

Primary care providers' observations on diabetes management  
for young adults in Ontario: Barriers and enablers to care and  
patient-provider communication

by

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## **Author's Declaration**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

## Abstract

**Background:** Type 2 diabetes mellitus (T2DM) is a global epidemic that is only projected to impact more people in the coming years. In Canada there has been a steady increase of people living with T2DM, including an increase in young adults living with the disease. To manage T2DM and minimize the complications of T2DM, primary healthcare providers often encourage their patients to partake in self-management care. This is an effective strategy to managing T2DM; however there are several barriers people face when trying to self-manage. For young adults living with T2DM there is very limited research on what prevents them from managing their diabetes. The research that has been conducted on young adults (aged 20 – 39) with T2DM suggests this patient population faces different barriers to care than other age groups because of their different circumstances and access to resources. Moreover, there is also very limited research on how patient-provider communication takes place in primary care settings with young adults living with T2DM, which is also problematic because patient-provider communication is a key component of self-management care. Thus, there is a need for research examining what prevents this patient population from engaging in care and communication with their primary care providers.

**Research aim and objectives:** The aim of the present study was to explore the barriers and facilitators to self-management care and communication between young adults with T2DM and their primary care providers. To achieve this aim there were two objectives for the study, which were: (1) to understand what providers perceive as barriers to self-management care and communication during the clinical encounter. (2) To understand what providers perceive as facilitators to self-management and communication during the clinical encounter.

**Methods:** This study used a convergent parallel mixed methods design that employed surveys to collect contextual and quantitative data, and semi-structured interviews to collect qualitative data. Data collection took place between November 2015 and February 2017 throughout southwestern Ontario.

Purposive and snowball sampling techniques were used to recruit participants into the study. Two study populations were included in this study, healthcare providers and young adults living with T2DM. The inclusion criteria for healthcare providers were: (1) they were primary care providers, and (2) had experience treating young adults with T2DM. The inclusion criteria for young adults were: (1) they were aged 20 – 39, (2) had T2DM, and (3) had been living with the disease for at least 6 months. The data collected were analyzed using Ritchie and Lewis' framework approach, which is made up of nine stages that create a structured and iterative process during analysis. The framework approach also integrates data from different sources, such as interviews and surveys.

**Results:** A total of 13 participants were included in the study, 11 were primary care providers and two were young adults with T2DM. Facilitators to self-management care identified for young adults with T2DM included: (1) fewer comorbidities in young adults and (2) use of technology to manage the disease. The major themes identified as barriers to self-management care for young adults with T2DM were: (1) young adults' denial of their diabetes diagnosis, (2) their sense of invincibility, and (3) their many responsibilities and their low prioritization of their health.

**Discussion:** The study confirmed well-known approaches to care such as patient-centred care and patient-provider collaboration enabled care for young adults with T2DM. The findings also revealed providers' roles during the clinical encounter were changing because of young adults use of technology to manage their diabetes. Additionally, young adults' denial of their diabetes diagnosis and their sense of invincibility are difficult barriers for providers to overcome making them highly problematic given the more aggressive nature of diabetes. The study also suggested young adults are stigmatized because of their diagnosis, which is a known challenge for patients living with diabetes and is well documented in the literature.

**Conclusions:** The findings from this study support the current literature on diabetes care while adding new knowledge about the challenges and opportunities primary care providers in Canada face with their young adult patients with T2DM. More research is needed to more fully understand how technology usage, denial, a sense of invincibility, and their many responsibilities impact young adults' self-management care and communication in Canada.

## Acknowledgements

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## **Dedication**

I would like to dedicate this thesis to Simon. You are my rock and thank you for always reminding me that even the smallest step forward is still one step closer to achieving my goal.

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## Introduction

Diabetes is a metabolic disease affecting approximately 285 million people worldwide [1]. In Canada, diabetes affects an estimated 2.4 million individuals [2], and the prevalence rate of diabetes is expected to climb from 11.6% in 2010 to 13.9% by 2030 [3]. Type 2 diabetes mellitus (T2DM) is the most common form of diabetes, with approximately 90% of people living with diabetes worldwide having been diagnosed with T2DM [1]. Additionally, the age of onset for T2DM is decreasing globally, with younger people being diagnosed with the disease more often than in years past [1]. The falling age of onset for the disease is of concern because T2DM is more aggressive in young adults, who have a harder time with glycemic control and have an increased risk of diabetes-related cardiovascular complications [4, 5].

To aid the growing numbers of people living T2DM in managing their disease researchers and healthcare providers have found self-management care to be an effective approach to managing diabetes [2]. Self-management care can help people develop self-care behaviours such as engaging in regular exercise or making necessary dietary changes, which is a key aspect of minimizing the effects of the disease [6]. The self-management approach to diabetes care focuses on empowering patients to manage their diabetes using interventions, such as learning problem-solving skills and patients participating in health-related decision-making [2]. While this is an effective approach to diabetes care there are some barriers that make it difficult for people with diabetes to manage the disease, such as time management issues, the cost of the disease, and access to diabetes-specific healthcare services [7]. Specifically, young adults with T2DM face additional barriers to self-management care such as a lack of diabetes education programs tailored to their needs [8].

In self-management care patient-provider communication is a fundamental component to improving the self-care behaviours and health outcomes of patients with diabetes [9-11]. To help foster

open patient-provider communication research has shown focusing on the patient-provider relationship, and developing trust between these stakeholders helps patients more openly share information about their circumstances, their ability to self-manage, and what they may or may not understand about their conditions [12-14]. It has been suggested when patients and providers cannot communicate openly patients do not manage their self-care behaviours very well [11]. Additionally, studies have shown identifying the needs of specific patient populations can lead to more open patient-provider communication where patients feel more comfortable discussing personal matters with their providers, which can positively impact patients' willingness to engage with their providers about their care [15, 16]. Thus focusing on the needs of young adults with T2DM (aged 20 -39) may lead to more open communication with their providers, which could positively impact self-care behaviours in this patient population.

There is a significant lack of research focusing on young adults with T2DM. The small amount of literature looking at this patient population indicates this group has not been studied to identify if they have any different needs that impact their ability to engage in self-management care creating a need for further research in this area [8, 17, 18]. There is also a lack of research looking at patient-provider communication with young adults with T2DM, and how that communication influences self-management care. Additionally, very little research exists that focused on young adults with T2DM diabetes in Canada. Research completed in Canada focused on the uptake of lifestyle modifications [17], but did not look at the barriers to self-management care for young adults, or how communication takes place in the clinical encounter. For this reason, there is a need for further research on young adults with T2DM and what prevents or enables self-management care for this population, as well as what prevents or enables them to engage in communication during the clinical encounter.

The study presented in this thesis aimed to address the gap in research on young adults with T2DM. The primary aim was to identify the barriers and facilitators to self-management care and communication between young adults with T2DM and their primary care providers. What enables or prevents young adults from receiving self-management care can have a significant impact on their self-care behaviours and overall health outcomes [7, 19, 20], making it an important area of study. Additionally, being able to communicate any problems or personal matters that are affecting their self-management care can have an impact on their ability to manage the disease [9-11]. Thus, identifying the barriers and facilitators to communication and self-management care can allow for improved diabetes management as providers work to strengthen the facilitators and break down the barriers. With the growing number of individuals diagnosed with diabetes in Canada [21], and the expected rise in young people with this disease [1] research on what allows and prevents young adults from self-managing is vital to providing diabetes care that is relevant and helpful for young adults with T2DM. Thus, a mixed methods study was conducted with primary care providers who treat young adults with T2DM in order to identify potential barriers and facilitators to self-management care and communication in the clinical encounter.

## Structure of this thesis

This thesis contains five chapters. The following brief descriptions outline the contents of each chapter. **Chapter 1** is a literature review that looks at self-management care for type 2 diabetes mellitus, known barriers and facilitators to patients receiving care for this disease, and the role of patient-provider communication in diabetes care. The review found there is little understanding of what prevents or enables young adults from engaging in self-management care in a primary health care setting. Additionally, there is little understanding of how young adults with T2DM communicate with their providers and how this may or may not impact their ability to manage the disease. **Chapter 2** presents the rationale for this study, while also outlining the aim and objectives of the study, and

discussing the anticipated impact of the research. **Chapter 3** focuses on the methodology and methods used in this study, which includes semi-structured interviews and surveys. There is an explanation on the utilization of these methods and how the data collection tools were developed, along with a detailed discussion on the recruitment and collection of data that took place during this study. The chapter also discusses how data analysis took place. **Chapter 4** focuses on the findings from the study, which primarily came from the interviews conducted with primary care providers who treat young adults with T2DM. **Chapter 5** forms the discussion of the thesis and provides the interpretations of the findings and how they relate to the literature. This chapter also covers the limitations of the study as well as the next steps in research to further current understandings of young adults with T2DM in Canada.

## 1.0 Literature Review

### 1.1 Type 2 diabetes mellitus

Type 2 diabetes mellitus (T2DM) is a metabolic disease impacting an individual's blood glucose and insulin levels. In some cases, an individual's pancreas cannot produce sufficient amounts of insulin to break down glucose into the blood stream [22], while for others the pancreas can produce insulin but the body's cells have become insulin resistant [22]. The exact cause of T2DM is unknown, but scientists believe a combination of genetic and environmental factors contribute to the disease [22]. Persons with T2DM can begin to develop the disease 5 to 10 years before symptoms of the disease emerge [22] meaning people are often diagnosed with diabetes when they are adults. However, in recent years, the increase in obesity in adolescents and children [1] has been linked with a rise of T2DM in children and adolescents [1, 4, 23]. The higher numbers of young people with diabetes has led to a steady global decrease in the age of onset for the disease [1]. Additionally, the global prevalence of diabetes has doubled over the past 30 years, with approximately 285 million people worldwide living with the illness, and scientists have projected the number of individuals living with diabetes to reach 439 million by 2030 [1]. Approximately 90% of people living with diabetes globally have T2DM [1]. Also, the increasing number of children and adolescents living with diabetes [1] indicates the disease is a concern for all ages, where it used to be more of concern for older individuals [1].

Canada has one of the highest prevalence rates of diabetes among individuals aged 20 to 79 in the world, third only to the United States and Portugal [23], with almost 2.4 million Canadians living with diabetes [23]. Between 1999 and 2009 Canada saw a 70% increase in the prevalence of diabetes nationwide [23] and as of 2010 the prevalence rate of diabetes in Canada was at 11.6%, with it projected to grow to 13.9% by 2030 [3]. The increasing prevalence of diabetes in Canada has increased the burden of the disease on the Canadian healthcare system. In Canada people with diabetes see their primary care providers twice as often as other Canadians, as well as costing the health care system four

times as much as other Canadians [23]. To help address the increased burden the Canadian Diabetes Association (CDA) has established clinical guidelines [2] to help prevent and manage the disease amongst people of all ages and potentially minimize the burden of diabetes on the healthcare system. The guidelines provide information on screening for type 1 and type 2 diabetes, reducing risk factors for the disease, the different types of care available, monitoring glycemic control, ideal targets for glycemic control, and a variety of therapies to treat the disease [2].

### **1.1.1 T2DM and young adults**

As mentioned, there has been a steady fall in the age of the onset of diabetes globally [1], and the age of onset is expected to continue to decline in the coming years [1]. In Canada of the 2.4 million people living with diabetes over 50% of those people are between the ages of 25 and 64 [23]. In 2009 alone there were 143,393 cases of individuals between the ages of 20 – 39 diagnosed with diabetes in Canada [23], with the prevalence rate of diabetes in this age group rising to 5.9% from 3.2% just ten years earlier [23]. Specifically in Ontario, the prevalence of diabetes for all ages has been steadily on the rise [24]. With these numbers it is clear diabetes is now a potential issue for younger adults as well as older adults. Researchers have speculated the rising number of obese individuals coupled with sedentary lifestyles may have increased the possibility for younger portions of the Canadian population to develop T2DM [23]. A higher prevalence of diabetes amongst people aged 20 – 39 (herein referred to as young adults) in Canada is problematic for two reasons. The first is the increased financial burden of diabetes on the Canadian economy and healthcare system [23]. The more individuals diagnosed with diabetes, no matter the age is going to create problems for Canada because the costs of diabetes in the country will increase [23, 25]. Diabetes is also an expensive disease for individuals because many of the expenses for the disease are paid for out-of-pocket [21, 23] making the disease a financial burden for Canada and individuals.

The second reason a higher prevalence rate of diabetes in young adults is problematic is the more aggressive nature of T2DM in young adults [26]. Research has shown young adults have poorer glycemic control and have higher mean glycosylated hemoglobin (HbA<sub>1c</sub>), which indicates an individual's average blood sugar levels, at diagnosis than older adults [5, 18]. Several studies have also found young adults are at a much greater risk of diabetes-related cardiovascular complications than older adults [4, 5, 26]. One study found that even when they controlled for age and sex young adults had a higher risk of diabetes-related cardiovascular complications than older adults [5]. This finding is particularly disconcerting because cardiovascular complications contribute to a significant amount of diabetes-related deaths [5, 23]. Overall, the clinical studies conducted on young adults with T2DM concluded these individuals are a high-risk population that needs aggressive treatment to help minimize the effects of the disease and maintain good glycemic control [4, 5, 26]. The studies also concluded that more research on the characteristics and risk factors of young adults with T2DM is needed because this area of the literature is currently very limited [4, 5, 18]. Moreover, there will be an increasing need to understand the young adult population as the prevalence of T2DM continues to increase. There was also no available literature exploring the risk factors and characteristics of young adults with T2DM in Canada, which is problematic because of the increasing numbers of young adults living with this disease in Canada. It is clear that there is a great need for clinical data on this patient group. However, in order to reduce complications related to T2DM, secondary prevention methods are also needed. The research presented in this thesis focuses on secondary prevention methods and disease management with young adults who have already been diagnosed with T2DM.

## 1.2 Diabetes management in primary care

Diabetes is a chronic disease with no known cure [22], meaning treating and managing the disease is an on-going process for individuals living with diabetes. Managing diabetes entails regularly monitoring blood glucose levels, taking appropriate medication(s), increasing/maintaining physical activity and making necessary dietary changes [2, 27-29]. A common approach to managing the disease is through self-management care, which is when providers encourage patients to actively participate in their diabetes care, and make decisions about their health [2]. In Canada, the Canadian Diabetes Association's (CDA) clinical guidelines promote self-management care by encouraging providers to focus on empowering patients with diabetes [2].

The purpose behind self-management in diabetes care is to empower patients to take control of their care on a daily basis and to actively modify or create self-care behaviours [2, 30, 31]. Self-care behaviours are “decisions and actions that an individual can take to cope with a health problem or to improve his or her health” [32]. In diabetes care, self-management focuses on self-care behaviours because these behaviours can influence the blood glucose levels of patients and the risk of diabetes-related complications, such as cardiovascular disease [6]. Thus, a large aspect of supporting self-management care for people with diabetes is providing them with the correct tools to modify their health [2, 6, 33]. Modifying self-care behaviours, like increasing physical activity can lead to positive health outcomes over the long-term as patients decrease risk factors for diabetes-related complications [2, 34, 35]. To help successfully modify self-care behaviour studies have found patients who actively participate in creating goals for behaviour change are more likely to adhere to the changes and see positive results [30, 33, 36, 37]. There is also evidence that patients with diabetes who have an increased sense of autonomy, meaning they feel capable of making health-related decisions have more positive experiences with their providers and are more willing to engage in their care [38, 39].

To achieve patient empowerment the self-management approach to diabetes care shifts the focus away from didactic discussions about managing diabetes between patients and their providers [2, 30]. In Canada, to help move away from this type of patient education the CDA's Clinical Guidelines [2] outline evidence-based self-management interventions that can lead to better health outcomes. These interventions include helping patients develop their problem-solving skills, creating action-based plans for behaviour modification, and engaging in shared decision-making with patients [2]. For these reasons self-management care is an ideal approach because it allows the patient to tailor care to their needs while also providing the tools they need to successfully manage their diabetes in their everyday lives. However, it is important to note that some people living with diabetes may not want to take on an overly active role in their care. People living with diabetes may wish to have more didactic discussions with their providers because they may not want to, or may be unable to take on the increased responsibility that comes with self-management care. While the evidence does suggest people can handle the increased responsibility in self-management care because of an increased sense of autonomy [38, 39] or feeling more empowered, it is important to remember this approach may not be ideal for everyone.

While self-management care may not be ideal for all people there is evidence that in diabetes care using self-management interventions have been shown to reduce HbA<sub>1c</sub> levels in the short term, maintain HbA<sub>1c</sub> levels over the long term, and minimize the risk of cardiovascular complications from diabetes [6, 34]. Studies have also shown when providers promote self-management care for chronic diseases it can create positive patient-provider relationships and lead to a better quality of life for patients [39, 40]. For these reasons, many countries including Canada use self-management care to improve self-care behaviours, reduce diabetes-related risk factors, and to improve health outcomes. However, in Canada only about 50% of people with T2DM are meeting clinical targets for HbA<sub>1c</sub> levels [41] meaning there is still room to improve how to engage people with T2DM in their care, which

includes addressing barriers to care. Unfortunately there are no data looking specifically at whether young adults with T2DM are meeting clinical targets, which indicates a need for research focused on this population to better understand how well they are managing T2DM.

In Canada, more than 80% of diabetes care delivery takes place in a primary care setting [2]. For this reason, primary care providers are the main educators on self-management care for patients living with diabetes. In 2008 the Ontario government created the Ontario Diabetes Strategy [42]. The strategy focused on increasing access to care for people living with diabetes, and increasing funding for diabetes care and related services in primary care settings [42]. In this strategy, the Ontario government established 51 new diabetes education programs across the province. The programs brought together multiple types primary care providers including nurses, dietitians and pharmacists who work with family physicians and nurse practitioners to provide care for patients with diabetes [42]. The diabetes education programs were designed to promote the self-management of diabetes, and offer patients more access to multiple providers who could support the different aspects of managing diabetes, such as having access to a dietitian to help with making dietary changes [42].

Even with the implementation of diabetes education programs and the use of self-management interventions, there are still barriers that prevent patients with diabetes from receiving the care they need. Many of the obstacles to self-managing diabetes are in peoples' everyday lives. One common barrier people deal with is the cost of diabetes and self-care behaviours [7]. People with diabetes often claim the cost of medication and supplies is burdensome making self-management difficult [7, 19, 20]. Self-care behaviours can be costly for people as well, such as purchasing more fruits and vegetables increasing food costs for many making it difficult to maintain the recommended dietary changes [7]. People with diabetes also find time management is a barrier to self-managing their diabetes because self-care behaviours can be time consuming, like preparing health meals [8, 19, 43]. There is also some

evidence that more health complications can act as a barrier because self-management care becomes increasingly complex with additional health complications [44]. Lastly, difficulty maintaining medication regimens was also an obstacle to self-management care for people with diabetes [36].

Several barriers to self-management care also exist in the healthcare system. To start, accessing the proper health care provider can sometimes be challenging for people with diabetes [20], making it difficult to receive self-management care. The Ontario Diabetes Strategy is an effort to decrease this barrier with the increased amount of diabetes education programs and diabetes educators in Ontario [42]. However, accessibility is still an obstacle for people with diabetes in Canada [20]. Another obstacle to self-management care is providers' limited knowledge or lack of training on how to properly deliver self-management interventions [44, 45]. Studies have found providers sometimes do not know what self-management care is or are unaware of the different interventions for self-management, resulting in providers delivering inaccurate or outdated self-management care for their patients [44, 46]. Lastly, consultation length is a barrier to self-management care for people with diabetes because there is not enough time for providers to engage with patients on all aspects of their self-management care [44, 47]. Overall, there are several barriers to self-management care that people with diabetes face, which researchers, providers and policy makers are working to minimize. The majority of the research examining self-management care and potential barriers either do not include young adults or do not differentiate between age groups, making it difficult to identify how young adults self-manage and what prevents them from receiving care.

### **1.2.1 Young adults and diabetes management**

Studies have found supporting and empowering patients in self-management care can vary between patient populations [18, 30, 31, 34, 48-54]. Research suggests the way providers interact with their patients should change depending on the gender, race or age of the patient because it helps to

better identify needs and engage patients in their care[17, 18, 55-58]. In diabetes care considering patient characteristics, such as gender, age or race is important because these characteristics may influence how people self-manage their diabetes. Currently, self-management interventions remain largely the same across all age groups with T2DM [18], which is problematic because, as the literature suggests, the needs of patients varies across different characteristics, such as age groups [17].

Differences in the needs of patients can also impact what prevents them from engaging in self-management care. There is a small amount of research on what may impact young adults' diabetes care [8, 18, 59]. These studies have compelling results that suggest young adults face some barriers that other people with diabetes may not. An Australian study found young adults do not feel supported because there are no diabetes management programs tailored to their needs [8]. The participants felt diabetes care was focused largely on older adults and was not applicable to their circumstances [8]. The participants had limited time to attend diabetes programs, which is a common barrier for people with diabetes [8], however the study found the limited time and lack of age-specific programs lead to higher duress in this patient population [8]. An American study focused on the barriers young adults face when compared to adolescents [59]. The researchers found young adults were worse off than adolescents because they no longer had parental support and were learning to live independently while also trying to manage their diabetes [59]. The study also identified health coverage as a significant issue for young adults with T2DM residing in the United States [59]. These studies show there are different barriers for young adults with T2DM, which may indicate there is a need for modifying self-management care to the specific needs of this population.

To date, there has been no research conducted on young adults with T2DM in Canada that examine barriers to care, which is problematic because the Canadian healthcare system may present barriers to care for young adults with T2DM that are not present in other healthcare systems. Health

services coverage varies between the different provinces and territories in Canada [60]. In Ontario patients are covered to visit their primary care providers and for many specialists without having to pay out-of-pocket. But drug coverage is very limited in Ontario, which means people can receive care from their providers but end up having higher out-of-pocket expenses for their medication, whereas in countries like the United Kingdom and the Netherlands this is not an issue [61]. Canadians also have a harder time accessing their primary care providers outside of typical office hours (9am – 5pm) than other countries like Germany and Australia [61], however the United States and the United Kingdom have similar issues with accessibility [61]. The differences in the Canadian healthcare system when compared to other countries and the variation in coverage between the province and territories in the country means research from other countries may not be entirely applicable in the Canadian context. Thus, research on young adults with T2DM in Canada is needed.

### **1.3 Patient-provider communication in diabetes care**

The interactions between patients and their providers are a significant part of diabetes management because of the ongoing care that is needed to manage chronic illnesses [62]. The Chronic Care Model (CCM), which many countries including Canada [2] use as a framework for chronic care delivery identifies the interactions between patients and providers as a key component to successfully managing chronic illnesses [63]. To facilitate interactions providers and patients alike suggest open and clear communication is needed [9, 11, 15, 64, 65]. Patients with diabetes have an easier time managing their diabetes and engaging in self-care behaviours when they can communicate openly with their providers on personal matters and concerns [9-11]. In one study patients with diabetes who were unable to discuss concerns or ask questions with their providers were less likely to engage in self-management activities when compared to patients with good patient-provider communication, meaning discussions were open and the patients were comfortable asking questions [11]. The study also found when patient-provider communication improved for patients the likelihood of engaging in self-

management activities, such as foot care increased as well [11], indicating patient-provider communication during the clinical encounter can influence patients' self-management. Moreover, clear communication between patients and providers makes it easier for patients to recall the information discussed in appointments, and it can make patients more willing to work with providers when making health-related decisions [66-69].

The literature suggests providers should focus on developing a strong patient-provider relationship and creating trust with their patients to achieve open and clear communication in self-management care. To create an open dialogue in the encounter providers have found they first need to focus on cultivating a relationship with their patients [12, 13, 70-72]. Patients also believe establishing a relationship is an important aspect to engaging in health care and are interested in doing so with their primary care providers [15, 73]. In chronic care management, the patient-provider relationship is particularly important because patients and providers need to interact more often to manage chronic illnesses, and a good relationship makes it easier to discuss care [15]. One study, which focused on individuals with musculoskeletal disorders, found participants valued a good relationship with their providers because it allowed them to feel comfortable enough to discuss their experiences with pain openly [74]. The ability to discuss their experiences with pain is important because pain levels are a key consideration for administering medications for these disorders [74]. Another study found a good patient-provider relationship led to improved self-care behaviours amongst patients with diabetes because the patients were more willing to listen to their provider's recommendations [39]. Providers are aware of the importance of the patient-provider relationship in care as well. When working with more vulnerable populations providers found patients were more open to recommendations when they had a good relationship with their provider [14, 72, 75].

When patients and providers trust each other, it can also facilitate communication in the clinical encounter. Trust between patients and providers is known to have a significant impact on interactions

[76], and can influence how willing patients are to communicate about sensitive topics with their providers [14]. When patients trust their providers, they are more willing to ask questions and open up about their concerns during the clinical encounter [15, 77-79]. Studies have suggested when patients with chronic illnesses trust their providers they are more likely to ask questions and address concerns, which is of particular importance when creating plans for managing the disease [15, 74]. Moreover, providers have found when they focus on building trust with patients, especially more vulnerable populations it is easier to identify barriers to care [16, 80].

In diabetes care, a patient's level of trust with their provider impacts their willingness to participate in care and to listen to the provider's suggestions for self-management [40]. Studies found patients with diabetes who had a higher level of trust engaged in care with their providers more often and were more willing to discuss managing the disease [36, 81]. Additionally, patients who trust their providers are more willing to partake in follow-up care, which is an important part of chronic care management [76]. One study found when patients were more willing to partake in follow-up care it built further trust and led to stronger patient-provider relationships over the long term [15]. The importance of follow-up care in chronic care management makes it critical for providers to continue to build trust with their patients with diabetes to benefit patient-provider communication and a patient's self-management care. When patients trust their providers and have strong relationships with them, it supports open patient-provider communication, which contributes to better uptake of self-care behaviours amongst patients with diabetes. In diabetes care, good patient-provider communication has resulted in increased patient autonomy leading to better uptake of self-care behaviours, such as diet modification and increased exercise [37, 40]. Patients who are more comfortable communicating with their providers are more honest with providers about their self-care behaviours and asked more questions about their care as well [37, 40]. In one study the patients who were more honest felt more capable of managing their diabetes and sustaining self-care behaviours over the long term [64].

Communication between patients and providers can also contribute to improved health outcomes for patients with diabetes [9, 39, 82]. One study suggested over time patients who had good communication with their provider had lower HbA<sub>1c</sub> levels when compared to patients who had poor communication with their provider [9, 39]. One study showed results of sustained weight loss for patients who had better communication with their providers, suggesting providers should focus on how they communicate and engage patients with diabetes because of the influence it can have on health outcomes [9]. Evidence of the link between patient-provider communication and improved health outcomes for patients with diabetes is compelling because it highlights the importance of interactions during the clinical encounter. It also suggests continued research on communication in the clinical encounter is needed to identify what may lead to poor patient-provider communication and what can be done to address barriers to communication.

The literature examining patient-provider communication has also suggested understanding the needs of specific patient populations can lead to better engagement and improved communication [14, 16, 73, 75, 83]. Studies in Canada focusing on specific patient populations, such as poor patients [16] suggested providers need be aware of the specific needs of their patients to engage them in care. A patient's illness also shapes communication in the clinical encounter. Researchers found the way patients wish to communicate is different between chronic diseases [65]. For patients with diabetes research found there was an increased fear of judgment from providers when patients did not meet their self-management goals, such as losing a certain amount of weight, or when glycemic control was not ideal [65]. Additionally, patients with diabetes wanted providers to be understanding of the difficulties linked to self-managing diabetes [65]. The researchers suggested factors, such as respect, that lead to good patient-provider communication were the same for different chronic illness, but the emphasis on factors varied [65]. Differences between patients with chronic diseases on what is necessary for good patient-provider communication suggests research on specific populations is useful

for self-management care because it shows how to best engage with certain patient populations when discussing care.

In studies that focused on communication with patients with diabetes young adults tended to be under-represented as the mean age of participants was often 50+ years of age [9, 11, 64]. The higher mean age in these studies is problematic because studies focusing on more general patient populations have documented differences in how young adults communicate in the clinical encounter when compared to older adults [84-87]. Moreover, in Canada, there is limited research on patient-provider communication during clinical encounters with patients affected by T2DM [88, 89]. Even more problematic is the lack of research looking at patient-provider communication with young adults with T2DM. Studies on young adults with T2DM often concentrate more on the characteristics of the population [4, 5], such as what high risk behaviours they engage (e.g. smoking or alcohol consumption) rather than how young adults interact with their providers during the encounter. Internationally, research on patient-provider communication with young adults living with T2DM is also very limited [8, 90]. However, the research does suggest communication with young adults differs when compared to older adults [8, 90], which means understanding patient-provider communication with young adults with T2DM is important to optimize self-management uptake, and minimize the impact of T2DM in the long term.

### **1.3.1 Theoretical framework for patient-provider communication**

In the presented study, Elliot Mishler's Lifeworld theory [91] was used to guide understandings of how young adults with T2DM and providers communicate with each other in the clinical encounter. Mishler's Lifeworld theory explores the different voices, or perspectives, of patients and providers when they interact in the clinical encounter [91]. Mishler observed that there are two 'voices' patients and providers embody during the clinical encounter. The first is the 'voice of medicine', this is the

perspective the provider uses during a clinical encounter [91]. The voice of medicine uses a technical approach to the symptoms and health care needs of a patient, which the provider uses to determine a diagnosis or treatment for the patient [91]. Mishler stated this voice was grounded in the biomedical model of health, removing the context of everyday life and focusing solely on the illness of the patient [91]. The second voice in the clinical encounter is the 'voice of the lifeworld', which Mishler states patients embody when seeing their provider. This voice represents the context and social reality a patient lives in [91]. It is the voice of the lifeworld that makes sense of a disease in a patient's life and represents how disease and illness impact and shape a patient's circumstances [91].

Mishler believed that in many circumstances the voice of medicine was the dominant voice in a clinical encounter, and would often drown out the voice of the lifeworld, making communication in the encounter asymmetrical [91]. Further, Mishler believed drowning out the voice of the lifeworld is problematic as the context in which a patient experiences his or her illness is important when considering how to improve health outcomes since a patient's characteristics and lifestyle can significantly impact their health [91]. Mishler believed that to improve communication and health outcomes providers had to adopt the voice of the lifeworld more often or allow for the voice of medicine to incorporate more than just a biomedical understanding of health. Mishler thought if providers did this it would create more collaborative communication in encounters where patients and providers voices are equally present [91].

David Silverman [92, 93] criticized Mishler's understanding of communication in the clinical encounter. Silverman stated that patients did not want providers to take on the voice of the lifeworld. Silverman believed the clinical encounter was primarily an asymmetrical interaction between stakeholders, where the provider is in control of communication during appointments because of their superior knowledge [92]. Therefore, he believed providers should not have to adopt the voice of the

lifeworld more in the clinical encounter because the clinical interaction is not meant to be symmetrical [92], as Mishler suggested [91]. Silverman's critique of Mishler's theory keeps the purpose of the clinical encounter in mind, which is the patient receiving care from the provider. Also, his critique acknowledges the diversity in patient-provider communication, as some patients do not mind having the voice of medicine as the main 'voice' during the encounter [92, 93].

Mishler's theory, balanced with Silverman's critique, offers a way to understand patient-provider communication with young adults with T2DM. Self-management care for T2DM involves more interaction between the voice of the lifeworld and the voice of medicine because a large part of self-managing is the patient implementing self-care behaviours. The need for patients to perform self-care behaviours in diabetes self-management may force the provider to acknowledge the voice of the lifeworld in encounters because of the influence a patient's social context has on self-care behaviours. For example, an impoverished patient may not be able to afford healthier food, and a provider must take this into consideration when treating their patient. Using Mishler's theory to understand how communication occurs in the clinical encounter can identify barriers and facilitators as well, because it may reveal any friction or cooperation between the voice of the lifeworld and the voice of medicine in the clinical encounter. Therefore, Mishler's Lifeworld theory along with its criticisms can aid in establishing the potential barriers and facilitators to self-management care and communication for young adults with T2DM.

## 2.0 Study Rationale

### 2.1 Research gap

Type 2 diabetes mellitus (T2DM) is a growing problem in Canada [23]. The prevalence rate of diabetes is on the rise in Canada and globally [94] making it imperative to find ways to prevent and manage the disease. Increasing numbers of young adults with T2DM (aged 20 to 39) in Canada is of particular importance because of the more aggressive nature of T2DM and the increased risk of diabetes-related cardiovascular complications [4, 5, 26]. Internationally there is very limited literature looking at self-management care for young adults with T2DM and the barriers they face [8, 59]. The research that has been done suggests there are obstacles to self-management care for young adults with T2DM [8, 59], however these barriers are specific to the countries in which the research took place. There is no research in Canada on the obstacles young adults with T2DM may face for self-management care, which is problematic because the Canadian health care system may present different challenges for this patient population. When considering the increasing prevalence rate of diabetes amongst young adults in Canada [23] research on possible barriers and facilitators to self-management care is critical to ensuring these patients can successfully manage the disease.

Next, patient-provider communication in the clinical encounter can have a positive impact on diabetes care and health outcomes for patients [9]. Research has shown patient characteristics, such as age influences communication and providers need to consider such characteristics when in appointments with patients [38, 84]. Furthermore, in Canada research has suggested that communication needs can differ between specific patient populations [16, 65], particularly when considering patients with chronic illnesses [65]. In diabetes care there is a lack of research looking at patient-provider communication in the clinical encounter with young adults with T2DM. The lack of research in Canada may be limiting providers' knowledge on how to communicate in a way that engages young adults in their care. Therefore, there is a need for research in Canada focused on young adults

with T2DM, because understanding patient-provider communication with these individuals will offer insight into what providers can do to have open communication and improve self-management support.

## 2.2 Research question and objectives

**Research Question:** What are the barriers and facilitators to self-management care and communication in the clinical counter for young adults with T2DM?

**Aim 1:** Explore the barriers and facilitators to self-management care and communication between young adults with T2DM and their primary care providers.

**Objective 1:** To understand what primary care providers perceive as barriers to self-management care and communication during the clinical encounter.

**Objective 2:** To understand what primary care providers perceive as facilitators to self-management care and communication during the clinical encounter.

### **2.3 Anticipated impact**

The findings from this research will contribute to the literature on what prevents and enables young adults with T2DM from engaging in self-management care and communicate with their primary care providers. This project is the initial step in establishing Canadian research on young adults in this area. Researchers will be able to use the results from the research to further understand how age-specific patient populations have varying needs when receiving diabetes care. Identifying the barriers and facilitators to self-management care and communication for young adults with T2DM will allow providers to take the necessary steps to minimize any barriers and maximize the facilitators for care in this patient population. Therefore, this research has empirical and practical implications for research in Canada and the Canadian healthcare system.

## **3.0 Methods**

### **3.1 Study design overview**

This study used a convergent parallel mixed methods research design, which is when qualitative and quantitative data are collected simultaneously using the same constructs or concepts [95]. The two sets of data are then analysed and compared together to strengthen the results [95]. The convergent parallel mixed methods design was used for this research because it created the opportunity to collect data with two separate tools, a semi-structured interview and a survey. Collecting data using qualitative and quantitative methods allowed the providers and young adults with type 2 diabetes mellitus (T2DM) to think about and express their thoughts and ideas in different ways. For example, the survey allowed the participants to identify what they discussed in appointments, which was then used in the interview to allow the participants to elaborate on why they felt certain discussions were important during appointments. The interview also provided the opportunity for participants to share their experiences during appointments, which offered another way for participants to express their thoughts. According to this research design collecting data in this way leads to more comprehensive findings because merging data from each method can strengthen and expand the findings more than data collected solely using qualitative or quantitative methods. The sections below address the research paradigm, data collection procedures and tools, and data analysis to support this study design.

### **3.2 Research paradigm**

A pragmatic worldview grounded this study design, and supported the research aims and objectives. The pragmatic worldview is concerned with understanding how experiences and beliefs influence a person's actions [96]. Pragmatism focuses on the consequences a person's actions have in a social situation [96], and how a person's experiences give meaning to social interactions [96]. Pragmatism is also concerned with how a person reacts to a problematic situation, and how a person acts to solve the situation or reach a desired outcome [96]. This approach to understanding social

situations was ideal for this study because the study was concerned with what prevents and enables communication in the clinical encounter, as well as what barriers to self-management care exist for young adults with T2DM. The experiences of the young adults and their providers shape how they interact in the clinical encounter and how they communicate with each other. In this study having young adults and providers speak of their experiences revealed problematic situations that prevented self-management care for young adults. Thus, a pragmatic worldview aided in understanding how the experiences of young adults with T2DM and their providers shaped communication in the encounter, and from the participants' perspectives what prevented young adults from their self-management care.

In line with a pragmatic worldview this study applied deductive and inductive approaches in the study design and analysis. A deductive approach was used to bring structure to the research through the use of Mishler's Lifeworld theory [91] to create the data collection instruments used in the study. Mishler's theory was also helped ground the deductive approach in the data analysis by offering a way to understand young adults' experiences communicating with their providers, and providers' experiences interacting with young adults. Using Mishler's Lifeworld theory [91] for the deductive approach maintained the pragmatic worldview of this study because it offered a way to understand the different ways young adults with T2DM and providers attempt to deal with a problematic situation (the impact of diabetes on young adults' lives). His theory also created a framework for how young adults' and providers' different experiences shaped their interactions in the clinical encounter.

An inductive approach was used during data collection to allow the participants to talk about topics that went beyond the focus of the interview questions, which led to the discussion of ideas the researcher had not previously considered. An inductive approach is also in line with the pragmatic worldview because it allowed the young adults and providers to discuss their interactions in the clinical encounter and potentially bring up problematic situations that could have further revealed how the participants acted to resolve a situation or reach a desired outcome [96].

### 3.3 Sampling and recruitment

#### 3.3.1 Sampling and inclusion criteria

This study used purposive and snowball sampling techniques. A purposive sampling technique was used to ensure recruitment of participants relevant to the study and to help focus the recruitment approach. Also, since the study was not intended to be representative of the Ontario population, a purposive sampling technique did not impact the validity of the research [97, 98]. Snowball sampling was also used in this study to increase awareness of the study for eligible participants and create rapport between the researcher and possible participants.

Two study populations were included in this study. The main study population was primary care providers who had experience treating young adults with T2DM. This study population was selected to aid in understanding the barriers and facilitators to self-management care and patient-provider communication for young adults with T2DM from the perspective of providers. The inclusion criteria for this study population were (1) participants had to be primary care providers, and (2) they had to have experience treating young adults with T2DM. A total of 11 participants from this population met the inclusion criteria and were included in this study.

The second study population was young adults diagnosed with T2DM between the ages of 20 to 39. The age range was selected because there is limited research on the facilitators and barriers to self-management care and patient-provider communication for patients with T2DM in this age range [8, 90, 99, 100]. As discussed in the literature review persons in this age range experience barriers to care that other people with diabetes do not [8, 59] and to achieve optimal self-management a clear understanding of what prevents and enables this population from receiving care is needed. The inclusion criteria for this study population were: (1) they must have been between the ages of 20 and 39, (2) had T2DM, and (3) were diagnosed with T2DM at least six months prior to participating in the

study. Participants were required to have been diagnosed with T2DM at least six months prior so they could draw on multiple experiences when completing the survey and interview.

Due to difficulties with recruitment, only two young adults with T2DM were included in this study. The researcher undertook multiple recruitment strategies, discussed below, to increase participation from young adults with T2DM, but the strategies proved to be unsuccessful. Overall Ontario has one of the highest prevalence rates of diabetes in Canada [23]. However there is a low number of young adults with T2DM in southwestern Ontario, where the study took place [101], which may be from the lower population density in the region. The low numbers of young adults with T2DM in this region is likely what caused the lack of participation from this study population. Additionally, patient confidentiality prevented the researcher from contacting potential participants because that would be in violation of patient privacy policies. These policies meant the researcher had to take a passive approach to recruitment where she was dependent on primary care providers and clinics giving out information, along with young adults making the decision to contact her to participate. The low number of young adult participants means the data collected were not used to draw conclusions on the facilitators and barriers to self-management care, or on communication in the clinical encounter. The data collected were instead used to offer some context to the data gathered from the main study population, the primary care providers. How the young adult participants' data provided context to the findings from primary care providers is discussed later on in this chapter.

### **3.3.2 Recruitment procedure**

Recruitment for this study took place between November 2015 and February 2017. A multitude of recruitment strategies was used in this study. The first recruitment strategy was to contact clinics throughout the Waterloo Region in Ontario via phone or email informing them of the study. The email template used to contact clinics is in Appendix A. Seven clinics were reached, and in November 2015 five clinics showed interest in participating in the study. In March 2016, four of the interested clinics, which

were all a part of a group of community health centres (CHC) declined to participate because of a previous commitment to another study focusing on patients with diabetes. In April 2016 after multiple failed attempts at communicating with the fifth clinic that initially showed interest it was deemed this clinic had also decided not to participate in the study.

In February 2016 the Waterloo region program coordinator for the Canadian Diabetes Association (CDA) was contacted and informed of the study. Through this contact, a clinic was recruited that agreed to post a research flyer in their offices to recruit young adults with T2DM. The study flyer is in Appendix B. The clinic also circulated an information letter to their primary care providers. The information letter for the primary care providers is in Appendix C. The program coordinator for the CDA also recruited a young adult with T2DM, who was emailed an information letter about the study and then contacted via the phone to discuss the study before deciding to participate. The information letter sent to the young adult is in Appendix D.

To further recruitment for young adults with T2DM research flyers advertising the study were posted on the University of Waterloo campus. The flyers were made available on campus from April 2016 to December 2016. Also, in April 2016 the study information letter for primary care providers was circulated among the providers at the University of Waterloo's Health Services to further the recruitment of providers.

In April 2016 the researcher attended an annual research forum presented by the CDA. The researcher had a booth at the forum and was able to hand out flyers and information letters to both young adults with T2DM and primary care providers. The recruitment materials from the forum are in Appendix E. One new clinic from the forum agreed to participate in the study. The clinic did not agree to put up research flyers for the patients, but providers were made aware of the study and agreed to inform patients who fit the inclusion criteria for the study and provide the information letter if a patient was interested. The providers were also emailed an information letter about the study. The providers

from this clinic who agreed to participate in the study also emailed their colleagues at the clinic and from other clinics informing them of the study.

The researcher attended an opening event for a new pharmacy in April 2016 as well to recruit more primary care providers into the study. No new participants were recruited from this event. Lastly, in April 2016 information regarding the study was posted on the University of Waterloo's website, and the study was included in the 'Participants Needed' section of the monthly e-newsletter the University of Waterloo's Graduate Studies department sends to all graduate students.

In May 2016 the researcher was invited to attend the Diabetes Educator Section (DES) Grand River Chapter Meeting, where approximately 60 diabetes educators from the region were in attendance. At this event, the researcher gave a five-minute oral presentation describing the study and who was needed to recruit as participants. An information letter, which is in Appendix F and the research flyer, was handed out to all the attendees. In September and October of 2016, all primary care providers who had previously participated in the study were contacted to inquire if they could forward information about the study to their colleagues. Clinics that had declined to participate previously were contacted once again to see if there was any interest to participate. From these sources, the remainder of the participants were recruited into the study.

Despite the various recruitment strategies outlined above there was very low recruitment of young adults with T2DM, but the strategies were successful in recruiting primary care providers. For this reason the study aim was changed from including the perspectives of young adults with T2DM and primary care providers to focusing solely on the perspectives of primary care providers. The research objectives were also refined to focus only on providers.

### **3.3.3 Ethics clearance for recruitment strategies**

In October 2015 an ORE 101 application for this study was submitted to the Office of Research Ethics at the University of Waterloo and was assigned ORE number 21020. After revisions, the application received full ethics clearance on December 23, 2015. On March 3, 2016, an ORE 104 modification application was completed, the application included amendments to the recruitment strategies addressed above. The modification received clearance on March 13, 2016. Another ORE 104 modification application was submitted March 29, 2016, to include recruitment from the CDA Research Forum, which received approval on April 4, 2016. A third ORE 104 modification application was submitted on April 15, 2016, to increase the study location area to include all of southwestern Ontario. Clearance for the third ORE 104 modification application was received on April 26, 2016.

## **3.4 Data collection**

### **3.4.1 Data collection procedures**

Data collection using the surveys and interview guides took place during one study session, which occurred either over the phone or in-person. For study sessions that took place in-person the participant was contacted via phone or email to select a date and location for the study session. Once the participant chose a date and place, he or she was emailed the information letter to review if he or she had not already received a letter. The participants were informed that they could ask any questions before the study session. In the study session, the participant was given another information letter to review and the participant was asked if he or she had any questions about the study before beginning. The participant would then complete the consent form, which he or she could also ask questions about before signing. The consent form is in Appendix G.

After the participant had completed the consent form, he or she filled out the survey. Two separate surveys were developed, one for young adults with T2DM and one for primary care providers. A copy of these surveys can be found in Appendix H. When the survey was completed a handheld

recorder was set up and tested to ensure the device captured the interview. The researcher asked permission to take notes during the interview when setting up the recorder. At this point, the participant was reminded that he or she could request to stop the recording at any time or decline to answer any questions he or she did not feel comfortable answering. The interview guide was followed with a set of pre-determined questions, which is in Appendix I. Two separate interviews guides were developed, one for young adults with T2DM and one for primary care providers. During the interview, probes were used to gather more information or clarification from the participant, and the researcher took notes throughout the interview.

When the interview was completed, the recording was saved and the researcher thanked the participant for being a part of the study. The participant was then given a gift card as remuneration for the study. For the first few study sessions, the researcher would inquire at the end of the study session if the participant would like a copy of the completed thesis from this study, however many of the participants expressed not wanting to read an entire thesis and would prefer to receive any articles written about the study. After hearing the participants' comments, the participants were then asked if they would like to receive any articles written about the study.

Study sessions that took place over the phone were completed in almost the same manner as the sessions completed in person with a few changes. Once the date and time of the study session were confirmed the information letter was sent to participants, as well as two URL links to electronic versions of the survey and consent form. The participants were informed they could complete the survey and consent form before the study session if they wanted or could wait to complete it while on the phone. The participants were also reminded they could contact the researcher via the phone or email if they had any questions about the consent form or survey. The study sessions completed over the phone were done in a private setting to ensure no other individual overheard or interrupted the interview. At

the conclusion of the interview, the participant was asked to email his or her work or home address for the researcher to mail the remuneration to the participant.

### **3.4.2 Data collection tools and methods**

As noted, a survey and interview were used for data collection. Separate surveys and interview guides were created for the young adults with T2DM and the primary care providers. The original aim of the study was to include young adults with T2DM and primary care providers as participants, leading to the development of separate surveys and interview guides for the young adults and the providers. Once the aim of the study was altered from the low recruitment of young adults with T2DM the survey and interview guide for the primary care providers become the sole data collection tools for the study. However, given the original aim of the study included data collection tools for young adults and providers they are both described in the sections below.

#### ***3.4.2.1 Semi-structured interviews***

The interview guides were developed for a semi-structured approach to the interviews. Semi-structured interviews were chosen as a method of data collection for this study because it allowed the researcher to gather rich data using constructed questions to guide the interview while also offering an inductive approach for gathering the data [97]. The semi-structured interviews guided discussions with the participants but allowed room for the participant to offer more detailed accounts and discuss topics that went beyond the scope of the interview questions [97].

Mishler's Lifeworld theory [91] and the aim and objectives of the study were considered when creating each interview guide. Mishler's Lifeworld theory was considered because it offered a way to understand young adults' and providers' different perspectives during discussions in the clinical encounter [91]. The theory was used to develop questions that determined how young adults and providers communicated during encounters, and what they thought of how their provider (in the case of

young adults) and their patients (in the case of the providers) communicated during encounters. Developing questions in this way helped to identify what aids or limits communication between young adults and providers in the encounter. Below is a table with examples of the questions used in both interview guides. The table also includes a column titled ‘aim’, which provides what the question was aiming to provide data for, and what the researcher considered when developing the question.

**Table 01: Sample interview guide questions**

<b>Sample questions for young adults with T2DM</b>	
<b>Question</b>	<b>Aim</b>
Can you tell me about a positive experience you had with a provider about your diabetes management?	Objective 2, Mishler’s Lifeworld theory
What is difficult to talk about with your provider?	Objective 1, Mishler’s Lifeworld theory
Does your clinic do anything to make it easier to see your provider?	Objective 2
<b>Sample questions for primary care providers</b>	
<b>Question</b>	<b>Aim</b>
Can you tell me about a positive experience you had with a young adult with diabetes?	Objective 2, Mishler’s Lifeworld theory
Tell me about an appointment with a young adult diagnosed with diabetes when you had to alter some aspect of their diabetes management.	Mishler’s Lifeworld theory
What makes it difficult to talk to patients this age who have diabetes?	Objective 1, Mishler’s Lifeworld theory

The interview guides went through several drafts and were refined to ensure the questions achieved the aim and objective of the study. An example of some changes the interview guides went through was to include initial questions that eased the participants (both young adults with T2DM and providers) into the interview making them more comfortable when answering questions about their experiences in the clinical encounter. For example for the young adults’ interview guide the following question was added: where do you usually receive care for your diabetes? For the providers’ interview guide the following question was added: how much involvement do you have with diabetic patients’ disease management? The final interview guides were then tested in mock study sessions with

individuals, one for the young adult's interview guide and another for the provider's interview guide. The mock interviews were not treated as data in the study.

### **3.4.2.2 Survey**

The second data collection instrument used was a survey. Two different surveys were created, one for young adults with T2DM and another for the providers. The primary purpose of the surveys was to gather demographic and contextual data that were later used in the analysis to determine if there were any patterns between the participant's characteristics and the results from the interviews. The other purpose of the surveys was to facilitate discussions in the interviews. The surveys went through several drafts to ensure the questions were providing useful information and achieving the aim and objectives of the study.

To create the surveys the researcher first referred to existing survey tools from other studies [89, 102] and pulled questions that addressed to some extent the aims and objectives of the study. After this, the researcher used these questions as references when creating the survey for the study, while also referring to resources focused on survey development [97, 103]. One question on the providers' survey and two on the young adults' survey were developed to ascertain what providers and young adults talk about during the clinical encounter. These questions were used to help facilitate discussions about patient-provider communication in the interview and to probe participants on what they talk about and why in an appointment. From the review of surveys with questions related to communication in the encounter [102] and looking at literature for survey development [97], these questions were developed using a Likert scale to offer more insight on how strongly the participant felt about discussing certain topics during appointments. The table below has a sample of some of the questions used in the surveys.

**Table 02: Sample survey questions**

<b>Sample questions for young adults with T2DM</b>						
<b>Questions</b>	<b>Aim</b>					
When were you diagnosed with type 2 diabetes?	Demographic information					
When in an appointment with your provider (family physician, nurse, dietician, etc.) do you:	Objective 1 and 2					
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A
a. Easily talk about personal things with your provider?	1	2	3	4	5	0
b. Easily ask questions about how you should manage your diabetes?	1	2	3	4	5	0
c. Answer the provider's questions in detail?	1	2	3	4	5	0
d. Let the provider know when you don't understand something?	1	2	3	4	5	0
e. Provide input into how your diabetes will be managed (i.e. make decisions about your diabetes management)	1	2	3	4	5	0
Have there ever been times when:	Objective 1 and 2					
				Yes	No	N/A
a. You had a difficult time understanding what the provider was talking about?				1	2	3
b. Been unable to meet with your provider because of time constraints, limited access to transportation, etc.?				1	2	3
c. Your provider or clinic made it easier for you to book an appointment/session?				1	2	3
<b>Sample questions for primary care providers</b>						
<b>Questions</b>	<b>Aim</b>					
What type of health professional are you?	Demographic information					
<input type="checkbox"/> Family physician <input type="checkbox"/> Nurse <input type="checkbox"/> Nurse Practitioner <input type="checkbox"/> Dietician <input type="checkbox"/> Diabetes Educator <input type="checkbox"/> Other: _____						
When in an appointment with a patient do you:	Objective 1 and 2					
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A
a. Ask the patient if he/she understands your explanation of test results?	1	2	3	4	5	0
b. Ask the patient if he/she understands your explanation of	1	2	3	4	5	0

treatment/management options?								
c. Ask patients to elaborate on personal matters that may impact their diabetes care?	1	2	3	4	5	0		
d. Involve the patient when making treatment and management decisions?	1	2	3	4	5	0		
Have there ever been times when:								Objective 1 and 2
				Yes	No	N/A		
a. Your patient has been unable to meet with you because of time constraints, limited access to transportation, etc.?				1	2	3		
b. You worked with a patient to make it easier for them to book an appointment/session with you?				1	2	3		

During the interview, the researcher would review the questions with the Likert scales then ask the participants to expand on the degree to which participants agreed with certain statements, such as discussing personal matters that may impact self-management care. The researcher chose to partly address communication in the encounter through the survey to simplify the interview guide and avoid asking repetitive questions to the participants. Presenting questions about communication on the survey allowed the participants to quickly answer and then explain their choice in detail during in the interview. For similar reasons a set of yes or no questions about potential barriers and facilitators to self-management care for young adults with T2DM were included in the survey. The surveys were tested in mock study sessions with individuals, one for the young adults’ survey and another for the providers’ survey. The mock surveys were not treated as data in the study.

**3.5 Data analysis**

The data collected for this study were analysed using the framework approach [104, 105]. The framework approach was established by Ritchie and Lewis [104] and refined by Smith and Firth [105]. This approach is systematic and iterative in nature creating a clear process to develop themes and key concepts, where the data can continuously be reviewed to further develop established themes or allow new ones to emerge [105]. This approach also integrates data from different sources, such as interviews

and surveys helping to identify patterns that may not have otherwise emerged from only one data source [104], making it a good choice for a convergent parallel mixed methods design. The approach also allows for the analysis of data using a deductive approach because during the initial stages of generating in-vivo codes and recording preliminary thoughts the transcripts can be read to allow for patterns to emerge while keeping the aims and objectives of the study, and Mishler’s Lifeworld theory in mind. There are nine key stages to completing analysis using the framework approach [104, 105], the following table briefly outlines each phase:

**Table 03: Ritchie and Lewis’ framework approach stages**

	<b>Stage</b>	<b>Description</b>
1.	Transcription	Transcribing interviews verbatim.
2.	In-vivo codes	This phase occurs when initially reading through transcripts. It involves identifying potential patterns in the transcripts and coding them with verbatim responses from the participants. At this stage, the codes will vary greatly between each transcript, but it is an important step to allow for initial patterns to stay true to the participant's responses. The codes created here are the initial codes placed in the coding index.
3.	Preliminary thoughts	This phase involves writing analytical memos based on the in-vivo codes in each transcript. It is during this phase when the in-vivo codes from multiple transcripts are first compared.
4.	Initial categories	This phase builds off the preliminary thoughts by beginning to label the in-vivo codes into general terms. The initial categories are established within each transcript and are not yet linked to other transcripts. This stage is when the coding index is refined to reflect more general responses from across the transcripts instead of specific codes for each transcript.
5.	Initial themes	At this point in the analysis, the initial categories from all the transcripts are grouped and sorted into broader categories that become the first set of themes.
6.	Refined categories	Refining the categories involves looking at the categories grouped into each initial theme and teasing out the deeper meanings attached to the participant's responses. This step sorts the categories into more meaningful groups.
7.	Final themes	The refined categories along with looking back at the responses of the participants bring together the final themes. This phase involves going over not only the refined categories but also every previous stage to understand the underlying themes that drive the participants' responses.

8.	Core concepts	Core concepts are broad, abstract ideas that relate back to the experiences of the participants and are found amongst many of the transcripts. Comparing current literature, the coding index and the transcripts is what shapes the final core concepts in the analysis.
9.	Matrix	The final stage involves creating a matrix that outlines the demographics, themes and core concepts associated with each participant from all the data collected. It is during this phase when all the information is compared to identify patterns and how concepts and themes may be connected to certain characteristics of the participants.

Below is a detailed explanation of each stage of data analysis. The data analysis described below is for the primary care provider participants in the study (n=11). Due to the low number of young adult participants (n=2) the framework approach to analysis could not be completed for these participants. A more detailed explanation of how the young adults' data was partly analysed is at the end of this section.

### 3.5.1 Transcription

All the interviews were transcribed verbatim shortly after the study session took place. All 13 participants were assigned pseudonyms following the study sessions. The interviews were transcribed into a Microsoft Word document; once the transcription was complete, the document was uploaded into the data analysis software NVivo.

### 3.5.2 In-vivo codes and preliminary thoughts

Once the transcripts were uploaded into NVivo, each transcript was read multiple times creating verbatim nodes, saved in NVivo. Nodes varied in length from containing only a few words, to containing a sentence or two. The nodes contained a complete thought or idea from the participant, meaning the length of the nodes varied depending on what the participant was talking about in the interview. To avoid missing statements in the transcripts that may be relevant to the study coding was done with a particular focus in mind based on the aim and objectives of the study, as well as theoretical framework

of the study. The foci were: (1) facilitators and barriers, (2) Mishler's Lifeworld theory, (3) communication and (4) miscellaneous findings.

The transcripts were first reviewed to create nodes that were related to facilitators and barriers to self-management care. After that the transcripts were reviewed to create nodes that reflected Mishler's Lifeworld theory. Specifically, these nodes were created when it appeared the voice of the lifeworld or the voice of medicine were coming through in the different scenarios the participants described, or when the participants described interactions between the world of the lifeworld and medicine. Once this was completed nodes were created related to communication, this was done to ensure all possible statements about barriers and facilitators to communication were captured. Finally, the transcripts were reviewed for nodes that did not fit in any of the first three foci but were compelling or interesting to the researcher. This was done to allow different or new ideas to emerge in the data. There were different foci during this initial stage of analysis to help ensure nothing was missed and that the aim and objectives were being achieved. While reading the transcripts, annotations were also added to certain statements that needed more consideration or were particularly interesting. The annotations also contained some initial thoughts from reading the transcripts.

The nodes generated from each focus were moved into separate folders in NVivo to keep the nodes organized. When all of the transcripts had been read multiple times the nodes were exported to a Microsoft Excel workbook, resulting in four separate workbooks for each focus. Within each Excel workbook, the nodes were further sorted into sheets for each participant. Once this was completed, all the verbatim nodes were reviewed and the key phrase or statement was identified and the conversational pauses (um, uh, repeating words) were edited out to clean up the statements. The annotations attached to each transcript were also exported and included in the spreadsheets. The annotations are in Appendix J.

When all the nodes were sorted the in-vivo codes and annotations were reviewed to make preliminary notes on all of the codes. At this stage, as outlined by Ritchie and Lewis, similar statements within each transcript were being linked together for the preliminary thoughts. During these stages the analysis was still contained within each transcript, the codes from all the participants were not yet compared.

### **3.5.3 Initial categories and initial themes**

To create the initial categories the NVivo nodes were reviewed, along with the edited in-vivo code and the preliminary thoughts for each code before assigning it to a more general category. The first set of categories was generated for each of the four foci (facilitators and barriers, Mishler's theory, communication, and miscellaneous). To keep the data organised a table similar to the one laid out in Smith and Firth's paper on the framework approach [105] was created, which contained the transcript statement (original NVivo node), description (edited in-vivo codes), preliminary thoughts, and initial categories. A sample of this table is in Appendix K.

Once the initial categories were created the categories for each participant were moved into one Excel workbook to be grouped together. This was the first time data from all participants were brought together. The initial categories were sorted removing duplicates, and grouped together into similar categories. The initial categories were then sorted and grouped into a broader set of themes that became the initial themes for the data. Again following Smith and Firth's paper [105], a table for each focus was generated containing the initial themes and initial categories. A sample of this table is in Appendix L.

### 3.5.4 Refined categories, final themes and core concepts

Keeping with Ritchie and Lewis' approach at this stage the initial categories that were grouped together in each initial theme were reviewed again. The initial categories were grouped together within the initial theme to create refined categories. It was at this stage the researcher was trying to pull out the deeper meaning of the categories. To help tease out the deeper meaning the in-vivo codes and preliminary thoughts were also reviewed to ensure the refined categories accurately represented the participant's statements.

When the refined categories were completed, they were grouped into broader categories to form the final themes. Once again, to ensure the final themes accurately represented the participant's statements each stage of the analysis was reviewed (refined categories, initial themes, initial categories, preliminary thoughts, in-vivo codes and NVivo nodes). The transcripts were also reviewed at this point to verify the context of the participant's statements was reflected in the final themes.

Generating the core concepts was the next stage in the framework approach. To create the core concepts the final themes were first looked over and then grouped into broad concepts. Once this was completed, all previous stages of analysis were again reviewed to ensure the concepts represented the data. The researcher also created the core concepts while keeping in mind her knowledge of the literature surrounding young adults with T2DM, self-management care, communication in the clinical encounter, and Mishler's Lifeworld theory on patient-provider communication. To keep track of the refined categories, final themes and core concepts a table was created with each of these stages in the analysis similar to Smith and Firth's table [105]. A sample of this table is in Appendix M.

At this stage of the analysis, the data were still being analysed through the four foci established at the very beginning (facilitators and barriers, Mishler's Lifeworld theory, communication, and miscellaneous findings). When the core concepts were completed, the researcher compared the findings across the four separate foci to identify any similarities. The foci on the facilitators and barriers to self-

management care were the main focus of the analysis, the core concepts from the foci on communication in the encounter, Mishler's theory, and miscellaneous findings were used to add different perspectives to the findings for the barriers and facilitators.

### **3.5.5 Matrix**

The final stage of the framework approach was creating a matrix containing demographic and other contextual data about each participant with the core concepts associated with each participant [104]. The survey data were analysed when the matrix was created. The survey data, which had been previously compiled in an Excel workbook, were brought together with the core concepts linked with each participant. The table was then filtered for different participant characteristics to identify any potential patterns in the core concepts. For example, the data from the different types of primary care providers was compared to see if there was a pattern between the type of primary care provider and the core concepts. The survey data collected and a note on the matrix are in Appendix N.

### **3.5.6 Analysis of data from young adults with T2DM**

As stated earlier in the chapter only two young adults participated in the study making it difficult to complete the analysis of the data. To gain some insight into the data collected from the interviews the transcripts were transcribed verbatim into Microsoft Word documents shortly after the interviews and uploaded into NVivo. The transcripts then underwent a similar analysis as the provider participants' transcripts. Each transcript was read multiple times keeping in mind the four foci established for the other participants' analysis. The nodes were then exported to a Microsoft Excel workbook where they underwent the same initial stages of analysis as the provider participants (editing in-vivo codes, preliminary thoughts, and initial categories). It was possible to complete these stages of the framework approach because the analysis was contained in the participant's transcript and there was no comparison of findings across other transcripts.

Once this stage was complete, the researcher was able to sort the initial categories into initial themes. However, because there were only data from two participants there were a multitude of themes, and some of the initial categories could not be grouped together. At this point, the analysis ceased and the transcripts and in-vivo codes were reviewed to gain some insight from the young adults. The tables for these participants can be found in Appendix O. To keep the perspective of the young adults somewhat present in the results the researcher decided to compare the young adult's statements with those of the provider participants' to look for similarities. The similarities were then used to add context or offer support to the findings from the provider participants.

To identify similarities and differences between the participants' data the core concepts and final themes from the provider participants were reviewed with the young adult's data. The initial categories from the young adults' data were reviewed and compared it to the providers' data in search of similar categories. The few similarities between young adults and providers were noted, and the researcher proceeded to review the transcripts to ensure the similar codes between the young adults and providers remained true to the data. While completing this part of the analysis, the researcher was aware the small amount of data from the young adults could not be used to verify what the providers were saying but instead offered a different perspective on similar topics, and supported what the providers were suggesting. The survey data collected from the young adult participants could not be used because of the small amount of data.

### **3.6 Ensuring research quality**

Several steps were taken to ensure research quality for this study. Lincoln and Guba's [106] four techniques were used to help maintain credibility throughout the study. Those four techniques were: (1) reflexive journaling and (2) debriefing throughout the study, while also completing (3) memos during the analysis and (4) taking notes in the study sessions. According to Lincoln and Guba [106] including these

techniques in a study aids in creating credibility because it helps keep the aims and objectives of the study, and any relevant theories clear in each phase of the research.

### **3.6.1 Reflexive journaling**

Reflexive journaling was completed throughout the research process. Reflexive journaling was used to allow the researcher to sort through thoughts and ideas that occurred to her during the recruitment, data collection and analysis phases of the study. It also offered a space to reflect on the data and how it was related or linked while keeping in mind the purpose of the study. The different journal entries were reviewed throughout the study to keep initial thoughts and ideas in mind while collecting more data and completing the analysis. Journal entries are in Appendix P.

### **3.6.2 Debriefing**

The researcher met with her supervisor several times throughout the study to debrief and discuss her observations and findings. The debriefings were useful as they allowed for an examination on the success of the study sessions and allowed the researcher to express her overall observations and impressions. Additionally, the debriefings were used to discuss and hear different perspectives or suggestions on what was emerging in the analysis. The debriefings also helped keep focus on the aim and objectives of the study throughout the course of the data collection and analysis. Lastly, the debriefings offered a way for the researcher to work through the different thoughts and understandings she had about the data.

### **3.6.3 Memos**

As discussed in the previous sections the annotations were attached to the transcripts during the analysis of the data. The annotations contained thoughts about certain statements or sections of the data, and potential links to Mishler's theory or the literature. The annotations are in Appendix J. More

general analytical memos were also completed for each participant throughout the analysis, which are in Appendix Q.

In addition to the annotations and memos, the third phase of Ritchie and Lewis' framework approach is recording preliminary thoughts on the in-vivo codes. Preliminary thoughts on all of the in-vivo codes for each participant were completed. These initial thoughts aided in linking together codes within each transcript and pulling together in some early thoughts on how certain codes related to the other transcripts. A sample of the preliminary thoughts is in Appendix K.

#### **3.6.4 Note taking**

During the interviews, the researcher took notes to record her thoughts while the participant answered the questions. The notes were about possible links to theory or the literature, links to the aim and objectives, while also recording possible connections to what participants said previous interviews. The notes were later used to compare the initial impressions of the data as it were collected with later impressions and ideas about the data during the analysis. The notes taken during the study sessions can be found in Appendix R.

## 4.0 Results

### 4.1 Participant characteristics

A total of 13 participants met the inclusion criteria and were included in the study, 11 providers and 2 young adults with type 2 diabetes mellitus (T2DM). Data were collected between April 2016 and February 2017.

#### 4.1.1 Primary care provider characteristics

There were 9 female and 2 male providers in this study. Based on the data collected from the survey the providers had between 4 and 41 years experience treating patients, with 8 participants between 4 and 10 years experience and three providers with 27+ years experience. The providers had 2.5 to 26 years experience treating patients with diabetes. A variety of providers participated in the study including: a nurse, nurses/ diabetes educators (n=3), dietitians (n=2), nurse practitioners (n=3), a family physician, and a kinesiologist.

The providers were asked approximately what portion of their patient population was 20 – 39 years of age. The lowest approximation was 4%, and the highest was 34% of the patient population. It is important to note that all of the providers except the family physician worked out of diabetes clinics meaning the providers likely had more interactions with young adults with diabetes concerning their diabetes care because the appointments were focused solely on diabetes management and not any other health concerns the patients might of had. Six of the providers worked in family health teams (FHT), one worked in a community health centre (CHC), two worked in a multi-professional diabetes clinic run out of a hospital, and two participants worked in a nurse practitioner led clinic.

The table below displays some of the providers' survey results. Also, these questions were developed using a Likert scale to offer more insight on how strongly the participant felt about discussing certain topics during appointments.

**Table 04: Survey answers**

Survey question:	Types of responses			
	Strongly Agree	Agree	Neutral	Not applicable/ I don't know
Ask the patient if he/she understands your explanation of test results?	4	6	0	1
Ask the patient if he/she understands your explanation of treatment/management options?	5	6	0	0
Ask patients to elaborate on personal matters that may impact their diabetes care?	6	4	1	0
Involve the patient when making treatment and management decisions?	8	3	0	0

Note: These questions were included in the responses to the more general question: When in an appointment with a patient do you?

The responses to the questions above were used to further discuss certain topics or they were used as probes during the interviews, as stated in the previous chapter. For example, the participants were asked to elaborate more on why they strongly agreed or agreed to ask patients about personal matters. The providers did agree on many of the responses indicating there were no significant differences between the different types of providers who participated in the study.

#### **4.1.2 Young adults with T2DM characteristics**

Two young adults with type 2 diabetes participated in the study; both were females in their 30s. One participant had children, while the other did not. One participant had lived with diabetes for 9 years while the other was diagnosed with diabetes 3 years ago. Since only two young adults participated in the study, no substantial results could be drawn from the data collected. As discussed in the methods multiple recruitment strategies were taken to recruit participants with T2DM but were found to be unsuccessful. The data collected from these interviews did, however, inform provider interview questions and probes, and also provided context with which to explain the provider data.

## 4.2 Enablers to accessing care

A variety of enablers to communication and care for young adults with diabetes were identified from the data collected from the providers. For this study, enablers can be defined as factors that aid young adults with diabetes in receiving care and communicating with their primary care providers. This includes factors from inside and outside the clinical encounter. During the analysis, the enablers that the providers identified were grouped into three main categories: (1) patient and provider level enablers, (2) enablers at the level of the clinical encounter, and (3) clinic or systemic level enablers. The enablers have been grouped into these categories because they aided care in different ways, from young adults directly enabling their care, to broad systemic changes or policies that allowed for better access to care. The findings discussed in this section and all following sections include data almost entirely from the primary care provider participants, but there is some supporting data from the young adult participants in the study.

### 4.2.1 Patient and provider level enablers

Patient level enablers were identified by the providers as factors that allowed for improved care for young adults that were directly related to the patient. The providers discussed two such enablers: (1) characteristics of young adults, and (2) technology usage by young adults.

Due to the younger age of this patient population, the providers observed young adults had fewer comorbidities and engaged in care more easily than older adults with diabetes. One provider stated it is easier to work with young adults because:

*“they don’t have the same comorbidities or complex conditions as others so, and often you know there’s not other things happening like their hearing isn’t going, their vision is still okay”.*

Treating patients with comorbidities or other complex conditions may make providing care harder for providers because, for example, the provider may need to take into consideration the interaction of

different medications and prioritize care to address the more serious condition. The participants indicated that the fewer comorbidities young adults had enabled care since the providers did not have to address or consider a multitude of health conditions when determining treatments or implementing lifestyle changes. In addition to having fewer comorbidities another provider, Jordan pointed out:

*“Oh they [young adults] don’t have, so elderly patients [have] hearing issues, mobility issues.”*

The providers found communicating during the encounter was easier with young adults because these patients did not often have hearing or vision issues, which the providers said made it easier to get through materials with the patient.

Being able to communicate more easily with young adults was also identified as a characteristic that made it easier when going over materials. One nurse, Sharon stated:

*“they talk quickly they understand things like, you seem to be able to get through things pretty quickly and when you do the teach-back method, can you tell what your plan is they got it”.*

Sharon also discussed how young adults with diabetes were more able to grasp the need to engage in their diabetes management:

*“you’re the patient with the condition you need to manage this, what can I tell you to help you understand how to manage this? So I find that’s an easier concept in the 20 to 39 age.”*

In relation to having an easier time engaging young adults with diabetes Martha, a nurse practitioner observed her young adult patients had an easier time making lifestyle modifications:

*“I think that younger patients sometimes are able to make changes a bit easier, a bit more readily. Sometimes it can be a bit more difficult with older patients to make significant lifestyle changes because they’ve been living their life a certain way for a lot longer. So they’re more kind of like set in their ways or set in their lifestyle. So I guess that would be often easier about younger patients.”*

Overall, the providers identified their young adult patients’ ability to more readily grasp concepts, and to be more adaptable when making lifestyle modifications as characteristics that made

communication and delivering care easier during appointments. Another characteristic of young adults with diabetes that providers found improved their self-management was the use of technology in their care. As one nurse noted young adults are the “generation of technology, they have already googled everything”. The provider suggested that increased access to information enabled young adults to find answers to their questions. Accessing the Internet for information can also increase young adults’ understandings of the disease, making it easier for providers to go through materials during appointments. Consistent with this finding from providers was a patient's account of her interest in looking up definitions and information:

*“So I always find myself going on Google, like I’m always copying like articles, like for instance I would um, go into, um Microsoft Explorer, ask a question like what is diabetes?”*

As seen in this statement and the one presented above young adults used the Internet as a tool to educate themselves about diabetes. Kate stated that during her appointments she found:

*“they’re just coming in for us to re-affirm or reassure them that what they heard or what they saw online was correct.”*

Kate's statement implies her patients were not solely dependent on their providers for their education on diabetes, and Kate's role during appointments needed to include verifying the information patients had looked up on the Internet. This also suggests providers may not have to spend as much time educating young adult patients with diabetes as they may come in already knowing about the disease.

The providers indicated they are aware of their patient’s increased use of the Internet to find information, and some providers spoke of enabling this behaviour further by giving patients resources they could access online. One provider stated:

*“giving people, in that age group a website to look at if they are willing to do it is...really helpful for them”.*

Here the provider was the one using technology to improve young adult’s access to care. This is interesting because it is the provider enabling the use of the Internet to access information. In addition

to using the Internet to access information the providers talked about young adults' increased use of phone applications to aid in managing diabetes.

*"They are aware of the use of technology in diabetes management, apps on phones to track blood sugars". (Ashley)*

*"They can get it on they phones, they can print it off, they can ask more questions". (Anna)*

*"They've usually got an app on their phone". (Jordan)*

The providers suggested using phone applications for diabetes management eased access to information for young adults because people have their phones with them the majority of the time. Also, as Anna had stated above when young adults could more easily track their test results and other aspects of their diabetes management they came into appointments with more questions for their providers. Increased access to information, such as test results, was suggested to allow young adults to gather the information that was relevant to them, as well as allowing providers to tailor care to what the patient was most interested in and the patients' needs.

The providers also suggested increased use of technology provided more ways to communicate with patients, allowing patients to receive the care they needed when they needed it. A common form of communication that providers used more often with young adults was email. For example, the providers indicated they used email more often to communicate with young adults and that using email to communicate with young adults offered more flexibility and better fit their patients' lifestyle. Ethan stated:

*"emailing can work sometimes, there's other ways that we can communicate that does fit a lot of their lifestyle a little bit better".*

For Ashley, when talking about her diabetes clinic, she said: "we try to email to be a little more flexible".

Monica, a diabetes educator, said she also emails her patients and even spoke of texting a patient to stay connected with her:

*“I had one patient I was texting just because she, that was the cheapest way for her to communicate with me”.*

Monica communicating with her patient through text message showed how technology not only provided different forms of communication, but enabled young adults who may have limited finances to communicate and stay connected with their providers. In this situation Monica was tailoring care to her patient’s needs, again showing that the providers were enabling and encouraging the use of technology in the clinical encounter.

Overall, the fewer comorbidities in young adults, their use of technology, and providers encouraging the use of technology allowed for more ways for young adults with diabetes to access information, manage their care and communicate with their providers. The characteristics of young adults also made providing care easier for healthcare providers, because the participants noted young adults' were easier to communicate with, were able to adapt more quickly to care, and used their mobile phones and the Internet more often to facilitate communication and self-management. Of interest is the providers encouraging the use of technology to aid in managing the disease and to communicate. The providers were further enabling young adults’ care because of their encouragement to use technology and providing reliable sources. The fewer comorbidities in this patient population also simplified care because providers could focus on treating diabetes and not multiple conditions, which allowed providers to focus more on treating diabetes itself.

#### **4.2.2 Enablers in the clinical encounter**

The clinical encounter between patients and providers has a large impact on the care a patient receives and on a patient's uptake of medication or treatments [33, 107]. For this reason, it is a significant interaction that can enable or prevent a patient from receiving the care they need. Both patients and providers influence what occurs during the clinical encounter, and as this is the primary source of patient-provider interactions, it is a vital part of a patient's care. Three main enablers for

young adults receiving diabetes care in the clinical encounter were identified from the providers' data: (1) patient centred care, (2) providers showing they cared, and (3) patient-provider collaboration.

#### **4.2.2.1 Patient-centred care**

The providers were concerned with ensuring the care they provided was focused on the patient, which for this research was defined as patient-centred care. This definition is in line with Moira Stewart's definition of patient-centred care which is: "taking into account the patient's desire for information and for sharing decision making and responding appropriately" [108]. One provider's concern came through when she framed her approach to care as "a customer service approach", demonstrating how the care she provides is guided by and focused on the patient. Anna reflected this approach when she said when speaking to patients she asks:

*"why are you doing this? What are your goals? How else do you think we can help you?"*

Monica showed this as well when she was talking about the kinds of conversations she has had with her young adult patients:

*"I will say you know what? Guess what? It's our job to help you get this better, that's why we're here".*

Ethan also reflected a customer service approach when he said when he provides care it is about "mak[ing] sure that they're getting the right care at the right time, at the right place". The providers suggested approaching care in this way enabled care for young adults because providers are focused on providing the care that the patient needs at the moment. These providers spoke of trying to allow the needs of the patient to shape the care as opposed to going into appointments with a pre-determined plan for the patient to follow. The providers believed focusing on the patient's needs in this way could lead to setting goals for self-management that were applicable and achievable to the patient, ensuring better care for young adults with diabetes.

The customer service approach also came through when the providers allowed the patients to lead the discussions during encounters. Ethan stated in his interview that when he communicated with patients he “tr[ie]d to talk about things that they want to talk about, letting them drive the conversation”, which enabled the patient to participate in care. Anna statement supported this sentiment when discussing how she frames questions for her patients; her goal was to ensure “the patient is talking for the majority of the appointment”. Ashley expressed a desire for patients leading discussions as well:

*"I try to discuss with them what ever they contribute, so it's very, tries to be patient led".*

Another provider, Sharon wanted the patient to lead the conversation from the beginning of the appointment.

*"The first thing I say is, so you came here today, what brought you in? And that statement regardless of the person surprises people. Because they think cause you called me? Okay, but you came; you came here, so why did you come here?"*

The providers said that they prefer that patients expressed their personal needs, and shaped what topics were brought up, ensuring the discussion was relevant and applicable to the patient. Martha stated when she is talking to her young adult patients she focused on:

*"asking what the patient understands about what you've communicated or...if they have questions about it...or what's important to them".*

These providers have made it clear they want to know what patients are thinking and their motives before coming to the appointment. Overall, the majority of the providers expressed the desire for the patients to do the majority of the talking in appointments. The providers said that to address the patient's needs, they had to determine what was important to their young adult patients. The providers indicated that they wanted all of their patients, not only young adults to do the majority of the talking in appointments, but patient-centred care is still important for young adults because the providers suggested it was enabling young adults to communicate in appointments.

The providers were concerned with making their patients comfortable as well, demonstrating a focus on the patient during appointments. When the providers spoke of making patients comfortable, they were focused on creating a calm environment that put the patient physically at ease. The providers were also focused on speaking to young adults in a way that made them feel more comfortable telling the provider about their situation and how they were feeling about their self-management care. When discussing comfort in the clinical encounter Anna stated:

*“diabetic patients have to have a place where they're comfortable going, where they feel safe asking questions and receiving answers to those questions”.*

Anna’s statement suggests, creating a safe space for young adults may allow for patients to open up about their diabetes management, making it easier for providers to deliver care that addresses the patient’s specific needs. Moreover, the providers were also focused on creating a comfortable environment to put the patient at ease. Karen stated:

*“in my office, I have a picture of one of my horses. And generally you find people that are enjoying animals and enjoy horses, so it kind of makes them a little more calm.”*

This type of environment or even relationship may also help in building patient’s confidence. Sharon spoke of how; once her patient was comfortable enough to call her she helped her build confidence in her ability to make decisions related to her diabetes:

*“So I had somebody yesterday, she's really better at self managing, so she's taking insulin 4 times a day. And she used to call me and say, well I don't know what to do, I don't know what to do, and after a few months and I would say okay well tell me what you think. Well, I don't know what to do. You know what to do we've talked, what do you think you should do? There's not a wrong answer, we've talked about what you should do”*

Specific to young adults with diabetes Anna said that her patients would ask questions over the phone that they would not bring up during appointments, which she believed happened because they were in a more comfortable environment. Once she made this observation she made it a habit of calling young patients more often to discuss their care. When approaching care Anna recognized that her

patients were more comfortable outside of the clinic, so she was enabling her young adult patients to ask her questions more openly when she contacted them over the phone. Another approach a provider used to create comfort was to, as she stated, "make it a little bit fun" when meeting with her patients. Based on what the providers observed they have a tailored approach to creating comfort for young adults with T2DM because the providers found it created a space where young adults felt they could bring up issues or concerns that were important to them.

Another approach the providers found helped young adults become more comfortable during the encounter was focusing on topics or aspects of their lives that do not directly relate to diabetes. Jordan explained providing exceptional care for the children of one of his younger patients with T2DM helped the patient feel supported and welcome during encounters. He also provided other services, which were not, diabetes-focused that helped the patient feel more supported in the clinic:

*"we have a Christmas charity program where they get a dinner and presents for the kids and stuff like that. And little things like that, it's not related to diabetes, but it helps her feel like she's supported and it helps her feel like part of our clinic and like part of our health team".*

Leah said in appointments she tries to:

*"have a real focus on anything except diabetes, [which] seems to be able to get them to open up a little bit more".*

Monica said that during initial consultations patients "just want to chitchat; it's the beginning of the therapeutic relationship and some visits we don't get much done with diabetes". These providers were focused on talking to their patients and getting them to open up instead of focusing on diabetes. In doing so, as Leah stated above, it helped "get them [the patient] to open up a little bit more".

In the clinical encounter patient-centred care that focused on the needs of the patient, allowed the patient to lead discussions and feel supported by their providers, enabled young adults to receive the care they needed to manage their diabetes. The providers expressed that how they approach providing care during appointments is important to ensure the patient was receiving the care that they

needed. While patient-centred care enables care for any patient with a chronic illness [62], considering factors such as: providing exceptional care to young adults' children, communicating with them over the phone to create more comfort, or focusing on topics unrelated to diabetes are all things providers can use when providing care for this patient population. The providers also observed that while these approaches to patient-centred care were not specific to diabetes management, they did help facilitate self-management care. These approaches can facilitate self-management care because when young adults receive patient-centred care in this way it communicates with them that their providers are there to support all of their needs and may lead to patient empowerment with this patient population.

#### **4.2.2.2 Patient-provider relationships: Providers showing that they care**

In appointments for young adults with diabetes, the providers were aware that how they communicated with patients and what they focused on could either enable or hinder care. The providers believed connecting with young adults, and being honest and transparent when speaking with them enabled care because it created a connection and established trust. Monica stated:

*"I think building that relationship, that trusting relationship is probably the best thing you can do as far as helping someone manage their diabetes even in that age group."*

Ethan believed he would not have an impact on his patients unless he focused on building a relationship with them, stating:

*"building that relationship is knowing who they are, where they come from so to speak and really sort of getting to know them better so you can build a relationship so you have some influence over them."*

Jordan also observed:

*"if you don't trust what someone is saying to you, it doesn't matter what they say, it could be completely true, but if you don't believe, if you don't care or, they've done something to put you off, then it's not going to work, and so you have to have communication and trust both ways."*

The statements above suggest that the providers viewed trust as an important part of their relationship with patients and they believed it could help foster better care for young adults with diabetes. They suggested building a relationship based on trust could foster better patient-provider communication. Here the providers' observations suggested they believe looking beyond the diabetes care they provide and focusing on their relationship could facilitate diabetes care for patients.

To develop a relationship, the providers were focused on getting to know their younger patients with diabetes, stating:

*"just getting to know them just that little bit better opened up that gateway conversation about their diabetes in the future visits". (Ethan)*

*"ask them what they do, or if they're working or are they going to school you have to show some personal interest". (Monica)*

*"speak to them and find out a little bit about their background and what they're interested in, how much they know about diabetes". (Karen)*

Leah got to know her patients in an effort to find common ground with them to establish a connection:

*"usually I ask about physical activity, they say oh yeah I go to the gym three times a day, three times a week. Oh, what gym do you go to? What classes do you like to do? Cause that's an interest that I have, oh I've got a picture of my kids and there's usually a comment about that, and so oh do you have any kids? So it starts like that. It's about finding a common ground."*

Karen, a dietitian who also has diabetes, found if she shared her experiences with patients she connected with them more, and eased any guilt the patient might have been feeling if they had a lapse in their diet:

*"I say I also make mistakes; I also have a piece of the this or a piece of that because I mean that's life right?"*

The statements suggest the providers were trying to show their patients they cared about them by showing their interest in patients and that they understand what patients were going through when trying to manage their diabetes. The providers had different ways of connecting with patients, whether through looking for some common ground, easing guilt, or asking questions about the patient. All of

these approaches were suggested by the providers to aid in developing trust with their young adult patients, leading patients to open up about their concerns or questions surrounding diabetes.

The providers were also willing to focus on the patient's personal life more in appointments if necessary show that they care. Kate, a nurse, spoke on what she does if she notices her patient is distracted or upset:

*"I deal with the presenting situation, so if it's emotional about a fight last night with a boyfriend, I just let them verbalize."*

Jordan also said:

*"if you're coming in and you're trying to talk to somebody about their diabetes and they're going through a divorce, you're not going to fix diabetes that day, that's not the biggest thing in their life".*

Allowing patients to talk about anything showed that the providers cared about their patients and it did not go unnoticed by patients. It can help patients feel more able to open up, one of the young adults in the study demonstrated this when she expressed feeling that she can speak to her nurse practitioner about any topic on her mind:

*"Interviewer: Alright so what is easy to talk about with your provider?"*

*Jane: Oh everything.*

*Interviewer: Everything?*

*Jane: Yeah, even like my basic life. Like living, everything, like anything that either I did within those 3 months or things coming."*

This young adult also said that speaking with her nurse practitioner was just like talking to a friend, which may have made her more receptive to the nurse practitioner's suggestions about her care. The openness and trust the patient has with her provider also came through when she was speaking about why she liked her provider:

*"that's why I think she's so good because, um if there's anything that I need to talk about with my diabetes I will talk about if I don't understand something I talk to her about that".*

The participant's ability to ask any questions about her diabetes suggested the trusting relationship she has with her provider might help improve her ability to manage her care because she was not afraid to ask questions or say what was on her mind.

Providers were also focused on being very honest with their patients with diabetes to further show that they care and to create more trust. When talking about how she speaks with patients, Sharon said:

*"I tell them at the beginning I will be very honest with you and the reason I tell people that is I want people to feel assured in the information I share with them".*

Another reason for her honesty was:

*"I think if they know I'm being really honest with them, then my hope is that they can be really honest with me too."*

Sharon believed her honesty built trust because it encouraged her patients to be honest about their management as well. If her patients are honest, then Sharon can provide care that will actually help patients better manage their diabetes, as opposed to Sharon not knowing how the patient is managing their care. Another provider, Leah found being transparent by thinking out loud in appointments not only created more trust but spurred the patient into participating in their care as well. She stated:

*"if I think out loud, then sometimes that helps as well. If I say well if we do this and we do this and we do this oh no wait this is not going to work, this is going to work. If they hear me sometimes even talking to myself about their different options of care, then they're able to interject and say oh yeah we can do it like this."*

Providers also observed being honest with patients helped them avoid uncomfortable situations during appointments. For example, Ethan said:

*"you have to ask them if their want to talk about their weight, because otherwise you would probably be offending them".*

Being up front and honest with patients helped address any potential barriers to keep care in the encounter. One of the nurse practitioners stated she has often said to patients who were not communicating openly:

*"I noticed that you're not interested in talking about diabetes and I noticed you're not talking; you're not interested in starting medication. What are your concerns?"*

Two providers stated when they felt patients shutting down or resisting some part of the conversation they would say:

*"I kind of feel that, um, so I kind of feeling there's a bit of tension in the room or something along those lines and then just kind of see where that goes". (Sharon)*

*"I see that your body language has completely changed there. What's that about? Can you tell me a bit more about that?" (Ashley)*

One of the nurses said if a patient was not coming in for appointments she would make sure to:

*"have a discussion about why they're not showing up to their appointments or how we can better support them".*

Lastly, Leah would "ask them straight up if they're nervous" if she sensed the patient was uncomfortable in the appointment. All of the providers found this type of up front communication in the appointment allowed the patient to open up, and gave the provider the opportunity to address any potential barriers to communication or care.

Providers described how they used their honesty when determining treatment plans to give patients more confidence in the care they were receiving and to show that the provider cared and was interested in the patient. Attempting to connect with patients on a more personal level, or allowing patients to talk about things unrelated to diabetes were approaches the providers used to show they care about their patients, which can enable a relationship with their patients or lead to more open communication.

#### **4.2.2.3 Patient-provider collaboration**

In appointments, the providers said that they found collaborating with patients increased the quality of care young adults received. The providers spoke of including patients when making treatment decisions or encouraging patients to participate. Sharon talked about often saying to young adults:

*“you're the patient with the condition you need to manage this, what can I tell you to help you understand how to manage this?”*

Ethan and Karen had similar sentiments stating:

*“you have to talk to a patient about what they want to do”. (Ethan)*

*“I usually say well you can be stricter with your diet or we can put you on a medication that will help, right? And so I kind of ask them to make the decision”.  
(Karen)*

The providers said giving the patient the ability to decide was a way to help young adults feel more in control of their care; Monica said she often pointed this out to young adults saying:

*“I often will say you know, this is manageable...you can make this better and I will often say the ball's in your court with this”.*

Kate placed patients in control of the appointment right from the beginning saying to her patients:

*“thank you for coming in today. I know you're busy, what is it you want to get from this visit? I would say that to them, what do you want from this visit? What can we do to help you?”*

Giving young adults this type of control in the appointment may empower them to participate in their care and help tailor the care to their specific needs, making it an enabler to their care.

Collaborating with patients does more than empower them; the providers suggested it also helped them make realistic goals for the patients. Ashley said:

*“It's more a conversation of working with them to see what would be more realistic for them.”*

The providers suggested that creating realistic goals for patients might have made it easier to manage their diabetes. The providers also suggested making smaller goals that were more realistic for young adults increased this patient populations' success at managing the disease. Making goals that were realistic for the patient also helped the patients and providers collaborate when setting a goal, which the providers encouraged and wanted to do with their patients, as shown above.

The providers were not only concerned with collaborating when discussing the patients' management; the providers wanted to have collaborative discussions about test results as well. The

providers said they did not want just to tell the patients their test results but discuss it with them.

Providers said they would say things such as:

*“when we look at things together, I say okay well what happened here. What do you think we should do?” (Sharon)*

*“I would say to them here’s your A1C result, what are you thinking? What do you think of this?” (Kate)*

The providers suggested trying to bring the patient into the discussion, as opposed to telling the patient the test results, might enable communication in the encounter. Involving the patient in discussions in this way gives young adults a stronger sense of being an active partner in managing their care, creating a sense of empowerment when managing their care. Additionally, there are a variety of decisions providers and patients need to make surrounding medication, such as deciding to take oral medication or injecting insulin. While the provider does need to be heavily involved in these decisions the providers in the study said the final choice for medication is up to the patient, meaning the patient needs to be fully informed and able to ask any questions they might have. Thus, the providers suggested collaborating with young adults could enable self-management care because they are informed and can make decisions regarding their care.

#### **4.2.3 Clinic level enablers**

A variety of strategies were used by the participating clinics to improve access to care for young adults with diabetes. The strategies helped all patients, not just young adults have greater access to care and included: increased hours of operation, longer appointments, access to multiple healthcare providers, medical directives, and the providers making themselves more available for follow up care. All of the clinics that participated in the study had implemented the strategies listed above with the exception of medical directives, which are directives allowing nurses to prescribe certain medications to patients with diabetes without needing approval from the patient’s physician. All of the providers stated their clinics have evening hours at least once a month for patients who are unable to come in during the

day. One nurse practitioner said in the past she has come in early for patients so they could see her before they go to work.

Except for the family physician, all of the providers who participated had longer appointments with their patients, with the shortest appointments at 30 minutes to the longest appointments at 90 minutes. The longer appointment times might have given patients the ability to discuss a multitude of topics or ask questions surrounding their care, and for the provider to have lengthier and more robust explanations for their patients.

Additionally, since all of the clinics that participated were either associated with or were diabetes clinics, multiple healthcare providers were available for patients. The type of healthcare providers available included but were not limited to: family physicians, nurse practitioners, nurses, dietitians, diabetes educators, pharmacists, kinesiologists, foot care nurses, social workers and psychologists. The providers commented that access to so many different types of healthcare providers from one clinic, or family health team greatly increased young adults' ability to see the providers they needed to ensure they are receiving optimal care. Moreover, young adults were able to see more than one healthcare provider when they visited the clinics, Sharon stated at her clinic:

*“we will try to arrange an appointment, so they will come see us at the same time that they are seeing their family doctor”.*

Three of the six clinics that participated in the study had medical directives in place for the nurses, dietitians and diabetes educators to prescribe medication to their patients. The providers at these clinics expressed how the medical directives simplified care for young adults because it eliminated these patients having to visit their family physician only to receive or refill a prescription. This streamlined the process of receiving the medication they need and saved young adults time, as they did not need to book another appointment.

Lastly, the providers believed made themselves more available for young adults to improve patient-provider communication and to increase young adults' access to care because young adults had

many responsibilities that made it difficult to find time access care, this barrier will be discussed in the next section. The providers spoke of doing phone follow-ups with patients either between appointments or when a patient was unable to attend an appointment in person, Anna said:

*“I also have prompts for my really resistant younger adults to call them in between appointments”.*

She explained she does this, because as discussed earlier she found young adults are more comfortable asking questions over the phone than in appointments. Ashley also spoke of booking follow up appointments as often as the patient needs it:

*“we have flexibility with how frequently we want to book follow-up”.*

From the clinic level, there were a variety of strategies the participating clinics employed to increase access to care for patients with diabetes. From more general strategies of increased hours of operation or medical directives to specific strategies of the providers making themselves more available for their patients, all of them increased access to care for young adults. Increased access to care enabled the young adults to manage their care better and communicate with their providers more often and regularly.

### **4.3 Barriers to care**

A variety of barriers to care were identified from the providers' data. The concepts discussed below prevented young adults from engaging in diabetes care, or limited open communication with their providers. These barriers have been grouped into three broad categories: (1) patient characteristics that create barriers to care, (2) barriers in the clinical encounter and (3) systemic barriers. The barriers have been grouped into these categories because they prevented young adults from engaging in their self-management care in different ways, from the patient not managing their diabetes because of their reaction to the diagnosis to broad systemic problems that prevented young adults from managing their care.

### 4.3.1 Patient level barriers

According to the providers in the study there were multiple ways young adults consciously or unconsciously prevented themselves from receiving the care that they needed. Mainly the way young adults perceived themselves or type 2 diabetes limited their ability to manage their diabetes. This barrier is related to young adults adjusting to life with a chronic illness. Adjusting to a chronic illness can be overwhelming for people, especially when managing the illness requires lifestyle modifications [109]. Patients who are overwhelmed from a chronic illness diagnosis react in different ways, some of which can limit their ability to manage the disease [109]. The sections below present some of the reactions providers observed in young adults with T2DM and how these reactions created barriers to care.

#### 4.3.1.1 Denial and perceived guilt for diabetes diagnosis

The providers in the study suggested that young adults with diabetes had a particularly difficult time accepting their diabetes diagnosis. Providers observed young adults did not want to talk about the diagnosis or treatment out of fear or denial, or guilt about their diagnosis. Any of these reasons for not accepting the diagnosis created barriers to receiving care because, as the providers indicated if young adults could not talk about the disease the providers were unable to implement medication or set goals for lifestyle modifications. In her interview Kate stated:

*“I think the difficulty starts when they are totally in denial and they don't want to be there”.*

Other providers made observations similar to Kate, stating:

*“they just don't want to deal with it”. (Jordan)*

*“There are some people where it seems no matter what you do they don't get it and they just don't like diabetes and they have never learned to embrace it”. (Monica)*

Some young adults did not attend appointments at all or went into appointments not wanting to be there making not only care but communication more difficult for the providers. Anna spoke of her difficulty in treating a particular young adult when she first started seeing him:

*“if I could describe his mood on the first day it was hopeless. I guess walls were up; he has this disease that he didn't believe in, he wasn't interested in treating it. He came in with a list of physical complaints that you know, I knew could be managed through diabetes control.”*

Anna's story shows that if patients come in already in denial delivering care can be more difficult for providers because the patient is not interested in talking about a disease they do not believe they have.

Leah shared that she has had to convince young adults they have type 2 diabetes:

*“I spend a lot of time trying to convince them that they do have a disease and that we need to take good control of it not to prevent complications”.*

Kate pointed out how difficult treatment was when they came in with this attitude:

*“if they're not there willingly and if they're not there with the sense that oh gosh I've got this diagnosis I've got to do something. Then it's difficult to engage them in any conversation that's worth while.”*

Ethan had a similar statement saying:

*“if they're not at a place where they can talk with their clinician and their provider about it then you know, we can't help them”.*

The providers made it clear that when young adults had a hard time accepting the diagnosis, it was harder to start them on a treatment plan. Instead the providers had to focus on convincing the patient of the reality of the situation. The data also suggest when a young adult is in denial it can limit communication between the patient and provider, as the provider is unable to talk about the disease.

Jessica, a dietitian, spoke of why informing younger patients of the disease is difficult, possibly offering some insight on why young adults may have a harder time accepting their diagnosis:

*“it can sometimes be a little more challenging too to talk to young adults because this is something they are going to have for the rest of their life right? And that can be a very depressing thing for people to have to come to terms with, right?”*

As Jessica suggested the younger age of this population could possibly make a diagnosis of type 2 diabetes more difficult to accept because they have many more years ahead of them living with this disease when compared to older adults. In addition to difficulties in accepting the diagnosis young adults

also had a hard time accepting the complications associated with the disease. Recently beginning to talk about the complications of type 2 diabetes with one of her younger patients Ashley explained:

*“for the first time we have a shared understanding of...the seriousness of it, which for him has been a motivator to start making some changes. Where previously it was an inhibitor, where he would shut down”.*

Similar to being in denial, if young adults are unable to talk about the complications linked to diabetes it can be difficult for providers to discuss treating diabetes since many of the lifestyle changes and medications are intended not just to control blood glucose levels in the short term, but to prevent long term complications. As demonstrated by Ashley's statement until her patient was able to accept the seriousness of the complications she was unable to discuss it with him and provide the necessary care.

The providers also spoke about the guilt young adults experienced from their diagnosis. Sharon stated:

*“your target population up to 50 kind of feels worse about themselves, like they've done something wrong like it's their fault.”*

She also added she often heard from young adults:

*“it's my fault I've done this to myself.”*

Monica spoke about young adults feeling embarrassed about their diagnosis:

*“they probably don't share it with a lot of people, because they are a bit embarrassed.”*

This guilt also goes beyond the initial diagnosis but to test results as well. The providers spoke about the guilt or fears patients felt when having to come in for follow up appointments. Leah talked about trying to be calm and open for patients because:

*“they're already really nervous about being here. Most of them are because they don't know what's to come; they feel like I'm gong to yell at them for not checking their blood sugar, or having such a terrible A1C.”*

Ethan found this guilt was specifically tied to having to go on insulin:

*“some people view themselves as quote on quote a “failure” if they have to go onto the needle”.*

While Anna stated she finds herself saying to patients:

*“the trend of your blood work is not a report card, you know it's not a reflection of how you are doing in life”.*

This guilt or fear of their test results, and in turn the provider's reaction to the results can also stop them from following up with their providers. Anna spoke of her patients cancelling follow up appointments with her because they felt guilty for not implementing the lifestyle modifications they said they were going to, or getting test results that were not ideal.

Providers also observed the stigma linked to diabetes made patients feel guilty about their diagnosis. The providers suggested that young adults with diabetes believed it was their fault for having diabetes, as Monica said:

*“People with diabetes I think feel guilty enough about not looking after their health as well as they should.”*

The providers also suggested patients with diabetes do not want to be judged for having type 2 diabetes. Sharon spoke of a young adult she sees who has kept her diagnosis a secret:

*“there's still very few people in her life that a) know she has diabetes and b) knows that she manages it will insulin and the reason for that is she just feels that is such a stigma associated with it.”*

One patient who participated in the study spoke about the stigma associated with diabetes as well. She talked about her family members judging her for having diabetes and taking insulin:

*“we were talking about hypoglycaemia, you know if your blood sugars drop. And I was explaining to them what my symptoms are like and stuff like that, and he [a family member] was kind of being ignorant and saying well it happens to me it's the same thing...It upset me because he basically said you know nothing about it and he said, and he actually told me 'what are you talking about? Diabetes isn't an illness, it's not a disease'...and that just turned into a huge fight and because I do take insulin, I don't hide what I need to do...Unfortunately one day he came home from work to pick up his son...And I was injecting myself with insulin, and he basically said to me 'that's gross. Why would you do that here? Why don't you go do that in your room?’”*

The experience of the participant showed her feeling judged by her family members because of her illness. This kind of behaviour from family or friends can make it difficult for young adults to properly engage in care and find the support they need to make lifestyle modifications.

The experiences of the participants suggests there is stigma surrounding the disease which may make patients want to avoid implementing lifestyle changes because it will identify them as someone with diabetes to their family and friends. Stigma for diabetes may also explain young adults' difficulty in accepting the disease. They may not want to be blamed for getting the disease or 'doing this to themselves' as Sharon observed patients say, particularly since they are younger and cannot blame age, which Sharon said her older patients often use as an explanation for the diagnosis of T2DM.

#### ***4.3.1.2 The perception of invincibility***

Invincibility is the idea that a person will not be affected by their choices, and this idea is often applied in a physical sense, for example, adolescent males engage in high-risk behaviours because they believe they are physically invincible from the potential negative consequences [110]. A sense of invincibility is a reaction that young adults have when adjusting to their diagnosis came through in the data, which can prevent them from engaging in their care. The providers believed this was a barrier specific to young adults with type 2 diabetes. The perception of invincibility, as indicated by the providers, acted as a barrier to care and patient-provider communication because it could (1) close patients off to implementing care because they did not believe they needed it, or (2) patients would not take the potential long-term complications from type 2 diabetes seriously.

The providers often found the main reason young adults became closed off to implementing care was because they felt well, and were not experiencing any symptoms or complications from the disease. Monica said she did run into this problem with young adults saying:

*“type 2s will survive and if they're not feeling bad, they just can't be bothered. They're invincible”.*

Leah said young adults have said to her:

*"I'm fine I don't need to do that".*

Karen speculated young adults did not take their care seriously because:

*"they don't have the symptoms and then they just forget about it".*

The challenge here, which Monica stated is that if young adults with type 2 diabetes do not manage their disease, they will survive, whereas for people with type 1 diabetes if they do not take their insulin the consequences could be fatal, which Jordan discussed in his interview. Young adults with type 2 diabetes not feeling the effects of the disease can create a serious barrier to care as the patients do not have a sense of vulnerability or urgency to treat the disease, which is demonstrated in the statements above.

The other challenge the providers faced was communicating the importance of acting now to prevent the long-term complications of the disease. The providers expressed the difficulties in explaining this idea to young adults:

*"Sometimes it is hard to explain [why] we are doing this now, even though you feel fine and you're having no problems...to try and prevent, what's going to, what might, MIGHT happen 20 to 30 years down the road." (Martha)*

*"We're humans and we respond to things that are urgent and so we don't respond to things that are going to affect us 10 years from now." (Jordan)*

*"It's hard to envision what your health is going to look like in 30 years anyway." (Jessica)*

For young adults, it was difficult to implement a change to prevent a complication that may or may not happen to them, as Martha pointed out. Jordan and Jessica suggested it was also hard for people to envision and act on scenarios that will happen far in the future, especially when young adults were not feeling any symptoms that may indicate developing complications in the future. In addition to the difficulties in thinking about one's health so far in the future young adults' sense of invincibility caused them to believe they would not experience complications. Kate called this an "It's not going to happen

to me kind of thinking", while Sharon expressed hearing her patients say 'it's not going to happen to me' when discussing potential complications with them.

The providers found if their young adult patients believed they would not experience the complications from type 2 diabetes then they would not take it seriously. Leah commented that young adults did not take their care seriously because they did not think they would experience these complications. Overall, the perception of invincibility young adults had about their diabetes was a difficult barrier for the providers to overcome because people's perceptions of themselves can sometimes overshadow the reality of the situation. This is made even more potent because young adults may feel well, creating a stronger perception of health and sense of invincibility surrounding the disease.

#### **4.3.1.3 Young adults' mental health**

Self-management in diabetes care encourages patients to be actively engaged in their care, particularly for lifestyle modifications [2]. If patients are resistant or do not want to engage in their care, it can limit their ability to receive the care they need [11]. Some of the providers spoke of encountering this difficulty with young adult patients. Kate spoke of an "I don't want to do this attitude" she sometimes faced when trying to provide treatment. Monica spoke of similar situations where some of her young adult patients did not want to be at their appointments, saying:

*"they don't want to be here and their body language is really um, really shows that they aren't even paying attention or listening but their only there because somebody sent them and that had to go."*

In these scenarios patients became their own barriers to receiving optimal care, and this was a very difficult barrier for providers to overcome because there could have been a variety of reasons patients were resisting care, such as being in denial or feeling invincible as discussed previously.

The providers also spoke of mental health creating a barrier to a patient's care, Monica mentioned one of her patients who was never interested in his care:

*"he just never did get it, so I think there was probably underlying depression and other, other issues".*

Underlying problems, mental health or otherwise made communication with removed patients difficult for providers. Leah spoke of how her patients under 25 were quiet in appointments and she admitted she was still trying to determine the best way to engage her younger adult patients. Leah went on to talk about one of her patients who was not engaged in her care:

*"I've got one younger, I guess she's 34 years old and she's actually supposed to come in today but she's cancelled her appointment and she's extremely depressed, and she's on insulin. She's supposed to be on insulin but never took it, not at all, never. She always came to her appointments though, and we got her to see the psychologist, and that I don't think is making any sort of progress, but the last time she came she said now my feet are starting to really, really hurt me. So I think I'll start taking my insulin now, so she was listening the whole time, she heard everything I had to say, every time she came to her appointment. But she wasn't ready to act on it until it was reality, that her feet are burning."*

Leah said when discussing medication there was no resistance from her patient but she made statements such as:

*"it's always okay, okay okay. But whether or not she actually does it is different."*

Leah's patient showed when patients are unable to engage in their care because of mental health issues healthcare providers can give information and make suggestions but are unable to move forward and make lasting improvements to the patient's health.

One of the young adults who participated in the study spoke of her difficulties with her depression and anxiety, and how it impacted her diabetes at times:

*"I also deal with depression and anxiety, so that's a big factor with my diabetes because if my mood isn't affected my diabetes isn't affected as well. For example, I could have a reading of, let's say, 5.5 in the morning and if my mood is off or if I'm stressed out about something, if I feel like I have anxiety it can jump up to double digits".*

A provider, Leah noted that she has offered psychology services more often to young adults with diabetes who see her, saying they needed more support to manage their diabetes.

For young adults with diabetes suffering from mental health problems, their anxiety or depression may act as barriers that are preventing them from properly engaging in their care, which the providers, especially Leah indicated in their interviews. It can also make it more difficult to self-manage as Jane demonstrated when talking about her stress levels impacting her blood glucose levels. Overall, a patient's inability to properly engage in their care can create a significant barrier that is hard for providers to overcome.

#### **4.3.2 Barriers to the clinical encounter**

Two main barriers that impacted clinical encounters were identified from the data: (1) poor communication in the encounter, and (2) lack of follow up. Both of these barriers prevented young adults from engaging in care either by limiting engagement during the clinical encounter or because young adults were not attending appointments. Both of these barriers impacted the communication between young adults and their providers, as well as young adults' diabetes management.

##### **4.3.2.1 Poor communication in the clinical encounter**

During the interviews, the providers stressed the importance of having open and clear communication with young adults and spoke of the ramifications if communication during the encounter was not open or clear. Leah put it simply that "if you don't explain yourself well they won't listen" when communicating with young adults with diabetes. Poor communication not only impacted how well patients listened; it also impacted the patient's self-management. Ethan spoke of a time when the way he communicated negatively impacted a patient and their care:

*"I've got another story of a patient, and in retrospect, this is horrible quite frankly, but you know I remember talking with a patient and then after the fact they told another clinician they went home and binge ate that night because of the discussion that we had."*

In this situation, Ethan believed because he did not communicate well with the patient it created negative emotions for the patient but also potentially closed the patient off to receiving care from him in future visits.

Sharon also spoke of a time when she did not ask if a young patient with diabetes wanted to attend an appointment with multiple healthcare providers, which led to a negative experience for the patient.

*“She struggled with control and she’d seen numerous educators and so she was struggling with getting adequate blood sugar control. And because her blood sugars weren’t well controlled and because she had seen so many people she was feeling kind of badly, I think, about herself. Anyways so we started seeing her and it seemed to be going well. But we really couldn’t figure out why we were seeing some variability in her blood sugar values; we tried to collaborate as a team, so a dietician who’s not working here any longer and one of the pharmacists that was here at the time we tried to collaborate as a team. But we did the collaboration in a way that wasn’t shared with the patient ahead of time and we all were in the room with the patient and the way we were talking in front of her made her really nervous and upset.”*

In this situation not communicating with the patient beforehand and conversing in front of the patient in a way that did not include her resulted in a negative experience for that patient. Especially when considering the patient’s emotional state around her diabetes care, as Sharon pointed out, poor communication in the collaboration furthered those negative emotions, potentially making diabetes care more difficult for the patient. Anna also reflected that if providers are not communicating with patients in a way to create discussions that are two sided then it will be difficult to know the patients and properly help them:

*“not getting to know them on a personal level...we’re not really helping them meet their goals”.*

Monica, a diabetes educator, spoke about needing to be aware of how she asks her patients questions about their management. She said:

*“if you make a patient feel guilty, like if you see a blood sugar of 21 let’s say. What did you eat? What did you do that for? Or why did you eat that? Like dieticians will*

*sometimes ask those questions, you know what the walls go up that's it... if you're going to make them feel worse, they're not going to come back."*

Martha also spoke of how easy it is to close patients off when providers make mistakes in how they choose to communicate:

*"if you don't provide the right information, the right tools sometimes that can have an effect on how somebody understands the disease and how willing they might be to engage in treatment."*

The above statements show the providers were aware that when they spoke to young adults in ways that closed them off to communication it made providing care difficult in appointments.

During appointments, the presence of spouses or parents also impeded communication. Some of the providers talked about past experiences where a parent or spouse either took the focus away from the patient, or was making the patient feel guilty. Karen mentioned having problems with spouses saying she has found:

*"some spouses are very pushy, you know she does this and she does that and she doesn't do this and you know? You try to get away from that, because that makes the spouse feel very bad."*

This kind of behaviour in an appointment took the focus away from what the patient could do to improve their health and instead focused on what they have done wrong, as Karen observed. This made it difficult for the provider to give the information the patient needed and properly empower the patient with their diabetes management. Spouses also took the focus away from the patient entirely, which

Karen also talked about in her interview:

*"Interviewer: What makes it difficult to talk to young adult patients with type 2 diabetes?"*

*Participant: Sometimes if they have a spouse and the spouse is always talking about themselves and not interested about, you know, talking about who's there for the diabetes."*

As Karen stated when a spouse was focused on himself or herself it moved the conversation away from the patient, who should be the focus of the conversation during appointments. This hindered patient-

provider communication and made it difficult for providers to keep the conversation centred on diabetes care for the patient.

This type of behaviour also happened with parents who accompanied their adult children to appointments. One provider shared a story of a parent who took the focus away from her daughter:

*“I had the other day a mother came and you know she only talked about herself and you know, you have to kind of put the you know, well it’s her daughter and we’re doing her life you know? I know you’re thin and she’s fat, you know that kind of thing? The mother was, the girl was heavy and but the mother was very thin and I’m going well we’re not really discussing yours and this, we want to talk about her diabetes and you know so. That makes it difficult.”*

Here the provider found it difficult to talk about the needs of the patient because the mother was focusing on herself. This can create barriers to care for the patient because the provider cannot fully focus on the patient. Shifting the focus back to the patient can also be challenging if parents are controlling when it comes to their children’s care. Kate spoke of a young adult patient she saw with a controlling mother:

*“Kate: We struggled to disengage the mother ‘cause she was controlling, away from the young fellow.*

*Interviewer: When the mom was there, what did you say to get him to talk?*

*Kate: If I would ask a question I would look directly at the son and ask the question with his name so the communication is I am talking to him. So I would direct my questions and conversations towards the son. And I think that mom caught on after a while, but she was, she was a tough one.”*

In this case the mother was preventing the son from properly engaging in care making it difficult for Kate to provide care for the patient.

Overall there are a variety of circumstances that can lead to poor communication between young adults and their providers during appointments. When patients and providers are unable to communicate effectively, it can take away from the diabetes care patients receive since it may hinder

the patient-provider relationship, or limit providers' ability to deliver care that is specific to the patient's needs and circumstances.

#### **4.3.2.2 Young adults' health is not a priority**

Type 2 diabetes is a chronic disease, meaning patients need to continuously follow up with their providers to track the disease and monitor their progress. For this reason following up with patients is important; however, the providers' data showed following up was difficult for young adults. Young adults' limited time and their many other responsibilities were what made it difficult for them to follow up regularly with their providers. The providers believed young adults' focus on work and their careers was the main reason for their limited time. Many of the providers pointed this out during their interviews:

*"They are in the early stages of a career or a job, they don't want to be taking time off". (Jordan)*

*"A barrier tends to be if there are full time employed." (Ashley)*

*"He had a lot of difficulty coming to appointments 'cause he worked shift work and all these erratic hours." (Martha)*

Work limited young adults' time, and being unable to take time off work or working shifts that were during clinic hours prevented them from coming in to receive the care they needed. Jordan made this very clear when he made this comment about his young adult patients:

*"They don't have time to come to an appointment at 10:30 in the morning on a Thursday."*

Karen also pointed out with young adults:

*"they go through a period of time when they are motivated and then they get busy. It's mostly work related".*

This shows that young adults may want to be engaged in their care but their limited time due to work made it difficult to maintain.

Maintaining lifestyle modifications and properly managing diabetes can be difficult; this is particularly true for the providers' young adult patients who had many other responsibilities to consider.

Jordan pointed out young adults' difficulty managing their care:

*"it's actually not that they don't want to engage it's that they are feeling that they are overwhelmed with life and they're not able to".*

Jordan went on to talk about one of his patients, who showed how different responsibilities made engaging with care difficult:

*"she often came with the kids and they are running around climbing on the chairs and she's having trouble managing her life, and then having a conversation about managing diabetes when kids are jumping around".*

Young adults have many responsibilities such as a job, a family, bills to pay, activities to attend, or maybe even school. All of these responsibilities make it difficult for young adults to focus on their health. Jessica stated:

*"their focus may be on raising their families and getting further ahead in their careers; those are the things that can sometimes take precedence or priority over you know always looking after their health".*

With so many responsibilities young adults needed to prioritize everything and it was clear in the interviews that young adults often did not put their health first. The providers made statements like:

*"Their health and themselves are not a priority". (Monica)*

*"Taking care of their own health isn't always a priority". (Kate)*

*"They have different priorities". (Sharon)*

*"They're working and always don't have time to look after themselves and they tend to forget that they have it". (Karen)*

Monica also went on to state some young adults might have decided against following up with their care at all because it impacts their other priorities:

*"some young people if it interferes with their job and their social life they may totally decide they don't want to be doing this at all."*

The providers' experiences and observations showed young adults with diabetes choosing to prioritize other responsibilities above their health impacts how often they attended follow up appointments, and how well they implemented lifestyle modifications. Young adults making their health a low priority can make it difficult for providers to help these patients make any lasting impacts on their health.

#### 4.3.3 Systemic problems

There was little substantial evidence of systemic barriers that came through in the provider's data, with the exception of patient's circumstances preventing young adults from properly accessing care. One provider mentioned family health teams who were paid based on the number of patients they serve were sometimes more reluctant to refer patients to diabetes clinics because of the lost revenue since they would not see those patients as often. None of the other providers mentioned this in their interviews, thus there was not enough evidence to suggest this is a significant barrier to care for young adults and it remains an area of further investigation. One other provider mentioned how the Personal Health Information Protection Act limits what they could communicate over email with their patients, which can be limiting for young adults who communicate more often through email. But again only one provider mentioned this, so no conclusion could be made on if this is a significant barrier to communication or care for young adults.

A patient's circumstances were however identified as a significant barrier to care, primarily through limited access to care or supplies. The provider's mentioned the socio-economic status of young adults as a limiting factor when accessing care because of problems such as food and home insecurity, which people of lower socioeconomic status may face. A barrier to care relating to socioeconomic status that appears to be specific to young adults that the provider's identified is their drug coverage. The Ontario Health Insurance Plan (OHIP) does not cover medication costs for Ontario residents, as a result of this medication is covered out of pocket or through private health coverage, which can be obtained by an individual or through an individual's employer.

For young adults with diabetes, drug coverage is not always guaranteed as paying for private health insurance can be expensive and not all employers provide health benefits or benefits that are sufficient enough to cover all medication costs. Moreover, any young adults who are working on a part-time, seasonal or contractual basis do not often receive health insurance coverage from their employers. As a result of this the providers stated that drug coverage did acts as a barrier to care for young adults, especially when considering the cost of purchasing insulin, other types of medication, and strips to test blood sugars. The providers also indicated that lack of, or limited health insurance also prevented young adults from accessing certain health care providers that are not covered by OHIP, such as seeing an optometrist, or a dentist. Thus, for young adults the providers believed the most significant barrier at a systemic level was their limited drug coverage.

## 5.0 Discussion

Primary care providers face a variety of challenges when promoting self-management in young adults with type 2 diabetes mellitus (T2DM). However, they also have tools and opportunities to ease delivering care and enable this patient population to better self-manage their diabetes. Awareness of the challenges and opportunities in providing care for young adults with diabetes can better prepare providers and the Canadian healthcare system for the increasing numbers of individuals aged 20 to 39 who are diagnosed with T2DM [23]. There were several findings from this study, which show the position providers find themselves when delivering self-management care to young adults with T2DM.

This study provided further evidence to support well-known self-management interventions for patients with diabetes, and more generally patients with chronic illnesses. Patient-centred care and patient-provider collaboration are well-documented approaches to self-management care that came through in the findings as approaches that enable young adults with diabetes to communicate more openly with their providers and have increased access to care. Developing the therapeutic relationship through providers showing they care about their patients was also identified in the study as an enabler to self-management care and communication in the clinical encounter. For young adults with T2DM, it became clear the characteristics of this patient population simplified delivering care making it easier for providers to focus on topics that specifically relate to the patient.

In the study, several barriers to care became evident as well. These barriers appeared to be specifically associated with young adults with T2DM. The providers found this patient population has more guilt surrounding their diagnosis, and are more often in denial about their diagnosis and the potential complications from the disease. In addition to these emotions, young adults with T2DM have a perception of invincibility surrounding the disease, closing them off to receiving the care they need or taking their diagnosis seriously. Another major challenge providers face with young adults is their priorities made follow up care difficult with these patients. The main reason for this challenge is the

limited time young adults have because of their various responsibilities (work, family, school, etc.) and in turn how they prioritize their different responsibilities over their health. Lastly, the study findings highlighted the challenges young adults face with their lack of or limited prescription drug coverage when attempting to manage their diabetes.

The following sections discuss these major findings at length in relation to current literature and the implications of these findings in clinical settings.

### **5.1 Patient-provider interactions enable self-management care**

The findings from this study highlight the positive impact patient-provider interactions may have on self-management care. To start a patient-centred approach to care came through as a key finding to enabling young adults with diabetes to engage in their self-management care. One of the provider's had framed her approach to care as a "customer service approach", demonstrating how the care she provides is guided by and focused on the patient. Overall, the providers were concerned with ensuring the care they provide is focused on the patient. This is consistent with current approaches to delivering care in the clinical setting and is a component of self-management care [2]. Patient-centred care has been outlined as an important aspect of providing quality care for patients by organisations such as the Institute of Medicine [111] and the Canadian Medical Association [112]. Both of these organisations have included patient-centred care in publications presenting outlines or frameworks on how to improve care delivery [111, 112]. Moreover, the findings on patient-centred care reflect the Ontario Diabetes Strategy, which is focused on not only improving access to care for Ontarians but empowering patients to engage in their health care planning [42].

The Chronic Care Model (CCM) also includes patient-centred care as a component to successful self-management [62]. Studies have found when providers focus on the specific needs of their patients during the clinical encounter it can lead to improved self-care behaviours and more positive experiences for patients [40]. The patient-centred approach to care the participants in this study used can also lead

to improved patient-provider relationships. Lee and Lin [39] found when delivering diabetes care providers who are focused on patient-centred care had stronger patient-provider relationships, and the patients had improved mental health outcomes. Other studies focused on chronic illnesses found a strong patient-provider relationship was important to patients and helped to facilitate better communication in appointments [113].

To support the patient-centred approach the participants were concerned with showing they care about their young adult patients, which the participants believed developed the therapeutic relationship and provided better care. These findings suggest providers wanted to connect with patients on a more personal level to tailor care that fit the young adults' needs and lifestyle. The participants discussed that in appointments patients would talk about things unrelated to diabetes creating opportunities to foster trust and demonstrate they are interested in the patient's lives, which the participants thought led to a more meaningful relationship between the patient and provider. The key point from connecting with patients by showing interest is the providers' approach their patients as people not just patients; recognising patients have complex lives that involve much more than diabetes. Hudon et al. [78] also found connecting with patients in this way created trust and deepened the patient-provider relationship. Hudon et al. concluded a good patient-provider relationship is a key aspect of enabling care for patients with chronic conditions [78].

The findings also suggest that providers in the study connected with their patients through honest communication. Being up front with patients when they become uncomfortable helped the providers show they were interested in helping patients because they are pushing to understand what may be preventing care in order to address it. Studies looking at vulnerable populations suggested when providers focused on building a trusting relationship it became easier for providers to identify and address any barriers to care [16]. For young adults, building trust may play a significant role in identifying barriers because if young adults do not trust their providers they might not be willing to open

up about the guilt they feel about their diagnosis, which the study identified as a barrier to care. The findings also show young adults with T2DM can be in denial about their diagnosis, which can make delivering care difficult for providers. However, as other studies have found if patients trust their providers they are more likely to listen to their provider's recommendations [16], so for young adults in denial if they trust their providers they may be more open to listening to their recommendations. Thus, building trust may be a key part of enabling self-management care and communication for young adults with T2DM who are in denial about their diagnosis.

In the clinical encounter, patient-provider collaboration was also found to play a role in supporting self-management care and enabling communication for young adults with T2DM. Patient-provider collaboration is an important aspect of self-management care for diabetes because it encourages participation from patients when making decisions about their care [2]. Involving patients when making health-related decisions and having discussions about their self-care behaviours does improve patient's ability to self-manage [39, 82]. The findings suggest this remains true for young adults with T2DM. Patients with chronic illnesses, regardless of age, need to be involved when setting goals for self-care behaviours because it can increase patient autonomy, which is also known to lead to higher engagement with self-management care [39]. Approaching care in this way is consistent with the Chronic Care Model [62] and the Canadian Diabetes Association Clinical Guidelines [2], which encourages collaboration between patients and providers to increase patients' ability to self-manage their diabetes. The findings also support the Patients First Act passed by the Ontario government in December 2016 [114]. The Patients First legislation's aim is to make healthcare more accessible for Ontarians by addressing a number of needs in the Ontario healthcare system, one of which is giving patients a more active voice in their healthcare planning [114]. The findings from this study suggest primary care providers are seeking to involve patients more in their care and helping to integrate the Patients First Act into everyday care.

While the findings from this research suggest young adults taking a more active role in their care and collaborating with providers did help enable their ability to manage their diabetes this may not be the case for all young adults. When looking at patient-centred care the ultimate goal is to tailor care to the patients needs, and while there is evidence to suggest when patients take a more active role there is greater success at providing tailored care [39] not all patients may want to be actively involved in their care. Patient-centred care and even patient-provider collaboration need to be focused on what the patient desires in their care and their relationship with their provider. For some patients this may mean having the provider direct most of the care and the patient taking a more passive role in their care. It is important for providers to keep this in mind when treating their patients with diabetes because pushing a patient towards a more active role when they do not want it may become a barrier to care as patients could become resistant to what the provider is suggesting. Thus, continued research on young adults with diabetes should remain focused on the core meaning of patient-centred care, which is tailoring care to the needs of the patient meaning allowing them to engage in care and communication to the level they are comfortable and desire.

The findings from this study also come from family health teams (FHTs), a community health centre (CHC), a nurse practitioner led clinic, and a diabetes clinic run by multiple healthcare professionals out of a hospital. It appeared these types of clinics allowed for more patient engagement with young adults with T2DM because of their ability to have longer appointment times with their patients. The clinics also offer comprehensive primary care that includes services beyond seeing a physician, such as seeing [diabetes educators, or dietitians within the same site, which may also increase patient engagement with this patient population](#). Working in clinics like this may offer an explanation for why patient-centred care and patient-collaboration were so well implemented and appear to be successful with young adult patients. It is not known what enables care for young adults with T2DM who are attending other type of clinics in Ontario. However, the findings from this study may indicate that

primary care models such as FHTs or CHCs that present more opportunities for specialized diabetes clinics and longer appointment times are good models for patient-centred care and establishing strong patient-provider relationships.

Overall, the focus on patient-centred care, building trust with young with T2DM and encouraging patient-provider collaboration is consistent with the literature surrounding self-management care for diabetes. To provide the tools for successful self-management, the three enablers identified from the study all contribute to improved engagement in self-management. The study findings of patient-centred care, connecting with patients and collaboration between patient and provider are also consistent with the literature on what leads to open patient-provider communication. This suggests that current approaches to self-management care and communication may have a positive impact on young adults with T2DM and may be effective strategies to address the barriers this patient population faces, such as guilt and denial around the diagnosis. The findings also highlight the importance of patient-provider interactions in diabetes care because of the influence they can have on young adult's engagement with their care.

### **5.1.1 The role of technology in patient-provider interactions and self-management care**

The participants identified technology as a tool that enables both patient-provider communication and self-management for diabetes. The use of emails and text messages to connect with patients was found to help providers stay connected with young adults. Communicating with patients through email and text messages is an increasing practice in healthcare that has shown promise in engaging patients in their care and staying connected [115, 116]. Griffiths et al. [117] conducted a study on the effects of digital communication of young adults and found there were multiple positive results from providers engaging in care through emails, text messaging or mobile phone calls. The providers were able to engage young adults who were previously disengaged as well as improve trust with their patients [117]. The providers also found it helped improve patient empowerment for the young adults in the study

[117]. Griffiths et al.'s study suggests increasing digital communication can further engage young adults in their care. The findings from the present study also suggest connecting via digital technology may make it easier for providers to keep young adults with T2DM engaged.

Communicating over email or text message may be a way for providers to engage their young adult patients further, but it is important to remember it cannot replace in-person communication between patients and providers. One study found young adults preferred to receive test results in person rather than in a text message [118]. Also, confidentiality and privacy requirements limit how much information providers can discuss with patients over email or text message. This means in-person communication is still needed and communicating with patients outside of the appointment should act as a way to keep young adults engaged between appointments. There is also still limited research on how communicating over email, and text messages impact patient-provider communication [115, 117], meaning continued research in this area is needed for young adults and other age groups.

When looking at patient-provider communication through technology, such as text message and email provider compensation needs to be considered as well. While increasing communication through technology can improve patient engagement [115, 117] it is not entirely clear on how providers will be compensated for interacting with patients outside of the clinical encounter. A systematic review looking at mobile usage in diabetes management [119] reported there is no research looking at the issue of compensation for providers, but it was expressed in some studies as a potential barrier to providing care through mobile technology. Another systematic review looking at patient-provider communication via email [120] did not report findings focused on compensation for providers, but it did mention developing a clear set of guidelines on provider compensation may help to increase providers' willingness to communicate through email. The providers in this study did not mention any reluctance to communicate with their patients because of compensation issues. However, future research on technology in diabetes management, or more generally chronic care management would benefit from

looking at how this issue is currently being addressed in clinics, and what can be done to make a clear set of guidelines for compensation on communication outside of the clinical encounter.

Young adults also used applications on their phones to aid in diabetes management. The participants did not comment on whether or not this aided self-management for young adults, but there is some evidence in the literature that mobile interventions through applications or text message do positively impact diabetes care [121]. Nundy et al. also suggested mobile interventions for patients with diabetes can reduce denial of the disease [122]. There is limited research on the usefulness of mobile applications in diabetes management, which is problematic as the use of mobile applications for self-management will likely increase as it continues to become easier for people to access not only information but tools to help with diabetes management.

The participants in the study also observed that young adults with T2DM used the Internet to learn about diabetes and to help with their diabetes management. The use of technology in this way may signal a potential change in the role providers have for diabetes care as patients use providers to verify the information they have found instead of getting all their information from providers. The participating providers did not see this change in their role as a negative one, but there is the potential for negative ramifications if young adults access unreliable information on the Internet.

Hoffman-Goetz, Donelle and Ahmed [111] speak of the different aspects of eHealth literacy, which is a person's ability to seek and understand health information online. They discuss the much more complex nature of eHealth literacy when compared to health literacy, because it includes a person's ability think critically about information found on the Internet and identify fallacies in the information. Hoffman-Goetz, Donelle and Ahmed also discussed that while young people can easily navigate and search for health information online, they had trouble discerning reliable information from unreliable information, which can potentially lead to young adults following or believing incorrect or untested information about T2DM. To help prevent young adults accessing unreliable information the

participants took a proactive approach by providing young adults with useful websites that contain reliable information about diabetes and diabetes management. In this way the participants still had some influence on the information young adults were accessing over the Internet. Moving forward providers are going to have to become more aware of their patient's eHealth literacy as Internet usage and access is projected to continue to increase in the coming years [111]. Providers will have to be proactive in addressing the eHealth literacy needs of their patients, as the participants in the study were doing, in order to ensure all patients regardless of age are accessing safe and reliable information online.

The findings from this study on the use of technology for communication and self-management suggest young adults will continue to engage in care through technology and there is a need for providers to adapt to this change. Increasing the use of email and text messaging as a form of communication with young adults may help them stay engaged in their care in between follow up appointments and aid in building further trust with their providers. Also, the role of providers is changing with increased access to information via the Internet. Providers can help young adults access reliable information by giving out websites and even suggesting mobile applications that are reliable and useful for diabetes management. Technology usage in healthcare will likely continue to increase, and it is imperative providers engage with technology in order to stay relevant and connected with patients.

### **5.1.2 Young adults' less complex care**

One finding from the study suggests that fewer comorbidities and other health conditions in young adults with T2DM made providing care easier for the participants. This is beneficial to providers and young adults with T2DM because a barrier to self-management in diabetes care identified in the literature is difficulty managing the complex care regimens for people with comorbidities or other health conditions [19]. Fewer comorbidities allow providers and young adults with T2DM to have a greater focus on diabetes, and presents the opportunity to prevent future complications and minimize the development of comorbidities. This can have a positive influence on young adults' quality of life and the

economic burden of diabetes on the healthcare system, as preventive care can minimize the chances of being hospitalized from diabetes or having to visit a specialist which are costs that are projected to increase as more people are diagnosed with diabetes in Canada [25].

Taking advantage of the less complex care young adults with T2DM require may not only benefit patients quality of life and the healthcare system, but it may also make it easier to establish a strong patient-provider relationship with this patient population. Less complex care may benefit patient-provider relationships because the providers can focus more on cultivating the relationship during the appointment since there are not as many conditions to discuss or address during the appointment. As discussed above the patient-provider relationship is a key facilitator for engaging young adults with T2DM in their self-management care. Thus providers should take advantage of this important opportunity. Overall, fewer comorbidities is a characteristic for young adults that presents opportunities for providers to improve a patient's health and set them up to have a high quality of life with diabetes in the future.

## **5.2 Denial and invincibility preventing self-management care**

Some of the major barriers that were identified in the study were the denial young adults felt about their diabetes diagnosis, and the sense of invincibility young adults have about the disease. The literature suggests denial of a diagnosis affects people of all ages [109], but some of the participants suggested they have to deal with denial more often in young adults. The participants indicated that they often have to address the denial young adults have surrounding their diabetes diagnosis, which impacts their ability to provide care and communicate with this patient population. When young adults are in denial about their diagnosis providers may not be able to start self-management care because young adults do not feel the need to manage their diabetes.

Denial is a known barrier to chronic illness management that is associated with patients adjusting to a chronic illness diagnosis [109]. Chronic illnesses can significantly impact a person's life because of

potential lifestyle changes, the need for continuous medication, and potentially deteriorating health [109]. With these potential impacts, people can have a difficult time accepting the diagnosis during the initial phases of the disease [109, 123], making providing care difficult. For example, one study examining people's emotional responses to a diabetes diagnosis found patients who were in denial about their diagnosis also had thoughts of uncertainty for the future [124]. The researchers believed there was a link between an uncertain future and denial in people with diabetes because people were unable to cope with the potential future complications of the disease [124]. Young adults with T2DM may have several uncertainties about the future because they are often in transitional life stages. The uncertainties young adults have about their future may be associated with the providers' observations of denial in their young adults patients with T2DM. Also, the study discussed above had some evidence that denial in diabetes is inversely associated to age [124]. The data suggest that participants used denial to 'cushion' the potential negative complications from diabetes by avoiding thinking about an uncertain future [124], which decreased as the participants become older because of increased certainty in present and future circumstances. This data could also provide some insight as to why some of the providers' experienced denial in their young adult patients more often. While the study did discuss the connection to age and their findings on denial in diabetes [124], there has been no research conducted focusing on young adults and any associations between their age and denial of their diabetes. Research focusing on denial in young adults may identify specific barriers this population faces that are associated with their denial of diabetes, potentially making it easier for providers to address denial in the clinical encounter.

Another barrier to care the participants identified was young adults' sense of invincibility. The participants discussed the difficulties they had when young adults did not take their self-management seriously. There is no literature looking at invincibility in young adults with T2DM, or any other age group. The literature on invincibility looks at young adults engaging in high-risk behaviour such as

reckless driving [110]. The high-risk behaviour young adults with T2DM are engaging in is choosing not to engage in their diabetes care, which is not explored in the literature surrounding young adults and high-risk behaviour. Young adults choosing not to engage in diabetes care may be more associated with denial around diagnosis and the link with an uncertain future, but there is no evidence to support that idea.

The health belief model may offer some explanation for young adults' sense of invincibility towards T2DM. According to the health belief model the interaction of four different types of belief lead to how a person chooses to react to a health problem [125]. The four types of belief are as follows: perceived susceptibility to a health problem, perceived seriousness of consequences of a health problem, perceived benefits of taking action, and perceived barriers to taking action [125]. For young adults they may not believe they are susceptible to the complications associated with diabetes, or they do not think the complications are very serious. If this is the case and young adults do not see the benefits to taking action because they do not see diabetes complications as a threat, it may create a sense of invincibility that prevents action on their part. Research using the health belief model, may lead to a greater understanding on why young adults have a sense of invincibility about their diabetes. It may even be useful for healthcare providers and researchers to develop health interventions using the health belief model for young adults with T2DM. Overall, research focusing on young adults' sense of invincibility is imperative because young adults are potentially setting themselves up for more serious complications later on in life in not engaging in self-management care.

The denial and invincibility the participants observed in young adults with T2DM are potentially serious barriers to self-management care and communication. The more aggressive nature of T2DM in young adults and the increased risk of cardiovascular complications means this patient population needs to be participating in their care and managing their diabetes. Denial over the diagnosis and a sense of

invincibility will limit active engagement in care and can prevent a provider's ability to proactively treat the symptoms to minimize the impact of the complications.

### 5.3 The stigma of diabetes and the associated guilt in young adults

The participants observed young adults with T2DM had guilt about diabetes and tended to feel worse about themselves than other age groups. The guilt young adults experienced is likely associated with the stigma associated with diabetes, particularly type 2 diabetes mellitus. Research has found people without diabetes do believe it is the person's fault for developing the disease, and this is especially true for people with type 2 diabetes who were overweight [126]. Individuals living with diabetes have also reported feeling stigmatized in everyday life [127]. The participants in the study for this thesis did observe some young adults with T2DM have not informed their friends or family of their diagnosis, but it could not be confirmed if this was out fear of being stigmatized. In this way, stigma can act as a barrier to self-management care because a patient not informing their family or friends of the disease can make managing care difficult as they may not follow the guidelines as closely. It might also prevent them from taking their medication regularly out of fear of being discovered and judged.

Stigma and guilt can act as barriers to care and communication in the clinical encounter as well. In the clinical encounter, some participants observed if young adults had less than ideal test results or had not implemented self-care behaviours they would avoid follow-up appointments. The participants also observed if young adults perceived judgement from providers they closed off communication in the encounter. The guilt and stigma young adults felt in these situations created barriers to self-management care and communication in the encounter. Browne et al. [127] had mixed results concerning stigma from healthcare providers, with some participants of the study experiencing it while other did not. They had similar results stating people with diabetes who experienced judgement from their provider avoided follow-up appointments, and in their study, some participants even sought new providers [127]. Experiencing judgement from providers is a serious barrier that could impact a person

with diabetes for a long time making self-management care difficult to receive, as they may be fearful of their provider's reaction to negative results and further avoid appointments. In this study participants suggested that they were aware how their communication with patients could have a negative impact on patient care. For this reason, the participants tried to promote a judgement free environment during encounters with young adult patients to avoid creating any sense of stigmatization. Promoting a judgement free environment is one way to prevent any problems with care arising from patients feeling stigmatized in encounters and further research on how to create judgement free environments for patients with diabetes would be beneficial for primary care providers.

People with diabetes may also be experiencing shame for not achieving the goals they set or maintaining self-care behaviours, which could also cause patients to avoid appointments with their providers. Feeling shame can create barriers to communication as well, because patients may be reluctant to be honest with their providers on their self-care behaviours. Although the idea of experiencing shame did not come through strongly in the findings for this study, the providers desire to create a judgement free environment may speak to an awareness of the potentially negative impact of shame on care. Further research that includes the perspectives of young adults with diabetes may be able to more clearly identify the interactions of feeling stigmatized, or fear or being stigma and feelings of shame with patients. Understanding how shame and stigmatization play a role in people's willingness to follow-up with their providers may help to address this potential barrier in the clinical encounter and give providers more insight on how their patients are reacting to difficulties in maintaining or achieving their goals.

Young adults also may experience more guilt than older people with the disease because, as one of the providers observed young adults feel they could not blame age for the development of the disease thus they felt as if more of the blame for the disease came from their actions. Self-blame can potentially become a significant barrier for young adults if they feel the diagnosis of diabetes rests solely on their

shoulders. There is no research on the guilt or self-blame young adults experience from diabetes or any other chronic illnesses, which is problematic because self-blame and guilt could become a significant stressor for young adults. Research on the effects of stigma and shame on young adults is needed as well because they may be large components of the increased self-blame and guilt the participants from the study observed with their young adult patients.

#### **5.4 The role of young adults' circumstances in self-management care**

Certain aspects of young adults' lives can act as barriers to receiving self-management care. The participants often discussed the limited availability of young adults with T2DM as one of these barriers. Time management is a well-known barrier to self-management for people with diabetes because of the various self-care behaviours people with diabetes maintain [19]. In the study, the providers spoke of young adults' lack of time making it difficult for them to engage in follow-up care as well as having difficulties maintaining their self-care behaviours. For young adults, the participants framed their limited availability as a result of differing priorities. Young adults have numerous responsibilities, such as work and family that takes up much of their time. The participants suggested these responsibilities make young adults' health less of a concern.

While time management is a known barrier to care to frame it as differing priorities changes the barrier. It becomes less about a young adults' ability to manage their time and more about what is important to them and what they are willing to spend their time doing. It is a tiny distinction, but understanding young adults' limited time in this way may make it easier to find solutions to this barrier. Young adults' different priorities are also more specific to them because, as the participants suggested, they often have young families and new careers which need much more attention whereas older adults may have older children and more stable careers making it easier to focus on their health. Prioritizing other responsibilities above health may prove to be problematic for young adults when considering the need for tighter glycemic control because of the aggressive nature of the disease [26].

Another aspect of young adults' lives that is a barrier to care is drug coverage. Diabetes is a costly disease, and without drug coverage, it can quickly become a burden for any person living with the disease [59]. The participants discussed the challenges young adults face because they may have little to no drug coverage. In Ontario the Ontario Health Insurance Plan (OHIP) does not cover the cost of pharmaceuticals meaning Ontarians must pay out-of-pocket for medication or find additional health coverage from an employer or independently [60]. This can make self-management difficult for people with diabetes because of the cost of medical supplies and medication. This applies in particular to young adults who may not have health coverage from an employer.

Neinstein and Irwin [59] discuss the challenges young adults with T2DM face because of their limited resources and lack of adequate health coverage. Neinstein and Irwin were discussing young adults with T2DM living in the United States, who have greater challenges with health coverage than young adults who live in Canada. However, young adults in Canada still face challenges with health coverage. In Ontario it was recently announced in 2018 individuals up to the age of 25 will have free drug coverage of over 4,400 different medications [128], which will ease the burden of medications costs on young adults with diabetes in their early 20s. However, a large portion of young adults with diabetes will still be dependant on private health insurance to cover their medication costs, or they will have to pay out of pocket for medication. The high cost of medication for diabetes and the limited drug coverage for young adults creates a significant barrier to care because they may be unable implement the self-management care the providers suggest making it difficult to manage their diabetes properly. This limitation makes drug coverage a barrier worth considering when looking at young adults with diabetes' ability to access care and manage their diabetes. There is no research on how drug coverage impacts self-management care for young adults in Canada, which is problematic because of the specific challenges of the Canada's healthcare system. Research on self-management care for diabetes in the

Canadian context is needed to fully understand how drug coverage or lack thereof impacts young adults' ability to self-manage their care.

### **5.5 Mishler's Lifeworld: A way to understand communication in chronic care management**

In this study, Mishler's Lifeworld theory [91] was used as a framework for approaching patient-provider communication in the clinical encounter. Mishler believed that in the clinical encounter there were two 'voices' present, the 'voice of the lifeworld' and the 'voice of medicine' [91]. The 'voice of the lifeworld' came from the patient's understanding of their illness and how it impacts their lives, while the 'voice of medicine' is the biomedical approach to illness that the provider often brings into the appointment. Mishler believed conversations in the clinical encounter needed to be symmetrical, meaning providers needed to allow the 'voice of the lifeworld' to come through in appointments more often in order to better serve patients and to understand how the patient's illness impacts their life. This study used this understanding of the two different 'voices' in the clinical encounter as a way to see how patients and providers communicate and interact with each other.

During the analysis of the data collected from the primary care provider participants, it was suggested that providers are aware of the 'voice of the lifeworld' and they are actively working towards more symmetrical conversations where patients can voice how diabetes impacts their lives. In the results, the participants spoke of wanting patients to lead conversations. The participants also talked about allowing patients to talk about their lives, sometimes not even addressing diabetes in an appointment. The participants suggested if providers were unaware of a patient's social context they would not be able to help patients successfully self-manage their diabetes. These results suggest providers know understanding the social context of a patient's life is a key aspect in delivering relevant care for patients. The participants were attempting to do what Mishler suggested by allowing the 'voice of the lifeworld' to come through in the clinical encounter to gain a better understanding of how

diabetes shapes or impacts a patient's life. The participants spoke of wanting more symmetrical conversations where the patient plays a more significant role in their care.

It is important to note David Silverman's critique [92, 93] of Mishler's theory when looking at the data from this study. Silverman believed patients desired asymmetrical interactions with their providers because patients go to providers for their expertise in medical matters. The providers in this study appeared to want more symmetrical conversations and interactions with their patients, however it should be kept in mind that some patients do not desire this kind of interaction. Moreover, remembering that the clinical encounter is meant for patients to receive help or information from an expert, the provider, makes it not entirely possible to have a perfectly symmetrical interaction or discussion. Keeping this in mind suggests that patient-provider interactions and communication are not necessarily as simple as Mishler and even Silverman believed. Communication in the clinical encounter is complex because of patient and provider's individual preferences for communicating and varying circumstances, which can make either more symmetrical or asymmetrical interactions appropriate depending on the situation, and the patient and provider involved.

Another aspect of Mishler's theory to keep in mind when looking at patient-provider communication is what the provider's motives are for encouraging the voice of the lifeworld to come out in the clinical encounter. Mishler suggested doing so would lead to better interactions between patients and their providers, and providers coming to understand their patients better. Mishler believed this would lead to more symmetrical conversations with more patient-provider collaboration. However, some providers may allow patients to discuss their lives to increase trust and in turn lead to higher compliance from patients. Using discussions to increase patient compliance does not necessarily lead to more symmetrical conversations or interactions as the provider uses this as a tool to instruct the patient on what they need to do. Some of the providers in this study did mention getting to know their patients was a way to have greater influence over them in their care, and while this is not necessarily a bad way

to approach care, it does not lead to a truly symmetrical interaction as Mishler had described. Providers encouraging the voice of the lifeworld to come out in this way may actually support Silverman's critique by showing the clinical encounter still remains an asymmetrical interaction.

Encouraging patients to share their lives to gain more influence over them may show that Mishler's Lifeworld theory, while an effective tool in understanding the perspectives patients and providers bring into appointments, may be oversimplified in looking at the symmetry or power balance in the clinical encounter. Silverman's critique brought light to this and this study suggests patient-provider interactions are more complex than Mishler believed, particularly when looking at chronic care management.

In chronic care management, patients often need to self-manage their illness meaning the context of a patient's life can significantly impact their ability to manage the disease. This is especially so for patients with diabetes because their circumstances can impact their capacity to exercise, eat healthily, minimize stress, or take medication regularly. For this reason, the 'voice of the lifeworld' almost has to come through in the clinical encounter and providers need to recognize it so they can adequately provide care. The participants in this study appeared to be aware of the necessity of the 'voice of the lifeworld' in the clinical encounter and suggested it is a key aspect in delivering self-management care and communicating with patients. This means Mishler's Lifeworld theory is a useful tool when looking at how communication occurs in chronic care management because it offers a way of understanding the perspectives patients and providers bring to appointments. Mishler's Lifeworld theory can also provide a way of understanding how patients with chronic illnesses perceive their illness, and how a chronic condition impacts patients every day lives. However, it is important to keep in mind that Mishler's belief that interactions should be more symmetrical and how to attain that symmetry are complex. Also, the motives behind how patients and providers interact in the clinical encounter need to be considered when trying to better understand patient-provider interactions and communication.

Future research looking at patient-provider communication in chronic care management can use Mishler's Lifeworld theory as a framework to approach how patients and providers interact.

## **5.6 Implications for clinical practice and future research**

### **5.6.1 Study relevance for clinical practice**

The findings from this study indicate there is a need for a greater focus on the needs of young adults with T2DM in Canada. The participants in this study observed current approaches to chronic care management do help engage young adults in their self-management care, such as patient-centred care. Thus, a continued focus on patient-centred care and collaboration will help young adults to manage their diabetes. A focus on providers showing their interest in patients is also needed in clinical practice. The findings suggested when providers took the time to show that they care about their patients it helped put young adults at ease and created stronger bonds that may have resulted in higher engagement in their self-management care. Providers should make sure they are focusing on this when treating their young adult patients.

Providers should also emphasise the use of technology in care, as the findings suggest it can help providers stay connected to their patients and engage them in their care. In clinical practice, if providers have resources ready for patients they can aid young adults in finding reliable information on the Internet. The participants observed that young adults access the Internet to self-educate and to aid in self-management, so the role of the provider needs to grow to include helping patients navigate the Internet for their self-management needs. Providers can also encourage the use of digital technology (text message, email) to stay connected with their young adult patients between visits. Although research is limited, the literature did support the findings that engaging with patients through digital technology can act as a facilitator to communication and care for young adults. Thus, in current and future practice engaging with technology can help providers stay relevant to young adults and keep them close. Engaging with technology to stay connected and to help limit patient's exposure to

unreliable information may also help address some of the barriers to communication and care for young adults with T2DM. If providers stay connected with young adults, it gives them more opportunities to provide follow-up care, helping to address young adults' limited time. It may also help make health a higher priority for young adults, as continued communication with providers may keep them more engaged in their care.

Also, young adults' denial and sense of invincibility are significant barriers providers can begin to address through the increased use of technology. Staying connected with patients can help them deal with their denial [116] and possibly help them come to terms with the potential future complications they will have if their diabetes is not managed. The participants in this study also suggested the importance of dealing with young adults' denial and the sense of invincibility because they can act as significant barriers to communication and care. Thus, in primary care, there needs to be a focus on denial and invincibility when treating young adults with T2DM. Overall, continued awareness of the specific needs of young adults with T2DM in clinical practice will help providers address the barriers this patient population faces, while also presenting more opportunities for providers to engage young adults in their self-management care. With young adults, providers have the opportunity to offer less complex care that can work towards preventing future complications, which can reduce the burden of diabetes on the patients and the healthcare system.

### **5.6.2 Future research on young adults with T2DM**

There is a need for further research on young adults with T2DM and what impacts their self-management care in the Canadian context. Continued research in this area will identify more potential barriers young adults face, while also properly assessing the strengths and weaknesses of the Canadian healthcare system for this patient population. This study did not focus on the impact of the Canadian healthcare system on young adults, thus it did not have a lot of data to shed light on this matter.

However, this study did suggest the move towards putting patients first, as outlined in the Patient First

Act [114] is working well in Ontario. This study also demonstrated the difficulties in recruiting young adults with T2DM for research, and in doing so highlighted the need for further research that includes young adults. Understanding the perspective of young adults with T2DM can improve the self-management care they receive and possibly lead to more open communication during appointments.

When considering the denial and sense of invincibility the participants in this study identified, research on young adults' perspectives on how they adjust and accept their diagnosis can help healthcare providers better understand how to break down these barriers in the clinical encounter. Young adults' sense of invincibility is also an important area for continued research considering there is little to no research looking at invincibility in the context of chronic care management. Continued research in this area could lead to a greater understanding of not only young adult patients with chronic illnesses but possibly teenagers as well.

Lastly, continued research on technology in diabetes self-management care is needed to understand how technology is changing the way patients and healthcare providers approach care and communication. Some research has been conducted outside of this study that suggests using technology to enhance self-management care, and patient-provider communication does have a positive impact on patients. More research in this area can also help minimize the potential negative impact of technology on self-management care, and lead to a greater understanding of how technology is changing healthcare providers' roles for their patients in chronic care management.

## **5.7 Study limitations**

The study had some limitations, which were: (1) the small number of young adults with T2DM participants and (2) the overall sample size. The original intent of the study was to have young adults with T2DM as the primary study population and use the primary care providers as a secondary study population to support and offer an alternative perspective to the barriers and facilitators to self-management care, and patient-provider communication. A higher number of young adult participants

would have offered more insight on what enables or prevents young adults from receiving the care they need and communicating with their primary care providers. Only having the perspective of the primary care providers is limiting, making it difficult to have a more comprehensive understanding of self-management care for young adults with T2DM.

The reason the focus of the study changed from young adults with T2DM to primary care providers was because of difficulties in recruitment. The researcher was aware recruiting young adults was going to be difficult; however, she did not anticipate having little to no interest from young adults to participate in the study. Additionally, a few of the clinics that were contacted were conducting research that included young adults with T2DM and did not want to over burden their patients with multiple studies. This limited access to young adults making recruitment even more difficult. Several new recruitment strategies were added throughout the recruitment period of the study, all of which were discussed earlier in the thesis, however this did little to increase young adults' interest in the study.

The findings from this study do offer an explanation for the difficulty in recruiting young adults with T2DM. The providers spoke of young adults being in denial about their diagnosis and how this sometimes limited their ability to speak of the disease. If young adults are in denial about their diagnosis then it is unlikely they would be interested in participating in a study about a disease they are having a difficult time accepting. Moreover, it was clear in the study that young adults with T2DM had many responsibilities that made attending appointments a low priority for them. This would be true for participating in a study as well; if young adults are unable or unwilling to make their health a priority they likely will not have time to participate in a study discussing their experience with diabetes. Future research with this patient population should take this into consideration when developing a recruitment strategy in order to maximize the possibility of successfully recruiting this patient population.

The small sample size of the study is a limitation as well. A total of 13 participants were included in the study, 11 of which were primary care providers who treated patients with diabetes. A larger sample

size would have offered more opportunities to identify patterns between the participants' characteristics and the core concepts that were identified from the interviews. The ability to link participants' characteristics to the themes found from the interview data could have provided more insight and understanding to the various barriers and facilitators the primary care providers identified. However, the sample size was large enough to identify barriers and facilitators to self-management care and communication for young adults with T2DM.

## 5.8 Conclusions

Type 2 diabetes mellitus (T2DM) is a growing problem in Canada and internationally, with the number of people living with the disease only expected to continue to grow in the coming years [3, 21]. The age of onset for T2DM has been falling and researchers believe it will continue to do so in the coming years[1]. For this reason, it is imperative researchers, and healthcare providers understand how T2DM impacts self-management care for young adults, which is the most common approach for managing the disease [2]. Understanding what influences patient-provider communication for young adults with T2DM is important as well because of the influence communication has on the self-care behaviours and health outcomes of people with T2DM [9, 11]. The more aggressive nature of T2DM in young adults [26] makes it even more important to understand what prevents and enables self-management care and communication for this patient population.

The mixed methods study presented in this thesis was done with the aim of identifying what enables and prevents care for young adults with T2DM in Canada. The study was able to identify several enablers to care, which included patient-centred care, providers showing they care, patient-provider collaboration, fewer comorbidities in young adults, and young adults' use of technology. The barriers young adults with T2DM face included denial of their diagnosis, young adults' sense of invincibility, the stigma and guilt associated with T2DM, young adults' differing priorities, and the young adults' limited drug coverage.

This study offered insight into what impacts care for young adults with T2DM in Canada while identifying several areas that need further research. The study also showed how Mishler's Lifeworld theory [91] could be used to understand patient-provider communication in chronic care management. Overall the study suggested young adults with T2DM do face specific barriers to self-management care and communication in the Canadian context. Focusing on the needs of this patient population in years to come will not only help young adults with T2DM but also help the Canadian healthcare system deliver care that is relevant and efficient to young people living with diabetes.

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## ***Appendix A: Clinic recruitment email***

Hello,

My name is Alana Armas and I am currently an MSc candidate in the School of Public Health and Health Systems at the University of Waterloo. I am contacting you today because my research project may be of interest to you. To fulfill my thesis requirements I am conducting a study examining communication between young adults with type 2 diabetes and their primary care providers/ diabetes educators. I am seeking clinics that can provide both providers and patients as participants for this project. Also, I am seeking assistance from participating clinics with the recruitment of patients, which includes advertising my study in clinics. Below is a brief overview of the project.

Self-management plays a central role in the prevention of diabetes-related health complications. However, there is a lack of research investigating communication between primary care providers and young adults (approximately ages 20 -39) living with type 2 diabetes mellitus (T2DM), and the impact it has on their self-management. This research proposes to, for the first time investigate the communication preferences of young adults about T2DM self-management. In addition to this, the research aims to identify any barriers or facilitators to communication about T2DM self-management.

I am looking to recruit 1 or 2 providers or diabetes educators who work regularly with T2DM patients, and approximately 3 to 5 patients between the ages of 20 – 39 who have been diagnosed with T2DM as participants in our study. All that I require from participating clinics is for a few team members to hand out information about my study to those who are eligible, and ask patients who show interest to contact us. All information and conclusions from this research will be shared with participating clinics upon completion of the project and the researchers will aid the clinics in integrating any valuable information into practice.

I have qualitative research training and experience working with patients through my Honours dissertation. Also, I was awarded a grant to conduct this research project by the Propel Centre for Population Health Impact.

Thank you for taking the time to read about my research project. Please do not hesitate to contact me at any point with questions or concerns. I look forward to hearing from you.

Sincerely,

Alana Armas

## **School of Public Health and Health Systems University of Waterloo**

### **PARTICIPANTS NEEDED FOR RESEARCH IN *TYPE 2 DIABETES***

We are looking for volunteers to take part in a study of *communication between individuals with type 2 diabetes and their healthcare providers.*

As a participant in this study, you would be asked to: *fill out a survey and participate in an interview.*

Your participation would involve 1 session, each of which is approximately 40 to 75 minutes.

In appreciation for your time, you will receive *\$20.00 gift card.*

For more information about this study, or to volunteer for this study, please contact:

*Alana Armas*  
*School of Public Health and Health Systems*

at  
226-338-7288 or  
Email: [aarmas@uwaterloo.ca](mailto:aarmas@uwaterloo.ca)

**This study has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee.**

Alana Armas  
226-338-7288  
[aarmas@uwaterloo.ca](mailto:aarmas@uwaterloo.ca)

## ***Appendix C: Information letter for primary care providers***

Dear Participant:

This letter is an invitation to consider participating in a study I am completing as a part of my thesis for my Masters of Science degree in the School of Public Health and Health Systems at the University of Waterloo. I am completing this thesis under the supervision of Assistant Professor Samantha Meyer, PhD. I would like to provide you with more information about this project and what you will be doing if you decide to be a part of this study.

This project aims to understand how people wish to speak with their healthcare providers when discussing type 2 diabetes management. In order to achieve this I am surveying and interviewing people aged 20 to 39 living with type 2 diabetes, and healthcare providers regarding how they speak with each other during appointments. Specifically, I wish to gather information on patients' and providers' experiences when talking about managing type 2 diabetes.

Participation in this study is voluntary. It will involve one study session with a short survey approximately 10 minutes in length and an interview approximately 30 to 60 minutes in length. The session will take place in a mutually agreed upon location. To ensure an accurate recording of your responses the interview will be audio recorded, and the researcher will be taking notes throughout the study session. You may decline to answer any of the survey or interview questions if you so wish by skipping a question on the survey, or informing the researcher you do not wish to answer the question.

In appreciation of your participation, you will receive a \$20.00 gift card. The amount received is taxable. It is your responsibility to report this amount for income tax purposes. A benefit to participating in this study is the conclusions from the research will be shared with you, so you can integrate any conclusions from the study into your practice, if you so chose. The findings from this research will benefit the scientific community by contributing conclusions on how people aged 20-39 with type 2 diabetes wish to communicate with their providers in Canada. This is beneficial because researchers will be able to use the results and tools from the study to further understand how age-specific patient populations have varying needs and ways of understanding their health.

You may decide to withdraw from this study at any time without any negative consequences by informing the researcher. All information you provide is considered completely confidential. Your name will not appear in the final thesis; however, with your permission anonymous responses may be used. Only researchers associated with the study will have access to the responses from the survey and interview. There are no known or anticipated risks to participation in this study. The data collected through this study will be kept for a period of 7 years in a secure location.

If you have any questions regarding this project, or would like more information to assist you in reaching a decision about participation, please contact Alana Armas at 226-338-

7288 or by email at [aarmas@uwaterloo.ca](mailto:aarmas@uwaterloo.ca). You can also contact my supervisor by email if you have any questions, Samantha Meyer, PhD at [samantha.meyer@uwaterloo.ca](mailto:samantha.meyer@uwaterloo.ca).

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. However, the final decision about participation is yours. Should you have any comments or concerns about your participation in this study, please contact Dr. Maureen Nummelin in the Office of Research Ethics at 1-519-888-4567, Ext. 36005 or [maureen.nummelin@uwaterloo.ca](mailto:maureen.nummelin@uwaterloo.ca).

I very much look forward to speaking with you and thank you in advance for your assistance in this project.

Yours Sincerely,

Alana Armas  
Lead Investigator

## ***Appendix D: Information letter for young adults with T2DM***

Dear Participant:

This letter is an invitation to consider participating in a study I am completing as a part of my thesis for my Masters of Science degree in the School of Public Health and Health Systems at the University of Waterloo. I am completing this thesis under the supervision of Assistant Professor Samantha Meyer, PhD. I would like to provide you with more information about this project and what you will be asked to do if you decide to be a part of this study.

This project aims to understand how people wish to speak with their healthcare providers when discussing type 2 diabetes treatment. In order to achieve this I am surveying and interviewing people aged 20 to 39 living with type 2 diabetes, and healthcare providers regarding how they speak with each other during appointments. Specifically, I would like to gather information on patients and providers' experiences when talking about managing type 2 diabetes.

Participation in this study is voluntary. It will involve one study session with a short survey approximately 10 minutes in length and an interview approximately 30 to 60 minutes in length. The session will take place in a mutually agreed upon location. To ensure an accurate recording of your responses the interview will be audio recorded, and the researcher will be taking notes throughout the study session. You may decline to answer any of the survey or interview questions if you so wish by skipping a question on the survey, or informing the researcher you do not wish to answer the question.

In appreciation of your participation, you will receive a \$20.00 gift card. The amount received is taxable. It is your responsibility to report this amount for income tax purposes. There are no personal benefits associated with the study. However, the findings from this research will benefit the scientific community by contributing conclusions on how people aged 20-39 with type 2 diabetes wish to communicate with their providers in Canada. This is beneficial because researchers will be able to use the results and tools from the study to further understand how age-specific patient populations have varying needs and ways of understanding their health.

You may decide to withdraw from this study at any time without any negative consequences by informing the researcher. All information you provide is considered completely confidential. Your name will not appear in the final thesis; however, with your permission anonymous responses may be used. Only researchers associated with the study will have access to the responses from the survey and interview. There are no known or anticipated risks to participation in this study. The data collected through this study will be kept for a period of 7 years in a secure location.

If you wish to contact the researcher directly with any questions regarding this project, or would like more information to assist you in reaching a decision about participation,

please contact Alana Armas at 226-338-7288 or by email at [aarmas@uwaterloo.ca](mailto:aarmas@uwaterloo.ca). You can also contact my supervisor by email if you have any questions, Samantha Meyer, PhD at [samantha.meyer@uwaterloo.ca](mailto:samantha.meyer@uwaterloo.ca).

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. However, the final decision about participation is yours. Should you have any comments or concerns about your participation in this study, please contact Dr. Maureen Nummelin in the Office of Research Ethics at 1-519-888-4567, Ext. 36005 or [maureen.nummelin@uwaterloo.ca](mailto:maureen.nummelin@uwaterloo.ca).

I very much look forward to speaking with you and thank you in advance for your assistance in this project.

Yours Sincerely,

Alana Armas  
Lead Investigator

## Appendix E: Recruitment flyers for CDA Research Forum



School of Public Health and Health Systems

### **PARTICIPANTS NEEDED FOR RESEARCH IN TYPE 2 DIABETES**

We are looking for volunteers to take part in a study of *communication between individuals with type 2 diabetes and their healthcare providers.*

**To be eligible to participate in this study volunteers must meet the following criteria:**

- 1) **20 – 39 years of age**
- 2) **Diagnosed with type 2 diabetes for at least 6 months**

As a participant in this study, you would be asked to: *fill out a survey and participate in an interview.*

Your participation would involve *1* session, which is approximately *40 to 75* minutes.

In appreciation for your time, you will receive ***\$20.00 gift card.***

For more information about this study, or to volunteer for this study, please contact:  
***Alana Armas***  
***School of Public Health and Health Systems at***  
***226-338-7288 or***  
***Email: [aarmas@uwaterloo.ca](mailto:aarmas@uwaterloo.ca)***

**This study has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee.**



School of Public Health and Health Systems

### **PARTICIPANTS NEEDED FOR RESEARCH IN TYPE 2 DIABETES**

We are looking for volunteers to take part in a study of *communication between individuals with type 2 diabetes and their healthcare providers.*

**To be eligible to participate in this study volunteers must meet the following criteria:**

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Your participation would involve *1* session, which is approximately *40 to 75* minutes.

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**This study has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee.**

## ***Appendix F: Recruitment materials for DES Grand River Chapter Meeting***

May 2016

### **A mixed methods investigation on patient-provider communication in the self-management of type 2 diabetes mellitus in young adults**

My name is Alana Armas and I am currently an MSc candidate in the School of Public Health and Health Systems, at the University of Waterloo. To fulfill my thesis requirements I am conducting a study examining communication between young adults with type 2 diabetes and their primary care providers/ diabetes educators. I am seeking clinics that can provide both providers and patients as participants for this project. Also, I am seeking assistance from participating clinics with the recruitment of patients, which includes advertising my study in clinics. Below is a brief overview of the project.

Self-management plays a central role in the prevention of diabetes-related health complications. However, there is a lack of research investigating communication between primary care providers and young adults (approximately ages 20 -39) living with type 2 diabetes mellitus (T2DM), and the impact it has on their self-management. This research proposes to for the first time, investigate the communication preferences of young adults about T2DM self-management. In addition to this, the research aims to identify any barriers or facilitators to communication about T2DM self-management.

From participating clinics, I am looking to recruit 2 to 3 providers or diabetes educators who work regularly with T2DM patients, and approximately 5 to 8 patients between the ages of 20 – 39 who have been diagnosed with T2DM as participants in my study. All that I require from participating clinics is for a few team members to hand out information about my study to those who are eligible, and ask patients who show interest if they are willing to provide their contact information so I may contact them. In addition to this I have flyers advertising my research that can be posted in participating clinics.

All participants in my research will be given an honorarium of \$20 in appreciation for their time. In addition to this all information and conclusions from this research will be shared with participating clinics upon completion of the project, and I will aid the clinics in integrating any valuable information into practice.

If you have any questions regarding this project, or would like more information please contact me at 226-338-7288 or by email at [aarmas@uwaterloo.ca](mailto:aarmas@uwaterloo.ca). You can also contact my supervisor, Samantha Meyer, PhD by email at [samantha.meyer@uwaterloo.ca](mailto:samantha.meyer@uwaterloo.ca) if you have any questions.

I would like to assure you that this study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee. Should you have any comments or concerns resulting about your clinic's participation in this study, please contact Dr. Maureen

Nummelin, in the Office of Research Ethics at 1-519-888-4567 Ext. 36005 or [maureen.nummelin@uwaterloo.ca](mailto:maureen.nummelin@uwaterloo.ca).

Thank you for taking the time to read about my research project. Please do not hesitate to contact me at any point with questions. I look forward to hearing from you.

Sincerely,  
Alana Armas

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## *Appendix G: Consent form*

### **CONSENT FORM**

By completing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

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I have read the information presented in the information letter about a research project being conducted by Alana Armas of the School of Public Health and Health Systems at the University of Waterloo, under the supervision of Samantha Meyer, PhD. I have had the opportunity to ask any questions related to this project, to receive satisfactory answers to my questions, and any additional details I wanted.

I am also aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am also aware that responses from the interview and survey may be included in the thesis of the research project, with the understanding that the results will be confidential.

I was informed that I can withdraw my consent at any time without penalty by advising the lead investigator.

This project has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this research project.

YES  NO

I agree to have my interview audio-recorded.

YES  NO

I agree to the use of anonymous responses in the thesis of the research project.

YES  NO

Participant Name: \_\_\_\_\_

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

Date: \_\_\_\_\_

*Appendix H: Surveys for primary care providers and young adults with T2DM*

**Provider Survey**

***You may skip any questions you do not feel comfortable answering.***

1. Please indicate your gender: \_\_\_\_\_
2. How many years have you been working as a health care provider? \_\_\_\_\_
3. Do you speak/ understand any other languages?
  - Yes
  - No

If so, please indicate all other languages you speak/understand:

\_\_\_\_\_

4. What type of health professional are you?
  - Family physician
  - Nurse
  - Nurse Practitioner
  - Dietitian
  - Diabetes Educator
  - Other: \_\_\_\_\_
5. How long have you been providing health care or health education to patients with diabetes? \_\_\_\_\_
6. Do you regularly treat diabetic patients?
  - Yes
  - No
7. Approximately, how many patients in your patient or client load are between 20 and 39 years old and have type 2 diabetes? \_\_\_\_\_
8. What is the average amount of time you spend with a patient in a typical appointment?  
\_\_\_\_\_

9. When in an appointment with a patient do you:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Not Applicable / I don't know
a. Ask the patient if he/she understands your explanation of test results?	1	2	3	4	5	0
b. Ask the patient if he/she understands your explanation of treatment/management options?	1	2	3	4	5	0
c. Ask patients to elaborate on personal matters that may impact their diabetes care?	1	2	3	4	5	0
d. Involve the patient when making treatment and management decisions?	1	2	3	4	5	0

10. Have there ever been times when:

	Yes	No	Not applicable
a. Your patient has been unable to meet with you because of time constraints, limited access to transportation, etc.?	1	2	3
b. You worked with a patient to make it easier for them to book an appointment/session with you?	1	2	3

## Patient Survey

*You may skip any questions you do not feel comfortable answering.*

1. Please indicate your gender: \_\_\_\_\_
  
2. Please indicate your age: \_\_\_\_\_
  
3. What is the highest level of education you have received?
  - No schooling completed
  - Elementary school only
  - Some high school, no diploma
  - High school diploma
  - Some college credit, no diploma
  - College diploma
  - Trade/technical/vocational training
  - Some university credit, no degree
  - University undergraduate degree
  - University post-graduate degree
  
4. Are you currently a student? \_\_\_\_\_
  
5. What is your cultural or ethnic background?  
\_\_\_\_\_
  
6. What city/town do you currently live in?  
\_\_\_\_\_
  
7. Is English your first language?
  - Yes
  - No
  
8. When were you diagnosed with type 2 diabetes? \_\_\_\_\_
  
9. How long have you been attending your current doctor's office?  
\_\_\_\_\_

10. Who do you currently see for your diabetes management? (Check all that apply)

- Family physician
- Nurse
- Nurse Practitioner
- Dietitian
- Diabetes Educator
- Other: \_\_\_\_\_

11. When in an appointment with your provider (family physician, nurse, dietitian, etc.) do you:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Not Applicable / I don't know
a. Easily talk about personal things with your provider?	1	2	3	4	5	0
b. Easily ask questions about how you should manage your diabetes?	1	2	3	4	5	0
c. Answer the provider's questions in detail?	1	2	3	4	5	0
d. Let the provider know when you don't understand something?	1	2	3	4	5	0
e. Provide input into how your diabetes will be managed (ie. make decisions about your diabetes management)	1	2	3	4	5	0

12. Rate how much you agree with the following statements:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Not Applicable / I don't know
a. I don't bring up things that I'm worried about when speaking with my provider.	1	2	3	4	5	0
b. I ask the provider to explain terms I don't understand.	1	2	3	4	5	0
c. I ask the provider to explain my test results.	1	2	3	4	5	0
d. I ask the provider to explain treatment/care options.	1	2	3	4	5	0

13. Have there ever been times when:

	Yes	No	Not applicable
a. You had a difficult time understanding what the provider was talking about?	1	2	3
b. Been unable to meet with your provider because of time constraints, limited access to transportation, etc.?	1	2	3
c. Your provider or clinic made it easier for you to book an appointment/session?	1	2	3

## ***Appendix I: Interview guides for primary care providers and young adults with T2DM***

### **PROVIDER KEY INFORMANT INTERVIEW GUIDE**

#### **Introduction:**

Hello, my name is Alana Armas and I'm a graduate student at the University of Waterloo, in the School of Public Health and Health Systems. Thank you for participating in this interview, and aiding me in the completion of my thesis research.

The purpose of this interview is to gather information on the communication preferences of health care providers when they interact with young adults with type 2 diabetes. The questions I will be asking you today will specifically look at your experiences speaking and interacting with young adults diagnosed with type 2 diabetes. Also, I will be asking you questions about what you believe prevents or enables young adults with this disease from visiting you to receive diabetes management care.

I selected you as my key informant because you are a health care provider who treats young adults with type 2 diabetes. The interview today should take about 30 to 60 minutes to complete. During that time I will ask you a set of pre-determined questions and take notes. With your permission I will be recording the interview so I can later transcribe it. I can assure you the transcribed interview will not be used for any other purpose outside my thesis research.

All your responses will be confidential and you can stop the interview at anytime if you wish. You may skip over any questions you do not feel comfortable answering, or you can ask for clarification on questions at anytime. Do you have any questions before we begin? (Wait for response)

Once again, thank you helping me with my research.

#### **Questions**

1. Do you see patients with diabetes at your clinic?
  - a. Clarifying questions
    - i. If so, what is your role with these patients?
    - ii. Do you see a patient with diabetes more than once? If so, how often do you see them?
2. How much involvement do you have with diabetic patients' disease management?
  - a. Clarifying questions
    - i. Would you tell more about your involvement? What specifically do you for patients?
    - ii. Is there anything else you would like to add?
3. Do you think patients this age are different from other patients in terms of treatment?
  - a. Clarifying questions
    - i. Can you give me an example of how they are/ are not different?

- ii. What services do you refer young adults with diabetes to? Is this different to patients with diabetes who are younger or older? How?
    - iii. Is your experience working with these patients different from other patients?
    - iv. Is there anything else you would like to add?
- 4. Can you tell me about a positive experience you had with a young adult with diabetes.
  - a. Clarifying questions
    - i. Why was this a positive experience for you?
    - ii. Would you tell me a little bit more about this experience?
    - iii. Is there anything else you would like to add?
- 5. Can you tell me about a negative experience you had with a young adult with diabetes.
  - a. Clarifying questions
    - i. Why was this a negative experience for you?
    - ii. Would you tell me a little bit more about this experience?
    - iii. Is there anything else you would like to add?
- 6. Tell me about an appointment with a young adult diagnosed with diabetes when you had to alter some aspect of their diabetes management.
  - a. Clarifying questions
    - i. Refer to survey question 9
    - ii. Would you tell me a little bit more about this experience?
    - iii. Is the way you manage young adults different with someone how is older?
    - iv. How did the patient respond to the change?
    - v. How did you tell them about the change that was needed?
    - vi. Is there anything else you would like to add?
- 7. What makes it easy to talk to patients this age who have diabetes?
  - a. Clarifying questions
    - i. Why does \_\_\_ make it easier to engage with patients?
    - ii. Would you tell me a little bit more about this experience?
    - iii. Is there anything else you would like to add?
- 8. What makes it difficult to talk to patients this age who have diabetes?
  - a. Clarifying questions
    - i. Why does \_\_\_ make it more difficult to engage with patients?
    - ii. Would you tell me a little bit more about this experience?
    - iii. Is there anything else you would like to add?
- 9. Go through survey to address question 10 and any other points that you want to touch on.
- 10. Do you think patient-provider communication is an important part of a patient's diabetes management?
  - a. Why do you think that?
  - b. Do you have any more comments on that?

**Closing:**

Do you have anything you wish to add?

If you wish I can provide you with a copy of the interview guide I used today. Thank you for participation and taking time from your day to do this.

## PATIENT KEY INFORMANT INTERVIEW GUIDE

### Introduction:

Hello, my name is Alana Armas and I'm a graduate student at the University of Waterloo, in the School of Public Health and Health Systems. Thank you for participating in this interview, and aiding me in the completion of my thesis research.

The purpose of this interview is to gather information on the communication preferences of young adults with type 2 diabetes when they interact with their primary care providers. The questions I will be asking you today will specifically look at your experiences speaking and interacting with your primary care provider. Also, I will be asking you questions about what prevents or enables you to visit your provider to receive diabetes management care.

I selected you as my key informant because you are a young adult with type 2 diabetes who has been diagnosed with the disease for at least 6 months. The interview today should take about 30 to 60 minutes to complete. During that time I will ask you a set of pre-determined questions and take notes. With your permission I will be recording the interview so I can later transcribe it. I can assure you the transcribed interview will not be used for any other purpose outside my thesis research.

All your responses will be confidential and you can stop the interview at anytime if you wish. You may skip over any questions you do not feel comfortable answering, or you can ask for clarification on questions at anytime. Do you have any questions before we begin? (Wait for response)

Once again, thank you helping me with my research.

### Questions

1. Where do you usually receive care for your diabetes?
  - a. Clarifying questions
    - i. Who is the person you see most often for your care? (Doctor, nurse practitioner, etc.)
2. What sources of information do you receive for your diabetes management?
  - a. Clarifying questions
    - i. Where did you get this information? Who gave you this information?
    - ii. Can you tell me about that?
3. What experiences of having diabetes do you think are unique to your age group?
  - a. Clarifying questions
    - i. Have you ever gone through any of these experiences?
    - ii. Can you give me an example?
    - iii. Do you have any more comments on that?
4. When you visit your provider for your diabetes management what do you talk about?
  - a. Clarifying questions
    - i. Would you tell me a little bit more about when you talked about...?
    - ii. Is there anything else you would like to add?

5. Can you tell me about a recent or past visit with your provider?
  - a. Clarifying questions
    - i. Could you tell me a little bit more about this situation?
    - ii. Is there anything else you would like to add?
  
6. Tell me what you remember from an appointment with your provider when you had to change some aspect of your management (for example being prescribed medication or changing medication, changing your diet, etc.)
  - a. Clarifying questions
    - i. Refer to survey question 11
    - ii. Would you tell me a little bit more about this experience?
    - iii. Is there anything else you would like to add?
  
7. Can you tell me about a positive experience you had with a provider about your diabetes management?
  - a. Clarifying questions
    - i. Why was this a positive experience for you?
    - ii. Would you tell me a little bit more about this experience?
    - iii. Is there anything else you would like to add?
  
8. Can you tell me about a negative experience you had with your provider about your diabetes management?
  - a. Clarifying questions
    - i. Why was this a negative experience for you?
    - ii. Would you tell me a little bit more about this experience?
    - iii. Is there anything else you would like to add?
  
9. What is easy to talk about with your provider?
  - a. Clarifying questions
    - i. Refer to survey question 11
    - ii. Why was this easy to talk about?
    - iii. Would you tell me a little bit more about this experience?
    - iv. Is there anything else you would like to add?
  
10. What is difficult to talk about with your provider?
  - a. Clarifying questions
    - i. Refer to survey question 11
    - ii. Why was this easy to talk about?
    - iii. Would you tell me a little bit more about this experience?
    - iv. Is there anything else you would like to add?
  
11. Is there anything that makes it difficult to see your provider?
  - a. Clarifying questions
    - i. Refer to survey question 13
    - ii. Why does \_\_\_ make it difficult to see your provider?
    - iii. Can you tell me about a time when this happened?
    - iv. Is there anything else that makes it hard to see your provider?

12. Does your clinic do anything to make it easier to see your provider?
  - a. Clarifying questions
    - i. Are there any other factors that make it easier for you to see your provider?
    - ii. Refer to survey question 13
    - iii. What does \_\_\_ make it easy to see your provider?
    - iv. Can you tell me tell me about a time when \_\_\_ made it easier to see your provider?
    - v. Is there anything else that makes it easier to see your provider, from inside or outside the clinic?
    - vi. Is there anything else you would like to add?
13. Go through survey to address question 12 and any other points that you want to touch on.
14. Describe communication preferences, then ask patient what their preferences are.
15. Do you think patient-provider communication is an important part of your diabetes management?
  - a. Why do you think that?
  - b. Do you have any more comments on that?

**Closing:**

Do you have anything you wish to add?

If you wish I can provide you with a copy of the interview guide I used today. Thank you for participation and taking time from your day to do this.

## Appendix J: Transcript annotations

Participant 02	
Transcript Statement	Annotation
they'll have different priorities	Not sure if this qualifies as a code when thinking about the Lifeworld, but I think it may indicate an awareness of the patient's life, though that depends on the context in which the statement is used. Think more on this.
as a health provider I can look at his blood work, at his complications, I can look at it clinically and be very concerned and alarmed and worried for his health and well being. I think it's positive because for the first time he is also acknowledging that, so perhaps for the first time we have a shared understanding of...the seriousness of it	I think this is very interesting, and I don't know if it quite fits, but it shows the patient looking at the Medical side of things, which is has led to a shared understanding, since (it appears) the provider is aware of the patient's lifeworld. So it's almost like the reverse of what Mishler was calling for. Something to think more about.
And so sometimes they just get the phone call from the nurse or whatever, or maybe even an admin staff saying go to this clinic, you have an appointment at this time	Would this be considered a barrier and/or facilitator? Do people show up because they were told? look into/ think about more
their perspective;	perspective, this can greatly impact communication, maybe someone how link to Fs/Bs?
to be patient led. Some people are one word answers so you do a little more talking, but I'm of the mind set that I don't want to just talk at somebody and often times I'll really try to ask do you want to know why you're here? Do you want to know what your doctors concerns might be?	Not sure if this is totally the lifeworld, but I think it is related because it's looking at the experience from the patient's perspective. Maybe this is just more patient-centred rather than specifically relating to Mishler's theory.
doctors who don't share EMRs with us we do send a fax letter to them	B or F? I guess it depends on how you look at it

<b>Participant 03</b>	
<b>Transcript Statement</b>	<b>Annotation</b>
So, but it's a matter of making it fit to what she needed and that, and at that time in her life	F? I think it can be, but I might need to add more context, which begs to question how big am I going to go with my codes? Or is it better to let it vary? Think more on this and look up some articles. Make sure I can justify it.
I think it was um, fear. And then there seems to be sometimes a sense of, um what's the work I'm thinking of. It's not going to happen to me kind of thinking.	Is this just another observation? Or can it be seen as a B? I suppose a lot of things can be seen as Bs/Fs depending on how you look at it, maybe I should come up with some concrete definitions or explanations on how I see Bs and Fs? Though I do think it is useful to go broader in order to catch everything.
Or are they just so in denial that we won't see them until, until they've got complications.	So I think this statement is confirmation that denial can be a B, for both communication and for just coming in to receive care.
if you my help again in the future here's my card, give me a call.	Maybe think of this as a F, like them maintaining the connection, leaving the door open kind of thing.
I think that's a segment of society that commonly doesn't um, get engaged until they are ready to be engaged in diabetes care.	Does this count as a B? It's more of an observation, but I guess this could count, kind of like how denial does.
was there was a lot of underlying stuff in the home. You know with some, how am I going to say this, with a very controlling mother. Who did all the talking, so the son didn't have the chance to say anything.	Not sure if this is a directly related to the Lifeworld, but I think when the providers use terms like the 'underlying issues' it is an indicator of them acknowledging things that influence care outside of the medical sphere.
So before you can fix the diabetes you have to be able to address all the other issues that might get in the way.	I think this a key statement showing that the provider is acknowledging the Lifeworld. And it supports my initial ideas that chronic care is more aware of this because the type of treatment directly impacts and is impacted by the patient's life and circumstances.

<p>The priority isn't about diabetes every visit, the priority is the person, so whatever they present with and sometimes it takes 2 or 3 visits before we really get beyond all the other things and we can talk about diabetes.</p>	<p>Another key statement showing what I mentioned in my previous annotation.</p>
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<p><b>Participant 04</b></p>	
<p><b>Transcript Statement</b></p>	<p><b>Annotation</b></p>
<p>why do you think this happened?</p>	<p>I think this is a simple, but good example of the provider acknowledging the influence of the patient's lifeworld on the test results and what happened, as opposed to the provider speculating or trying to solely link it to a medical reason.</p>
<p>trying to dig for more information you know, to kind of understand what their fear or barrier is to the medicine to see is it true? Is it a myth? Is it financial? What is it?</p>	<p>Not entirely sure if this is a F, I guess it can be viewed that they way the provider communicates, how they ask questions, how much information they try to get out of the patient can act as a F or B? Maybe, think more on this and see if this comes up more.</p>
<p>I'm pretty open with people I tell them at the beginning I will be very honest with you from the very get go, um, and the reason I tell people that is I want people feel assured in the information I share with them.</p>	<p>Trust as a F, if they trust you they will open up.</p>
<p>Because I think if they know I'm being really honest with them, then my hope is that they can be really honest with me too.</p>	<p>Important quote I think.</p>
<p>I would hear that, it's my fault I've done this to myself and when they are talking about their food choices their sedentary lifestyle um, or being busy, or having all these competing priorities</p>	<p>I don't think this is a direct link to Mishler's theory, but I think it shows that the provider is digging for it and allowing the patient to talk about how their Lifeworld is impacting their health. She is allowing them to provide the context in which they live.</p>

<p>The first thing I say is so you came here today, what brought you in? And that statement regardless of the person surprises people. Because they think cause you called me? Okay, but you came; you came here, so why did you come here?</p>	<p>I think this is an interesting statement; it's using focusing on the patient as a F. This supports the idea of patient centred care. It supports the literature.</p>
<p>There's a shift in chronic disease management from doctor say and I do to you're the patient with the condition you need to manage this, what can I tell you to help you understand how to manage this?</p>	<p>I don't think this is directly related but I think it demonstrates the key difference between chronic care and acute care and the shift in focus. It can relate to how often acknowledgement of the lifeworld comes up.</p>
<p>So when they come in, the way, the appointment progresses is dependent on what that person's priorities are, not so much on their age I guess.</p>	<p>This has come up a couple of times now, in the other transcripts I have reviewed as well. I think this is an important difference that priorities are a big deal as opposed to age. While this is correct, is it not arguably somewhat age dependent, as younger people tend to have more competing priorities? It can be generalized to all ages, but it may be more applicable to this age group. Is a part of Bs and Fs, but more of a general observation of care maybe? Think more on this.</p>

<p><b>Participant 05</b></p>	
<p><b>Transcript Statement</b></p>	<p><b>Annotation</b></p>
<p>because change is challenging</p>	<p>I don't know if this is necessarily a B, but I think it is something to consider that might hinder people to receive treatment just in general. This could maybe tie into fear in a subtle way, or people's willingness to receive care to make it every more general. I will have to think more on this</p>

<b>Participant 06</b>	
<b>Transcript Statement</b>	<b>Annotation</b>
cause they have very similar struggles to others in the similar age demographic. A good example of that is you can have type 2 diabetes from being overweight or sort of or it's a factor in it of course. However, someone who is overweight at the same age group doesn't, doesn't necessarily have diabetes. So, just because they have diabetes doesn't make them different from that same person who, or that similar who is also over weight, so I wouldn't really say necessarily.	I think he is getting at what I am looking for with this question. But he brings up is an interesting thought that they aren't any different from other people their age; they all have the same struggles. Something to think on more, maybe a spring board for talking about this age group in general with chronic disease and health.
some of the best successes I have are just sort of explaining to people how to set appropriate goals for what they want to achieve.	Maybe more of a patient centred comment, but it jumped out for me, possibly showing the acknowledgement of the lifeworld, in stating helping patients achieve the goals they want. Maybe it doesn't quite fit with Mishler's theory
influence over them	Interesting word choice here, influence over them, suggesting a power dynamic where the provider is in control. Not necessarily a bad thing, but the wording jumped out at me.
they usually have a lot better influence over their patients	Again with this idea of having influence over the patient, another suggestion of the power dynamic between patients and providers from this informants perspective. Maybe go back through on the 3 'read through' to see if this pops out with another of the other transcripts.
you can sort of get into a little more of a robust conversation about aspects that are important to the patient.	key word here is what is important to the patient, this shows a patient-centred approach.
family health teams they get, they can bill you know based off of metrics and when they refer someone out to a secondary or tertiary clinic they actually lose that little bit of money that comes in for that patient. So there is a system that's set up here that doesn't necessarily mean that a patient is gonna be referred out at the appropriate time	First mention of system related barriers to care, go back and look at other transcripts when comparing to see if they mentioned this and I missed it, or already coded and forgot.

<b>Participant 07</b>	
<b>Transcript Statement</b>	<b>Annotation</b>
I'd say between 20 – 25 is a little different. After 25-39 I'd lump them together.	I feel like this might have come up in previous transcripts, it might be useful to explore this differentiation, look into how this might impact care or at least be something worth mentioning. Might not be a theme, more of an observation. Think on this.
their priorities	Again this idea of priorities
It really depends on who it is, the approach that I take, um sometimes the scare tactic, sometimes it's these are the facts, this is what it is and this is what you need to do, and if you don't do it, there's nothing I can do about it. If you choose not to take your oral medication, that's your choice and I can support you in any way that I can, but this what I'm recommending. Sometimes I do a little bit of a, um, strong approach like that, not a lot of coddling, I find it very difficult to do that.	It's interesting thinking about participant 06's transcript when he was mentioning having influence over the patient, where here it feels more like compromising. I don't get the impression of the same power dynamic. I mean maybe with the scare tactic bit, but that seems more like trying to convince rather than have influence over, which at least to me suggests a more equal playing field. Just a thought, something to think about.
Um, people don't take it seriously, they come to their appointments once in three months, or once in six months and they will say you know, yeah, yeah, yeah and they'll get their blood work done and it's the same results. Are you taking your meds? And they say yeah, but you know if they call their pharmacy, they haven't filled it in three months. No positive type 2s of that age range, that's difficult.	I think this may relate back to what another provider said about having a difficult time with follow through or follow up, they come but they don't do what they should be doing, or what they said they are going to do. Another read through of the transcripts or comparing codes might show this from other transcripts as well.
She's supposed to be on insulin, but never took it, not at all, never. She always came to her appointments though	Again with the follow through, coming in but not following through.
it's because she didn't do her meds they way she was supposed to back when she was just diagnosed	I wonder if this is a reflection of the interaction of the Lifeworld and the medical one. I wish I had dug a bit more on this question; did the provider try to figure out why she wasn't taking her medication? She is depressed, but was there an exploration of why that is?

<p>a lot of are you taking your medication? How are you taking your medication? When are you taking your medication? How does that make you feel when you do it? How does it make you feel when you don't do it? And usually you get the right answer and then it's something like would, doesn't that feel good when you take your medication? So maybe instead of taking it 4 times a week we can try for 6 times a week. And it's a lot of negotiating like that with this particular patient. Can we try and check blood sugar twice a week? Like maybe Monday and Friday? Those are the two days you're going to check your blood sugars, there's a lot of negotiating.</p>	<p>Again with the provider maybe not acknowledging the Lifeworld here, not looking into what is causing her not to take her medication properly.</p>
<p>she's unique because her depression is so bad.</p>	<p>Keep this in mind when coding, not just for her but in all the transcripts, don't take it out of context.</p>

<p><b>Participant 08</b></p>	
<p><b>Transcript Statement</b></p>	<p><b>Annotation</b></p>
<p>the other cool thing is we work in the same office, so there are hallway consults where she will just say hey, I saw your patients you know and ask me a few clarification questions or just tell me how their doing</p>	<p>I'm not entirely sure if this counts as a code for a F, but I think it does lend to better care. Think more on this, possibly discuss with Sam at next meeting.</p>

<p><b>Participant 10</b></p>	
<p><b>Transcript Statement</b></p>	<p><b>Annotation</b></p>
<p>I have a really hard time getting him to follow up</p>	<p>Again coming back to what Phil said about follow up with these patients. It is difficult with them for a variety of reasons. I will have to see how many times this pops up</p>

<p>it makes me think and reflect on my practice and about um yeah I mean am I providing exceptional care um to my diabetic patients? Am I sort of you know, kind of pushing my beliefs and stuff about their management too much on them you know? And not kind of treating it like an equal partnership to manage their health. It's definitely, it's definitely like a very interesting disease and yeah the management can be quite um complicated.</p>	<p>I don't know if I can code this for anything, but it is interesting. Maybe, when I am look for communication patterns then I can code this. But it is interesting.</p>
<p>Am I sort of you know, kind of pushing my beliefs and stuff about their management too much on them you know?</p>	<p>This might relate back to the medical world vs. the lifeworld.</p>

<p><b>Participant 11</b></p>	
<p><b>Transcript Statement</b></p>	<p><b>Annotation</b></p>
<p>yes I think it does require a different tact, because for our, and that goes for almost every condition I think, uh that I see people with depending on their age and where they're coming from, uh you know developmentally, socially, family, in that stage in life.</p>	<p>Not really sure if this should count as a code for Fs and Bs, but I coded it anyways, so I can reflect on it more later. Either way, it is just a good observation about this age group in general for all types of conditions.</p>
<p>I would say that as people get nearing the retirement age, they are either nearing retirement or if they haven't been working and they have those issues then they're still are probably more homogenous then the group in this age group</p>	<p>Once again, this isn't necessarily a code for Fs and Bs, it is more an observation for the age group. It might not even be anything because I think he's the only person who has mentioned this. Maybe the other providers said it in different ways, I will have to go back and look at the transcripts again.</p>
<p>it's these people having the ability to come back in and say okay we're getting back on track. And that's the same thing with diabetes and that's why having those recall systems, and having different ways that people can access care, through the diabetic clinic, through endocrinologists, through me, through our diabetic education nurse.</p>	<p>Not sure if I should break this down into more than one code, but I don't know if I can without losing the context of what he is saying. I will look at it more closely when I start to compare the codes.</p>

<p>just letting people talk is a huge, huge thing cause they'll say a lot and we want to jump in and say oh here's your sugar level but if you have people talk for a little bit that's a, that's a big thing</p>	<p>This here demonstrates his understanding that the Lifeworld needs to be allowed to come out in a consultation. The medical world cannot dominate, because it won't allow for context.</p>
<p>So I need to use those uh, resources our diabetic nurse educator, our diabetic education clinic, because people can go there, they can meet with the dietitian and talk about their meals for the next 3 weeks.</p>	<p>So I think this is really interesting, because it can sort of relate back to the Lifeworld and his acknowledgement of it, but his understanding as well that he can't always be the provider to allow it to really come out in an appointment because of time constraints.</p>
<p>it probably means um making sure we are on the same page in terms of the goals, because my goal may be getting the A1C under 7, their goal may be making sure they keep their job</p>	<p>This is a nice example of showing the two different worlds that Mishler explores in his theory. This provider is acknowledging both and showing that there needs to be a bridging there to bring the two together.</p>
<p>they don't have time to sit down for two hours in the middle of the day to do an interview, if they had that time they'd probably manage their diabetes better.</p>	<p>An important quote to maybe put into the reflection/ discussion on the thesis when talking about the difficulties in recruitment</p>

**Appendix K: Table 05: Transcript statements, in-vivo codes, preliminary thoughts, and initial categories (Sample from participant 08)**

<b>Transcript statement</b>	<b>Description (in-vivo codes)</b>	<b>Preliminary thoughts</b>	<b>Initial categories</b>
And he said that that was the first time someone had ever explained to him why he has to take them (medication)	explained to him why he has to take them	Education, a big part of the appointment, general	Educating patient on medication
And when my patients say that to me now in my practice I say would any of those can be non-compliant, like define compliant for me? Walk 150 minutes a week, um eat exactly this number of carbs, don't eat this, don't do that. Like none of us would be quote compliant	and when my patients say that to me now in my practice I say would any of those can be non-compliant, like define complaint for me?	I think this relates back to the provider not wanting to be judgemental, she is trying to take away factors that could make the patient feel guilty about what they have done. Taking it out of the world of medicine and placing it in the lifeworld	Use of language with negative connotations
But kind of think the idea is exploration; so she's happy to tell me how to use, or abuses the insulin, but I just say you know why are you doing this? What are your goals? How else do you think we can help you?	I just say you know why are you doing this? What are your goals? How else do you think we can help you?	Opening up communication, trying to explore the patient's lifeworld? Open ended questions to get the patient to talk more	Allowing patient concerns to shape the conversation
describing how the medication works inside the body is what I do, um I like explaining,	describing how the medication works inside the body is what I do...I like explaining	Explaining, education	Educating patient on medication
Diabetic patients have to have a place where they're comfortable going, where they, um feel safe asking questions and receiving answers to those questions	Diabetic patients have to have a place where they're comfortable going, where they...feel safe asking questions and receiving answers to those questions	Comfort, no judgement. Again this idea of a moral attachment to the disease or the person, somehow seen as not smart or lazy, or something. This is also about building a relationship	Creating a comfortable, judgement free space for the patient
follow up and keeping that patient close	follow up and keeping that patient close	Follow up, important facilitator but I think a difficult one for this age group	Keeping the patient close
or a patient where, you know I mentioned the fasting blood work can be a bit of a barrier. They haven't had time to fast, then you kind of have to negotiate on you know, doing a random sugar instead just to get	the fasting blood work can be a bit of a barrier	Time, priorities. They don't have time to be doing this	Lack of time

those numbers.			
his words 'I don't think I really have diabetes',	his words 'I don't think I really have diabetes'	Denial	Denial
I also have prompts for my really resistant younger adults to call them in between appointments, just one quick phone call kind of just to say, you know I realize I'm not going to see you for 4 weeks but I thought I would check in to see how you're doing.	I also have prompts for my really resistant younger adults to call them in between appointments	Availability again, being available for these patients	Staying connected to the patients, showing they are present
I do find my younger population they can get it on their phones, they can print it off, they can ask more questions.	they can get it on they phones, they can print it off, they can ask more questions	Technology and it's role in all of this	Use of technology in care - apps
I don't know if maybe it's a comfort, like they're at home or it's a less clinical environment	maybe it's a comfort, like they're at home or it's a less clinical environment	Again comfort, needing to be comfortable	Putting the patient at ease - their environment
I guess walls were up; he has this disease that he didn't believe in, he wasn't interested in treating it.	he had this disease that he didn't believe in, he wasn't interested in treating it	Denial, doesn't think he is sick	Denial - does not want to treat it
I just sorta meet her where she's at	meet her where she's at	Meeting the patient half way, doing what is needed for the patient	Doing what is needed for the patient
I use a bit of caution and move on. Otherwise, yeah she won't come back.	I use a bit of caution and move on. Otherwise...she won't come back	Can't push people too much or they are lost to follow up	Directing conversation based on patients reaction
I would say the amount of time we have with them	the amount of time we have with them	Longer appointments, definitely something that is important	Appointment length
I would say to then their number one is, you know fear. They're not meeting my expectations, or fear you know that they just received a bad report card. They haven't followed through with the physical activity and they said they've been going for a walk once	fear they're not meeting my expectations, or fear...they just received a bad report card, they haven't followed through with the physical activity	Fear of judgement, feeling guilt, shame. Again moral attachments to their health	Fear of judgement from provider

if I make a change to a medication, be it over the phone or in office I like to see them between 2 and 4 weeks after a medication change to make sure their tolerating it, their okay with resuming the medication	if I make a change to a medication...I like to see them between 2 and 4 weeks after a medication change to make sure they're tolerating it	Follow up	Staying connected to the patients
if we're not communicating with our patients with diabetes and not getting to know them on a personal level um we're not really helping them meet their goals.	not getting to know them on a personal level...we're not really helping them meet their goals	The importance of the relationship, or getting to know the patient in order to make sure they are receiving the best care possible	Not getting to know the patient
It's good 'cause it opens up a whole bunch of you know, communication like remember this, I'm not your teacher grading you. You know this is something you learn to live with.	remember this, I'm not your teacher grading you	Again trying to be judgement free, trying to take the moral attachment away	Judgement free care
it's something I want to explore then I can say, you know these medications are quite expensive how are you coping with the costs? Or I noticed you have, we do phone follow-ups with a certified diabetes educator on top of your appointments with me, how is that going?	you know these medications are quite expensive how are you coping with the costs? Or I noticed you have, we do phone follow-ups with a certified diabetes educator on top of your appointments with me, how is that going?	Speaking over the phone, and acknowledging the situation the patient is in. Being aware of what is going on with the patient outside of their normal appointments	Awareness of patient's situation
I'll say sometimes they do their blood work a little early like before their appointment, like 2 weeks out, I'll give them a little call and say you know I'm going to see you in 3 weeks from now, but I wanted to let you know that these were your results	I'll give them a little call and say you know I'm going to see you in 3 weeks from now, but I wanted to let you know that these were your results	Follow up, so important	Staying connected to the patients - phone calls
I've actually have patients in the younger population ask questions over the phone that they didn't bring up um, in my office over the phone.	in the younger population ask questions over the phone that they didn't bring up...in my office	Comfort, being comfortable talking on the phone being in an environment that maybe doesn't provoke judgement	Putting the patient at ease - their environment
just open-ended questions and eventually, eventually it took a couple of appointments but he opened up	just open-ended questions	Allowing the patient to open up, or maybe forcing them to open up (I don't really like that word, I will have to think of a better way to describe it). This is a facilitator to communication in the clinical encounter	Opportunities for patient to open up - open ended questions

let them know that it's not just me, and that they have a lot of free and very available resources that they can pick and choose who their healthcare team is.	they have a lot of free and very available resources that they can pick and choose who their healthcare team is	Access, resources and to HCPs	Increased access to care → free services. Access to multiple healthcare providers
Like at my clinic it's 40 minutes to an hour depending on um, my relationship with the patient, um so having that extra time to explore rather than making them feel rushed	it's 40 minutes to an hour depending on...my relationship with the patient, having that extra time to explore rather than making them feel rushed	Appointment length	Appointment length
Maintaining that close relationship, so it's not like a report card type review every time they come in	maintaining that close relationship, so it's not like a report card type review every time they come in	Again judgement free, developing a comfortable relationship	Judgement free care
my first question is how are you, how are you tolerating the medication? Um, and that's because I've learned, if you don't ask if they're taking the medication then you don't really know why the numbers are the way they are	I've learned, if you don't ask if they're taking the medication then you don't really know why the numbers are the way they are	Have to get to know the patient, talk to them, find out what's really happening	Being up front with the patient
my strategy is that the trend of your blood work is not a report card, you know it's not a reflection of how you are doing in life.	the trend of your blood work is not a report card, you know it's not a reflection of how you are doing in life	Again moral attachment to things	Shame and guilt on not ideal test results
now in 2016 patients can access their own lab, so they can compare, we offer a print out or a trend of their lab at every appointment is that something that they are interested in	patients can access their own lab, we offer a print out or a trend of their lab at every appointment	Technology and it's role in all of this, creating more access	Use of technology in care - increased access to information
So if they're seeing a dietitian, a certified diabetes educator, a pharmacist, and myself um the patient is quite overwhelmed and therefore their less really interested in talking about this,	if they're seeing a dietitian, a certified diabetes educator, a pharmacist, and myself the patient overwhelmed and therefore they're less really interested in talking about this	Overwhelming the patient, this is a good point with having a family health team. Potentially a downfall. But also shows that it isn't always beneficial to talk about diabetes at every appointment	Focusing on what the patient wants to talk about

that would be the number one reason, that they either just don't show up, cancel last minute or delay booking a follow up.	they either just don't show up, cancel last minute or delay booking a follow up	I need more context, but this does relate back to follow up. I think it has to do with feeling guilty about things. It does I checked the context	Lack of follow up
the other cool thing is we work in the same office, so there are hallway consults where she will just say hey, I saw your patients you know and ask me a few clarification questions or just tell me how their doing	we work in the same office, so there are hallways consults	I'm not entirely sure if this counts as a code for a F, but I think it does lend to better care. Think more on this, possibly discuss with Sam at next meeting.	Healthcare provider collaboration - working in the same clinic
the patients that are quite closed off to communication. Um, if they've verbalized a poor experience in the past, say in the emergency department um, or if their new patients of mine, previous providers	they've verbalized a poor experience in the past	personal experience, can definitely shape how they act in an appointment, general barrier	Poor personal experience
well active listening, so I'm not typing at a computer or writing anything down, I turn my chair and like I face them.	active listening, so I'm not typing at a computer or writing anything down, I turn my chair and like I face them	Facilitator to communication in the appointment, general but an important one, this is mentioned by one of the other providers	Active listening, engaging with the patient
we're open two evenings a week,	we're open two evenings a week	evening hours, availability	Increased access to care - evening hours
with that population phone call follow up as much as I can	phone call follow up	Modes of communication, flexibility	Staying connected to the patients - phone calls
Young adults, I would say um, small realistic goals	small realistic goals	This is probably general, but I do think it is an important solution for people who are busy as the patients in this age group. I will have to think more on this, but if possible I would like to talk about it	Tailoring care to the patient - small realistic goals

**Appendix L: Table 06: Initial categories and initial themes  
(Sample from analysis of barriers)**

<b>Barriers</b>	
<b>Initial Themes</b>	<b>Initial Categories</b>
<b>Patient's perspective of care and disease</b>	Patient's perspective of information provided
<b>Patients as barriers themselves</b>	Patient's personality
	Patients are allowed to make their own decisions - free will
	I don't want to do this attitude
	Reluctance to start medication
	Patient needs to be motivated
	Patients are allowed to make poor decisions
	Reluctance to start insulin
	Aren't interested in care
<b>Denial</b>	Denial
	Do not accept diagnosis
	Don't want to be there
	It's not going to happen to me
	Invincibility and denial - it's not going to happen to me
	Do not believe they have a disease
	Does not want to treat it
	Cannot accept the disease
	They are feeling fine, invincibility
	They want to ignore the disease
	Don't want to deal with the disease
<b>Patient perceptions of disease</b>	Stigma associated with having type 2 diabetes
	Complications in distant future
	Length of time living with the disease
	Insulin stigma
	Don't take it seriously
	Large amount of diversity on how people react to diagnosis
	Not feeling effect of the disease
	Complications in the distant future, Feeling fine
	They feel fine
	Stigma - shame associated with the disease
<b>Systemic barriers</b>	Clinics not referring patients - gatekeepers

	Gatekeepers
	Limited knowledge of system
<b>Mental health</b>	Mental health problems
	Mental health problems, underlying issues
	Mental health problems, financial impact of disease
<b>Problems with communication</b>	Not getting consent to address topics during encounter
	Patients not ready to discuss treatment and/or diagnosis
	Perceptions of provider judgement
	Patient not engaged in the discussion
	Patient not opening up
	Unclear communication
	Poor personal experience
	Young patients not opening up
<b>Patient - provider interactions</b>	Differing life experiences between patient and provider
	Poor patient provider communication
	Difficulty relating to patients
	Fear is an ineffective motivator over the long term
	Lack of provider patient relationship
	Lack of trust
	Not getting to know the patient
	Not confirming patient's understanding
	Poor education of disease leads to poor engagement
	Lack of open communication between patient and provider
	Fear of judgement from provider
	Scare tactics an ineffective motivator
	Judging patients during encounter – creating guilt for them
	Judging patients during encounter – creating guilt for them. Not understanding patients perspective
	Lack of trust
<b>Patient's education and literacy level</b>	Education level
	English as a second language
	Health literacy
	Literacy, education
<b>Socio-economic status</b>	Food insecurity
	Socio-economic status

	Socio-economic status instead of age
	Financial issues
	Socio-economic status, life circumstances
	Transportation issues
	Home insecurity
<b>Do not see the patient often</b>	Limited or lack of follow up
	Difficult to follow up
	Small patient population - limited knowledge
	Work preventing attending appointments
	Lost to follow up
<b>Emotions around disease</b>	Self blame - disease is their fault
	Fear - does not want to accept the diagnosis
	Fear
	Fear of judgement - self blame
	Shame and guilt on not ideal test results
	Self blame - guilt around diagnosis
<b>Sense of invincibility</b>	It's not going to happen to me,
	Invincibility and denial - it's not going to happen to me
	Invincibility
	Invincibility, complications in distant future
<b>Limited access to supplies and/or services</b>	Lack of support groups
	Limited or lack of drug coverage
	Unsecure work, lack of drug coverage
	Limited or lack of access to different health care providers
	Economic ability, drug coverage
<b>Limited or lack of time</b>	Full time employment
	Lack of time
	Shift work
	Work
	Not enough time
	Work hours, access to transportation
	Schedule conflicts
	Young families
	Changing work schedule
	Lack of time, work limits access to care
	Work limits access to care, young families limits access to care
	Young families, difficulty finding time for themselves (or for their health)
	Stressors and busyness in life limiting

	engagement in care
	Busyness, lack of time
	Lack of time, limited schedule
<b>Technology and the Internet</b>	Potentially poor information online
	Cannot email - privacy act
<b>Influence of others on care</b>	Controlling parents
	Home issues
	Parental impact - Patient is not there by choice
	Parents impacting care
	Misinformation about diabetes
	Patient not coming out of own volition
	Social interactions
	Spouse judging patient in encounter - shame, guilt
	Spouses taking focus away from patient
	Parents taking focus away from the patient
	Impact of personal life on care
<b>Priorities</b>	Health isn't a priority
	Competing priorities, health is not a priority
	Varying priorities
	Competing priorities
	Multitude of stressors
	Work, young families, competing priorities
	Health is not a priority, work is a priority
	Competing priorities, health is not a priority, work limits access to care
	Families, their health and themselves are not a priority
	Competing priorities, Don't want to deal with it - health isn't a priority
	New/ young career
	Priorities, work
	Health is not a priority - life gets in the way

**Appendix M: Table 07: Refined categories, final themes and core concepts (Sample from analysis of facilitators)**

<b>Refined Categories</b>	<b>Final Themes</b>	<b>Core Concepts</b>	
Increased appointment length	Clinic services and policies	Systemic enablement	
Providers only treating diabetes			
Diabetes focused programs			
Patients being able to easily access a variety of HCPs			
Collaboration between HCPs to increase access to care			
Clinic providers free supplies to increase patient access			
Services and policies of clinics increasing access to care			
Primary health care model enabling access to care			
Adjusting appointments for patients to increase access to care			
Providers advocating for patient's health to increase access to care			
Government providing coverage enabling access to supplies	Systemic services and policies	Systemic enablement	
Systemic changes to enable access to care for patients			
Available programs enabling access to care			
Systemic policies to enable access to care			
Provider being available for the patient to provide care	Provider availability		Availability
Provider being flexible to increase access to care for patient	Continuity of care		
Staying connected to the patient to provide continuity of care			
Ensuring patient understands the different types of medications available	Patient education		Patient-centred care
Ensuring patient is educated to enable treatment uptake			
Ensuring patient is educated to enable access to care			
Provider focused on the interests of the patients	Patient-centred care		
Patient centred care			
Focusing on the patient's concerns			
Focusing solely on the patient during the encounter			
Probing in conversations to identify underlying issues preventing open communication	Addressing underlying issues		
Addressing the underlying issues with patients before addressing diabetes treatment			
Addressing the patients stressors before providing diabetes treatment			

Aiming to not over burden the patient with information	Avoiding overwhelming the patient	
Focusing on topics that will not create anxiety for the patient		
Creating a comfortable environment for the patient to help relax them		
Slowly introducing diagnosis, education and treatment to avoid creating too much anxiety for patient		
Employing different approaches to education to address patient health literacy level		
Making small goals to simplify patient care		
Simplifying care to enable patient to make changes		
Placing patient in control during appointment	Patients make treatment decisions	Patient-provider collaboration
Enabling patients to make treatment decisions		
Shared decision making		
PP Collaboration	Patient and provider collaboration	
Shared decision making		
Engaging patients in a way to enable two way communication	Two way communication	
Using a variety of communication tools to address patient health literacy level and to better engage patient		
Treating the patient like an equal partner when communicating		
Convincing as opposed to telling the patient what to do during the encounter		
Provider actively listening during encounter	Provider interpersonal skills	Provider transparency and empathy
Provider interpersonal skills enables better care		
Finding common ground to better relate to the patient	Connecting with patient on personal level	
Showing a personal interest in patient to build a relationship		
Allowing patients to share personal experiences to build a PP relationship		
Provider directness during encounter to enable communication	Honest and transparent communication	
Provider's honesty during encounter to enable communication		
Provider's transparency during encounter to enable communication		
Respecting how engaged the patient wants to be	Building trust	
Provider creating comfort through their actions		
Provider patience and understanding to build a PP relationship		
Trust as a key piece in developing a PP relationship		
Positive change as a motivator for patients to continue treatment	Positive results	Positive test results

Scaring the patient into continuing or starting treatment	Fear as a motivator	Fear as motivation
Stigma of diabetes used as a motivator for care		
Family and friends enabling treatment uptake for patient	Family and friends enabling care	Friends and family
Patients are more actively using technology to assist in their care	Technology in care	Technology usage
Patients using technology more to access information about care		
Employing different methods of communication to increase access for patient		
Increased use of email to connect with patients		
Using technology to stay connected to the patient beyond appointment		
Electronic charting to simplify care with multiple HCPs		
Using technology to simplify care		
Increased use of email to communicate with providers	Patient characteristics	Patient population characteristics
Patient's have better physical functioning		
Patient's have better cognitive functioning		
Younger age group tends to have a higher education level		
Younger age group is more adaptable to making lifestyle changes		
Drug coverage enabling access to supplies		

**Appendix N: Table 08: Survey data from primary care provider participants**

	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9, A	Q9, B	Q9, C	Q9, D	Q10
<b>P 02</b>	Female	4 years	Yes: French	Nurse, diabetes educator	5 years	Yes	Approx. 10 - 20	45 minutes	Agree	Agree	Strongly Agree	Agree	A: Yes B: Yes
<b>P 03</b>	Female	27 years	No	Nurse	26 years	Yes	2% of patients (90/month)	1 - 1.25 hours	Agree	Agree	Strongly Agree	Strongly Agree	A: Yes B: Yes
<b>P 04</b>	Female	10 years	No	Nurse, diabetes educator	5 years	Yes	10 - 15%	30 minutes	Agree	Agree	Strongly Agree	Strongly Agree	A: Yes B: Yes
<b>P 05</b>	Female	5 years	No	Dietitian	5 years	Yes	Approx. 10%	40 minutes	Agree	Agree	Agree	Strongly Agree	A: Yes B: Yes
<b>P 06</b>	Male	5 years	Yes: Some written French	Kinesiologist	5 years	No	1177 out of a total population of 3471	30 to 60 minutes	Strongly Agree	Strongly Agree	Strongly Agree	Strongly Agree	A: Yes B: Yes
<b>P 07</b>	Female	10 years	No	Nurse practitioner	2 years, 4 months	Yes	25%	Initial consult – 1 hour, follow-up - 30 mins	Strongly Agree	Strongly Agree	Agree	Strongly Agree	A: Yes B: Yes
<b>P 08</b>	Female	8 years	No	Nurse practitioner	8 years	Yes	20	40 minutes	Strongly Agree	Strongly Agree	Strongly Agree	Strongly Agree	A: Yes B: Yes
<b>P 10</b>	Female	8 years	No	Nurse practitioner	8 years	Yes	Unsure	30 minutes	N/A, I don't know	Agree	Agree	Agree	A: Yes B: Yes
<b>P 11</b>	Male	7 years	Yes: French	Family physician	7 years	Yes	4	15 minutes	Agree	Agree	Agree	Agree	A: Yes B: Yes
<b>P 12</b>	Female	41 years	Yes: Dutch	Diabetes educator	25 years	Yes	20 -30	30 - 60 minutes	Agree	Strongly Agree	Strongly Agree	Strongly Agree	A: Yes B: Yes
<b>P 13</b>	Female	30 years	No	Dietitian	20 years	Yes	25 - 30%	1-1.5 hrs for initial, .5 for follow up	Strongly Agree	Strongly Agree	Neutral	Strongly Agree	A: Yes B: Yes

Due to the size of the matrix it was not possible to include it in the Appendices of this thesis.

**Appendix O: Table 09: Young adults with T2DM analysis (Sample from participant 01)**

Transcript statement	Description (in-vivo codes)	Preliminary thoughts	Initial categories
And he is amazing, um from the first day that I met him um, he looked at my eye and he was, from his tone he was quite upset because he said to me, what was your optometrist doing in the last 3 to 6 months that he'd seen you? Why were you not sent to someone?	he is amazing, um from the first day that I met him um, he looked at my eye and he was, from his tone he was quite upset because he said to me, what was your optometrist doing in the last 3 to 6 months that he'd seen you?	The provider showing empathy and concern, this connects the patient and provider allowing for the relationship to build and improve reception of care	Provider empathy and concern creates connection with patient
And I think that's such a huge thing having a good connection and communication with your healthcare provider, because not everyone is like that. And I think that is you are in a field of healthcare and you know providing that help is hard, don't be an ass	I think that's such a huge thing having a good connection and communication with your healthcare provider, because not everyone is like that	Recognizing having a good connection with provider is key to care	Strong connection and good communication with provider
And I was like yes, so then we just continued talking, like she didn't make it awkward, like anything like that, it was just like normal to her, you know she didn't make me feel like, I was you know weird you know different in any way.	we just continued talking, like she didn't make it awkward, like anything like that, it was just like normal to her	The provider accepting whenever the patient has to say and creating a safe space for her to express her emotions.	Patient can express herself in appointments, talk about emotions
Interviewer: Are they in the same office? Participant: Yes, they are, yeah.	are they in the same office? Participant: Yes	Easy of accessibility with having the providers in the same office	Providers work out of the same clinic
But having someone there to talk to, you know, even my nurse practitioner, just having someone there to like understand, and kinda let you talk and let you vent. I think that's very helpful	But having someone there to talk to, you know, even my nurse practitioner, just having someone there to like, understand and kinda let you talk and let you vent	Provider allowing the patient to shape and lead the conversation. Also, allowing the focus to go beyond diabetes and into underlying issues, and emotions	Provider allows patient to talk about what she needs to

But if I ever feel like I'm down or I need just to talk or vent or, I could basically make an appointment with you. I, I don't call the receptionist, I actually call to her extension and um she usually is able to fit me in within that week	I don't call the receptionist, I actually call to her extension and um she usually is able to fit me in within that week	Easy access to provider, this also shows the provider being available for the patient, being there when she needs her.	Provider is easy to contact and ease to see on short notice
But we basically talk about everything and anything, and the thing is for me,	we basically talk about everything and anything	Open communication, definitely a facilitator to care	Patient and provider have very open communication
but with her I felt a connection right away, 'cause she's easy to talk to.	with her I felt a connection right away, 'cause she's easy to talk to	Provider interpersonal skills, she is easy to talk to, which eases the development of a relationship	Provider has strong interpersonal skills that established a connection early on
especially when there's good readings, you kinda see like what you've accomplished and happy	especially when there's good readings, you kinda see like what you've accomplished and happy	Good test results as a motivator, makes the patient feel empowered	Positive test results creates a sense of accomplishment
she kind of just sat back and let me have my little tantrum, even though I'm almost 32 years old (laughs). And uh I was kind of cooled down a little, she always provided me with tissues, she knows when it's going to happen and was like 'feeling better now?'	She kind of just sat back and let me have my little tantrum, even though I'm almost 32 years old (laughs). And uh I was kind of cooled down a little, she always provided me with tissues, she knows when it's going to happen and was like 'feeling better now?'	Allowing the patient to direct the conversation and allowing the conversation to focus on whatever the patient needs to say in the visit. Also, creating a safe space for the patient to express her emotions	Provider allows the patient to express all her negative emotions during the encounter
I believe that every time I go see her she always follows up with my family doctor.	I believe that every time I go see her she always follows up with my family doctor	Continuity of care, and HCP collaboration, making sure everyone is on the same page	Providers are collaborating and communicating patients care
I find that to be so helpful and also just going on the Internet and reading about it, you know that's where you find all the information.	I find that to be so helpful and also just going on the Internet and reading about it, you know that's where you find all the information	Increased access to information through the Internet	Patient using the Internet as a tool to further educate herself
I go for my follow up with her we usually have a good like half hour, a 45 minute discussion about everything that's going on.	I go for my follow up with her we usually have a good like half hour, a 45 minute discussion about everything that's going on	Length of appointment, having enough time to talk about everything the patient feels she needs to talk about	Longer appointments allow the patient to discuss everything she needs to

I kind of said what I had to say 'cause I was really upset and I raised my voice and stuff like that, which you know I'm not proud of, but I am who I am and you know she understands that	I was really upset and I raised my voice and stuff like that, which you know I'm not proud of, but I am who I am and you know she understands that	Again creating a safe space for the patient to express her emotions and allowing the patient to take the lead	Patient is comfortable expressing herself because the provider understands her
I mean I met Heidi when she was doing her um program at um Shoppers	I mean I met Heidi when she was doing her program at Shoppers	Diabetes programs in accessible locations	Diabetes programs are available to the patient
I really have to kind of give it to her because she has so much patience for me	I really have to kind of give it to her because she has so much patience for me	Provider patience, this comes up once with the provider transcripts, but I think it is reflected in letting the patient talk about what they want in an appointment	Provider patience strengthens PP relationship
I think it's important you kind of stick to them, you don't give up on them and there's so many times, like there so many times, it's been a long time since I've been able to keep my sugars under control. You know it's always up and down with me right?	I think it's important you kind of stick to them, you don't give up on them	Continuity of care, seeing the same provider can improve care	Patient wants continuity of care
I was so happy when my results were good and to see the expression on her face, and for her to know that she is like helping, that she is doing what, all that she can, and I think that is such a positive thing too	I was so happy when my results were good and to see the expression on her face, and for her to know that she is like helping, that she is doing what, all that she can, and I think that is such a positive thing too	Again positive results motivate the patient and seeing the joy from the provider as well. Shows how influential the provider can be on the patient	Positive test results and reaction from provider lead to positive feelings for the patient
like I saw the dietitian, I saw the pharmacist, um I saw um, a nurse there that was working with Heidi to do the whole, you know like become um part of the diabetes association thing. And it was just, it was really fun and I asked them 'oh are you guys going?	I saw the dietitian, I saw the pharmacist, um I saw um, a nurse there that was working with Heidi	Access to multiple HCPs definitely helps with care, as well as access to diabetes programs (CDA)	Patient has access to multiple different types of HCPs
I like when we talk it's like, it doesn't even feel like she's my healthcare provider. Um, I'm myself when I talk	it doesn't even feel like she's my healthcare provider. Um, I'm myself when I talk to her	Strong relationship and open communication, the patient is completely at ease with the	Patient and provider have a strong relationship

to her, when I go see her.		provider and can speak her mind	
I'm very lucky that I have benefits because we all know that the dentist costs an arm and a leg and also another arm	I'm very lucky that I have benefits because we all know that the dentist costs an arm and a leg and also another arm	Care is expensive and can prevent people from receiving the care they need. Also a facilitator because this patient has benefits to help cover those costs	Patient has health benefits to cover extra expenses (dentist)
I'm, it's really hard for me to diet and exercise, the dieting part it's, I can, I could, I try it and I feel good about it because I see results.	it's really hard for me to diet and exercise, the dieting part it's, I can, I could, I try it and I feel good about it because I see results	Making multiple changes is difficult for this patient, focusing on her diet is easier for her.	Patient focusing on the aspect of care that makes her feel good
we have very good communication and a relationship. Uh, I've never felt anything with her.	we have very good communication and a relationship	Good communication and a positive relationship is definitely an important factor for care	Strong communication between the patient and provider
My sister bought the CD and my dad burnt it and we both had a copy to use. And it was good, because my sister was doing it with me and I actually lost 10 pounds	it was good, because my sister was doing it with me and I actually lost 10 pounds	Support for family helps a lot with implementing the changes needed for managing the disease	Supportive family makes implementing lifestyle changes easier
she is a type 2 diabetic as well, so that was a huge thing for me.	she is a type 2 diabetic as well, so that was a huge thing for me	Relating to the provider, seeing the provider deal with the disease creates a stronger connection	Provider has diabetes, creates instant connection and understanding for patient
she totally gets where I'm coming from, and she understands you know the struggle and like the eating, the dieting, the exercise.	she totally gets where I'm coming from, and she understands you know the struggle and like the eating, the dieting, the exercise	Again relating to the patient through shared experience of the disease	Provider understands the difficulties associated with managing disease
She uh, writes it all in the report and she, they, I guess get together and discuss it. And then he looks it over and everything like that.	writes it all in the report and she, they, I guess get together and discuss it	HCP collaboration and continuity of care between her nurse practitioner and family doctor	Providers are collaborating and communicating patients care
she's easy to talk to.	she's easy to talk to	Provider's interpersonal skills	Provider has strong interpersonal skills

She's like you know what? You don't need to see anyone that you don't want to see. Um, you can see me as long as you want, um like basically I'm here to support you,	She's like you know what? You don't need to see anyone that you don't want to see	The patient is in control; she doesn't have to do anything she doesn't want to do.	Provider is giving patient control over care
she's very, very good and flexible	she's very, very good and flexible	Provider flexibility, this definitely came up in the other interviews and it is important for this age group and in general as well	Provider is flexible for patient
So I always find myself going on Google, like I'm always copying like articles	I always find myself going on Google	Increased usage of the Internet to access information and to educate herself. This is again consistent with the providers transcripts	Patient using the internet as a tool to further educate herself
so she doesn't push me to...okay you need to do this, that and that. She kinda gives me one task and then says okay do that and if it's working out then slowly, gradually, you know go walk, or do a little exercise, like don't do too much at one time	she doesn't push me to...okay you need to do this, that and that. She kinda gives me one task	Again making small tasks for the patient, making sure they are comfortable and not pushing them before they are ready	Provider focusing on one task at a time for management, avoiding pushing the patient too hard
sometimes I even like she's my friend, so um it's nice. But, I, I have a really good connection with her,	she's my friend...I have a really good connection with her	Really strong relationship here, the patient definitely feels comfortable with her provider	Strong connection and relationship with provider
the thing is I'm very fortunate that I have such a huge, huge support system.	I'm very fortunate that I have such a huge, huge support system	Having a strong support system definitely helps with care	Strong and big support system in place for patient
There's you know, you, you get respect; you earn respect from giving respect.	you earn respect from giving respect	The need for equality in the relationship for this patient, their needs to be mutual respect from both parties	Equality in patient and provider interactions can help with communication
Interviewer: Yeah the forum. Participant: Yeah, I'm going too.	Yeah the forum. Participant: Yeah, I'm going too	Access to diabetes programs	Attending local diabetes programs
Your healthcare provider making you feel, that you are capable of doing something,	You're healthcare provider making you feel, that you are capable of doing something	Empowering the patient, that is what she is mentioning here. This definitely facilitates care	Provider empowering the patient

Your healthcare provider making you feel that you are capable of doing something, and even though like the last 3 months the sugars weren't good due to different reasons, always get back on that wagon, she's so positive for things, and I really appreciate it	always get back on that wagon, she's so positive for things	Can always come back and turn things around, acknowledging that the patient is only human and can make mistakes	Provider makes patient feel that it is okay to make mistakes
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## Appendix P: Reflexive journal log

Entry Date	Entry
01-Apr-2016	I had my first interview today, which is very exciting. It went really well and was a lot longer than I was anticipating; she definitely had a lot to say. I was worried that my phone wouldn't pick up our voices while recording but listening to it afterwards it did pick everything up which is a relief. It also means I can do other interviews in public places without having an issue with the recording. I have a lot to think about from this interview too, I took a ton of notes, I think I may have gone a little overboard but that is probably better than not taking enough notes. I hope my recruitment starts to pick up now, it has been really difficult so far and I was really starting to get anxious about recruitment. Contacting the CDA has been amazing and I really hope I get a good amount of participants from the research forum I am attending on the 12 <sup>th</sup> .
07-Apr 2016	So I have completed transcribing the first interview and it took forever. I am going to have to stay on top of the transcription so I don't fall behind once I start getting more participants.
13 -Apr-2016	<p>The research forum went well, it was harder than I thought to put myself out there and talk to people about my research but I did it fairly well I think. There weren't a lot of young adults there, which is a bummer although I was kind of expecting that from what Heidi told me. I did meet one person who met my criteria, I gave her my contact information and I really, really hope she gets back to me. I am kicking myself a little for not asking for her contact information, but I guess it's too late now.</p> <p>I also met a professor from McMaster who seemed genuinely interested in my research and gave me her contact info. She says she might be able to get me into a diabetes clinic run out of McMaster university, which is super exciting. I am going to have to talk to Sam to see if I need to apply for another ethics modification. It is exciting though!</p>
17-Apr-2016	Heidi invited me to a DES meeting where I can present my study to a whole bunch of providers! This is great, I hope I can get into a bunch of clinics from this meeting and possibly recruit some providers into my study. It is a little scary to think about presenting to a room full of providers but I can't pass up this opportunity.
05-May-2016	The DES meeting went really well, there seemed to be some genuine interest from the providers and I handed out a ton of information letters and flyers, so hopefully I start to hear from people soon.
25-Jun- 2016	So I have completed a couple provider interviews and they went well. It is definitely different interviewing them as opposed to the one patient I have interviewed so far. But I think I did well and I got some good info. It is starting to worry me though that I haven't heard anything from any patients, I really hope someone contacts me soon.
15-Jul- 2016	<p>I should put more of an effort to write in here more often, but it's difficult with me working now and still doing Karate. I am going to take off a few days near the end of July to go up to Dad's and just get a bunch of work done. I have so much to do before then and I don't know how I'm going to get it all done.</p> <p>I have had 6 participants now, which is great, but still only one patient. I am at a bit of a loss at this point on what else I can do to recruit them. The providers I have interviewed said they are asking their patients and one provider said she thinks a few of her patients will participate. So fingers crossed that works out. It's hard for me to see Merryn and</p>

	everyone moving along so much faster than me and getting everything done. It makes me feel like I am doing something wrong, but I know it's just because I picked a hard population to recruit. Sigh, I just love making my life difficult.
19-Jul- 2016	I have transcribed all of the interviews and I am starting to notice some common phrases and things coming out of the interviews. It seems like the providers who have been practicing longer see more of a connection than the younger providers. I have already talked to Sam about this, and there seems to be this idea of denial that is coming out in the interviews like the young adults can't accept they have the disease. It does relate back to something my first participant said about her sister, so that is interesting. I will have to keep that in mind.
25-Jul- 2016	So the days off at Dad's was a complete bust. I am so pissed off at myself. I can't believe I got sick, what a waste. And I took time off work and everything. I am panicking a little bit now because I don't know how I am going to get all this work done, while working and dealing with everything else that has been happening. Bah.
16-Sept- 2016	Wow it's been too long since I have written in here. I have completed another interview and there are definitely patterns I'm starting to see in that data. But to be completely honest I have lost a lot of momentum. I have still only interviewed one patient...one!!!! I don't know what to do, I keep emailing the clinics and providers I am connected with, and Sam and I are trying to come up with new ideas but it all seems a little hopeless. What am I supposed to do? It's getting harder and harder to keep pushing forward when it feels like I'm not getting anywhere. I have a hard time motivating myself to do school work when I get home from work too, with my increased hours I don't know when I am going to find time to do it all. I just hope I can stay productive on the Fridays I have off.
16-Dec- 2016	I have really started to read through my transcripts now and it is exciting to be really diving into the data. I am keep reminding myself to keep the aim and objective of the study in mind. It is a lot easier now that I only have the one aim to complete. I am disappointed that the focus of the study has shifted to the providers instead of the patients, but at there wasn't a lot I could do. I did have another interview with a patient, so at least I have 2 patients to draw from, even though there won't be a lot if anything I can conclude from such a low number.
28-Dec-2016	Participant 5's was challenging to read through today, I didn't find a lot in terms of Fs and Bs in the first reading. I remember now thinking the interview wasn't as successful (maybe that's not the right word) as the others. I think when I look over for communication it will be easier, there were some good things she said in terms of that, I mean the way she communicates. I'm also really tired today, so I don't think I'm as sharp as I was yesterday and I might have missed some things. I will definitely have to go back and read hers again more thoroughly. I think I am only going to read through hers today, I should probably do more work but I honestly don't think I can properly identify things, my mind is wondering too much or I'm just zoning out.
21-Jan- 2017	I read some more transcripts, I am proud to say I got a lot done today and I am feeling really good. That's not to say I don't have a ton more work to do, but I think it is a really good start. I want to have as much as possible ready for my meeting with Sam, but I do need to make sure I am not rushing, but taking my time with the data and really allowing the codes to present themselves to me as opposed as looking for things. Even though I am looking for something specific, my fear is that I don't want to force the data into any ideas I might have myself, I want it to speak for itself. I think as long as I keep that in

	<p>mind I will be okay.</p> <p>I'm going to read through the transcript again to see if I got everything, but that will be hard with the way the coding stripes are in NVivo, which is frustrating. I understand now what Merryn meant, I will have to devise a strategy for reviewing the nodes in the transcript, I wish it highlighted where you marked the source material with the node other than in the coding stripes....maybe it does I will have to figure that out. I also understand what Kelsey meant by just spending time thinking about things when doing the analysis, I already want to just sit and think about the Fs and Bs and go back through this the transcripts I have finished.</p> <p>I can also already see how some of the nodes will be grouped into initial categories, but I'm trying not to get too ahead of myself, like I tend to do with these things.</p>
27-Jan- 2017	<p>I am stopping for the day, I need to rest my brain, like I already said my head is buzzing and I need to make sure I take breaks so I don't miss anything. I can understand Merryn's hesitancy to move forward with groupings and wanting to read the transcripts over and over, I feel like every time I read these transcripts I find something new, I wish NVivo highlighted the areas of the transcript that were coded so I can see where I already have codes, or where codes overlap, hm maybe that could be something I do on my own in the word documents, I could colour code it for the 3 read throughs, or more for the three general foci I have, that way if I read them more than three times (which let's be honest I will likely have too), then it won't get too confusing. Yeah, I think I will do that, maybe tomorrow after I am finish reading the next transcripts, if there is time permitting I can start to do that.</p>
07-Feb-2017	<p>I need to start to organize my codebook tomorrow, I am not necessarily going to start looking through the codes yet, I think it is still too early but I think just getting myself organized will make things a bit easier. I also need to think of a way to organize the codes for my different read throughs. I think it will be a good exercise to write up a rationale for why I am doing the read throughs this way, that way I am being clear and I can make sure it makes sense.</p>
23-Feb-2017	<p>I am officially done recruitment, which is a huge relief. I can really focus in on my analysis now. I have am going to focus on the new transcripts this week so I can complete the first stage of the framework analysis.</p>
25-April-2017	<p>I kind of forgot about doing my reflexive journaling while doing the analysis. I hope that isn't a bad thing. I have a bunch of analytical memos, so I think that is probably okay. I was also pretty good with doing the journaling during data collection and recruitment, and I did do it for the first part of my analysis. I think it will be okay, hopefully.</p>

## Appendix Q: Analytical Memos

Analytical Memos	
Participant 02	<p>I realized very quickly in going through looking for Fs and Bs that I there are two ways I'm looking at it: 1. Fs and Bs that prevent or enable the patient from coming into the office and receiving care. 2. Fs and Bs that prevent or enable the patient from communicating with the provider. But the more I think about it the 2nd way I have been thinking about it is more a subcategory of the 1st, right? Because the two aren't mutually exclusive, or maybe they are different categories, but it is okay that they aren't mutually exclusive? Maybe something to talk to Sam about, or reflect on as I read more of the transcripts.</p>
Participants 03 & 04	<p>I keep reminding myself to keep an open mind about what I'm reading and not to look for things that I have observed in the other transcripts. I am making sure to stay focused as much as I can on the transcript that I am currently working in order to stay true to the participant.</p>
Participant 06	<p>This interview was interesting, there were definitely some talk about the Fs and Bs to receiving care and communication, but not nearly as much as with other transcripts. I wonder if there is because of his role, something to think about. His wording was interesting in bringing up the power dynamic in this kind of relationship, I will have to think about and look into the literature on how that can work into being a B or F. I would think it definitely can, but I need to read up on it a bit first.</p> <p>He also brought up something interesting, that I'm pretty sure the other providers have mentioned about being able to relate to people because of being in the same age category as the patient. I know that isn't something that can be helped but it's an interesting observation anyways as a potential B or F. I know I feel more at ease with a provider who appears to be around the same age as me. Something to think on more, or see if it comes up more. He was also the first, I believe, to mention the health care system as a potential barrier, I will have to see if this pops up in other interviews, I can't let it influence my in-vivo coding though, I need to make sure I am focusing solely on the transcript I am working on when I'm working on it.</p>
Participant 07	<p>This one was a bit harder, I found myself questioning if it was an actual F or B, or if I was just tagging it because it was communication related. Not that it's a bad thing because I will be looking at communication next, but I think I will have to keep that in mind when I am sorting through the codes I generated for her later on. I also have to keep in mind context to the transcript, not just for her but for everyone. I will really have to make sure that I go back and read the section where the code comes from to make sure I stay true to what the participant said.</p>
Participant 08	<p>Her focus was definitely more on communication than some of the other providers, especially with the Fs and Bs she did talk about. I'm not sure if she was tailoring her answers because she knows I am looking at communication, but her</p>

	<p>points were interesting. I hope there is some of what she was talking about in the other interviews. I will have to go back and look through to see, none of them were maybe as explicit as her, or maybe it's more an awareness. Something to think about a bit more.</p>
Participant 10	<p>I think her transcript will be most useful when looking at communication and how providers communicate with their patients. She did have that saying 'meeting them where they are at' thought, which is exciting. I really can't wait to start comparing all the transcripts to see how many times that shows up. It might not come up as much I am thinking, but if it's sticking out in my mind then it must have come up enough to stand out. I will just have to wait and see.</p>
Participant 11	<p>This was an extremely useful interview, he had a lot of things to say about Fs and Bs. I have the highest number of nodes from this interview. I think that is mostly because he talked the most out of all the providers.</p> <p>- There is a lot of useful information there, the idea of priorities came up in his interview. That was something I have been seeing with the other interviews. I will have to see how much it came up. I can't wait to start comparing the transcripts, it's going to be awesome looking at the different patterns.</p>

## Appendix R: Notes taken during interview

Participant #	Notes
1	<p>Things to keep in mind:</p> <ol style="list-style-type: none"> <li>1. One question at a time</li> <li>2. Leave questions open → how does diabetes affect your life?</li> <li>3. Keep the questions simple</li> <li>4. Keep aims and objectives in mind – are you answering them?</li> </ol> <ul style="list-style-type: none"> <li>- Go back to talk about experience with optometrist <ul style="list-style-type: none"> <li>o Young people why it's important, point about being in denial</li> </ul> </li> <li>- Go back to talk about differences with nurse practitioner and family doctor</li> <li>- Very comfortable</li> <li>- Depression and anxiety → look back over literature for this</li> <li>- Ability to control → loss of control after diagnosis</li> <li>- All about respect → being spoken too like an adult (Szasz)</li> <li>- She thinks people focus on older people</li> <li>- Does not want gift card</li> <li>- Optometrist – idea of respect, not caring</li> <li>- Family support</li> <li>- Work life</li> <li>- Barely said anything (said in interview) <ul style="list-style-type: none"> <li>o Communication preference</li> <li>o Not happy about this</li> </ul> </li> <li>- What happens in her experience shapes her attitudes of future health care providers</li> <li>- Optometrist isn't speaking to her, she is not happy with this/ impressed by this</li> <li>- 2<sup>nd</sup> optometrist is helping</li> <li>- Moving through HC system → barrier? <ul style="list-style-type: none"> <li>o Breakdown of communication, having to constantly say things to people</li> </ul> </li> <li>- Complications have been really trying</li> <li>- Career plans? → future greatly affected</li> <li>- No one was direct with her → she wanted to know <ul style="list-style-type: none"> <li>o Wants open communications</li> </ul> </li> <li>- Idea of invincibility challenged <ul style="list-style-type: none"> <li>o Importance of maintaining health</li> <li>o More awareness</li> </ul> </li> <li>- This idea of denial in young people</li> <li>- Importance of close friends</li> <li>- Want people to let her talk → preference</li> <li>- FHT, talk about everything</li> <li>- NP → put time in that work for her, facilitator?</li> <li>- Idea of trust, facilitator and barrier for her</li> <li>- Idea of similarities between her and her NP, makes it easier for her to talk to</li> <li>- See physician for more critical issues</li> <li>- A lot of complications in 2015</li> <li>- Emotional tie to disease is important</li> <li>- Trust, come back to this</li> </ul>

- Questions 5, NP
- No power dynamic
  - o Lifeworld, didn't take it out of lifeworld context when ranting
  - o Created a personable connection
- Wanting to read and learn more
- Dietician → idea of control again
  - o Relates to Szasz model of communication
  - o Adult – adult interaction
- Personal preferences to be taken seriously, listened to
- Wanting to know things
  - o How does this related back to older adults?
- First time going to a seminar with Heidi
- Multifaceted care, going to see a lot of people
- Wants to offer support and get support, age related?
- Wants to talk about alternative medicine, idea of knowledge
- Keep this (interview) – points at eye
- Did tell NP about natural medicine
- Wants to be involved
- Again idea of control with diabetes → how does this relate back to communication
- Covers everything → explains all her aspects
- Creating a sense of empowerment, supporting each other
- Strong connection
  - o How does this relate to Mishler's model of communication?
- Relationship building, wants a sense of familiarity
- Idea of moving through HC system again
  - o Communication is key
  - o Open communication
  - o Gratitude
  - o Relationship building, creates the plan with her
- No negative experiences with NP
- Physician, not bad, wanted her to see another diabetic specialist
- Negative experience → specialist
  - o Treated like a child
  - o Feeling worthless
  - o Created doubt
  - o What are you doing about this? (Specialist said)
    - Switching to a child – adult model, didn't like this
- Very open person with everything
- Dad, family → facilitator for access
- Insurance, age group, pressure to work, dealing with these things
- Parents as a support → age group?
- Optometrist → closed lines of communication, feels strongly about that
  - o Wasn't asking the right questions
  - o Complications with younger people → eyes
- Needs people to care
- Problems with HC system again
  - o Breakdown in communication
- Complications have a huge impact → only 31, she has a much longer amount of time to

	<ul style="list-style-type: none"> <li>live with this</li> <li>- Optometrist → idea of lifeworld and world of medicine interacting, a breakdown? <ul style="list-style-type: none"> <li>o Idea of openness</li> </ul> </li> <li>- Idea of denial again, especially with young people</li> <li>- Challenging the idea of invincibility</li> </ul>
2	<ul style="list-style-type: none"> <li>- Re-evaluate question 9 <ul style="list-style-type: none"> <li>o Framing of the questions</li> </ul> </li> <li>- Wants to open up (patient) to be able to</li> <li>- Mishler, lifeworld → acknowledging and wants to understand where they are coming from</li> <li>- Joining the 2 worlds a bit</li> <li>- Wants teen/ adult</li> <li>- Doesn't want to talk at someone</li> <li>- Health literacy → awareness</li> <li>- Working with them, again adult preference <ul style="list-style-type: none"> <li>o Connection to the lifeworld again</li> </ul> </li> <li>- 6. Think about changing wording</li> <li>- Not receptive → lifeworld</li> <li>- Not a big emphasis on age, more about SES</li> <li>- Health literacy, education, these are more important than age</li> </ul>
3	<ul style="list-style-type: none"> <li>- Feels very different with the age (compared to participant 02)</li> <li>- Does see a difference in this age group</li> <li>- Trying to see their perspective → lifeworld a little bit</li> <li>- Want to be involved</li> <li>- Much better compliance</li> <li>- Understand them → more involved</li> <li>- Parents involvement <ul style="list-style-type: none"> <li>o Trying to treat the patient</li> </ul> </li> <li>- Often financial, they bring it up</li> <li>- Let them start the conversation</li> <li>- The communicator → journal</li> </ul>
4	<ul style="list-style-type: none"> <li>- Would like a copy of the article</li> </ul>
5	<ul style="list-style-type: none"> <li>- Wants to read the article when research is done</li> </ul>
6	<ul style="list-style-type: none"> <li>- 1177 out of 3471, 75% use insulin</li> <li>- Doesn't see a difference between ages</li> <li>- Focus on physical activity <ul style="list-style-type: none"> <li>o Behaviour change</li> </ul> </li> <li>- Lifeworld – looking at what the patient wants to change</li> <li>- More concerned about socio-economic status</li> </ul>
7	<ul style="list-style-type: none"> <li>- Does see a difference between younger and older populations, busier and thinks they are more difficult to talk to.</li> <li>- She seems to be a bit more teen than adult, but she is still encouraging of the patients, I got the impression it was more the traditional patient-provider relationship with her, but analysis is needed to be sure.</li> </ul>
8	<ul style="list-style-type: none"> <li>- NP</li> <li>- Finds there is more counselling, more support, more disappointment with young adults</li> <li>- Denial</li> </ul>

	<ul style="list-style-type: none"> <li>- Using insulin to lose weight</li> <li>- Meeting them where they are at</li> <li>- This idea of control, who has the power?</li> <li>- I won't be happy with their blood work</li> <li>- Incrementalism</li> <li>- Maintaining the close relationship</li> <li>- Phone call – in between appointments</li> <li>- Ask questions over the phone not in the appointment</li> <li>- Patient-centred care</li> <li>- Meeting their life world</li> <li>- Non-complaint</li> <li>- Wants a copy when finished.</li> </ul>
9	<ul style="list-style-type: none"> <li>- Unique participant, has a lot of factors impacting her care</li> <li>- Would like a copy of the article</li> </ul>
10	<ul style="list-style-type: none"> <li>- Would like a copy of the article</li> </ul>
11	<ul style="list-style-type: none"> <li>- Very aware of the lifeworld.</li> <li>- 'Meeting people where they are at', that statement keeps coming up.</li> </ul>
12	<ul style="list-style-type: none"> <li>- Patient responsibility</li> <li>- Doesn't use scare tactics</li> <li>- Wording more neutral <ul style="list-style-type: none"> <li>o More positive</li> </ul> </li> <li>- No guilt</li> <li>- We're here to help you</li> <li>- Pressure off them</li> <li>- Underlying depression <ul style="list-style-type: none"> <li>o Word underlying again</li> </ul> </li> <li>- Couldn't work <ul style="list-style-type: none"> <li>o Lifeworld</li> </ul> </li> <li>- Buy into it</li> <li>- See them really often</li> <li>- Regular follow up</li> <li>- Lots of communication types</li> <li>- Availability</li> <li>- Don't have a choice</li> <li>- Would like to read the article</li> </ul>
13	<ul style="list-style-type: none"> <li>- Get to know them</li> <li>- Don't have time to look after themselves <ul style="list-style-type: none"> <li>o Forget they have diabetes</li> </ul> </li> <li>- Spouse or partners <ul style="list-style-type: none"> <li>o Focus on them</li> </ul> </li> </ul>