life stages or transitions in accordance with expected developmental milestones presented in the lifecourse perspective. The COMH suggests people do not experience CD until late life. However, all five participants developed type 1 diabetes at earlier ages – ranging from childhood to adulthood. This subtheme was evident throughout my research, which can simply be understood by reviewing *Table 1*. Reiterating this idea that type 1 diabetes challenges typical and traditional views of aging is also present in *Figure 2*. This visual demonstrates the age of participants when diagnosed with type 1 diabetes in comparison to the projected age made by the COMH. If we reconsider the COMH with the current North American average life expectancy of 80 years of age, the majority of adults would be diagnosed with CD or comorbidities approximately between the ages of 70 and 75 (Crimmins, 2004; Fries, 1980; Laditka & Laditka, 2000; Michel & Robine, 2004). There is thus a need to expand and include experiences of chronic disease in earlier parts of the lifecourse.

**Figure 2: Age Comparison Chart**



The information that has been gathered on type 1 diabetes through literature and data collection confirms that CD does exist and persist throughout the lifecourse.

Consider Paul's description. He said:

“From the onset of it, it seemed that it, it's not a visible type of a thing. Someone who is injured and has lost a limb or something, then it's an obvious visible defect that they have. Diabetes is something you can't see but it's still there.”

Although participants have admittedly gone through phases of adjustment and acceptance, their health statuses as people with type 1 diabetes have not changed – even throughout numerous decades. As such, their status of living with CD challenges the concepts of transitions and trajectories; as participants' social experiences of health were persistent throughout most stages of development (e.g. adulthood, parenthood, employment and retirement), and have potentially influenced their experiences, transitions, and trajectories.

The experiences of older adults living with CDs such as type 1 diabetes challenge our understandings of transitions. Transitions are often conceptualized as temporary states of being or specific events or occasions that introduce a new status or role (Elder, 1998; Grenier, 2012; Hareven, 1978; Hareven & Adams, 1982). When looking at the lifecourse as a whole, transitions may be considered identifiers of an overall phase(s) of change; transitions represent relatively short-term periods of movement (Elder, 1998; Grenier, 2012; Hareven, 1978; Hareven & Adams, 1982). These perceptions of transitions are thus incongruent with the trajectory of type 1 diabetes, as identification, adaptation and acceptance of the treatment and management of the disease are long-term and lifelong.

Their experiences also challenge suggested lifecourse patterns. Within the lifecourse framework, the timing of events combined with the degree of individual drive, desire and participation play a huge role in how one experiences their journey. Falling outside of the idealized theoretical perceptions of normalized stages can be viewed as problematic (Grenier, 2012). This begs the question of where type 1 diabetes fits within the traditional model of the lifecourse perspective? Should type 1 diabetes be considered as a transition or trajectory? What are the implications of type 1 diabetes on developmental stages and does the impact of type 1 diabetes fluctuate throughout the stages of the lifecourse?

Older adulthood itself, typically understood as a time of disease and despair, was also overlooked in the lifecourse framework until recently. Modern technology and medicine has redefined aging. Yet, traditional models of the lifecourse fail to consider long-term CDs, especially those acquired in previous stages. CDs such as type 1 diabetes,

often diagnosed in childhood and persistent into late life, have been completely overlooked in the lifecourse perspective (Grenier, 2012). Therefore the lifecourse perspective truly needs to be broadened in order to better accommodate non-traditional pathways. Not only do the requirements need to be adjusted but so do the perceptions around fixed stages such as parenthood and employment.

### **CD as an interruption of life stages**

According to participants, a diagnosis of type 1 diabetes impeded the progression of traditional lifecourse stages, and caused interruptions of some life transitions (see Elder, 1998; Uhlenberg, 1978). While such age-based stages are not necessarily strictly defined, they are socially acceptable boundaries of behaviours and roles within society and thus impact participants' expectations of their lives (Hareven, 1978). This emphasis on normative development of the lifecourse perspective however, becomes problematic when considering how a diagnosis of type 1 diabetes can occur at any stage.

For individuals who had children prior to their diagnosis of diabetes, their experiences didn't seem to be as dramatic or life-altering. However, views varied between participants. For example, Janice did not seem to have much trouble throughout her parenting stage, as a result of her type 1 diabetes. When asked about specific times or stages where it seemed most difficult or frustrating to be living with type 1 diabetes, she replied:

“As a young adult. Not necessarily through, there was a bit through the marriage because I was already married, already married like 15 years when I was diagnosed with type 1. So, a young adult, what would you call that? ... I was 36. So I'm still young and now I'm... definitely there were. The difficulties were understanding what the disease was and how to cope.”

Yet, when asked about parenting or being a parent with type 1 diabetes and whether or not she had any challenges she said no. She was confident that type 1 diabetes had not interfered with her parenting and she proceeded to explain the only difficulty she had with her daughter was in high school; her daughter went through identity experimentation with makeup and even dressed in all black and white clothing, which Janice attributed to normal adolescent development.

Similar to Janice, Paul also had a daughter prior to his diagnosis. In fact, the birth of his daughter was one of the contributing factors for his diagnosis.

“When I became a parent that was kind of a bit of a wake-up because I was so woozy in the delivery room. ‘Yeah, you’re probably diabetic. You better get checked out.’ So, that was the effect on that particular thing. As I was, the rest of the times, I don’t think the diabetes really was more difficult or frustrating at any point because I knew what I had; I knew how to control it.”

However, Fred, the only other participant who was diagnosed with type 1 diabetes in adulthood differed from his counterparts when he said:

“When I first discovered I was diabetic, at that point in time I was working in an office and I, I was just an accountant, with aspirations of being more. But I had a young wife and two kids. By the time I was diagnosed they were two and two and a half, three. Yeah, they were young. So I figured, ‘Okay, I’m diabetic. How is this going to work?’”

Fred seemed to struggle not only with his new diagnosis, but also as a parent. He described sentiments and emotions of fear, confusion and isolation. He could not seem to help himself, which prevented him from completing his roles as a husband and a father.

Fred's experience of diagnosis was different from Paul and Janice as his struggle bled into all aspects of his life.

On the other hand, Sandra and Dalton's experiences were different altogether as they had developed type 1 diabetes prior to adulthood and parenthood. Unlike Dalton, Sandra had decided to have kids but intimately discussed some of the challenges she faced <sup>1</sup>.

“When you have five kids in the house and you wake up in emerg and who's got the kids at home? So at that point along the way, I had two babies. I said to the endo, I said, ‘I can't do this. I cannot get myself down to five and safely do that. My husband is gone to work all the time. I can't do it.’ So I said, ‘I'm not going to focus on the five and I set my roles there. I need to raise the kids, I don't need to be unconscious in bed or driving a car.’ That's happened. So I set the rules a little differently for myself for safety and you know, if I see a 7.2 A1C, I'm quite happy.”

Continuing with transitions, trajectories and personal beliefs that challenge more traditional views of the lifecourse perspective, I will conclude this section with experiences from Dalton's interview. Dalton did not marry for the first time until he was in his 30s, which he deemed as late in comparison to the general population. That idea alone demonstrated the power and control that traditional lifecourse views portray within society. In an effort to continue his rebellion against conventional lifecourse patterns and pathways, Dalton decided not to have children; he completely abolished the stage of parenthood from his personal lifecourse. In the following statement he discussed a genetic

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<sup>1</sup> Fasting blood glucose targets for people with type 1 diabetes are between 4-7 mmol/L, while targets two hours post meal should be between 5-10 mmol/L. Targets for HbA1C (average blood glucose over two to three months) should be 7.0% or less (Canadian Diabetes Association [CDA], 2013b).

disorder, hemophilia, which is rampant throughout his wife's family. He made comparisons to type 1 diabetes.

“I would much prefer to see a lot of diseases drop out. Actually, within the family now ... a bunch of the children have, ‘What's the bleeding disease?’ And we were somewhat annoyed when the first [diagnosis of hemophilia] turned up that they had another [child] and another [child]. And you know, you got three of them ... but anyway it's the same sort of thing where I'd like to see [diabetes] go. It's not, you know. I realize the fact of having a family is always a nice attribute. You know, the name carries on but you put people through a lot of stuff when you have children. And I prefer to see it disappear.”

### **Type 1 diabetes challenges circumstances and timing of employment and retirement**

Employment and retirement were two other important stages within the lifecourse that were challenged by living with type 1 diabetes. The information I received from my participants regarding these two experiences truly reflected the premise of the lifecourse perspective whereby each stage is considered to build on the other. The lifecourse perspective contends that actions later in one's life are preceded by earlier choices, which was definitely present within this research (Elder, 1998; Hareven, 1978; Hareven & Adams, 1982). For example, in most cases, stages of retirement were dependent on employment, and employment was highly dependent on one's diagnosis of type 1 diabetes. This demonstrated that experiences of employment and retirement are influenced by a life with type 1 diabetes.

Not only were specific stages dependent on previous ones, but participants also held various unique experiences, which made their employment far from normal. As



previously mentioned, Sandra took up a career as a registered nurse and currently works in a diabetes clinic where she educates others about type 1 diabetes and helps people with type 1 diabetes on a regular basis. Aside from her job, Sandra has lived with type 1 diabetes for over 50 years. She discussed the burnout she often experiences:

“Sometimes to the point where, and this might be interesting to you, is that you get a little burnt out because it’s like 24/7 diabetes plus diabetes. And I had tried a year ago or so to get out of the world of diabetes and get into a different perspective in healthcare like chronic disease in family health teams. Or I tried to do something else. Or clinical leader of family health teams but they didn’t think I was qualified enough because my entire career has been focused on diabetes. So I’m thinking, ‘Aw!’ So how do I get out of that now? Anyways, so at this stage I don’t really care anymore. I guess I’ll keep going.”

Another participant, Janice, also worked in the field of diabetes. She differed from Sandra in the way that she was an advocate for type 1 diabetes and loved her various jobs. Janice had worked for the CDA in their resource centre. She educated others about diabetes and assisted newly diagnosed patients in learning the various products and technologies used for daily treatment and management of type 1 diabetes. Janice was very proud of this position and mentioned that she was in her “glory days” at that job. After her resource centre closed, Janice held various other jobs. She continued in the field of diabetes as a pharmaceutical representative for Medtronic and as a clerk in the call centre for Clothesline – a chain of the CDA, which accepts donations of used clothing and household items. Although there were positive and negative experiences from her employment history, Janice maintained a strong connection to her job at the CDA resource centre.

Unlike Janice's career, which was an outcome of her positive relationship and connection with type 1 diabetes, Dalton's experiences were quite negative. He had trouble trying to find or obtain a job due to his type 1 diabetes, which left him feeling segregated. Dalton spoke of the discrimination he had experienced with regards to work.

“One of the things was the difficulty in getting jobs – particularly in North America. When I came, I had changed. I had been an apprentice and I had got another job and diabetes made no difference. I came here, the doors were all closed to you because any good job, which had a drug plan wouldn't hire you. Like, I got several jobs when I first came to Canada and soon as they did a medical, ‘Sorry, we can't start you.’ And that was pretty hard. It held me back a lot, I'll be honest with you. There were jobs that didn't have any benefits, which, you know is something of a hardship in some ways. But I used to buy my medications and just carry on ... Well, the fact that you could do the job and do it better than most, like I was considered a highly skilled person and you know, you're just ostracized. It's like being a black person.”

The employment experiences of participants also led to financial difficulties. Aside from the purchasing of medications and necessary supplies, participants incurred additional financial barriers. For example, Paul is the primary financial supporter for his family; he is the sole provider for his wife and adult daughter who lives at home. Although his daughter does some small side jobs, she did not have a steady income. Instead, she worked as the primary caretaker for Paul's wife who fell several years ago, and was left with some mobility issues. Perhaps this was the leading factor for Paul's career-oriented mindset. Paul's daily routine, including his type 1 diabetes treatment and management regimen, is completely dependent on his job.

“... but it's probably gonna be quite a few years because I've gotta, I've gotta work for quite a while to build up my retirement funds. ... Gotta keep building up the financial side of things so I'm probably not gonna retire too soon. I'm very likely gonna be going 'til something or somebody forces me to retire.”

As we can understand through Paul's message, living with type 1 diabetes not only impacts one's employment but also has major repercussions on one's retirement. Currently at age 55, Sandra discussed her need to work much longer, just to provide adequate funds for her retirement.

“At this point in life, I think I would love to work less, but the cost of living is what's killing me, or would kill me. So the cost of drugs, unless I'm 65, the cost of drugs is what's gonna ... life is life ... I think one of the stupidest things I've done is that I never expected to live this long. And I'll share this with you, but I never expected to live this long because as a teenager, or as a kid, for some reason, my brain thought I would live to be maybe 25. Right? 'Cause in the old days, once you had type 1 diabetes it was a life sentence. So, okay, I'll live to be 25. Then I got to be 25, and okay, well life goes on. And then somewhere along the way I realized, 'How stupid are you? You didn't save for retirement because you didn't expect to live this long.' So now, I've saving every penny [Laughter]. But really, I mean, I never expected to do this well, to live this long because for some reason my brain had told me you won't live that long – don't worry about it. But the new way of treating diabetes, the new outlook is different.”

After reviewing current perceptions and understandings of CD within gerontology literature, it is evident that the trajectory of type 1 diabetes challenges traditional theories such as the COMH and the EOMH. The ability of a type 1 diabetes diagnosis to occur at any life stage, coupled with increased medical and technological advancements in disease treatment and management, permit an unexpected trajectory throughout the lifecourse. The timing of life stages and transitions such as parenthood, employment and retirement

are greatly affected by complex personal and emotional experiences of living with type 1 diabetes. The gerontological literature therefore, needs to expand its perceptions of age and stage-based milestones, especially when considering the lives and experiences of older adults in the contemporary context of medical and technological advancement.

### **Theme Three: Older Adults Welcome the Use of Technology**

#### **Type 1 diabetes technology as a form of social governance**

Participants discussed their relationships with the ADP and its impact on their type 1 diabetes care. In this program, the province of Ontario, Canada offers the most exemplary financial assistance program for people living with type 1 diabetes. The ADP offers eligible patients the opportunity to have up to a certain dollar amount of their insulin pump supplies covered by the province. The program, as explained by participants, was extremely important for their health care as it eased some of the financial burden they experienced as a result of living with type 1 diabetes. Sandra thought highly of the program and understood the reason why there are eligibility markers in place.

“...Basically you have to prove that you're managing your diabetes as well as you can. If you have a pump and you're using it as a fancy syringe – forget it. But yeah, so you have to be testing so many times a day and you have to follow, see a physician every so many months and so forth, A1C and so forth. And the government paperwork includes the doctor has to sign it all off and I think they want the last two or the last A1Cs ... and it works out to be \$200 a month towards your supplies. I've been able to be really cheap and get it, it costs me about \$28 a month now. It's not too bad. So really what it's [ADP] doing is making the person that's getting the pump supplies, accountable for their health – financially accountable. So it's keeping accountability where it should be, I feel.”

Fred also understood the ADP and was absolutely grateful for the impact it's had on his experience with type 1 diabetes.

“See I go there [local diabetes education centre] three times a year with the grant, now that I get, with the pump. That's \$2400 bucks they give me a year, which is too much for me. I know for other people it's not enough. But I'm thankful for that. Thank you taxpayers of Ontario. Because of that regime they want compliance, right? They want to make sure you're actually doing what you're supposed to do and not running the races ... I went today and took her [nurse at education centre] grant letter; my annual compliance letter where she'll fill in and sign and it will continue for another year.”

When discussing technology as a form of social governance and its ability to impact the public, Fox et al. (2006) claimed, “These developments challenge law- and policy-makers and professionals to balance a paternalistic responsibility for others against individual freedoms and rights” (p. 316). This is specifically true in the case of type 1 diabetes and its role within the healthcare industry. Ontario's ADP, clearly exists as a result of general concern for the [financial] well being of individuals living with type 1 diabetes. The ADP provides people with type 1 diabetes with financial independence and freedom however, it is controlled by the provincial government and is only implemented if the individual applies and meets the qualifications. Therefore, according to Fox et al. (2006), the ADP can be considered a form of technology as it struggles to find a balance between paternalistic [governmental] responsibility and the rights and freedoms of people with type 1 diabetes.

When considering the social governance of technology, we must explore and expose some of the actors that aid in developing such programs and policies. Actors are

different elements or processes included in networks of technology and they can be human or non-human including tools, organisms, money and culture (McDonnell et al., 2009). Actors in healthcare technology may include rules, guidelines, practices, tools, or even language used between professionals and patients that affect one's uptake of the technology (McDonnell et al., 2009).

Elaborating on the role of actors, I will refer back to the ANT. This theory suggests boundaries beyond human relations may be extended in order to understand connections and associations amongst actors (McDonnell et al., 2009). Technological meaning is therefore derived from the links between each element in the social process (McDonnell et al., 2009). Therefore, it is important to explore the social worlds of individuals with type 1 diabetes as all aspects of their experience of living with a CD (i.e. emotional, physical or social) may impact their relationship with technology.

Expanding on this understanding of technological meaning, Symon and Clegg (2005) believed technology transcends knowledge of artefacts to the creation of meanings, and they argued that the SCOT has become significant among many populations. The identification older adults with type 1 diabetes had with technology used in their daily treatment and management regimens, reiterates the power and ability for technology to be socially constructed and act as a form of social governance over their CD. The fascination goes beyond the user's reliability and validity to question whether their identity is socially constructed to fulfill political obligations (Symon & Clegg, 2005). Keeping this in mind, let's take a look at some of the experiences participants shared about their relationships with technology.

### **Persistence with upgrades and advancements**

One theme that was extremely salient throughout the interviews was the idea of independence, to the point of insistence and persistence. The older adults I interviewed had a strong connection to technology. In fact, many of them were so pleased with technology that they were constantly seeking new developments, advancements and upgrades to improve their health. This pattern is consistent with Fox and Ward's (2006) position on technology used in healthcare whereby older adults' identities with type 1 diabetes are formed based on their relationship with technological devices. Janice verbalized such sentiments well when she said:

“Technology itself, I mean, I'm really impressed with what's available for us today. And the way we are able to download our information, take a look at all of our graphs from the Care Link and see where we need improvement, see the times of days that we're not doing as well as we could be.”

With dramatic advancements in health technologies, patients are now becoming the experts on their healthcare (Fox & Ward, 2006). This form of immediate technological care and support allows an individual to take control and responsibility for their health; monitoring symptoms, using medications appropriately, appropriately using community resources, adopting a health lifestyle, and developing appropriate interactions with health care providers are all examples of expert patient behaviours (Fox & Ward, 2006). Although some critics may argue that the expert patient ignores structural power or more traditional forms of healthcare, Fox and Ward (2006) contend people who combine their own expertise and knowledge with traditional medical models of healthcare, display

a more desirable outcome; they adopt self-management and more accurate understandings of health.

To further highlight the relationships between self-management, health responsibility and technology, I believe it is important to understand the types of current type 1 diabetes technologies the participants were using. For example, the majority of participants (Janice, Fred and Sandra) were using an insulin pump, while Paul and Dalton were using insulin pens and a combination of insulin pens and disposable syringes respectively (see Table 3). With that being said, I will begin by elaborating on the experiences of the three who were using insulin pumps.

**Table 3: Methods of Treatment and Management Across the Lifecourse**

<b>Participant</b>	<b>Initial Method</b> <i>(at diagnosis)</i>	<b>Current Method</b>	<b>Other Methods</b>
Paul	1. Urinalysis with test paper and hemostat 2. Insulin vial (NPH) with disposable syringe 3. Diet	1. Glucometer 2. Insulin Pens (Lantus 45u/day & NovoRapid 50u/day) 3. Diet (carb counting; fixed meals) 4. Diabetes Clinic	1. Toronto and NPH insulin mix (30:70)
Janice	1. Urinalysis with chem strips 2. Insulin vial (NPH, Novolin R & N) with disposable syringe	1. Glucometer 2. Insulin pump 3. Diet (carb counting) 4. Exercise 5. Diabetes Clinic	1. Insulin pen 2. Diet 3. Exercise
Fred	1. Urinalysis 2. Insulin vial with disposable syringes (10 or 15u once or twice/day) 3. Diet 4. Exercise  <i>* Doctor had a glucometer but not patient</i>	1. Glucometer 2. Insulin Pump 3. Diet (carb counting) 4. Exercise 5. Diabetes Clinic	1. Insulin pen



Sandra	<ol style="list-style-type: none"> <li>1. Urinalysis with Clinitest</li> <li>2. Insulin vial with boiled syringe (one shot daily)</li> <li>3. Restricted diet</li> <li>4. Exercise</li> </ol>	<ol style="list-style-type: none"> <li>1. Glucometer</li> <li>2. Insulin Pump</li> <li>3. Diet (carb counting)</li> <li>4. Exercise</li> </ol>	<ol style="list-style-type: none"> <li>1. Disposable syringe</li> <li>2. Insulin pen</li> </ol>
Dalton	<ol style="list-style-type: none"> <li>1. Urinalysis with chemical methods and heating with a Bunsen burner</li> <li>2. Insulin vial with boiled syringe</li> <li>3. Restricted diet (1200 calories per day)</li> <li>4. Exercise</li> </ol>	<ol style="list-style-type: none"> <li>1. Glucometer</li> <li>2. Pens and disposable syringes Lantus (2x/day) NPH (multiple/day)</li> <li>3. Diet (carb counting)</li> <li>4. Exercise</li> <li>5. Diabetes Clinic</li> </ol>	<ol style="list-style-type: none"> <li>1. Clinitest</li> </ol>

Sandra, who was diagnosed at the age of 5, discussed the first time she took charge of her health care at the age of 11. She was a girl guide and had wanted to go to camp but she was not allowed to go to camp unless she could take her own insulin. She had refused to inject herself until the opportunity came for Girl Guide camp, which was the motivating factor for her to take responsibility for her health.

Post type 1 diabetes diagnosis, Janice discussed the desire to further educate herself on the disease and learn as much as she could to improve her health. Once she began her job at the CDA supply and resource centre, she began to gather a plethora of information about type 1 diabetes. After a NovoNordisk pharmaceutical representative visited her at the centre and provided her information about insulin pens, she was intrigued.

“And he came in and showed me a Novolin pen. I took the pen to the clinic and said, ‘I’d like to start using this.’ And it was me that instigated the technology. Which I thought was really odd. Yeah, so from there, I’ve always been that kind of outward person. If I see something new and I see the benefit than I want to try it ... So that’s what I did. I jumped in the pool and decided, ‘I’m not going to be shy and I’m going to wear it on my sleeve and I’m not going to compromise my health.’”

Fred also had a similar experience to Janice, as he was constantly questioning his health care team about an insulin pump. However, due to the financial burden of the device, Fred could only afford it if and when he was eligible for the ADP in Ontario.

“They brought it [ADP] in for kids. That’s when I first heard about it and I kept asking here, ‘Why can’t I get the pump? Why can’t I get a pump?’ And it was only, I think it was two years before that, 2008, I think 2008, I told [Name of Doctor], I said, ‘I want a pump. This injecting and carrying all this stuff with me is a pain.’ ... It was going to cost me \$7200. I didn’t have \$7200. So I said, ‘Okay fine. I’ll stay on injections.’ ... I just figured it’d be easier ... I save 30 shots every three days. I usually take one, two, three, four shots a day. So I save all those needles and everything else. I even did a cost benefit on it [laughs].”

Consistent with the ideas of Fox and Ward (2006) we can see, Sandra, Janice and Fred were personal experts and advocates for their health care. Despite the unexplained reasoning, their healthcare teams were not informing them or insisting they look at the latest advancements in type 1 diabetes technology. This experience may be one of the reasons Dalton, an insulin pen user, is not on an insulin pump.

“You know, with the pumps and that which are out now, I thought, ‘Oh maybe I’ll go for one of those,’ but the specialist said, you know, I’ve been managing for so long that you might as well. For me personally, it’s not a big issue. I am still fairly energetic at times and with a pump it would carry on feeding insulin into you when you don’t need it sometimes. It would probably create more problems for me than doing it on me own. The down side of that is the consistency of the insulin pumps. I can see their benefits but I’ve done pretty well.”

Perhaps some of the broad misconceptions about older adults being digitally challenged or uncomfortable using technology, as mentioned earlier, come into play in such circumstances. There seems to be a gap of knowledge between healthcare professionals and older adults with type 1 diabetes, as noted with Dalton.

### **Type 1 diabetes technology as boundary object**

The relevance of boundary objects in healthcare is key when it comes to older adults. The purpose of a boundary object is to be an accessible, universal device that defies barriers and eliminates boundaries (Fox, 2011a). Malanowski et al. (2008) have suggested that accessibility is the most crucial component for successful uptake of technology by older adults. Adopting an accessible or universal product design for devices to be easily used by people of any age or ability (sans modification) is the key to accomplishment. Providing a barrier-free product or environment actually allows the older adult to feel more comfortable and confident (Malanowski et al., 2008).

Boundary objects, and technology more broadly, play an important role in the formation of health identities. As previously mentioned, an individual’s health identity is constructed based on the body’s physical, psychological, emotional and social relations or

attachments, which include technological devices used in the daily care of type 1 diabetes (Fox & Ward, 2006). Health and illness are extremely politicized as they are impacted by physical and cultural surroundings of the body (Fox & Ward, 2006). Fox and Ward (2006) explain that society is becoming increasingly aware and interested in unique forms of health and embodiment such as body modification, pharmaceuticals, genetic therapies and online technologies. Various websites, forums, and blogs allow individuals to share and discuss information related to their disease and treatment. All of these services are transformed into health technologies, which gradually form health identities of its users (Fox & Ward, 2006).

The relationship between health technology and the formation of health identities amongst individuals with type 1 diabetes was salient among participants. For Paul, his use of technology was defined by his work schedule and routine. He discussed his shift from syringes to insulin pens when he started going out for breakfast on Friday mornings with his co-workers. He wanted something that was more flexible and convenient. When talking about future advancements in technology, he mentioned he might like to see some sort of an injectable capsule to monitor blood sugar. He envisioned such capsule conversing and transmitting results to some sort of a receiver that could be worn on a belt. His response was quite interesting.

“That’s [capsule and receiver] something that I’d like to see people working on. Now I’m not really sure whether a component of that technology is already in place in insulin pumps. If it is, then that means the insulin pump is a really good thing. For me, an insulin pump is kind of out of the question at this stage in the game. It might be something I might do in the future but not now because of my work. I have to get into some pretty tight spaces and, you know, you squeeze in between a piece of duct work and a water heater to get at a furnace and you gotta hold your breath to squeeze through. It would rip the insulin pump off of my belt and out of my skin and everything. It’s just not a practical thing to get involved with while I’m still working.”

It is evident that technological devices used for the treatment and management of type 1 diabetes contain similar properties to those of boundary objects defined by Fox (2011a). The need for accessibility and universal design is crucial. For participants who were not on an insulin pump - the most advanced management device used in the treatment of type 1 diabetes - accessibility, workability and convenience played a large role in their decision not to pursue the technology.

#### *Advantages of technology*

The technological uptake by participants was evident and for the most part, positive. Janice was instrumental in sharing her confident relationship with technology used in type 1 diabetes management. She discussed Care Link – a computer based software compatible with her insulin pump. She talked about how convenient it is to connect to the pump wirelessly and download all of the necessary data from the past month. She can e-mail it to her healthcare professionals or she can download it at the diabetes education clinic she attends. Janice also displayed her optimism for the future of type 1 diabetes technology.

“Now you’ve got the Internet. You’ve got all of your social medias that are available now. I mean, you can talk to a complete stranger who lives on the other side of the world for Pete’s sake. You have your chat lines. You have anything – Facebook, Twitter. It doesn’t matter. It’s all there! Totally different than what we had.”

Fred also discussed his satisfaction with the insulin pump:

“Using the pump, I use, which has been a Godsend because I got this January 3<sup>rd</sup> 2010. So, it will be three years next January. So that was great for me because I fluctuate quite badly; I’m a brittle diabetic ... by keeping track, by having a blood tester, that’s a Godsend.”

Sandra echoed the same sentiments as Fred:

“Well, I think the pump has been my savior. I’m on an Animas pump with the ping – Animas ping. And so if I don’t have that, I’m totally lost. Every now and then I get fed up and I go off the pump and I don’t last for two days. I’m sort of happy-go-lucky type; structure doesn’t work for me ... So the pump has been my savior because this way I can be more spontaneous, which would be my personality. It’s the only way to succeed I’ll tell ya.”

Not only were participants engaged with the technology of the insulin pump, but each individual had a suggestion for a new technological device or research idea of how to improve treatment and management technologies for type 1 diabetes. Both Dalton and Paul respectively discussed incorporating type 1 diabetes technology with some sort of a watch.

“I think some of the insulin pumps now do have incorporated a continuous blood monitoring system, and something of that major where you just have it stuck on your arm and leave it there, I think that would be a handy thing. Like I’d just look at it and it’s like watching the clock. Something like that would be a handy device. And maybe they’ll come out with one soon that will talk to you and tell you what your blood pressure is, not your blood, your blood sugar is.”

Paul mentioned a similar sort of device:

“It would be nice if they combined a blood glucose monitor with a wristwatch. ‘Cause the wristwatch, if you had a sensor that was inside your arm and it was transmitting to the watch, then you could push a button and you could tell where you were with your blood sugar.”

Both Janice and Sandra respectively explained their expectations for more of a modern form of technology:

“I’d like to see technology upgraded even further than where it is today. Thinking about going forward too as we age and our sight might deteriorate, it might be nice to have, if we can’t get a closed-looped system, something that might be a little more audible for us ... Oh as far as the sight is concerned, yes. To have maybe something that’s audible. Something that’s voice-activated.”

Sandra, however, would like to see her glucometer be incorporated into an everyday device such as a cellphone.

“I would like my ping [glucometer] to become my blackberry and vice versa ... I know there’s one meter that plugs into the iPhone but it still doesn’t communicate to the pump. So if you take your ping, make it part of your iPhone. No, I can’t I have a blackberry. So make it part of your blackberry or iPhone or whatever so you’ve got everything in one hand.”

As far as research goes, the most common response had to do with biological cures for type 1 diabetes.

“I mean, we’re already, with type 1, at risk. We sit there all the time and as far as organ transplants, I mean, wouldn’t it be wonderful if they got the success rate up to 100% for a pancreas transplant? I mean, to me, the technology that’s going on out west isn’t really successful. I mean, they’ve only had a handful of people that have been off insulin for a year. So, I mean, that would be wonderful to be able to have a pancreatic transplant.” – Janice

“I'd like to see some sort of implant but it's going to require a lot of technology and it's either going to be implants from the glands and coping with the weeks to make sure they work or an implant for the, the best thing would be an implant for the pump. So you would have an implant and it would read your blood and give you the insulin you need. Just like your pump or your pancreas does now.” - Fred

It is understood that there are serious components to biological treatments of type 1 diabetes. Although biological treatments may alleviate some of the current hindrances of type 1 diabetes, such as multiple daily insulin injections, they have not been perfected; success rates are relatively low and additional health management is usually required. Despite some of the positive outcomes of biological cures (i.e. saying goodbye to the insulin pump), for people with type 1 diabetes like Janice and Fred, the risks still outweigh the benefits. Often times, individuals who have undergone a biological treatment end up requiring some sort of insulin injection, or another round of treatment. Patients who have been through this process are usually required to take immunosuppressive drugs, which decrease the strength of an already weakened immune system (JDRF, 2011; JDRF Canada, 2011). This concept is even more problematic when considering the natural declines associated with aging. The use of immunosuppressive drugs could be even more dangerous for individuals who experience decreased physical mobility and frailty (Crimmins, 2004). This reasoning may explain why both Janice and Fred had some reservations about transplants and implants.

### *Disadvantages of technology*

Considering a large component of type 1 diabetes care revolves around self-management, dispensing the majority of power and control to the patient is important



(Berlin et al., 2002; Clarke & Foster, 2012; Davison, 2003; Edge & Ellis, 2012; Goldman & MacLean, 1998; Mol, 2000; Ockleford et al., 2008; Selam; 2010). Technology provides individuals with a unique opportunity to culturally mediate their embodiment experiences, while still suggesting a constant presence of biomedical power (Fox & Ward, 2006).

With that being said however, not all of the participants' experiences were positive. Most participants recognized and acknowledged the fact that technology is not perfect. They understood that they were relying on a device or program to assist with their needs, and some individuals interviewed discussed their experiences of technological failure. In some instances the experience of technological failure was accompanied by negative emotions, whereas others understood it and accepted it as a realistic outcome. For Janice, it was more so feelings of doubt, distrust or concern in technological outcomes. She said,

“You know, when we think of type 1 diabetes, there's lots of shoots. You know there's high risks involved. You know, our general overall health with heart and stroke. I mean, we're already, with type 1, at risk. We sit there all the time. And as far as organ transplants, I mean, wouldn't it be wonderful if they got the success rate up to 100% for a pancreas transplant?”

However, Sandra had some trouble with specific devices.

“My one pet peeve with the current technology is when I'm camping, and we camp an awful lot. When I'm camping, I can't see the screen when I'm outside. That pisses me off!”

Similar to Sandra, Fred expressed some issues he faced with technology.

“It’s [insulin pumps] a real pain when you go swimming and stuff like that. You gotta take it off, cover your infusion site, swim like a maniac with the grandkids for an hour, come back out, and make sure you don’t miss your hourly drip.”

Furthermore, technology has the ability to compromise serious aspects of the daily routine of people with type 1 diabetes. Reflecting on the hypoglycemia events described earlier, Paul’s experience with failure of technology has caused him some major grief.

“As new technology advanced and the glucometers became much better I changed them and got newer ones and I’m currently using two different ones because for test purposes – to find out which one is more accurate. And I’ve done quite a few other things to try to figure it out. A lot of times I’ll use both of them; 99% of the time I use both meters with one blood sample. So that eliminates that error ‘cause it’s the same sample. And they come out different in a lot of cases. There are times when the one meter reads double what the other one does.”

Technology in other forms may also cause grief. While the ADP offers great financial support, it still has its downfalls. When talking about the ADP with Fred, he began mentioning his content with the continuous glucose monitoring system. Since he said he really liked the system, I asked Fred if he wore one.

“Oh no! It’s \$47 for those. So you only use them once. Put it on for three days. Three days! It talks to your, it talks to my blood sugars. Talks to this [points to pump] but \$47! And it’s not covered.”

One of the most important messages to take away from all of the abovementioned experiences is that imperfections within technology used for the treatment and management of type 1 diabetes create a cause for concern for the futures of adults as they age (Malanowski et al., 2008). Technology used in the daily treatment and management

routines of people with type 1 diabetes definitely provides a sense of independence, spontaneity and freedom. This concept is important to convey as older adults are often perceived as being hesitant to use technology due to natural physical impairments such as declines in vision and hearing. In fact, technology may permit older adults to remove such myths, as they are adamant to remain independent even during stages of advanced care – a time frequently associated with rapid physical decline.

Natural physical, biological and developmental changes that occur as one ages, may demand that type 1 diabetes management technology be more accessible and adaptable, as it has not taken into consideration changes of vision or hearing loss. Although the current technology is good, it ignores the practical implications of increased care needs, which are common among older adults. Some of the participants mentioned some of the issues they foresaw.

“I have, at work, a 78 year old on Q-IV insulin. He plays hockey. Crazy man. So when I look at these, the meters are not big enough print. So I think as society ages, the diabetes society ages, we need, these companies need to start building things.” - Sandra

“Because we were talking about surgery and going on ... and how challenging that is. Yeah, well if we're put into hospital, I mean, they really don't have ... they think there's a protocol in place now for patients on insulin pumps. And we were talking about retiring and going into retirement homes and the skillset there and is there a protocol for people that pump there? So there's some issues that really need to be addressed and I would say the first one is to make sure you have a family member that knows how this works.” - Janice

“I think you're right on the ball when it comes to the older adults with diabetes – type 1 or type 2. I see very poor care in long term care, for diabetes. And so far, I think our whole healthcare system and our whole provider system needs to start looking at that and should've started looking at this 10 years ago ... So one of our endocrinologists in [name of city] is working on a project for nursing home and the elderly for diabetes. So she's doing some work there now but definitely the whole care system for diabetes for the aging adults needs to be addressed.” - Sandra

Sandra spoke in detail about a specific patient of hers at the local diabetes community centre. She told me about how he feared and was worried about his upcoming hospital visit where he would have to stay a few days post surgery. He was concerned about how his blood sugars would be managed as he was on a pump. He was nervous for the moment he would no longer have control over the management of his type 1 diabetes. Sandra truly believed there were issues of psychological well-being, comfort, independence and confidence that may be compromised in such situations. In Sandra's opinion, issues of psychological functioning and the relationship or trust between healthcare provider and patient are major problems within our current healthcare system. This relationship was especially concerning when considering the treatment and management of individuals with type 1 diabetes in addition to care settings that have overly rigid routines, which may conflict with personal regimens.

### ***Overview***

Despite all of the disadvantages to technology used in the care of type 1 diabetes, the general consensus was that technology was extremely useful and beneficial for the

daily dissemination of type 1 diabetes care regimes. Janice made a comment that truly tied such sentiments together:

“Technology has phased into my life and has been very important for me to stay on top. And my personal experiences because I’m so positive, like you are, I think that has a lot to do with our wellness and how we look at thing and how we deal with things. I never panic. I never get myself upset. If my pump quits, I know I’ve got a back-up. I always have an extra syringe and a vial at home. I have Novolin pens at home. I still have cartridges in the fridge, so I never panic about things like that.”

### **Technological advancements may increase QOL**

After exploring the impact of technological devices on the daily lives of older adults living with type 1 diabetes, it is evident that individuals showed increasingly positive sentiments towards the incorporation of technology as part of their daily routine. Despite all of the possible malfunctions and disadvantages of technology, older adults living with type 1 diabetes not only eluded that technology improved their current care regimens but it also provided an optimistic view of their future living with type 1 diabetes. This leads me to believe that technological advancements used in the treatment and management of type 1 diabetes has the potential to increase the QOL for older adults living with the disease.

### ***“Could be worse” attitude***

One common trend I found throughout the majority of interviews was the idea that individuals’ health could always be worse. Such behaviour and way of thinking suggested that life isn’t as bad as it could be because type 1 diabetes is a manageable disease. The individuals I interviewed believed that they could be worse off if they had been diagnosed

with a different CD, or if they had an alternate disability. All individuals had the ability to sympathize for others and not dwell on their own health implications. For example, Fred discussed the impact type 1 diabetes has on children and despite having the same disease, he felt as though he were better off because he was an adult and has the control to manage it properly. However, with children, it may be more difficult to control other hormones get involved, especially during puberty.

When Fred compared his situation to others, he said:

“I used to be the chair of a growing charity of people with long term disabilities; people assigned to wheelchairs, you know, people with real problems. They used to meet, at the meeting they would come in with big chairs, and some guys would only speak with their thing, eh? They could still talk by their screen. And he said, ‘I’m so sorry you’re diabetic.’ And I said, ‘Are you kidding me?’”

Dalton also shared these sentiments when he said:

“I say, it [type 1 diabetes] becomes second nature. I enjoy life, you know. So, you have a zest for life and consequently, you just do it. You know, to me, nowadays it’s part of eating. It becomes part of your menu and you just carry on and do all of the things you have to. It’s like, you know, I’ve known people, several people with colostomies and things like that. They’re much more of a problem in lots of ways, yet they’re not considered in the same light. A lot of people think, ‘Oh, you know it’s the end of the world.’ Well, it can be but it doesn’t have to be. It’s manageable and should be taken much more, I won’t say lightly because it’s still got some chronic side effects, but I’ve seen people have chunks of leg sawn off. It’s like the cancer and smoking. If you wanna smoke, you gotta pay the penalty. If you don’t want to do your medications and that you’re gonna pay the penalties.”

Lastly, Paul summed up this idea quite nicely when he said:

“You’re gonna live for a decent length of time and getting bent outta shape about the fact that you got a chronic disease, now there’s probably a lot of other chronic diseases that other people have that would be far more serious than diabetes that would cause a lot more grief. There are some people that have overcome tremendous adversity and made a life of themselves and they’re okay and they’re contributing parts of society. There’s a website called ‘Life Without Limbs.’ It’s run by this guy that has no limbs whatsoever. He’s got no legs, he’s got no arms. He’s still alive. He’s a great speaker. He’s contributing to society ... Joni Eareckson Tada. Another perfect example, right? She’s quadriplegic. But she’s okay. She’s helping other people and there’s a lot of these people that are far, far worse off than I am that are contributing to society and doing a really good job of it; a whole lot better than I am. So I got no cause to complain.”

## **CHAPTER SEVEN: CONCLUSIONS**

This chapter provides the reader with a general overview of the research study as it mentions potential limitations of the project and its design. This section is a reflection of the research findings and conclusions that can be made from such an important and timely project. More specifically, this chapter discusses practical implications for healthcare policy and the lifecourse perspective as well as direction for future research in the fields of gerontology, chronic disease and technology.

### **Research Limitations**

Although a qualitative research design drawing grounded theory was most appropriate for this research study, there were some limitations and drawbacks. The goal of this study was to give a voice to the unheard participants and share their experiences. There was no intention of reaching causation, explanation or generalization, rather the objective was to uncover the relationships between older adults with type 1 diabetes and their connection to technology. Recognizing contrasts and comparisons was simply a way of demonstrating the diversity, individuality and uniqueness of the disease. With that being said, I did incur some research limitations, which may have impacted the outcome of my study. More specifically, I must recognize the difficulty I had with the population sample, the participant recruitment, and my positioning as a researcher (critical reflexivity).

### **Population sample**

Coming to terms with developing the specificities of the population sample was difficult, as I was truly hoping to interview individuals who had a lengthy history and



personal lifecourse with type 1 diabetes. My ideal participant was someone who had been diagnosed as a child and who was currently an older adult. The reasoning for this was primarily due to the more traditional classifications and diagnostic trends of the disease itself; type 1 diabetes used to be synonymous with childhood and adolescence (Rock, 2005). From a gerontological standpoint, I wanted to interview someone who was in their 60s as 65 seems to be the most commonly used marker of older adulthood.

Given these preconceptions the participant criterion was more broadly set at age 55 to incorporate or adjust for the potential difficulty finding participants. As type 1 diabetes forms only a mere 10% of all diabetes cases, I envisioned the recruitment phase as being difficult (CDA, 2008; IDF, 2013). The more common participant criteria included an individual who had type 1 diabetes and was insulin-dependent.

### **Participant recruitment**

Despite the criterion and the previously considered challenges, the recruitment phase was extremely challenging. Although I had some connections within the diabetes community, I was not receiving any calls other than those from haphazard encounters and word-of-mouth. After three months of advertising with posters and word-of-mouth I had only gained two participants and it was necessary for me to change my recruitment strategy. With the assistance and connection one of my committee members had with the HHS DCRP we decided it would be best to pitch my idea to the clinicians at the centre, in hopes they would pass my information along to their patients. Considering the information about my study was coming from a valuable, educational and trusted source,

it was my hope that participants would then start calling. Sure enough, I began receiving calls within a few days of my presentation.

Although I jumped at the chance to interview anyone who met my participant criteria, I had to be more flexible with what I had in mind. After receiving ethics approval in August 2012, I had anticipated I would be able to begin the recruitment and data collection processes shortly thereafter. Knowing that I had personal connections with local diabetes organizations (e.g. Animas Canada, CDA, Juvenile Diabetes Association, HHS DCRP), I had predicted I would be able to recruit participants with minimal difficulty. My vision was that the majority of participants would fit my ideal participant criteria: individuals who were older than 60 years of age (preferably between ages 65 and 75) and who had lived with type 1 diabetes since childhood. This would provide me with the most extensive history of the individual and their relationship with the disease. I understood the population I was seeking might be particularly difficult to find yet given my small number of required participants, I figured the recruitment and data collection would be seamless. I had planned to target individuals within the Greater Hamilton Area, with most of my interviews taking place within the city as I have limited transportation.

Due to a lack of response from my initial recruitment methods, none of the participants fit my ideal, targeted individual as mentioned above. It was not until I had arranged a presentation of my research to the clinicians at the HHS DCRP that I started receiving calls from interested individuals. The individuals who called all had aspects of the individuals I was seeking, so I became less rigid with my sample qualifications. Looking back, I do believe the range of various participants made for an interesting

research study. Had I arranged for a presentation at the HHS DCRP in the beginning stages, perhaps I could have been more selective with participants and have completed the recruitment phase much earlier than anticipated.

Considering this particular qualitative research study drew on aspects of grounded theory, I had estimated I would conduct between five and 10 in-depth semi-structured interviews with older adults living with type 1 diabetes. After acquiring participation from no more than five individuals, I had obtained a wealth of data despite reaching saturation. Although this number was low considering Creswell's (2013) guidelines for reaching saturation after approximately 20 to 60 interviews for grounded theory methodology, I believe justification can be made for my research. Support for my methodology is evident when considering Charmaz's (2006) more flexible approach to grounded theory, as well as the allotted timeframe for completion of the project and the length of the interviews. Situated within a lifecourse approach, the interview questions were largely framed permitting an historical life review of participants' life experiences, dissecting components of various transitions and trajectories. There was no time limit for each interview; however, if the participant required additional time or preferred to answer the questions in sections, it was arranged.

### **Positioning and reflexivity**

It was evident from early on that my interest and investment in this research topic was personal as I was diagnosed with type 1 diabetes at the age of 17. Living with type 1 diabetes for the past six years, in combination with my passion for gerontology, led me to the research idea and topic at hand. Despite considerations for the positioning of myself

as a researcher or my attempts to remain critical and reflexive through bracketing techniques, there is no doubt in my mind that I held personal inferences and opinions on this research topic. Although I maintained the ability to put aside those personal thoughts and beliefs when necessary and only resort to them appropriately, they still exist.

The knowledge I have gained through my personal journey as an individual with type 1 diabetes can be put aside for research but can never be erased. I believe this was important in my research as it led to more fruitful and rich data in some cases. I believe my insider positionality truly led some participants to connect with me on a level that any other individual without type 1 diabetes would not be able to achieve. The bond and connection two people share through their experiences living with a CD cannot be ignored or replaced. I recognize my positionality may be viewed as a limitation within my research data however, I personally believe it was definitely an advantage.

### **Reflections of a Personal Journey**

This research project has truly been an amazing experience for me – not only as a researcher but also as someone who lives with type 1 diabetes. I am thrilled to have had the opportunity to study and conduct research on two subjects I am most passionate about: gerontology and type 1 diabetes. Using my M.A. thesis to explore such topics has been a great experience and I would not change it for the world. I am so grateful to have had tremendous support from peers, staff and educators to allow me to pursue this research.

Although I was hesitant to spend two years of my life devoted to additional research and education, I do not regret the decision I made. This thesis project gave me

the opportunity to get involved with organizations like the CDA and JDRF in Hamilton and meet new people. Most importantly, this research introduced me to my participants for whom I have great respect. Getting to know the participants through such in-depth interviews allowed me to share a personal bond and connection with them. Learning from others who have had both similar and different life experiences than I, has made me more realistic and grounded about living with type 1 diabetes. Despite being well educated about the repercussions of type 1 diabetes, my participants taught me to be more aware of the severity of the disease through their personal experiences. Although I have never had a severe hypo- or hyperglycemic event, near-death experience, or been hospitalized due to type 1 diabetes, I have a newfound appreciation for the fear, stress and trauma that can occur. It has also made me cognisant of the technology I use to manage my type 1 diabetes and how it affects me socially, emotionally, physically and psychologically.

Overall, this research experience has been wonderful, as I have learned much more about type 1 diabetes than I could have imagined. I have also become more confident with how I self-manage the disease and have understood that I cannot control the repercussions of type 1 diabetes. I have been able to appreciate the experiences of others, even those living without CD. I have realized that type 1 diabetes and other CDs not only impact the individual but their entire network of friends and family. This research has taught me to be patient and accept that the outcomes of living with type 1 diabetes – in combination with aging – are unpredictable.

## **Conclusions**

Despite the potential limitations of this project, it was conducted in an effort to answer one main research question and three corresponding objectives (listed below). This was achieved through a qualitative research study, through which in-depth, semi-structured interviews were conducted and analyzed drawing on methods of grounded theory.

### **Research question**

- How do older adults with type 1 diabetes relate to advancements in technological treatments?

### **Objectives**

1. Explore the experience of aging with a CD (type 1 diabetes)
2. Describe the function of technology used for daily treatment and management of type 1 diabetes
3. Understand the relationship between older adults with type 1 diabetes and the technology used for daily treatment and management of the disease

The purpose of this research study was to understand the daily experiences of older adults living with type 1 diabetes and to make sense of the relationships between older adults and technological treatments necessary for survival. This research extended beyond the limitations of current understandings of aging and CD, to explore uncharted territory. The disconnect between academic literature in the fields of gerontology, CD and type 1 diabetes had acknowledged the relationships between older adults living with CD(s) but had yet to explore the repercussions of living with a throughout the lifecourse.

Such a gap in the literature of relevant topic areas created the need for the experiences of adults living with type 1 diabetes to be explored.

I believe these questions were answered with the three themes respectively discussed in the *Findings* chapter. The results of this research study have shed light on the experiences of older adults living with type 1 diabetes. Insight into the social worlds of older adults living with type 1 diabetes have led to three broad themes.

- Theme One: Living Longer with Type 1 Diabetes
- Theme Two: How Type 1 Diabetes Challenges Traditional Models of Aging and the Lifecourse Perspective
- Theme Three: Older Adults Welcome the Use of Technology

#### **Living longer with type 1 diabetes**

Older adults are now living longer with type 1 diabetes as the diagnostic criteria, treatment and management of the disease has drastically changed. The increase in research and medical technology has helped to eradicate acute diseases of the past and provide treatments or management techniques for those living with CD. The identity of an individual with type 1 diabetes was formed as a result of their adjustment and acceptance of the diagnosis and the disease itself. Self-management techniques, including a large focus on routine-based activities and behaviours are a necessary component to a successful and healthy lifecourse. Older adults with type 1 diabetes who are living longer have the desire to educate and mentor newly diagnosed patients.

### **How type 1 diabetes challenges traditional models of aging and the lifecourse perspective**

Upon the completion of this research study it was evident that type 1 diabetes does in fact situate itself within the lifecourse perspective. Reflecting on original principles and concepts of the lifecourse as designed by Elder (1998), individuals may have similar introductions to their lifecourse yet experience completely different transitions, trajectories and pathways. In reference to this research, participants with type 1 diabetes were all diagnosed with the same disease however, despite many similarities, they all maintained unique life experiences - none of the participants were the same.

Type 1 diabetes permitted unexpected trajectories throughout the lifecourse, while emotional and personal experiences of the disease affected the timing of life stages such as parenthood, employment and retirement stages. In fact, many of the participants had different lifestyles, family profiles, and disease or health outcomes; some had comorbidities despite following proper guidelines while others with more risky behaviours had no complications. The recognition, management, risks and repercussions of type 1 diabetes were truly individualized.

Although this acknowledgement has been made, type 1 diabetes also questioned traditional models of aging (COMH and EOMH) and the lifecourse perspective as this particular CD is most commonly diagnosed before middle age. A diagnosis of type 1 diabetes can occur at any age or stage throughout the lifecourse and is often unexpected. Type 1 diabetes, unlike some cases of type 2 diabetes, is not preventable. Additional complications or comorbidities may also be unpreventable. This trend challenges some of



the Canadian provincial healthcare policies, which provide financial assistance for people with type 1 diabetes on insulin pumps. For example, the provinces of British Columbia, Quebec, New Brunswick, Nova Scotia, Manitoba, Newfoundland and Saskatchewan all maintain insulin pump coverage for people with type 1 diabetes but the eligibility only covers individuals until they reach ages of 18, 19 or 25. This model of healthcare prevention is truly problematic when it comes to type 1 diabetes.

Lastly, type 1 diabetes challenged models of aging as people who live with type 1 diabetes for a prolonged period of time will experience changes in their disease treatment and management, as well as their transitions throughout the lifecourse. Individuals who are aging with type 1 diabetes are forced to manage their disease in combination with the normative aging process. People with type 1 diabetes may have to change their self-management techniques to incorporate and account for normal developmental decline such as vision, hearing or memory loss. These disruptions, along with those of other age-related diseases such as dementia, have an impact on their daily self-management of the disease. It is important to acknowledge that health and aging policies need to be more flexible and supportive when considering all aspects of caring for an individual with type 1 diabetes as they age.

### **Older adults welcome the use of technology**

Technology used for the treatment of type 1 diabetes maintained many qualities of boundary objects as most devices permitted accessibility and allowed older adults to maintain freedom and independence. However, technology used for the treatment and management of type 1 diabetes is not perfect. Technology still has the ability to fail as it

is not completely universal and is not congruent with social and physical changes associated with aging (i.e. vision and hearing loss). Despite the flaws of technological devices used in the treatment of type 1 diabetes, older adults were extremely satisfied with their care regimens. Older adults displayed a “could be worse” attitude, stating type 1 diabetes is manageable and their health could always be worse. This optimistic view of personal health has the ability to increase one's QOL.

Despite the satisfaction rates of type 1 diabetes technology, older adults living with type 1 diabetes are part of a specific culture filled with its own language and meaning. Older adults living with type 1 diabetes are governed by the rules and guidelines of technology used for disease treatment and management. For example, technological devices, programs and policies that aid older adults with type 1 diabetes, such as the ADP, are a form of self and social governance as they have the ability to control the behaviours and actions of individuals. The likelihood of technological uptake by an older adult living with type 1 diabetes directly depends on the qualifications and eligibility criteria for such technology.

Older adults living with type 1 diabetes who meet the necessary criteria have an intricate bond with the technology used for the daily upkeep and management of their disease. Type 1 diabetes technology has been socially constructed as a necessary component to successful treatment and management of the disease. As such medical technology has advanced, people with type 1 diabetes are constantly relying on tools and devices to help monitor and control their blood glucose levels. Individuals living with type 1 diabetes have become reliant on specific results and numbers produced by such

necessary technology to the point of distorting reality. In a sense, older adults are dependent on the results they receive from technology and plan their self-management accordingly, ignoring physiological symptoms and messages. This sense of reliance has allowed older adults with type 1 diabetes to acknowledge both the potential downfalls of technology. Moreover, the reliance of technology for type 1 diabetes treatment and management has instilled a sense of fear and anxiety in individuals who have experienced technological failure.

The relationship between older adults with type 1 diabetes and the technology they use for daily treatment and management of their disease has highlighted important considerations, which could be made within CD, more broadly. The relationships between human beings and technological devices used in the treatment and management of CDs have maintained a distorted sense of reality and created a strong reliance to specific details within one's management regime. Although such technology may provide more independence, flexibility and spontaneity it disconnects the individual from truly experiencing certain aspects of their disease as they become reliant on the functions of the technological device and not their physiological feelings or symptoms. The role of technology used in a medical or healthcare setting may need to be re-evaluated when it comes to disease management.

### **Practical implications**

Practical implications of this study largely surround the role and positioning of behaviours and attitudes held by healthcare professionals. It is evident that traditional views of aging and barriers to technology still exist as many older adults with type 1

diabetes had to personally instigate the use of their health technology. The disconnect between healthcare professionals and older adults needs to be addressed as policies within healthcare environments regarding the use of technology for the treatment and care of type 1 diabetes are flawed. Many older adults fear the loss of independence and freedom when admitted to hospital and long-term care (LTC) facilities. Since type 1 diabetes is largely dependent on self-management strategies, the loss of freedom and independence may be detrimental to the health of an older adult; some sort of common ground, understanding and practice must be put in place to bring both groups together. Future research should strive to eliminate the gap between theory and practice. Being open-minded to the unheard voices of older adults living with type 1 diabetes will help shed light on an otherwise ignored population.

#### **Direction for future research**

To be more specific, future research projects should be focused on the relationship between older adults using type 1 diabetes technology and the integration of people with type 1 diabetes into LTC facilities, ensuring the maintenance of their independence. Possible suggestions for this next phase would be to conduct a four-step research study permitting collaboration between individuals with type 1 diabetes, healthcare professionals, and pharmaceutical representatives.

The first step would be to determine an approximate number of adults living with type 1 diabetes (though the Ministry of Health and LTC) who exceed the age of 65. Once this is determined the course of action should be to communicate with the older adults and

ask about their health care plans for the future and create a dialogue about their expectations.

The second step of this study would be to discuss current protocols for dealing with type 1 diabetes in hospitals and LTC. Conducting interviews with nurses and healthcare professionals would be beneficial. The third tier of this research would also investigate professionals, rather those in the pharmaceutical industry. This would be necessary to learn more about current technological developments and devices being marketed to people with type 1 diabetes.

The fourth step of this project would be to bring together members or representatives from each section into a focus group. This would provide all individuals with a realistic understanding of the needs and expectations of all parties involved. The focus group would take place after interviews with all three groups have been completed. This would ensure that the researcher(s) has ample time to transcribe, analyze and develop an understanding of the data. Therefore, the principal investigator would be able to appropriately facilitate the discussion within the focus group.

Investigating the technological needs of older adults during phases of advanced healthcare is crucial as the international population continues to age. Not only would this research be important for the field of gerontology, but it would also impact CD (more specifically type 1 diabetes) literature. Bridging the gap between self-management of type 1 diabetes and the provision of care for older adults is imperative to maintain independence and QOL throughout the lifecourse.

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## APPENDICES

### Appendix A – Historical Timeline of Diabetes

Date	Significant Diabetes-Related Event
Middle Ages	Writers made note of a disease with symptoms including excessive urination, thirst and wasting (Purdy, 1890).
1500 BC	Ancient Egyptians had developed remedies of ground-up bones, grains and soil mixed with water to feed people who passed too much water. Directions included, “Mix[ing] cakes, wheat grains, fresh grits, green lead, earth, and water. Let stand moist, then strain, then take for four days” (Witters, Luciano, Williams, & Yang, 2008, p. 37).
276 BC	Historians believed the Greek Demetrius of Apamea was the first to coin the term diabetes when he compared excessive urination to racking – the process of siphoning wine between two pots to remove unwanted sediments like dead yeast, and to improve the aging process (as cited in Witters et al., 2008).
First century A.D.	Arataeus of Cappadocia was the first to write the chronic nature of diabetes when he described excessive urination as a breakdown of bodily flesh with death soon to follow. Aretaeus explained it as “a melting down of the flesh and limbs into urine” (as cited in Bliss, 2007, p. 20; Witters et al., 2008)
Mid 1600s	Thomas Willis referred to diabetes as “the pissing evile” (Bliss, 2007, p. 20). This description led to the clarification between the terms <i>diabetes mellitus</i> and <i>diabetes insipidus</i> (Rock, 2005, p.468), the Latin words for “honey” and “lacking flavor” (p. 468) respectively (Rock, 2005).
1775	Dobson demonstrated that odd, sweet taste of diabetic urine was due to the levels of sugar by evaporating the urine into sugar crystals (Purdy, 1890).
Early 1800s	Chemical tests were introduced to indicate and measure the presence of sugar in the urine (Bliss, 2007).
Early 1800s	Doctors gave people with type 1 diabetes (who were in comatose states) alkali solutions such as sodium bicarbonate in an effort to neutralize fatty acids (Bliss, 2007).
Early 1800s	Opium was introduced as a treatment for diabetes. Codeine and morphine were used as second and third options respectively if opium was not available (Bliss, 2007; Purdy, 1890).
Early- Mid 1800s	Daily considerations to ensure optimal body temperature and the prevention of daily stressors became important. People with type 1 diabetes were ordered to wear wool undergarments from head to toe to economize body heat; they were also instructed to wear a breathing apparatus to facilitate the oxidation of the lungs. People with type 1 diabetes were also encouraged to take warm bathes, preferably infused

	with baking soda followed by a rubbing of the skin with brushes or coarse towels (Purdy, 1890).
1850	Jules Maumene developed first reagent strip where drops of urine were added to strips of sheep's wool. If the wool turned black, glucose was present (Clarke & Foster, 2012).
Late 1850s	Piorry, a French doctor ordered his diabetic patients to eat extravagant amounts of sugar. This practice stemmed from the belief that diabetics needed extra nourishment to replace the nutrients lost in the excessive amounts of urine (Bliss 2007).
1869	Paul Langerhans, a German student at the Berlin Pathological Institute, described the physiology of the pancreas in his 1869 dissertation. He noted that the pancreas holds two types or systems of cells, the first type which he referred to as the acini, meaning cluster or cells, which secreted some sort of pancreatic juices. He claimed there was another type of cell floating within the pancreas and piercing the acini cells but he was not sure of their function (Bliss, 2007; Karamitsos, 2011; Pompei, 2006).
1870	French doctor Bouchardat began designing patient-specific diets for diabetics. He also noted that patients who exercised had more tolerance for carbohydrates, and said, "You shall earn your bread by the sweat of your brow" (Bliss 2007, p. 23).
1875	The presence of diabetes was noted in two distinct groups: young children or older adults. The onset of the disease seemed more acute for young children as the disease had more noticeable implications such severe weight loss and death typically followed. Older adults on the other hand tended to be overweight and lived longer (Rock, 2005).
Late 1870s	Gustave-Édouard Laguesse, another French expert, expanded on Langerhans' developments by coining the term for the second type of pancreatic cells, which he named the <i>îles de Langerhans</i> in 1893 (Bliss, 2007, p. 25). Translated into the islands or islets of Langerhans, Laguesse figured these cells were responsible for some other sort of pancreatic function although he could not pin point it (Bliss, 2007).
1889	Joseph von Mering and Oscar Minkowski determined diabetes occurs when the pancreas is removed. In fact, enzymes within the pancreas deemed vital for the digestion of fat. They learned this by removing a dog's pancreas and observing it in a laboratory setting at the University of Strasbourg. They noted the dog's frequent urination despite the fact it was housebroken and taken outside regularly. Some accounts suggest Minkowski was made aware of this issue because flies were often attracted to the dog's [sugary] urine (Bliss 2007; Karamitsos, 2011).
1890	It was suggested there was a relationship between cases of diabetes deaths and climatology. Mortality rates for people with type 1 diabetes were more prominent in colder countries than warmer ones and it was suggested that high altitudes, diminished levels of atmospheric pressure

	and oxidation all contributed to the mortality of patients with diabetes (Purdy, 1890).
1890 – 1910	Approximately 400 researchers looked at treating diabetes through pancreatic extracts (Karamitsos, 2011).
1893	E. Hédon wanted to determine how the pancreas controlled and metabolized sugar. He performed a pancreatectomy on a dog and transplanted a small section of the pancreas under its skin. The dog did not develop diabetes. However, once the skin graft was removed and the dog no longer had any portion of its pancreas, diabetes rapidly developed (Bliss 2007; Karamitsos, 2011).
Late 1800s	Cantoni, an Italian specialist, and his German disciple Bernard Naunyn quarantined their patients under lock and key for upwards of five months to avoid sugar (Bliss, 2007)
1901	Eugene Opie, an American at Johns Hopkins University in Baltimore determined a connection between damage to the islets of Langerhans and diabetes. This allowed researchers to understand such cells produced an alternate secretion within the pancreas (Bliss, 2007).
1902	Von Noorden introduced his “oat-cure” (p. 24) for diabetes. People with diabetes could increase their carbohydrate consumption as long as they were meals made from oatmeal. Other diets highlighting foods such as milk, rice and potatoes were later introduced (Bliss, 2007)
1902	Starling coined the term “hormone” to describe chemical messengers (adrenalin), which aided in the flow of pancreatic juices. Starling and colleague Bayliss realized certain glands like the thyroid could produce important secretions to cure diseases like cretinism and myxedema. The entire endocrine system was understood as a vital part of the body and was just as important as the nervous system (Bliss, 2007).
Early 1990s	<ul style="list-style-type: none"> <li>- Urine tests became a common routine procedure for those admitted to the hospital as well as those applying for life insurance (Bliss, 2007).</li> <li>- Presence of diabetes seemed to be more prominent among prosperous and well-nourished people. Diabetes was most commonly found in richer countries like the U.S. and Germany but a particular trend was noted among wealthy Jewish people (Bliss, 2007).</li> </ul>
1900s	Diabetes was classified as one disease of which juvenile patients were more greatly affected (Rock, 2005).
1902-1904	Scottish researchers John Rennie and Thomas Fraser fed five diabetic patients an extract of boiled fish islet cells but found the fifth to develop a certain toxic reaction. They settled for unconvincing results (Bliss 2007).
1900s	Lydia Dewitt projected that medical research was most focused on the

	islets of Langerhans than any other bodily organ or tissue (Bliss, 2007).
June 21, 1906	Georg Ludwig Zuelzer believed adrenaline and pancreatic secretions could decrease sugar levels in the urine of people with diabetes. After testing this on dogs, he injected eight cubic centimeters of this extract to a 50 year-old, comatose diabetic in Berlin. The next day, Zuelzer injected the patient with an additional 10 cubic centimeters. Although the levels of sugar could not be measured, the patient's overall symptoms seemed to improve, as he was no longer comatose (Bliss, 2007).
July 2, 1906	Zuelzer eventually ran out of his extract (acomatol) and the Berlin patient died (Bliss, 2007).
1907	Zuelzer approached a drug company called Schering about re-trying his injections of acomatol on humans. They supported him technically and financially while working on a patent for his product. Zeulzer injected five human with his extract and noted the decline of their diabetic symptoms (Bliss, 2007).
1908	Zeulzer published his results and suggested it was possible to eliminate the excretion of sugar and other acids (i.e. acetone and acetoacetic) in diabetic patients via the injection and without alterations to diet. However, Schering retracted their support and patent of Zuelzer's extract. (Bliss, 2007).
1911	Hoffman-La Roche, a chemical firm agreed to help Zeulzer by providing him with a lab and some assistants (Bliss, 2007).
1912	Zeulzer took out an American patent of his extract called "Pancreas Preparation Suitable for the Treatment of Diabetes". Once the first batch (100kg) was released and injected into animals, they started to experience convulsions (Bliss, 2007).
Fall of 1912	Frederick Banting enrolled in medicine at the University of Toronto (Bliss, 2007).
1913	Frederick Madison Allen published a journal article titled "Studies Concerning Glycosuria and Diabetes" in which he highlighted that diabetics were sensitive to fats and proteins in addition to carbohydrates (Bliss, 2007).
1914	Zeulzer was hopeful for another attempt at laboratory experimentation but his workspace was being summoned for a war hospital and he himself was called to war (Bliss, 2007).
1919	Dr. Frederick Allen, an American diabetologist, admitted that using opium to treat diabetes was becoming a problem; it was a hard habit for diabetics to break as it eased despair (Bliss, 2007).
1919	Frederick Allen published a second volume of work titled "Total Dietary Regulation in the Treatment of Diabetes" which set the tone for hospital regimens. During this time, people with diabetes admitted to hospital were place on a liquid diet until the sugar and acidosis levels dropped.

	Once this was achieved, a diet measuring carbohydrate tolerance through the weighing of foods was completed. A day of fasting would occur then the patient would be placed on a fixed caloric and carbohydrate diet (Bliss, 2007).
1919	Israel Kleiner, a young American took an interest in pancreatic extracts and blood glucose levels. He took fresh ground pancreas, distilled in salt water and made it into a solution. He injected the solution into dogs that had their pancreases removed. He took blood sugar readings before and after the injections and noted a drastic decline in blood sugar levels – sometimes upwards of 50% (Bliss, 2007).
1920	Roughly 0.5 to 2.0% of developed and industrialized populations were diabetic (Bliss, 2007).
October 31, 1920	Banting prepared to give a talk to physiology students at the University of Western Ontario where he had recently taken a part-time job as demonstrator in surgery and anatomy. The topic of this particular talk was carbohydrate metabolism and diabetes (Bliss, 2007).
November 8, 1920	Banting approached Professor Macleod at the University of Western Ontario about doing research on the internal secretion of the pancreas (Bliss, 2007).
1923	Banting and Best won the Nobel Prize in Medicine for the isolation and first administration of insulin to a human patient in Toronto General Hospital (Pompei, 2006).
Mid 1930s	Hans Christian Hagedorn developed the first intermediate-acting insulin, which was a combination of crystalline zinc and peptide protamine (JDRF, 2011; JDRF Canada, 2011).
1940	Nordisk began producing this Hagedorn's form of insulin and called it neutral protamine Hagedorn (NPH) (JDRF, 2011; JDRF Canada, 2011).
1949	Ontario Diabetic Association was formed (Canadian Diabetes Association [CDA], 2012).
1950	The measurement of insulin in the human body led to the differentiation between insulin deficiency and improper usage (Rock, 2005).
1953	The Canadian Diabetic Association was formed and cofounded by Charles Best (CDA, 2012).
1955	Oral agents for type 2 diabetes were introduced (Rock, 2005).
1959	The distinction was made between type 1 diabetes as insulin dependent and type 2 diabetes as non-insulin dependent (CDA, 2012).
Early 1960s	The very first insulin pump was introduced. It was roughly the size of a standard backpack (Kesavadev et al., 2010).
1966	The first successful human pancreatic transplant was completed at the University of Minnesota Hospital (CDA, 2012).
Late 1970s	Type 1 diabetes was understood as an autoimmune disease (Rock, 2005).

1980	The World Health Organization (WHO) establishes an international definition of diabetes (Rock, 2005).
1985	Insulin pens are introduced (check text)
1990s	More user-friendly versions of insulin pumps are introduced (Kesavadev et al., 2010).
1990s	The success biological treatments influenced Harvard Medical School to open the very first JDRF Center for Islet Transplantation. The awareness of this centre led to the establishment of Human Islet Distribution Programs, which looked after the supply, demand and attribution of islet cells (JDRF, 2011; JDRF Canada, 2011).
1993	Diabetes Complications and Control Trial (DCCT) ended after data suggested complications could be reduced with tighter control and blood glucose management (CDA, 2012).
1999	Edmonton Protocol was a name given to the research community at the University of Alberta when the first successful islet cell transplant was completed by Dr. James Shapiro (CDA, 2012; Senior et al., 2012))
2006	Medtronic MiniMed insulin pump was released to the public (Kesavadev et al., 2010).
2006	JDRF Launched Artificial Pancreas Project (JDRF, 2011).
2006	United Nations declared Nov. 14 <sup>th</sup> as World Diabetes Day in celebration of Banting's birthday (CDA, 2012).
December 1, 2006	The province of Ontario was the first in Canada to implement The Assisted Devices Program (ADP). The ADP was introduced to cover the costs of insulin pumps for children and youth under the age of 18 living with type 1 diabetes (Diabetes Advocacy, 2012; Canadian Diabetes Association [CDA] & Diabetes Québec, 2010; Ontario Ministry of Health and Long-Term Care, 2012).
April, 2007	The province of Newfoundland implemented insulin pump coverage for youth under the age of 18 (Diabetes Advocacy, 2012; CDA & Diabetes Québec, 2010).
July 1, 2007	The province of Saskatchewan implements insulin pump coverage for individuals under the age of 18 (Diabetes Advocacy, 2012; CDA & Diabetes Québec, 2010; Government of Saskatchewan, 2012a).
September 1, 2008	The province of Ontario expanded the ADP to offer insulin pump coverage to adults (anyone) with type 1 diabetes (Diabetes Advocacy, 2012; CDA & Diabetes Québec, 2010).
November 17, 2008	The province of British Columbia offered insulin pump coverage for children and adolescents age 18 or younger with type 1 diabetes (Diabetes Advocacy, 2012; CDA & Diabetes Québec, 2010).
March 29, 2010	The province of Newfoundland expanded their Insulin Pump Program to include young adults up to 25 years of age (Diabetes Advocacy, 2012; CDA & Diabetes Québec, 2010).
2010	Banting and Best declared Canada's greatest innovators by Maclean's

	magazine for their discovery of insulin (CDA, 2012).
April 16, 2011	The province of Quebec implemented an insulin pump reimbursement program to cover insulin pumps for individuals age 0-18 with type 1 diabetes (Diabetes Advocacy, 2012; Diabetes Québec & Canadian Diabetes Association, 2010).
November 18, 2011	The province of New Brunswick introduced its Pediatric Insulin Pump Program (PIPP) for youth 18 years of age and younger living with type 1 diabetes (Diabetes Advocacy, 2012; CDA & Diabetes Québec, 2010).
January 1, 2012	The province of Saskatchewan increased insulin pump coverage to include all individuals less than 25 years of age (Diabetes Advocacy, 2012; CDA & Diabetes Québec, 2010; Government of Saskatchewan, 2012b).
April, 2012	The province of Manitoba offers insulin pump coverage for Type 1 Diabetics under the age of 18 (Diabetes Advocacy, 2012; CDA & Diabetes Québec, 2010).
April 9, 2013	The province of Nova Scotia announced its program to cover insulin pumps for children up to the age of 19, and insulin pump supplied for people with type 1 diabetes under the age of 25. This program will take effect July 31, 2013 (Canadian Diabetes Association [CDA], 2013).
May 30, 2013	The province of Alberta implemented insulin pump coverage to people with type 1 diabetes of any age (CDA, 2013a).
Present	Provincial insulin pump coverage programs have yet to be offered in Prince Edward Island and the three territories. Insulin pump coverage has yet to be offered to individuals living with type 2 diabetes.

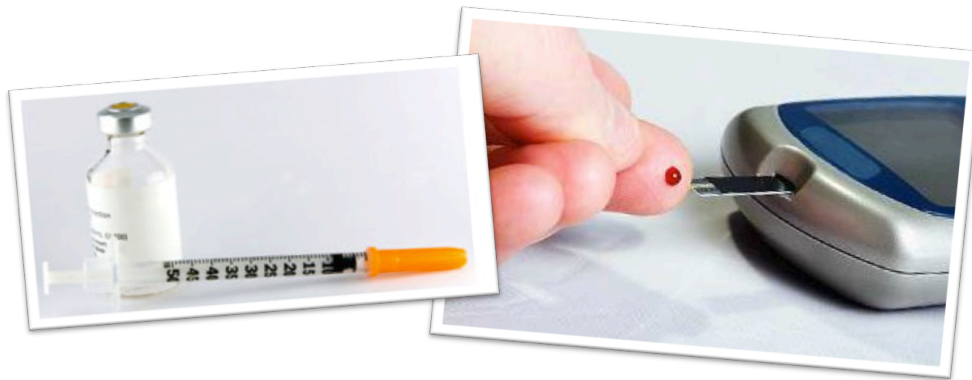


Appendix B – Recruitment Poster



# Type 1 Diabetes Study

Are you a Type 1 Diabetic over the age of 55?



This study is interested in interviewing individuals with Type 1 Diabetes over the age of 55. Type 1 Diabetes (formerly known as Juvenile Diabetes) is typically diagnosed in childhood, adolescence or young adulthood and the cause is unknown. Type 1 Diabetes forces its patients to require multiple daily insulin injections. If you fit this description, we would like to learn more about your first-hand experience of living with a chronic illness.

For more information please contact Julie Mahoney:  
905-807-6759



Type 1 Diabetes Study  
905-807-6759

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## Appendix C – Telephone/E-mail Recruitment Script

### **Telephone/Email Recruitment Script** **Julie Mahoney BA,** **Masters Candidate in Health, Aging & Society** **Type 1 Diabetes in Older Adulthood: Relationships with** **Technological Treatments**

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**E-mail Subject line:** Type 1 Diabetes in Older Adulthood: Relationships with Technological Treatment

I am inviting you to participate in an interview, which will take a few hours of your time (approximately 3 to 4 hours). As part of the graduate program in Health, Aging and Society at McMaster University, I am carrying out a study to learn about how older adults with Type 1 Diabetes relate to advancements in technological treatments used for daily care and management of the disease. I'm interested in learning how such relationships with technology impact the daily routine, health, and quality of life for adults aging with Type 1 Diabetes. The interviews may be lengthy, as some sections require the recollection of personal experiences and/or events from your life course (i.e. past, present and future). For this reason, interviews may be completed in multiple sessions.

I received your name from a list of either telephone or e-mail messages indicating your interest in participating in this study. You contacted me as a result of my recruitment poster placed in various locations (often frequented by diabetics) throughout the city of Hamilton.

It is expected that there will be minimal risks to you in taking part in this interview. However, if you experience any sort of discomfort, it is your right to refuse to answer any question(s); you may also stop the interview and/or choose to discontinue your participation in this study at any time. I have attached a copy of a letter of information about the study that gives you full details. This study has been reviewed and cleared by the McMaster Research Ethics Board. If you have any concerns or questions about your rights as a participant or about the way the study is being conducted you can contact:

The McMaster Research Ethics Board Secretariat  
Telephone: (905) 525-9140 ext. 23142  
c/o Office of Research Services  
E-mail: [ethicsoffice@mcmaster.ca](mailto:ethicsoffice@mcmaster.ca)

We would like to thank you in advance for your time and consideration. If you are still interested we will set a date, time and location for the interview to take place.

**Julie Mahoney BA, Masters Candidate (2013)**  
Department of Health, Aging & Society  
McMaster University, Hamilton Ontario  
Tel: 905-807-6759  
[mahonej@mcmaster.ca](mailto:mahonej@mcmaster.ca)

## Appendix D – Interview Guide

### Demographic Interview Questions

1. What is your gender?
  - a. Male
  - b. Female
  - c. Other
  
2. In what year were you born? \_\_\_\_\_
  
3. Are you married?
  - a. No
  - b. Yes
  - c. Common law/partner
  - d. Separated
  - e. Divorced
  - f. Other
  
4. Do you have children?
  - a. No
  - b. Yes

If you answered yes, please indicate their gender and age below.

<b>Child</b>	<b>Gender</b> <b>(F = Female; M = Male)</b>	<b>Age</b>
Child 1		
Child 2		
Child 3		

5. Do you have a family history of Type 1 Diabetes? If yes, please specify.
  - a. No
  - b. Yes
    - i. Child
    - ii. Sibling
    - iii. Parent
    - iv. Grandparent
    - v. Other

6. Do you have friends with Type 1 Diabetes?
  - a. No
  - b. Yes

If you answered yes, please indicate their gender and age below.

Friend	Gender (F = Female; M = Male)	Age
Friend 1		
Friend 2		
Friend 3		

7. In what year were you diagnosed with Type 1 Diabetes? \_\_\_\_\_
8. What was the initial method of treatment used to control and manage your Type 1 Diabetes?

**Probing Question:**

- a. What tools have you used in the past?

*(Examples: Urinalysis, blood glucose meter, insulin (vial, pen, and pump), diet and/or exercise)*

9. What is your current method of treatment used to control and manage your Type 1 Diabetes?

**Probing Question:**

- a. What tools do you currently use?

*(Examples: Urinalysis, blood glucose meter, insulin (vial, pen, and pump), diet and/or exercise)*

## Interview Questions

### **SECTION I – BACKGROUND/GENERAL INFORMATION**

1. Can you start by telling me a little about yourself...

When did you first come to know that you were a diabetic?

Can you now tell me a little about the experience leading up to your diagnosis?

**Probing Question:**

- *Were you experiencing any symptoms? If yes, what were they?*

2. I am interested in understanding more about the diagnosis itself. Can you tell me about the moment you were diagnosed with Type 1 Diabetes?

**Probing Questions:**

- *What do you remember most about the diagnosis?*
- *Who was it that diagnosed you?*

3. Part of my study focuses on care regimes. Please take a few moments to tell me how you care for your Type 1 Diabetes.

**Probing Questions:**

- *What is your relationship with healthcare professionals? (Example: dietician, nurse, doctor, endocrinologist, and other specialist).*
- *How would you describe their care? Do they seem interested in the experiences you share?*
- *Are there practices you have come to appreciate? Is there anything that troubles you about this relationship?*
- *Have you ever attended a Diabetes Education Centre?*
  - o *No – Do you know about them? Are there any reasons why you have decided not to attend?*
  - o *Yes – Could you tell me a little more about this?*

### **SECTION II – RELATIONSHIP WITH CHRONIC ILLNESS**

4. Please tell me what being a Type 1 Diabetic means to you.

**Probing Questions:**

- *Do they words “diabetes” or “diabetic” carry a positive or negative meaning for you? Why or why not?*
- *How do you associate yourself in relation to the word “diabetes”?*

- *Are there any specific phrases or terms you prefer more than others?*

5. What has been the most challenging aspect of living with Type 1 Diabetes?

**Probing Questions:**

- *What makes this difficult? Do you have a lack of resources or support?*
- *Do you get frustrated? How do you handle the situation? What sort of coping mechanisms do you use?*

6. Please tell me about two or three important life events you may have experienced in relation your Type 1 Diabetes.

**Probing Questions:**

- *Were they positive or negative events?*
- *How did they make you feel?*
- *What is the most significant part of that experience?*

7. Who do you find helps you most with your diabetes? What does this person(s) do? How do they support you? Has this changed across the lifecourse?

**Probing Questions:**

- *Do you receive help or support from family, friends or other community members?*
- *How do these people support you? (Example: physically, psychologically or socially)*

8. What can you tell me about the technology and tools you use to manage your Type 1 Diabetes?

**Probing Questions:**

- *What do you make of the tools? Are there some that have worked better than others? What is it about them that works for you?*
- *Do you find your tools accessible or easy to use?*
- *How do others (friends, family, healthcare professionals) respond or engage with your tools? Do they understand how they function?*
- *Are you satisfied with the way you manage your Type 1 Diabetes?*

9. As someone who uses this technology on a regular basis, what would you like to see change? Are there any instruments or tools you have thought of that currently do not exist or are not on the market?

What about research? What type of research or innovation would you liked to see developed in the coming years?

**Probing Questions:**

- *What types of tools would you like to see?*
- *What type of topics would you like to see researched?*

**SECTION III – AGING WITH TYPE 1 DIABETES**

10. Reflecting on your life thus far, was there a specific time or stage where it seemed more difficult or frustrating to be living with Type 1 Diabetes? (i.e. young adulthood, marriage, parenthood, grandparenthood)

**Probing Questions:**

- o *No* – Why not? What has made your life as a Type 1 Diabetic easy/manageable?
- o *Yes* – What experience was this? Why was it difficult?
- Do you find it challenging to incorporate Type 1 Diabetes into new transitions or stages throughout your life (i.e. career/work life)? How do you cope with new experiences?

11. As someone who has lived with Type 1 Diabetes for many years, what can you tell me about living with a chronic illness for a prolonged period of time?

**Probing Questions:**

- What is it like to live with Type 1 Diabetes throughout multiple stages of your life?
- How have you dealt with Type 1 Diabetes as you age?
- Have your treatment or management regimens changed?
  - o *No* – How have you maintained consistency? What are some of the strategies you use to ensure consistency among your routine?
  - o *Yes* – What do you do differently now that you didn't do before?

12. As you age, how well do you adjust to changes in technology or tools you use to manage your Type 1 Diabetes?

**Probing Questions:**

- Do you find it more difficult to understand and navigate new tools or technology?
  - o *No* – Why not? What do you do to facilitate your understanding of new tools? Do you read the instruction booklets? Do you ask for help?
  - o *Yes* – Why does it seem more difficult? What might you do to make this experience easier?

13. How do you envision your future with Type 1 Diabetes unfolding?

**Probing Questions:**

- Do you think living with Type 1 Diabetes will get easier as you continue to age?
    - o No – Why not? What type of problems or obstacles can you envision?
    - o Yes – What is your reasoning behind this? What do you think will make this process easier for you?
  - Do you think Type 1 Diabetes will be cured in your lifetime?
14. Reflecting on your experience, what advice would you give to someone who has just been diagnosed with Type 1 Diabetes?

**SECTION IV - CONCLUSION**

15. Is there anything I have forgotten to ask that you feel is important to add to our conversation today?



## Appendix E – Written Consent Form



DATE: \_\_\_\_\_

### LETTER OF INFORMATION / CONSENT

#### A Study about Type 1 Diabetes and Aging

##### Investigators:

##### Principal Student Investigator:

Julie Mahoney  
Department of Health, Aging & Society  
McMaster University  
Hamilton, Ontario, Canada  
**(905) 807-6759**  
E-mail: [mahonej@mcmaster.ca](mailto:mahonej@mcmaster.ca)

##### Faculty Supervisor:

Dr. Amanda Grenier  
Department of Health, Aging & Society  
McMaster University  
Hamilton, Ontario, Canada  
**(905) 525-9140 ext. 26540**  
E-mail: [grenier@mcmaster.ca](mailto:grenier@mcmaster.ca)

##### Purpose of the Study:

I am conducting this research as a requirement for my Master of Arts Thesis through the Department of Health, Aging and Society at McMaster University. The title of this research study is *Type 1 Diabetes in Older Adulthood: Relationships with Technological Treatments*. The purpose of this study is to understand the relationships Type 1 Diabetics have with advancements in technology used and/or required for daily care, treatment and management of the disease. Little is known about how individuals diagnosed with Type 1 Diabetes (typically in childhood or adolescence) experience aging with a chronic illness. This research study hopes to learn and understand the everyday experiences of older adults living with Type 1 Diabetes, especially in relation to their health and quality of life.

##### Procedures Involved in the Research:

By participating in this research study you will be asked two different types of questions. The first type, demographic questions, ask you to provide some background personal information such as when you were diagnosed and whether or not you have a family history of diabetes (i.e. "In what year were you diagnosed with Type 1 Diabetes?" and "What was the initial method of treatment used to control and manage your Type 1 Diabetes?"). The second set of questions is the actual interview questions. There are fifteen (15) of these questions and they ask about the specific tools you use to manage your diabetes as well as they support you receive as a diabetic (i.e. "Please tell me about the type of support you receive for your Type 1 Diabetes" and "What can you tell me about the tools you use to manage your Type 1 Diabetes?").

The interviews may last up to two or more hours. The interview period is flexible and can be arranged over multiple sessions if necessary. Interviews will be tape-recorded while I take handwritten notes. Both will be used as data for the research study. As the participant, you have the opportunity to refuse to be audio tape- recorded and in this case I will only use hand-written notes for our interview. All of the notes, tapes and tape- recorder will be kept safe and secure in a locked filing cabinet at McMaster University. Only my faculty supervisor and myself will have access to the research data. All of your personal information will be destroyed once the study is complete.

**Potential Harms, Risks or Discomforts:**

The risks involved in participating in this study are minimal. You may feel uncomfortable (anxious, embarrassed, uneasy, stressed) when discussing your feelings and personal health-related experiences. You may even feel uncomfortable answering specific questions. Your personal responses and identity will not be directly linked or declared to the diabetic community or healthcare professionals, although your identity may be recognized by the stories you tell. The information you provide will be used for the research study thesis paper. If the thesis is published, there is no control over the audience by whom it is read; members of the general public, the diabetic community and healthcare professionals could read it. Your personal identification information (name, address, etc.) will not be used in any publications of research results, as each participant will be given a randomized 5-digit code number. Each code number will be transformed into a pseudonym (false name) for writing purposes only. The name will have no connection to your real name aside from the gender connotation (i.e. if your name is Bill you could be given another name such as Paul or John).

As a participant, you can refuse to answer any of questions at any point throughout the interview, without questioning. You may also refuse to continue your participation at any point, if necessary. Should this be the case, your decision will not be questioned and any records or personal information will be destroyed.

**Potential Benefits:**

The benefits of this study allow us to better understand how older adults living with Type 1 Diabetes experience aging, including changes or shifts in their treatment regimens. Conducting interviews with this group will provide information about a group that has never been researched, whose insights could prove extremely beneficial for healthcare. Despite your anonymity, the potential results of the study such as the personal experiences and life events you share, may assist healthcare professionals, diabetes educators/specialists, Type 1 Diabetics, and families in learning more about aging with Type 1 Diabetes and treatment in an effort to develop the most effective treatment strategies. Your shared stories may suggest ways to modify healthcare services, or strategies for improved daily treatment and management of Type 1 Diabetes.

**Confidentiality and Legally Required Disclosure:**

You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. The data collection process will consist of tape-recorded interviews, which will later be transcribed by myself onto my computer. Your personal identification information such as name and address (mailing and e-mail) will be edited from the original data to the transcripts to ensure your confidentiality. Pseudonyms (false names) will be given to each code number for the writing process only. Although your personal identification will not be used, your identity may be recognized based on the stories you tell and the information you provide. Tape-recorded interviews will be kept in a locked cabinet or drawer within a locked office, which is only accessed, by my faculty supervisor and myself. Only my faculty supervisor and myself will be aware of your participation in this study, unless you choose to tell others. Once the study has been completed, the data will be destroyed.

Although I will protect your privacy as outlined above, if the law requires it, I may have to reveal

certain personal information (i.e. elder abuse, caregiver misconduct). If legal authorities request such information, which is included in your interview data, I may be required to reveal it.

**Participation and Withdrawal:**

Your participation in this study is voluntary and it is your choice to participate. If you decide to be part of the study, you can refuse to answer any question(s) or decide to stop (withdraw), at any time during the study, even after signing the consent form or providing verbal consent. If you decide to withdraw, there will be no consequences to you. Any personal information or data you have provided will be destroyed and will not be considered part of the study. However, you can no longer withdrawal or request your information be removed from the study after Wednesday May 1, 2013 as the findings of this study will be written and submitted for publication.

**Information about the Study Results:**

As a participant you have the right to receive an overview of research results once the study is complete. The results may be sent to you via mail or e-mail. If you would like to receive the results of this research study, you must specify at the end of this consent form.

**Questions about the Study:**

If you have questions or need more information about the study itself, please contact me, Julie Mahoney, at:

Tel: 905-807-6759

E-mail: [mahonej@mcmaster.ca](mailto:mahonej@mcmaster.ca)

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance.

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat

Telephone: (905) 525-9140 ext. 23142

c/o Research Office for Administrative Development and Support

E-mail: [ethicsoffice@mcmaster.ca](mailto:ethicsoffice@mcmaster.ca)

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**CONSENT**

- I have read the information presented in the information letter about a study being conducted by **Julie Mahoney**, a graduate student in the Department of Health, Aging & Society at McMaster University.
- I understand my personal information will not be disclosed or used for publication purposes.
- I understand that the interviews will be tape-recorded and the data is safely and securely kept in a locked filing cabinet within a locked office at McMaster University.
- I understand I have the right to refuse being tape-recorded and in turn, my answers will be hand written.
- I understand that if I agree to participate in this study, I may refuse to answer any question(s) or withdraw from the study at any time. If I withdraw, I understand my personal information will be destroyed and not be considered part of the research.
- I understand I cannot withdrawal or request for my information to be removed from the study after Wednesday May 1, 2013 for writing and publication purposes.

- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.
- I have been given a copy of this form.
- I agree to participate in *Type 1 Diabetes in Older Adulthood: Relationships with Technological Treatments* research study.

Name of Participant (Printed): \_\_\_\_\_

Signature of Participant: \_\_\_\_\_

I **do NOT** wish to receive a brief overview of research results

I **do** wish to receive a brief overview of research results

*If yes, please provide **ONE** of the following:*

E-mail:

\_\_\_\_\_

Mailing address:

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Appendix F – Verbal Consent Log**

*Type 1 Diabetes in Older Adulthood:  
Relationships with Technological Treatments*

**Researcher's Log for Recording Verbal Consent**

<b>Participant's Unique ID Number (i.e. 1A3V9)</b>	<b>Participant's Name</b>	<b>Date</b>

## Appendix G – Thank-You Letter

Dear \_\_\_\_\_

Your participation in the research study *Type 1 Diabetes in Older Adulthood: Relationships with Technological Treatments*, was extremely valuable. The information that you shared about your personal experience with Type 1 Diabetes will help us to understand living with Type 1 Diabetes and to make insights into the social experiences of people living with chronic illnesses. Sharing your personal stories will help us to work toward our goal of making a difference in the field of Type 1 Diabetes care. Thank you again for your valuable input and allowing us the opportunity to better understand your experiences as a Type 1 Diabetic. Your participation was extremely appreciated.

Sincerely,

Julie Mahoney, BA, MA Candidate 2013  
Principal Researcher and Interviewer  
*Type 1 Diabetes in Older Adulthood:  
Relationships with Technological Treatments*  
Department of Health, Aging & Society  
McMaster University  
Hamilton, ON

Dr. Amanda Grenier, Associate Professor  
Research Supervisor  
*Type 1 Diabetes in Older Adulthood:  
Relationships with Technological Treatments*  
Department of Health, Aging & Society  
McMaster University  
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