The Three I’s of Diabetes Integration in Emerging Adulthood: Developing a Framework to Individualize Diabetes Care

by

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Institute of Medical Science
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Abstract

Transition to adult diabetes care occurs during a challenging stage of life known as emerging adulthood. As emerging adults are tasked with increased responsibility for diabetes management, they are faced with competing demands in work and education. This study employed a narrative approach to elucidate the lived experiences of emerging adults with Type 1 diabetes. In-depth interviews were performed with 33 participants (18 to 24 years of age). Narrative analysis defined story typology and themes across first-hand accounts. Participants narrated life with diabetes through one of three ‘lenses’: ingrained (n=14), intrusive (n=12) and inconspicuous (n=7). Participants conveying an ingrained lens described actively integrating diabetes within their lives. Through an intrusive lens, participants described struggles trying to accept diabetes and striving for control. Participants conveying an inconspicuous lens expressed a desire to minimize attention towards diabetes to protect their normalcy. This conceptual framework presents opportunities to individualize support accordingly.
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Chapter 1
Introduction

As the avid hockey fan that I am, when I think about Type 1 diabetes, the first person that comes to mind is Max Domi (Macleod, 2015). Max is a 23-year-old professional hockey player who is living with Type 1 diabetes. What Max cites as inspiring him towards pursuing his dream of playing in the National Hockey League was the story of Bobby Clarke, an ex-professional hockey player who also had Type 1 diabetes (Macleod, 2015; McGran, 2018).

Stories are an integral part of medicine and humanity (Riessman, 2008). Some believe the human species should be described as Homo narrans, given our propensity for storytelling (Bamberg, 2016). Humans are social beings, and telling stories brings people together.

At its core, this thesis is based on stories about life with Type 1 diabetes. Specifically, I have focused on the Type 1 diabetes experience from the perspectives of individuals between 18 to 24 years. These years are widely known to bring forth challenges for diabetes management (Peters & Laffel, 2011). During this time, young people will be leaving familiar relationships with pediatric providers and transitioning into the adult care setting. This transition will be occurring at the same time as new roles in various other life domains are being taken on. Some individuals may be enrolling in university programs and moving away from the parental home, while others might be taking on full-time employment for the first time. As young adults are faced with newfound independence, there are risks for deterioration in glycemic control, loss to follow-up in clinical care, increased occurrence of acute complications and onset of microvascular complications (Peters & Laffel, 2011).

It is important to keep transitioning patients engaged with the health care system, as the relationship between patient and provider is an integral source of support. Through effective communication, many components of diabetes management (e.g. nutrition, insulin administration or self-monitoring of blood glucose) can be tailored towards a patient’s needs and preferences (Chiang et al., 2014). With an individualized self-management plan, Type 1 diabetes can be integrated within even the most physically demanding lifestyles, such as Max’s. This has been referred to as individualization of care (Chiang et al., 2014), and it has great potential for a
population of transitioning patients whose lifestyles do not fit neatly into the traditional categorizations of either pediatric or adult patient.

Before any of the intricacies of management can be individualized, adult care providers must establish a strong relationship with a newly transitioned patient. Through a narrative research approach, I set out to try to understand the lived experience of individuals with Type 1 diabetes with the hope that this information may improve individualization.

This thesis is a presentation of my research findings. It is organized into nine chapters. The first chapter serves to provide an overview of what my thesis is about and introduces the research problem to be addressed. In Chapter 2, I provide a scholarly context for the thesis research as I review literature on Type 1 diabetes and the transition to adult care. In this review, I highlight deficiencies in existing strategies to improve the health care transition and I make a case for using a narrative approach as a means for informing providers of the lived experiences of emerging adults with Type 1 diabetes. Following this, in Chapter 3 I provide a detailed presentation of my narrative methodology. I explain the qualitative study design, and outline ethical considerations, practical procedures (recruitment, data collection/analysis). In Chapter 4, I contextualize the sample population, as I present demographic and clinical characteristics of participants and three case stories about life with diabetes during emerging adulthood. Next, in chapters five to seven, I present three chapters in which I discuss interpretations of three ‘lenses’ through which participants viewed life with diabetes: ingrained, intrusive and inconspicuous. These lenses represent three types of narratives portrayed by participants within this study. In Chapter 8, I compare participants according to their lens. Finally, in Chapter 9 I conclude this thesis with a discussion of the main findings and future directions.
Chapter 2
Background Literature Review: Moving Towards Individualization of Care for Emerging Adults with Type 1 Diabetes

2.1 Chapter Overview

In this chapter, I review what is known about the challenges faced during transitions to adult diabetes care and make a case for using a narrative approach to individualize support for emerging adults with Type 1 diabetes. I start this chapter by providing a biomedical overview of Type 1 diabetes to contextualize the research problem. Next, I highlight known risks for transitioning patients with Type 1 diabetes, which include: gaps in clinical care, deterioration in glycemic control, increased occurrences of acute complications and signs of chronic complications. Following this, I review existing strategies designed to ease the transition to adult diabetes care. Reflecting on these attempts, I outline limitations in the current emphasis on practice-based interventions. To provide a broader focus for understanding the lives of transitioning patients, I introduce the concept of emerging adulthood. Through a review of socio-demographic trends, I point out the individualistic nature of this stage of life, which is especially apparent in the widespread use of social media. This section on social media and stories will help illuminate my research question and objective, which I propose to be best addressed by using a narrative research approach.

2.2 What is Type 1 Diabetes? A Biomedical Overview

Type 1 diabetes is part of a family of metabolic disorders collectively known as diabetes mellitus (also including Type 2 diabetes, gestational diabetes and other specific types) (American Diabetes Association, 2014; Punthakee et al., 2018). The physiological onset of Type 1 diabetes occurs from an autoimmune destruction of pancreatic beta cells, which ultimately leads to insulin deficiency (Chiang et al., 2014).

Diagnosis of Type 1 diabetes is based on detection of hyperglycemia (Punthakee et al., 2018). On diagnosis, an individual will typically present with the symptoms of polyuria,
polydipsia and weight loss (American Diabetes Association, 2014). Diabetic ketoacidosis (DKA; hyperglycemia and a fall in blood pH due to ketone body production) can occur at the time of first presentation with Type 1 diabetes (Dabelea et al., 2014). DKA is a life threatening complication of diabetes and usually requires inpatient admission (sometimes within an intensive care unit). Even if individuals are not in DKA at the time of diagnosis, they require prompt initiation of insulin therapy along with intensive education about how to manage blood sugar levels (e.g. carbohydrate counting and blood glucose monitoring).

Type 1 diabetes affects over 300,000 Canadians (Public Health Agency of Canada, 2011). Although most people living with Type 1 diabetes are adults (Chiang et al., 2014), diagnosis is most frequent between the ages of ten to 14 years (Dabelea et al., 2007; Rogers et al., 2017). Globally, Canada is known to have a relatively high annual incidence for Type 1 diabetes amongst young people ≤14 years old (approximately 25/100,000, compared to Chinese and South American populations showing low incidence [<1/100,000], and European countries that show the highest, notably Finland and Sardinia [36/100,000]) (Karvonen et al., 2000). The number of new diagnoses each year can vary depending on the province. For instance, Quebec had a Type 1 diabetes incidence of 15 cases per 100,000 people 18 years and under (Legault & Polychronakos, 2006), while Newfoundland and Labrador had one of the highest incidence in the world for children 15 years and under between 1987 and 2010 (45 cases per 100,000) (Newhook et al., 2012). The latest Public Health Agency report identified about 3,000 new diagnoses of Type 1 diabetes in Canadians aged one to 19 years in 2008 to 2009 (Public Health Agency of Canada, 2011).

An existing hypothesis for the etiology of Type 1 diabetes is that response to environmental factors (e.g. diet, early life exposure to enteroviruses or decreased microbiome diversity) leads to an autoimmune destruction of pancreatic beta cells, with genetic risk being a background factor (Gale, 2006; Rewers & Ludvigsson, 2016). Generally, Type 1 diabetes is slightly more common in males than females (Diaz-Valencia et al., 2015), and it appears to be most common in individuals with ethnic backgrounds described as white and from northern European descent (Noble, 2015). Children of fathers with Type 1 diabetes are at greater risk for diagnosis compared to children of mothers with the condition (Weires et al., 2007). There is a one in 20 lifetime risk of developing Type 1 diabetes if either parent is living with it, compared to a 1 in
300 lifetime risk for people who do not have a parent with Type 1 diabetes (Redondo et al., 2001).

With Type 1 diabetes comes a greater risk of long-term health complications. Cardiovascular disease is the leading cause of death in individuals with Type 1 diabetes (Libby et al., 2005). Studies have found an eight to 13 year shorter life expectancy for individuals with Type 1 diabetes, due in large part to premature morbidity and mortality linked to cardiovascular disease (Huo et al., 2016; Livingstone et al., 2015). In addition to macrovascular complications, microvascular complications can also manifest from Type 1 diabetes. These include damage to the eyes (retinopathy), nerves (neuropathy) and kidneys (nephropathy). Evidence suggests that puberty can accelerate the occurrence of long-term microvascular complications (Cho et al., 2014). Gender may also influence the onset of long-term diabetes related complications; women with Type 1 diabetes were found to have a higher rate of all-cause premature mortality and adverse vascular events compared to men with Type 1 diabetes (Huxley et al., 2015).

Over the past 25 years there has been a decrease in the occurrence of microvascular and macrovascular complications (Fullerton et al., 2014; Lachin et al., 2014). This is a reflection of the advances in treatment and care (Barnett, 2018). When a person is diagnosed with Type 1 diabetes, they (and their families) are educated as to the importance of maintaining blood glucose concentrations as close as possible to those seen in people without diabetes, to reduce long-term complications (Diabetes Control and Complications Trial Research Group, 1994; Nathan, 2014; Nathan et al., 1993). Intensive insulin therapy is the primary means for managing glycemic levels. The two main methods for insulin therapy are multiple daily injections (three or more injections of insulin per day) and continuous subcutaneous insulin infusion from an insulin pump (Chiang et al., 2014). For both methods, basal-bolus administration regimens are followed to control blood glucose concentrations throughout the course of a day (McGibbon et al., 2018; Wherrett et al., 2018). Basal insulin doses are given once or twice a day to help stabilize glucose levels in the fasting state and between meals (or continuously with an insulin pump). Bolus insulin doses are rapid or short acting, as they are used to control the glycemic rise at meals and to correct hypoglycemia. The mealtime insulin dose is determined based on the carbohydrate content and carbohydrate-to-insulin ratio of the foods an individual is about to eat, and factors such as physical activity, time since last insulin dose and blood glucose level at time of meal need to be considered (McGibbon et al., 2018).
A common limitation of intensive insulin therapy is hypoglycemia. This is an acute complication that can be potentially life threatening amongst people with Type 1 diabetes. In populations of individuals with Type 1 diabetes, the frequency of severe hypoglycemia events (requiring assistance from others) occurs at a rate of 16 to 20 per 100 person-years, while more traumatic hypoglycemic events (loss of consciousness or seizures) occurs at a rate of two to 8 per 100 person-years (Cengiz et al., 2013; Karges et al., 2015). Glucagon is an emergency medication that can be used to treat severe instances of hypoglycemia (Chiang et al., 2014). In terms of fatality, hypoglycemia accounts for four to 10% of Type 1 diabetes related deaths (Feltbower et al., 2008; Patterson et al., 2007; Skrivarhaug et al., 2006). Hypoglycemic events have been decreasing over time (O'Connell et al., 2011), due partly to continuous glucose monitoring technology, which helps to maintain optimal glycemic levels over the course of a day (Juvenile Diabetes Research Foundation, 2010; Tamborlane et al., 2008).

Monitoring blood glucose levels is an integral part of daily living with Type 1 diabetes. Performing three or more self-tests is highly recommended (Driskell et al., 2014). During periods of acute illness (such as when experiencing a flu) or in other scenarios when blood glucose levels may be prone to rise, ketone testing is recommended to prevent the acute complication known as diabetic ketoacidosis (DKA) (Berard et al., 2018). Hospital admissions of DKA occur at a rate of one to 10 per 100 patient years in individuals under the age of 18 years with Type 1 diabetes, and are linked to 13 to 19% of all Type 1 diabetes related deaths (Feltbower et al., 2008; Karges et al., 2015; Patterson et al., 2007).

Glycemic control is considered the cornerstone of Type 1 diabetes management, as it is a means to reduce risk and enhance quality of life. In Canada, glycated hemoglobin (HbA\textsubscript{1c}; reported in the National Glycohemoglobin Standardization Program’s units of %) is used to measure glycemic control (Berard et al., 2018). HbA\textsubscript{1c} is an estimate of the mean plasma glucose levels over the previous eight to 12 weeks, and its measurement provides an estimate of treatment effectiveness (Berard et al., 2018). To reduce the risk of complications, clinical care guidelines stress the significance of pursuing an HbA\textsubscript{1c} target of less than 7.5% for pediatric patients (18 years of age and under) (Imran et al., 2018), and a target of less than 7% for adults (Imran et al., 2018). Following diagnosis, and routine clinical care visits thereafter, people living with Type 1 diabetes will have their HbA\textsubscript{1c} tested approximately every three months in a clinical laboratory, or by a point-of-care analyzer.
Keeping \( \text{HbA}_1c \) within target range is a primary goal of diabetes management, yet most people between the ages of 18 to 24 with Type 1 diabetes do not meet their target \( \text{HbA}_1c \) range of less than 7% (Miller et al., 2015). With a worsening of glycemic control, there is not only an increased risk for complications (Diabetes Control and Complications Trial Research Group, 1994), there is a greater likelihood a young person with Type 1 diabetes will experience psychological problems (Hassan et al., 2006). At its biomedical core, diabetes is a disease governed by glucose, and if a young person does not meet glycemic goals set out for them, this can set the stage for negative interactions with the health care setting and family members.

Unlike other chronic illnesses (such as hypertension for example), Type 1 diabetes is a chronic illness that requires daily active involvement to reach glycemic goals (Sherifali et al., 2018). Whether it is related to insulin administration, blood glucose monitoring, diet or physical activity, living with Type 1 diabetes involves meticulous self-monitoring and decision-making to ensure blood sugar levels are in an optimal range.

Self-management is known to be especially challenging around the time of transition into adult diabetes care (typically when an individual with diabetes is 18 years of age) (Garvey et al., 2012). The Canadian Pediatric Society has referred to this event as being a “graduation”, in which a young person with a chronic illness is viewed as an autonomously functioning adult patient (Canadian Pediatric Society, 2007). Although clinical care guidelines advise providers to gradually prepare young people with Type 1 diabetes for this event (Diabetes Canada recommends for transition preparation to commence around 12 years of age) (Wherrett et al., 2018), a worsening of glycemic control during the late teens and early twenties suggests that there are challenges associated with handovers in responsibility (from parent to child) (Wiebe et al., 2014; Wysocki et al., 1996). At the same time as transitioning patients are taking on greater responsibility for diabetes management, they will be faced with many competing priorities as they start university or take on full-time employment (Monaghan et al., 2015). Keeping diabetes self-management within focus is critical, yet hard to adhere when there is so much else going on in a transitioning patient’s life.
2.3 Risks of the Transition to Adult Diabetes Care

The transition to adult care has been defined as the “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (Blum et al., 1993). This transition can be a time of great flux in the management of an individual’s Type 1 diabetes (Canadian Pediatric Society, 2007). Greater responsibility is shifted to a transitioning patient, as parents are expected to take a step back. Given that many individuals with Type 1 diabetes are diagnosed during childhood, this change in roles for management can be overwhelming for both parent and child (Allen et al., 2011).

Fundamental differences exist between pediatric and adult diabetes care (Peters & Laffel, 2011). Pediatric care is described as being more of a family-based approach. Primary education about living with Type 1 diabetes will be taught by pediatric providers to ensure patients and their families are equipped with knowledge about the foundations of management (e.g. carbohydrate counting or insulin dose adjustments) (Wherrett et al., 2018). Upon entering the adult care setting, which typically occurs between the ages of 18 to 20 years (Garvey et al., 2012), young people with Type 1 diabetes will be met with a different approach (Chiang et al., 2014). Adult diabetes care providers focus more on the autonomously functioning individual, who is expected to be competent in making management decisions on their own. Clinic visits tend to be shorter and oriented around glycemic control. This is in contrast to pediatric care, when young people with Type 1 diabetes will usually have a long-standing relationship with a pediatric provider who knows more about their social history.

Successfully establishing a new relationship with providers and adjusting to a new role is challenging for transitioning patients. Unlike in pediatric care, where patients are under the close supervision of parents and providers, becoming an adult patient means that individuals with Type 1 diabetes are expected to be accountable for their actions. The adjustment period for this uptake of greater personal responsibility is widely known to be a risky time for Type 1 diabetes management (Peters & Laffel, 2011).
2.3.1 Gaps in Care

Gaps exist between ending pediatric and starting adult care, which have been termed loss to follow-up. In Toronto, Frank performed interviews with 41 patients who ended pediatric care at the age of 18 (mean age 21.7 ± 0.5 years at interview), and discovered that 24% of interviewees did not have a follow-up visit within the year following their last pediatric care appointment (Frank, 1996). Similarly, in Montreal, Pacaud et al. surveyed 135 patients with Type 1 diabetes (mean age 18.5 ± 0.1 years at last pediatric appointment), and found 28% had experienced gaps greater than six months between their last pediatric and first adult visit, while a further 17% had gaps in care greater than one year (Pacaud et al., 1996). These authors administered the same survey in Calgary to 81 patients who had ended pediatric care, and reported that 31% had experienced delays greater than six months in establishing adult care and 14% reported delays greater than one year (Pacaud et al., 2005). Infrequent diabetes care visits are known to have negative consequences, as there is a greater risk of acute and chronic complications amongst adolescent and post-adolescent patients who are lost to follow-up (Holmes-Walker et al., 2007; Jacobson et al., 1997; Mainous et al., 2004).

It is important for newly transitioned patients to learn how to become an active participant in clinical care interactions. If lines of communication between patient and provider are compromised, an individual with Type 1 diabetes is at a significant disadvantage when tasked with glycemic control in their daily lives (Monaghan et al., 2013). Similar to learning how to drive a car, if an individual learning how to self-manage Type 1 diabetes does not have a strong foundation of support, skills and knowledge, it will be difficult to make management decisions in real time.

2.3.2 Deterioration in Glycemic Control

Glycemic control is seen to deteriorate around the time of transition (Bryden et al., 2003). Few transitioning patients meet guideline recommended targets for glycated hemoglobin (HbA$_{1c}$). The SEARCH for diabetes in youth study revealed that only 32% of youth with Type 1 diabetes between 13-18 years and 18% ≥19 years achieve target HbA$_{1c}$ levels (≤7.5% for patients 18 years and under, and ≤7% for patients above the age of 18) (Petitti et al., 2009).
A number of physiological and psychosocial factors can play a role in influencing glycemic control for patients around the time of transitions in care, for example insulin resistance related to puberty, fear of hypoglycemia, and normative psychological challenges (e.g. distress related to academic performance for university) (Maahs et al., 2010). In addition, the SEARCH study identified statistically significant demographic correlates that were linked to poor glycemic control amongst individuals 20 years of age and under, which included: longer diabetes duration, living in a single parent household compared to living in a two parent household, race/ethnicity other than non-Hispanic white, being female and lower parental education (Petitti et al., 2009).

The timing of the transfer to adult care has also been linked to poor glycemic control. Nakhla and colleagues examined the population-based Ontario health care administrative databases, and found that out of 1507 patients who were expected to transfer care, transitioning to a new adult physician was associated with a 77% increased risk for hospitalization compared with those who remained with their pediatric care team (Nakhla et al., 2009). Similarly, Lotstein and colleagues found that the odds of having an HbA1c >9% are 2.5 times higher for patients who transitioned into adult care, compared to those who remained in the pediatric care setting (which was after controlling for sociodemographic and disease related factors) (Lotstein et al., 2013). Also, Helgeson noted that transition prior to high school graduation was associated with poor glycemic control and self-care skills (Helgeson et al., 2013).

With difficulties maintaining glycemic control during these transitional years, there is a greater risk for both acute and chronic complications. A few years of poor glycemic control during the late teens or early twenties can have long-lasting adverse effects on the risk of diabetes complications even decades later (Nathan, 2014).

2.3.3 Occurrence of Acute and Chronic Complications

Lifestyle changes characteristic of the post-adolescent years can challenge a transitioning patient’s capacity for glycemic control (Monaghan, 2015). Increases in alcohol consumption, erratic sleep patterns and inconsistent diets are potential challenges for young people with Type 1 diabetes as they separate from the close guidance of their parents (Hanna 2012). Compared to older adults, individuals between 20 to 24 years of age in the Diabetes Control and Complications Trial had a higher rate of severe hypoglycemia (Diabetes Control and Complications Trial Research Group, 2014). Furthermore, population studies have revealed that
Acute complications are the most common cause of death amongst individuals with Type 1 diabetes who are less than 30 years (Skrivarhaug et al., 2006). Although less common than acute complications, chronic microvascular complications may also begin to emerge in individuals with Type 1 diabetes during the post-adolescent years, for instance approximately 10% of transitioning patients develop microalbuminuria (Alleyn et al., 2010).

Providing support is critical for reducing complications amongst transitioning patients, but it is difficult to define developmentally appropriate approaches to self-management support (Farre et al., 2015). Variability in demographics and development during the post-adolescent years hinders the formation of a standard definition for “developmentally appropriate care” (Farre et al., 2016). From one transitioning patient to the next, there can be great variability in how individuals take responsibility for self-care (Hanna & Decker, 2010; Hanna et al., 2013). This has made it difficult to design practice-based interventions that are oriented towards one patient population with similar support needs.

2.4 Strategies to Smooth Transitions in Care

There is no one “gold standard” for transitional care (Wafa & Nakhla, 2015). Multiple strategies have been reported within the literature, which have been assessed using a range of outcome measures (e.g. clinic attendance, mean HbA1c, self-reported “transition experience”, presence of complications, complication screening rates and DKA admissions) (Crowley et al., 2011; Hanna & Woodward, 2013; Lyons et al., 2014; O’Hara et al., 2017). There are also a myriad of factors that can impact outcomes (e.g. pre-transition glycemic control, family relationships, technology use or vocation) (Garvey et al., 2012; Helgeson et al., 2013; Garvey et al., 2013; Los et al., 2016; Monaghan, 2015; Monaghan et al., 2013). With this vast array of outcome measures, influencing factors and in many cases, no comparative groups within studies (Wafa & Nakhla, 2015), it is difficult to determine which transition strategies will generally be well received. Nonetheless, there are transitional care models that have shown promise for smoothing the transition into adult diabetes care.
2.4.1 Transition Coordination

To help bridge the gap between pediatric and adult care, coordination programs have been implemented (Garvey et al., 2012). The transition coordinator has been a role created within some diabetes clinics to maintain continuity in care following the exit out of the pediatric setting. For instance, in Manitoba, Van Walleghem assessed the effectiveness of a “Maestro” whose job was to help patients (18 to 25 years) navigate adult care services (Van Walleghem et al., 2008). The Maestro maintained telephone or email contact with patients to provide ongoing support with appointment bookings and rebooking. This program was helpful for reducing loss to follow-up and reconnecting those who had stopped attending clinic for a period of time (Van Walleghem et al., 2011).

Similarly, in Italy, Cadario et al. evaluated a structured transition plan in comparison to an unstructured transition experience (Cadario et al., 2009). The structured transition group received support from a coordinator, and had a joint last visit in the pediatric setting, in which adult providers met with patients before they arrived in the adult care setting. There was a 23% decrease in loss to follow-up in the three years post-transition amongst the participants who were in the structured group (compared to an unstructured group who had their first adult care appointment booked for them and were discharged with a medical history) (Cadario et al., 2009). Furthermore, rates of screening for complications (retinopathy, foot examinations and nephropathy) were higher for patients who had a structured transition (Cadario et al., 2009). The gap between ending pediatrics and starting adult care was shorter for the structured transition group. In terms of glycemic control, HbA1c was lower one year following transition for patients who had a structured transition compared to those with an unstructured transition (Cadario et al., 2009).

2.4.2 Young Adult Clinics

In addition to coordinators, young adult clinics have demonstrated positive transition outcomes (Schultz & Smaldone, 2017). Young adult clinics (typically tailored to patients between 18 to 24 years) are designed to meet the unique developmental needs of transitioning patients (Markowitz et al., 2017a). Issues that are considered developmentally appropriate for this population include: birth control/pregnancy planning, prevention of sexually transmitted illnesses, alcohol/recreational drug use, smoking, driving and mental health (Markowitz et al., 2017a).
Multidisciplinary care teams are implemented within young adult clinics to provide holistic care during this unique stage of life. This includes a range of care providers, such as endocrinologists, dieticians, diabetes nurse educators, social workers and mental health professionals. Many young adult clinics also report implementing after hour phone or email support to keep patients engaged with health care services.

Prior to commencing any design, recruitment, data collection or analysis for this study, I observed the functioning of a young adult diabetes clinic at St. Michael’s Hospital in September 2015 (Markowitz et al., 2017a). My supervisor, Dr. Andrew Advani, was the endocrinologist for this clinic. During my time shadowing clinic visits and attending meetings amongst providers, I was introduced to what were considered developmentally appropriate topics for emerging adults with Type 1 diabetes. Within pre-clinic meetings, popular topics of discussion were: drugs and alcohol (the use of marijuana and how that impacts diabetes management; this was especially pertinent given its upcoming legalization in Canada), parental involvement (there were many questions surrounding the nature of this involvement) and technology use. Although health care providers within this clinic were trying to orient their approaches to the developmental needs of emerging adults with Type 1 diabetes, they were uncertain if their approaches were indeed developmentally appropriate.

Despite difficulties in defining developmentally appropriate care (Farre et al., 2016); young adult clinics for a transitioning population do appear to have positive benefits for transitioning patients. In the United Kingdom, Johnston and colleagues found that patients attending a young adult clinic were twice as likely to have good attendance (defined as one or no missed appointments during 15 to 18 months following transfer) compared to patients who transitioned into a general adult clinic (Johnston et al., 2006). In Israel, a young adult clinic that incorporated a transition coordinator was able to “rescue” 17 patients who had been lost to follow-up (stopped attending a diabetes clinic for six months or more) (Levy-Shraga et al., 2016). Furthermore, 68% of the entire cohort (n=53) who were enrolled in the young adult clinic had attended three or more visits per year. There was also a decrease in HbA1c levels from a mean of 8.3% at entry into the clinic compared to 7.4% after one year of attending (Levy-Shraga et al., 2016). Within an Australian setting, Holmes-Walker and colleagues developed a young adult clinic that reported data over a five-year period (Holmes-Walker et al., 2007). Participants of this program experienced a decrease in HbA1c of 0.13% per visit over their first four visits, and DKA
admissions rates declined by approximately two thirds compared to admission rates before entering the program (Holmes-Walker et al., 2007).

Despite signs of success, the evidence base for implementing transitional care models is not vast (Wafa & Nakhla, 2015). Methodological issues are apparent in existing studies, which reflect small sample sizes, inconsistent outcome measures, selection bias (e.g. a lack of inclusion of young adults who have been lost to follow-up) and absence of control groups for comparison (Hanna & Woodward, 2013; Hynes et al., 2016; O’Hara et al., 2017). There are also cases when studies examine multiple interventions (e.g. transition coordinators and young adult clinics) (Levy-Shraga et al., 2016), making it difficult to ascertain which is the most effective interventional approach. Taken together, I interpret these methodological deficiencies to demonstrate that there has not yet been a clearly defined framework for evaluating and implementing strategies to ease transitions in care.

2.4.3 Limitations of Existing Strategies

Unlike the discrete nature of the healthcare transition at 18 years of age, learning to live with Type 1 diabetes is a long-term process that occurs within the broader developmental context of an individual’s life (Paterson & Thorne, 2000a). To capture the gradual nature of learning to live with Type 1 diabetes, “transition” may be better defined as,

… the purposeful, planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults as they grow up learning to live with their lifelong health condition” (Dovey-Pearce & Christie, 2013) (p.175)

This broader focus for transition is absent in studies of practice-based interventions that focus on how to help pediatric patients best fit the role of adult patient (Allen & Gregory, 2009).

A need for a new research approach to study transition is apparent from the limited impact existing interventions have had on clinical care guidelines (Hanna & Woodward, 2013). In 2018, Diabetes Canada released guidelines that included a section on the “transition to adult care”, with only one recommendation for providers (Wherrett et al., 2018),

To ensure ongoing and adequate diabetes care, adolescents should receive care from a specialized program aimed at creating a well-prepared and supported transition to adult care that is initiated early and includes a transition coordinator; patient reminders; and
support and education promoting autonomy and self-care management skills [Grade C, Level 3 evidence].

In the context of these guidelines, “Grade C, Level 3” evidence refers to “Non-randomized clinical trial or cohort study; systematic overview or meta-analysis of level 3 studies” (Sherifali et al., 2018b). In addition to Diabetes Canada, the American Diabetes Association also offers recommendations for providers during transitions in care, and similarly their recommendations do not originate from what is considered to be high standards of biomedical evidence (most recommendations are based on expert consensus or clinical experience) (American Diabetes Association, 2018; Peters & Laffel, 2011).

Taking a biomedical approach to research limits how transition is studied, as the scope of the researcher cannot explore broader psychosocial factors that may be influencing self-management practices (Young-Hyman et al., 2016). Existing biomedical approaches have not examined intricate concepts related to transitions, such as identity, agency or responsibility (Kralik et al., 2006). There is thus a need for new research approaches that can elucidate social mechanisms influencing transitions in diabetes care.

2.5 Qualitative Studies of Transitions in Care

Qualitative studies have been reported within the literature that aim to better understand the psychosocial context surrounding transitions to adult diabetes care (Sheehan et al., 2015). From a qualitative stance, diabetes researchers have tried to examine aspects of the transition care experience that cannot be easily quantified. For instance, Ritholz and colleagues (2014) assessed how patients experience the patient-provider relationship as they exit pediatric care and commence adult care. In this study, post-transition patients (mean age 26.2 ± 2.5 years) discussed their experiences in focus groups stratified according to participant HbA1c (Ritholz et al., 2014). Differences in accounts about patient-provider relationships were found amongst participants according to their HbA1c results (Ritholz et al., 2014). Those who had higher HbA1c exhibited a theme of “wanting to go” (i.e. they wanted to end pediatric relationships), compared to the theme of “sad reluctance” for leaving pediatric care for those with lower HbA1c results (mean HbA1c for participants demonstrating “wanting to go” was 9.8 ± 1.0% versus 7.4 ± 0.6%
for participants conveying “sad reluctance”) (Ritholz et al., 2014). This study, along with similar qualitative research on the transitioning patient population (Scholes et al., 2012), suggests that patients may interact with parents and providers differently depending on their HbA1c throughout the transition to adult care.

Looking beyond HbA1c, autonomy is a key element influencing the psychosocial context surrounding transitions in care (Spencer et al., 2010). Qualitative studies have captured parent and patient perspectives regarding handovers in responsibility (Allen et al., 2011; Garvey et al., 2014). Unlike their greater presence in pediatric care, parents have been known to describe challenges trying to relinquish control of their child’s diabetes management (Allen et al., 2011). The initial years adjusting to less parental support can be difficult, as qualitative studies with transitioning patients have demonstrated that patients can feel underprepared for the practicalities that constitute their new role of autonomous ‘adult’ patient (Garvey et al., 2014). To better understand how transitioning patients take on greater responsibility, qualitative studies have interviewed transitioning patients to understand how they integrate diabetes within their lifestyles outside of the clinic (e.g. in university or work contexts) (Hill et al., 2013; Pyatak, 2011).

Although transitioning patients are unique from typical pediatric or older adult patients, this patient population represents a diverse group of individuals who have unique experiences with Type 1 diabetes. From one transitioning patient to the next, the ways in which individuals take on responsibility for self-management can vary. There is a need to better recognize the distinct perspectives seen across transitioning patients.

2.6 Emerging Adulthood

Across multiple ethnic groups, social classes, and in studies using both questionnaires and interviews, people recurrently state three common criteria for reaching adult status: accepting responsibility for oneself, making independent decisions and becoming financially independent (Arnett, 2000, 2015). Unlike more traditional measures, such as getting married or having children, these criteria demonstrate that the journey towards adulthood has become more ambiguous and gradual.
More people in their twenties are experiencing delayed entries into typical adult roles. For instance, with rising house prices, only 1 in 10 people younger than 24 years can afford to buy a first home, which is down from 1 in 3 in the mid 1980s (Anderson, 2015). In addition to extended periods living in the parental home, longer stays in education and delays in taking on full-time employment characterize the post-adolescent years (Statistics Canada, 2012, 2013, 2018). The result of this delayed trajectory towards adulthood has been an evolution of a distinct “in-between” stage of life. This developmental stage has been termed emerging adulthood and it broadly spans the ages between 18 to 29 years (Arnett, 2016).

In contemporary developmental psychology, emerging adults are depicted as valuing the attainment of independence and self-sufficiency before making adult commitments. A central feature of emerging adulthood is that it is an individualistic stage of life (Arnett, Žukauskienė, & Sugimura, 2014). Even in countries traditionally considered to have collectivistic cultures (such as Japan), the individuality of emerging adulthood and postponement of adult roles now exists (Arnett et al., 2014). As Arnett (a developmental theorist) states, “emerging adulthood can be said to exist wherever there is a gap of at least several years between the time young people finish secondary school and the time they enter stable adult roles in love and work” (Arnett, 2015).

The theme of individuality is helpful for understanding emerging adulthood. Unlike adolescence, when virtually all adolescents are enrolled in high school, emerging adulthood brings forth much more individual variability. For instance, most emerging adults will complete a university or college degree at some point during their twenties, but the pace at which they do so varies (Statistics Canada, 2018). Some may take a gap year after high school to work or travel. Others may take a gap year after completing an undergraduate degree, before deciding to return to education to pursue a graduate degree. There is much choice during emerging adulthood, which is a reflection of individualistic westernized societies that provide young people with multiple alternatives in various life domains (e.g. education, romance or work) (Schwartz et al., 2013).

Looking at demographic characteristics during emerging adulthood, I have recurrently noticed this theme of individuality. For instance, emerging adults are avid users of dating technology that allows an individual to explore potential romantic partners before finding the
“right” match or their so-called soul mate (The Canadian Press, 2015). Fifty three percent of people who use the dating application called “Tinder” are between the ages of 18 to 24 (The Canadian Press, 2015). Also, in religion, emerging adults are less likely to attend group faith activities, such as attending church or synagogue, and they are more likely to participate in individualistic spiritual practices, like yoga or meditation (Uecker et al., 2007). In terms of entertainment, rather than going to movie theatres or watching generic cable television, emerging adults have demonstrated a preference for having movies and television shows personalized to their viewing preferences. In the USA for instance, 60% of emerging adults (18 to 29 years of age) primarily use online streaming services to watch television (PEW Researcher Center, 2017).

2.6.1 Stories and Social Media

The most remarkable sign that emerging adulthood is a time of great individual expression is the popularity of social media outlets. Nearly all Canadians (94%) over the age of 18 years have an account on at least one social media platform, such as Facebook, Twitter, Snapchat or Instagram (Gruzd et al., 2017). Emerging adults between the ages of 18 to 24 years are considered the most ubiquitous and frequent users of social media platforms, as they represent the highest percentage of users on all major platforms common in Canada (Gruzd et al., 2017). Facebook is considered the most frequently used social media platform in Canada (having the highest percentage of daily users), followed by Instagram then Snapchat (Gruzd et al., 2017).

A common feature of most social media platforms is storytelling. Along with getting news stories from these outlets, emerging adults are able to share their own stories and see the stories that their peers post. Through social media, it has now become commonplace for emerging adults to think about their lives as stories for others to see.

There is no reason to believe that emerging adults with Type 1 diabetes are any different than their peers without diabetes, except in regard to their health condition (Fergie et al., 2016). Comparative studies have examined emerging adults with versus without Type 1 diabetes and have found no evidence that suggests Type 1 diabetes delays psychosocial maturation (Pacaud et al., 2007). Emerging adults with Type 1 diabetes will choose similar life paths and engage in similar activities (Palladino et al., 2013). But, unlike their peers without diabetes, emerging adults with Type 1 diabetes will need to learn how to integrate their demanding chronic condition into their evolving life story.
2.7 Research Question and Objectives

The therapeutic and research potential of storytelling during the transition to adult care has been overlooked by practice-based interventions that have had minimal impact. At its essence, the transition to adult care is a situation in which new relationships need to be formed. There is a need for stories as providers welcome emerging adult patients into their clinics and try to orient themselves to the unique perspectives of their new patients (Frank, 2004). Accordingly, the research question that I set out to address was **how does type 1 diabetes fit into an emerging adult’s evolving life story?** The primary objective that accompanied this question was to **characterize the lived experiences of emerging adults with Type 1 diabetes.** Because my background work had suggested that relationships (and especially family relationships) played an important and often overlooked role in diabetes transitions (Markowitz et al., 2017a), I set a secondary objective to **understand the relationship between diabetes related family interactions and responsibility during emerging adulthood.**

By addressing this question and objectives, I wanted to help diabetes care providers better understand how they could individualize support during emerging adulthood. The approach I used to address this research problem was grounded in postmodern narrative theory (Bamberg, 2012b; Fontana, 2003; Frank, 2005).

2.8 Why Choose a Narrative Methodology?

2.8.1 Narrative Medicine

Today’s medical culture has moved towards putting the patient experience at the forefront of clinical care (Canadian Institutes of Health Research, 2011). Health care providers are trying to incorporate patient stories into clinical practice and decision-making, as patients are considered the experts at what it is like to live with an illness (Greenhalgh, 1999; Charon et al., 1995). The notion of ‘narrative medicine’ has been proposed as a way in which providers can better understand the illness experience, and ultimately, adopt care approaches that are more patient centered (Charon & Wyer, 2008; Misak, 2010).
This is especially relevant for Type 1 diabetes, as individuals spend a fraction of time within a clinic (about one to four hours a year), compared to the majority of time spent managing the chronic condition within the social contexts that encompass their everyday lives (Young-Hyman et al., 2016). Given the chronic nature of diabetes, narratives bring coherence and meaning to the complex interplay of psychosocial factors influencing experiences with Type 1 diabetes (e.g. personality, family dynamics or gender). In this sense, narratives help to think about a person holistically (Lindsay & Schwind, 2016).

Narratives from the first-person perspective can be defined as being about “people (characters), who act (events) in space and time; typically across a sequence of events (temporality)” (Bamberg, 2012b). The terms story and narrative have been used interchangeably and distinctly within medical literature. For the purposes of this thesis, I have defined narrative as the broad skeleton that encompasses the unique stories individuals tell about living with an illness (e.g. Terry Fox’s story can be generally described as a narrative in which he used illness as a catalyst for positive change) (Frank, 1998).

2.8.2 Narrative Research and Emerging Adulthood

A narrative methodology becomes increasingly appealing as one thinks about the transitional time of life known as emerging adulthood (McLean & Breen, 2014). Emerging adults with Type 1 diabetes will be leaving familiar relationships with pediatric providers, starting new relationships with adult care providers and modifying relationships with parents (Sparud-Lundin et al., 2010). They will be trying to become the author of their own life stories, and they must take diabetes along for this ride (McAdams, 2013). Instead of being dependent on a patient chart sent over from the pediatric clinic, hearing the stories told by emerging adults with Type 1 diabetes as they arrive in the adult care setting presents an opportunity to look beyond conventional HbA1c focused diabetes care, towards a more holistic approach.

Emerging adults nowadays have more tools than ever to think about their lives as stories, as social media outlets have gained considerable popularity (McLean & Breen, 2014). A narrative approach is well suited to emerging adults who have become accustomed to using storytelling technology on a daily basis (Duggan & Brenner, 2013).
The self has become a popular reference point for emerging adults. When emerging adults want to acquire knowledge or learn about an experience they turn to readily available social media outlets. For instance, “Vlogging” has become a popular tool on the internet to depict a wide range of experiences through video, which include illness experiences (Sheriff et al., 2018). Numerous Vlogs have been posted on Youtube (in some cases generating over 20,000 views), which document a day in the life of an individual living with Type 1 diabetes (Youtube, 2017). In these videos, the main character (typically an individual in their emerging adult years) will highlight how they manage Type 1 diabetes throughout a day (from morning blood glucose checks to a final blood glucose check before bedtime). I find this to be demonstrative of the individualistic nature of emerging adulthood, in which emerging adults want to learn from the experiences of others. Although endocrinologists may have biomedical expertise about managing Type 1 diabetes, emerging adults living with Type 1 diabetes are considered to have the practical knowledge about what it entails to manage the condition on a daily basis (Gray, 1999).

In addition to social media technologies, there is also a rapidly evolving technological landscape that can aid Type 1 diabetes self-management during emerging adulthood (DiMeglio et al., 2018). For instance, new continuous glucose monitoring and flash glucose monitoring technology allows people with Type 1 diabetes to track their blood glucose concentrations on their smart phones (virtually all emerging adults in Canada have a smart phone) (Berard et al., 2018).

The benefits of using a narrative research approach during emerging adulthood allow for contradictions and complexities to be interpreted (Frank, 1998). Issues such as lack of continuous glucose monitoring technology use during emerging adulthood (Tamborlane, 2008) can be understood within the broader context of an emerging adult’s personal story about life with Type 1 diabetes (Frank, 2002, 2005).

A narrative approach to research offers more than simply a cataloguing of the facts of a story. Stories collected in a research setting allow the researcher to examine what the teller of the story was like and why they told a story in a certain manner (Riessman, 1993). Through this research approach, a researcher has the capacity to explore life transitions from the perspectives of the emerging adults who are experiencing them (Lieblich et al., 1998), while also zooming out
and interpreting how broader social influences (e.g. dominant discourses or master narratives, such as transition as a “graduation”) play a role in shaping experience and perceptions (Lindsay & Schwind, 2016).
Chapter 3
Methodology

3.1 Chapter Overview

Throughout this chapter I will outline the methodological framework that forms the basis for my qualitative research. I start by describing the design of my narrative study. Next, I define practical procedures that I employed during the study. Issues of sampling and recruitment, interview procedures, data analysis/interpretation, and study rigour will be presented.

3.2 Study Design

Qualitative research is a scientific approach that aims to understand complex social issues in medicine (Centre for Critical Qualitative Health Research, 2018). At its essence, this qualitative study was designed to characterize the lived experiences of emerging adults with Type 1 diabetes. To do so, I took a narrative approach that was in line with postmodernism and social constructionism (Fontana, 2003; Georgakopoulou, 2015). Postmodernism is a theoretical perspective that contextualizes illness within the broader social environment that surrounds a patient’s life (Gray, 1999), while social constructionism is a theory that puts forth the notion that people make sense of illness through their interactions and relationships with others (Conrad & Barker, 2010). For instance, from a post-modern, social constructivist stance, a researcher might explore how a constellation of relationships and social interactions (e.g. with family, health care providers, peers, etc.) influence how an individual comes to terms with their illness (Parsons et al., 2008).

Given that it is not realistic for health care providers to listen to patient autobiographies for many hours within a typical clinical care encounter, my focus was to design a narrative study that would have applicability to the “here and now” of clinical care interactions (Bamberg, 1997, 2012a; Bamberg & Georgakopoulou, 2008). Regardless of whether it was about what happened yesterday, a vacation a few months back, an upcoming exam or being diagnosed with Type 1
diabetes, I tried to understand why emerging adults told their stories in a certain manner (Riessman, 2008).

Reflexivity was a guiding principle of my study and is a term used to denote the self-awareness that is required on behalf of a qualitative researcher (Doyle, 2013; Finlay, 2002). I was reflexive of how my demographic and professional profile (a white man who was working as a graduate student) could have influenced how participants told their stories. The probing questions I decided to use, along with my demeanor, may have influenced the responses told throughout the course of interviews (Manderson et al., 2006). If participants were interviewed in the future or with a different interviewer (such as a health care provider) their responses may have taken on a different form (Pezalla et al., 2012). Aside from my acknowledging my presence during interviews, I also tried to use my presence creatively during analysis. I viewed my demographic background (an emerging adult who was 24 years old) as a tool for interpreting the data, as I tried to empathize with participants by thinking about what they were saying in the context of my own life. For instance, I often thought about how interactions with my parents would change if diabetes had entered the family dynamic. Given the subjective nature of this study, I have tried to make my voice transparent with regard to that of the voice of participants when reporting the findings. A reader more versed in a positivist scientific tradition might be unaccustomed to this first-person writing style with which I have engaged (Nicholls, 2009). But this is a common element of writing up qualitative research findings, in which a researcher must self-acknowledge their presence throughout the research process (Finlay, 2002). Rather than act as a distant observer, I interacted with participants to better understand how they viewed life with Type 1 diabetes.

3.3 Sampling Approach

I approached sampling with the intention of recruiting a diverse sample of emerging adults who were willing to speak in great detail about their experience with Type 1 diabetes. I employed a convenience sampling approach (Schreier, 2018). Based on the availability of patients attending emerging adult diabetes clinics at St. Michael’s Hospital and Women’s College Hospital, I sought to recruit emerging adults with Type 1 diabetes between 18 to 24 years of age. Each clinic was oriented to meet the unique developmental needs of emerging adult patients 18 to 24
years of age. Referrals were received from pediatric hospitals across Toronto. The referral practice for these clinics was not based on any specific criteria and was advertised to any patients (18 to 24 years of age) who wished to have their care transitioned to a specialty transition clinic prior to entering the general adult clinic.

Over the course of recruitment, I approached emerging adults from a range of social and clinical backgrounds, which included different: ethnicities, genders, occupations, educational status, sexual orientations, countries of origin, living arrangements (i.e. residing with and without parents or caregivers), duration of living with diabetes, and insulin administration methods (insulin pump or multiple daily injections). I also recruited individuals from varying family structures, such as those from divorced parent families, single parent families, single child families, and families with other immediate family members living with diabetes. My intention was to explore the diabetes experience from a range of social contexts. I monitored the demographic and clinical characteristics of participants over the course recruitment so that there was not an overrepresentation of similar features (e.g. I tried to ensure there was a relatively equal proportion of men and women).

The first-hand accounts elicited in my study provide rich representations of everyday interactions and relationships that constitute life with Type 1 diabetes during emerging adulthood (Schreier, 2018). I will remind the reader here that this study was dialogical rather than epidemiological in nature (Frank, 2005). By this, I intend to mean that this was case-based research, in which my focus was to provide in-depth accounts about how each individual participant made sense of their experiences with diabetes. The research was context-dependent in that a sample of emerging adults with Type 1 diabetes from a different context (e.g. those attending a general adult diabetes clinic, or living in rural areas) might have experienced diabetes differently. Despite potential contextual differences across populations, I wanted to provide the reader with insights and conceptualizations that could inform their own perspectives when interacting with emerging adult patients in similar circumstances. Aside from Type 1 diabetes, the portrayal of the experiences of the participants may also have transferability to emerging adults with other chronic health conditions, as the notion of transition was a significant concept integral to the narratives of participants.
3.4 Recruitment Procedure

At the outset of designing this study, I familiarized myself with key ethical issues constituting my role as a qualitative research investigator (Ryen, 2007). Central ethical issues involved with the conduct of this study included: *informed consent* and *confidentiality* (Mertens, 2018). Prior to commencement of recruitment, the study protocol was reviewed and approved by the Research Ethics Boards at St. Michael’s Hospital, the University of Toronto and Women’s College Hospital (Toronto, Ontario, Canada).

Recruitment took place at two emerging adult diabetes clinics that were both located in the same urban city (Women’s College Hospital and St. Michael’s Hospital, Toronto, Ontario, Canada). Patients at the two clinics who met the following inclusion criteria were deemed eligible to participate: sufficient proficiency in the English language, diagnosed with Type 1 diabetes for one year or greater and between 18 to 24 years of age. Eligible patients were identified through electronic medical records or patient charts and were approached by health care providers within their circle of care between October 2016 and April 2017. Interested patients were introduced to me at the end of their clinic visit.

After introducing myself, I provided a detailed description of the study to those individuals who conveyed interest. I reviewed the consent form (Appendix A) and provided further clarification or elaboration when necessary. The consent form provided an overview of the study in layman’s terms, which included sections about the purpose of the research, description of the research procedures, potential harms and benefits, confidentiality, privacy, reimbursement and withdrawal. After discussing the consent form with interested individuals within the clinics, prospective participants were given a consent form to take home and I encouraged them to deliberate further with any family or friends. I also collected contact information from interested individuals before they left the clinic. On a later date (usually two to four days after our initial interaction) I contacted participants, using a St. Michael’s Hospital telephone or my St. Michael’s Hospital email account, to see if they wanted to schedule an interview date. Each individual who decided to enter the study was given a unique identification number and a pseudonym in place of their actual name. All participant names that are referred to within this thesis are pseudonyms that I created.
3.5 The Interviews

For data collection, I chose the method of in-depth, in-person interviews (Kvale, 2007a).

3.5.1 Interview Setting

All interviews took place at Women’s College Hospital or St. Michael’s Hospital, Toronto. When scheduling interviews, I provided participants from both sites with the options of being interviewed at the Emerging Adult Diabetes Clinic at Women’s College Hospital, or the Emerging Adult Diabetes Clinic, Applied Health Research Centre or Li Ka Shing Knowledge Institute, each at St. Michael’s Hospital. Nineteen participants were interviewed within the Applied Health Research Centre, seven participants were interviewed at the Emerging Adult Diabetes Clinic at Women’s College Hospital, five participants were interviewed at the Emerging Adult Diabetes Clinic at St. Michael’s Hospital and two participants were interviewed at the Li Ka Shing Knowledge Institute.

Each interview took place within a private room without the presence of any other individuals within the interview room. There were occasions when friends or family came with participants to their interviews, or met them afterwards, but these other individuals did not enter the interview room. I did make a note of their presence outside of the interview room, as it provided insight into parental relations, and how friends were supportive figures within their diabetes care.

3.5.2 Interview Procedure and the Interview Guide

After settling into the interview room, each interview began by me reiterating the main goals of the study, and providing a brief explanation of the open style of interview questions that I would be asking. I then asked the participants if they had any questions or concerns regarding their consent prior to beginning. After receiving their signed consent form, I started the audio recorder. The data collection procedures that ensued after this point took on two structures. For the first ten interviews, I began with open-ended questioning, while for the following 23 interviews I started with a series of demographic questions before entering into the open-ended questions (the rationale for this decision will be discussed in the proceeding paragraphs). Upon the completion of each interview, participants were provided with a $10 honorarium to a retail store to thank them for their time and efforts.
For interviews one through five, data collection began with me asking the first question on the initial interview guide, “What has your experience been like living with diabetes?” (Appendix B). Throughout these interviews, I tried to address all of the questions that were on the guide.

By the fifth interview, I realized that I needed to make improvements on how I was engaging in dialogue with my participants. The initial five interviews ranged between ten to 30 minutes in length, which I found to be an indication that I needed to alter my approach to interviewing if I were to elicit rich accounts from participants. I sought advice from experienced colleagues, which led me to literature regarding semi-structured qualitative interviews (Hermanowicz, 2002; Kvale, 2007a). At this point, I realized I needed to encourage participants to tell their stories in a manner they saw fit without rigidly trying to follow an interview guide.

For interviews six through ten (which ranged between 25 to 70 minutes), I started to become more flexible in my interviewing approach. I began asking questions about a variety of lifestyle aspects that I was finding helpful for eliciting dialogue about the participant’s diabetes experience.

At the 11th interview, I changed my approach by beginning each interview with a series of demographic questions. My intention for doing this was to ‘break the ice’ and familiarize myself with participants’ background information before moving on to the more open-ended questions. This acted as a warm-up, in which I could set the stage before gradually entering into more in-depth dialogue with participants. Prior to this change in structure at the 11th interview, all previous interviews had ended with the participants completing the full demographic questionnaire (Appendix C). The 23 interviews after the initial ten ranged between 40 to 125 minutes. The average length of an interview for this study was 52 minutes.

Despite equipping myself with a questionnaire and guide for each interview, my approach to interviewing in this study can be described as being conversational (Hermanowicz, 2002). By being conversational, I do not wish to imply that I spoke about myself. I intend to convey that I encouraged participants to tell their stories in a manner they saw fit, as I did not try to follow the guide in a linear manner (Frank, 2000). Participants were allowed to talk about any aspects of their diabetes experience that they felt should be addressed (Van Manen, 1997). I wanted participants to feel as though they were interacting with an interested listener who
wanted to learn about their unique experience with diabetes, and find out what it is like to live with diabetes (Lindsay & Schwind, 2016). The dialogue took on the form of being free or open, and I used the interview guide to help carry on the conversation when needed (Constantino, 2008). By the end of interviewing, the guide evolved into a collection of open-ended questions that I found useful for helping me to elicit conversation (Appendix D). The questions on the guide can be thought of as orienting prompts to aid in the dialogue process (I did not try to address every single question) (Kvale, 2007a). Questions were designed to capture descriptions about past experiences with diabetes, elicit accounts about day-to-day lives as emerging adults with diabetes and acquire insight into self-perceptions.

3.5.3 Transcription

All audio recordings of interviews were transcribed verbatim with the goal of depicting the original oral style as closely as possible (Kvale, 2007b). Pauses, breaks and aspects related to tone (such as laughter and crying) were included within transcriptions. Although there are inherent differences between the oral and transcribed version of the interview, the transcripts served the purpose of helping to facilitate meaningful interpretations of the stories collected (Lapadat, 2000). I transcribed audio from 26 interviews, and a professional transcriptionist transcribed the remaining seven interviews.

3.6 Data Analysis

Narrative analysis occurred concurrently with recruitment, interviewing and transcription (Green et al., 2007). In the context of this study, the narrative analysis that I performed was an inductive meaning-making process (Riessman, 1993). I used participant stories to try to understand how participants made sense of their diabetes experiences.

After each interview was transcribed, I familiarized myself with participants by reading the transcript in its entirety as a story (Ayres et al., 2003). During these initial readings, I highlighted sections of the transcript that resonated with me and I listened to the audio recordings to detect emotional and affective elements that could be missed when reading the transcripts (Pamphilon, 1998). I developed case stories of participants from these initial readings.
(e.g. see Abdullah’s story in Chapter 4), which allowed me to map out my interpretations from the interviews (Kleinman, 1988).

As interviewing and analysis progressed, I engaged with multiple readings and comparisons of transcripts to interrogate my evolving data set (Butler-Kisber, 2010; Lieblich et al., 1998; Pamphilon, 1999). In some instances I isolated narratives and I studied them as separate components of the whole of an interview, while other times I analyzed narratives in the context of their interviews (Ayres, et al., 2003). There were occasions when I compared passages of text from different participants, or times when I compared whole transcripts between participants (Sandelowski, 2011). Throughout my analysis, I used ‘constant comparison’ to examine similarities and differences in how participants told their stories (Ayres, et al., 2003; Butler-Kisber, 2010). For instance, I questioned why a participant might use the analogy of a peanut allergy when describing their diabetes, while another participant compared their diabetes to electricity. I compared narrative elements (such as symbolism or analogies) across the sample to help make sense of what the tellers of the stories were like (Bazeley, 2009; Sandelowski, 2011).

After conducting my 22nd interview, I experienced an analytical breakthrough. I realized that I was seeing three distinct patterns within accounts. These patterns spanned across and within interviews, and were demonstrative of distinct narrative types (Frank, 1995). For each type of narrative, I was noticing characteristic narrative devices that were shaping my overall impression (Czarniawska, 2004), such as storylines (e.g. the ‘difficulty to launch’ narrative, which was about participants who experienced difficulties moving away from the parental home and losing parental support), contradictions (e.g. ‘I’m fine on my own/I had a near death experience’), figures of speech (e.g. I noticed instances of personification as participants described themselves as embodying diabetes), discursive styles (e.g. participants told accounts about having to “fight” diabetes on their own), and character portrayals (e.g. subordinates versus role models). I began to interrogate the devices that encompassed each type of narrative, and I compared devices between the different types. Eventually, I developed themes that defined my conceptualization of each narrative type. I came to understand that the use of the word theme for this study was representative of a non-constraining term or phrase that helps to convey the core meanings of each narrative type.
By the 33rd interview, I reached agreement with my academic committee that the conceptual framework I developed helped make sense of how participants were telling their stories about life with Type 1 diabetes. At this point, when I was seeing no alternative explanatory frameworks for the data set, I determined that I achieved conceptual saturation, in which I felt as though I had developed a justifiable narrative of my own regarding my data that needed to be told (Bowen, 2008).

Although this study was qualitative in nature, I decided to collect demographic and clinical information about participants to enhance the clinical utility of the interview findings. After narrative typology and themes had been defined, I performed a statistical comparison of demographic and clinical characteristics amongst participants grouped according to three common types of narratives. Quantitative clinical and demographic data are shown as mean ± standard deviation. Continuous variables were compared by one way ANOVA followed by Fisher least significant difference post hoc test using GraphPad Prism 7 for Mac OS X (GraphPad Software, La Jolla, CA) and categorical variables were compared using Fisher’s exact test (GraphPad). The statistically significant differences found during this comparison can act as clinically relevant signposts to help health care providers better recognize my depictions of participants.

3.7 Rigour

To assess the rigour of a qualitative research study, standardized guidelines or checklists have been proposed (Popay et al., 1998; Seale & Silverman, 1997). Although these standardized appraisal tools serve as convenient measures to assess rigour, I came to understand that the trustworthiness of qualitative findings could be demonstrated by a researcher’s understanding of their chosen methodology (Eakin & Mykhalovskiy, 2003). A narrative methodology guided my approach and decision-making throughout conducting this study (from designing the protocol to writing up my findings in this thesis). From this narrative stance, I interacted with participants to help health care providers think about how emerging adults perceive Type 1 diabetes. The use of first-hand accounts is intended to justify the interpretations I will put forth while presenting my findings about the participants.
Throughout the course of this study, I cross-referenced my interpretations with existing literature that has explicated the experience of chronic health conditions and I engaged in ongoing analytical discussions with academic committee members (two of these members were actively working as diabetes care providers for emerging adult patients and the three others had expertise in the area of qualitative research methods). Literature checks and discussions about the emergent analysis helped me determine if my interpretations were producing in-depth and original insights that were beyond a superficial level. By having an interrogating stance towards the data, I was not simply accepting my initial interpretations; I was constantly reevaluating my analysis by engaging with multiple analytical perspectives and thinking about alternative explanations. Through ongoing analytical meetings, I was able to learn how to synthesize opinions from multiple academic disciplines (e.g. comments made from an endocrinologist versus those made by a bioethicist). For instance, glycated hemoglobin (HbA1c) not only had biomedical significance, but also moral implications within participant narratives (e.g. it was portrayed as reflecting the goodness or badness of a participant’s glycemic control).

3.8 Chapter Summary

This chapter has framed the methodological and epistemological context that underlies this study’s findings. Transparency in a qualitative researcher’s methodological decisions is critical given the subjective nature of this type of research (Carter & Little, 2007), and I have tried to be transparent throughout this chapter by discussing my decision-making during recruitment, data collection and data analysis.

The overall aim of my narrative methodological approach was to understand what it is like to be an emerging adult living with diabetes. Participant recruitment occurred through a convenience sampling approach, in which the main goal was to efficiently recruit emerging adults from diverse social contexts who were willing to talk in-depth about their diabetes experiences. Semi-structured, in-depth interviews were used as the primary source of data collection. Narrative analysis of interviews occurred while recruitment and interviewing were ongoing. Eventually, as I began to uncover three distinct narrative types, I began to define this study’s analytic framework. The next chapter will contextualize the sample and set the stage before the key interpretive themes are discussed.
Chapter 4
Contextualizing the Sample Population: A Descriptive Prologue to the Interpretive Findings

4.1 Chapter Overview

I intend for this chapter to act as a descriptive introduction to the participants in this study. It is a prologue to the more in-depth interpretations of interview accounts that will be presented in the next three chapters. Within this chapter, I will start by illustrating an aggregate portrait of the sample population by providing demographic and clinical characteristics. Then, I highlight the ‘in-between’ stage of life participants described themselves to be in. I conclude this chapter by presenting three case stories. These stories will serve as examples of three types of narrative about the Type 1 diabetes experience during emerging adulthood.

4.2 Summary of Clinical and Demographic Characteristics

Over the course of recruitment, I approached 67 individuals within the clinics (45 of them were receiving care at St. Michael’s Hospital and 22 of them were receiving care at Women’s College Hospital). Out of the 67 individuals that were approached, 33 agreed to participate (26 of these participants were recruited from St. Michael’s Hospital and seven participants were recruited from Women’s College Hospital). Thirty-three individual interviews with 33 different participants were completed between October 2016 and April 2017. Diverse demographic and clinical characteristics were present amongst the sample population (Table 1). There were a relatively equal proportion of men and women (16 men / 17 women). Eighteen participants self-identified ethnically as White (55%), whereas other ethnic identities represented included: Asian, Black, Filipino, Italian, Latin American, Middle Eastern, South Asian and West Indian. Participants ranged between 18 to 24 years of age and the mean age of participants was 20.6 ± 0.3 years (mean ± standard error of the mean). Twenty-four participants were living with a parent or caregiver (73%), seven lived with a roommate (21%) and two lived by themselves (6%). Twenty-two participants were students at a university/college (67%), five were working...
full-time (15%), five were working part-time (15%), and one was unemployed (3%). Out of the 22 participants who were students, one was completing their post-graduate studies in a doctoral program, while the remaining students were working on undergraduate degrees. Thirty-one participants sexually identified as heterosexual (94%), one participant identified as bisexual and one identified as gay. Thirteen participants reported that they were in a romantic relationship (39%) and none were married. The range in duration living with Type 1 diabetes was 3 to 20 years and mean duration of diabetes was 12.0 ± 0.8 years. HbA$_1c$ (measured before and closest to the time of interview) ranged between 6.3% to 12.5% (mean 8.4 ± 0.3%). Twenty participants were using an insulin pump as their method of insulin administration (61%), whereas 13 were using multiply daily injections (39%). Five participants had a parent with Type 1 diabetes or Type 2 diabetes (15%) and four participants had a sibling with Type 1 diabetes (12%).
### Table 1: Demographic and clinical characteristics of the study population

<table>
<thead>
<tr>
<th>Demographic and clinical characteristics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participants (n)</td>
<td>33</td>
</tr>
<tr>
<td>Number male (%) / number female (%)</td>
<td>16 male (49) / 17 female (51)</td>
</tr>
<tr>
<td>Age at interview (years)</td>
<td>20.6±1.7</td>
</tr>
<tr>
<td>Duration of diabetes at interview (years)</td>
<td>12.0±4.8</td>
</tr>
<tr>
<td>HbA1c (%) at most recent visit pre-interview</td>
<td>8.4±1.5</td>
</tr>
<tr>
<td>Insulin administration, n (%)</td>
<td></td>
</tr>
<tr>
<td>Number using CSII</td>
<td>20 (61)</td>
</tr>
<tr>
<td>Number using multiple daily injections</td>
<td>13 (39)</td>
</tr>
<tr>
<td>Ethnic identity, n (%)</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>18 (55)</td>
</tr>
<tr>
<td>Other self-identified ethnicities (e.g. Middle Eastern, Filipino, Black, Italian)*</td>
<td>15 (45)</td>
</tr>
<tr>
<td>Sexually identify as LGBTQ, n (%)</td>
<td>2 (6)</td>
</tr>
<tr>
<td>Number in romantic relationship (not married), n (%)</td>
<td>13 (39)</td>
</tr>
<tr>
<td>Living arrangement, n (%)</td>
<td></td>
</tr>
<tr>
<td>Number living with parent or caregiver</td>
<td>24 (73)</td>
</tr>
<tr>
<td>Number living without parent or caregiver</td>
<td>9 (27)</td>
</tr>
<tr>
<td>Number with parent who has Type 1 or Type 2 diabetes, n (%)</td>
<td>5 (15)</td>
</tr>
<tr>
<td>Number with sibling who has Type 1 diabetes, n (%)</td>
<td>4 (12)</td>
</tr>
<tr>
<td>Occupation, n (%)</td>
<td></td>
</tr>
<tr>
<td>University/college student</td>
<td>22 (67)</td>
</tr>
<tr>
<td>Other (full time work, part time work or unemployed)</td>
<td>11 (33)</td>
</tr>
</tbody>
</table>

CSII=continuous subcutaneous insulin infusion; LGBTQ = lesbian, gay, bisexual, transgender or queer (1 participant was gay and 1 participant was bisexual). Values are mean±S.D.

*I have only provided a few self-reported ethnicities as examples to avoid the potential of participant identification (i.e. there were ethnic categories for which only one participant was a part of).*
4.3 Conceptions of Adulthood

Participants portrayed themselves as gradually pursuing greater independence, although most still maintained a close relationship with their parents. Heather explained that there were times she needed a more “adultier adult” (her mother) to do certain tasks for her:

I feel like I’m half way there maybe, I don’t know. Sometimes I feel like I need a more like adultier adult to do things for me {laughs}. That’s where my mother comes in. But like I feel like in many situations I still am an adult, like I have a job, I’m pretty self-sufficient, I have a car, like that kind of stuff. But I feel like a lot of stuff, like doing my own tax return, I’m not too sure about. There’s still stuff I need to learn…

As Heather alludes to, parents still played an active role within participants’ lives. Most participants were still living within the parental home (24/33). For the few that were not living in the parental home, they did not yet feel financially independent from their parents (e.g. their parents were described as taking care of foundational living expenses such as rent or tuition).

Across the sample population, being financially independent was seen as a significant marker of achieving adult status. Many participants described that they would feel more like an adult if their parents were no longer the primary financial source in their life. For example, Karen remarked,

I think of an adult as someone who has matured enough psychologically to be completely— not completely—to be financially, and I don’t want to say mentally, but to definitely be like financially independent from their previous support system… So to be like paying rent to your parents, I see that as kind of like an extension of adolescence because you’re still very much intertwined with your support system. The moment that you have to start reaching out to get to your old support system is the point where I think adulthood is reached because you’re starting to be a little bit more forging in your path.

Despite feeling as though she could be “mentally” independent (which I interpreted as her capacity to make choices by herself or think for herself), Karen was not yet financially independent. She spoke about how financial independence would be a signal to her that she had reached adulthood.

Participants conveyed a sense of transience, as they described themselves as being in non-permanent positions. They felt as though their lifestyles would look different in the near future. Rather than feeling as though they had reached adulthood when they turned 18 years of age, participants were in the process of taking on greater personal responsibility.
4.4 Three Case Stories

To help prepare the reader for the key interpretive findings that will be presented in the following three chapters, in this section I present three case stories about the diabetes experience described by three participants.

These participants were purposely chosen because of the differences in which they exemplified diabetes as being a part of their life according to a foreground–background spectrum. On one end of this spectrum (the foreground), diabetes was presented as being a prominent and dominating feature of an individual’s life. On the other end of the spectrum (the background), diabetes was presented as being situated away from the center stage of an individual’s life, as it was described as not interfering with other more central features (such as vocation).

The first participant, Abdullah, embodied an individual who had learned how to settle diabetes within the background of his life. His narrative was about a highly positive experience with diabetes, as he spoke about acceptance.

The next participant, Lindsay, provided a stark contrast to Abdullah as she conveyed more negativity. She characterized her experience with diabetes as being a struggle, as she portrayed diabetes as being difficult to accept.

Lastly, a case story about Jennifer will be presented to distinguish a more ‘neutral’ narrative in comparison to Abdullah and Lindsay. Jennifer spoke about her experience with diabetes using minimizing language as she outlined a desire to keep diabetes away from the spotlight of her life. Similar to Abdullah, Jennifer did not appear to be burdened by her diabetes, but she indicated that she tried to avoid diabetes rather than accept it.

4.4.1 Abdullah’s Story

Abdullah was 23 years old at the time of our interview and he was diagnosed with Type 1 diabetes when he was 16 years old. Instead of trying to fight against his diabetes, Abdullah described an ongoing willingness to learn how to adapt to living with diabetes. Acquiring knowledge had helped Abdullah to combat initial fears about diabetes, illness and death. At the time of our interview, he felt comfortable living with diabetes:
…when I was young and naive I did not understand certain things. So I look at these
diseases like diabetes, cancer, all this stuff as like super bad, like someone is going to die
if they have them. So when I was diagnosed, that fear aspect, that, “Oh no, I have
diabetes, am I going to die? Like what is going to happen if I eat this? And is this going
to kill me? Is this going to kill me?” so all these things were running through my head.
But through proper education and proper teaching by facilitators at [pediatric clinic
name] and now where I am at with [emerging adult clinic name], it taught me that I can
still be like everybody else, but I have just got to do it in a more gradual kind of
conservative type of way…

Ultimately, with time and trusted knowledge, Abdullah embraced his diabetes as being a part of
who he was:

Like when you are young you feel like it’s a burden but now that I am older it’s like, it’s
not really a burden it’s just part of my story. Like I’ve said, “Oh yeah, I’m this year, this
is how old I am, I go to school, this is my background, I am a diabetic.” It like literally
became part of the backbone of who I am.

A strong foundation of support from others was particularly helpful in facilitating
Abdullah’s acceptance of diabetes. Abdullah saw his parents, brother and sister as providing him
with ongoing and valuable support. At our interview, he was living in the parental home with his
family and he saw each family member as being involved with the support of his diabetes.
Abdullah told accounts illustrating his sister as being a dietary support resource (e.g. packing
him lunches) and his brother providing him with “mental support” while his parents took on the
role of ‘moral support agents’:

…they [his parents] are always asking, they are always calling, texting, saying, “Hey, I
know you are out busy, I know you are a busy guy but did you happen to eat? Did you
happen to check your blood sugar? How are you doing? Are you staying late tonight? If
you are, don’t forget that this is your time, this is your time.” So they’re there for like the
moral support. When I feel like I am losing my way with the diabetes they just kind of
tug me back and be like, “Oh no, this is the direction you want for life and diabetes, don’t
only focus on this or don’t only focus on that, here is the perfect path for both.”

As noted above, there were occasions when Abdullah described his self-management as
challenging, but Abdullah’s family was described as working hard to support him in prioritizing
diabetes when other lifestyle activities were threatening to overtake his focus. In this way, his
family provided a safety net to support him when he felt like “[he] was losing [his] way with
diabetes”.

38
Abdullah also felt like he received strong support from his college administration and professors. This support helped to further normalize diabetes for Abdullah and provided the necessary understanding and resources to allow him to manage his diabetes comfortably and confidently while at school:

… so with the disability services at [college name] as well as like some of the faculties and professors there, it was easier to become more independent because they are understanding. Some of them could even relate too and bringing family members that they have themselves who are connected to diabetes. So it allowed me that sense of comfort to know that I can manage it well because the people I am going - like the professors I go to the classes with and the whole school system itself understands the situation and can relate. So I get that ongoing support if I need for my diabetes through the disability services at [college name].

The use of technological aids further facilitated Abdullah’s sense of comfort with diabetes. For instance, at the time of our interview, he was using an insulin pump and he saw it as having a positive impact on his life. As a college student, he found that there are busy periods in his life, in which his daily focus can “get clouded on tasks or assignments” and he can lose track of the timing of his meals. But the pump permitted him the necessary flexibility to manage well alongside other competing tasks:

…it allows me to manage my sugar levels in a way that if I have a busy schedule the insulin is delivered 24 hours, so like I don’t have to worry about, “Okay, now I have got to take out the pen, I got to go do this, I got to do that.” As long as I just prick myself, program it on my pump and deliver… it’s something I can do while I am waiting in line ordering the food. So it makes it more convenient instead of having to stand in line, wait, grab my food, calculate the carbs, right? And then from there, order the food, wait for the food to be delivered, go to the bathroom, take out the injection, do the injection in the bathroom in a secure spot then come back, grab my food and then start eating…like with every company now they have nutrition facts, telling the calories… the carbs and everything on all their meals. So with that it allows me to properly calculate my insulin to carb ratio and then it’s just as simple as typing it onto a device, hitting enter and the insulin being given to me. So I find that my pump has contributed very well to my overall aspects for diabetes.

Abdullah was a practicing Muslim and viewed his diabetes as motivating him towards becoming “more religious.” He demonstrated a heightened spiritual consciousness that shaped his positive outlook on life with diabetes:

So I felt like diabetes got me also to be a little bit more religious, understand the certain blessings in life that God gives you and the certain challenges that God gives is for a good thing, not really for a bad. And it’s because, I don’t know, maybe you were
probably destined to do some good or you are destined to do something great, this is just a challenge and like how you take it will determine what you do as you proceed forward in life.

As will be discussed further in Chapter 5, my analysis of Abdullah’s interview and other interviews like it, helped form my interpretation of an ingrained lens. Through this lens, participants described diabetes as being smoothly integrated within their life. Whether it was when speaking about religion, family or academics, Abdullah demonstrated that he felt at ease living with Type 1 diabetes.

4.4.2 Lindsay’s Story

Lindsay was 21 years of age at our interview. Reflecting on her diagnosis experience (she was diagnosed with diabetes when she was six years of age), she recounted feeling like the ‘odd one out’ as she returned to grade school:

… I think I probably got really like my first kind of thing with diabetes where I noticed it made a difference was… you know when it’s your birthday in like elementary school and you bring in treats? That was kind of like my pivoting moment, when I couldn’t eat the Timbits [doughnuts] that my friend had brought in.

Lindsay referred to this moment as influencing her towards switching onto an insulin pump,

I was in grade six when I first got it [an insulin pump] and I loved it when I first got it. So just ending elementary school, starting high school, being like, “It’s okay, I can eat whatever I want, I can do whatever I want,” I didn’t have to, because like the Timbit [doughnut] scenario, I remember going down to the main office giving my mom a call saying, “Can I please eat it?” she’s like, “You got to wait till you get home,” and so the fact that like next time I could just do that on my own was huge for me.

Although she felt a greater sense of dietary freedom when using an insulin pump, it eventually brought forth new challenges for her within the high school environment,

… I hated the fact that I had a cord on me at all times and if you looked at me, like I am so open about my diabetes but I don’t like when someone looks at me and just they see that device, like it just reminded me of something you see in the hospital, and I didn’t like that look of being so sick, having an infusion set and everything. So I grew and I just resented it, so I would not give myself the insulin even if it was on me all the time. And then my sugar ended up just getting a lot worse.
Lindsay was no longer using an insulin pump at our interview, but she still was sensitive towards how others viewed her diabetes,

… my friend actually was buying chocolate at [grocery store name] right beside [university name], and she was just talking to the cashier, and she is like, “Oh, this is going to help me stay awake in class,” and he is like, “This is going to help you get diabetes.” And just like hearing that from someone else sucked because it was like, you have no idea what goes on behind it…

Behind the scenes, Lindsay experienced great difficulties with the practicalities of daily management. She described learning about diabetes management secondhand through her parents, which she believed to be her “downfall”:

… everything I was learning was second hand through my parents. And I think that’s where I had a lot of my downfall just because I was getting bored of the way they were doing it, I didn’t like the nagging and so that’s when I just stopped completely rather than, like I wish there was a program that I went into when I was turning 16 that helped me manage it because I don’t think I had the best idea of it.

Rather than feeling prepared before entering emerging adulthood, Lindsay found that she was trying to make-up for lost years of learning.

At our interview, Lindsay was completing her undergraduate studies and she was living in the parental home. Her parents were active figures within her diabetes care. For instance, her dad would drive her to clinic appointments and her mother would help manage her insulin supplies. But her parents were also noted as being a source of stress. Neither of her parents had the opportunity to pursue a university level education, which intensified her own educational pursuit. She remarked,

… my dad had a job out of high school to help his parents work, my mom never had the chance to go to university… that’s why like whatever we do, whatever me and my sisters do, they are so proud of us. They are not pushing us for anything, but I kind of have that, that idea to do better, to do the best I can, so I put myself in a lot of stress…

As a university student, Lindsay was prone to experiencing disruptive instances arising from her diabetes:

I study a lot, like I am on the dean’s list, I try to maintain my grades, and I know that if my sugar is high or low, I can’t study. And I usually stay in the library morning till night. And I know that, okay, if my sugar is low or high I have to think about when I can eat, what’s the best time for me to go home at, so that’s really annoying. Also writing exams I
know I have to be in that prime sugar because I remember one exam I wrote, I was at, I was really, really high. I had four and a half hours to write it, the first four hours I was just so high working on getting my sugar down I couldn’t do anything, and then finally the last hour I felt good enough to write it.

I found quotes like the one above to indicate Lindsay’s lack of self-confidence in her management capacity. She described a sense of vulnerability.

In addition to her academic work, Lindsay was involved in numerous extracurricular activities, and fitting diabetes into her busy lifestyle was described as being extremely difficult for her.

I put so much on my plate… I strive to do so well in school, I joined as many committees as I can and I enjoy that so much, and so fitting in diabetes and kind of understanding that if I don’t take care of it nothing else matters is hard for me. Just because it’s like, I will look around and be like, “You don’t have to do this, you don’t have to do this, why do I have to do it?”

Lindsay expressed a sense of resentment towards her diabetes. She had two sisters without diabetes, and she portrayed herself as being the ‘unlucky’ one. She explained that it was like she had been struck by an affliction:

… the day I was diagnosed, no one in my family had it, so the only other factor that we kind of connected it too was like three months before I had gotten food poisoning, so it was kind of just like my body couldn’t fight that, and so my other cells, like my pancreatic beta cells took a shot to it… it was like, when I got food poisoning, my sister got food poisoning, and it was kind of like, “Well, why did this happen to me and not her?”… “Why me? Why not any other kid who already had stuff going on with them?” like, “Why was it me?” I was perfectly healthy.

Lindsay spoke of trying to stay motivated but struggling to keep up with what she described as the ‘mundane nature’ of daily management:

I am just always like that person who tries a lot, and for me it was hard because I don’t try for diabetes and I think that’s just, it’s boring. And I hate not doing my best and I know I can do better, but, I don’t know, I guess I am bored of it, I guess I am just tired of it, like no one else has to do it…

I think everything else in my life I am choosing, like I am choosing to work at camp, I am choosing to be on these committees, I am choosing to do school, I am choosing to get these grades and then this is like you are not choosing it and you just have it…
Unlike voluntary activities that she was choosing to do, she felt that she was forced into her diabetes self-management regimen.

Overall, I interpreted Lindsay’s story to convey a distressed tone. My intention of presenting her story is to familiarize the reader with what I came to understand as an intrusive lens, through which participants’ described struggling to settle diabetes within the background of their life (a further presentation of this lens is presented in Chapter 6).

4.4.3 Jennifer’s Story

Jennifer was diagnosed with diabetes at the age of seven years and she was 21 years of age at our interview. Jennifer referred to her diabetes as being comparable to a “peanut allergy”:

I think it’s a part of me only because it affects like everything I do, from the moment I wake up to what I eat is going to affect how my blood sugar is going to react during the day, which will affect how I can perform at work. And so it’s made me a more responsible person even though I’ve been at times really irresponsible with it. But I don’t think it’s necessarily something that defines who I am, like I don’t necessarily like being defined as someone who is diabetic, like it’s just something that happens to be part of it, kind of like an allergy. So I think just because it affects more of your day-to-day, people are more like aware of it. But to me it’s this same as if you were allergic to peanuts, like it’s not something that you like introduce yourself with.

Although people with food allergies need to be cognizant of the contents of the food they eat, they do not need to constantly monitor their blood sugar levels or engage with intensive ongoing insulin treatment regimens and they are not at risk of future serious complications related to their health condition. By comparing her diabetes to a “peanut allergy”, I interpreted Jennifer to be trying to minimize the presence of diabetes within her life.

When recounting her experience as a high school student, Jennifer provided further insight into her minimizing tendencies:

As I got into high school, I didn’t want to manage diabetes anymore. So I would skip testing my blood sugar or I would do, like with the pump that I had you could—I’m assuming that it’s with all of them—but at least with the one I had you could just give out like 20 units of insulin without having to like really give it like as a bolus or anything. And so I would just kind of do that and be like, “Oh, that’ll carry me over for the rest of the day.” So that was really counterproductive and probably not the safest option but it was so I could be as normal as possible in high school, like it was something that I could just sort of forget while I was there…
During adolescence, Jennifer remembered that her mother would try to shake sense into her:

Whenever there was a pattern of me not testing or me not giving myself insulin or that kind of thing, I guess in the attempt to like shake sense into me she would kind of try and like scare me, which is rather counterproductive because I still didn’t feel like testing and now I just don’t feel like testing and now I’m worried about being blind. Like I don’t know, it was very {laughs}, I don’t think it was the best method but I think it was her like desperation… because it’s very unsettling as a parent to see like your child actively not do anything for themselves that they need to do, it can be kind of frustrating, like you want to pull at their hair.

As Jennifer notes within the quote above, she believed it was unsettling for her mother to witness her “actively” not managing her diabetes. I want to emphasize the term actively here, as keeping diabetes away from the spotlight of her life was described as involving work and effort.

Jennifer preferred to keep her diabetes concealed, as she grew weary of how people reacted when they found out about her diabetes:

I hid it from my friends. I still have friends that don’t know actually. I hid it from people, I didn’t want like that sort of, like I felt that when people find out they tend to like treat you differently, they’re like, when you’re going to eat something, they’re like, “Oh, are you sure you can eat that?” Like, “Are you sure can do this? Are you sure you can do that?” So I try to keep it like as under wraps as possible. And the pump helped cause you can kind of like go under the table and give yourself whatever insulin you need and stick it back in your pocket and no one knows. So I only have like me and my very, very immediately close friends are the ones that know. So they’re okay with it, like they don’t really ask questions.

At the time of our interview, Jennifer was living with her mother and brother. She described herself as having a close relationship with her mother, who used to have an even stronger role in her diabetes care throughout her childhood and adolescent years:

She was always a little bit overbearing, like always very like constantly would be, I don’t know, like sending me a text to remind me to test and then reminding me to give myself insulin and it was kind of like suffocating at times almost…

As Jennifer grew into emerging adulthood, she felt the overbearing nature of her mother’s role lessen, and she began to feel a greater sense of independence.

Jennifer was working full-time, and she travelled frequently for work. With increased autonomy, she was able to propose a switch to multiple daily injections after transitioning into
adult care. She felt that this method of insulin administration was better suited for managing diabetes while travelling:

… when I wanted to come off the pump, if I had been at the pediatric clinic it would have been something that I would’ve had to ask my mom to ask my doctor. Whereas like I went in and was like, “I have this idea, what do you think?” he was like, “I mean, sure, why not?” and I was like, “Oh okay, cool,” like so that was fine… cause at the end of the day it is me that we’re discussing, so it’s nicer if I can at least put in my two cents, even if I had told him that I wanted to switch and he was like, “No that’s a terrible idea, we’re not doing that,” at least he had heard me say it…

Jennifer valued her independence. She enjoyed being in command of her diabetes decisions. Unlike most of the participants in this study who were using an insulin pump (see Table 1), Jennifer deviated from this norm and made the uncommon switch to multiple daily injections.

Jennifer’s account provides an example of a distinct minimizing language. Throughout her interview, she spoke about trying to divert attention away from her diabetes, as she did not want to be viewed differently because of diabetes. Although she compared diabetes to a “peanut allergy”, others (such as her mother or new people she could meet) perceived diabetes as being more serious. I chose the term inconspicuous to describe this unique lens through which participants tried to make diabetes play a minor role within their stories (this lens is further illustrated in Chapter 7).

4.5 Chapter Summary

All participants within this study similarly appeared to be situated at an ‘in-between’ stage of life. They shared the common belief that they were in the midst of making career pursuits and working towards financial independence.

Despite common conceptions of adulthood, participants within this study demonstrated three distinct narrative types. Firstly, Abdullah’s story represents a relatively smooth transition into emerging adulthood. He perceived his diabetes as becoming comfortably integrated within his day-to-day life. Lindsay’s story provided stark contrast to Abdullah’s. She spoke of her resentment towards diabetes as it interfered with her daily life. Lastly, I presented Jennifer’s
story. She described actively trying to keep diabetes in the background of her life. Unlike Abdullah or Lindsay, she spoke about ‘minimization’ rather than ‘integration’ or ‘disruption’.

I found these three narrative patterns to be representative of three lenses through which participants viewed life with diabetes (*ingrained, intrusive* and *inconspicuous*). I chose a lens analogy to emphasize that life as an emerging adult with Type 1 diabetes would be experienced differently depending on the lens one was looking through. Just as lenses for glasses can be simply described according to a person’s general needs, such as whether they are farsighted or near sighted, I developed simplified descriptions of these lenses that I was interpreting. Over the course of the next three chapters, I outline my interpretations of the ingrained, intrusive and inconspicuous lenses.
Chapter 5
An Ingrained Lens of Diabetes: ‘Diabetes is Comfortably a Part of My Norm’

5.1 Chapter Overview

In this chapter, I explore an ingrained lens; a lens characterized by comfort, confidence and control. I start by providing a broad definition of this lens (i.e. what it means to view diabetes through an ingrained lens), as I draw on the experiences of participants and how they described life with diabetes. In the following three sections, I breakdown an ingrained lens into three core narrative themes: becoming a self-doctor, finding moderation and earning trust. I intend for this thematic framework to indicate that 14 participants similarly viewed diabetes as comfortably a part of their norm.

5.2 What does it mean to View Diabetes through an Ingrained Lens?

Informed by the experiences and perceptions of 14 participants, I came to define an ingrained lens as a view in which diabetes is settled within a participant’s life – it was accepted, normalized and for some participants, some of the time, it was even embraced. For participants who conveyed an ingrained lens, life did not revolve around diabetes. Indeed, when diabetes was viewed through this lens, participants felt as though they had embraced living with diabetes as their norm. The following quote, and others like it, helped to shape my definition of an ingrained lens:

…it’s just life to me, I don’t think it’s that different than anything, I obviously can’t turn my diabetes off…I’ve never been like, “I need a day off of my diabetes,” like you just have to keep going, you can’t stop. And that’s where I don’t understand when people say that kind of stuff and… articles where it’s like, “It’s okay to take a day off of your diabetes.” But is it really though? Cause how often are you taking that day off? And what are you doing on that day off? Like, you can’t just stop giving insulin…
In this quote, the notion of taking a day off from life with diabetes is seen as an unrealistic desire for Heather. From her perspective, diabetes was not representative of an additional chore.

Rather than perceiving diabetes as an inconvenience, participants who conveyed an ingrained lens described rarely thinking about diabetes as being disruptive throughout the course of a typical day. Instead, it was seen to operate quietly within the background:

… it’s just, it’s something that’s completely normal or invisible, like electricity for example, it’s just there, it’s not—obviously it’s very relevant—but it’s not noticeable anymore, it’s just part of our [Ardit and his family], everybody’s lifestyle, mine and theirs including as well. So it’s just something that we’ve come to accept and it’s like, it’s just in the back the whole time, you know.

Just as electricity would flow throughout a house without the residents noticing it, through an ingrained lens, diabetes was not disruptive within Ardit’s household. It was intertwined within the gestalt or whole that constituted everyday life.

The 14 participants who conveyed an ingrained lens acknowledged themselves as having a distinct view of diabetes, different from some of their peers who were living with Type 1 diabetes. In these comparative discussions, they tended to emphasize their expertise in diabetes management, describing it as not being “especially hard”:

I’ve had friends who have had really, really rough diabetes adventures and journeys and all that kind of stuff, but like diabetes overall is pretty challenging, but, I don’t know, it’s kind of integrated into my life at this point that I don’t- nothing really sticks out to me as especially hard.

Although participants conveying an ingrained lens had encountered frustrations, their overall view towards life with diabetes was broadly characterized by comfort, confidence and control.

5.3 Becoming a ‘Self-Doctor’

The notion of becoming a self-doctor helps the reader to understand the mentality of participants who conveyed an ingrained lens. That is, they had embraced a greater sense of agency, which ultimately helped them to form a strong sense of expertise for their management. I use the term agency here to demonstrate that participants conveying an ingrained lens took command of their
management. They wanted to learn for themselves how their bodies reacted in different situations.

Ardit provides an example of this active transition towards becoming a self-doctor. When Ardit was diagnosed with diabetes at the age of 16 years, he remembered taking action against the “sympathy” that was given towards him,

… many people in my family were very shocked to know about it. And at first, personally there was a lot of sympathy that was given and that was okay I guess. But after a while… I got really tired of it… I was sort of tired of that sympathy, so I took it up to myself to learn as much as I can of the disease, how my body reacts to it, how I can better manage it. So over the years I’ve been trying to, you know, learn as much as I can and, you know, how to control it better and what not.

Ardit did not passively sit back and accept the sympathy that was shown to him. He described adopting an attitude in which he wanted to take matters into his own hands.

When Ardit was 18 years old, he moved out of his parental home to live with extended family in a different country, which he described in terms that made it seem similar to a test of his self-management capacity,

… I controlled it as much as I can with as much as whatever I knew about it, tried to stay very active avoiding different foods that weren’t familiar with me cause it’s a completely different culture and, you know, they use a lot of like dough as well, and they make these- so it’s a lot of carbs in one meal. And that was a really interesting experience just to sort of take the, the bicycle—what’s it called? Training wheels off and sort of go on my own and sort of manage it on my own.

Ardit characterizes management in terms that make it similar to a craft or skill. He speaks as though he had to acquire practical knowledge through firsthand experience. Just as learning how to ride a bicycle without training wheels involves trial and error, he alludes to a similar experimental process of learning about diabetes management.

Ardit believed that over time, as he became more familiar with the practicalities of management and developed a better understanding of his body, he began to feel as though he had achieved a sense of competency,

You have to be sort of a self-doctor, cause your doctor may give you these, “What to avoid,” and, “Hints and tricks,” and, “How your body works,” and what not, but only you can really measure how your body reacts to different scenarios… So you have to be very
vigilant and very aware of your body in certain times. Once you know the, you know, the different ways your body reacts, then it just becomes like you know your blood sugar, how it’s going to react, and maybe at times you don’t have to check as often. You still check three to four times but you know that if you drink, you know, a cup of orange juice, for example in my case I know it’s going to be higher than usual. So I can arrange that beforehand, before, you know, instead of checking and then arranging it or what not. So as time goes on it gets easier.

In this excerpt, Ardit highlights the notion of developing personal responsibility, as he felt that he had to become accountable for his actions. He portrayed himself as being an expert at understanding his own body. Unlike the general guidelines his doctors gave him, becoming a “self-doctor” meant that he had to experiment with his body and analyze how it was reacting in “different scenarios”. As he became more “vigilant” and “aware” of his body, management no longer felt like a strict or stringent routine, it felt more natural for him.

Similar to how physicians have their own moral obligations, participants within this study also spoke about a moral context related to self-management. Throughout this thesis, when I refer to the term “moral” I intend to mean, “concerned with the principles of right or wrong” (Barber, 2005). For participants who spoke of becoming self-doctors (those who conveyed an ingrained lens), they described themselves as exemplary figures that were focused on figuring out how to make the most well informed decisions for self-care. In a sense, they presented themselves as being ‘morally conscious leaders’ of their diabetes management.

For instance, I noticed this moral consciousness in accounts about sick day management. Daniela explained that she would seek the opinion of her pharmacist to help her decide on which cold medications would be most optimal for her diabetes,

I would say my pharmacist is a huge part of my life. Every time I’m sick, like I talk to her… so like I’ll be like, “Oh, like could I take this if I’m taking this?” Or like if I have a cold or something, like I can’t take like a certain [cold medication name]… So I’ll like always talk to her. When I’m sick I’ll be like “Oh is it okay to take this?” Or like I’ll tell her about like my sickness and stuff.

In the quote above, Daniela exemplified herself as being a responsible self-manager. She was careful not to make the wrong choice of cold medication and she actively sought advice from her pharmacist.
The moral consciousness that accompanied being a self-doctor was also highlighted as participants spoke about their perceptions of peers with diabetes. Daniela had a cousin living with Type 1 diabetes and she referred to him as being one of “those diabetics”:

My cousin who is diabetic, he doesn’t take care of himself properly, like at all… he’s really, like he’s those diabetics that don’t, they act like they don’t have it… very like, “I don’t care about it.” So he like smokes all the time and it kind of like bothers me when I see him, like, “You should take care of yourself,” but I don’t say anything. But I’m not very- if someone tells me to do something, if I don’t want to do it, I don’t do it, like I don’t get peer pressured into things.

As Daniela describes within the quote above, she was bothered when she would see her cousin engaging in behaviours that were evidently harmful to his health, such as smoking cigarettes. Daniela emphasized that she was different from her cousin (one of “those diabetics”). She had developed a habit of being careful of her health behaviours, and she also felt like she was more of a leader than a follower, as she would not get “peer pressured” to act in certain ways.

In Trevor’s case, he began to convey his moral attitude as he reflected on a past experience he had in pediatric care,

… they [his pediatric care providers] had this, what’s the right word for it, inhuman or cruel [pause] barbaric, they had this barbaric policy of letting diabetics run high so that they would never have to deal with the low. And that was terrible cause having a high blood sugar; it’s like having a hangover. Thankfully I’ve never had a hangover so I can’t say what a hangover actually feels like. But people who have had hangovers and high blood sugars have said having a high blood sugar is like having a hangover and a bad hangover at that one.

Within this quote, as Trevor was critiquing this “barbaric policy”, he suggests that there are ‘right’ and ‘wrong’ approaches to managing blood sugar levels.

Elsewhere within his interview, Trevor further highlighted his consciousness towards morals related to management when he discussed his opinion regarding recent articles he had read about ‘good and bad blood sugars’,

… there’s this whole movement on, “There’s no such thing as a good blood sugar and no such thing as a bad blood sugar,” and that’s supposed to make young diabetics not feel worse when they get high blood sugars or low blood sugars, but that’s all nonsense. There is such a thing as a good blood sugar. There is such a thing as a bad blood sugar. A bad blood sugar is when you feel bad, you know, if you’re like 1.6 or you’re like 25 or something, that’s not good, you know, you can’t say, “Oh, alright I’ve got a good blood sugar
sugar,” and go eat all you want or something, because you’re going to end up feeling bad. But, yeah, I think what that movement should be doing is teaching people, is teaching these young kids that while you can get a bad blood sugar it’s not always your fault. And, yeah, but sometimes it is your fault… usually if I get a high blood sugar or any other form of bad blood sugar it’s because of a mistake I made. Sometimes the pump site will fail or something and that’s obviously not my fault, I can’t prevent a pump site from failing. But a lot of the time, like if I forget to bolus on something or I underestimated how many carbs something has, by this point the majority of high blood sugars are my fault… But even though I think they’re judging me [his parents] I still don’t agree with the whole, “There’s no such thing as a bad blood sugar” movement.

In a sense, participants conveying an ingrained lens accepted the role of being a self-doctor, and they realized there was no way of avoiding the moral context that accompanied this full-time assignment. As Arvin explained,

I think the sooner you can embrace the frustrations that come with this kind of lifestyle, the more comfortable you can be in the long run. Because I think when people get frustrated, like at least based on personal experience, whenever I was frustrated, part of that frustration came from this idea that it’s because I didn’t understand it and it’s because I felt like I was alone; that I didn’t understand what was going on and why I was experiencing this high glucose level in particular or this episode of hypoglycemia. So the number one thing is to expect that frustration and to expect just as much that, that you can learn to embrace it even, that you embrace this lifestyle.

Arvin had reached a point in life where he was past contemplating as to why it was him who was diagnosed with diabetes, and at times he felt that he could even “embrace this lifestyle”. Although he did not initially choose to pursue this lifelong job of being a diabetes manager, he knew he could make his life easier if he tried to understand the nature of the work. He portrayed his body as the machine that he was faced with learning how to operate,

… my diabetes to me was a kind of a learning lesson and a process. And that it was my way of understanding that we aren’t perfect and that you kind of have to humble yourself because you’re not perfect. And that because you are flawed through your diabetes, because you’re flawed, you kind of have to understand your health better; you have to pay attention to its effects on your body.

As Arvin points out above, the body became the subject of his focus. He viewed the human body in terms of imperfection, in that if he were assigned another body to manage there would be other flaws and blemishes that he would have to deal with.

Over the course of my interviews and analysis, I began to understand that living with diabetes could be thought of as trying to navigate difficult terrain. Participants with an ingrained
lens had become self-doctors as they navigated this challenging terrain with a sense of confidence. That being, they felt as though they had acquired expertise for coping with the practicalities of their management and they spoke with an expert’s knowledge of the functioning of their body. They also demonstrated what could be known as moral consciousness, as they were committed to trying to make the most well-informed and responsible decisions for their body.

Working full-time as a self-doctor did come with its annoyances and frustrations. But those participants who portrayed themselves as self-doctors described learning to accept and embrace the annoyances and frustrations that can accompany their lifestyle. They believed that they were able to skillfully moderate their diabetes.

5.4 Finding Moderation

I use the phrase finding moderation to refer to the theme of learning how to live an enjoyable lifestyle without having to overindulge or ignore diabetes to achieve satisfaction. Participants with an ingrained lens were not overwhelmed by their emotions or social surroundings as they told accounts illustrating their ability to maintain a steady state of physical and mental well being. They depicted themselves as being able to find balance.

Abdullah exemplified this theme of finding moderation. He described having an accepting attitude of diabetes. That is, he was able to define his boundaries and work within them,

… So I’ve learned to be like, “Okay, so let me find out what I really can’t do or what I really can do with it and then just accept it,” like, cause to try to fight something is like you’re wasting a lot of time and energy when really you can just understand it and then adapt to it.

As he indicates within the quote above, Abdullah recognized that there were ways to find compromise with his diabetes. He spoke as though he was not resentful that he was diagnosed when he was 16 years of age, he wanted to learn how to peacefully assimilate diabetes into his life. For instance, when it came to his diet, he spoke about trying to find alternative recipes to foods he enjoyed,
So I feel like for as far as the food aspect it’s always a new challenge. It’s a challenge nevertheless but it’s always a new and interesting one. So I might figure out that, “Oh this was a good, this was amazing, this tasted amazing but the dough had a high sugar content that I didn’t consider.” So I am like, “Okay, maybe if I make it at home I can use a different type of dough or maybe a diet version of it,” and everything like that. So the ongoing like meal struggle has not been that hard, it’s more like it’s always a learning lesson.

Kevin also provided an example of an individual who had learned how to find moderation within his life. He remembered that his mother and pediatric endocrinologist instilled a fundamental understanding within him at a young age:

… I ate anything and everything {laughs} … we were a family who, like my mom worked late hours so we got fast food and we did stuff like that a lot. And even my early experience with my endocrinologist was like, “No, you can do that stuff if you manage responsibly.” So I just learned how to manage responsibly. And even to this day I would not say I have a great diet by any means, but I still have like fairly great control over my diabetes. So it evens out.

As can be seen within this quote, Kevin emphasized that he was able to live a normal life. His mother and endocrinologist instilled a philosophy within him, that responsible management was the key. In a sense, through this quote, he was emphasizing to me that he was in control over his diabetes, rather than feeling as though his diabetes was forcing him to live a certain way.

Elsewhere in his interview, Kevin spoke of his sense of control as he portrayed himself in stark contrast to his friend from university who had Type 1 diabetes:

… they [his roommates] had like a pretty good grasp of diabetes, but their world of diabetes was like, like my friend [who his roommates used to live with before living with Kevin], great dude, not great care of his diabetes. They’re like, yeah, “We’ve seen him just like pass out on a driveway and our first thing is like test his blood, so we test his blood and we’re like, ‘That’s not good,’ and we got to wake him up.” And I’m like, “Yeah, I don’t do that, we’re cool.” So living with them it was a change for them cause they’re like, “Yeah, you’re self-sufficient, like half the time we forget you have it. With like this guy though, it’s like some of the times it’s like, wow.”

Later, I will discuss how participants conveying an intrusive and inconspicuous lens felt as though they were under scrutiny of others. Here, we see the opposite. Kevin shares this story as a way of portraying himself in a positive light. Kevin expressed having a strong ability to remain disciplined during his university experience. Unlike his roommate, Kevin conveyed a stronger capacity to independently navigate potential pitfalls while living away from the parental home.
With moderation came success, as some participants conveying an ingrained lens were able to surpass expectations of physical fitness capacity. In Charlotte’s interview, she recalled making a gradual progression towards running a half-marathon. She was diagnosed at 19 years of age and remembered feeling shocked about her diagnosis. She began to think about her freedom, and what she could or could not do. To combat initial uncertainties, she focused on the practicalities of living with diabetes. Initially she focused on better understanding how carbohydrates would impact her blood sugar levels during the day,

I mean in the first six months I just kind of wanted to keep eating the same thing. It was almost like, not rebellious- maybe rebellious. Well I was still managing my sugars really well, but after the first six months I started to notice if I, sort of my total carbohydrate intake all day. If it was a lot lower, I would be able to manage my blood sugars a lot better. So I definitely changed up the way I was eating, with fewer carbohydrates…

Whether it was with her meals, her bed times or the alcoholic beverages she would drink, Charlotte spoke of trying to maintain consistency within her life. Her capacity to develop routines helped her eventually feel as though she could moderate diabetes. She conveyed the belief that diabetes was not an overpowering or restraining component of her life:

… it hasn’t restricted me from doing things, I think it’s just caused me to plan more, be a little bit more careful. It hasn’t prevented me from doing anything, like I guess on this past Sunday I ran my first half-marathon, so like that was really cool. And I, actually some of these things I don’t know that I would have done necessarily without Type 1 diabetes cause I’ve tried to push myself in some instances.

But I guess in terms of things that have made it harder, just planning more, I guess. I don’t even—I guess a year ago I would have said I still thought about it—but I don’t even think about it anymore, it’s just part of my daily routine.

As Charlotte describes above, diabetes was not especially challenging or burdensome for her. In fact, it allowed her to re-define her limits as she formed a new understanding of what she was physically capable of doing.

When participants, such as those considered above, were able to find moderation within their lives, they became trusting of their self-management capacity, and they earned the trust of their parents, peers and health care providers. They did not feel as though they constantly had to be checked up on about their diabetes. They saw themselves as being in control over their diabetes, and they felt that this was evident to others in their lives.
5.5 Earning Trust

Over the course of my analysis, I began to notice a distinct theme that I termed earning trust, which was present in narratives told by participants sharing an ‘ingrained lens’. Participants who demonstrated this theme spoke as though they were no longer subordinates within their relationship with parents or health care providers. They felt as though they had proven their competence as self-managers, and they saw themselves as being exemplary figures.

Heather grew up in a family with many other health conditions. Her father and brother were living with chronic illnesses and she had a sister with a neurological disorder. Her mother was the primary caregiver for her family and she was described as having her ‘hands full’. Heather felt as though she had to “grow up really quickly” and she described herself as becoming “self-sufficient” at a young age. Her mother recognized her self-sufficiency early on in her life as Heather recalled that she was assigned to sleep in the same room as her sister because her mother was worried about her sister’s epilepsy rather than Heather’s diabetes (“I was sharing a room with my sister because my sister had epilepsy so my mom wanted like someone in the room with her”). Compared to her sister, Heather viewed herself and her brother as being able to earn the trust of their mother:

Like my mom says you parent different kids different ways, so my brother and I, it was kind of like, “Here’s a metro pass be free.” But my sister, it’s, my mom is very on top of her and her stuff. She’s kind of a slacker. Meanwhile, like my brother and I were very driven in school.

As she describes in the quote above, Heather recalled that she and her brother had been granted freedom by their mother.

Although through Heather’s eyes she perceived that she had earned the trust of her mother from an early age, I found the extent of this trust to be limited as elsewhere in her interview she talked about her mother being closely involved in her blood glucose monitoring,

So my mom, when she gets up at like five [AM] she’ll test mine and my brother’s sugars {laughs}. So that’s like our first check I guess… like I don’t ask her to. Like sometimes if I’m- my sugar is kind of high or low before I go to bed and I know she’ll be up for kind of a while, I’ll be like “Can you wake me up in like an hour so I can test my sugar again?” Cause sometimes like I won’t wake up to my alarm or whatever, or like just to make sure that I’m not turning my alarm off. And she’ll be like, “Yeah, okay.” But, yeah, I don’t know, she always tests my sugar at five AM. I mean, when we were kids she
would test it at like midnight, five [AM] and then whenever she went to bed, like that type of thing.

Despite her mother’s ongoing blood glucose monitoring throughout her life, Heather did not feel as though she was lacking the trust of her mother. At the age of 20 years, she was not embarrassed that her mother was still closely involved within her diabetes care. She seemed to have embraced her mother’s ongoing support within her life.

In Heather’s case, the notion of trust seems to extend past her mother’s actions and be more closely related to their verbal interactions. She conveyed a sense of mutual respect:

… it’s not like she has no concept of how hard diabetes is and how hard it is to manage it. Like she doesn’t—obviously she doesn’t know personally—but she can see how hard we work. And she obviously knows that when our A1c is 8.0, like it’s nothing we’ve been doing, maybe we’re just having a rough three months or something like that, like she knows. And she won’t kind of ride us on it and like bring it up a lot, like she’s pretty good. Or like if we have a good one, like she’ll be really happy about it and like really proud of us.

Heather believed that she and her mother had found common ground with each other over the topic of diabetes. She kept her mother updated with her diabetes management without feeling that she would be judged. She felt as though her mother was sensitive towards the daily realities of managing diabetes, and she was understanding of Heather’s perspective towards life with diabetes.

As can be seen in Heather’s case, when participants’ believed that parents and other family members were trusting of a participant’s self-management capacity, this reinforced the participant’s own beliefs that they were competent managing on their own. For instance, Ardit felt that he was able to prove to his parents that he was a competent “self-doctor”:

As time went on, I sort of took it upon myself to you know be a self-doctor in a sense with this, and they’ve [his parents] noticed that and we’ve discussed this many times. They have the biggest confidence in me, in terms of, “Okay, he’s perfectly fine, he knows what he’s doing.” It’s not as big of a concern as it was when I was first diagnosed. So for them it’s as if, you know, nothing has happened and they have the biggest confidence in me that I know how to manage my diabetes…

Ardit was speaking as though he had passed a test of competence. His self-proclaimed label of being a “self-doctor” was approved by his parents.
Outside of the family, participants also felt under the scrutiny of friends.

Abdullah saw himself as being a “learning tool” for his friends and colleagues who were not well informed about diabetes:

… there’s sometimes I am looked at as the disease, like, “Oh, Abdullah you have diabetes, you shouldn’t be eating this, it’s not, it’s not safe for you, it’s not good for you.” And I am like, it’s understandable, but at the same time I also know that through proper facilitations and proper training from my diabetes doctors and nurses I have learned that I can have that, it’s just I can’t have the ration you have. I can have this much, you can have whatever your heart’s content. I have to learn how to be satisfied with this much, that’s the only difference.

So I feel like their views changed… Like the negative is like, oh they are scared that one day I lose control and I will take a big bottle of pop and start drinking it and, “Oh no, Abdullah you are going to die, you are going to go into a coma and you are going to do this.” But then there are times where like, “Oh, Abdullah… like come have a bite with us, it’s okay… we have measured it for you, we know how much is okay for you,” so like their views have been more open, and it allows them through me to learn what is okay for my diabetes and what’s not okay. So I am pretty much, in an everyday sense, a learning tool for them to know for their own, for my sense or for anybody that they know that might have it, “Oh… by the way my uncle has diabetes Abdullah, how do you have, how do you manage this?” Or like, “I have never, I have never really taken the curiosity to know with my uncle but now that you have it I want to ask, how is this?”

Illness refers to how a patient experiences disease from their own perspective, while disease is defined as the physical disorder that is apparent within the human body (Morris, 1998). In this study, Abdullah provides an example of this distinction, as there are times when his peers look at him as though he is “the disease” (in biomedical terms). But, over time, he described changing peoples’ perspective of diabetes. With support from his health care team, he found himself to become an example of an individual who could live a normal life despite diabetes. No longer did he feel like his friends viewed him as “the disease”, rather he was seen as a person with diabetes. I found Abdullah’s story to provide an example of personification, as he put a human face to diabetes, which is contrary to when his peers viewed diabetes as a foreign entity.

As can be seen in Abdullah’s case, participants conveying an ingrained lens tended to see themselves as role models. Health care providers were described as providing reassurance that participants conveying an ingrained lens were doing a good job of managing diabetes. From an ingrained perspective, interactions with health care providers began to feel as though they were being spoken to as if they were on the same level rather than being spoken down to. Participants
conveying an ingrained lens described taking on a more mature role compared to when they were in pediatric care. It no longer felt that they were a student reporting to class, or that they were being tested, judged or critically evaluated. They described their interactions with health care providers as if they were knowledgeable and trusted partners. Arvin described his transition into an emerging adult diabetes clinic as feeling like a “graduation”,

… they put in a lot of effort at [pediatric clinic name] to make it feel like a graduation. They wanted to make you feel like you had kind of worked your way up through the ranks and just succeeded and essentially they wanted to make you feel like, “Here you are, you’re growing up and you’re doing a great job, so we want you to actually feel like you’re actually experiencing this responsibility,” in a—not even in an intimidating way—but in a very welcoming and encouraging way.

Arvin spoke about this health care transition as though it were an accomplishment, as he had put in work towards achieving a strong grasp of the basics for his management. He conveyed that he was worthy of handling greater responsibility when he progressed into adult care.

Compared to his time being a pediatric patient, Arvin described himself as taking on a more “active” and “articulate” role within adult care,

… it’s always you who experiences everything first and you’re kind of relaying that information to everyone else. So they’ll never truly know what that moment feels like unless you articulate it. So as a pediatric patient it’s always very passive I guess. Whereas as an adult in adult care, you have to take an active role, you have to ask the questions, you have to make sure that you know what works and what doesn’t.

Arvin tells of embracing a greater sense of personal responsibility as he progressed into adult care. He felt as though he had to take ownership of his condition, and that he had to be engaged in his interactions with providers.

During these interactions, he felt as though he was on “equal terms” with his providers:

… it feels like a team. I mean it’s very sentimental I know, but—it’s very sappy—but it definitely feels like a team because everyone is involved and you talk to them as though they’re, you’re on equal terms in the sense that you are all just trying to make you better. And so it’s very, very casual and very relaxed and very genuine… so it was definitely, it was like a team, it was like a family in a sense, I’ll admit.

Arvin conveys having a strong connection with his providers, and he did not feel intimidated or inferior when he would talk to them.
Whether it was with health care providers, peers or parents, participants conveying an ingrained lens described achieving a point in which they were confident talking about their diabetes with others. They spoke highly of themselves and they felt as though they were worthy of the praise they had received.

5.6 Chapter Summary

Throughout this chapter I have outlined my interpretation of the *ingrained lens* of diabetes in emerging adulthood. A broad definition of this lens was initially presented (life does not revolve around diabetes, but diabetes is integrated within one’s daily life). ‘Ingrained’ was applied to characterize the view of participants who had adopted the mindset that diabetes was embedded within their norm. To help illustrate this lens, I have provided interview examples from participants organized according to three central themes: *becoming a self-doctor, finding moderation* and *earning trust*.

I used the term self-doctor to convey a sense of expertise. That is, over time, participants with an ingrained lens felt as though they had achieved a firm grasp of the practicalities of their diabetes management. They portrayed themselves as becoming experts at understanding how their bodies reacted in different scenarios. The role of self-doctor included more than just this practical sense of expertise; it involved taking ownership of one’s self-management choices. Participants conveying an ingrained lens spoke as though they were focused on trying to make the most informed health care decisions, as they described a sense that they were personally invested and devoted to optimizing their health.

After presenting the theme of becoming a self-doctor, I turned the reader’s attention towards the theme of *finding moderation*. This theme was intended to demonstrate that participants conveying an ingrained lens were satisfied with their lifestyles. They were able to find middle ground, as they tended to speak about moderation rather than extremes. They accepted that being careful and attentive towards one’s diabetes was a key towards living a normal life.
Lastly, the final section that I presented was based on the theme of *earning trust.* Participants conveying an ingrained lens did not feel as though they were subordinates in relation to their parents, despite accounts that made it seem like parental involvement may have been excessive. Their interactions with parents regarding diabetes were characterized in terms of mutual respect and described in positive terms. They were accepting and grateful of parental support at this stage in their lives, and they felt as though their parents believed in their capacity to self-manage diabetes. Participants conveying an ingrained lens also described earning the trust of friends and colleagues. They portrayed themselves as exemplary figures and competent self-managers that could teach others about the realities of diabetes management. In terms of health care providers, participants conveying an ingrained lens felt as though they had worked themselves up the ranks as they spoke about no longer feeling as though they were immature pupils or students. As they described their transition into adult care, they provided highly positive accounts about maturing into a more active and engaging role.

Taken as a whole, I envision the ‘ingrained’ narrative to represent an *integration* of diabetes. Through an ingrained lens, emerging adults feel as though diabetes has become settled within the background of their daily life.
Chapter 6
An Intrusive Lens of Diabetes: 'There’s the Rest of My Life and Then There’s Diabetes’

6.1 Chapter Overview
In this chapter, I outline my interpretation of an intrusive lens of diabetes. I came to define this lens based on interviews with 12 participants, which had a distressed tone. These participants explained that they were striving for control, but struggling to integrate diabetes within their lives.

I will begin the chapter by broadly defining an intrusive lens. Following this, I present two key narrative themes: playing catch-up and developing moral sensitivities. Overall, I intend for this chapter to demonstrate my interpretation of experiences with Type 1 diabetes that were plagued by challenges and difficulties.

6.2 Defining an Intrusive Lens
I chose the term intrusive to describe a lens through which diabetes was seen as an unwanted and unwelcomed presence of a participant’s life. Despite feeling as though they were working hard to be independent, the 12 participants who conveyed this lens described struggling to manage diabetes on their own.

When comparing themselves to peers without diabetes, participants conveying an intrusive lens felt as though their peers were “lucky” that they did not have to deal with the pervasiveness of diabetes. Whether it was eating meals with friends, writing a university exam or trying to sleep, participants conveying an intrusive lens felt vulnerable to being continuously reminded of their diabetes. Mary wanted to be more spontaneous with her friends, but she felt limited by her diabetes,

… all my friends like can just drink [alcohol] and keep going and not have to worry about anything, I have to like go and check my blood sugar and do a little shot of insulin and like all this stuff. And because I know that if I don’t, then I am going to get so, so, so
sick. So it’s, I don’t know, I guess… I feel like I can’t have as much, like fun or as much freedom.

Drinking alcohol is an example of a situation that helped to illustrate the intrusive nature of diabetes within participants’ lives. Through an intrusive lens, participants explained that it was hard to enjoy outings with friends, as diabetes tended to interrupt the continuity of normal life.

When viewed through an intrusive lens, diabetes was described as being intrusive both mentally and physically. For instance, Anne explained,

… you have to like stick stuff in yourself all the time, like always. I have like scarring on my fingers from like checking my blood sugar, which is annoying… Sometimes I am just like, “I just don’t need to do this.” In my head I am like, “My sugar is fine right now but I should check it.”… And then I just see that other people don’t have to do anything and it kind of makes me think…

Rather than viewing diabetes as becoming a part of her norm, it appeared as though Anne’s diabetes was seen as an incongruous aspect of herself. If it were not for diabetes, Anne implied that life would be easier.

Although participants conveying an intrusive lens described working hard to integrate diabetes within their lives, diabetes was prone to unpredictably act out against them. Edith used the analogy of nagging ankle pain to describe what it feels like to live with diabetes through an intrusive lens:

… so now I twisted it [ankle], so it hurt… but I am walking with a little limp and every so often, like… it throbs, so then I am more mindful of it. It’s kind of like having diabetes, like it’s a small pain, but it will act out. And sometimes like it will just hurt for no reason and it’s not understandable. So I guess it’s conflicting in the sense that it’s always there and sometimes it’s good, but sometimes it’s not. And so it’s hard to not like feel annoyed by it because you don’t want to feel in pain sometimes, like you don’t want to bounce back between highs and lows, but it’s like my life, like I can’t change…

As seen in the quote above, ambivalence could be detected within intrusive narratives. Although participants conveying an intrusive lens tried to find positivity, they were often overwhelmed by negativities during their interviews. From an intrusive perspective, participants like Edith described that it was discomforting to know that they could fluctuate between high and lows.

Participants conveying an intrusive lens perceived themselves as lacking a strong foundation for self-management. Rather than describing themselves as being able to withstand
stress, they were vulnerable to feeling overwhelmed. In summarizing her experience with diabetes, Cindy highlights her vulnerability,

I think when I was younger it was like second-nature to me and I didn’t really think about it, and obviously my mom helped to take care of it and stuff like that. And then I guess like when I hit adolescence I think my blood sugars were kind of harder to control. And I think since then it’s kind of been more like downward in terms of management. And sometimes it’s frustrating cause you feel like you have to deal with something extra that other people don’t, you know, like that extra two minutes it takes to change your site or, you know, “O crap, like, I forgot to change my reservoir, I got to do that like right now.” And I think sometimes I’m scared, like for example if I were to go camping or something like that I’m kind of scared just because you know you’re in the middle of nowhere…

Accounts like the one above helped shape my definition of an intrusive lens. As Cindy exhibits, with a lack of confidence in one’s self-management capacity, the intrusive nature of diabetes was heightened during emerging adulthood.

To help the reader recognize emerging adults demonstrating an intrusive lens, I have outlined my subsequent analysis around the narrative themes of playing catch-up and developing moral sensitivities.

6.3 Playing Catch-Up

Rather than experiencing a gradual handover in care, some participants felt as though the responsibility for diabetes management was abruptly thrust upon them. As they entered emerging adulthood at the age of 18 years, abrupt handovers from parent to child foreshadowed great upheavals as participants struggled to adjust to newfound independence.

Angelica experienced a sudden drop off in parental involvement when she turned 18, as technically she was considered an “adult”,

So the first time that my doctor at [pediatric clinic] referred me to [emerging adult clinic] that was the first time I went by myself cause I remember my dad or my mom, whichever, would tell me like, “Oh yeah, you have an appointment with your new doctor at [emerging adult clinic]”, like, “You’re going by yourself,” and then I’m like, “Yeah, I know.” And they’ll be like, “You know how to take the train there?” and stuff like that. I’m like, “Yeah, I think so.” You know cause 18 is the year that, you know, you’re technically, you’re an adult, so yeah, they just kind of like pushed all those responsibilities on me and… it was overwhelming at first.
Rather than gradually ramping up responsibility, Angelica remembered her transition into adult diabetes care as a jarring experience. She had been thrust into a new role with greater independence.

Instead of presenting herself as being accustomed to management, it appeared that Angelica was trying to learn how to make diabetes a normal part of her life. Despite living with diabetes for 19 years, Angelica described the everyday task of insulin administration in terms that made it seem like it was exhausting:

Just like taking the time, like the time out of like I guess an hour when let’s say I’m meeting with my friends, like to just go to the washroom and like do like my insulin stuff, like I’d be so annoyed. Like my phone would go off or my meter would like start beeping and I’m like, “Oh, really? I have to do it again and stuff.” Yeah, just kind of like being reminded like, “Oh, Angelica, you have diabetes, you gotta take care of it”…

It was tiring for Angelica to constantly feel as though she was interrupting outings with friends to deal with diabetes. To her, diabetes felt like something extra she had to worry about.

The notion of struggling to manage diabetes ‘on my own’ was evident for participants like Angelica. But, instead of seeking support, becoming an adult meant that participants had to battle against diabetes on their own. As Cindy explained,

Like at this point I think my parents helped me when I was younger and then kind of, you know, when you transitioned to an adult, it’s kind of I’ve taken on the responsibility, not that they’re not willing to help, but I think they, you know, they can’t really do anything about it, if I’m not gonna help myself, they can’t help me. So, like I think they’re there for me, I just don’t maybe ask for their support.

Even friends were not able to help Cindy during this “fight”,

I mean I can always talk to my friends about whatever, like school or something, and they can help like I guess make me feel a bit better. But I think, you know, sometimes you have to fight it on your own, kind of get through it, like no matter how nice your friends are and stuff, sometimes it just like it isn’t enough to like make you go from bad to okay, it’s just you have to ride the wave for the week.

Rather than feeling as though she could dictate the course of her diabetes, Cindy conveyed a belief that management was out of her control.
Cindy felt that there was a way to take control, but she could not seem to figure out how to do so. As a university student, her lack of routine was described as an obstacle for optimal management,

I think like I should set more of a routine. Like right now because I wake up at different times every day and I go to bed at different times and I eat lunch at different times it’s really hard for me to say I have it in routine, but I think I really want to get it in routine. I think then it will be easier and more like back to second-nature. Whereas like now, I’m like, “Okay, I have to remember, I have to remember.”

Unlike the past, Cindy had lost this second-nature feeling she once had. She wanted to make diabetes a part of her norm, as it was burdensome to try to find the time to attend to it.

Similarly, Angelica used the analogy of having a “little bug” in her head to describe what life is like living with diabetes,

Like when you just want to sleep, like you just want to rest but then there’s just that little bug in your head saying, “You have to take your needle, and, “You have to do your insulin,” like that’s just that little voice in your head like, “You have to do it, you have to do it, if you don’t do it,” like I refer to like symptoms of like DKA and stuff like that, hyperglycemia, like just going to the washroom a lot, oh my gosh, it’s so annoying.

Just as someone may want to silence a buzzing bug, Angelica suggests that she would like to silence her diabetes. She appeared to be working hard to try to improve her management, but she could not keep diabetes under control.

Angelica was actively seeking better ways to manage diabetes. She changed her diet, set reminders on her cell-phone for insulin administration and she even tried to use her parents as support resources. But their support would often come off as nagging,

… I’m starting to open up more to them because I really don’t, I dislike when they nag me, cause when they nag me it’s just, it’s annoying. Like I’m pretty sure everyone else on this planet that’s my age would say like it’s the most annoying thing of living with your parents, like they’re just going to nag you and nag you and nag you until you actually do it, which like, even just thinking about it now, like it just annoys me. But what I find is that like even with my phone, that’s annoying too, like it actually does help, like just the nagging, it actually does help.

I found Angelica to be in a state of trial and error. She was open to try different approaches to improve management, as she had not yet found the one that was right for her.
Angelica was in a process of change. She said that only a few months prior to our interview is when she changed her lifestyle and started being more accepting of diabetes,

Like looking back I feel so much better like in the inside cause like before I’d feel like sluggish and you know like after you eat junk food you get really, like you just feel really gross? I don’t know, like you just… like the need to sleep. And basically, so, but now, like I’m always on my feet, I can’t just stay still, like I need to be active. So before I was a very like lazy, like I didn’t really want to, you know, like if my friends would ask or my boyfriend, “Oh, do you want to work out?” I’d be like, “No, are you crazy?” Like, now, like I work out, I eat better. It all contributes to just like changing my whole lifestyle. So, and, yeah, like maybe if I were to do this interview like two years ago, I’d literally be balling, like I would not be able to vocalize myself cause like I knew I had such a hard time accepting the fact that I had diabetes. So it’s only maybe up to a couple of months ago that I started to accept that I had, like you know, that I had that lifestyle.

At our interview, Angelica was in the midst of changing her outlook on life with diabetes. She felt ready to try to tackle management on her own, but this was only years after her initial move into the adult care setting (she was 23 years old at our interview).

I intend for this presentation of the theme of playing catch-up to illustrate the gradual nature of the maturation process that accompanies the uptake of responsibility for diabetes management. Instead of being ready to handle management on their own when they turned 18, participants conveying an intrusive lens, like Angelica and Cindy, found themselves to be not yet ready to accept the great responsibility of self-management. At their interviews, they found themselves to be in a catch-up state, as they were trying to make-up for a lack of preparation.

6.4 Developing Moral Sensitivities

All participants within this study articulated a moral context surrounding their self-management. As self-managers of diabetes, they were expected to perform in a certain way as their actions were under the constant scrutiny of others. Parents, providers, siblings and peers constituted an ever-present audience that might judge their behaviours. At this point in their lives, it was expected that participants knew how to manage diabetes the “right” way, as they were now considered adults.

Within narratives, HbA1c was described as a trigger that could elicit moral reactions. As Karen explained,
… it’s easier to separate a test score [referring to academic tests] from your personal value than it is to separate a health score, right? Cause that’s essentially what you are, it’s in your blood, it’s so difficult, I hate it.

Karen perceived HbA1c as offering objective evidence of what was actually happening in her body. It was hard for her to ignore her HbA1c, as it was not just a test score, but something that could impact her emotional well-being.

The moral implications of HbA1c influenced how participants experienced diabetes. For participants who spoke about having a “bad” HbA1c, this brought forth tension in relationships with providers and parents. In Karen’s case, she felt that she would have to walk out of a room after disclosing her HbA1c to her parents,

When I tell them [parents] my A1c they definitely take it as a score and so that’s why I never offer it up voluntarily, it’s if they ask then I’ll tell them, but once I tell them, I know to walk out of the room because I’m not entering a conversation about it. Because what they have the privilege of seeing is the people who are in the Animas and the Mini-Med magazines and the, you know, the showgirls. That’s not me; it’s definitely not me. So that’s the big difference, is that, you know, I’m not Chris Jarvis and I’m not all these celebrity diabetics who have found the miracle because I don’t think that there is one.

Karen expressed much hostility towards her HbA1c, as it could be used against her as irrefutable evidence that she was doing a bad job of managing diabetes.

Karen was sensitive towards how her parents judged her diabetes management, and she explained that she had minimized the flow of information from her diabetes clinic to them,

… I often wouldn’t divulge information to them, I would say it’s good, I would give them my most recent blood sugar, I would tell them that kind of information, but I wouldn’t show them charts or anything like that. I just had enough negative experience of being judged based off of that stuff that I didn’t want to do that anymore.

BM: So they would judge you based off charts and things like that?

Karen: Or just be very concerned and that would make me feel very guilty. But then after the concern came the, “Okay, we’re going to solve all your problems portion,” and it often consisted of a lot of sitting and like changing different rates and what not, and I know that my issues don’t stand with my rates, my issues stand with like lifestyle, that there’s certain things in my lifestyle that I just need to make more consistent and that that’s really what’s going to change my diabetes performance, right? That and having that conversation with them about the long battle rather than, “Look at today, look at yesterday, look at the day before,” that’s something that we haven’t gotten to. Because when you are in charge of every single part of your child’s day, right? If you’re in charge
of what’s going into their lunches, if you know when they’re going out for gym class or
recess then it’s very easy to look at those types of patterns, but I don’t have a lifestyle
now where I have patterns like that. And so the way that I have to adapt is different from
the way that they’re used to seeing diabetes. And for both of our own good, I just kind of
built a wall.

Karen became weary of her interactions with her parents when she sought their advice.
Although she realized that she needed to make adjustments, using her parents as support
resources made her prone to view herself as a bad manager.

As Karen has pointed out, diabetes management was described as a performance for
participants conveying an intrusive lens. Unlike accounts about earning the trust of others (as
was apparent for ingrained narratives in Chapter 5), in intrusive narratives participants depicted
themselves as struggling to earn approval from parents and health care providers.

Although Karen had access to a multi-disciplinary support system, after a traumatic
experience in the pediatric setting, she became selective as to which health care providers she
would interact with,

… when I was 14 I was at [pediatric clinic name] and they asked if they could see me
alone… and when I went to see her [doctor], we were talking a little bit about diabetes
and about how I was feeling with my diabetes, and something that came up was food and
weight loss, which was kind of an interesting subject because I really only knew what I
knew about the relationship between diabetes and weight loss through the internet and of
course that was a terrible place to learn about all this because I didn’t know how to read
critically on the internet. And so I had all these questions and I felt very defeated, and so I
went to go talk to her.

It also didn’t help that my A1c wasn’t perfect, that, you know, I wasn’t that model
diabetic. And so when I was speaking to her about it, she suggested that I talk to the
social worker there. So I went and I spoke with the social worker all the while my mother
is sitting out in the waiting room. And the social worker started to really hound me about
certain eating disorders that are associated with diabetes. So she was stating all of these
behaviours, saying, “Oh, well are you doing this? Are you doing this? Are you doing this?”
and all things I had never thought about in my entire life. And it was a very jarring
experience. And I distinctly remember sitting in that room with her speaking to me and
maybe it was because I was scared of adults at the time or maybe because she was speaking
in a pretty aggressive tone, but she was just hounding me about, you know,
“Are you not bolusing when you eat?” like, “Oh, maybe your A1c isn’t 7.0 because you
aren’t bolusing when you eat, maybe you’re disconnecting from your pump,” da da da da
da. And just wasn’t stating things in a way that was telling me, “Hey, this can happen,
this happens to a lot of people, but like this is why we hope you won’t fall under this type
of behaviour.” Instead it was very, “Well, what if you are? What if you are?”
And so I distinctly remember that was the first time that I went to see the doctor alone and I hated it, that was terrible, it was a terrible experience, I was there for hours and I ended up in tears. I ended up going to see the doctor again, my mom finally came into the room after I asked repeated times if my mom could come in and she was just shocked because she was like, “What happened? This never happens when I’m in the room,” and now she’s in tears. And so after that point in time they still enforced that I went to see the doctor alone, but anytime that they asked if I could see the social worker I said no because of course I did not want that experience again.

Entering this study, I did not expect HbA1c to play a major role within a dramatic narrative like Karen’s. Rather, my thinking was that narratives about acute complications, such as past experiences with DKA or hypoglycemia, would be told in a more dramatic fashion. Hearing Karen tell this story helped me form the idea that HbA1c was not just a standard or routine procedure within the lives of participants. It had a strong influence on how participants interacted with health care providers and parents.

HbA1c was also capable of eliciting moral reactions at diabetes camps. Similar to how students may compare a test score to see who has done better, Karen perceived this comparative mindset to be present amongst campers at her diabetes camp,

Working at [diabetes camp] the A1c was a really big part of what made me, kind of like my personal diabetes very private but my diabetes otherwise very public and was where I drew that line. Because if you imagine you’re in a camp setting with a bunch of kids and everyone starts talking about their A1c’s and yours is around the middle, you don’t actually feel good about yourself, you don’t think, “Oh, I’m average,” you think, “Oh, I’m not the best,” or maybe that’s just me, that’s what I think. That really solidified the line for me. And having that experience when I was a camper made me very conscious of it as a counsellor, and then later as coordinating the [leadership development] program because I didn’t want anyone else who was going through like their very foundational years of developing their personality to think, “Oh, I need to be ashamed of how I manage my diabetes,” because that’s very volatile, especially when you’re that age, the way that you’re managing your diabetes. Maybe you’re managing it alone. Maybe you’re managing it with your parents. Maybe you’re not managing it at all; it’s just your parents, right? Maybe you’re in your honeymoon stage? Don’t want to be comparing your A1c to someone who’s A1c doesn’t reflect having years and years of diabetes behind it, right? There’s just so many variables and everyone’s relationship with their diabetes is very different. I just hate, yeah that’s another pet peeve, I hate it when people start, you know, sharing their A1c’s as if it’s like a score, oh, I hate it.

I found Karen’s HbA1c to be her Achilles heel. By telling me about her leadership position at camp, I found her to emphasize to me that there was much more to her than her HbA1c could reveal.
Apart from her HbA1c, Karen spoke about a life filled with accomplishments. She was proud of herself for taking on a leadership position at a diabetes camp, and she also mentioned taking on a volunteer role within a medical research laboratory. By telling me about these other accomplishments, I found Karen to emphasize that her diabetes management was not a true reflection of her character.

Although all participants were liable to encounter similar situations throughout their lives, participants conveying an intrusive lens seemed to develop a heightened sensitivity towards judgment. Aside from being sensitive towards how others judged them, participants conveying an intrusive lens also demonstrated being critical of their own management. There were times when participants felt as though their management went “downhill”, which made them feel worse about themselves. In Haya’s case, she explained that she would fluctuate between good and bad periods for self-care,

... the thing is with me, I am also a kind of a person I either go in like 100% and I am fully involved or like I just, I just barely give it an effort. And that really affected me in the sense of dealing with my own, like dealing with diabetes. Because for a period of time I am, I am exercising, I am eating well, my blood sugars are good and then after, after some time like everything just goes downhill and I am like, “You know what? I am already eating junk food, whatever, I don’t care, I don’t want to check my blood sugar because I know it’s high and, and I am going to feel bad about myself that it just spirals down.”

Haya felt that her all or none mentality left her vulnerable to losing control over her diabetes. She could not seem to find middle ground, as she was either doing a good or a bad job of managing diabetes.

Participants conveying an intrusive lens were sensitive towards the right and wrong behaviours for diabetes management. Themes such failure and perfection were apparent within their interviews, as they were prone to criticism from others and themselves.

6.5 Chapter Summary

Within this chapter, I have presented my analysis of interviews with 12 participants who similarly experienced difficulties trying to adjust to life with diabetes during emerging adulthood.
I opened the chapter with my broad definition of an intrusive lens. Through this lens, I came to understand that diabetes was seen as an additional hassle separate from one’s daily norm. Participants who shared this lens described not being able to settle diabetes within the background of their lives as they explained that they were constantly trying to remember to account for it, rather than feeling as though they were accustomed to it.

After providing this definition, I presented my findings regarding a distinct narrative trajectory that I termed playing catch-up. This presentation began with an examination of abrupt handovers in responsibility that occurred when participants reached 18 years of age. Despite expectations, participants recalled not being ready to take on greater responsibility for management as they reached this point in their life. At their interviews, they were speaking from a stance of reflection. They explained that they now felt more ready to try to accept diabetes, but were struggling to do so as they were lacking a strong foundation of support.

Finally, I turned attention towards the theme of developing moral sensitivities. This had to do with moral judgement that participants perceived others made about them, be they parents, peers at a diabetes camp, health care providers or other people in their lives. This offered me further insight into why participants conveying an intrusive lens felt as though they were struggling to manage diabetes on their own. Becoming sensitive towards how other judged them limited their willingness to seek support resources.
Chapter 7
An Inconspicuous Lens of Diabetes: ‘I Try Not to Notice Diabetes or Make it Noticeable’

7.1 Chapter Overview

In this chapter, I outline my interpretation of an inconspicuous lens conveyed by seven participants. I start by defining the inconspicuous nature of diabetes when viewed through this lens, as I highlight minimizing language. Next, I present two narrative themes, keeping diabetes out of the spotlight and minimizing the moral context of management. Overall, I intend for this chapter to illustrate a distinct narrative type, in which the storytellers were protective of their sense of normalcy.

7.2 Why ‘Inconspicuous’?

Based on interviews with seven participants, I came to recognize a distinct view of diabetes, in which participants’ described diabetes as not attracting much attention. In some instances, this meant preventing others, such as co-workers or fellow students from finding out about diabetes. While in other cases, this involved learning how to minimize one’s own attention towards management. The term that helped me define this unique lens was inconspicuous (“not easily noticed”) (Barber, 2005).

From an inconspicuous perspective, participants tried to minimize the presence of their diabetes. As Ken explained,

… they [his schoolmates in high school] asked me like where I was for the past few months, “Oh, I was diagnosed with diabetes,” but I didn’t really play it, like I didn’t really explain it to them in the fashion that they realized how big of a deal it was. I kind of, like I tried to downplay it as much as possible… I didn’t want, I didn’t want people treating me differently really, so I, I tried to, like I, like, like if they asked me about it I told them about it but I, I tried not to really let them know how much of a burden it was on me.
… I’ve always kind of like wanted to have diabetes like having the like minimum role in my life that it needs to… like have the least amount of impact that it can have. So I have always kind of like tried to, yeah, like downplay it.

Like Ken, Jerry provides another example of this distinct rhetoric:

… I always tried to make it [diabetes] as minimal as possible where I wasn't going to make a big deal out of it and if I did need something then I would get it and I would know, but I would never try and, I would always try to deal with it on my own as opposed to bring it to their [coaches] attention.

The ability to live a normal life (comparable to their peers without diabetes) was important for participants conveying an inconspicuous lens and diabetes was a threat to their sense of normalcy.

To avoid being treated differently, participants conveying an inconspicuous lens were discrete about their diabetes. Jennifer provides an example of this,

I think there’s a lot of stigma and a lot of people think, when they think diabetes, they sort of think more of like what people know more about Type 2 diabetes versus Type 1. And so with Type 2 you do have more of a restricted diet and stuff whereas not with Type 1. So I think people tend to think, “Oh, well are you sure you can eat that? Cause like my grandma has diabetes and she can’t eat this”, right. So that’s also one of the reasons that I don’t tell people cause that way we avoid that whole shenanigans.

In Ken’s case, he too experienced frustrations when people would mistake Type 1 diabetes for Type 2 diabetes,

… everybody like associates Type 1 diabetes with Type 2 diabetes. And I, and I actually do remember like when I would first tell people like they would be wondering like, “Oh… were you eating too much sugar?” like, “What were you doing wrong that you got diabetes?” And like and it was kind of hard in that sense that like, like cause you knew when you told people there was kind of like an immediate reaction where they thought that like there was something that you were doing wrong that you kind of ended up in that situation. But like obviously like you, you’d explain it to them and like kind of enlighten them that like, “No, this is different than Type 2 diabetes.” And like, and, yeah, and it was hard because people would try and sympathize with you by telling you like, “Oh my, grand-, my grandparents have diabetes,” and stuff. And like they try and empathize with you like by telling you that but it really wasn’t the same situation at all. So, yeah, like I, yeah, I definitely kind of, like, like when I was younger I always kind of felt weird that people were associating me with people with Type 2 diabetes.
Hearing other people link diabetes to sugar or being compared to peoples’ grandparents was frustrating for participants like Ken or Jennifer. Avoiding uncomfortable interactions appeared to be a reason as to why participants decided to minimize attention towards diabetes.

In the following two sections, I outline two narrative themes that further characterize participants who conveyed an inconspicuous lens: *keeping diabetes out of the spotlight* and *minimizing the moral context of management*. Through this subsequent analysis, I intend to demonstrate that participants conveying an inconspicuous lens wanted to live a normal life, and they did not want diabetes to impinge on their lives.

### 7.3 Keeping Diabetes Away from the Spotlight

Over the course of analysis, I began noticing a recurrent theme in which participants spoke about actively trying to minimize the presence of their diabetes. I use the phrase *keeping diabetes away from the spotlight* to highlight the act of minimizing attention towards diabetes to protect one’s sense of normalcy.

Rather than being the odd one out, Jerry wanted to be seen as equal to his peers without diabetes. Although he tried to “mind [his] own business”, his mother brought unwelcome attention to his diabetes,

… I felt like at times the spotlight was on me, I felt like my mom, she took an extra effort to make sure the principal knew and the teacher knew. I remember transferring over in grade one, I transferred over to a closer school, my mom actually talked to the class about it; it was kind of embarrassing at the time… like she's kind of singling you out and I don't like putting myself in the spotlight unless I do something, you know. … I feel like I like to be self-sufficient, even at that age I kind of just like to mind my own business and, yeah, it was just kind of embarrassing.

Jerry used this past episode to highlight his sense of constancy over time. When reflecting on his years as a grade school student, he described himself as being the same type of person who liked to mind his own business. Diabetes could come into conflict with his usual minimizing approach, as it might bring forth unwanted attention.

Although Jerry believed he was fine managing diabetes on his own, his mother tried to control situations throughout his life,
Jerry described his mother as having trouble relinquishing control over his diabetes. In hindsight, Jerry felt like this caused him to miss out on a normal childhood.

Over time Jerry learned how to protect his normalcy, as he adopted strategies to minimize attention towards diabetes. While playing on sports teams, Jerry would avoid telling coaches or teammates about hypoglycemia,

… at times I thought, “Alright, if I take it easy maybe I can keep going and no one would have to know,” and like, again, I didn't like to bring attention to myself and I felt that if I said, “Alright,” I have to stop during our practice or something like that, then I would have to bring attention to myself and people would be like, "Oh, why'd you stop?" And I would have to explain to them and someone might be like, "Oh, you're making an excuse." Whereas if I would just kind of watch, like pay attention, eased out of it a little bit, jogged around here and there, you'd use less energy, you can get out of it; you can grab your juice at the end of it. That's normally what I did as opposed to kind of stopping on the spot. I know that's not the right way to do it but its kind of my way.

Jerry characterized his approach to management in terms of not drawing attention to it. He demonstrates that he perceives there to be a “right” way to manage diabetes, but he preferred to manage his own way. This helped him keep diabetes to himself.

Although it might be considered commonplace to tell a manager at work about diabetes, Jerry was unsure if his managers knew,
… I'm not too sure if my managers would know, if they know I'm a diabetic cause again, I mind my own business, yeah, I like to manage it myself, like if I need to I'll buy a [sports drink] if I need it, but, yeah, if they need to know then I'll tell them, yeah.

Keeping diabetes to himself appeared to be a tactic that Jerry was using to avoid any special attention directed towards himself. He had learned a lesson from his grade school years, and was careful not to let himself be singled out at work.

Minimizing attention towards diabetes was a common thread throughout Jerry’s interview.

Over the years, Jerry described learning how to manipulate management accordingly to his needs. He came to understand that smoking marijuana involved less maintenance of diabetes compared to drinking alcohol,

I think I enjoy smoking weed more than I do drinking, just cause I feel like with drinking, with what you drink, it's like 11 carbs for a beer and you know like 20 grams for a vodka or something like that, it's hard to keep track as you're going. I feel like if you're smoking, it's kind of like once and you're done, you know, like you're done for the night. If you feel yourself going high, you give yourself a little insulin; you can test yourself as you go along. It's not to the point of alcohol where you have to have a couple here and there and you have to keep going and you have to constantly watch unless you go high and then the alcohol brings you low as well and it's just tough to manage and watch, but at times I like it.

Jerry appeared to be aware of the tricks of the trade for diabetes management. Not only did he want to minimize attention towards diabetes, he felt as though he knew how to do it.

In other cases, some participants would go to great lengths to hide their diabetes. Ken recalled an elaborate plan to avoid injecting insulin in a university cafeteria,

… I remember not really wanting to take my injections right in the cafeteria because like I was kind of self-conscious about like taking out needles and stuff and doing that right in the cafeteria. So I would, I would either eat and then go back to my room and take my injection, which was kind of not good because I was like taking it after my meal, or I would kind of, like I’d take my injection and then go to the cafeteria and then really quickly try and grab food so that I could—so that was a little, I guess that was a little bit difficult.

University presented as a social environment in which diabetes was prone to being pushed out of focus. In Hazel’s case, she recalled learning how to deprioritize practical tasks for management,
The one thing I have run out of a couple of times is tubing for my reservoirs. Cause I, cause the, so they come with the sites when you buy them, but they also have packages that are just the insulin sites with no tubing, and those ones are like thirty bucks cheaper, so usually I buy those and I reuse the tubing like one time so I get like twice as much use out of them. But sometimes I’ll like forget to buy the ones with tubing for like a long time and then I’m like, I’m using this one tube that’s like all cracked and has got, it’s like all gummed up and I forget, yeah, that I need another one.

I found Hazel to be a savvy individual who knew how to take shortcuts with management. Although this was helpful at times, this came with the risk of overlooking diabetes.

But Hazel’s mishaps were something she could joke about, rather than feel ashamed about,

… this past year I’ve met actually two people, so one person who’s now doing a Masters at [university name] and one person who’s been in a couple of my classes and both of them have Type 1 diabetes. Oh yeah, and this one other guy who I volunteer with also has diabetes. So, yeah, so sometimes I talk to them about, mostly just about like how terribly we take care of our health {laughs}, mostly jokes but, yeah.

BM: So what makes the health terrible? Is it you’re A1c?

Hazel: Yeah it’s not, it’s not, I shouldn’t say terrible, but it’s mostly just like, you know, forgetting to put a site in on time or like, oh, I put a site in but I like, just it hurts so much, so you just got to take it out and do it again. Or like, oh, I forgot to check my blood sugar all day today, that kind of stuff, yeah.

Although Hazel did experience difficulties with her management, it was through quotes like the one above that I found her to try to downplay the impact of diabetes within her life. Rather than describing diabetes management as constantly weighing down on her, she tended to speak as though it was something she could forget about.

I intend for these examples to give the reader a sense of what I mean when I use the phrase keeping diabetes away from the spotlight. As participants conveying an inconspicuous lens took on more autonomy, they were able to manipulate the presence of diabetes within their lives, which helped them protect their sense of normalcy.
7.4 Minimizing the Moral Context of Management

Rather than trying to manage diabetes the “right” way, participants who conveyed an inconspicuous lens spoke about being content managing diabetes their own way. Jennifer explained that she preferred to keep diabetes to herself as she liked her diabetes to be a “me thing”,

... I like my diabetes to just be like a me thing, so I don’t know if I’d like to involve other people cause that would make it maybe more upfront, like there’s other people that can have you accountable to it I guess, I don’t know. So I like keeping it to myself.

Jennifer implies that if others knew how she was managing diabetes, she may no longer be able to continue using her approach. By keeping diabetes to herself, she could avoid the potential moral predicament of feeling like she needed to change her ways.

Aside from the judgment of other people, blood glucose monitors were capable of eliciting moral reactions from participants. Steve explained that he stopped checking his blood sugar levels to avoid feeling depressed:

... I’ve just never liked it [blood glucose testing]. There’s a couple theories going around still and I think the biggest one is that seeing my blood sugar numbers kind of depressed me a bit. So I go based off of how I’m feeling when it comes to blood sugars and insulin now.

Not checking his blood sugar levels was the lesser of two evils for Steve. He would rather not check, than check and feel depressed.

Similarly, Hazel explained that she did not like to prescribe “moral value” to health activities,

... sometimes if I’d have like a bad A1c I’d lie and tell them [parents] it was lower or if I—or I shouldn’t say that, I don’t like to prescribe moral value to like health stuff, but like a high A1c, you know, I would just say it was lower. Or like if they [health care providers] said, if they made changes to like my basal rate I, basically I just wouldn’t tell my parents everything, I would just say it’s fine, mostly because once I’d been there [emerging adult clinic], once I hit that point I was doing my diabetes all on my own. So I wasn’t like, I didn’t really care about what they had to say because they would just be like, “Oh, that’s bad, you should do this,” but they like weren’t managing my diabetes...
With greater autonomy, Hazel was able to control the flow of information to her parents. By letting them see too much information, Hazel felt that her parents could make her feel like she was doing a bad job of managing diabetes.

Hazel lived in the parental home, and she recalled having to tip toe during the night to avoid waking up her parents when treating a low.

… sometimes I do get lows and then it’s kind of weird tip toeing, like everyone in the house can hear what happens in everywhere else cause it’s a two bedroom apartment… like I got to go to the fridge and get juice but I got to be quiet about it cause maybe my parents are sleeping, or I have to be quiet about it cause then if I’m not they’ll like ask, like, “Why are you up? Are you getting juice?” and it’s like, the obvious answer is that I’m low, but it’s like saying it is something different.

Rather than using her parents as a source of support, Hazel adopted a mindset in which the less they knew about her diabetes the better. She presented herself as not being able to communicate on equal terms with her parents, as she portrayed them as authority figures.

Through past negative interactions, participants conveying an inconspicuous lens adopted an avoidant coping strategy. This involved learning how to keep diabetes to themselves, rather than leave oneself susceptible to the scrutiny of others.

7.5 Chapter Summary

Throughout this chapter, I outlined my interpretation of an inconspicuous lens. I chose the term inconspicuous to characterize this lens, as seven participants similarly spoke about diabetes as not being especially noticeable within their lives.

After defining an inconspicuous lens in the first section of the chapter, I presented the theme of keeping diabetes away from the spotlight. Using interview excerpts, I illustrated the work and effort involved in minimizing the presence of diabetes to protect one’s sense of normalcy.

Next, I presented findings related to the theme of minimizing and the moral context of management. Participants conveying an inconspicuous lens described knowing how to distance themselves from judgment related to their diabetes management.
Ultimately, with this chapter, I intend to demonstrate that the Type 1 diabetes experience during emerging adulthood took on a distinct form when narrated from an inconspicuous perspective. Participants conveying an inconspicuous lens told stories about learning how to manage their way, rather than what may be considered the “right” way.

In the next chapter, I further distinguish participants according to their lens, as I draw on demographic and clinical characteristics to guide my comparisons.
Chapter 8
Comparing the Lenses

8.1 Chapter Overview

In this chapter, I examine demographic and clinical characteristics of participants according to their lens. I begin by highlighting significant differences between lenses for gender, glycemic control, method of insulin administration and living arrangement. I then compare the presence of these variables within participants’ interview accounts. In addition to these variables, I also discuss similarities and differences in how participants spoke about their relationships with health care providers. Lastly, I highlight how participants experienced the broader social context related to living with diabetes. My intention throughout this chapter is to help the reader think about potential factors that may have influence on whether an emerging adult adopts an ingrained, intrusive or inconspicuous lens and how that lens may influence certain clinical characteristics.

8.2 A Statistical Comparison of Demographic and Clinical Characteristics

Although I did not set out to perform a quantitative or mixed-methods study, I performed a statistical comparison of the demographic and clinical information I collected to further examine differences and similarities amongst participants according to the lenses I was interpreting. Statistically comparing demographic and clinical characteristics amongst participants according to their lens revealed significant differences for this sample (Table 2). Within the following sections, I outline my interpretations regarding gender, glycemic control, method of insulin administration and living arrangement. Using excerpts from interviews, I uncover how these factors relate to a participant’s lens.
Table 2: Comparison of the demographic and clinical characteristics according to lens

<table>
<thead>
<tr>
<th></th>
<th>Ingrained lens</th>
<th>Intrusive lens</th>
<th>Inconspicuous lens</th>
<th>p value</th>
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</thead>
<tbody>
<tr>
<td>N</td>
<td>14</td>
<td>12</td>
<td>7</td>
<td>N/A</td>
</tr>
<tr>
<td>Number men/women</td>
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<td>2/10</td>
<td>5/2</td>
<td>0.02</td>
</tr>
<tr>
<td>Age at interview (years)</td>
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<td>20.8±0.5</td>
<td>19.7±0.6</td>
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</tr>
<tr>
<td>HbA1c at most recent visit pre-interview (%)</td>
<td>7.4±0.7</td>
<td>9.3±1.6</td>
<td>8.6±1.5</td>
<td>p&lt;0.01 ingrained vs. intrusive; p=0.0645 ingrained vs. inconspicuous; p=0.26 intrusive vs. inconspicuous</td>
</tr>
<tr>
<td>Duration of diabetes at interview (years)</td>
<td>11.9±4.8</td>
<td>13.3±4.2</td>
<td>10.1±5.8</td>
<td>0.44</td>
</tr>
<tr>
<td>Number using CSII/MDI,</td>
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<td>7/5</td>
<td>2/5</td>
<td>0.09</td>
</tr>
<tr>
<td>Number living with a parent or caregiver, n (%)</td>
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<td>5 (42)</td>
<td>7 (100)</td>
<td>0.01</td>
</tr>
<tr>
<td>Number university/college student, n (%)</td>
<td>10 (71)</td>
<td>8 (67)</td>
<td>4 (57)</td>
<td>0.89</td>
</tr>
<tr>
<td>Number identifying ethnically as white, n (%)</td>
<td>9 (64)</td>
<td>6 (50)</td>
<td>3 (42)</td>
<td>0.67</td>
</tr>
</tbody>
</table>

CSII=continuous subcutaneous insulin infusion, MDI=multiple daily injections.
Values are mean ± S.D..
Statistical comparisons by Fisher’s exact test for categorical variables and by one way ANOVA followed by Fisher least significant difference post hoc test for continuous variables.
8.3 Gender

Unlike the biological notion of sex, gender refers to the “socially constructed roles, behaviors, expressions and identities of girls, women, boys, men and gender diverse people” (Canadian Institutes of Health Research, 2014). In Table 2, the greater proportion of women conveying an intrusive lens (10 women versus two men) brings forth questions as to how gender may play a role in shaping an emerging adult’s experiences with Type 1 diabetes.

I found the analogy of navigating an obstacle course to be helpful for understanding the differing narratives told by women from the ingrained and intrusive perspectives. The idea for this analogy came after my interview with Mariel (a woman who conveyed an ingrained lens),

BM: Have you ever felt limited by your diabetes?

Mariel: I’d say not anymore. I used to, cause there was this one time when I went on a camping trip… it’s with the girl scouts and we had to do an obstacle course and I did the obstacle course but I got so tired that I started like, I think I’m getting lows that I’m starting getting dizzy and all. And one of the advisors was saying, “Hey if you didn’t want to continue it, you could have just told us,” …but I went on with it anyway. I mean I think I manage my diabetes pretty good that I don’t think it makes me sick or not do anything anymore.

If one were to imagine an obstacle course as being symbolic of how an emerging adult navigates the challenges and barriers related to self-management in daily life, women conveying an intrusive lens appeared to find it especially difficult to navigate through the course. I formed the impression that women conveying an ingrained lens believed they were self-sufficient and could handle self-management on their own, while women conveying an intrusive lens were prone to feeling overwhelmed by their self-management. Lindsay (a woman conveying an intrusive lens) said that administering insulin was her “biggest problem”:

Right now my biggest problem with diabetes is just not giving myself the insulin. It’s like I know I have to, but sometimes I will forget. Or even yesterday I was out with friends and we were all eating and I knew I should have, but the idea of just going in my bag and taking out my tester, actually giving myself insulin was so much for me, so I just didn’t do it.

Romantic relationships were described as being important support resources for women from the intrusive and ingrained perspectives. For example, Angelica (a woman conveying an intrusive lens) described her boyfriend as being more supportive than her family,
He’s actually really involved, surprisingly. He actually, like it’s only this year that he started like trying to actually do like my blood and stuff cause I told—like I taught him how to do that and like cause I gave him like certain scenarios, like, “There might be times when I have a seizure and like you need to know what to do, cause if you don’t know you’re just going to look like a crappy boyfriend.” But like, he tells me like, “Oh, did you check your needle?” I’m like, “Yes.” He’s kind of like my parent in the relationship. But it’s not more so like nagging that he does it, it’s like for more so my wellbeing. So yeah, he’s very supportive. I would say he’s probably the most supportive out of all, like all the family.

Similarly, Bridgette (a woman conveying an ingrained lens) felt as though her boyfriend would check-in to see how she was doing with her self-management,

He’s really good, like he’s very supportive, checks in on me, you know, he wants to know about it, so he’s always making sure, like, “Oh did you give yourself insulin?” Like not in an annoying way. But he’s, yeah, he’s very supportive.

Without an established romantic relationship, the intrusive nature of diabetes became more apparent, as women spoke about the seemingly daunting task of disclosing diabetes to a potential romantic partner. For instance, in Mary’s interview (a woman conveying an intrusive lens), she demonstrated a sense of insecurity when talking about how men might view her diabetes,

… I am really open with like my friends. I have like a good group of friends, but they are all girls. And I am super open with my family. But like anything with guys, like I can’t talk about it, I cannot and I will not… like if there’s a guy in my life who knows I have it, like if he finds out, like I can’t like have him in my life… I think just me personally I have always thought this, like since I’ve had it, like I think it changes the way they see me, like not in a good way. I think they think like, “Oh my God, like this girl is a freak.” Like, “No, I don’t want to like be involved with someone who has to like, like can give herself like insulin and like can get really sick and stuff,” like I just think it freaks them out.

This quote made me think about how conceptions of a woman living with diabetes may conflict with traditional stereotypes. Societal expectations can present the ‘ideal’ woman as being one who is motherly or caring, able to take care of children and a spouse. Here, Mary demonstrates her belief that potential romantic partners could associate diabetes with sickness, which may make her appear less attractive to a prospective partner.

Contrary to Mary, Charlotte (a young woman conveying an ingrained lens) had a different mindset towards diabetes and romantic relationships. When asked how she would feel about disclosing diabetes to a potential partner, she replied with,
I think that’s definitely a hesitation and it definitely has been a hesitation. It’s not, not that I’m like embarrassed about it or anything, but it’s just something different. So I definitely think it would be, it’s like an added complexity. But not, I don’t know, I don’t think that it would be a huge issue, it’s more just like if somebody doesn’t understand, then fine, they’re probably not worth it anyway, that’s kind of how I think of it.

Although there might have been some hesitation, I found Charlotte’s response to contrast starkly with Mary’s account. Charlotte portrayed herself as having more willingness to share her diabetes experience, noting that even if a romantic partner was not understanding of her diabetes, she felt she could move on and find someone better. On the other hand, Mary seemed to speak with a great sense of insecurity and sense of concern about how she might be judged by men in terms of her desirability. From her perspective, diabetes was a mark of illness, and might deter potential romantic partners, which influenced her willingness to discuss diabetes.

From an inconspicuous perspective, diabetes may remain entirely hidden in some women’s romantic relationships during emerging adulthood. Jennifer revealed an occasion when she did not tell a romantic partner about her diabetes,

BM: Have you ever been in a relationship in the past?
Jennifer: Mhm.
BM: Did you tell who you were with about diabetes or things like that?
Jennifer: No.
BM: No?
Jennifer: Which in retrospect is probably really unsafe…
BM: Did they ever kind of catch on or were curious?
Jennifer: No it helped that I didn’t have a pump. That helps. But I’ve gotten very good at being very secretive about it, so, no, it never came across.

As seen above, there are signs that each type of lens has its own implications towards a woman’s experiences of forming romantic relationships during emerging adulthood. The act of finding a partner who understands diabetes was described as being an especially daunting task for women conveying an inconspicuous or intrusive lens.

Gender is a concept intertwined with other social statuses, such as ethnicity or religion, and it is important to acknowledge that being a man with Type 1 diabetes or woman with Type 1 diabetes may have different implications depending on an emerging adult’s cultural background.
Haya explained that in the context of her Middle Eastern background, having an illness is a major deterrent when seeking a romantic partner,

… “Oh, you know, she’s that really nice girl,” whatever, whatever they are going to say, but, “Oh, she is the diabetic [sic],” like, that will be kind of like my closing line, you know, like that’s, that’s, that’s what’s defining me to people. And when it’s there, it’s a very, it’s a big thing… I know certain people who are like, “Oh yeah, you know, my, my son actually likes this girl and like they’re, they’ve been dating for a while,” whatever, “But like he told me like one of her family members is diagnosed with something, I wouldn’t want my son—I am just like, I wouldn’t want my son to get, to get with someone who, who knows someone in their family who has a history, a medical history.”

Although I have grouped participants according to lenses, this quote serves as a reminder that participants had highly nuanced experiences with diabetes. Factors, such as one’s cultural background, may interact with gender to adversely influence experiences with diabetes during emerging adulthood.

Men within this study also spoke about their experiences of romantic relationships. Similar to women, there were instances when hesitancy with disclosing diabetes could be detected in accounts told by men. Tim (a participant conveying an intrusive lens) demonstrated this as he explained that he was “slowly” telling his girlfriend about diabetes on a “need to know basis”,

Well I’ve been with her for three years now and like it’s kind of, it—like I’m slowly telling her like on a need to know basis, like when I first met her, I’m like, “Hey, I have these test kits. Here’s a glucagon, here’s how to use it, and hopefully you don’t have to use it.”

A sense of hesitancy was also apparent in David’s ingrained narrative,

BM: Did you find it at all difficult explaining your diabetes to her [his girlfriend]?

David: For, yeah, for a long time—not a long time, for maybe the first month or two she didn’t know. And then I kind of, for more months going on, she knew. But I didn’t really talk about it or explain anything about it then, you know, then there kind of—it eventually got to the point where it was like, “Okay if I’m going to, you know, be in a relationship with her, I need to trust her.” So I kind of just told her everything and, you know, what would happen in this situation or what not…

The sense of hesitancy depicted in the above quote appeared to be out of place in the broader context of David’s interview. At various points throughout his interview, David spoke positively about living with diabetes, talking about how it had become “normal” for him, and that it could even be “advantageous” at times,
… as I got older and life just started being normal with diabetes, I hold myself to a standard of everyone else if not higher in that regard cause I feel I have, you know, I have an advantage. Especially in sport I hold myself in a higher regard. I don’t let myself—I can’t see myself any different and if not I see myself more advantageous because I have a better sense of what’s going on in my body then most people would, because they don’t have anything going on where they really have to understand.

Although David was trying to reassure me that he was in command of his diabetes, I was also aware that gender is known to play an influential role in how people present themselves in qualitative interviews (Järviluoma et al., 2003). It could be the case that women with Type 1 diabetes may be more articulate and open about their struggles, while men (such as David) may try to protect their masculinity by trying not to show any weaknesses (i.e. portraying themselves as strong or brave).

In other interviews, men specifically distinguished themselves from women that they knew who also had Type 1 diabetes. Compared to their female counterparts, men as a whole in this study generally gave an impression that diabetes was not that big of an issue for them. For example, Sam (a man conveying an ingrained lens) said,

… it’s [diabetes is] just like a little bit of like a mental kind of thing were you just have to focus on something else that usually most people wouldn’t have to worry about. It’s just an extra, added, like worry, not a worry, but like a, you know, somewhere else that you have to devote like attention and time to…But I feel like other people, like everyone’s got their own thing, you know, like if it’s not diabetes then it’s something else…I have a friend who’s diabetic as well and she sometimes gets frustrated about it and, I don’t know, I feel like that’s not really going to help me with anything.

Kevin (a man conveying an ingrained lens) also explained that he took a different approach than a women he knew who had Type 1 diabetes,

… we’re both like totally different in our diabetes care, like… she’s like very stringent about it. Not very, but she’s more stringent than I am about it. And like she’s one of those people if it’s like out of range, she’ll like kick herself, she’ll be like, “What the f***, like I did everything right, like, why isn’t this working?” Whereas like I’ll see that and I’m like, “Oh, that’s not good, alright let’s just get to work, get it done, get it fixed.” Yeah, so I think we both have like very different approaches to it.

Underlying the lenses that I have depicted in this study is the notion of gender, which may influence how emerging adults with Type 1 diabetes take responsibility for self-management. Revisiting the obstacle course analogy, accounts about romantic relationships appear to indicate
that the course could bring forth different challenges or barriers depending on one’s gender. As Haya or Mary explained, they did not want to be viewed as ‘diabetic girls’.

8.4 Glycemic Control

A significant difference can be seen in Table 2 for HbA1c, with HbA1c being lowest for the ingrained lens group and highest for the intrusive lens group. Based on interview responses, it appears that there are differing ways HbA1c may influence self-management practices. For instance, in ingrained and inconspicuous narratives there were occasions when HbA1c bolstered self-confidence. In contrast, in intrusive or inconspicuous narratives, there were times when HbA1c made participants feel worse about their self-care and led them towards avoidant measures of coping (e.g. Karen and Hazel’s experiences of avoiding parental support). Although there are signs that HbA1c may shape experiences with diabetes, accounts such as Haya’s description of her all or none mentality (Chapter 6) suggest that personality traits may predispose an emerging adult to difficulties with glycemic control, which in turn can make diabetes feel more intrusive. With that being said, I do not wish to imply causation between HbA1c and the adoption of a distinct lens, rather I want to point attention towards HbA1c as having a seemingly prominent role in narratives about the transition to adult care.

Within intrusive narratives, Angelica provides an example of how negative interactions around her HbA1c can influence perspectives on clinical care,

I loved my team [in pediatric care], the only down side that I would find is like my A1c. A lot, most of the time, it was, for a kid, like my blood sugars were fairly high. But I really liked the atmosphere, like I loved the clinic, like I loved everything about it. It’s just like when I’m sitting down with my endocrinologist there and he sits there and is like, “So, your A1c is high again”, and I’m like, “Oh, interesting, I know.” You know. But at the time the person that managed my diabetes was my parents, so I just kind of followed whatever they said. A lot of the time now when we look back on it, they like tell me, “I regret not managing your diabetes properly, that’s why, like that’s why you’re in this state,” or whatever.

The theme of playing catch-up can be detected in this excerpt. Angelica believed that her parents were responsible for starting her off on the wrong foot with her management. She felt as though she inherited poor glycemic control, which negatively impacted her health care.
experience. Upon transitioning into an emerging adult clinic, Angelica decided to stop attending clinic visits for a period of time,

So I started at [emerging adult clinic] when I was 18 and then I went in to appointments for about a year and a half and then after I stopped going because I thought it was like a hassle, like I was in school, I was working, I thought it was a hassle to just go… Over time like I thought I could just manage my diabetes by myself, like my thoughts were, “Oh like it’s so simple, like I’m just going to inject myself with insulin, take my blood sugar and, you know, go from there, just kind of eye ball it.”… like, “I don’t need to go to like a doctor and a nurse and then like a dietician and talk to them about stuff.” Like that was my attitude towards it at the time. But now it’s like, it’s like I’m back and I’m like, “Wow, you’re so stupid.” That’s what I tell myself when I look back at it.

And like recently, like my A1c was really high, the first time in three years that I went to [emerging adult clinic]… like the first time I went to [emerging adult clinic] after a long time, like my A1c was fairly high… so I went to my family doctor, like I had not like frequent appointments with him, but when I would, he’d be like, he’d talk about like, in the future, if you want children, if you want to start a family. And I’m like, “Oh yeah, that’s right,” like, you know. I’m like, “That’s true,” like, you know, everyone wants to have a family I guess. I don’t speak for everyone, but that’s kind of what triggered it, like, “Oh, if I want kids”, like I love working with children and of course I’d want to have kids. So that was kind of one of the reasons… cause I realized that in the two years or three years that I wasn’t going to [emerging adult clinic] that my blood sugars had been fairly high so, and I know that like if I continued that kind of behaviour with my blood sugars, like maybe when I’m like 30, 35 trying to have a kid, like its either like the kid will not survive or I won’t.

HbA1c played an important role in Angelica’s narrative about her transition in care. She used HbA1c to demonstrate her maturation process. In pediatric care, it was her parents who were managing for her, and she did not perceive interactions about HbA1c as being personally meaningful. But, when she met with her family doctor during emerging adulthood, she came to a realization she had more personally invested in her HbA1c.

To provide an example of how Angelica’s transition experience may have sounded different if she had a better HbA1c, Heather (a participant who conveyed an ingrained lens) provides a contrasting example of arriving at the adult clinic with strong glycemic control,

When I first came to adult clinic my A1c’s were really good, they were like 6.9, 7.0, like really, really good. So then I felt really good about my diabetes and I felt like I was super in control. The only time I really felt out of control… is like the teenage years were pretty tough. But that’s just cause like your body is changing and all that kind of stuff. But I’ve never—yeah, I usually feel pretty in control, it’s just life to me.
Heather spoke with confidence in her ability to self-manage diabetes. Aside from abnormalities she accredited to puberty, she felt as though her HbA1c ‘report card’ had been strong since childhood.

Similarly, Ivan (a participant conveying an ingrained lens) believed his pediatric care providers had difficulties letting him go because his HbA1c was so strong.

So I was supposed to leave at 18 and I think they kept me until I was about 19. We [him and his mother] assume, but we don’t know, it was because my hemoglobin was always 6.5. It never, like it never even hit seven and we had assumed it was just because the doctor liked seeing that on his reports. So we had assumed that’s why I stayed there so long.

Given the perceived “moral” significance of HbA1c, it was dejecting for participants to receive bad HbA1c results. Not being able to get her HbA1c to come down led Jennifer (a participant conveying an inconspicuous lens) towards avoidance,

I always felt that I couldn’t get my A1c to come down, which was a frustrating thing, like I would feel like I was doing a lot of the steps that I was being told to do and it would never come down. So that was frustrating cause you end up losing faith in doing it, you’re just like, “Oh well, whatever,” like, “This isn’t going to change,” so that was frustrating.

A similar quote to the one above is presented in section 7.4: minimizing the moral context of management, as Steve spoke about avoiding blood glucose testing when he recurrently felt depressed after seeing bad results. By not seeing good results for their glycemic control, it was difficult for participants like Jennifer or Steve to stay engaged with their self-management routines.

On the other hand, in Jerry’s case (a participant conveying an inconspicuous lens), having what he considered to be a good HbA1c helped him to feel good about himself despite having seizures,

BM: What are the types of things that you would ask them [providers] about during your visits?

Jerry: I just ask them, like to be honest, I don't really know because my A1c for the past couple of times that I've been there has been really good. But, yeah, again, I find myself really in control, at times, like obviously there have been times where I've had my own seizures and stuff, but again, they're learning experiences. Yeah, at this point I don't know
a life outside of diabetes, right, so there's not much that's new to me, yeah, there's not really much.

Having a good “HbA\textsubscript{1c}” provided Jerry with reassurance that he had his diabetes under control. He felt that there was not much else to talk about with his health care providers considering that his HbA\textsubscript{1c} was in a good state. I found this to indicate a potential preoccupation with HbA\textsubscript{1c} within diabetes care interactions. This can potentially backfire on emerging adults like Jerry, who may be overlooked as in need of support due to the HbA\textsubscript{1c} category he falls under.

8.5 Insulin Administration: Pump versus Multiple Daily Injections

Continuous subcutaneous insulin infusion (CSII) from an insulin pump was the predominant method of insulin administration within this sample of emerging adults with Type 1 diabetes (20 participants were using CSII compared to 13 participants using multiple daily injections [MDI]). But, there were a significantly high proportion of MDI users amongst participants who conveyed an inconspicuous lens (70%), compared to other lenses (40% of participants conveying an intrusive lens were MDI users and 20% of participants conveying an ingrained lens were MDI users).

In some inconspicuous narratives, vocation influenced the decision for using MDI. As Jennifer began full-time work and travelled more frequently, she realized that MDI helped make management feel easier,

I like using them [needles], I find that they’re easier for like travelling and stuff, which is what I really like to do. It’s easier to adjust with the needles then it was with having like a basal rate and everything, cause with the pump you kind of had to go in there and like change the time and then change the dosage, whereas with the insulin, like instead of doing it, I give it at 11pm at the place that I’m in. So that’s helped a lot which has been good.

In Ken’s case, he believed that switching on to a pump would take time away from his co-op placement,

… these co-op situations are only four months long, you can’t really take very, like very much time off, like you’re trying to get the most as you can at the company that you’re at, in the four months that you are there. So if I was to go on the pump and have to take like
every, every other Thursday or every like many days off to like kind of get onto the pump, it, like it would kind of have a negative effect on my co-op experience.

Throughout his interview, Ken spoke about wanting to have diabetes play a minor role within his life, so it is no surprise that he chose not to opt for what he found to be a time consuming endeavor (switching to CSII).

Although using MDI appeared to be more convenient for Ken and Jennifer’s work lifestyle, it seemed counter intuitive that participants conveying an inconspicuous lens would want to use MDI after hearing Mike talk about it (an equivalent quote is presented from Ken’s interview in Chapter 7),

… you have to do an insulin shot and there’s long lines and you can’t find tables, it kind of restricts what you can eat. Like I only pick the Tim Horton’s because there’s a bathroom nearby and a lot of tables, right, so if I didn’t have diabetes I probably wouldn’t eat at Tim Horton’s, I’d probably go to the main foyer, you know.

Depending on an emerging adult’s life circumstance (e.g. work versus university lifestyles), there can be different reasons for choosing an insulin administration method, and different challenges that arise from using that particular method. For instance, using an insulin pump may have its own visibility issues. In Lindsay’s case (a participant conveying an intrusive lens), she switched off of an insulin pump because she felt that it was similar to “something you see in the hospital” (see Lindsay’s story in Chapter 4).

Contrary to Lindsay, for participants conveying an ingrained lens, the move to CSII was described as being a monumental moment in their lives as it set the stage for smooth transitions into emerging adulthood. Bridgette compared what life was like before and after her change to an insulin pump,

… before I’d have to wake up before nine, like have a snack at 10:15, have lunch at 12:30, so it was really like a major schedule. But like growing up, you know, and being an adult, it’s nicer to have flexibility. And being able to sleep in on the weekends, you know. I don’t have to have a snack if I don’t want to, like you can manage the insulin and stuff on the pump, so it makes it a lot more easy.

Similarly, the pump helped make life easier for David as well,

You know what, getting diagnosed young, you know, I really had my parents there to guide me through everything, to build good habits, to help me out with that. And then as soon as we got on that pump it just, it was a switch, our life was just actually easier, you
know. I go throughout daily life, it never really, it never really gets in my way. I do a lot of training [athletics]... so for the exception of, you know, always having to make sure I’m taking it off or anything like that, I’ve never really had any, I guess any trouble, anything, you know, in the way of managing it or giving me excess trouble I guess.

Hearing David speak about his move on to CSII made it seem like it was a major reason as to why diabetes became a comfortable part of his life. Notably, 80% of participants who conveyed an ingrained lens were using CSII, and many told similar stories about experiencing life-changing moments as they switched to an insulin pump.

8.6 Living Arrangements

Moving away from the parental home was described as a great leap for participants conveying an intrusive lens. Edith recalled being thrown into a situation that she was not yet ready for,

I remember that when I was at home like my parents are super healthy eaters. So I think when I got to school I definitely, so literally I had never eaten a [fast food restaurant] sub or like I never went to [fast food restaurant] because my parents just like don’t, they just eat like healthy food. So I think I rebelled by eating out and eating at like weird times and weird food, like I remember eating like a lot of chocolate for breakfast, which is weird. So I think the transition was I had to mature.

Edith reflected on this moment as being her first taste of independence and she took it as an opportunity to rebel against her diabetes.

As Edith outlined, I recognized a distinct narrative about difficulties launching into independent living. This was about past experiences of feeling overwhelmed by independent living. Instead of reflecting on smooth progressions into independence, a difficulty to launch narrative refers to a rocky journey, in which participants felt there was more they needed to learn before setting out on their own.

Turmoil within the family dynamic during childhood foreshadowed difficulties adapting to independent living. Prior to leaving her parental home at the age of 18 years, Leah (a participant conveying an intrusive lens) described her diabetes as being a “sore spot” within her family dynamic:
… it kind of became like a sore spot between me and my parents a lot of the time, because there was a lot of stuff that we would fight over, like I would lie about my blood sugars or I wouldn’t bolus and they would get mad at me for different diabetes related things, and it would like make for like tense times in the house.

Signs of moral sensitivity appear within this quote. Leah outlines a sense of guilt that could arise as she disclosed a bad HbA$_1c$, which strained the relationship with her parents. Around the time she was 18 years old, she felt excited to leave this rocky relationship behind her and experience living on her own. But, she soon realized she was unprepared for this,

I feel like when I moved out, it was kind of like a shock to my system, like how much you really have to do for diabetes. So I felt like I was really unprepared to be on my own. So like if I was stressed at school, it would affect my diabetes. If I had a high sugar I would stress out even more. Like it was just kind of like this vicious circle of spiraling downwards with my control.

Unlike when she was living at home, Leah lost the ongoing support of her mother,

… my mom kind of did everything for me when I was living at home. And like I tried to take on some of that independence, like I did my own laundry, like I cleaned up after my meals and stuff like that, but it was still kind of a shock to my system, like how much there actually is to do when you live on your own.

As Leah highlights, diabetes was just one of many other responsibilities that came with living on her own. The accumulation of these many responsibilities overwhelmed her.

Similar to Leah, Mary (a participant conveying an intrusive lens) outlined the events that precluded her hurried move out of the parental home. During her teenage years, Mary experienced conflict with her parents,

I would always be really angry because my mom was literally so scared of me dying. We have like talked about this because I was so bad with it. Like, and I would always be in the hospital and my mom was so scared of me dying that she would literally just insert herself in every single thing that I did and like wouldn’t let me do things if I didn’t take my insulin, and like would literally try and control everything. And then I just felt so angry and that made me like rebel more. And then my dad, like, my dad, we never like really had a good relationship and he knew that I hated having diabetes, so he would like kind of like throw it in my face with stuff, so, and that caused like conflict between us.

Eventually, as she turned 18, Mary decided on attending a university away from the parental home. At the time, she remembered her parents were happy about this choice,
… they were like really happy. They were like, “Yes, our daughter is going to university, she is going to be independent because she is like five hours away, like, get it girl,” that’s what they were like.

But as she entered the university environment, she was met with an overwhelming sense of freedom:

… in high school, I was so used to my mom and dad being like, “Take your insulin, check your blood sugar, do it now or you are going to get in trouble.” And then as soon as I went to university, I like had all this freedom and I was like. “What do I do?” And then I was just like, “You know what? No, whatever, I am going to eat whatever I want, I am going to go out drinking, I am going to do all of this,” ended up very, very sick for a good chunk of that year.

Accounts like the ones above demonstrate why participants conveying an intrusive lens may have found themselves to be in a catch-up state. A lack of preparedness for independent living set them up for challenging starts to emerging adulthood. Rather than experiencing inclines in confidence since adolescence, their confidence hit a low point as they turned 18 years of age and moved out of the parental home.

8.7 Relationships with Health Care Providers

In interviews, participants spoke in depth about relationships with health care providers. For most (32/33 participants), relationships with diabetes care providers began in the pediatric care setting.

In ingrained narratives, pediatric providers were portrayed as heroic figures. Heather described her pediatric endocrinologist as being like a “dad” to her, and Kevin said that his pediatric endocrinologist was like a “god” to him,

My endocrinologist at [pediatric hospital name], so I saw him from when I was seven to when I was 18, [doctor name], who was just like a god. He was the one who really imposed like very stringent and strict care and I used to hate it when I was younger, cause I was like, “I don’t want to follow all these rules,” but like now that I’m an adult it’s like just changed my life.
This experience of having positive relationships with pediatric care providers was common from the ingrained perspective. For Bridgette (a participant conveying an ingrained lens), her pediatric nurse inspired her to become a nurse,

… I loved my nurse growing up so I guess she was kind of like my inspiration to become a nurse and then I always grew up just knowing that’s what I wanted to do.

In Daniela’s case, she too remembered her pediatric nurse in highly positive terms,

I think I just liked my nurse a lot so whatever she told me to do, I did, whether it was like I wanted to do it or not. Like when I got diabetes, like they taught me I guess the right way and like, not that I was like different or anything, so I always like thought it wasn’t a big deal. It’s just something I had to live with. So I guess I just stayed like that.

These positive accounts about pediatric care experiences are in contrast to participants conveying an intrusive or inconspicuous lens. I did not find participants conveying an intrusive or inconspicuous lens to speak as though their relationships with pediatric care providers steered them in positive directions. In Jennifer’s case, her sensitivity towards stigma (refer to section 7.2: Why ‘Inconspicuous’?) may be linked to her “Type 2 diet” as a pediatric patient,

When I first got diagnosed I got put on a very strict Type 2 diet for, I don’t really know why, which was kind of annoying as a child cause like you want to be able to go to parties and like birthday parties and eat cake and do all that kind of stuff which I couldn’t do.

Unlike the context of pediatric care, when speaking about relationships with health care providers at an emerging adult diabetes clinic, there was generally more positivity in participant accounts regardless of lens type. For instance, in Jennifer’s case (an inconspicuous narrative) she felt that her voice had finally been heard when she entered an emerging adult clinic,

It’s good, I really like it. It’s a very different approach I guess than when you go to the pediatric clinic, like it’s much more involved there I guess, cause you’re a young adult. So I guess they care more about what you’re sort of saying whereas at the pediatric clinic you kind of just like sit in a corner and like your mom and the doctor talk about you as if you’re not there {laughs}. 

This different approach gave Jennifer the opportunity to make the switch from an insulin pump to MDI,

I guess because the approach from the beginning was different, so I was like, I had wanted to switch for a while, so I was like maybe this is a good chance to ask cause this
man [her endocrinologist] seems to listen. So it was really soon into going there, cause I switched over when I was like 18.

Omar (a participant conveying an ingrained lens) similarly described establishing a positive relationship with his endocrinologist at an emerging adult diabetes clinic. He credited his endocrinologist for steering him in the right direction after experiencing past difficulties with glycemic control,

… well health care providers, such as [doctor name], really, if I were to say they played a tremendous role I would be undermining what they do. He’s the one who actually just got me to start really taking care of myself and told me, “Hey, listen, you really need to get it down, to get your A1c down and take care of yourself better.” And when he saw that I actually made progress, he would actually commend me on my progress. And that just goes a long way. And letting me know that you’re doing the right thing and you need to continue. And ultimately he’s only striving for my well-being. So like the support that he—that comes from him really is indescribable I’d say.

Omar thought it was helpful that his providers were stern with him, as it provided him with a reality check for the risk of long-term complications,

… the only advice I would give the adult clinic is to keep doing what they’re doing; commending anyone’s progress, if you need to scare someone in order to set them straight, do it. Because that is actually what worked for me. Like when [doctor name] actually told me, “Oh wait, you could be facing one, two, three and four when you’re older because you’re not taking care of your diabetes now,” that was one of the major factors that woke me up and told me, “Hey, you need to take care of yourself better.” So I’m just going to tell them, keep doing what you’re doing.

Similarly, Charlotte (a participant conveying an ingrained lens, and the only participant to start diabetes care in the adult setting) described not being afraid of getting “chewed out” by her providers,

And coming into this clinic was huge because there’s just so many different—like you see a nurse, diettian, everything. I don’t think you see that anywhere you go, so that’s definitely a huge impact… I know for some people it’s kind of like scary when they come every time, like cause they’re scared of being like chewed out or whatever, but I find it’s a very supportive environment and if I have an issue I can just come in or send an email and it can be resolved pretty quickly.

Charlotte and Omar’s interpretation of support was different than participants conveying an intrusive lens. From the intrusive perspective, participants enjoyed an emerging adult
diabetes clinic because the providers were not as hard on them. As Cindy described, she encountered less judgement than pediatric care,

I guess they [adult care providers] help me to remember like my goals because it’s kind of like, you know, they’re checking on me. Like I want to make sure that I kind of have good stuff to show and it’s like a nice reminder. And I feel like sometimes it encourages me in the right step to continue to want to, to better my diabetes management and sometimes they do give me like good pointers and stuff, which is really nice. And I like that they don’t make me feel like I’m the worst diabetic in the world, like its actually really nice cause I know I’m like not the best, but they aren’t too hard on me, which I really appreciate at [emerging adult clinic]. Yeah, I can’t say all my experiences were like that {laughs}, so I really do appreciate that with [doctor name] and stuff.

Similarly, Leah (a participant conveying an intrusive lens) also felt that her emerging adult clinic used less of a “guilt based” approach,

Yeah, I really enjoy [emerging adult clinic name] just cause the clinic I was at before, it was very guilt based. Like if I had a high sugar, it was my fault and like there was something I could have done and it was kind of like scare tactics almost. But here, I find the staff is like a lot more supportive and understanding and like wanting to help for the sake of me rather than wanting to help for the sake of diabetes.

Despite feeling as though there was less judgement compared to pediatric care, I recognized that participants conveying an intrusive lens still felt that they had to look good in front of providers. As Cindy alluded to in her earlier quote her adult care providers did not make her feel like the “worst diabetic in the world”, but she still felt she had to put together “good stuff to show”. Furthermore, Tim (a participant conveying an intrusive lens) said it was a major stress trying to prepare for clinic visits:

… just like every three or four months it’s like major stress trying to make sure that I have all the right like bolus information and blood sugar history in my pump, making sure that my A1c is gonna be like within the right range.

In Anne’s case (an intrusive narrative), she similarly felt this stress of trying to maintain her HbA1c between clinic visits,

… I find they [adult care providers] are very like, I don’t know, especially with the A1c, like it has to be so like tight and they make you anxious about like what might happen to you later in life if it’s above this level. And like that can be sort of, like it makes you disappointed in yourself that you didn’t try harder.
From an ingrained perspective, narratives about attending clinic visits took on a different form. Participants were less concerned about judgement. Ardit felt as though he took on a more mature and engaging role in patient-provider dialogue, rather than feeling as though he was being checked up on (a similar quote can be seen from Arvin in Chapter 5),

I really like meeting my endocrinologist, my team and what not just cause personally I like to ask a lot of questions as well. And I think that’s the role that the diabetes team should play; they should be a, sort of a center of information, providing just information how—you know, cause they won’t give you specifics on how your body works unless they have like a three months or six months, you know, blood sugars and they can see with you, but you sort of have to come to your own conclusion on how your body reacts and the more information you have from your support system, the better you know what to do, or even the ratio at times. Obviously I’m not saying to change the ratio… but you know more or less if it’s working or not cause you’re the one constantly checking, you’re the one constantly—so it’s sort of like an experiment, you know, you have a variable that changes and you constantly have to check on it to see if it’s in the right range or not and then you have to accommodate for it, so you either have to increase your insulin dosage or lower it. And so, you know, more or less. And they’re there, just like I said, to support whatever decision and you know to better understand for yourself how your body reacts. So, yeah, they’re there for support but I think the diabetic [sic], they have to take the initiative to really take care of their body. It’s not like a disease where you can depend everything on your endocrinologist and whatever he says or she says then that’s how it must be done… So you have to sort of learn on your own what works and what doesn’t work and then whatever question comes up and what you’re curious about then those questions you direct it to your support team, we can say then they better advise you if it works or doesn’t work.

… And I really enjoy as well listening to some studies that they shared with me of what’s going on right now, like a [university name] study that’s happening on, you know, the rigorous exercise and how that affects your diabetes and what not. So, yeah, I feel like you can, it’s a more detailed conversation. You can go more into detail about things. Whereas on the, you know, before at the [pediatric clinic] it was not as detailed you can say. Maybe personally, myself, I wasn’t asking that many questions, but still, it’s a different dialogue that happens, it’s more mature, more detailed I guess, that’s the key word.

Unlike Ardit’s account, it appeared that the nature of patient-provider dialogue would be different in a clinic visit for a participant conveying an intrusive or inconspicuous lens. Aravan (a participant conveying an intrusive lens) seemed to have to brace himself for his providers’ questioning,

… they’re [adult care providers] always telling me like you have to watch how many carbs are in this and how much insulin to take, and adjusting insulin with me and teaching me how to adjust it myself, and stuff like that.
Similar to intrusive narratives, this heightened sense of judgement could be detected in accounts about health care from the inconspicuous perspective. As Hazel explained, overall she felt that her providers were doing a good job, but there were times when she felt condescended to,

BM: How is your relationship with the providers there [emerging adult diabetes clinic]?

Hazel: They’re good, yeah, yeah, sometimes I feel condescended to but… yeah, I’ll just say that, sometimes I feel condescended to but overall it’s good.

BM: Feel free to say whatever you want, yeah, so by condescended, what would an example of that be?

Hazel: I guess like, I can’t think of a specific example, just feeling like I should have known something already or feeling like my, like my A_1c is high because I made a mistake that I shouldn’t have made or like that kind of thing.

As seen in previous quotes from participants conveying an intrusive or inconspicuous lens, HbA_1c brought forth judgement within their narratives, including in the context of health care.

Hazel further illustrated her sensitivity towards the moral context related to HbA_1c, as she spoke about getting “judging looks” whenever she decided to use a point-of-care HbA_1c analyzer,

I mean my doctor was like, it’s much more accurate [referring to lab testing], and I was like, “I don’t know if I care that much”, but then I, like, I get the judging looks whenever I don’t do it so I’m like, okay.

Based on their interview responses, it seemed like participants conveying an inconspicuous lens would be the candidates most likely to take advantage of point-of-care HbA_1c testing. Mike explained that the lab testing system at his emerging adult diabetes clinic was terribly inconvenient,

I mean the way they have it set up where you have to go, pull your, your A_1c or whatever and get the blood work done two weeks in advance, I mean that’s a terrible system. [pediatric clinic] would have it, get your A_1c you wait like ten minutes and then they will have it done. I mean the fact that I have to come here two times, waste four tickets [referring to public transportation] it’s just a pain.

Like Mike, Ken described inconvenience when speaking about getting blood work done for his clinic appointments,
I kind of haven’t done blood work in the past little bit… Actually it was a lot easier when I did go to [pediatric clinic] because I was able to actually, like they could do the blood work right at the hospital. So, like, like I’d go, I’d go in and do the blood work in the morning and, and like they could usually, actually like because it was right in the hospital it seemed that they could send the results right away to the, like so I didn’t actually have to, I didn’t have to like get it in advance when I was there, I was able to actually like go get the blood work and they were able to send the blood work like immediately to the doctor like as, as I kind of like, so yeah, it, it like, it, it is a little bit more challenging when I have to get the blood work done like a week in advance and, and try to find a place like yeah, like find another time for me to get the blood work done.

8.8 The Relationship between Diabetes Related Social Interactions and Responsibility during Emerging Adulthood

At the outset of this study, my secondary objective was to understand the relationship between diabetes related family interactions and responsibility during emerging adulthood (refer to Chapter 2). Initially, this objective was developed from my preliminary observations of an emerging adult diabetes clinic (Markowitz et al., 2017a). But as this study progressed, it became apparent that family interactions were one component of a multi-dimensional social context depicted in the narratives of participants.

Rather than focusing specifically on family interactions, participants revealed that they wanted to talk about the broader social climate influencing their uptake of Type 1 diabetes self-management. For instance, when asked about her relationship with siblings, Angelica branched out to speak about her diabetes related experiences with social media,

BM: How are they [siblings] involved with your diabetes?

Angelica: … like whenever we like go to like restaurants, like if it’s just us four, they’d be like “Did you take your needle? Are you sure you’re allowed to have that much sugar?” and stuff like that. Especially if we go out for deserts, they’ll be like, “Are you sure you’re allowed to have that?”… and it’s also like my friends as well, like if I tell like my friends like, “Oh I have diabetes.” So they’re like, “Oh, so you’re not allowed to have a lot of sugar?” like, “Are you allowed to have that chocolate bar?” Like I know like when I speak to my best friend cause she also has Type 1 cause we relate, so when I told her that, she was like, “Yeah me too”…like we find that its very ignorant cause like people they relate diabetes to like sugar, like you cannot have any sugar whatsoever. And I found that very annoying in high school and like even now, just seeing like pictures of deserts on like Instagram or Snapchat and then people comment like, “Oh my god, that’s diabetes in a bowl.” And I’m like, I get like taken back, I get actually offended, it’s like, “You don’t know what it is so you can’t really say.”
It was difficult for Angelica to separate herself from the moralistic tone of societal discourse surrounding diabetes. It was frustrating for her to know that others associated diabetes to sugar. Constantly, she said she encountered a similar discourse; if you eat too much sugar you can get diabetes, or that if you have diabetes you should not be eating sugar. Even her siblings had these misperceptions about what someone with diabetes should or should not be eating.

Unlike participants who conveyed an intrusive lens (such as Angelica), from an ingrained perspective, I formed an impression that diabetes was smoothly integrated into their social lives. Ivan said that he used his diabetes as an ‘ice-breaker’ at college,

I always tell everyone, whenever I meet someone new or if I’m going to be spending time, like for example school or stuff like that, I always let people know, I’m like, “Hey, by the way, like, I’m diabetic.” It’s also a great conversation starter, right? Like breaking the ice with new people and stuff like that.

Aside from university or college environments, in ingrained narratives, diabetes was portrayed as being comfortably intertwined within one’s social surroundings at work. In Bridgette’s narrative, she felt supported by her co-workers and managers,

I worked as a cashier and so all my like girlfriends who worked there knew I was diabetic. So sometimes I might just be like, you know, “I need to go grab a snack, I’ll be back in five minutes.” My managers all knew and they would always say, you know, like, “Make sure you have your breaks,” like they were good cause I always had my breaks… they always made sure that everyone had their 15s, everyone had their lunch. So when I had to leave for like a few minutes, it never really was an issue.

Meanwhile, in Angelica’s intrusive narrative, she felt discomfort when faced with taking breaks when working at a retail store,

… with co-workers as well, it has an aspect as well. Some people might be like, like in retail for sure is that they’d be like, “You don’t have a break for another two hours, what are you saying… you’re going to be away for like five minutes from your spot?”

Aside from stories about managing diabetes at work or college, accounts about grade school experiences further illustrated differing participant perspectives on how diabetes became socialized in their lives. Tim (a participant conveying an intrusive lens) recalled experiencing “paranoia” when he returned to his grade school class after his diabetes diagnosis,

BM: How was that experience of being first diagnosed for you?
Tim: It wasn’t fun, like school made it really difficult cause I think I was in grade five or something and my teacher found out and it was like instant paranoia cause like, I’d just be like, “Hey I have to go to the washroom”. “Alright, okay who’s going to go with him?”

For Jennifer, a participant conveying an inconspicuous lens, she similarly expressed feeling “weird” when returning to school after her diagnosis,

It was weird at first. When I first got diagnosed, for a while my parents would come at lunch and like test my blood sugar…so that was a little strange, cause like “Why do her parents show up every day at lunch?” kind of thing.

In contrast to Jennifer or Tim, Heather recounted a highly positive experience assimilating diabetes into her social surroundings,

… all of my classmates were very accepting. I remember I used to have an alarm on my pump five minutes before recess and lunch to test my sugar, and my friends used to love that, like all my classmates, because it would let them know that recess is coming. And then for the last five minutes before, no one would do anything. I don’t think I’ve ever had an issue like talking about my diabetes, maybe that’s just because I grew up in like an environment where there’s a sharps bin in every bathroom in my house and like…my house like kind of revolves around diabetes sometimes. Like I never thought diabetes made me different…

Throughout interviews, participants articulated navigating through a constellation of social interactions and relationships (with family members and many other characters). Stories about the judgmental gaze of others had a profound presence in interviews with participants who demonstrated an intrusive or inconspicuous lens. Rather than feeling as though diabetes could be used as an ‘ice-breaker’ or that diabetes did not make them feel different, participants conveying an intrusive or inconspicuous lens experienced difficulties trying to assimilate diabetes into their social lives.

8.9 Chapter Summary

I intend for the interpretive findings presented throughout this chapter to further distinguish participants according to the ingrained, intrusive and inconspicuous lenses. I began this chapter by highlighting gender, glycemic control, method of insulin administration and living arrangements as key areas of divergence within this sample. Next, I outlined differences and
similarities in accounts about assimilating diabetes into relationships and experiences with diabetes related interactions.

First, gender was analyzed in the context of narratives. An obstacle course analogy was used to illustrate that women conveying an intrusive lens spoke about struggles trying to navigate self-management challenges and barriers. In contrast, men tended to present themselves as being strong in the face of adversity, describing diabetes as not especially burdensome.

In terms of glycemic control, HbA1c helped to illuminate why participants experienced an intrusive lens of diabetes during emerging adulthood. When HbA1c was considered to be good in pediatric care, this set the stage for smooth transitions, while rocky journeys awaited participants who experienced early difficulties with HbA1c. Contradictions could also be linked to HbA1c within narratives, as some participants felt that HbA1c was a poor reflection of their character, while others used their good HbA1c to bolster confidence despite experiencing adverse diabetes related events.

Most participants within this sample were using continuous subcutaneous insulin injections (CSII) from an insulin pump as their method of insulin administration. However, the majority of participants conveying an inconspicuous lens were using multiple daily injections, with some citing that it was the more convenient method at this stage of their life. This seemed incongruous given that it was also described as bringing forth difficulties in inconspicuous narratives, as it made diabetes more public. In contrast to speaking of any difficulty arising from insulin administration, participants conveying an ingrained lens viewed their insulin pump as a positive life-changer as it brought forth great freedom and flexibility. Unlike these positive accounts, participants conveying an intrusive lens described the insulin pump as a nuisance.

Next, narratives about difficulties adjusting to independent living were presented. These narratives illustrate how moving out of the parental home set the stage for premature leaps into independence. This overwhelming experience indicated that participants conveying an intrusive lens were not yet ready to manage diabetes on their own when they turned 18 years of age. At their interviews, they were in the process of trying to regain confidence after being humbled by difficulties launching out of the parental home.
Following this, I highlighted participant accounts about relationships with health care providers. This section was intended to demonstrate how participants described experiences interacting with providers in both the pediatric and adult care settings. In ingrained narratives, highly positive accounts were told about inspirational pediatric providers. There was generally more positivity in accounts from all participants in the context of the adult care setting, yet there was more concern of judgement from the intrusive or inconspicuous perspective, as participants felt as though they had to look good in front of providers. From the ingrained perspective, participants demonstrated that they had matured into a role of partners in care, as they were working with adult care providers, rather than feeling like providers could look down upon them.

Finally, I outlined my interpretations regarding the broader social context surrounding the Type 1 diabetes experience during emerging adulthood. Aside from family relationships, participants were faced with trying to assimilate diabetes into their work and academic settings. Along with in-person interactions, participants also spoke about interactions with diabetes on social media. From an intrusive or inconspicuous perspective, it appeared difficult to live a normal life when participants were prone to being treated differently because of their diabetes.

The comparisons I have presented throughout this chapter help situate the ingrained, intrusive and inconspicuous lenses within the context of emerging adulthood. This comparative discussion highlights many moving parts impacting the multifaceted stories told by participants.
Chapter 9
Discussion

9.1 Chapter Overview

In this study, I put forth a heuristic that helps understand how emerging adults perceive Type 1 diabetes. Through an ingrained lens, participants spoke about how they integrated diabetes seamlessly into their everyday lives. Participants adopting this lens spoke about achieving competency for self-management and depicted themselves as exemplary self-management figures that learned to live with diabetes, rather than feel as though diabetes was an overwhelming responsibility. From an intrusive perspective, another set of participants recounted lacking sufficient preparation for taking on greater personal responsibility during emerging adulthood. Their narratives about living with Type 1 diabetes were about struggles adjusting to newfound independence, as diabetes was portrayed as being ever present and was characterized as a burden to be shouldered. Participants conveying an inconspicuous lens described actively trying to manipulate the presence of their diabetes. Their narratives suggested that they were not simply ignoring diabetes, but were working hard to keep diabetes away from the spotlight of their lives. From this perspective, participants felt that people could treat them differently when they found out about their diabetes; therefore it was important for them to avoid any unwanted attention.

These findings are supported by first-hand accounts that reveal important nuances and complexities about the lived experience of Type 1 diabetes during emerging adulthood. Participants spoke in-depth about social interactions, which appeared to shape their perspectives and in profound ways. Portrayals of relationships with parents, providers and peers demonstrated that there was a moral context surrounding diabetes management during emerging adulthood.

Moral messages were central within participants’ narratives and these were described differently according to the lens being adopted. This had implications for support, as the moral context of management became an influential factor in how they recounted receiving and seeking support. Through an ingrained lens, participants felt as though they achieved a sense of mutual
respect with parents and providers, as they described themselves as partners in care. In contrast, participants conveying an intrusive lens spoke about feeling threatened by ongoing judgments that they perceived from parents, providers, peers and many other sources (e.g. from social media or from cashiers at grocery stores), which subsequently led them to feel like they were battling against diabetes on their own. Unlike participants conveying an intrusive lens, those who conveyed an inconspicuous lens were able to distance themselves from the judgments of others. These participants spoke about learning how to manage diabetes in their own way, rather than what others considered the “right” way.

In this chapter, I situate my findings in relevant literature and outline their applicability to clinical practice. I start by examining how my lens interpretations can help to improve patient-provider dialogue during transitions in care. Next, I highlight the risk of HbA₁c becoming a self-fulfilling prophecy in the narratives of emerging adults with Type 1 diabetes. Following this, I use my findings to help better understand the nature of parental involvement for diabetes management during emerging adulthood. Lastly, I discuss strengths and limitations of this narrative approach, outline directions for future research and provide concluding remarks.

9.2 Contributions of the Lenses for Improving Patient-Provider Dialogue during Transitions to Adult Care

In ingrained narratives, diabetes became comfortably a part of a participant’s daily life. These narratives suggested that participants had developed a sense of expertise for self-management. They explained learning how to apply medical advice in the context of their daily life. This involved having an understanding of bodily cues and experiential logic. As Ardit put it, over time management no longer felt like it was a stringent routine.

The concept of developing expertise has been studied within the context of Type 1 diabetes (Paterson & Thorne, 2000a, 2000b; Thorne & Paterson, 2001), and these findings further illustrate that expertise evolves from a transformation of being a passive recipient to an active participant in diabetes care. Components such as confidence, competence and social support were equally if not more significant to metabolic control in making participants feel in command over diabetes (Paterson & Thorne, 2000a). Health care providers should recognize that glycemic
control might not be the primary goal for emerging adults with Type 1 diabetes (Thorne & Paterson, 2001). It was through other measures that participants adopted an ingrained lens of diabetes, such as forming a new way of being with parents and providers (i.e. becoming partners in care). Diabetes care providers can learn from ingrained narratives, and use this knowledge to foster change in the perspectives of emerging adults who may be accustomed to thinking about management in terms of compliancy (Paterson & Thorne, 2000a). As Arivn described, being able to speak to his health care providers as though he was on the same team made him believe that he had finally worked his way up the ranks and become a respected self-manager.

Through an ingrained lens, clinic visits no longer felt like participants were being checked up on, rather participants were working with providers to stay on track. There was a sense of collaboration within their narratives, as clinic visits exemplified an opportunity for participants to ask questions about self-management and fine-tune areas that needed improvement. Family members and providers were seen as their pit crew who were there to support them when needed, but the participant was the one driving the car.

Accounts told from an ingrained perspective indicated that participants had established trusting relationships with health care providers. This was especially apparent in ingrained narratives about pediatric care, in which participants depicted past health care providers as “Gods” or “Dads”. This phenomenon has relevance to attachment theory (Daneman & Daneman, 2012), as strong early bonds with pediatric care providers may lead transitioning patients towards developing a more secure attachment style characterized by a greater sense of trust with adult care providers.

The majority of participants within this sample did not view diabetes care visits from the same ingrained perspective, which provides insight into why clinic attendance has become a concerning issue during the transition to adult care (Garvey et al., 2012; Peters & Laffel, 2011). From an intrusive or inconspicuous perspective, I formed the impression that going in to clinic was more of a formality (something that was expected) rather than something that was personally meaningful. Jerry provided an example of this as he spoke about not knowing what else to talk about with his providers given that he believed his HbA1c was “good”. But when participants did not have an HbA1c within a desirable range, for instance in Hazel or Karen’s case, going in to see providers was highly stressful. It meant that some participants felt obliged to take information
home that they did not want to show their parents. I found this comparable to how students may feel hesitant to taking their report card home if they got a bad grade. The emphasis placed on HbA\textsubscript{1c} readings by both providers and patients may inadvertently serve to drive some emerging adults away, if they perceive themselves to be ‘failing’ in their attempts at management. Whether or not this is language that patients and providers actually use, the fact that some participants viewed it this way is deeply troubling, suggesting that some are bearing a significant burden, one that they express in terms of ‘moral failing’ with respect to their everyday management. Seen in this way, it seems understandable why some emerging adults living with Type 1 diabetes might be reluctant to attend clinical visits.

Similar to certain prevalent discourses concerning high school experiences (e.g. “dropping out”), this study suggests that a similar (moral) discourse has made its way into the realm of health care transitions (Canadian Pediatric Society, 2007; Grant, 2014; The Hospital for Sick Children, 2016). How participants took up these discourses had implications for how they interacted with parents and providers. It appeared that many participants conveying an intrusive or inconspicuous lens were not yet treated as partners in care, as they portrayed parents and providers to be authority figures. Many participants spoke about management in terms that made it seem similar to academic performance, wherein the teachers (or health care providers) and parents are judging the emerging adult’s performance. A useful way of thinking about this scenario could be that intrusive or inconspicuous participants had not adopted a mindset in which they were using clinic visits to hone a craft or skill, as it seemed like attending clinic was seen more as a mundane responsibility forced upon them, which has resemblance to a student who might feel obligated to attend a class they are not interested in.

This school analogy brought my attention towards the broader discourse surrounding health care transitions. The “Good 2 Go” Transition Program at the Hospital for Sick Children in Toronto reveals that the dominant discourse in the pediatric setting seems to be modeled after high school (The Hospital for Sick Children, 2017). That is, patients are groomed to “graduate” into an adult patient. It is no surprise that Karen told such a dramatic story about her pediatric care experience, as she felt she was not one of their model ‘students’.

Thinking about health care transitions from a graduation perspective sets the stage for transition failures (Skelton, 2002). Instead of likening the age of 18 years to be a time of
graduation, the ingrained narrative suggests that providers and parents may be better off thinking about the transition to adult care as the start of a marathon (Paterson & Thorne, 2000a). Just as marathon runners need people supporting them at every major turn, emerging adults with diabetes need ongoing support as they are learning how to integrate diabetes within their everyday lives. Rather than viewing parents or providers as judges that they have to look good in front of, emerging adults with Type 1 diabetes should be enabled to view their providers as partners in care (Thorne & Paterson, 2001). To do this, providers should think about how they can shift the thinking of emerging adults away from compliancy and towards a more engaging role, in which emerging adults are honing the craft of diabetes management.

9.3 The Risk of HbA\textsubscript{1c} Becoming a Self-Fulfilling Prophecy for Emerging Adults with Type 1 Diabetes

This study highlights how important the medical test of the HbA\textsubscript{1c} is in the lives of emerging adults with Type 1 diabetes.

Negative experiences with HbA\textsubscript{1c} began in the pediatric setting for participants within this study. As Angelica remembered, her pediatric endocrinologist would speak to her about her high HbA\textsubscript{1c}, yet she felt that her parents were doing most of the work for her management at that time. Other research in Canada has found that those with poor HbA\textsubscript{1c}s were more likely to transition out of the pediatric care setting earlier and more abruptly than those with what may be considered good HbA\textsubscript{1c}s (Mistry et al., 2015).

Within psychological literature the phenomenon of expectancy theory has been examined (Rosenthal, 1994; Rosenthal & Jacobson, 1968), and this study indicates that it appears to have applicability within the context of transitions in care. This theory puts forth the idea that when individuals are labeled as being something (such as a bad self-manager based on their HbA\textsubscript{1c}) expectations can turn into reality, which can be referred to as a self-fulfilling prophecy. Self-fulfilling prophecies have been studied within performance-based situations, such as classrooms (teachers forming impressions of good versus bad students) and athletic teams (coaches who allocate more time helping the so called good players compared to the bad ones) (Rosenthal & Jacobson, 1968; Weaver et al., 2016).
This study suggests that HbA1c may become a self-fulfilling prophecy through the use of avoidant coping measures. Steve demonstrated this, as he spoke about feeling “depressed” whenever he checked his blood glucose monitor. Eventually, he turned to avoidance and stopped checking. These findings provide further insight into a “passive avoidant coping style” demonstrated by emerging adults with Type 1 diabetes (described as “emerging adults who do not succeed in accepting their illness or in actively dealing with it and, regressed to a state of passivity or avoidance”) were more likely to have higher HbA1c scores (Luyckx et al., 2010). Furthermore, over time there is a risk that having a poor HbA1c may lead to avoidant coping strategies, as an emerging adult feels as though their work and effort towards self-management are not leading to any positive outcomes. Jennifer provides an example of this as she spoke about losing faith in her self-management plan (see Chapter 8). Similarly, Rassart et al. studied HbA1c longitudinally amongst a sample of emerging adults with Type 1 diabetes and found higher HbA1c levels to be associated with increases in avoidant coping strategies over the course of five years (Rassart et al., 2016).

Contrary to avoidant behaviour, the ingrained narrative was reflective of individuals who spoke about accepting the, sometimes frustrating, work of self-management. Participants conveying this lens spoke about not feeling the need to forget about or ignore diabetes. Within quantitative and qualitative studies on emerging adults with Type 1 diabetes, this has been defined as diabetes integration, which is characterized as individuals who try to tackle diabetes related challenge and accept diabetes as an integral part of their lives (Hernandez, 1996; Luyckx et al., 2015; Oris et al., 2016). Abdullah provides an example of this, as he spoke about diabetes becoming a part of his backbone. In terms of glycemic control, Luyckx and colleagues found that emerging adults who actively integrate diabetes within their lives demonstrate better glycemic control (Luyckx et al., 2010).

9.4 Implications of the Lenses for Understanding the Nature of Parental Relationships for Emerging Adults with Type 1 Diabetes

Parents played a key role within the narratives of participants. The nature of this role varied according to the lens that was depicted.
From an ingrained perspective, the theme of mutual respect characterized parental relationships. Participants who conveyed an ingrained lens demonstrated a willingness to speak openly about their diabetes with their parents. Heather provided an example of this as she spoke about her mother still checking her blood sugar levels at 5am in the morning. In contrast to this, Hazel had to tip toe during the night to avoid having her parents wake up when she was going to the fridge to treat a low. Previous research identified parental knowledge as being indicative of a relationship characterized by trust (Helgeson et al., 2017). In relationships with open lines of communication about diabetes, emerging adults tend to demonstrate better psychological well being (Helgeson et al., 2014b; Keijsers & Poulin, 2013).

This study further illustrates that parental relationships during adolescence may have an enduring impact into emerging adulthood (Helgeson et al., 2014a). The theme of playing catch-up and difficulties launching into independent living provide examples of the negative impact of adolescent relations with parents. While there were cases when early parental relationships seemed to have a protective effect during emerging adulthood, such as when Kevin remembered his mother always telling him that he could still be like everyone else (he had fond memories of her taking him to fast food restaurants).

When parenting is controlling during adolescence, the greater independence that accompanies emerging adulthood can be overwhelming. In Edith’s narrative, she lost a sense of dietary control as she moved away from home for university. It may be that this incident reflects the end result of finally breaking free from controlling parenting (Goethals et al., 2017). There is also evidence to suggest that higher quality parental relationships during adolescence is a predictor of lower rates of drinking alcohol and lower binge drinking during the early stages of emerging adulthood for individuals with Type 1 diabetes (Helgeson et al., 2014a).

Similar to this study, Lucykx et al. found a significant diversification of glycemic control into three sub-classes during emerging adulthood (Luyckx & Seiffge-Krenke, 2009). In their study, the optimal control class was characterized by having the most optimal family climate during adolescence. Furthermore, women were most representative of the deteriorating control class, possibly reflecting greater tension related to Type 1 diabetes in the families of women. As Leah said in her interview, diabetes became a “sore spot” between her and her parents.
By not meeting glycemic targets, women in this study felt vulnerable to being looked down upon as though they were doing a bad job of managing Type 1 diabetes. Although parents may be attempting to provide support, perceptions of judgement seemed to be especially disruptive to lines of diabetes related communication between parents and their emerging adult daughters. As Karen explained, she had to walk out of the room when she told her parents about her HbA$_{1c}$. Eventually, she decided to build a psychological wall that blocked her parents from accessing information about management. For Hazel, she also became weary of how her parents reacted to information about glycemic control. In some instances, she turned to lying as a way in which she could avoid the uncomfortable feelings of judgment that came with disclosing a high HbA$_{1c}$. This sensitivity towards judgement is similar to findings in other studies, in which having a high HbA$_{1c}$ was noted as being a deterrent for seeking support amongst emerging adult women with Type 1 diabetes (Luyckx et al., 2010; Rasmussen, O'Connell, Dunning, & Cox., 2007; Scholes et al., 2013).

This study suggests that parental trust is harder to establish for emerging adults with higher HbA$_{1c}$ levels, which helps to make sense of a separate study I performed on parental involvement within an emerging adult diabetes clinic (Markowitz et al., 2017a). In that study, I found that HbA$_{1c}$ was significantly higher for emerging adults with Type 1 diabetes who attended clinic visits with a parent more frequently (Markowitz et al., 2017a). If parents are worried about an emerging adult’s high HbA$_{1c}$, they may experience more difficulties relinquishing control. As Karen explained, her parents would try to solve her problems for her rather than with her. Parents who are overly involved (trying to solve management problems for their child, rather than with them) may predispose their child to difficulties adjusting to independence during emerging adulthood. Lindsay highlighted this risk in her account related to the theme of *playing catch-up*, as she explained that a ‘refresher program’ would have been helpful for developing a stronger foundation of management skills and knowledge prior to taking on greater responsibility (see Chapter 4). Moreover, in relation to this theme of playing catch-up, it would have been helpful to have collected information on the socioeconomic status of parents. Socioeconomic status has been associated with patient glycemic control for transitioning patients (Petitti et al., 2009) and this demographic factor could have helped to explain why some participants may have experienced negativities surrounding their glycemic control (e.g. Angelica’s account about inheriting poor glycemic control from her parents in
section 8.4: Glycemic Control). Difficulties dealing with financial stressors may challenge parent or caregiver capacity to dedicate time and effort towards learning about glycemic control, and as seen in this study, it could be the case that emerging adults then experience difficulties trying to learn “second hand” from their parents (e.g. see Lindsay’s story in Chapter 4).

9.5 Strengths and Limitations

This study has provided a nuanced depiction of the relational aspects that accompany life with Type 1 diabetes during emerging adulthood. Unlike quantitative measures (such as coping questionnaires), a narrative methodology allowed me to examine the abstract moral context that surrounds diabetes management during the emerging adult years. The ingrained, intrusive and inconspicuous lenses are thinking tools that I developed to help understand how an emerging adult experiences diabetes. This lens conceptualization brings forth an opportunity for providers to improve their own interactions with patients who are going through similar circumstances. By appreciating the characteristic themes that were linked to each lens, adult care providers can better understand what the self-management practices of emerging adults with Type 1 diabetes are like outside of the clinic and orient clinical care interactions accordingly. These findings illustrate the notion that a narrative offers more than simply a cataloging of facts, but a narrative way of knowing provides memorable portrayals of the characters in stories. The moral messages and lessons of these stories have the potential to make a lasting impact (Frank, 1998).

A narrative methodology has brought forth a new way of thinking about Type 1 diabetes experiences during emerging adulthood, but as with any study, mine has a number of limitations. Although each interview provided me with an opportunity to develop rich interpretations of the lived experiences of participants, using only one-time interviews from a cross-sectional dataset does present a limitation. If I had been able to conduct a more longitudinal design – for example with follow-up interviews, this would have helped me to understand the ‘stability’ of these narrative styles through time and the extent to which individuals may move through different lenses to interpret their experiences over time (Whiffin et al., 2014). Seeing if similar themes and patterns were noticeable in subsequent interviews could have helped assess the fluidity of these narrative typologies and allow me to further test out my initial interpretations (Calman et al., 2013).
In addition, the single method of data collection used in this study (in-person interviews), could be perceived as a limitation. This study was informed by a “small story” approach to narrative research, and this lends itself to analyzing stories in everyday encounters (Bamberg & Georgakopoulou, 2008; Georgakopoulou, 2015). My interest was not in developing autobiographies for each participant; rather I took on a social constructivist perspective during this study, in which I was focused on the here and now of stories. I wanted to understand why participants were telling their stories in a certain way at a given moment in time. How they told their stories was interpreted as being important to understanding their everyday experiences. While I chose to interview the participants on their own, using this social constructivist stance, I could have collected data in the clinical care setting (Elwyn & Gwyn, 1999). For instance, I could have collected stories told within specific clinical encounters between emerging adult patients and their diabetes care providers (a dyadic approach) (Schoenthaler et al., 2018). This would have been especially useful, given that for about three months, I observed clinic visits within an emerging adult diabetes clinic. I could have analyzed what types of stories were told during clinical interactions and compared them to those told within interviews (Elwyn & Gwyn, 1999). Moreover, I could have supplemented such interactional data collection with observations (Schoenthaler et al., 2018). In addition, the small story approach to narrative research would have been a fitting methodology to study stories shared on popular social media outlets (such as Facebook, Snapchat, Instagram or Twitter) (Georgakopoulou, 2015). Many participants in this study spoke about these applications as though they were commonplace in their daily lives, and it would have been interesting to see how diabetes was a part of their social media profiles. This would have allowed me to probe more deeply into where diabetes fits into the daily lives of emerging adults.

The theme of “one” continues in this limitation section, as only one stakeholder in the health care transition was studied. The transition to adult care involves multiple stakeholders. Parents and providers are considered other key stakeholders within this process (Agarwal et al., 2017; Allen et al., 2011; Garvey et al., 2014). By interviewing only emerging adults with Type 1 diabetes, I limited the completeness of the picture that I was painting. Through incorporating other key perspectives of parents and providers, I could have developed a more nuanced analysis of diabetes transitions from multiple perspectives.
Furthermore, applying a qualitative research tool known as “member checking” could have assessed the accuracy of my analysis (Birt et al., 2016). Given my post-modern theoretical stance during the study, it would have been appropriate to see what participants thought of my interpretations. Upon reflection, there were occasions in the study when I could have pursued member checking, as one of the participants emailed me at one point to see how the ongoing study was progressing. Looking back, this could have been an opportunity for me to ask if they would be interested in providing feedback.

Lastly, with this depiction, it is unclear how emerging adults may fluctuate between an ingrained, intrusive or inconspicuous lens. By studying emerging adults using a cross-sectional design, I was unable to determine if the notion of fluidity exists for this lens concept (Paterson, 2003). This seems to be especially relevant given that the participants who demonstrated an intrusive lens showed signs that they were in a process of change (see Angelica’s narratives related to playing catch-up for an example). Over time, an individual conveying an intrusive lens might develop an ingrained mindset for their diabetes after more years of experimentation. As seen in ingrained narratives, learning how to integrate diabetes within one’s daily life was described as a long-term endeavor that involved much trial and error. An ingrained lens could be the end state that emerging adults may strive to reach. Similar to this study, participants in Paterson’s research described feeling that once they achieved a sense of expertise; they never went back to a role of compliant patient (Paterson & Thorne, 2000a).

9.6 Future Directions

If time were to permit, there are a number of directions for future research that warrant discussion.

These findings were specific to a Type 1 diabetes population, but future research could examine their transferability to other transitioning populations of emerging adults with Type 2 diabetes or other chronic illnesses (e.g. cystic fibrosis or congenital heart disease) (Crowley et al., 2011). In this study, HbA1c played a prominent role within transition experiences; it would be interesting to see if biochemical markers in the context of other chronic illnesses have moral implications during transitions in care. For instance, routine surveillance tests of bone mineral
density or pulmonary function could play a similar role in transition narratives about cystic fibrosis, as patients feel their management practices (e.g. exercise or diet) are under the constant scrutiny of parents and providers (The National Institute for Health and Care Excellence, 2017).

Determining how early interactions related to glycemic control (or similar biochemical markers for other chronic illnesses) impact coping during emerging adulthood should be explored further. In the narratives of participants within this study, having a poor HbA₁c during pediatric care foreshadowed difficulties in emerging adulthood. It would have been interesting to track the HbA₁c history of participants from their pediatric care charts, which would have helped examine the concept of HbA₁c becoming a self-fulfilling prophecy. I am also curious to compare the nature of pediatric care interactions between patients who have what may be considered a “good” HbA₁c versus those who have what could be considered a “bad” HbA₁c. Based on interview responses, it appears that HbA₁c may bring forth stronger feelings of judgement in the pediatric care setting (refer to Cindy and Leah’s quotes in section 8.7: Relationships with Health Care Providers).

Additional research opportunities lie in exploring how public discourse and media can influence an emerging adult’s experience with Type 1 diabetes (Bamberg & Andrews, 2004). As Karen pointed out, she was well aware of the experiences of Chris Jarvis (a famous Canadian rower with Type 1 diabetes). The degree to which public figures (such as Chris Jarvis or Max Domi) inform patient experiences of Type 1 diabetes would be an especially relevant issue for an emerging adult patient population who are frequent users of social media in their daily lives (Gruzd et al., 2017). Participant responses in this study suggested that emerging adults are well versed in articles posted in diabetes communities (for instance, Heather noticed articles about ‘taking a day off of diabetes’, while Trevor similarly recognized a movement, “There is no such thing as a good blood sugar”). Given that much content posted on social media and the internet is not critically reviewed (Jones et al., 2013), understanding what online support resources emerging adults with Type 1 diabetes use, and how they use it would be an important direction for further research.

Public perceptions of Type 2 diabetes had an influence on participants’ experience with Type 1 diabetes in this study. Much media attention is given to Type 2 diabetes in comparison to Type 1 diabetes (Dickinson et al., 2017), and future research should explore how stigma may
influence self-management practices of emerging adults with Type 1 diabetes. In this study, participants conveying an inconspicuous lens referred to stigma as being a reason as to why they tried to keep diabetes discrete. This appeared to negatively impact the university experience for Ken and Mike, as both of them experienced difficulties administering insulin in the highly social cafeteria setting. Future research could elaborate on this knowledge along with existing literature (Balfe, 2009; Balfe et al., 2014) and start to uncover differences in Type 1 diabetes related challenges during emerging adulthood for individuals who are working compared to those in university.

This study reinforces the notion that there appears to be harmful public discourse surrounding diabetes (Browne et al., 2014). I can attest to this with a short anecdote. In June 2017, I took a plane ride down to San Diego for a conference hosted by the American Diabetes Association to present a related project during my Master’s studies (Markowitz et al., 2017b). Sitting next to me on this flight was a man and his friend who were flying down for a trip unrelated to the conference. The two men were curious to know why there were so many poster tubes aboard the plane, and I explained that there was a diabetes research conference that many passengers were attending. At one point in the flight, as the drink cart stopped by our seats, I distinctly remember one of my seatmates asking for coffee and an extra package of sugar. He looked at me jokingly after asking for the extra sugar and said something along the line of, ‘Jeez, I hope I don’t get diabetes before the end of this flight’. Hearing a comment like this, made me think about Ken’s interview response, “I actually do remember like when like I would first tell people like they would be wondering like, ‘Oh… were you eating too much sugar?’” Future research could examine how diabetes is portrayed in media, and educational interventions could be aimed at changing the language people use to talk about diabetes (Dickinson et al., 2017).

Women within this study appeared to be especially more sensitive towards how others judged them. As Haya and Karen explain, there was a risk that they could be labelled as ‘diabetic girls’. This appeared to be especially harmful in the context of romance. As Mary explained, she was worried about what potential romantic partners would think about her diabetes. Future qualitative inquiry can explore how emerging adults with Type 1 diabetes experience romance (Helgeson et al., 2015).
Finally, it is important to note that this study was focused on what is known as the early phase of emerging adulthood. It may be the case that new social pressures and challenges can bring forth a different experience with Type 1 diabetes during the later phase (~25 to 30 years) (Balfe et al., 2013; Vallis et al., 2018), and the lenses described herein may not apply to this later phase, or new types of lenses may emerge (Paterson, 2003). There is also the potential that physical changes, such as brain development, may have implications towards decision-making for management in everyday life, which could in turn influence the experience with Type 1 diabetes (Arnett, 2016; Dovey-Pearce & Christie, 2013). With greater cognitive capacity (e.g. improvements in self-regulation or impulse control) (Stupiansky et al., 2013) and more practical experience (Paterson & Thorne, 2000a), the development of a sense of expertise for management may be more likely to occur. Further research could explore if there are differing narrative styles that older emerging adults (25 to 30 years of age) use to tell their stories about life with Type 1 diabetes. With time, it may be more likely that parents develop a greater sense of trust in their emerging adult child’s self-management capacity, and issues such as adverse moral reactions to HbA1c begin to lessen in intensity. Alternatively, it may be that the three “lenses” that I have described are not limited to the emerging adult years in the life of a person with Type 1 diabetes and that these perspectives remain valid throughout a person’s life.

### 9.7 Concluding Remarks

In this study, the notion of passivity or passive-resignation (Luyckx et al., 2010) did not seem to be applicable to participant narratives. Regardless of lens, participants described working hard to live a normal life, but their perceived capacity to do so appeared to differ. Participants demonstrating an ingrained lens gave accounts in which they were exemplary figures that learned how to live a normal life with Type 1 diabetes. On the other hand, participants conveying an intrusive lens felt as though they were struggling to live a normal life, as it appeared to be a great burden (both physically and psychologically) to manage diabetes on their own. For participants conveying an inconspicuous lens, they described feeling content managing diabetes their own way rather than the ‘right’ way because it helped them protect their sense of normalcy. It seemed like diabetes was not especially burdensome from this inconspicuous
perspective, as participants explained that managing diabetes their own way allowed them to minimize attention towards it.

This research has implications for clinical practice during healthcare transitions (specifically the relationship between patient and provider). I envision these findings to help health care providers promote partnerships with their transitioning patients. Far too often participants spoke about judgment as deterring them away from support. There needs to be a greater openness in dialogue between emerging adults, parents and providers during transitions in care. Communication “walls” should be broken and HbA$_1c$ should not dictate the role a patient will play during their transition. Armed with an understanding of these lenses, diabetes care providers can look beyond HbA$_1c$ and move towards a more holistic approach to transitions in care.
References


American Diabetes Association (2014). Diagnosis and Classification of Diabetes Mellitus. *Diabetes Care, 37*(Supplement 1), S81-S90.


Popay, J., Rogers, A., & Williams, G. (1998). Rationale and standards for the systematic review of qualitative literature in health services research. *Qual Health Res, 8*(3), 341-351.


Appendix A: Consent Form

LETTER OF INFORMATION AND CONSENT TO PARTICIPATE IN A RESEARCH STUDY

“Understanding the relationship between diabetes ‘responsibility’ and family interactions during emerging adulthood”

Introduction:
Before agreeing to take part in this research study, it is important that you read and understand the information in this research consent form. This form includes details we think you need to know in order to decide if you wish to take part in the study. If you have any questions, ask the researcher. You should not sign this form until you are sure you understand the information. Your participation in this research is voluntary.

Principal Investigator:
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Co-Investigators:
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Dr. Geetha Mukerji, MSc, MD, FACP, FRCPC
Clinician in Quality and Innovation, Women’s College Hospital
Tel: (416) 323-6013; geethamukerji@wchospital.ca, (Mon.-Fri. 9am-5pm)
Purpose of the Research:
You are invited to consider participating in a research study that will examine the nature of the relationship between diabetes responsibility and family interactions during emerging adulthood. The term emerging adulthood is used to describe the period in life roughly between the ages of 18 and 29 years. There is a lot that needs to be known about how people look after their diabetes during emerging adulthood. For example, how does the relationship with family change after adolescence, or who affects an emerging adult’s ability to manage their disease.

You are being asked to consider taking part in this study because you are either 18 to 24 years old with diabetes, or a family member or health care provider of someone who is 18 to 24 years old with diabetes. Specifically, we are interested in your lived experience with diabetes or being someone involved in the care of people living with diabetes.

Description of the Research:
This study is being supported by funds from the RDV Foundation, St. Michael’s Hospital Foundation and the Ontario Ministry of Health and Long-term Care.

As a participant of this study, you will be asked to participate in a face-to-face, one-time, in-person interview. The interview will be approximately 60 minutes in length and will take place in a private room at either St. Michael’s Hospital or Women’s College Hospital. During your interview, you will first be asked to reflect on your experiences of either living with diabetes or in caring for a young person with diabetes. You will then be asked about how ‘others’ influence diabetes during the stage of life known as emerging adulthood. We hope you feel comfortable to speak freely because your stories about diabetes during this phase of life are so valuable for this study.

The interview will be audio recorded, and the researcher will make notes during the interview. We are audio recording so we do not lose any details of our conversation. Notes will be made to document information unable to be obtained from audio recording, such as non-verbal communication, emotional aspects, and interview dynamics. At the end of the interview, you will be asked to complete a demographic questionnaire. As such, this study entails the collection of personal health information, which includes your experiences of living with diabetes or being involved in the care of persons with diabetes, as well as the demographic information collected. We will use this information to help us analyze the interview. Along with this, if you are a patient with diabetes, we will collect your most recent HbA\textsubscript{1c} result from your clinical chart and use it as a descriptive variable to help with the analysis.
Potential Harms:
A possible risk for participating in this study is the potential trigger of emotional responses. If at any time during the interview should you feel the need to seek support for the triggered emotional response, please let the researcher know, and the researcher will refer you to appropriate services at St. Michael’s Hospital or Women’s College Hospital.

Potential Benefits:
You are not expected to benefit directly from this study. However, based on our previous experiences of interviewing, some participants expressed that in-depth explanation of their experiences, perspectives, and knowledge was a positive experience.

Confidentiality and Privacy:
You will be asked not to reveal any identifiable information, details, or comments during the interview. However, if identifiable information, details, or comments do appear in the interview, they will be removed from the transcript (typed document of the interview). A participant identification number will be used to label the audio recorded file, transcript, and notes – this is called de-identifying data. A log book will be used to link your identifiable information (name, phone number, and email) to your study data via this participant number. This log will be securely stored separately from study data at St. Michael’s Hospital.

All electronic files (audio recordings and transcripts) will be securely stored at St. Michael’s Hospital. Audio recordings will be destroyed upon completion of analysis. Similarly, transcripts, notes, and the log book will be destroyed within 5 years of the study completion. When you sign this consent form, you authorize researchers of this study and members of the St. Michael’s Hospital and Women’s College Hospital Research Ethics Boards to access the collected data.
Your authorized access will only be used for the purpose of verifying the authenticity and accuracy of the collected data, without violating your confidentiality to the extent permitted by applicable laws and regulations. No one other than those mentioned above will have access to your information or identifying information without your permission, unless required by law. You will be given a signed copy of this consent form to keep for your records.

Collected information may be used in academic publications, dissertation, or presentations. In such cases, a participant identification number will be used to protect your identity.

Please be aware and understand that despite these great measures for confidentiality and privacy, there continues to be the risk of unintentional release of information. The researchers of this study will do everything in their power to protect your records and to keep all of your information confidential. The chance for collected data to be unintentionally released is low.
For patients, Federal and Provincial Data Protection regulations, including the Personal Information Protection and Electronic Documents Act (PIPEDA 2000) and the Personal Health Information Protection Act (PHIPA 2004) of Ontario, protect your personal information. They also give you the right to control the use of your personal information (including personal health information) and require your written permission for this personal information to be collected, used, or disclosed for the purposes of this study, as described in this consent form. You have the right to review and copy your personal information collected in this study. However, if you decide to be in this study or choose to withdraw from it, your right to look at or copy your personal information related to this study will be delayed until after the research is completed.

In no way does signing this consent form surrender your legal rights nor waive the researchers of this study or involved institutions from their legal and professional responsibilities.

**Reimbursement/Compensation:**
Upon completion of this interview, you will be granted a $10 gift card in appreciation for your participation.

**Participation and Withdrawal:**
Your participation in this research is entirely voluntary. If you do decide to participate, you can at any time during the study change your mind and withdraw from the study. You may also decline to answer any questions during the interview. If you make the decision to withdraw from the study before the data have been analyzed, your collected information will be permanently destroyed upon your withdrawal. Your relationship at St. Michael’s Hospital or Women’s College Hospital for you and for other members of your family will not be influenced in any way should you decide to participate, not participate, or should you decide to withdraw from the study.

For healthcare providers, participating in this study will have no impact on your professional standing with your colleagues, or at your organization now or in the future.

**Research Ethics Board Contact:**
If you have questions regarding your rights as a research participant, you may contact Dr. David Mazer, Chair, Research Ethics Board at 416-864-6060 ext. 2557 during business hours.

**Study Contacts:**
If you require further information or have questions concerning the research study, please contact:
Principal Investigator:
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Co-Investigator:
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For the results of the study, please contact the Principal Investigator who will share with you a copy of any papers reporting the results, once published.
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

“Understanding the relationship between diabetes ‘responsibility’ and family interactions during emerging adulthood”

Principal Investigator:
Dr. Andrew Advani, BSc MBChB (Hons), PhD, FRCP (UK)
Clinician Scientist, Keenan Research Centre for Biomedical Science
Li Ka Shing Knowledge Institute of St. Michael’s Hospital
Tel. (416) 864-6060 ext. 8413; advania@smh.ca, (Mon.-Fri. 9am-5pm)

Declaration of Consent:
The research study has been explained to me, and my questions have been answered to my satisfaction. I have the right not to participate and the right to withdraw without affecting the relationship and the quality of medical care at St. Michael’s or Women’s College Hospital for me and for other members of my family. As well, the potential harms and benefits of participating in this research study have been explained to me. I understand that the researcher may use direct (word for word) or paraphrased (summary) quotes from my interview in the study results, academic publications, dissertation, and presentations. I understand that the interview will be audio recorded and transcribed.

I have been told that I have not waived my legal rights nor released the investigators or involved institutions from their legal and professional responsibilities. I know that I may ask now, or in the future, any questions I have about the study. I have been told that records relating to me and my care will be kept confidential and that no information will be disclosed without my permission unless required by law. I have been given sufficient time to read the above information.

I consent to participate. I have been told I will be given a signed copy of this consent form.

________________________________________________________________________
Name of Participant       Signature of Participant       Date

________________________________________________________________________
Name of Person Obtaining Consent          Signature of Person Obtaining Consent       Date

Appendix I          Consent Form, Version 1 (03-Sep-2016)       Page 6 of 6
Appendix B: Initial Interview Guide

Understanding the relationship between diabetes ‘responsibility’ and family interactions during emerging adulthood

Interview guide for patients

Introduction after recording starts

Thank you for taking the time to participate in this interview. Before we begin, I want to clarify a few things:

1. You may stop this interview at any point. Even after the interview, you can withdraw from this study without giving a reason.
2. If you decide to withdraw from the study after the interview is complete, I will permanently destroy all of your information upon your withdrawal.
3. After the study is complete, I may present the findings through academic outlets (such as publications and a dissertation) and may use a quote from your interview. But any identifying information about you will not be revealed.
4. This interview will take approximately 60 minutes. I will be audio recording the interview so I do not lose any details of our conversation.
5. I may look away from you at some points during the interview because I will be making notes to help with the analysis. But, please do not feel like I am not listening to you. I hope you speak freely because your perspective and experience is so valuable for this study.

That is all I would like to say before we start. Do you have any questions before we start? If not, let’s begin.

Part 1: The individual’s experience living with diabetes.

1. What has your experience been like living with diabetes?

2. How would you describe what it’s like managing your diabetes?
   Probes:
   - Do you feel supported?
   - Does anything (e.g. people, technology, occupation) make it more difficult to manage? Why?
   - Does anything (e.g. people, technology, occupation) make it easier to manage? Why?

3. If you could talk to another person who was just diagnosed at the same age that you were, what would you tell them?
   Probe:
   - Is there anything they should expect?

Part 2: Interactions with family.

Appendix A: Interview guide for patients
Version 1 (20-July-2016)
4. How would you describe the relationship with your family?
Potential probes:
  • How are they involved with your diabetes?
  • Have you ever noticed that this relationship has changed? If so, describe why it felt different.

Part 3: Influence of health care providers.

5. Describe the role that health care providers play in your diabetes.
Potential probes:
  • How would you describe what they do?
  • Is there any advice you would give to them?
Appendix C: Demographic Questionnaire

Study Title: Understanding the relationship between diabetes ‘responsibility’ and family interactions during emerging adulthood

DEMOGRAPHIC INFORMATION SHEET

We are collecting the following information about you and your health to help us better understand your experience with Diabetes. Remember that you may choose to skip any question you are not comfortable answering.

1. Age in years: __________
2. Gender: [ ] Male [ ] Female
3. Type of Diabetes:
   a. [ ] Type 1
   b. [ ] Type 2
   c. [ ] Other – please specify: __________
4. How old were you when you found out that you had diabetes? Age: __________
5. Do you have a family doctor? [ ] Yes [ ] No
6. If yes, how often did you see your family doctor for diabetes care in the last year?
   a. [ ] None
   b. [ ] 1 time
   c. [ ] 2 times
   d. [ ] 3 times
   e. [ ] 4 times
   f. [ ] >4 times
7. How often did you see your diabetes care team (endocrinologist/nurse/dietitian) in the last year?
   a. [ ] None
   b. [ ] 1 time
   c. [ ] 2 times
   d. [ ] 3 times
   e. [ ] 4 times
   f. [ ] >4 times
8. Type of Insulin Therapy:
   a. [ ] Pump
   b. [ ] Multiple daily injections
   c. [ ] Other – please specify: __________
9. Financially, how do you obtain your insulin?
   a. ☐ Personal insurance or expenses
   b. ☐ Family insurance or expenses
   c. ☐ Other – please specify: ______________________

10. Do you identify with any of the following groups:
    a. ☐ young adult (18-30 years)
    b. ☐ transplant
    c. ☐ unable to afford medications
    d. ☐ pregnant patient
    e. ☐ LGBT

11. Diabetes Complications – are you currently living with?
    a. ☐ None
    b. ☐ Nephropathy (Kidney problems or protein leak in the urine)
    c. ☐ Neuropathy (Pain/numbness in feet)
    d. ☐ Retinopathy (Eye problems due to diabetes)
    e. ☐ Other: ___________________________

12. How many times have you been hospitalized for diabetes in the last year (aside from the first time you were diagnosed)?
    a. ☐ None
    b. ☐ 1 time
    c. ☐ 2 times
    d. ☐ >3 times

13. How many times have you had severe low blood sugar reactions (requiring assistance from others) in the last year?
    a. ☐ None
    b. ☐ ≤ 1 time
    c. ☐ 2-4 times/year
    d. ☐ 4-7 times/year
    e. ☐ 10 times/year
    f. ☐ > 10 times/year

14. How many times have you had a diabetes emergency in the last year? This includes emergency room visits and 911 calls (aside from the first time you were diagnosed).
    a. ☐ None
    b. ☐ 1 time
    c. ☐ 2 times
    d. ☐ >3 times

Appendix D: Demographic information from patients
Version Date: 20-July-2016
Page 2 of 4
15. How would you best describe your ethnic background? (You can check more than 1 option if you are mixed)
   a. ☐ White, Caucasian
   b. ☐ Latin American
   c. ☐ First Nations, Aboriginal
   d. ☐ West Indian
   e. ☐ South Asian (Eg. East Indian, Sri Lankan, Bangladesh, Pakistani etc.)
   f. ☐ Southeast Asian (Eg. Vietnamese, Thai, Cambodian etc.)
   g. ☐ Asian (Eg. Chinese, Japanese, Korean etc.)
   h. ☐ Middle Eastern
   i. ☐ Filipino
   j. ☐ Black
   k. ☐ Pacific Islander
   l. ☐ Other – please specify __________________________

16. Were you born in Canada?
   a. ☐ No
   b. ☐ Yes (Skip next question)

17. How long have you lived in Canada? (Choose the BEST option)
   a. ☐ Less than 5 years
   b. ☐ 5-10 years
   c. ☐ 11-20 years
   d. ☐ Over 20 years

18. What is your living situation? Check all that apply.
   a. ☐ Living with parent(s)
   b. ☐ Living on my own
   c. ☐ Living with spouse/partner
   d. ☐ Living with friend(s)/roommate(s)
   e. ☐ Other: __________________________

19. What is your HIGHEST level of education completed?
   a. ☐ Elementary school (kindergarten to Grade 8)
   b. ☐ High school (Grades 9 to 12)
   c. ☐ University or college
   d. ☐ Postgraduate study

20. Are you currently in school?
   a. ☐ No
   b. ☐ Full-time student
   c. ☐ Part-time student

Appendix D: Demographic information from patients
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d. Other: ________________

21. Do you work?
   a. ☐ No
   b. ☐ Full-time
   c. ☐ Part-time
   d. Other: ________________

Thank you for participating in our study!
Appendix D: Revised Interview Guide

Guiding Questions and Probes (revised Guide)

1) Tell me about your experience of being diagnosed.
   a. (if applicable) How did your lifestyle change after being diagnosed? What made it feel different or similar? (e.g. diet)
   b. Did anything scare you or worry you about the diagnosis?
   c. What was it like going back to school/work?
   d. How did your family members react to your diagnosis?
   e. How do you think your diabetes affected your family dynamic or relationships with any family members?
   f. How did it feel living at home after the diagnosis?
   g. How did the diagnosis impact your family financially?

2) How did you learn how to manage your diabetes?
   a. How have your parents been involved in your management? Siblings? Grandparents?
   b. When did you feel like you first understood what diabetes was? When did you feel like you first understood how to manage diabetes?
   c. Was there a time when you first felt independent with your management?
   d. How would you describe what it’s like to manage diabetes?

3) Has having diabetes changed the way that others view you? (family, friends, teachers, co-workers, new people you meet)
   a. If so, in what ways?

4) Have you ever felt limited by your diabetes? Have you ever felt that diabetes has interfered with any parts of your life?

5) Have you ever felt motivated by your diabetes? (e.g. physical activity, diet)

6) (if applicable) Tell me about your grade school experience.
   a. Do you think that diabetes impacted this experience?
b. Who supported you with your management during this time? Did anyone help you with your management during lunch time?
c. Were you comfortable telling other people about your diabetes?
d. Did you have any friends with diabetes?
e. What were some of the activities you were involved with during this time?

7) (if applicable) Tell me about your high school experience.
   a. Do you think that diabetes impacted this experience?
   b. Did you work during this time? What types of activities were you involved with?
   c. Did you feel like diabetes interfered with any parts of your life during this time period?
   d. What was your relationship like with your parents during this time? Siblings? Grandparents?
   e. What was your social life like?
   f. Were you in a romantic relationship?
   g. Did you have any friends with diabetes?
   h. Did anything challenge your diabetes management during this time?

8) Tell me about your experience attending diabetes clinic(s).
   a. (if applicable) How is pediatric care different than adult care? What changed? What was the transition like?
   b. How have your parents been involved in your clinical care?
   c. When did you start going to clinic visits alone? Tell me about that experience. What made you decide to start going alone?
   d. How did you decide to go to the young adult clinic?
   e. What do you currently want from your health care team?
   f. How would you describe the role of health care providers in your diabetes management?
g. How frequently do you have to go for blood work?

9) Have you ever travelled without your parents?
   a. When was that? Tell me about that experience.
   b. Was this challenging for your management? If so, what made it challenging?

10) Have you ever attended a camp during the summer time? If so, tell me about that experience.

11) What did you decide to do after high school?
   a. How did your diabetes influence this decision?
   b. Did any of your family members influence this decision?

12) What is a typical day like for you nowadays? Tell me about what you do.
   a. What is it like managing while working? While being a student?
   b. Do you view your current insulin method as fitting your lifestyle needs?
   c. Does anything challenge your management?
   d. Does diabetes interfere with any aspects of your life nowadays?
   e. Do you view yourself as being in control of your management? If so, what does being in control mean to you?
   f. Do you ever worry about anything related to your diabetes throughout the day?
   g. Do you or have you used any diabetes technology? (e.g. apps, cgm)

13) How would you describe your diet nowadays?
   a. Do you feel that your diabetes restricts your diet at all? (i.e. do you feel you have eating restrictions when you compare yourself to your friends?)
   b. Do you cook your own meals? Do you do your own grocery shopping?

14) Tell me about your home life/family life now.
   a. What is your relationship like with your parents? Siblings? Grandparents?
   b. How do you think your family members are affected by your diabetes?
   c. (If applicable) when do you see yourself moving away from your parents' home?
15) Are you in a romantic relationship now?
   a. If so, how is your partner involved in your diabetes management?

16) Tell me about your social life nowadays.
   a. What do you like to do with your friends?
   b. Do you have any friends with diabetes?
   c. Are you comfortable telling other people about your diabetes? (e.g. friends, co-workers) If so, when would you feel the need to tell them?
   d. Does anything bother you about what other people say about diabetes?

17) Have you ever tried alcohol or recreational drugs?
   a. If so, how do you manage your diabetes while using?
   b. What do you enjoy about using?

18) Have you ever been involved in a religion?
   a. If so, did being involved with the religion help with your diabetes management?
      How?

19) How does diabetes affect you financially?
   a. When did you start paying for your supplies on your own?
   b. Or, when will you have to pay for your supplies on your own? Does this worry you?

20) How is your life now different or the same from someone else’s your age?
   a. How is it similar? How is it different?

21) How do you describe yourself? (i.e. how do you talk about yourself?)
   a. Do you view yourself as a person living with diabetes?
   b. Do you view yourself as an adult? Young adult? Student? Worker?

22) Do you ever think about the future?
   a. What types of things do you think of related to the future? (e.g. marriage, parenthood, career, diabetes complications)
b. How does diabetes influence your future plans?

Is there anything else you want to add?