

**Examining complex diabetes and patient illness experiences: utilizing syndemic and  
health capabilities approach**

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## **Abstract**

Health complications often accompany complex diabetes. Compared to the biomedical model, this study uses a syndemic and health capabilities approach. The purpose of this study was to explore how social factors shape the health of those who experience complex diabetes, and the perceived challenges these individuals encountered when interacting with the healthcare system. Data collected in this study came from multiple sources including secondary data, surveys, and interviews. Findings of this study demonstrate most individuals perceived the cause of their health and psychosocial condition to be associated with genetics or lifestyle habits. A person's health capability was often reduced by: competing ailments, social circumstances, financial insecurity, and inaccessibility to healthcare resources. Implications of this study suggest that access to social and economic resources built into the structure help shape a person's health capability. Fundamental to the syndemic phenomenon associated with complex diabetes is the failure and insecurity of social context.

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*“Hardships often prepare ordinary people for an extraordinary destiny” - C.S. Lewis*

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**Dedication:**

I would like to dedicate this thesis to all my family members who have lived and struggled to manage complex diabetes. You are not alone in your journey.

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## **1. Chapter One: Introduction**

### **1.1 Statement of the problem: Diabetes a local, provincial, national, and global problem**

#### **1.1.1 Diabetes: a global problem: the world wide epidemic**

The prevalence of diabetes has stormed nations by epidemic proportions and has become the largest global health emergency in the 21<sup>st</sup> century (Berends, & Ozanne, 2012). In 2015, an estimated 415 million people worldwide were living with diabetes (International Diabetes Federation (IDF), 2015). This number is expected to rise dramatically to 642 million by 2040, and has been linked with population ageing, urbanization, and associated lifestyle changes (IDF, 2015; Chen, Magliano, & Zimmet, 2012).

The human cost and impact diabetes have on individuals and their communities is often neglected. For example, in 2012 1.5 million deaths were estimated by the World Health Organization (WHO) to be directly associated with diabetes, with over 80% of these death occurring in low and middle income countries (WHO, 2015). Furthermore, the IDF estimates that nearly 46.3% of people with diabetes remain undiagnosed, and are advancing towards diabetes complications (IDF, 2013).

Chronic non-communicable diseases such as diabetes not only require active self-management, but can also coexist with other chronic conditions (Narayan, Echouffo-Tcheugui, Mohan, & Ali, 2012). Moreover, if organized integrated care systems are not in place, coexisting chronic conditions may advance to complex health conditions, resulting into detrimental health consequences (Narayan, Echouffo-Tcheugui, Mohan, & Ali, 2012). For example, in many countries diabetes is the primary cause of renal failure, visual impairment, and blindness (WHO: Global Health Observatory, 2016). Among developed countries, lower limb amputations are ten times more common in individuals with diabetes compared to those without (Icks et al., 2009). What is most worrisome is that diabetes predominantly impacts the most vulnerable in society, placing an

overwhelming burden on those who are socially and economically disadvantaged in any country (IDF, 2013; Unwin, Whiting, & Roglic, 2010; Hu, 2011).

#### 1.1.2 Diabetes: a national problem- Diabetes in Canada

Across Canada, diabetes is on the rise and is becoming an epidemic where no province, territory, or community is immune. In fact, since 2000 the number of people living with diabetes have doubled, with 8.9% of Canadians being diagnosed with diabetes in 2015 (Canadian Diabetes Association, 2015b). As a consequence the incidence of diabetes will continue to rise if action is not taken (CDA, 2012).

As age increases, so does the prevalence of diabetes. This was evident when Statistics Canada reported the highest rates of diabetes among individuals who were between the ages of seventy-four and seventy-nine (Public Health Agency of Canada, 2011). Furthermore, the prevalence of complex diabetes (diabetes and diabetes-related complications) was found to be disproportionately higher among lower income Canadians and Aboriginal groups (CDA, 2015b).

According to Statistics Canada, in 2014, 14.6% of obese Canadians 18 years or older were reported to have diabetes, compared to 5.2 % of those who were not obese (Statistics Canada, 2015). Moreover, the prevalence of individuals being diagnosed with diabetes increased especially among individuals ages 35 to 44 (Public Health Agency of Canada, 2011). The increase in diabetes diagnosis among younger and older age groups has been associated to increased rates of obesity and an aging baby boom population (CDA, 2011).

Throughout Canada, Canadians with a higher diabetes diagnosis average resided in: Newfoundland and Labrador (9.0%), Nova Scotia (8.2%), New Brunswick (8.4%), and Ontario (7.4%) (Statistics Canada, 2015). In 2014, it was estimated that 3.3 million Canadians were living with diabetes, while 5.7 million people in Canada were living with prediabetes (CDA, 2014). It is believed that one in four Canadians live with diabetes, prediabetes or undiagnosed diabetes (CDA, 2012).

The national surge in the prevalence of diabetes can be attributed to various factors including: demographic structures (e.g. age, ethnic and cultural background, and immigration from high risk communities such as Southeast Asia); socioeconomic factors (e.g. household income and low socioeconomic status (SES)); and a person's biology (family history of diabetes) obesity, and lifestyle (e.g. lack of physical exercise).

As mentioned previously, some Canadian populations are more burdened with diabetes than others. This is especially true for certain subpopulations including: Aboriginal peoples, immigrants, some ethno-cultural communities, low-income Canadians, and women (CDA, 2012). Moreover, ethno-cultural communities such as individuals from Southeast Asian, Aboriginal, African, and Hispanic descent, were reported to have higher rates of diabetes at a younger age (CDA, 2008).

Earlier in section 1.1.2, it was stated that diabetes and its complications appeared to be higher among low income Ontarians compared to those of higher income. This finding is also reflected on a national level, as diabetes complications continue to be uncommonly higher among low-income Canadians. (CDA, 2015b).

According to the Canadian Institute of Health Information (CIHI, 2010), adults from lower income groups (less than \$20,000) were two fold likely to be living with diabetes (8%), than adults from higher income groups (income of \$60,000 and more) (4%). The increase in diabetes complications among low income Canadians may be affiliated to a lack of resources needed to improve health conditions.

Diabetes self-management demands drastic lifestyle changes in order to prevent the onset of complications. Canadians with limited social, economic, and cultural resources may not be able to implement lifestyle changes and adhere to prescribed diabetes management recommendations, due to a lack of resources (Rabi et al., 2006). This reality some Canadians face is evident, as only 21% of low-income individuals receive recommended diabetes care, compared to 42% of high income individuals (CIHI, 2010). According to the CDA (2015 b) 15% of

Canadians living with diabetes reported to not have access to insurance for prescription medication, while 30% did not have insurance to cover blood glucose monitoring supplies and equipment. Increased out-of-pocket costs severely impact low income individuals living with diabetes. This is because people with diabetes must choose between the necessities of life (food/ rent/ utilities) and adhering to prescribed diabetes management recommendations/ buying medications (CDA, 2015 b). This reality many Canadians endure, places the individual within a vicious cycle, where the inability to implement preventative measures may lead to the rise of diabetes complications and poor quality of life.

#### 1.1.2.1 Diabetes in Canada: Mortality

According to the CDA, among peer developed countries Canada ranks third highest in diabetes-related mortality with eighteen deaths per 100,000 individuals. In 2004/05, approximately 120,050 deaths in Canada were caused in relation to diabetes (Statistics Canada, 2014). Although diabetes-related death varies by neighborhood income, deaths among low income groups were almost double compared to high income groups (Peters, Oliver, & Carriere, 2012). For example, among low income groups 67.1 deaths per 100,000 were associated with diabetes, compared to 31.4 per 100,000 among high income groups (Statistics Canada, 2014).

#### 1.1.2.2 Diabetes in Canada: Economic cost

People living with diabetes in Canada often encounter out-of-pocket costs that are associated with diabetes management. In addition to differences existing in diabetes coverage across Canada, and shrinking health insurance plans in some provinces, there is less public coverage for type 2 diabetes and more public coverage for types 1 diabetes (CDA, 2015b). As a result, in order to receive treatment, people living with type 2 diabetes pay approximately \$723 to \$1,914 a year (CDA, 2015b). Additionally, seniors across Canada must devote 36% to 70% treatment costs from their own pockets (CDA, 2015b). Furthermore, some people

living with diabetes may dedicate over 3% of their annual income towards diabetes medications, devices, and supplies (CDA, 2011).

Shouldering the highest out-of-pocket cost for diabetes treatments are low income groups (CDA, 2011; Wellesley Institute, 2015). Approximately 57% of Canadians with diabetes are unable to adhere to diabetes recommendations, due to insufficient healthcare insurance coverage and a lack of resources (Law, Cheng, Dalla, Heard, & Morgan, 2012). Individuals unable to comply with diabetes self-management regimes are at an increased risk of developing diabetes complications such as: cardiovascular disease, stroke, blindness, kidney failure, neuropathy, and depression (CDA, 2011).

### 1.1.3 Diabetes a provincial problem: Diabetes in Ontario

According to the Canadian Diabetes Association (CDA) (CDA, 2015a) the prevalence of diabetes in Ontario is approximately 10.2%, and has projected this number to rise to 13.4% by 2025 (CDA, 2015a). The estimated number of people living with prediabetes in Ontario is 2.27 million, and is expect to increase to 2.54 million by 2025 (CDA, 2015a). Conversely, if proper preventative measures are not taken, individuals with prediabetes are at a great risk of developing diabetes complications such as nephropathy, neuropathy, retinopathy, etc.

Interestingly, from 2005/2006 to 2013/2014, diabetes complications have decreased from 6.0 per 100 people to 4.1 per 100 people (Health Quality Ontario, 2015). However, despite this progress, low income Ontarians or those living in rural areas, are more likely to experience diabetes complications (Health Quality Ontario, 2015). In fact, diabetes complications appear to be higher in low income neighbourhoods compared to high income neighbourhoods (4.6% vs. 3.8 % respectively) (Health Quality Ontario, 2015).

With diabetes complications being concentrated among low income groups, the demands and resources diabetes self-management require becomes a strain on household finances. For example, based on a \$43,000 annual income, the estimated out-of-pocket cost for type 2 diabetes in Ontario is \$2,594 (CDA, 2015a).

#### 1.1.4 Diabetes: a local problem – Diabetes in the Durham Region

With 10% of the Greater Toronto Area (GTA) population residing in Durham Region, most of the population concentration is in Oshawa and Whitby (Durham Region, 2015). Moreover, Oshawa currently has the largest population of individual's ages sixty-five and over (Durham Region, 2015).

Within the Durham Region, diabetes prevalence is considerably higher compared to the rest of Ontario and rates appear to be lower in rural areas and higher among populations of recent immigrants and visible minorities (The Regional Municipality of Durham, 2015). Diabetes prevalence is highest especially in municipalities of Ajax, Oshawa, and Pickering. (The Regional Municipality of Durham, 2013).

Findings in the 2012-2013 Community Care Access Centre Report, reveals that diabetes rates in Scarborough and Durham Region surpassed both the Central East LHIN and provincial average of 6.6% (Central East LHIN, 2014). Approximately 60% of the population in Durham region are overweight or obese, while 7.1% are said to be living with diabetes (Statistics Canada, 2013). In addition to increased obesity rates, unemployment rates in Durham grew in 2011 to 8.6% compared to 6.3% in 2006 (Durham Region, 2015). It was reported that the average income per individual was around \$44, 443 (Durham Region, 2015). What is more alarming is that 25% of residents in Durham Region spend more than 30% of their income on shelter, while 10% of Durham region residents were low income (roughly under \$20,000) (Durham Region, 2015; Statistics Canada, 2016).

Additionally, although diabetes mortality rates have been on the decline since 2000, rates among males have been consistently higher than in females, both in Durham region and Ontario (The Regional Municipality of Durham, 2015).

## 1.2 What is Diabetes?

Diabetes Mellitus is a chronic complex metabolic disease that disrupts normal glucose homeostasis in the body (Goldenberg & Punthakee, 2013).



Characterized by hyperglycemia, diabetes is caused by insufficient insulin secretion, increased insulin destruction, or ineffective use of insulin (Goldenberg & Punthakee, 2013). This disruption causes a metabolic imbalance and if not managed may have serious or life-threatening health consequences that affect the heart, blood vessels, eyes, and kidneys (Goldenberg & Punthakee, 2013).

The concentration of glucose in the blood is regulated by two antagonistic hormones: insulin and glucagon that are produced in the pancreas (Campbell et al., 2008 p. 981-984). Throughout the pancreas cluster of endocrine cells known as the islets of Langerhans are dispersed. Each islet of Langerhans contains alpha and beta cells. Alpha cells are responsible for synthesizing glucagon, while beta cells synthesize insulin. However, because insulin and glucagon have opposing effects in controlling blood glucose levels in the body, these two hormones are regulated tightly by a negative feedback loop (Campbell et al., 2008 p. 981-984).

For example, when blood glucose concentrations exceed normal levels, beta cells of the pancreas are signaled to release the hormone insulin. Insulin acts like a key to the door of cells, triggering cells to uptake glucose, and therefore decreases blood glucose concentrations. Insulin also decreases blood glucose concentration by reducing the breakdown of glycogen in the liver (Campbell et al., 2008 p. 981-984). The three types of diabetes are: type 1 diabetes, type 2 diabetes, and gestational diabetes mellitus.

### 1.2.1 Type 1 Diabetes

Traditionally known as juvenile diabetes or insulin-dependent diabetes mellitus, type 1 diabetes is a less common form of diabetes, and typically occurs in children and young adults (CDA, 2016). Approximately 10% of people living with diabetes have type 1 diabetes (CDA, 2016).

Type one diabetes occurs when the immune system destroys the beta cells in the pancreas (CDA, 2016; Ekoe, Punthakee, Ransom, Prebtani & Glodenberg, 2013). As a result, none or little insulin is released. Due to the absence of insulin, glucose concentration builds up in the blood instead of being converted into energy (CDA, 2016; Ekoe, Punthakee, Ransom, Prebtani & Glodenberg, 2013).

The immune-mediated response that destroys beta cells can be initiated by environmental factors in genetically predisposed individuals (Ekoe, Punthakee, Ransom, Prebtani & Glodenberg, 2013). Latent autoimmune diabetes in adults (LADA) is also a form of Type 1 diabetes. LADA describes a small percentage of people who have appear to have type 2 diabetes and experience immune-mediated loss to pancreatic beta cells (CDA, 2016).

### 1.2.2 Type 2 Diabetes

Type two diabetes (non-insulin-dependent diabetes mellitus) is far more common than type 1 diabetes, for approximately 90% of people living with diabetes have type 2 diabetes (CDA, 2016). When the body is unable to use insulin effectively or produces insufficient insulin glucose concentration increases and type 2 diabetes occurs (CDA, 2016).

One of the hallmarks of type 2 diabetes is the progression of insulin resistance in muscle, adipose, and liver cells (Whitney & Rolfes, 2008, pg. 638-340). With reduced sensitivity in these cells, the beta cells in the pancreas increase the amount of insulin it secretes to carry out a biological effect, which usually requires a lower amount of insulin in a normal health state (Whitney & Rolfes, 2008). Insulin resistance occurs when insulin receptors are improper or defective, leading to the down regulation of insulin receptors (Mckee & Mckee, 2009). With an increased request for insulin, the beta cells of the pancreas become exhausted (Mckee & Mckee, 2009).

The process of beta cells from the pancreas secreting insulin is exacerbated, impairing insulin secretion and reducing plasma insulin concentration (Cox & Nelson, 2008). Failure to produce adequate insulin is reflected in the body's inability to regulate blood glucose levels. It is important to note that, similar to type 1 diabetes, where blood glucose levels are elevated, in type 2 diabetes, blood insulin levels are also elevated (Sizer, Whitney, & Piché, 2012). However, in type 2 diabetes, glucose does not enter the cells, but instead accumulates in the blood (Whitney & Rolfes, 2008). Such phenomena can lead to both acute and chronic problems. Continual elevated blood glucose can modify

glucose metabolism in cells, sometimes converting excess glucose to sugar alcohols, exhibiting a toxic effect and cell distention (Whitney & Rolfes, 2008).

Historically rare among young people, prevalence of type 2 diabetes among children and adolescents has become more common as rates of obesity climb. Furthermore, individuals with type 2 diabetes may go years undiagnosed or unaware of their condition, due to unrecognizable symptoms (Ekoe, Punthakee, Ransom, Prebtani, & Goldenberg, 2013; CDA, 2016). Risk factors for T2DM are outlined in table 1 (adapted from Ekoe, Punthakee, Ransom, Prebtani, & Goldenberg, 2013).

Table 1: Risk Factors for Type 2 Diabetes Mellitus

Family history of diabetes	Individuals over the age of 40	Member of high risk populations (e.g. Aboriginal, African, Asian, Hispanic, or South Asian decent)	Having prediabetes
History of gestation diabetes	Organ damage associated with diabetes	Elevated HDL cholesterol	Hypertension
Being Overweight	Abdominal obesity	Polycystic Ovarian Syndrome	Acanthosis Nigricans
	Psychiatric disorder (bipolar disorder, depression, schizophrenia)	Elevated triglycerides	

\*(Table adapted from Ekoe, Punthakee, Ransom, Prebtani, & Goldenberg, 2013).

### 1.2.3 Gestation Diabetes

Gestational diabetes mellitus is a temporary onset of glucose intolerance that coincide during pregnancy, affecting 2-4% of all pregnancies (CDA, 2016a). Across Canada, between three to 20 % of pregnant women develop gestations diabetes (CDA, 2016b). Alarmingly, as many as 30% of women develop diabetes within fifteen years after having gestational diabetes (CDA, 2016b). Gestational diabetes places both mother and child at an increased risk of developing type 2 diabetes (CDA, 2016a).

Gestation diabetes occurs when the body is unable produce adequate levels of insulin due to changes pregnancy brings (CDA, 2016c). These changes include the effects of a growing baby and fluctuating hormone levels. As a result of these changes, glucose levels rise due to the shortage of insulin (CDA, 2016a).

The outcome of undiagnosed or untreated gestational diabetes is that of high glucose (sugar) levels, which increases risk of baby weight being over four kg (nine pounds) (CDA, 2016a). Furthermore, gestation diabetes increases

delivery complications, and increases future risk of child becoming overweight and developing type 2 diabetes (CDA, 2016a).

According the Canadian Diabetes Clinical guidelines, all pregnant women at 24-28 weeks of gestation should be screened (Thompson, Berger, Feig, Gagnon, Kader, Keely, Kozak, Ryan, Sermer, & Vinokuroff, 2013). Screening is especially important for individuals who are at a high risk of developing gestational diabetes. Risk factors include: previous diagnosis of gestation diabetes, prediabetes, a member of a high- risk population (e.g. a person of Aboriginal, Hispanic, South Asian, Asian, or African ethnicity), age  $\geq 35$  years, BMI  $\geq 30/\text{m}^2$ , Polycystic ovarian syndrome/ acanthosis nigricans, corticosteroid use, history of macrosomic infant, or current fetal macrosomia or polyhydramnios (Thompson et al., 2013).

#### 1.2.4 Prediabetes

According to the CDA, across Canada more that 5.7 million people have prediabetes (CDA, 2016d). Prediabetes refers to impaired fasting glucose (IFG), impaired glucose tolerance (IGT) or an A1C of 6.0% to 6.4% (Goldenberg and Punthakee, 2013). This is because although blood glucose (sugar) levels are more elevated than normal, it is not high enough to be diagnosed as type 2 diabetes (CDA, 2016e).

Compared to people living with diabetes, those with prediabetes are not at risk for microvascular disease. However, individuals with prediabetes are at higher risk for developing cardiovascular disease (CVD), and stroke (Goldenberg and Punthakee, 2013). In fact, IGT is strongly linked to CVD and shares many characteristics with type 2 diabetes, such as the inability to use insulin effectively, obesity, and advancing in age (Goldenberg & Punthakee, 2013; International Diabetes Federation, 2013).

#### 1.2.5 Diabetes complications

If left untreated or unmanaged, diabetes may develop into a costly and life-threatening disease (CDA, 2016f; Public Health Agency of Canada, 2011).

Unmanaged diabetes can lead to short-term and long-term complications such as: cardiovascular disease, kidney disease, neuropathy, blindness, limb amputations and premature death (Solli, Stavem, & Kristiansen, 2010). These complications are not only linked to increased rates of morbidity and mortality, but also exacerbate health disparities and increase disease burden among individuals with diabetes (Deshapande, Harris-Hayes, and Schootman, 2008).

One of the cornerstones of diabetes management is glycemic control. However, if glucose levels go unmanaged over time this can have detrimental impact on organ function, eliciting life-threatening complications (Public Health Agency of Canada, 2011; National Institute of Diabetes and Digestive and Kidney Disease (NIH), 2013). A trademark of diabetes complications is the development and progression of microvascular and macrovascular complications. Development of microvascular and macrovascular complications usually occur among people who were undiagnosed and unaware of their diabetes, and those living with diabetes for a long time (Cade, 2008). Examples of microvascular complications affiliated with diabetes include: retinopathy (diabetes complications related to eyes and vision (Boyd et al., 2013); neuropathy (nerve damage in organs as a result of hyperglycemic (Public Health Agency of Canada, 2011)), and nephropathy (kidney disease triggered by presence of diabetes due to increased blood flow into kidneys (NIH, 2009)).

Macrovascular complications associated with diabetes include: CVD, cerebrovascular disease, and peripheral artery disease (Cade, 2008). Both microvascular and macrovascular complications reduce quality of life, elevate risk of premature death, forbid people's ability to work and place increased strain on a fragile healthcare system (Public Health Agency of Canada, 2011).

Among Canadian adults, diabetes is the major cause of blindness, end stage renal disease, and non-traumatic amputation (CDA, 2013). Seven out of ten non-traumatic amputations have been linked to diabetes complications (CDA, 2016f). Even more, around one-third of individuals living with diabetes for over fifteen years will develop kidney disease (CDA, 2016f). Also, approximately, 10%

of acute care hospital admissions is associated with diabetes and its complications (CDA, 2016f).

Preventing diabetes complications is contingent on both individual self-management and the care received from health professionals (e.g. doctors, nurse practitioners, nurses, pharmacists, dietitians, and diabetes educators). Individuals' inability to manage diabetes can also be traced to inadequate social support, healthcare access, lack of resources for medications, treatments, and lifestyle changes, and the demands of competing illnesses (Public Health Agency of Canada, 2011).

#### 1.2.6 Diabetes and depression

It is estimated that 25% of people living with diabetes, also experience depression (CDA, 2016f). Medical evidence goes onto the describe the correlation between diabetes and depression as a bi-directional relationship depression (Sacco & Yanover, 2006; Chen, Chan, Chen, Ko, & Li, 2013; Egede & Eillis, 2010; Golden et al., 2008; Mezuk et al., 2008; Talbot & Nouwen, 2000).

It is thought that diabetes can result in the onset of depression, due to the psychosocial burden of diabetes self-management (Renn, Feliciano, & Segal, 2011; Golden et al., 2008). However, decreased quality of life, poor diabetes self-care, reduced glycaemic control, and increased risk in developing diabetes-related complications, have also been traced to the onset of depression (Nouwen et al., 2010). Many researchers have postulated the biological mechanism between diabetes and depression. Depression maybe be associated with diabetes, due to biochemical fluctuations and the experienced burden of managing a chronic illness (Renn, Feliciano, & Segal, 2011; Kinder et al., 2002; Knol et al., 2007).

Researchers also have suggested that depression may increase the risk of diabetes due to depression being linked to biochemical changes and reduced health care behaviours (Knol et al., 2006). Although such postulations concerning the bidirectional relationship between diabetes and depression have been made, the biological mechanism still remains unknown and requires further investigation.

### **1.3 Diabetes Health Disparities and Socioeconomic factors**

Uncontrolled diabetes and increased rates of complications are examples of health disparities that are significant in the growing prevalence of diabetes (Morgan et al., 2009). Despite the development of new and more effective diabetes medication and delivery systems, most people living with diabetes cannot achieve optimal blood glucose control, which consequently produces poor health outcomes (Wallace & Matthews, 2000; Diabetes Control and Complications Trial Research Group, 1993; and Matthews, 1999).

Furthermore, although the WHO (2014) declared health equity a moral right, inequalities among social groups remain. As a result of existing inequalities, current environmental infrastructure go onto promote and exacerbate health disparities (Wilf-Miron et al., 2010; and Jones, 2010). The underpinnings of health disparities can be attributed to unequal distribution of both social and economic resources (Phelan, Link, and Tehranifar, 2010). These factors increase the prevalence and risk of disease among low income populations, and lead to an array of negative health outcomes such as diabetes (Willson, 2009; Frohlich, Ross, & Richmond, 2006; Abel & Frohlich, 2012; Pilkington et al., 2010; Pilkington et al., 2011). For example, compared to those of a higher socioeconomic status (SES), individuals of lower SES have disproportionate rates of morbidity and a shorter life span (Frohlich, Ross, & Richmond, 2006).

Moreover, income is not only a key indicator of economic resources, but also access to social and cultural resources (Bourdieu, 1986; Abel, 2008; Weaver, Lemonde, Payman, & Goodman, 2014). All three categories of resources (e.g. economic, social, and cultural) combine to affect health outcomes (Abel, 2008; Weaver et al., 2014). Therefore, because a healthy lifestyle is built on the access to physical and non-physical resources, health may not be attainable for individuals who lack access to these resources (Abel, 2008).

According to Dinca-Panaitescu et al., (2011) and a 2009 Canadian Institute for Health Information (CIHI) report, diabetes is most prevalent among persons with a household income of less than \$20,000 (Figure 1). There appears to be a



gap in the delivery of diabetes health care services between what is recommended and what is actually accessible to patients (CIHI, 2009; Lutfey & Freese, 2005). For example, according to the Canadian Diabetes Practice Guidelines, adults with diabetes are recommended to have completed: an HbA1c test every three months, screening for nephropathy via a urine test every 12 months, an eye exam screening for signs of retinopathy every one to two years, and an annual foot examination for signs of neuropathy (CIHI, 2009).

Compared to people from higher income brackets, it was found that persons of lower income groups are unable to meet these practice guideline recommendations (CIHI, 2009). For example, individuals with incomes less than \$20,000 had fewer eye exams in the past two years, compared to those with incomes of \$60,000 and above (54% vs. 71% respectively (CIHI, 2009)).

Findings of a 2014 study found that an inadequate supply of economic, social, and cultural resources weaken dietary management among individuals with diabetes from lower resource groups, compared to those of higher resource groups (Weaver et al., 2014). Due to differential access to certain social and cultural resources, it was observed that individuals belonging to higher resource groups were more active and socially engaged than those in the lower resource groups, and more able and motivated to maintain their health (Weaver et al., 2014). If health disparities among individuals with diabetes continue to be ignored, serious health outcomes for patients with fewer resources will continue to rise and will result in an increased costs for the health system (CIHI, 2009 and Singer, 2009).

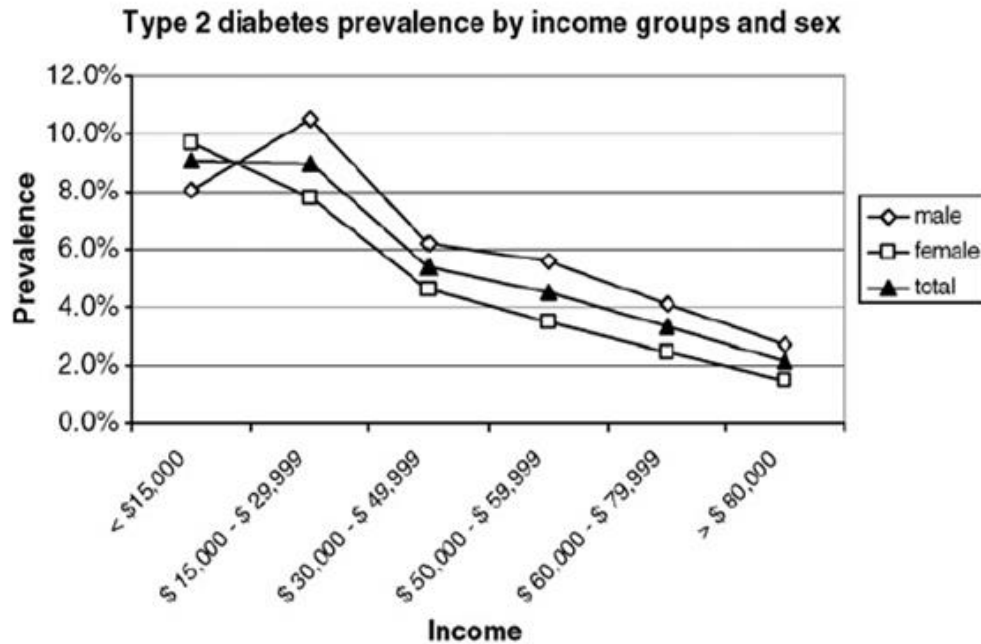


Figure 1. Prevalence of diabetes among income groups and sex (from Dinca-Panaiteanu et al., 2011, with permission).

#### 1.4 Significance of Study

Diabetes is a chronic disease associated with various complex health complications that lead to life-threatening outcomes that impact the quality of life. The prevalence of diabetes is steadily increasing worldwide, and carries significant adverse, complex, and costly complications, often attributed to or worsened by economic, social, and cultural factors (Schoitz et al., 2011; Mackenbach et al., 2008; Kumari, Head, & Marmot, 2004).

The milieu in which an individual is situated greatly impacts his or her behaviour and ability to live a healthy lifestyle (Cockerham, 2005; Abel, 2008; and Weaver et al., 2014). Contextual structures imposed by institutions and social forces not only reinforce social disparities and suffering, but also support health disparities among disadvantaged populations. In this study, health capabilities approach and a syndemic framework are used to explore how social environments produce health disparities by compromising a population's natural defence, resulting in exposure to a cluster of disease (Singer, 2009; Weaver & Mendenhall,

2013). This framework offers a holistic perspective on the social, psychological, and physical distress experienced by individuals living with diabetes and diabetes-related chronic conditions/ comorbidities (from this point known as complex diabetes).

To date, investigations that use a syndemic framework and health capabilities approach remain comparatively limited. Traditionally, the healthcare system has taken a downstream approach that focuses on the disease and individual behaviour. However, many highlight the need for holistic approach that examine interactions among social determinants, health outcomes, and health disparities experienced by people with complex diabetes (Page-Reeves, Mishra, Niforatos, Regiona, & Bulten, 2013; Del Prato et al., 2005).

Despite the recent progress and upstream shift in diabetes care, new tools and intervention strategies is needed for improving the psychosocial care of people living with diabetes (Uplinger, Turkel, Adams, Nelson-Slemmer, & Pierce, 2009; World Health Organization, 2002; Skovlund, & Peyrot, 2005). For example, revision of guidelines to reflect psychosocial aspects of diabetes care and research regarding psychosocial and person-centered diabetes care (Harkness, Macdonald, Valderas, Coventry, Gask, & Bower, 2010; American Association of Diabetes Educators, 2007).

To design a healthcare program utilizing a holistic-lens, more attention is needed to discern how sociocultural, political-economic, psychological, and biological factors corroborate clustering of complex diabetes-related conditions (Rock, 2003; Kilbourne, Switzer, Hyman, Crowley-Matoka, & Fine, 2006). This can be done using the syndemic framework, which encapsulates the interplay and interaction between sociocultural, political-economic, psychological, and biological factors that aid in clustering of complex diabetes.

Reducing the prevalence of diabetes and its array of complications requires interventions that strategically focus on not only treating the disease, but also consider the political-economic and psychosocial factors associated with health inequality among individuals. Poor access to economic, social, and cultural resources ultimately undermine a person's ability to self-manage their diabetes

(Weaver et al., 2014; Hill & Fox, 2013). Consequently, difficulties managing diabetes can be exacerbated through the progression of diabetes complications. The advancement of diabetes complications can ultimately result in a negative feedback loop in which, further life-threatening complications begin to manifest, diminishing both quality and duration of life.

Furthermore, the inability to access economic and social resources may have a detrimental effect on human health and overall well-being, as individuals are unable to access resources that are vital in improving and maintaining health. As a consequence of not being able to improve lifestyle and health conditions, resources continue to be depleted and health conditions worsen, thus initiating a negative feedback loop. For example, co-morbidities of people living with type 2 diabetes may cause them to lose their jobs, severing much needed financial resources. As financial resources become depleted, implementing lifestyle changes and preventative measures becomes even more challenging, as individuals are forced to choose between using limited resources to survive or to improve their health conditions.

The health capabilities and syndemic approach challenges the broader healthcare community to evaluate the political-economic, psychosocial, and biological challenges, which coalesce to exacerbate social suffering and increased disease burden among people with complex diabetes (Singer & Clair, 2003). Utilizing the health capabilities and syndemic approach, this study aims to critically assess how social attributes/ characteristics and current circumstances shape complex diabetes. This study will critically examine the challenges that individuals with complex diabetes face when interacting with the healthcare system. This will be done by exploring the life experiences of people with complex diabetes, who has exhausted all potential options for care within the healthcare system.

## **1.5 Purpose of Study**

The purpose of this study is to examine how the social environment influences the clustering of complex diabetes and the role of the healthcare system

in illness experiences among individuals with complex diabetes. The significance of this study is that it is designed to advance patient centered care and enhance the understanding of how social, political, economic, and psychological factors influence illness experiences and suffering. It is hoped that the study's design and findings can assist health professionals in designing improved programs that integrate the biocultural and psychosocial frameworks that address the social environments in which diabetes complications are experienced.

### **1.6 Research Questions**

This study uses the health capabilities and syndemic approach, and is focused on critically examining how social factors (e.g. social support, social responsibilities, SES) shape the health and well-being of those who experience complex diabetes. It also explores the challenges patients with complex diabetes encounter when interacting with the healthcare system. Thus, this study asks the following research questions:

1. How do patients with complex diabetes perceive the causes and consequences of their current psychosocial and medical conditions?
2. What are the social attributes/ characteristics, background and current life circumstances that influence the onset and management of complex diabetes?
3. What are the perceived challenges, persons with complex diabetes encounter throughout their lifetime when interacting with the healthcare system?

## **2. Chapter Two: Literature Review and Theoretical Framework**

### **2.1 Snapshot of Healthcare in Ontario**

#### **2.1.1 Ontario Chronic Care Model**

The hallmarks of disease and illness have changed considerably within the last century in Canada. Once preoccupied in combating acute infectious disease outbreaks, Canada is now faced with the silent sufferings of individuals who experience chronic illness. In 2005, 89% of all Canadian deaths were thought to be caused by chronic disease (Ontario Health Quality Council, 2008). In 2003, it was estimated 3.7 million people were living with a chronic condition (Ministry of Health and Long-Term Care, 2007) and that 70 % of chronically ill Ontarians over the age of 45 were living with multiple chronic conditions (Ministry of Health and Long-Term Care, 2007).

In Ontario, the prevalence of chronic disease is predominant among certain communities (Institute for Clinical Evaluative Sciences, 2012). This includes individuals residing in northern Ontario, First Nations communities, and certain rural areas of southwestern and eastern part of the province (Institute for Clinical Evaluative Sciences, 2012). Between 2006/07 and 2010/11, two out of every ten adults from these communities were living with diabetes, in addition to one or more chronic complications (e.g. lower-limb amputation, end-stage kidney disease, or cardiovascular hospitalization). Also, many Ontarians who experience chronic complications are located in urban areas. For example, it was reported that rates of chronic complications among individuals with diabetes were found to be three fold greater among urban centres (Institute for Clinical Evaluative Sciences, 2012).

As the prevalence of chronic illness continues to surge, detrimental health, societal, and economic costs are incurred, due to increased mortality rates caused chronic diseases (Ontario Health Quality Council, 2008). Chronic diseases are long-term disease that develop slowly over time, often progressing in severity and can be controlled, but rarely cured (Ministry of Health and Long-Term Care, 2007). Chronic disease have serious impacts: they not only cause premature death, but have major adverse effects on the quality of life of affected individuals and

create hostile economic conditions for families, communities and societies in general (CDA, 2014). Often caused by a group of complex intertwined factors, chronic diseases can appear dormant for a period of time, before taking its toll. Once manifested, there is no spontaneous resolution or cures for chronic conditions, and managing these conditions can be difficult (Patra, Popova, Rehm, Bondy, Flint, & Giesbrecht, 2007). Several reports link chronic disease to a substantial portion of morbidity and mortality among Canadians (Patra, Popova, Rehm, Bondy, Flint, & Giesbrecht, 2007).

However, many of the risk factors that help perpetuate the manifestation of chronic illnesses can be prevented. These risk factors include: unhealthy diets, physical inactivity, alcohol, and tobacco use (Ezzati, Lopez, Rodgers, Vander Hoorn, & Murray, 2002; Patra, Popova, Rehm, Bondy, Flint, & Giesbrecht, 2007). Modifiable factors such: poverty inequality, poor education, and exposure to environmental factors have also been found to be closely tied to socio-economic disadvantages (The Chronic Disease Prevention Alliance of Canada, 2004). For example, women under the age of forty from a low-income background are 62% more likely to be hospitalized compared to women in a higher income bracket. In addition to using a physician's services more regularly compared to those of a higher income, low-income groups have are mostly likely to have higher rates of: smoking, obesity, physical inactivity, and being at risk for cardiovascular disease (The Chronic Disease Prevention Alliance of Canada, 2004). According to the Chronic Disease Prevention Alliance of Canada (2004), \$4 billion per year in healthcare costs and approximately 6,366 deaths related to heart disease are strongly correlated with poverty in Canada.

It is estimated that 42% (\$39 billion dollars/ year) of direct medical care expenses in Canada are due to chronic diseases (The Chronic Disease Prevention Alliance of Canada, 2004). Most of the care for chronic diseases takes place in a primary healthcare setting (Ontario Health Quality Council, 2008). Canadians living longer lives combined with a surplus of patients with chronic illness, places an overwhelming demand for primary care services on an already battered system (Ontario Health Quality Council, 2008).

Modeled to address individuals afflicted with acute health conditions, there is a growing pressure for the health care system to adopt delivery of systematic care for chronic diseases (Ontario Health Quality Council, 2008). In response to this pressure, increased prevalence a chronic disease among Ontarians, and the ballooning cost in treating individuals with chronic disease, the Ministry of Ontario Health and Long-Term Care (MOHLTC), introduced a new policy framework in May 2007, “Preventing and Managing Chronic Disease: Ontario’s Framework (Ministry of Health and Long-Term Care, 2007).

Within this new approach, the Ministry recognizes the need to depart from the regular practices of treating acute diseases, and adopt appropriate mechanisms of care for individuals with chronic disease. The Chronic Disease Prevention and Management (CDPM) framework also acknowledges, apart from biological factors that with the right treatment and support, people living with chronic disease can improve their health and quality of life. This can be accomplished by addressing determinants of health, which ranges from the biological makeup of a person, to socioeconomic factors such as social environments, SES, and education (Ministry of Health and Long-Term Care, 2007)

The aim of the CDPM is to provide multi-faceted, planned, pro-active seamless care in which the clients are full participants in managing their care and are supported to do this at all point by the system. When Ontarians become equal partners in their own health, they can become full collaborators in managing their condition. The framework is evidence-based, population-based, and client centered, and supports the transition from a health care system that solely focuses on episodic, acute illness to one that will support the prevention and management of chronic disease (Figure 2).



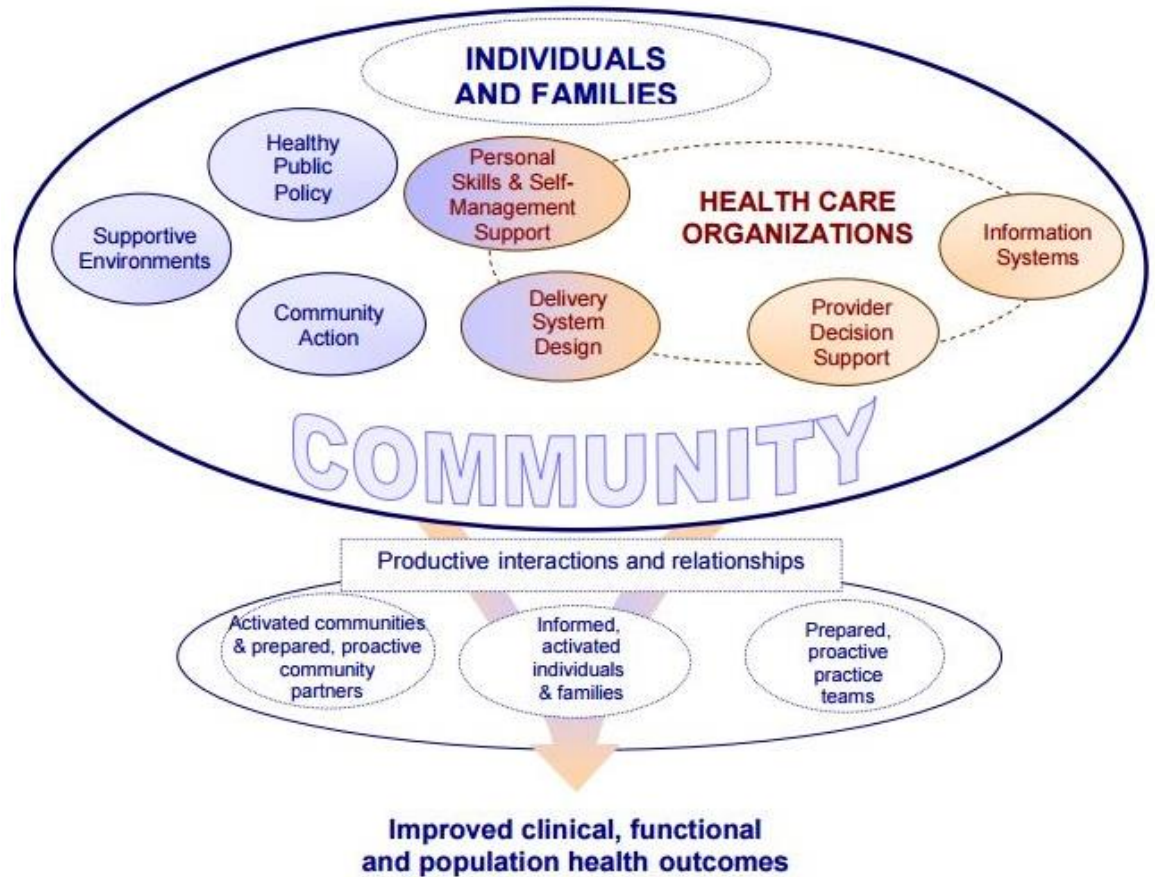
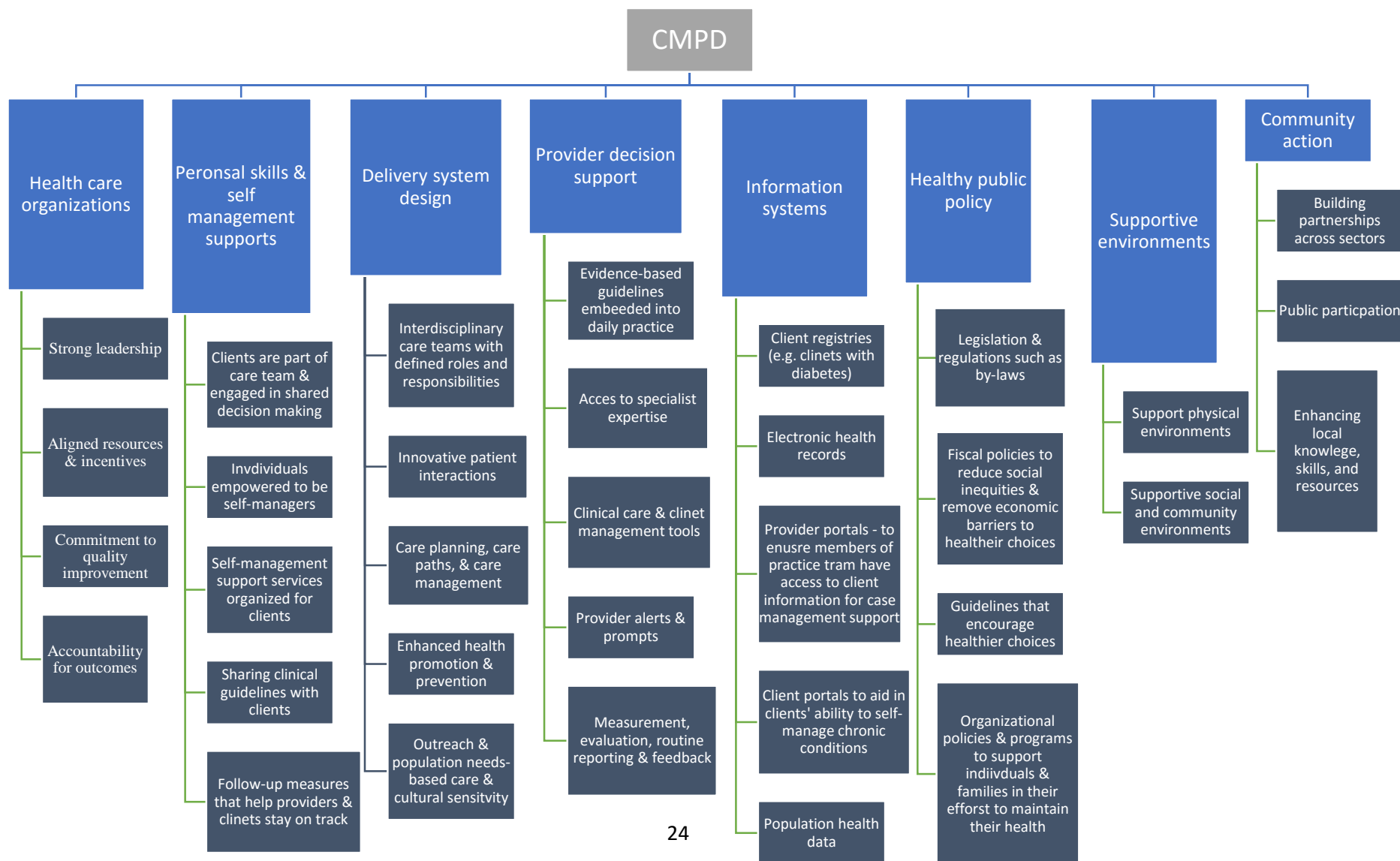


Figure 2: The Ontario Chronic Disease Prevention and Management Framework (Ministry of Health and Long-Term Care, 2007).

This framework also identifies key elements that are vital in establishing a health care system that can effectively and efficiently manage chronic disease and health care system resources. These elements include:



### 2.1.2 Diabetes and its cost

In 2015, approximately 1.5 million Ontarians were living with diabetes. This number is expected to rise to 2.3 million by 2025 (CDA, 2015). Moreover, nearly 2.2 million people are estimated to have prediabetes (CDA, 2015). As mentioned previously, if not managed well, diabetes will sooner or later take its toll manifesting into complex diabetes. This means that an individual is no longer burdened in managing one ailment but several ailments.

Individuals with diabetes use the healthcare system about two times more often than the general population. This not only cost Ontario's health-care system \$5.8 billion in 2014, but is expected to rise to \$7.6 billion in 2024 (Ministry of Health and Long-Term care, 2014). It is estimated that Canada spent \$9 billion annually on issues related to diabetes, such as health care, disability, work loss, and premature death (Ontario Ministry of Health and Long term care, 2012). More specifically in Ontario approximately \$1 billion is spent on treating individuals experiencing diabetes and its complexities that include: blindness, end-stage renal disease, and non-traumatic amputation among Canadian adults, and is strongly associated with the onset of cardiovascular complications, hypertension, stroke, cataracts, and glaucoma (Ministry of Health and Long-Term Care, 2009).

Furthermore, individuals with diabetes are hospitalized more often compared to the general population. For example, people with diabetes are hospitalized: with cardiovascular disease three times more, with end-stage renal disease twelve times more, and twenty times more with non-traumatic lower limb amputation (CDA, 2015). In addition to developing physical ailments, individuals with diabetes are at a great risk for mental illness, such as depression. In fact, approximately 30% of individuals with diabetes have clinically depressive symptoms (CDA, 2015). Likewise, according to the Canadian Diabetes Association (CDA) 37% of Canadians with type 2 diabetes reported not wanting to disclose that they had diabetes (CDA, 2015).

As practitioners brace for the exponential rise in diabetes among Ontarians, the economic burden related to treating diabetes and its complications is also

increasing. An individual with diabetes usually accrue medical costs that are two to five folds higher compared to individuals without diabetes (Ontario Ministry of Health and Long term care, 2012). This means that treating and managing diabetes can add up to \$4,500 annually per person, thus burdening an already fragile system. Additionally, because individuals with diabetes are at an increased risk for developing life threatening complications, these complications are not only more costly, but require intensive management (Ontario Ministry of Health and Long-Term care, 2012).

A diabetes epidemic not only impacts the economy but also an individual's personhood and the rest of society (Ontario Ministry of Health and Long-Term care, 2012). From a clinical perspective, providing quality care to individuals with type 2 diabetes can be tremendously demanding and overbearing. As the prevalence of type 2 diabetes surges, immense pressure is placed on the system, dampening governing institutions abilities in providing adequate funding for healthcare (Ontario Ministry of Health and Long-Term care, 2012).

Among certain Canadians some sub-populations, such as South Asians, Asians, Africans, Hispanic, Aboriginal descent, elderly, and low income earners, are at a greater risk of developing type 2 diabetes (CDA, 2015). The burden of managing diabetes not only includes various medical costs, but also personal costs as well. However, what is most appalling is that 57% of Canadians are unable to access prescribed treatments due to high out-of-pocket costs for medications, devices, and supplies (CDA, 2015). Canadians spent >3% or > \$1,500 of their income towards managing diabetes (CDA, 2015). It has been reported that among Canadians who have their blood glucose levels check, only 50 % of Canadians adhere to this regime (CDA, 2011). For example, in order to successfully control glucose levels the following are need: insulin, oral medications, lancets, glucose meters, glucose meter strips, and dietary changes, all which are inaccessible without insurance, while current government coverage keeps on shrinking (Ontario Ministry of Health and Long term care, 2012). This lack of compliance later translates into incurred adverse health conditions linked to diabetes (CDA, 2011).

In 2013, the Ontario government introduced changes to the number of blood glucose test strips. This change impacts people with non-insulin dependent diabetes, and may hamper self-management efforts especially among low income groups as patients will receive only 200 blood glucose test strips a year (Ontario Ministry of Health and Long term care, 2015). Additional costs associated with medical treatments that are not subsidized include transportation to health facilities, lodging, and child care. The lack of access to these resources can significantly undermine the ability of Canadians with diabetes to self-manages, especially individuals from low SES (Ontario Ministry of Health and Long term care, 2012).

### 2.1.3 Ontario Diabetes Strategy

The prevalence of diabetes in Ontario from 2000 to 2010 rapidly increased from 1.3 million (4.5%) to 2.5 million (8.3%) respectively (CDA, 2014a). During 2008-2009, one in every 10 Canadian adult deaths was linked to diabetes (CDA, 2014a). Without proper management, diabetes not only possesses the power to destabilize a person's life by its arrays of financial costs, but can also negatively impact an individual's mental health. In addition to the personal cost diabetes warrants, many Canadians are indebted with fitting the bill of treating diabetes-related complications (CDA, 2014a).

A common belief among all Canadians is that individuals at risk or living with diabetes sustain the right to afford diabetes cultural and linguistic supports in a timely manner (CDA, 2014a). According to the Diabetes Charter for Canadians governments are responsible in responding to the needs of vulnerable populations and addressing barriers to that prevent the care that is so vitally needed. (CDA, 2014a). This includes Canadians that are at an elevated risk or currently living with diabetes,

Most care provided to individuals with diabetes in Ontario is delivered through their primary care physicians (Institute for Clinical Evaluative Sciences, 2012). In efforts to improve services that are being delivered and reimbursed, the primary care system in Ontario has experienced some transformations over the

past decade (Institute for Clinical Evaluative Sciences, 2012). One of the hallmarks of this transformation includes transitioning from an “acute care model” to a “chronic care model.”

One of the aims of successfully achieving this transition is utilizing a proactive and structured approach to care, and responding to adverse outcomes resulting from chronic illnesses by taking preventative measures (Institute for Clinical Evaluative Sciences, 2012). However, it has been reported that despite financial incentives, a significant proportion of Ontarians living with diabetes are not receiving the recommending care (Institute for Clinical Evaluative Sciences, 2012).

In efforts to deter the rising prevalence of diabetes among Ontarians, and control the escalating cost of treating individuals with diabetes, the Ontario Ministry of Health and Long-Term Care (MOHLTC) launched the Ontario Diabetes Strategy (ODS) in 2008 (Ministry of Health and Long-Term Care, 2009; Institute for Clinical Evaluative Sciences, 2012). This strategy included a hefty investment of \$741 million to fund a four year comprehensive strategy in effort to prevent, managing and treat diabetes among individuals 18 years and older (Ministry of Health and Long-Term Care, 2009; Institute for Clinical Evaluative Sciences, 2012).

Ongoing efforts to improve health and health care among Ontarians include increased access to: team based care, insulin pumps and supplies, chronic kidney disease services, bariatric surgery, and education among high risk populations (Ministry of Health and Long-Term Care, 2009). Major components of the ODS launched in 2008 is highlighted in Figure 3 (CDA, 2014c; Institute for Clinical Evaluative Sciences, 2012; & Amirthavasari, Dudar, Gandhi, Phillips, & Sherifali, 2012).

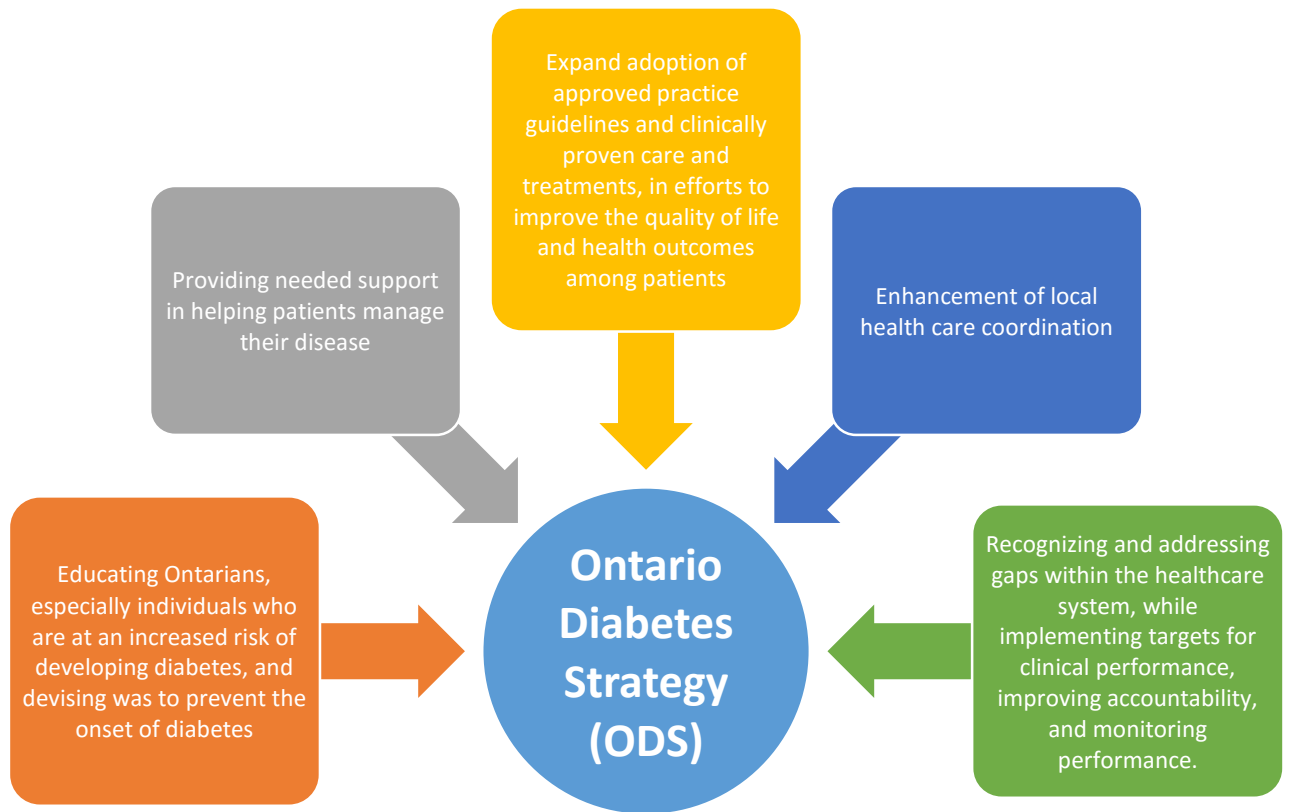


Figure 3: Ontario Diabetes Strategy Outlined

In accordance with the Ontario Chronic Care Model, the Ministry adopted the Kaiser Chronic Disease management model to illustrate the stratification of diabetes care and services (refer to Figure 4: from Ministry of Health and Long-Term Care, 2012). This model is divided into three levels reflecting greater diabetes disease complexity and more intensive diabetes management. The fourth level is aimed at individuals who are at an increased risk of developing diabetes, while “system enablers” stand as pillars in executing and accomplishing the overall vision of the strategy (Ministry of Health and Long-Term Care, 2012).

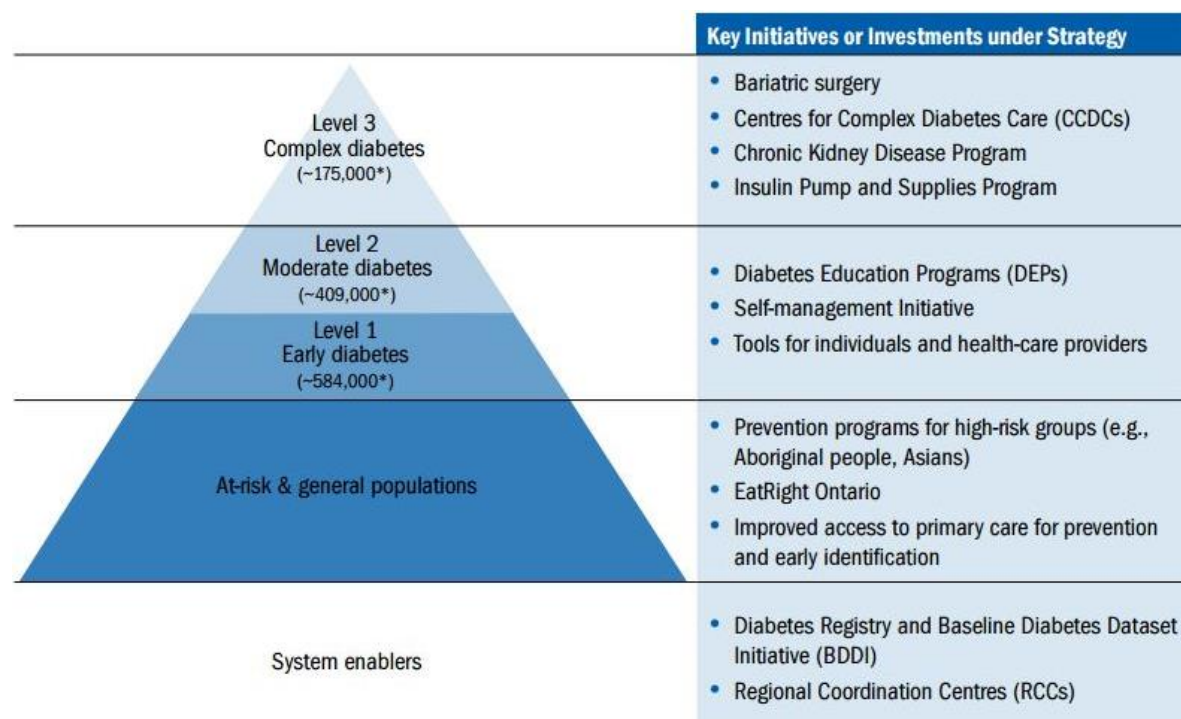


Figure 4: Modified Kaiser Permanente Chronic Disease Management Model.

(Source: Ministry of Health and Long-Term Care, 2012).

As part of the ODS platform, many programs and services were established in hopes of increasing access to specialized diabetes treatment and care. Some of these programs include: Centres for Complex Diabetes Care (CCDC), Diabetes mobile outreach services, Diabetes Regional Coordination Centres (DRCC), and Diabetes Education Teams (DETs) (CDA, 2014c). Services offered at the CCDC are aimed at patients who are trying to manage complex chronic conditions, in addition to diabetes. At CCDC, patients are provided with a single point of access to a variety of healthcare clinicians (CDA, 2014c). This includes access to specialist services, while maintaining a relationship a primary care provider. Diabetes mobile outreach services targets nine communities in northern Ontario, including four First Nations communities. These communities include individuals who encounter barriers in accessing health services, such as diabetes care and treatment. DRCC provide tools and resources to all 14 Local Health Integration Network (LHINs) in Ontario (CDA, 2014c). This is done to support and maintain the implementation of Diabetes best practices and quality of



healthcare provided across the province. DRCCs do not provide direct patient services, but collaborate with the LHINS in order to understand current gaps that exist and services that are needed. In collaboration with LHINs and local service providers, DRCCs play a pivotal role in orchestrating strategies to address these gaps. A huge part of preventing diabetes is education (CDA, 2014c).

DETs are comprised of a registered nurse, a dietitian who collaborate with family physicians and other diabetes care experts to help patients navigate through the world of diabetes, adopt managing skills, and avoid the development of diabetes-related health complications (CDA, 2014c). Another key initiative of the ODS in 2008, was developing online Electronic Health Solution (EHS) (Amirthavasar, Dudar, Gandhi, Phillips, & Sherifali, 2012). EHS was aimed at empowering an individual's ability to self-manage diabetes, in addition to providing healthcare providers with up-to-date and accurate patient health records (Amirthavasar, Dudar, Gandhi, Phillips, & Sherifali, 2012).

### **Recommendations and Accomplishment regarding ODS Platform:**

The number of Ontarians living with diabetes is rapidly growing and as this epidemic gains momentum, so does the annual cost in treating individuals experiencing diabetes. It is estimated that by 2020, diabetes will cost the Province of Ontario \$7 billion (Ministry of Health and Long-Term Care, 2012). With this knowledge, MOHLTC debuted the 2008 ODS and a four-year \$741 million investment plan. It is widely known that approximately 90% of people diagnosed with diabetes have type 2 diabetes (Ministry of Health and Long-Term Care, 2012). Given that Type 2 diabetes can be prevented or deferred by effective education, proper nutrition, and exercise, only 3% of \$741 million was earmarked for preventative measures, while 97% were allocated in treating individual who had diabetes (Ministry of Health and Long-Term Care, 2012) (Figure 5).

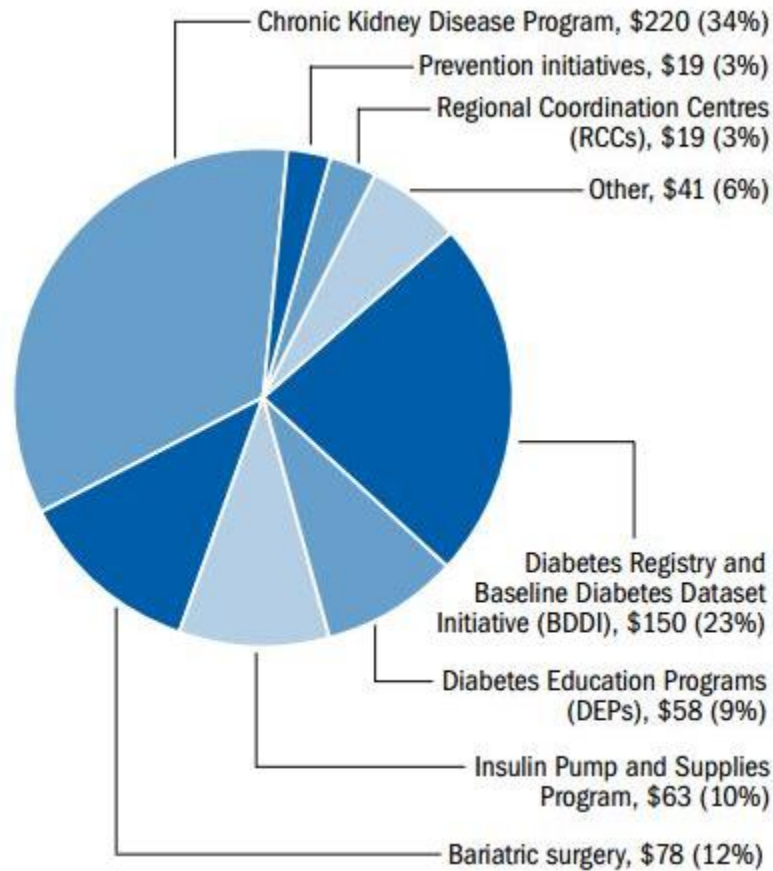


Figure 5: Allocation of ODS funding by Key Initiative 2008 – 2012 (Source: Ministry of Health and Long-Term Care, 2012).

According to the Auditor General of Ontario report in 2014 (Ministry of Health and Long-Term care, 2014), many diabetes service providers orchestrated with Strategy funding were underused, and suggested that the funding being received should be redirected to preventative measures. Additionally, initiatives by eHealth Ontario to establish an electronic Diabetes Registry to enable physicians and the Ministry to monitor patient data was terminated in 2012 due to contracting difficulties. It was observed that 90% of DEP were under-used due many duplicate diabetes education programs. This is because many hospitals and clinics established their own education programs resulting in an overlap in services (Ministry of Health and Long-Term care, 2014).

After careful revision of the ODS, the Auditor General had made several recommendations, some which have been fulfilled, and some that are still pending full implementation. These recommendations include:

1. To enable efficient and effective diabetes surveillance at the provincial level and assess the progress of the ODS, the Ministry of Health and Long-Term Care (Ministry) should work closely with eHealth Ontario (eHealth) and Infrastructure Ontario.
2. In order to improve prevention and early detection of diabetes as long-term, cost effective strategies, a revision of allocation only 3% of the ODS funding for prevention projected must happen.
3. To strengthen the Ministry of Health and Long-Term Care oversight of diabetes education programs (DEPs), and beneficiaries of funding, in order to ensure that DEPs are providing diabetes patients with consistent and quality care, and in compliance with applicable policies.
4. To improve co-ordination among diabetes-care providers and access to specialized diabetes care.
5. To ensure that people receive adequate, timely and quality bariatric surgical services across the province (Ministry of Health and Long-Term care, 2014).

### **ODS Accomplishments:**

In 2008, the ODS was established to address the lack of diabetes programs and services accessible to many Ontarians, as well as addressing escalating economic costs in treating diabetes (Reichert, Harris, & Harvey, 2014). A major driving force in this strategy was to not only improve the quality of life and outcomes of those living with diabetes, but also to prevent the onset of diabetes among individuals at an increased risk.

However, among the many recommendations in regards to the unveiled ODS, there have been many accomplishments. According to our knowledge, some of these initiatives have been accomplished. For example, in six LHIN regions, there has been an establishment of CCDCs (Reichert, Harris, & Harvey, 2014). Also, in all 12 LHINS self-management education and training programs have

been implemented, serving to empower and equip people with tools in successful diabetes management (Reichert, Harris, & Harvey, 2014). Additionally, collaboration between the ODS and the Ontario Stroke Network, allowed for improved detection and management of high blood pressure among individuals with diabetes and other chronic ailments (Ministry of Health and Long-Term Care, 2015).

In 2014, the government was reportedly investing \$10 million towards local programs focused on preventing type 2 diabetes (Ministry of Health and Long-Term Care, 2015). It is hoped that the programs support local community projects such as: behaviour medication programs; health professionals and educators training programs directed at using culturally specific behaviour medication programs for communities at greater risk; programs aimed at screen for risk factors of T2D, and campaigns to raise awareness of T2D locally (Ministry of Health and Long-Term Care, 2015).

## **2.2 Access to Diabetes Care throughout Canada**

A 2015 CDA survey found that most people with diabetes (91%) have a regular doctor who assist with diabetes management (CDA, 2015b). However, in remote, northern regions, and among Aboriginal people, quality health services have been deemed poor. Key barriers that have been recognized in prohibiting access are: geography, lack of infrastructure and staff, language/ cultural differences, and lower SES (National Collaborating centre for Aboriginal Health, 2011). Presently, people living with diabetes encounter restricted Public coverage for some essential diabetes management health services (CDA, 2015b). This is especially true when trying to access specialists (e.g. chiropodists/ podiatrists) or off-loading devices that are not publically funded in any jurisdiction in Canada (CDA, 2015b).

Moreover, diabetes management often rests on the shoulders of the person living with diabetes and their family members. Therefore, diabetes education is vital in supporting optimal management, helping to either avoid or delay the onset of diabetes complications. However, while most people living with diabetes have

attended education programs, it was reported that 26% of people have not (CDA, 2015b). A 2004 report suggest that 72% of people with diabetes in Ontario did not have access to a structured education program offered by the diabetes education and care centres (DECCs) (CDA, 2015b).

Although the Canada Health Act (CHA) declares that all Canadians should receive equitable access to publically funded, medically necessary hospital and physician services, this level of public coverage greatly differs across provinces and territories (CDA, 2015b). This inconsistency in funding for diabetes medications, devices and supplies present real barriers and negatively impact diabetes management (CDA, 2015b).

Diabetes medications, devices and essential care is not always covered by a person's insurance (CDA, 2015b). In fact, 15% Canadians living with diabetes reported not having insurance to pay for their prescription medications, while 30% do not have insurance for diabetes-related equipment or supplies to monitor blood glucose (CDA, 2015b). This reality is quickly felt particularly in Ontario. For example, as mentioned before, in 2013 the Ontario government reduced funding for blood glucose test strips, impacting people with non-insulin dependent diabetes (Ontario Ministry of Health and Long term care, 2015).

Furthermore, health practitioners witness firsthand how a shrinking provincial health insurance plan tamper with diabetes self-management efforts. According to a local diabetes pharmacist, this reality materializes especially for patients who depend on government assistance plans such as the Ontario drug benefit, Ontario Disability Support Program (ODSP), and the Trillium Drug Plan (R. Dole, personal communication, June 9<sup>th</sup>, 2016). Moreover, some patients age 65 and over do not qualify for Ontario drug benefit or ODSP, and cannot afford the Trillium Drug Plan's deductible (R. Dole, personal communication, June 9<sup>th</sup>, 2016). As a consequences of financial insecurity and not being able to afford diabetes medication or supplies, people may experience poor control with respect to their diabetes (R. Dole, personal communication, June 9<sup>th</sup>, 2016).

Results from the 2011 Survey on Living with Chronic Disease in Canada reflect variations in provincial insurance coverage, most coverage was allotted to

dental and eye care, while the least amount of coverage was medication, devices and supplies (Figure 6), (CDA, 2015b).

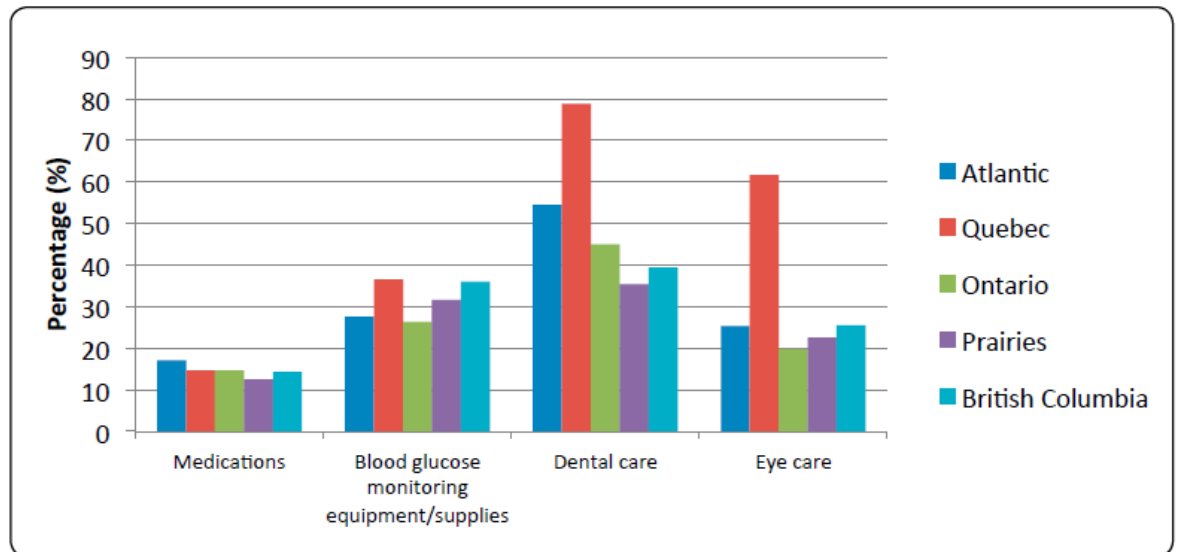


Figure 6: Type of support provided by provinces across Canada for Canadians living with diabetes with no insurance  
(Source: Canadian Diabetes Association: 2015 Report on Diabetes- Driving Change)

As mentioned previously, low income individuals are particularly at a great risk of developing diabetes (CDA, 2015b). What is more distressing is that a higher proportion of low income ( $\leq \$50,000$ ) individuals reported not having insurance coverage, compared to those earning a higher income ( $\geq \$50,000$ ) (CDA, 2015b). More importantly, 18% of people living with diabetes expressed encountering difficulty in attaining insurance coverage due to their disease, with the highest proportion in people who earn less than \$35,000/ year (CDA, 2015b). (Figure 7).

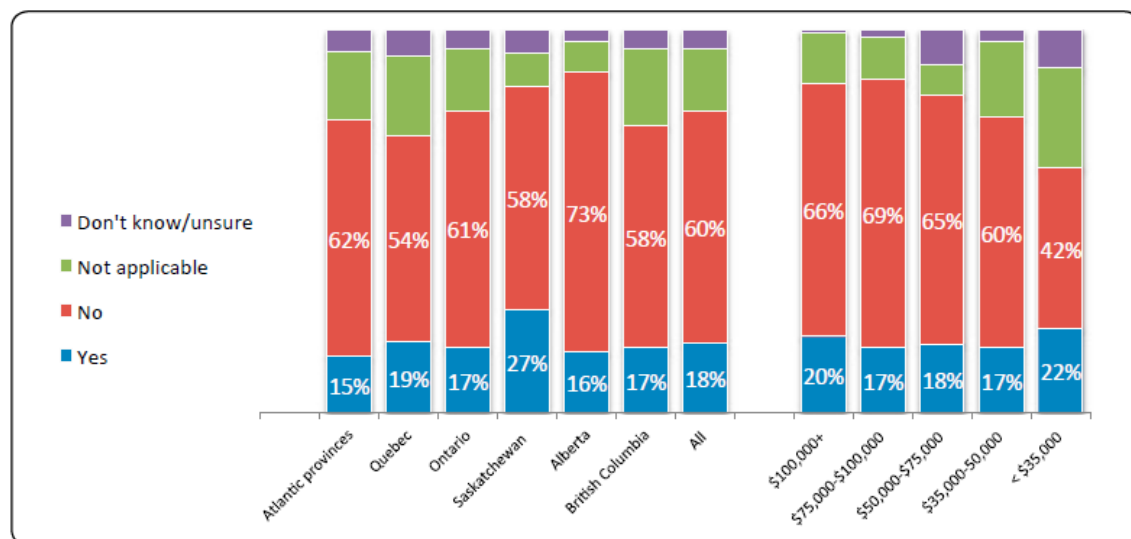


Figure 7: Canadians living with diabetes who are unable to attain insurance due to their health condition

(Source: Canadian Diabetes Association: 2015 Report on Diabetes- Driving Change)

Furthermore, most provinces offer no financial help for people living with type 2 diabetes with an income of \$40,000 or more (CDA, 2015b). For seniors living with type 2 diabetes who are of low income, provinces across Canada subsidizes less than 10% of costs, leaving individuals to carry the burden of out-of-pocket costs (CDA, 2015b).

## 2.3 Gaps within the Healthcare System

For years the healthcare system in Canada has been built to face the war against acute illnesses. However, there is little accommodation in treating patients with chronic diseases, such as diabetes, who require ongoing partnership between themselves and clinicians. According to the Canadian Diabetes Association (CDA, 2014b) individuals with diabetes in Ontario are not receiving the care they require, robbing them from fulfilling health potential.

Diabetes, a chronic illness known for its complications can quickly lead to a downward spiral if not managed properly. Barriers in accomplishing optimal

outcomes can range from accessibility to services, to affordability of supports that are vital for self-management (CDA, 2014b). Despite clinical goals and evidence-based guidelines for diabetes management, care gaps continue to abound as real-life clinical practice realities clash with these guidelines (Reichert, Harris, & Harvey, 2014). According to the CIHI, is that roughly 32% of Canadians reported adhering to Clinical Practice Guidelines recommendations. More importantly, compared to individuals of high household income, low household income individuals were 50% less likely in receiving recommended tests (Webster, Sullivan-Taylor, & Terner, 2010).

Furthermore, there appears to be ineffective coordination among: a) health professional disciplines, b) organizations (e.g. between primary care organizations, medical laboratories, specialty clinics, home care facilities and hospitals), and C) government ministries (e.g. Amid provincial, federal (First Nations healthcare services) (CDA, 2014b). This lack of communication across specialities not only hinders improvement of diabetes care, but aids in diminishing patient's access to diabetes programs and services (CDA, 2014c; Institute for Clinical Evaluative Sciences, 2012). Although diabetes care is predominantly accessible in Ontario's urban areas, diabetes education programs are not thoroughly distributed throughout the province. Inequitable access to endocrinologist and other specialist remains, particularly among some sub-populations such as individuals from a low socioeconomic background (Institute for Clinical Evaluative Sciences, 2012).

## **2.4 Introduction to Syndemics**

### **2.4.1 Defining syndemics**

Stemming from medical anthropology in the early 1990s, the term “*syndemic*” combines two concepts: *synergy* and *epidemic* (Singer, 2009, pp.28-30). A *syndemic* framework describes socioenvironmental contexts (such as poverty) that reinforce synergistic interactions between two or more epidemic diseases or disorders (Singer, 1994; Singer & Clair, 2003; Singer, 2009, pg. 28-



30; and Singer et al., 2006). The three fundamental principles that characterize the syndemic framework include:

1. Clustering of two or more diseases/ illnesses that are present within a specific population.
2. Inclusion of contextual and social conditions (e.g., structural violence), which encourage clustering of disease.
3. Disease clusters that promote possible adverse interactions (vicious cycles), and increase disease burden and health disparity (e.g., more than two comorbidities) on impacted populations (Mendenhall, 2012; Weaver & Mendenhall, 2013).

Syndemics arise when illness-related issues cluster by person, place or time (Singer & Clair, 2003). Moreover, the syndemic approach examines how adverse micro and macro social conditions create health disparities by compromising a population's natural defence, exposing it to a cluster of diseases (Singer, 2009; Weaver & Mendenhall, 2013). This approach not only accounts for interactions between two or more illnesses, but also the multiplicative impact illnesses have on one another (Weaver & Mendenhall, 2013).

As discussed by Weaver et al., 2014, the manifestation of illnesses not only increases the risk for other illnesses, but may also diminish social resources and status, exacerbating the negative interaction between illness and low social resources. The syndemic approach aims to understand the social, psychological, and physical distress that is experienced (Weaver & Mendenhall, 2013). Besides the clustering of disease, the syndemic framework analyzes social disparities that contribute to health disparities (Singer, 2009).

#### 2.4.2 Syndemic vs. Biomedical approach

Compared to the more prominent biomedical model, the syndemic approach offers a more holistic approach. When viewed through the lens of biomedicine, disease is often reduced as “distinct, discrete and disjunctive entities that exist (in theory) separate from other diseases and from the social structures in which they are found” (Singer & Clair, 2003, p.424). This reductionist approach

omits the social, psychological, and behavioural dimensions that characterize a disease, and places emphasis solely on the biochemical and pathophysiological problems associated with a disease (Engel, 1977; Singer, 2009; and Mendenhall, 2012). As well, the biomedical model does not account for variation in the prevalence of multiple ailments among different populations.

The syndemic framework takes a holistic approach that views biological disorders as embedded within and fostered by their social and environmental context (Singer, 2009; King, Hurd, Hajek, & Jones, 2009). This is because similar to the biopsychosocial approach; the syndemic framework does not exclude the psychosocial aspects of an illness in favor of the biology of an illness, but embraces the psychosocial aspects of an illness, as well as the biological underpinnings of a disease (Engel, 1977; King, Hurd, Hajek, & Jones, 2009; Moeller, Halkitis, & Surrence, 2011; Singer, 2009, Singer & Clair, 2003).

Even more, the syndemic framework examines how biology interacts with social, political, economic, and psychological factors, which contribute to excess disease burden among vulnerable populations (Weaver & Mendenhall, 2013; Herring, D., & Sattenspiel, 2007). The syndemic approach also considers the political-economic and social processes that shape individual illness experiences (Engel, 1977; Singer, 2009).

The syndemic framework combines the workings of medical anthropology with biocultural anthropology. Medical anthropology explores how social, psychological, and biological factors shape illness experience across cultures and time (Weaver & Mendenhall, 2013). Biocultural anthropology seeks to understand how sociocultural and political-economic forces impact human biology, and how compromised health conditions endanger the social fabric of society (Weaver & Mendenhall, 2013; King et al., 2009). When combined both these approaches create a platform for the syndemic model. Offering a more holistic approach, the syndemic model examines the biological interaction with social, political, economic, and psychological factors, that contribute to excess disease burden of among vulnerable populations (Herring, D., & Sattenspiel, 2007; Singer & Clair,

2003). The syndemic approach also evaluates the political-economic and social processes that shape individual illness experiences (Engel, 1977; Singer, 2009).

Additionally, the syndemic model views social structural factors that operate upstream as “fundamental causes” of health and illness, as fundamental (if not more so) as more proximate biological factors to which our health is most often attributed (Link & Phelan, 1995; 2010). Moreover, insofar as the syndemic framework aids in our understanding and unveiling sociocultural and political-economic factors that contribute to health inequalities, it forms a basis for a critique of current structures and institutions (including healthcare), and thereby may serve to foster social and political change. The syndemic model not only sheds light on such factors, but can be used to contextualize risk factors (e.g., identifying factors that increases the risks of individuals susceptible) and influence policy development aimed at reducing resource inequalities (Weaver & Mendenhall, 2013; Singer, 2009; Phelan, Link, and Tehranifar, 2010).

#### 2.4.3 Syndemics and HIV/ AIDS (SAVA)

The syndemic framework was used to describe the combination of substance abuse, violence, and AIDS (SAVA), that prevailed among low-income Puerto Ricans living in urban areas in the United States (Singer et al., 2006; Mendenhall, 2012). Singer and colleagues (2006) argued that the AIDS epidemic was not simply due to needle sharing practices, but connected to a web of social factors, that perpetuated the spread of AIDS among marginalized and impoverished population. Exposed to harsh social realities, social environments characterized by poverty, decreased rates of employment, low education status, and alcoholism, foster increased youth involvement in: gangs, drug trade, and violence (Singer et al., 2006; Mendenhall, 2012; Weaver & Mendenhall, 2013). This involvement encourages risky behaviours and exacerbates poor health conditions (Mendenhall, 2012; Weaver & Mendenhall, 2013). Singer (2009) characterizes the syndemic theory as social inequalities imposed on certain populations. These inequalities not only initiate, but sustain the clustering of substance abuse, violence, and AIDS. Singer also defines this phenomenon as

*SAVA syndemic* (Substance Abuse Violence and AIDS) (Singer, 2009; Mendenhall, 2012; and Weaver & Mendenhall, 2013). *SAVA* embodies a triangulation of dynamic health-related problems, which interact with one another (Singer, 2009). This synergistic interaction is illustrated in the simultaneous presence of drug use, AIDS, and violence. In combination, these three factors generate a multiplicative effect detrimental to health and well-being (Singer, 2009).

#### 2.4.4 Syndemics and Diabetes

Similar to the *SAVA phenomenon*, the diabetes, related complications and co-morbidities also have been associated with populations subjected to urban lifestyles and social inequalities (Hill, Nielsen, & Fox, 2013; Espelt et al., 2013). A lack of social and economic resources not only discourages positive diabetes management, but may trigger clustering of health complications (Weaver & Mendenhall, 2013). However, while several studies document clustering of hypertension, hyperlipidemia, and obesity among individuals with diabetes (Schmidt et al., 1996; Seftel, Sun, & Swindle, 2004; De Sereday et al., 2004; and Crawford et al., 2010), they seldom consider the complex interactions among social, structural, and biological conditions that reinforce and exacerbate the phenomenon, and which prevail in some but not other populations. Overlooking the interaction between biological, social, and economic forces, not only increases disease burden on individuals, but inhibits efforts to improve patient-centered health care delivery. Reducing diabetes solely to a biological phenomenon, and ignoring social, cultural, and economic conditions that might underlie diabetes and related health issues limits consideration of options that might curtail its growth in our population and the suffering of its individuals.

The co-occurrence of health conditions often compromises diabetes self-management. For instance, patients often receive contradictory medical advice, particularly when diverse health professionals fail to coordinate management plans (O'Shea, Teeling, & Bennett, 2013). Moreover, distinct health conditions command different attention, priority, time, and energy for patients who often also

face other personal, social, and work demands (O'Shea, Teeling, & Bennett, 2013). Therefore, such vast needs requires a holistic approach, that considers the structural contexts that foster and sustain the occurrence of complex chronic conditions among individual with diabetes, and the interplay of biological, social, political, economic, and psychological factors in vulnerable populations (Singer & Clair, 2003; Weaver & Mendenhall, 2013; Singer, 2009).

#### 2.4.5 VIDDA Syndemics

First coined by Mendenhall (2012a), the VIDDA syndemic model, emphasize the influence of political-economic and social forces on diabetes and related conditions. It also describes how these combined forces shape the clustering of depression and diabetes among Mexican immigrant women in Chicago (Mendenhall, 2012a, Mendenhall & Jacobs, 2012; and Mendenhall, Fernandez, Alder, & Jacobs, 2012). The VIDDA syndemic model encompasses the five core facets of health and social well-being that formulate diabetes and depression: **V**iolence (e.g., structural, symbolic, and every day); **I**mmigration and feelings of social **I**solation (e.g., relationship factors); **D**epression; **T**ype two **D**iabetes (e.g., sociocultural factors); and interpersonal **A**buse (Mendenhall, 2012b, pp. 23-24,105-106; and Weaver & Mendenhall, 2014). As the stress of interpersonal abuse, structural violence, poverty, and immigration merge, they synergistically produce distress among individuals, prompting health conditions to deteriorate (Mendenhall, 2012b, pp. 23-24,105-106). Similarly, the clustering of diabetes and depression is also shaped by a fusion of macro and micro forces (Mendenhall & Jacobs, 2012).

The prevalence of diabetes with depression has steadily increased (CDA, 2011). According to a large body of medical evidence, there appears to be a bi-directional relationship between diabetes and depression (Sacco & Yanover, 2006; Chen, Chan, Chen, Ko, & Li, 2013; Egede & Eillis, 2010; Golden et al., 2008; Mezuk et al., 2008; Talbot & Nouwen, 2000). This is because diabetes can result in the onset of depression due to the psychosocial weight of diabetes self-management (Renn, Feliciano, & Segal, 2011; Golden et al., 2008). However,

decreased quality of life, poor diabetes self-care, reduced glycaemic control, and an increased risk in developing diabetes-related complication, have also been contribute to the onset of depression (Nouwen et al., 2010). Many have postulated that the biological mechanism of depression as a precursor for diabetes may be due to the biochemical fluctuations associated with diabetes, which stimulate the nervous system, increasing the risk of diabetes in individuals with depression, compared to those without (Renn, Feliciano, & Segal, 2011; Kinder et al., 2002; Knol et al., 2007). It has also been suggested that depression may lead to the onset of diabetes due to the nature of biochemical changes that occur with depression and its treatments (Knol et al., 2006). Nevertheless, the biological mechanism between diabetes and depression still remains unknown, requiring further research.

The biomedical model suggests that this phenomenon can be solely treated with pharmaceuticals and behavioural modifications. However, the VIDDA syndemic model conceptualizes and acknowledges the biologic phenomenon, but emphasizes the interplay between political-economic and social conditions that facilitate the distribution and congregation of diseases in certain population (Mendenhall, 2012a; Weaver & Mendenhall, 2013; and Mendenhall, 2012b).

Furthermore, VIDDA syndemic provides insight on how political-economic and social inequalities exacerbate social suffering (e.g., increased diabetes clusters) among the poor in high-income countries, and highlights the need for integrative health care for the poor.

#### 2.4.6 Health disparities and Structural violence

The term “structural violence” was first introduced during the 1960s by Johan Galtung and describes how social structures such as economic, political, legal, religious, and cultural deny certain groups of people from living to their full potential (Galtung, 1969). Structural violence is often embedded deep within the political, economic and social structures in which we live in, and are normalized through the state of stability among institutions (Farmer, Nizeye, Stulac, & Keshavjee, 2006). A major component of structural violence is violence, which

expresses the suffering and human pain that is born of social inequality, which then produces sanctioned social brutality (Singer, 2009). This is because structural violence situates individuals and groups in harm's way, subjecting them to injury, and limited opportunities, thus amplifying relations of social inequality that perpetuates human suffering and ill health (Farmer, Nizeye, Stulac, & Keshavjee, 2006; Page-Reeves, Niforatos, Mishra, Regino, Gingrich, & Bulten, 2013).

According to Farmer (2003) structural violence denotes a “host of offenses against human dignity such as: extreme and relative poverty, social inequalities resulting from racism to gender inequality, and the more spectacular forms of violence that are uncontested human rights abuses” (Singer, 2009). Known as social suffering, structural violence aims at specific classes of people, denying their rights and subjects them to forms of lived oppression (Singer, 2009; Bourgois, Lettiere, & Quesada, 1997).

Visible to the naked eye, physical violence when committed against an entire group of people is detectable. However, structural violence like an undiagnosed disease, is a silent killer. This is because, embedded within the workings of domineering institutions, these violent acts that are committed are often invisible except to its victims. Rarely dressed as a contributing factor of health inequity among populations, structural violence is legal and goes unpunished, while often denying populations access to basic conditions for a decent life – e.g. food, safety, housing, and healthcare (Singer, 2009).

According to Whitehead and Dahlgren (2006), health inequalities are quantifiable differences in health outcomes and experiences between various populations, which are based on socioeconomic status, location, age, disability, gender, or ethnicity (Whitehead & Dahlgren, 2006). However, structural violence can be seen a form of health inequity. Health inequities are differences in life chances/ opportunities accessible to populations which later lead to unequal life changes and inaccessibility to health services, nutritious food, and suitable housing (Singer, 2009, p. 140-142; Whitehead & Dahlgren, 2006).

The impact on health due to structural violence is not always direct. That is, those who uphold the structure of society for the main purpose of stability also

use their influence to indirectly generated deplorable social conditions which deteriorate health conditions (Singer, 2009; Page-Reeves, Niforatos, Mishra, Regino, Gingrich, & Bulten, 2013). This is because health is largely based on diet and nutrition. However, when access to macro- and micronutrients and nutritious foods are denied, while access to increase levels of carbohydrate and sugar consumption remains, this sparks the onset of health complications is set. As groups of people are exposed to the tragedy of their reality, they begin to adopt various coping mechanisms to combat the social suffering this violence inflicts (Page-Reeves, Niforatos, Mishra, Regino, Gingrich, & Bulten, 2013). These mechanisms may consist of alcohol and drug abuse, gambling, and sexual promiscuity. In essence, structural violence perpetuate health inequities, which often determine who will survive and who will die (Page-Reeves, Niforatos, Mishra, Regino, Gingrich, & Bulten, 2013).

#### 2.4.7 Syndemics and Health Capabilities

The ability to lead a healthy lifestyle is dictated by opportunities which provides choices made available to people, based on their life chances (Cockerham, 2005). The pursuit of health and well-being depend on the accessibility of opportunities and resources. Transforming a variety of resources into health-related resources may contribute to the improvement of a person's health (Weaver et al., 2013). However, this transformation process hinges on the access to resources individuals have. Economic, social and cultural resources all shape a person's health and well-being (Weaver et al., 2013). For example, economic resources can widen an individual's opportunities in terms of education, employment, and health resources. Additionally, economic resources position individuals within social connections, broaden their opportunities and availability of choices (Weaver et al., 2013).

Acquired by socialization and communicated via language, a person's belief is largely determined by culture (Hjelm, Bard, Nyberg, & Apelqvist, 2005). However, economic resources supply cultural and social factors, which in turn



shape a person's health capabilities, manifesting into positive or negative impact on health.

In stark contrast to the traditional paternalistic view of treating patients and managing diabetes, the health capabilities approach tries to incorporate various views by respecting an individual's autonomy and agency. The concept of human agency involves the ability of a person to act as an agent of change, by realizing their own ability to accomplish valued health goals (Ruger, 2010). Even more, health capabilities can be viewed as choices that are influenced within a social and institutional environment that has a severe impact on health outcomes (Weaver et al., 2014).

Health capability can be defined as the ability to confidently and successfully accomplish optimal health, regardless of current biological and genetic disposition and access to social, cultural, and economic resources, with respect to the health agency of an individual (Ruger, 2006). In fact, health capabilities can also be viewed as choices that are influenced within a social and institutional environment (Weaver et al., 2013).

Likewise, the syndemic framework describes how adverse social realities (e.g., poverty, food insecurity and lack of social resources) unite to shape a person's illness experience and also the distribution of disease among populations (Mendenhall, 2012a; Singer 1996, 2009a, 2009b; Singer and Clair 2003). Additionally, the syndemic approach combines social, cultural, psychological, and biological elements that congregate to cultivate experiences of individuals who experience complex diabetes (Mendehall 2015).

Health capabilities and a syndemics framework can work in tandem with each other as a person's health capabilities can be severely influenced by the social strata they are situated in, which in turn can impact their ability in attaining optimal health. Similarly, health capabilities and the syndemics approach place emphasis on exploring the social constructs that heavily influence health and well-being. Both approaches provide a holistic theoretical lens that examines the social, psychological, and physical distress that is experienced by individuals with complex diabetes. These experiences are framed by socialization and access to

resources, which therein severely impact a person's health capability to improve health conditions and quality of life.

### **3. Chapter Three: Methodology**

#### **3.1 Qualitative study**

Diabetes management is often affiliated with various responsibilities, which overtime can diminish quality of life, increase financial burden and require significant behavioural and lifestyle changes for patients and their families (Nagelkerk, Reick, & Meengs, 2006). Once diagnosed, people with diabetes are expected to incorporate major lifestyle changes and adhere to certain behavioural regimes immediately (Nagelkerk, Reick, & Meengs, 2006). For some, incorporating and adapting these changes can sometimes be difficult and unrealistic due to social circumstances. Such barriers include: time restraints, inadequate coping skills, poor patient –provider relationship, lack of social support, access to care, the financial cost for medication, testing supplies, and implementing nutritional changes, insufficient resources, and support systems (Nagelkerk, Reick, & Meengs, 2006; Rahim-Williams, 2011). As a result, individuals aiming to improve their health frequently encounter barriers in implementing these changes (Nagelkerk, Reick, & Meengs, 2006). Furthermore, these barriers can often affect diabetes self-management adherence and behavioural outcomes. Individuals experiencing diabetes, manage diabetes and make decisions based on their: knowledge, beliefs and perceptions; attitudes/ behavioural patterns; and access to resources and support systems (Nagelkerk, Reick, & Meengs, 2006; Rahim-Williams, 2011).

The association between ill health and socioeconomic status (SES) has been long linked to the prevalence of Type 2 diabetes (Williams et al., 2010). In fact, exposure to SES factors at an early age may contribute to development of unhealthy behavioural patterns. Overtime, these behavioural patterns may promote risk factors for type 2 diabetes, which can later contribute to poor diabetes management outcomes (Williams, Tapp, Magliano, Shaw, Zimmet, & Oldenburg, 2010). For example, if a person perceives that existing structural barriers impede their access to resources to manage diabetes, this may hamper a person's behavioural response to adhere to diabetes self-management recommendations. In

addition to patient behaviour being critical in diabetes management, health beliefs and perception also play a vital role.

Consequently, this study utilizes qualitative methods in hopes to advance understanding of the beliefs, attitudes, behaviours, and experience of individuals living with complex diabetes (Polgar & Thomas, 2008). In addition to providing individuals with a platform to express their stories and life experiences, qualitative methods enable diabetes researchers to answer questions that quantitative methods often ignored or are unable to answer (Morse & Field, 1995). Therefore, gaining insight into patients' perceptions will enable us to design more effective interventions. This research utilizes a qualitative approach not only to explore people's life history, but to also gain a richer understanding of how social environment shape their experience with complex diabetes. Qualitative studies on diabetes enable us to identify facilitators that uphold or inhibit effective diabetes care.

### **3.2 Research Setting**

This research study took place at the Centre for Complex Diabetes Care (CCDC), which is based within a community hospital in the Greater Toronto Area. The CCDC is part of the Ontario Diabetes Strategy (ODS) and was implemented by the Ministry of Health and Long-Term Care (MOHLTC). The CCDC was established to provide further contact, more resources and additional follow-up for patients across healthcare and social services system (Luke, 2014). However, patients who experience fewer complex needs are referred to the Diabetes Education Program (DEP).

There are currently six CCDC sites across Ontario. In the fall of 2011, three of these sites were initiated, and in 2012 an additional three sites were created. Currently, in the Central East region of Ontario, there is one CCDC which is situated at three different sites. These sites are located in the Central East include Lakeridge Health (Whitby site), Peterborough Regional Health Centre, and The Scarborough Hospital (General Campus) (Luke, 2014).

Built on the Kaiser Permanente Chronic Disease Management Model, the CCDC assesses and supports individuals with complex diabetes, by providing services for individuals with co-morbid conditions who require intensive case management (CCDC, 2013). The Kaiser Permanente Model categorizes patient care based on the severity of patient's conditions (e.g., Level 1, 2, 3) (Ontario Medical Association, 2009). The CCDC primarily receives Level 3 patients, who suffer with progressive diabetes, complex co-morbid conditions, complex psychosocial issues, frailty, and are in need of intensive/ case management (Luke, 2014).

At the CCDC, intensive care is provided by an interprofessional team composed of a: nurse practitioner, nurse, dietitian, social worker, and pharmacist. These health care providers collaborate to provide clinical case management and develop care plans that are centered on the individual's needs and self-management goals, through coaching and mentoring (CCDC, 2013).

Patients referred to the CCDC must be 18 years of age or older, living with Type 1 or Type 2 diabetes, and experiencing one or more of the following: 1) severe mental health issues, barriers in accessing health care, advanced age and frailty, mobility issues, and other determinants of health; 2) multiple episodes of insufficient glycemic control and/ or significant comorbidities impacting glycemic control; 3) recurrent emergency department visits or hospitalization; and 4) benefit from an interprofessional team approach to address their multiple complex needs (CCDC, 2013).

One of the reasons the CCDC setting was chosen for this study was the patient population characteristics. Patient attending the CCDC experience complex conditions that are associated with the progression of diabetes, in addition to other social and economic life challenges. For many of these patients, the CCDC serves as a last resort to receive care and improve diabetes management. In a typical healthcare setting, these patients often fall through the cracks, due to inadequate support, existing barriers to care, and lack of resources. This is why the CCDC is pivotal in helping and empowering these patients to

manage diabetes by providing further contact, more resources, and additional follow-up across healthcare and social services systems.

### **3.3 Ethical Consideration and Research approval**

Ethical approval to conduct this study was sought and approved, from both the Research Ethics Boards (REB), of the University of Ontario Institute of Technology (REB File #: 14-048), and Lakeridge Health (RID# 2014-055). This study complied with the ethical considerations required by both REBs to ensure that the welfare, rights, dignity, and safety of research participants was protected, and that participant confidentiality was maintained. Details of process provided in Appendix A.

### **3.4 Data Collection**

This study draws its data from three sources: (1) secondary data CCDC staff collected for Ministry reporting; (2) a socio-demographic questionnaire of eleven CCDC patients interviewed; and (3) qualitative data from semi-structured interviews of CCDC patients.

#### **3.4.1 Sampling and Recruitment**

This study utilized a purposive sampling approach to recruit eleven participants from a pool of approximately 90 active CCDC patients. Prior to study commencement, an information session was held at the CCDC clinic to educate clinic staff about the research.

As outlined in appendix B, with the aid of the CCDC team, potential participants were purposively identified. This identification process was based on the inclusion/ exclusion criteria (see Table 3.1) in combination with the CCDC team's experience and understanding of each patient. This enabled the CCDC team to determine suitable candidates for this study. Once potential participants were identified, the CCDC team was provided with an information package, containing an invitation letter (see Appendix C) and a consent form (see Appendix D) regarding the study. Patients identified appropriate for this study were mailed

an information package concerning the study by the CCDC team. This procedure allowed potential participants the time to read the consent form and discuss it with family and friends at their leisure. During appointment calls, the CCDC staff asked potential participants if they received the information package, and whether they had any questions or concerns regarding the study. At patient's next appointment at the CCDC, the CCDC staff inquired whether potential participants were interested in participating in the study.

If patient agreed to participate, a consent form (as per tri-council REB policy) (see Appendix D) was given to the individual and reviewed thoroughly with the CCDC staff. During this time, any questions or concerns patients may have had concerning the study was answered by the CCDC staff. Participants were also made aware that they were volunteering and could withdraw from the study at any time, and would receive a \$20 Tim Horton's gift card as a token of appreciation. If a patient consented to participate and the CCDC staff received signed consent from the participant, a meeting with the researcher to complete the sociodemographic survey (Appendix E) and interview (Appendix F) was scheduled following his or her next regular visit by the CCDC staff. At this appointment, participants were invited to complete a sociodemographic survey (Appendix E), followed by an in-depth semi-structured interview (Appendix F). During this period, participants were verbally reminded by the research of their right to withdraw from the study at any time.

#### 3.4.2 Description of CCDC Population: Secondary Data

To characterize the overall patient population that regularly access care at the CCDC, secondary data comprised of in-depth descriptive statistics was gathered with assistance of the CCDC. The information is manually collected by the CCDC staff during their initial assessment of patients as mandated by the Ontario Ministry of Health and Long Term Care, and enables the CCDC team to determine the best approach in helping patients better self-manage their diabetes.

Secondary data used in this study consisted of 115 patients (n=115) (excluding study participants) and was collected by the CCDC staff for the

Ministry of Health. This data was gathered prior to the commencement of this study. This data was used in this study, to describe the overall population accessing services at the CCDC. The information collected included patient's age and sex, mean BMI, and comorbid and chronic conditions. It is important to note that in this study, all secondary data used was stripped of patient identifiers by the data analyst at Lakeridge Health. Access to this data was granted by the completion and agreement to *the Lakeridge Health Statement of Confidentiality form and The Research Confidentiality Agreement form*.

#### 3.4.3 Description of Study Sample: Sociodemographic data

Sociodemographic surveys (Appendix E) were used in this study to gather descriptive information and included questions inquiring about participant's age, sex, highest education level, ethnicity, country of birth, city/ town they reside in, occupation, current household annual income, marital status, number of children, number of people living in their household, and whether or not they rented or owned a house/ condominium.

This survey was used to determine and describe the characteristics of the sample population (n=11) from the overall CCDC population. On the day of the interview, I administered sociodemographic surveys to study participants to complete. This was done to ensure that the interviews were fully focused on participant's perspectives and life experiences related to this study.

#### 3.4.4 Semi-structured interviews

The semi-structured interview took place at the CCDC located at Lakeridge Health, Whitby, in a private room for approximately forty minutes to an hour and a half. To ensure participants were comfortable in sharing their stories and to permit in-depth exploration of their experiences, this study took place at the CCDC, where staff was on hand to help, in case participants became very upset in telling their stories (Charmaz, 2006, pg. 25). Each individual participant took part in one interview. With participant's permission, each interview was audio recorded and participants were referred to by an agreed pseudonym they choose.



On the day of the interview, I verbally explained the study and consent form to each participant. This was done to ensure that participants understood the study and were aware of their rights (e.g. right to withdraw from study and pass on questions). Once verbal consent was given, each participant was asked to complete a sociodemographic survey (Appendix E). Following this, each participant was invited to engage in an interview. Throughout the interview, I reminded participants of that they may withdraw from the study at any time by notifying me and stating they would like to withdraw.

The interview schedule included a number of several semi-structured open-ended questions and probe questions as prompts to elicit further dialogue (see Appendix F). The use of a semi-structured interview format permitted open-ended questions to be asked, which allowed participants to express and reflect on their life experiences (Bowling, & Ebrahim, 2005). To protect participant identity and ensure confidentiality, participant were referred to by their chosen pseudonym throughout the interview, which was then cross-referenced with numerical codes on sociodemographic survey.

In qualitative research, the researcher builds rapport to facilitate interaction during the interview, which is vital in gathering rich data regarding participant's thoughts, feelings, and life experiences (Poggenpoel & Myburgh, 2003, p.418). Questions asked during the interview were designed to prompt and generate feelings, thoughts, and experiences in relation to social conditions, complex diabetes, diabetes management, health history, and healthcare system interaction. Questions were primarily focused on enabling patient to tell their story, while giving insight into how they experienced the healthcare system with complex diabetes.

Following each interview, I debriefed each participant after the recorder was turned off. Each participant also was verbally thanked and presented with a \$20 Tim Horton's gift card as a token of our appreciation. Participants were informed that once the study was completed, they may request a copy of the executive summary regarding the study by contacting me or the CCDC.

Prior to each interview, I also composed interview field notes, documenting an overall summary of each interview, my impressions, and tentative preliminary themes that arose from each interview. The use of field note summaries enabled me to reflect on each interview before transcription of each interview. Additionally, the combined use of field notes and transcripts enabled me to compile three biographical composites that are fictional representations that exemplify participants' collective experiences. Composites were compiled and derived from careful review of the transcripts which entailed detailed life experiences and challenges and barriers that participants had collectively encounter throughout their lifetime. The composites are exemplars and intended to give expression to the combined challenges and demands of living with complex diabetes, in conjunction with social demands/ roles/ responsibilities/ and stresses that participants typically encounter on a daily basis.

It is important to note, that all information gathered from each interview was protected and held private. Data protection was ensured by the transfer of all data (e.g. digital audio recordings, transcription, and sociodemographic information) onto an encrypted electronic drive, both electronic and hard copy data was stored in a locked UOIT office. Only research team members have access to the information and data. All study data (electronic and hard copies) will be kept for five years and will then be destroyed.

#### 3.4.5 Inclusion/ Exclusion Criteria

To help identify individuals suitable for this study, participants were purposively identified from a pool of approximately ninety active patients at the CCDC, by the CCDC team during their regular routine visits. Throughout participant recruitment, potential participants were identified based on the inclusion/ exclusion criteria (see Table 2), along with the CCDC team's experience and understanding of each patient.

The patient population of this study included participants who meet the criteria for inclusion/ exclusion criteria. It is important to note that the inclusion / exclusion criterion was developed in collaboration with CCDC team. The

inclusion criteria include: patients who are 18 years of age and older, diagnosed with type 2 diabetes and two or more comorbidities. Due to linguistic barriers or severe mental/ physical conditions, individuals excluded from this study were those who are non-English speaking, individuals who suffered from: serious unstable mental health issues (ex. Schizophrenia, dementia, etc.), blindness, hearing impairment, speech impairment, or a post stroke patient with severe speech impairment.

**Table 2** Inclusion and Exclusion criteria for study recruitment

Inclusion Criteria							Exclusion Criteria	
Type 2 Diabetes	Obesity (BMI > 30)	Eating disorder	Current Malignancy	Other determinants of health (e.g. socio-economic barriers, barriers to access of health services, etc.)	Chronic complication (e.g. amputations, skin conditions, lipohypertrophy, diabetes myonecrosis, foot problems, Stiff Man's syndrome, fractures)	Genetic syndrome	Non – English Speaking	Post – stroke patients with severe impairment of speech
Depression / stable mental illness	Patients with viable transportation	Post-stroke patients	Thyroid disease	Frequent hospital admissions due to diabetes complications	Peripheral vascular disease	Neuropathy	Blindness	Serious unstable mental illness (e.g. schizophrenia, dementia, etc.)
Hypertension	Hyperlipidemia	Cardiovascular disease	Obstructive sleep apnea	Be of either sex	Celiac disease	HIV/ AIDS	Type 1 Diabetes	Hearing impairment (due to nature of study)
Chronic kidney disease	Pulmonary disease	Retinopathy	Pancreatic disease	18 years old or older	Liver disease	Non- healing wound		

\* **Note:** The inclusion criteria includes: patients who are 18 years of age and older, diagnosed with type 2 diabetes and two or more of the above comorbidities/ chronic conditions.

### **3.5 Analysis**

#### **3.5.1 Semi-structured interviews analysis**

All interviews in this study were audio recorded and transcribed. I personally transcribed each interview to ensure accurate representation of each participant's story (Bowling and Ebrahim, 2005; Potter and Hepburn, 2013). Prior to each interview being transcribed, I carefully reviewed each interview field note summary that was composed after each interview. After interviews were transcribed, each transcript was read line by line, while the interview recording was replayed to ensure accurateness and that all components of the interview were being captured. To become familiar with the corresponding interview, I also read each transcript several times before performing open coding.

This study utilized thematic analysis which consisted of the researcher examining: commonality, differences, and relationships (Gibson & Brown, 2009, pg. 128-129; Percy, Kostere, & Kostere, 2015; Braun & Clarke, 2006). Following the completion of transcribing, interview transcript files were imported into the research analysis software QSR NVivo10, where transcripts were organized and analyzed. QSR NVivo enabled me to identify emerging themes from each interview, and shed light on participants who expressed similar thoughts/ experiences. This was done by thoroughly examining, sorting and categorizing data into corresponding nodes (codes) (Braun & Clarke, 2006).

Transcripts from each participant was analyzed individually with the goal or maintaining an open view to all possible theoretical directions and staying close to the data (Charmaz, 2006 pg. 47-49). Once data from all participants were analyzed individually, text segments from interview transcripts that reflected a common emerging theme / shared experience among participants, were grouped and arranged within nodes. These nodes represented preliminary emerging themes/ cluster of items that were related/ connected in some way. Text segments within each node were then further carefully studied and analyzed to develop overarching emerging themes (Percy, Kostere, & Kostere, 2015; Braun & Clarke, 2006). Overarching emerging themes and corresponding interview text segments

were then shared with research committee to encourage discussion of overarching emerging themes. This included exploring meaning, similarities, differences, patterns, and relationships of emerging thematic elements (Guest, MacQueen, & Namey, 2012, pg. 49-79; Braun & Clarke, 2006).

### 3.5.2 Saturation

The number of participants required for this study was based on data saturation. As themes emerged from each interview and became repetitive, it was clear that saturation was attained. This meant that the invitation to new participants may not produce new trends in collected data (Polgar & Thomas, 2008; Charmaz, 2003; Morese et al., 2002:12). Although each participant's story is unique, common themes emerged and were replicated in subsequent interviews. Therefore, since no new insights were obtained and no new themes were identified, we concluded that saturation was reached, with the total number of participants involved in this study being eleven individuals (Strauss and Corbin, 1990).

### 3.5.3 Achieving trustworthiness

To ensure methodological rigour, Lincoln and Guba's (1985) naturalistic inquiry guidelines for trustworthiness in qualitative data was used. Keeping with Lincoln and Guba's guidelines, multiple techniques were carried out to achieve, credibility, transferability, dependability, and confirmability. The techniques that were utilized in this study to ensure consistency and reliability are described below:

#### **Credibility: Peer Debriefing**

Lincoln and Guba (1985, p. 308), describes peer debriefing as a process where another peer is exposed to exploring aspects of inquiry. This may help in unearthing granted biases, perspectives, and assumptions the research may have, which may undermine credibility of the findings. Peer debriefing was used in this study via constant reviews

and meetings with supervisory committee members, who were able to give guidance in study analysis. Peer debriefing with supervisory committee members who specialized in certain areas (e.g. diabetes management care, qualitative research) also enabled the primary researcher to become aware of personal biases, and tested formulated assumptions.

### **Transferability: Thick Description**

Thick description helps convey comprehensive account of the field experience and contexts that surrounded them (Shenton, 2004). According to Lincoln and Guba (1985), by describing a phenomenon with in-depth detail, enables external validity, where the extent to which conclusions can be drawn, and are transferrable to other times, settings, situations, and people. In this study, thick descriptions were formulated through a rigorous literature review (literature reviewed occurred before initiation of study), the construction of in-depth field notes after each interview session, the collection of a sociodemographic survey, and the use of secondary descriptive data to supply a rich description of population characteristics being studied.

### **Dependability: External Audits**

To ensure the findings of this study were dependable, external audits were used. External auditors were members of the supervisory committee who were not explicitly involved in the research process, but examined the development, progression, and findings of this study. According to Lincoln and Guba (1985), having external audits, permits evaluation of accuracy and examines findings, interpretations, and conclusions that are supported by the collected data (Guba, 1981). Therefore, the guidance, feedback, and challenges the external audits addressed throughout the progression of this study, was vital. This

enabled me to continuously revise and assess the dependability of data and preliminary results.

### **Confirmability: Audit trail and Reflexivity**

#### **A) Audit Trail:**

Audit trail is described by Lincoln and Guba (1985, p.310-319) as a step-by-step description of the study progression, which accounts for all phases of the study (e.g. development phase to conclusion phase). This allows any observer to follow the course of the research through the procedures described (Shenton, 2004). To ensure confirmability, this study maintained an audit trail, which included field notes from interviews, a research diary, process notes, and data reconstruction and synthesis products, which includes structure of categories drafts, and preliminary findings reports.

### **3.6 Research Questions**

As mentioned before, this study uses the syndemic framework and is focused on critically examining how social factors (e.g. social support, social responsibilities, SES) shape the health and well-being of those who experience complex diabetes. It also explores the challenges patients with complex diabetes encounter when interacting with the healthcare system. Thus this study asks the following research questions:

4. How do patients with complex diabetes perceive the causes and consequences of their current psychosocial and medical conditions?
5. What are the social attributes/ characteristics, background and current life circumstances that influence the onset and management of complex diabetes?
6. What are the perceived challenges, persons with complex diabetes encounter throughout their lifetime when interacting with the healthcare system?



## **4. Chapter Four: Description of Complex Diabetes population**

### **4.1 CCDC population: Secondary Data**

The secondary data used in this study was gathered from all past CCDC patients, and was used to characterize the overall population that receives care at the CCDC. Information gathered included patient's age and sex, mean BMI, patient's initial A1C levels, and top five comorbid and chronic conditions experience by patients. Univariate (e.g. mean, median, mode, and standard deviation) statistics was performed on data collected by the CCDC team, with the aid of Microsoft Excel by a Lakeridge Health Analyst.

### **4.2 Population Descriptive: Sociodemographic Surveys**

The sociodemographic surveys was utilized to collect descriptive information for the sample used in this study. The sociodemographic survey tool is provided in Appendix B. With the aid of Microsoft Excel, univariate (e.g. mean, median, mode, and standard deviation) statistic was performed on data collected from sociodemographic surveys. This was done to provide a better description of the overall participant population in this study.

### **4.3 Sex and age of CCDC and participant populations**

Secondary data used in this study was gathered from past CCDC patients. This data included a total of 115 past patients (n=115), where 57 were male and 58 were female. The mean age of males attending the CCDC was 59 years, whereas among females the mean age was 63 years.

In terms of gender and age distribution, we were able to collect equal population of males (n=6) and females (n=5), a total of eleven study participants (n=11). In contrast to the secondary CCDC population age distribution, the mean age among males study participants was 70.5 years, while among females it was 60 years (Table 3).

Table 3: Sex and age of CCDC and participant populations

	CCDC patient population (secondary data)	Study participant population
<b>Sex</b>		
Male	N = 57	N = 6
Female	N = 58	N = 5
<b>Age</b>		
Male	59 years	70.5 years
Female	63 years	60 years

#### 4.4 CCDC Secondary data: BMI and Weight of CCDC population

Initial assessment of weight and BMI among CCDC male patients was 227.12 lbs, and 34.1 respectively. In contrast to the male population at the CCDC, the initial assessment of weight and BMI was less among female patients, where the mean weight was 190.39 lbs, and mean BMI was 33.1.

#### 4.5 CCDC Secondary data: A1C levels from CCDC population

Glycosylated haemoglobin (A1C) is often used to diagnose diabetes and estimate the mean plasma glucose levels over a period of three to four months (Berard, Blumer, Houlden, Miller, & Woo, 2013). A1C is used at the CCDC, for it enables healthcare providers to assess treatment effectiveness. According to the Canadian Diabetes Association clinical practice guidelines, A1C should be assessed every three months, especially when glycemic goals are not being met and when diabetes therapy is being altered (Berard, Blumer, Houlden, Miller, & Woo, 2013).

Furthermore, Clinical guidelines also recommend that individuals with type 1 or type 2 diabetes should aim to achieve an  $A1C \leq 7.0\%$  (Iman, Rabasa-Lhoret, & Ross, 2013). However, in some individuals with type 2 diabetes a target  $A1C \leq 6.5\%$  may be recommended, in efforts to lower the risk of nephropathy and retinopathy (Iman, Rabasa-Lhoret, & Ross, 2013). Target A1C of 7.1-8.5% may also be suitable for patients with type 1 or type 2 diabetes, who live with any

of the following: limited life expectancy, high level of functional dependency, extensive coronary artery disease, multiple comorbidities, history of severe hypoglycemia and hypoglycemia unawareness (Iman, Rabasa-Lhoret, & Ross, 2013).

A1C levels among the CCDC population ranged from 5.6 to 13.3, where the mean level was 8.8 (n=115). It is important to note that many patients attending the CCDC also lived with various comorbid conditions (Table 4).

Table 4: A1C results from clients after Initial Visit at CCDC

A1C during Initial Visit	
<b>Mean</b>	8.8
<b>Median</b>	8.1
<b>Mode</b>	9.9
<b>Range</b>	5.6 - 13.3

#### 4.6 CCDC Secondary data: Most common comorbidities and chronic conditions among CCDC population

As described in prior chapters, individuals attending the CCDC experience various medical conditions in conjunction to diabetes. Thus, patients must juggle various health conditions on their own, which overtime may compromise efforts to self-manage diabetes due to limited time and resources.

Comorbid conditions tend to arise when a person is experiencing two or more disorders or illness simultaneously or sequentially. During patient's initial visit at the CCDC, 96% of the CCDC population (n=115) reported to be experiencing two or more comorbidities. What is even more astounding is that 68% of all patients at the CCDC were found to have four or more comorbidities, while the mean comorbidity among the patients was 4.89.

Secondary data from the CCDC also reported that the five most common comorbidities among CCDC patients were: chronic kidney disease, cardiovascular disease, hyperlipidemia, mental health, and hypertension being the most common comorbid condition (Table 5). Similarly, 64% of the CCDC population (n=115) are said to have experienced one or more diabetes-related chronic complication (a mean of 1.53 chronic condition among CCDC patients).

Unlike acute diseases, chronic diseases (also known as noncommunicable diseases (NCDs)) are not transmitted from person to person. Instead, chronic disease are present for a long period of time and slowly progress, often becoming more severe or worse over time (WHO, 2015). Managing diabetes and other related chronic conditions not only makes living with diabetes complex, it also places restraints on self-management goals. For example, the five most common diabetes-related chronic conditions among the CCDC patient population (n=115) ranging from most common to least common are: nephropathy, retinopathy, wounds (non-healing), and cardiovascular disease, respectively (Table 5). As health conditions worsens, complications arise increasing the disease burden, especially when multiple ailments may become demanding and overwhelming if patients have limited or decreasing resources and support.

Table 5: Most prevalent comorbidities and diabetes-related chronic disease among CCDC population

<b>Most Common Comorbidities among CCDC patients</b>	
<b><u>Comorbidities</u></b>	<b><u>Occurrence among CCDC patient population (n=115)</u></b>
Chronic Kidney Disease	5%
Cardiovascular Disease	5%
Hyperlipidemia	6%
Mental Health	24%
Hypertension	40%
<b>Most Common Diabetes-related Chronic Conditions among CCDC patients</b>	
<b><u>Chronic Conditions</u></b>	<b><u>Occurrence among CCDC patient population (n=115)</u></b>
Cardiovascular Disease	6%
Wounds (non-healing)	6%
Retinopathy	8%
Nephropathy	15%
Neuropathy	52%

#### 4.7 Sociodemographic Surveys: Marital status, education level, and occupations of study population

Participants had various backgrounds and life circumstances, which included: marital statuses, education, and occupation. For example most people in this study were married (6), while some were either single (2), divorced/ separated (2), or a widow (1). Furthermore, the level of education among participants ranged from the majority attaining a college diploma (5) and a high school diploma (3), and three participants completed a baccalaureate degree or higher (2), or had less than high school (1) (Table 6).

With participants predominantly over the age of 55 (refer to table 1), majority of individuals in this study were retired (6). However, some participants were currently working (2), or forced to retire due to disabilities caused by work related injuries or other medical conditions (2). There was one participant in this study who was semi-retired (Table 6). It is important to note, that participants in this study primarily consisted of persons of European decent, with the exception of one participant who was a visible minority.

Table 6: Study population demographics: marital status, education, and occupation

<b>Marital Status</b>	<b>Study Population (n=11)</b>
Single	2
Married	6
Divorced/ Separated	2
Widowed	1
<b>Education</b>	<b>Study Population (n=11)</b>
Less than high school	1
High School	3
College diploma	5
University	2
<b>Occupation</b>	<b>Study Population (n=11)</b>
Disabled / retired	2
Retired	6
Semi-retired	1
Working	2

#### 4.8 Sociodemographic Surveys: Household income of study population

Similar to the findings of education and occupation, household income varied between participants. Individuals with a household income of less than

\$25,000 or between \$35,000 - \$49,000 were predominant (3 individuals respectively, 6 in total). Conversely, household incomes between \$25,000 - \$34,999 were the second most common among participants (2 individuals). Least common, were persons with a household income exceeding \$50,000 and above (3 individuals in total). In regard to their place of residence, six participants rented, while five participants owned their own home (Table 7).

Table 7: Study population socioeconomic status: household income and place of residence

<b>Current Household Income</b>	<b>Study population (n=11)</b>
Less than \$25,000	3
\$25,000 - \$34, 999	2
\$35, 000 - \$49, 000	3
\$50, 000 - \$74, 000	1
\$75, 000 - \$99,999	1
\$100, 000 - \$149, 000	1
<b>Residence</b>	<b>Study population (n=11)</b>
Rent	6
Own	5

## **5. Chapter Five: Research Findings – Interview Analysis**

### **5.1 Introduction**

This chapter describes the findings gathered from semi constructed interviews that were conducted at the CCDC. It is divided into five major themes which corresponds with the three research questions. Findings of this study be will also be discussed and explored using health capabilities and a syndemic framework.

### **5.2 Questions 1: How do patients with complex diabetes perceive the causes and consequences of their current psychosocial and medical conditions?**

#### **5.2.1 Theme 1: History repeats itself**

##### **5.2.1.1 Sub-theme 1: Family History**

Nine out of eleven participants in this study were related to a person living with diabetes. Many of these participants recounted what it was like witnessing a family member being diagnosed with diabetes and having to manage their condition. Being diagnosed with the same condition a relative has struggled with often was described as overwhelming and hard to cope with, especially if that relative experienced negative health outcomes such as decreased quality of life. Furthermore, almost all participants held the belief that if diabetes runs in your family, “it will get you.” However, a few participants in this study expressed that if one has a family history of diabetes, not being overweight and not exercising does not necessarily mean that one will not have diabetes. For example, one participant recounted that not being overweight does not guarantee immunity, because if diabetes is in your family, your fate is already pre-destined.

Roy, for example who grew up with limited access to food due to his families’ economic situation, worked most of his life in a retirement home complex. After a work related injury he was forced to go on disability and currently lives with multiple ailments with his wife by his side. Reflecting on his experience with diabetes, Roy perceived diabetes to be a disease that “*some people have ...right in their blood.*”

Bob who grew up on a farm with five siblings, has worked over forty years at a motor company, also shares Roy's belief of diabetes running in the family. Bob shared the struggles of managing diabetes day to day and noted that a number of his siblings also share these struggles. He stated "... *diabetes does run* [in my family], *well my mother had it, [...] My older brothers got diabetes, and now my brother that's one year older than me, he's started taking metformin to. ... My sister doesn't have it yet, but her doctor has her testing all the time, because of the family history with diabetes.*"

Some participants, such as Jill, concluded being diagnosed with diabetes is inevitable or unescapable once it's in your family history. Jill, who was born in Scotland but grew up in Canada, reflected on what it was like to have strong maternal history of diabetes in her family. After year of working in a financial institution, Jill was forced to retire early due to her marriage ending, failing health, and subsequently was diagnosed with diabetes. She recounts:

*You know ... I think if you're going to get it, you're going to get it. I mean sometimes ... they talk about people who are heavy, overweight ... oh you're going to be diabetic. I see people walking around and they are not diabetic. I think if it's in your family ... it's going to get you...*

People living with diabetes like Roy, Bob, and Jill appear to perceive their condition to be directly linked to their family history. This belief may hamper preventative measures and discourage positive self-diabetes management, as individuals with a family history of diabetes perceives their health condition to be pre-destined.

#### 5.2.1.2 Sub-theme 2: Lifestyle

Lifestyle habits and choices have long been associated with the onset of diabetes. In fact all participants perceived prior lifestyle and dietary habits to be, in part, of the root cause of their diabetes. Some participants attributed their poor eating habits, being overweight, inactivity, and lack of knowledge to the onset of diabetes. For example, Victoria voiced the restraints economic resources placed on her ability to afford food appropriate for diabetes management. In addition,



participants like Victoria also revealed how poor lifestyle habits can be transferred from one generation to another.

Victoria who comes from a British family and grew up eating traditional British food, also instilled eating patterns passed down to her from her parents to her children. Coupled with her lack of financial resources, and a lifetime of unhealthy lifestyle habits, controlling diabetes with diet and exercise became a stumbling block for patients like Victoria. Victoria also expressed her lifelong battle with weight and perceived that once a person is diagnosed with diabetes, taking prescribed medication is inevitable.

*Victoria: ... I think because of my own ignorance of what diabetes was, and the consequences and the impact it was gonna have on my life. I was pretty ignorant of all those things ... I have always been an overweight person. And the older I got the more weight I put on and the harder it was to take off. So they first suggested I used diet to control the diabetes, and that doesn't work, and I don't know anybody who doesn't eventually end up on medication, which I did. I think it was then, that I started to take it more seriously.*

Altering dietary patterned behaviours forged over decades possess as a challenge for persons with diabetes. Victoria reveals that she perceived the cause of diabetes to her own ignorance or lack of education of diabetes and what leads to the onset of diabetes. She also stated her perception that preventative methods are not effective, and controlling diabetes via diet is ineffective, and that it is only a matter of time until a person has to adhere to medication regimens. Victoria also views medication adherence to treat diabetes as a consequence of having this medical condition.

Similar to Victoria, Smiley also conferred his perception of lifestyle choices which may have triggered the onset of complex diabetes. Smiley immigrated to Canada from the Caribbean over thirty years ago. Acknowledging that his mother had diabetes, and the genetic component to his diagnosis, Smiley also stated that he perceives his lifestyle to be associated with diabetes. Smiley deduces that he developed his diabetes from living in Canada, and leading a sedentary lifestyle with access to food rich in fat, carbohydrates, and sugar.

*Smiley: “maybe it was the eating habit, back then you eat anything. A lot of sweets, a lot of carbohydrates... I thought my weight was just normal ... When [I] came here [to Canada] now with eating all these things and less exercise ... I guess it’s just care free life that cause that [diabetes]. I’m not a smoker, I’m not a drinker, so those two you can cancel it....”*

In Smiley’s perception, moving to Canada from the Caribbean and adapting to a different lifestyle and adhering to cultural habits and dietary norms may have led to the onset of diabetes. Smiley’s reasoning for his belief is grounded in the fact that he does not qualify for many of the other lifestyle activities that elevate the risk of diabetes. In fact, his adopted dietary habits and sedentary lifestyle may become a challenge in terms of diabetes management. This is because much of this learnt behaviour and adopted norms must change in order to successfully manage his diabetes.

**5.3 Question 2:** What are the social attributes/ characteristics, background, and current life circumstances that influence the onset and management of complex diabetes?

#### **5.3.1 Theme 2: Health complications deplete health capability**

Ten out of eleven participants in this study were dealing with various health complication, in addition to living with type 2 diabetes. Throughout the interviews participants often expressed how the stress of managing complex diabetes, in conjunction with balancing the demands of everyday life, can often lead to frustration. For some participants, as other health complications developed, increased care, resources and attention were needed, and managing diabetes no longer was a priority. Many times, these participants found themselves in a vicious cycle as resources continued to be depleted and unavailable and their health conditions began to worsen.

Billy Bob is facing economic hardships as he lives with complex diabetes and other co-morbid conditions at the age of seventy-five. Billy Bob has been living with diabetes for around thirty-five years and has received informal

diabetes care and support for his friend. However, over the past few years Billy Bob's health has significantly decline, as he was diagnosed with terminal non-alcoholic non-hepatitis fatty liver sclerosis. With a daughter under fourteen, and no chance of receiving a liver transplant, Billy Bob faced a downward health outlook. Billy Bob discussed his experience of living with complex diabetes, and the various side effects of liver sclerosis:

*"I've got terminal non-alcoholic, non-hepatitis fatty liver sclerosis. The only treatment for that is a liver transplant. At my age, they won't even put my name on the list. So there's no hope [...] I have all the side effects ... hepatic encephalopathy is one of them. Where my brain gets scrambled by the toxins in my blood [...] I'm just not functioning 100% mentally. [...] this foot doesn't work, this leg doesn't work properly. Ummm but you know a lot of it is the side effects, and medication side effects. The disease itself, time to figure out which is it? That's the problem [...] day to day we are juggling stuff.*

The frustration and challenges of living with complex diabetes and other conditions can often lead some participants, such as Roy, to experience a feeling of loss of hope and becoming depressed. As previously discussed, Roy who endured financial hardship as a child, was forced to go on disability insurance due to a work injury. He expressed that he endures a lot of pain in his back, and often, diabetes management can be hard to cope with. This is because after being diagnosed with diabetes, Roy had a stroke that significantly impacted his mobility and vision. Not being able to engage in paid work, the bulk of Roy's care and financial support of the family, is placed on the shoulders of his wife. Roy further expressed that the emotional impact of living with complex diabetes has resulted in depression and loneliness:

*"I've already had vision problems. And after the stroke I'm down to 30 percent. That's all I could see [...]. I just feel depressed and lonely. [...] So I got a lot of injuries. I've been dealing with a lot of pain for quite a while now. My back problems right now is my biggest problem. But at first the diabetes was just another add on to my other problems [...] I can't walk to*

*good... Right now I've had the stroke that's even worse [...] very depressing... at times a lot of things I used to be to do, I can't do anymore.*

As participants were forced to deal with both physiological and psychological impact that complex diabetes produce, they found themselves alone with little social support. The combination of having multiple health restraints and not being able to contribute in everyday life appeared to be a challenge both Roy and Billy Bob faced. In addition to enduring financial hardships, and being confronted by life threatening health conditions, both Roy and Billy Bob also experienced decreased quality in life and psychosocial issues. For example, like Roy who is depends on a scooter to get around, Billy Bob is confined to a wheel chair, which disables both Roy and Billy Bob from getting exercise. Furthermore, other health complications may tamper efforts to improve current health.

### **5.3.2 Theme 3: Social circumstances affect health capability**

All participants in this study were currently experiencing or had encountered some form of social adversity, this ranged from family issues to employment concerns. In addition to meeting the demands of complex diabetes management, participants often found themselves trying to balance the demands of the personal and social aspects of their lives. This included caring for other ill family members, to dealing with loss in various ways. In this section social circumstances that participants encountered and how these circumstances may have impacted participants' diabetes or diabetes management is discussed.

#### **5.3.2.1 Sub-theme 1: Family stress – a caregiver living with diabetes**

Many individuals in this study were not only dealing with their personal health conditions, but were responsible for managing the health conditions of others in their social sphere. With competing demands, and family expectations, little time is left for individuals to attend to their own physical needs. These demands not only places restraints on a person living with diabetes, but can sometimes inhibit diabetes self-management practices. This was illustrated in Bob's story. As mentioned before, Bob was employed by a motor company. After

working over thirty-five years he was able to retire and receive a benefit package which included medical coverage. As such, Bob had some financial security to help manage complex diabetes, yet the competing demands of his social life present challenges in managing complex diabetes. Presently, Bob is the primary care giver to his wife, daughter, and grandson. With a special needs daughter and grandson, Bob is also responsible for caring for his wife, who is also experiencing various health complications. Due to his wife's health complications, Bob's wife has limited mobility and is restricted in helping with family responsibilities and duties. Bob goes on to describe his situation by saying:

*We've got a girl ... [with] MS ... [she doesn't have a] bright future ahead of her ... [My grandson] he [is] special needs to, and needs quite a bit of extra [work] ... Like right now my wife goes to the nurse twice a day and gets a bandage put on her stomach ... so, I have to take her to the nurse at 9 am and 6pm at night. The 6 pm at night is right in the time range, so I have to fluctuate a little bit on that one ... But [I am] still taking [my] dose when [I] eat now.*

As a consequence to his current social circumstance, Bob's ability to manage his diabetes "fluctuates" and sometimes take a back seat due to competing priorities. Furthermore, because of Bob's present family situation, he is unable to take his medication doses on time, or properly adhere to prescribed diabetes self-management regimens. Like many individuals with complex diabetes, Bob must juggle the demands of everyday life with his own self-care. Without proper support, these demands can sometimes compromise management efforts, which may lead to worsening health conditions and poor health outcomes.

#### 5.3.2.2 Sub-theme 2: Family stress – violence within the homes

Two female participants in this study revealed that they had experienced violence within their lifetime. This ranged from verbal, emotional, and physical abuse, and often took place within the family/ home setting. Violence experienced within a family/ home setting, may have a great impact in a person's socialization experience and overall mental health. Dealing with such issues may sometimes be

a greater and more stringent task, depleting much needed time, energy, and resources complex diabetes management requires. As a result, diabetes management is compromised and may result in uncontrolled health outcomes.

Elucidating this, Joan a mother to four daughters, now lives with a disability after surviving a severe car accident. Suffering with debilitating injuries (e.g. fibromyalgia) Joan was forced to quit her job and become a staying at home mom. During her marriage Joan recalls of encountering several forms of abuse from her ex-husband.

Joan describe the most devastating periods in her life as including when her husband left her and the children with no money and the death of her beloved father. These life altering events had a severe impact on Joan's physical and mental health. After her divorce, Joan was later diagnosed with diabetes and various forms of mental health issues. Joan discloses her experience with violence and her husband leaving her by stating:

*"I started to cry and do the panic thing ... [I'm] not going to get hit anymore, [I'm] not going to be called names anymore ... [He'd] yell at me, throws stuff at me, I duck when he goes to hit me... So now I have fibromyalgia ... [and] osteoarthritis...I have diabetes which is totally out of control ... but I have a lot of stresses, I have law suits coming out ... You know so the stresses are there and you know, it's just what they are."*

Joan's story depicts challenges a person encounters when struggling to manage complex diabetes in addition to coping with the aftermath of abuse, divorce, and various forms of stress. As Joan attempts to deal with the many family social issues in her life, diabetes management no longer takes preference in personal priorities. This can be especially true for people who take on the roles of primary caregiver and breadwinner in the family setting.

Joan's life experience, also exemplifies how a lack of social and economic resources can lower a person's life chances, followed by decreased health capabilities and worsening health conditions. For example, Joan revealed that before her father's death, he was her support mechanism, while she was going through her divorce. Now with her father not alive, Joan is faced with limited

economic and social support, and continues to encounter worsening health conditions, despite CCDC intervention. With limited resources, and lowered health capabilities, Joan ability to improve her health conditions appears to be hampered by her psychosocial reality. As a result, Joan continues to experience clustering of multiple health conditions in addition to diabetes and fibromyalgia, such as osteoarthritis, and various mental health issues.

#### 5.3.2.3 Sub-theme 3: Loss and isolation – Job loss

Managing diabetes along other life priorities was sometimes overwhelming for participants living with complex diabetes. Seven out of eleven participants reported experiencing some form of work-related stress. Work-related stress had both a direct and indirect impact on participant's ability to manage diabetes and quality of life. In some cases, one participants lost her job due to the demands of caring for family members, while another was forced to retire prematurely due the restraints her illness experience had created.

Like Jill, all participants in this study have experienced the adverse side effects that are associated with health complications. Jill who experienced a domino of health issues after her divorce was choose to retire early. As she began to encounter a plethora of health issues including Bell's Palsy and diabetes, Jill often found herself with less energy and motivation to complete day to day tasks. Jill goes on to expand "*I ended up with some health issues... like I just ... didn't have the energy to do things the way I use to do them. So uhmm... yah I decided to retire.*"

#### 5.3.2.4 Sub-theme 4: Loss and isolation – death of significant other

The emotional despair loss brings can be a life altering experience. Loss of a loved one not only interrupts the social norms and context in which an individual lives, but requires a change in the perception of meaningfulness in a person's life. All participants in this study have encountered the death of a family member or significant other. The death of a loved one can represent for most people the passing of a life and the end of a relationship or support mechanism.

One participant who was left devastated by the passing of his wife was Mac. Mac, an Irish immigrant came to Canada and toiled alongside his wife to make a life for his family. Once the owner of a prominent contracting company, Mac now resides with his daughter. After losing his wife to colorectal cancer, Mac was shattered, for his life partner was no longer with him. Mac goes onto to explain the depth of his grief by exclaiming *“the biggest stress I’ve have in my life so far, was the death of my wife. She passed away 5 years ago from colorectal cancer and it was devastating for me.”*

The realization that a significant other is no longer present for additional counsel and social support can be detrimental to a person’s overall well-being. In addition to managing the demands of diabetes, Mac was left to cope and grieve the death of his wife with little support.

#### 5.3.2.5 Sub-theme 5: Loss and isolation – divorce

Two out of eleven participants had experienced divorce which constitute a significant change in their life and family dynamic. For two participants divorce was not only perceived to be a loss of family ties and partnership, but was seen as a forced that propelled the onset of health complications. As mentioned prior, Jill and Joan had both experienced divorce. As the social context in which the lived drastically changed, both Jill and Joan were forced to live on their own without the support of a partner. When their husbands left the family both participants described experiencing a loss of security as well as support, and found themselves isolated.

Both women described themselves as dependant on their husbands, for in their family the husband was the sole breadwinner and provider. Joan’s husband left taking all financial assets, leaving Joan and her girls with nowhere to go. Joan describes her experiences as:

*“No warning, but he’d been planning it, his whole family helped him moved everything. So I felt very alone, very distraught, very betrayed. I didn’t know what had happened...I went home with my kids and it was empty and I said we’re not staying here we got to go get something to eat.”*



*Let's got to the bank and get some money. Nothing there and [on] every card....There was no reason for any of this to go down."*

Joan's traumatic experience of betrayal, loss of security and financial support was one of the many stresses she was working through. After her husband abandoned their family, Joan was left to care for her daughters, attending to their needs while not having the time and space to cope with her new reality. Such new demands leave little time for Joan to manage complex diabetes. As a consequence, Joan expressed earlier that her diabetes is out of control due to the various stresses she faces day to day.

With divorce comes the change in social relationships among friends and family, which can sometimes result in isolation. Jill who currently lives alone, reflected on the partnership with her husband she had envisioned after retirement. After Jill's husband walked out, this dream quickly dissipated, and she now finds herself alone, surrounded by friends living her dream:

*"Isolation sometimes ... I mean the other day ... I hadn't talked to a soul. Like I hadn't opened my mouth and talked. I sounded like a frog came out when I did... I have a good source of friends. And as I said they're all still married ... it's different when you're a single. I find I'm not as included in some things as I used to be.*

Divorce not only severed a partnership for Jill, but a change in her community in terms of her friend's attitudes and inclusiveness. As a result of Jill's new status, she is left with limited sources of social support. A lack of social support/ resources may impact Jill's ability to manage complex diabetes. This is because she no longer has a partner to help support her in the demands of diabetes management (e.g. meal preps, and adherence to medication).

### **5.3.3 Theme 4: Financial insecurity depletes health capabilities**

#### **5.3.3.1 Sub-theme 1: Limited access to economic resources**

Financial insecurity was a common theme among six participants. In addition to facing financial hardship as a child, some were also encountering

financial insecurity during adulthood. Due to socioeconomic realities, many people in this study expressed their struggle in attaining necessities such as healthy food, rent, parking, and diabetes management related medication or equipment (e.g. needles, testing strips, and specific medication). The burden of financial inequality is further elucidated by data collected from sociodemographic surveys administered in this study. As discussed in section 4.8, five out of eleven participants had a current household income less than \$34,999 annually and three had a current household income of less than \$50,000 annually.

Exemplifying this finding, is 37 year old Mickey, who became the major financial support for her family. At the age of 17 years old, Mickey became the primary care giver to her mother and at a later age to her father. As an adult, Mickey lost her hearing and subsequently her job. After her father was placed in long-term care, Mickey was homeless with limited resources. Currently, Mickey shares an apartment with her ill father. Though she has a place to live, her socioeconomic status has not changed. This is because Mickey's access to care and resources remains very limited because of a lack of employment opportunities. With restricted financial resources, Mickey exclaims "*the money is just not there.*" She also goes on to express how her lack of resources hinders her ability to adhere to diabetes dietary recommendations: "*it's a lot of pasta, which isn't the best. It's grilled cheese, its cheap meals, but which is then not good either, because you are not getting the protein, vegetables, the grains, the fruits, veg, like you're not getting a balanced meal. But the money is just not there.*"

Like Mickey, Victoria also struggles with adhering to diabetes dietary recommendations. Coming from a typical British family, Victoria exclaims "*you know what my eating patterns have never been good. I come from this typical British background, where its meat and potatoes and custard, cream cakes, and doughnuts ... And I didn't instill good eating habits in my kids either... I think because of my own upbringing, and partly because of a lack of money ... We didn't eat pasta ...but meat, potatoes, not a lot a fresh vegetables, or even fruit.*" Aware of the culture influence her background has had on her diet, Victoria also expresses how such eating habits was also instilled in her children, which in her

case may have triggered the onset of diabetes. Much of Victoria's earlier financial hardships was due to being a single parent to two boys, and not receiving social support from her family or the social system. Currently, she lives on a small old age security pension. Although Victoria is conscious of the types of food she should consume, due to economic restraints she is forced to forgo healthy options and purchase as she stated: *"the cheapest food, the most food for the dollar. [...] Because the foods that are good for you, are really expensive. Like I'll go in the store today, and I'm not paying \$3 for a broccoli or \$5 for a cauliflower... I have a small pension and government old age. So, there was economic issues, and I guess my background how I was brought up in terms of what I eat. And that's still a battle for me.....it's very hard."*

Adhering to prescribed dietary guidelines is an essential cornerstone in diabetes management. However, without access to economic resources and unchanging socioeconomic situations, many participants continue dietary practices known to aid the onset of diabetes. These habits forged over time and sustained by economic realities may also result in further health complications and an overall decrease in quality of life. Moreover, the lack of economic resources due to structural inequality have aided in nurturing unhealthy eating habits and behavioural patterns. The lack of resources after being diagnosed with diabetes acts as a stumbling block for many lower socioeconomic patients, as they are reminded of their inability to attain optimal health partially due to socioeconomic realities.

Mickey and Victoria's life experiences illustrates the intertwine working of health capabilities concepts and the syndemics approach. For example, both Mickey and Victoria's ability to acquire much needed resources appears to be hampered, because of ill health and a lack of economic resources that appears to be linked to structural inequality. With limited economic resources, Victoria goes on to shed light on the reality many low-income patients with complex diabetes face, as they are forced to choose between funneling limited resources towards healthy food and other necessities.

#### 5.3.3.2 Sub-theme 2: Access to economic resources

Compared to the six participants who were facing financial insecurity, five participants in this study were able to afford the demands of diabetes such as medication and food. Having the financial ability to provide the necessities complex diabetes demands was associated with financial gains from prior or current professions, divorce settlements /investments, and family inheritance. Due to their financial security, these participants were able to focus on improving their health condition. Conversely, both groups of participants (with resources and those without resources) seem to be encountering a lack of support in regards to diabetes, both social and within the healthcare system.

As mentioned prior, Jill suffered from various health conditions after her divorce. Due to the change in her family, Jill was able to receive additional funds, which she currently lives off. This financial security, not only supplies Jill with access to resources but helps her manage complex diabetes: *... I got half of [my ex-husband's] pension, and I was able to put it into investments. And [I am] able to have a decent life, and I'm not talking about frivolous things you know. Ummm just so there is enough there for rent, food, and ummm but I wouldn't say I'm destitute. ...I'm actually going to the cardio, ummm cardiovascular clinic across the street in the abilities centre. Yah and that's free through OHIP.*

Like Jill, Bob also illustrate how financial security may help in improving overall health, coupled with diabetes management coaching and support. As discussed previously, Bob worked over thirty-five years at a motor company. During his time at the motor company Bob explains: *"I always had a fairly new car [...] we've always had lots to eat, lots to do, and never really was on the poor side at any time. [...] No I'd say we lived quite comfortably.* After retiring Bob was able to receive health coverage from his former employer. Bob goes onto state that *"everything is covered by Green Shield. The only is you pay for the first three order of needles or something. [...] so there's no real problem in getting the medication. The drug plan covers the drugs."*

Despite having financially security and ability to improve physical health, these five participants are not immune to the difficulties associated in managing

multiple ailments. In fact, all eleven participants in this study articulated that they experienced a lack of support both socially and within the healthcare system.

### **5.4 Questions 3: What are the perceived challenges, persons with complex diabetes encounter throughout their lifetime when interacting with the healthcare system?**

#### **5.4.1 Theme 5: Challenges in accessing healthcare**

##### **5.4.1.1 Sub-theme 1: Medication and out-of-pocket-costs**

Individuals without access to private health insurance from employment must cover the cost for healthcare services that are not funded by the healthcare system in Ontario. Limited access to much needed health services comes as a result of a shrinking healthcare plan offered by the province. This not only adversely impacts the economy of families, but adds to exasperating current health disparities experienced by persons living with diabetes. Due to a lack of funding and limited resources Jill, Joan, and Victoria all described the difficult decision involving either paying for their medications or for necessities, such as food.

After her husband left, Jill was able to receive a divorce settlement which enabled her to make investments. Currently living off these investments, Jill described the difficulty in obtaining medication. She stated: *“no health insurance... a few of my doctors that I had gone to would try and get me some medication without going through the pharmacy.... [I take] like 20 drugs ... and some of them are like \$50 or \$70 ... [And] well people who are low income find it very hard to be able to get their drugs you know.*

Similar to Jill, Joan describes the struggle in attaining diabetes medication with no subsidization for individuals of a lower SES. As mentioned prior, Joan's husband left her after years of emotional and physical abuse, and she now lives on disability insurance and cares for her daughters. Joan declares *“I have zero benefits right now. I can't go to the dentist [because] I have no money to pay for... My medication. If wasn't for the [CCDC], I wouldn't have insulin .... Test strips for \$100 for 100 of them. I don't have \$100 to throw out test strips. I mean*

*if I had to choose between a box of test strips for \$100 and feeding myself for the week, I'd eat ... [The CCDC] been giving me needles here to, so I have enough of them. But before I had this place ... I wouldn't take the needle of...just take some alcohol and use it again.*

As Joan's experience illustrates, limited resources are funnelled to where they are needed most. This hinder diabetes management and hampers quality of life as diabetes distress is increased while patients are forced to choose between following healthcare providers' recommendations and buying the necessities for living. This reality low income patient's face becomes a vicious cycle that prohibits persons with diabetes from improving their overall health. Furthermore, Joan revealed that prior to receiving care at the CCDC, she would re-use needles, due to limited financial funds. The lack of support from the healthcare system for individuals of lower SES, forces patients to reuse equipment, exposing them to increased chances of infection and dwindling health outcomes. Furthermore, despite some patients with diabetes have access to the Provincial Health plan, not all drugs used to treat diabetes is covered. This was revealed through Victoria's story when she expressed that: *"I take victoza...isn't covered under Canada health plan at all. So I'm having a really hard time with that."*

#### 5.4.1.2 Sub-theme 2: Care for persons with disabilities

Patients with disabilities can sometimes find it extremely difficult to navigate the healthcare system, especially when much needed care is out of reach. Out of eleven participants, Mickey who lives on disability and with her elderly father, was the only participant with a hearing impairment. Mickey stated that she communicated with health professionals by reading their lips. However, when it came to accessing much needed help and care, it was a serious battle. Due to most healthcare professionals not being equipped or trained to care for individuals who are hearing impaired, Mickey found herself being tossed from various corners of the social system, including the healthcare field. Mickey explained that: *"I don't have a lot use for social workers, because they normally [go by the] text book ... personally, they've never had to deal with it [a hearing impaired person]. Or*

*they've never had a client dealing with it, so they don't have [a] clue .... I'm the behind the closed door forgotten person. Like they don't even know I exist type of thing. I [am] yelling, and screaming and pounding on the door, and kicking, and screaming my head off, and I'm in a sound proof room with the door locked and they don't even know I exist... I'm struggling like I said, I'm frustrated."*

Mickey, who did not fit the typical patient profile, faced many challenges in accessing appropriate and timely care, while health conditions continued to worsen. As mentioned before, Mickey currently lives with limited financial security, has limited economic resources, and tend to the care of her sick father. As social circumstance intertwined with issues encountered in the healthcare system, attaining care and support for diabetes management has becoming overwhelming. As a consequence of Mickey's present realities, diabetes management is no longer a priority as attaining care has become a struggle.

#### 5.4.1.3 Sub-theme 3: Healthcare professionals and attitudes

Access to healthcare professionals have been a challenge for many participants, especially when related to diabetes management. In addition to long wait times to see a healthcare professional, two participants voiced that a substitute needs to be in place when healthcare professionals are away. The absence of a substitute not only severs participants' access to care, but jeopardizes their health, especially in light of managing other complex health conditions. Furthermore, a vast number of Ontarians do not have access to a family doctor, this was also true for two participants who was seeking a doctor near to their place of residence before attending the CCDC.

Even with viable access to economic resources, Gracie currently struggles to receive social support and patient centered care. Shedding light on her frustration with the healthcare system, Gracie states: *"Oh go see your family doctor; well I'm sorry my family doctor is on a month's vacation what am I supposed to do ... They can't see, like everybody is individualist with diabetes, people want to be able to cope with it in their own fashion."*

When patients are not able to access care, this may impede diabetes management efforts, resulting in poor health outcomes. Furthermore, inaccessibility to healthcare professionals becomes barriers in improving complex diabetes condition. More importantly, health professional's attitudes and mannerisms can have a deep impression on patients, especially when it comes to diabetes self-management. Although patients view health professionals as a source of knowledge and support, if support is not present there is a breakdown in communication.

A health professional's perceptions and beliefs can sometimes inhibit and discourage positive diabetes self-management behaviour. PV a former pastor who lives with his wife and is a professor at a seminary school, spoke of his experience with a healthcare professional after being diagnosed with diabetes. PV also experiences other health complications including angina issues, and tendon problems in his ankles and knees. At the moment, PV has increased financial security due to his wife's career, but worries about affording medication and supplies when his wife retires. While tending to his angina complication, PV was diagnosed with diabetes. Recounting his experience with his doctor after being diagnosed, PV stated he was left with a sense of hopelessness and despair. This is because PV's doctor depicted diabetes as a negative experience and downward spiral of health problems. As a result, PV's perception was greatly influenced by his doctor's negative attitude towards diabetes. PV now fears what diabetes means to his life and the inevitability of worsening health conditions as these negative outcomes were confirmed by his physician. PV said: *"I was concerned about the angina, because my mum had died of a heart attack ... I think ...my concern about diabetes was more ... like it was kind of ah ... downward spiral. The doctor I had there was quite negative about it. And uhmm pessimistic about it ... But like he said you know this is where you are starting and this is where you're gonna end up. Just sort of the worst case scenario."*

PV's experience demonstrates the impact healthcare provider perceptions have on how patients view their own disease, potential, quality of life, and treatment. In fact, a healthcare provider's perception not only sets the foundation



on how an individual's views their disease, but also the potential a person possess in improve their condition.

#### 5.4.1.4 Sub-theme 4: The CCDC experience

The CCDC has been a pivotal landmark site in coaching and empowering patients with complex diabetes in the Durham Region. Overall, all participants expressed their deep gratitude for the help they have been receiving at the CCDC, and the ongoing collaboration between their doctors and CCDC staff. Participants mentioned that one of the highlights of receiving care from the CCDC, is increased access to various health providers. This included receiving care from a nurse practitioner, pharmacist, dietitian, nurse, and social worker. Being able to access support and active communication from the CCDC not only empowered the participants, but enabled them to thrive in self-managing their complex diabetes. By listing the benefits in attending the CCDC, participants described their experiences and also expressed various issues they felt could be improved to better patient healthcare delivery. These issues included: professional development and training, and increased hours of services, and are discussed below.

##### 5.4.1.4.1 The CCDC experience: Professional development

As previously stated, the present healthcare system neglects to assist individuals with certain disabilities in accessing care. This gap in the healthcare system is also reflected in the level and quality of care that is being offered at the CCDC. For example, although the CCDC enabled Mickey who has a hearing impairment, to access other social services, many staff members have not been trained or equipped in caring for patients with a hearing impairment. As a result, Mickey continues to encounter difficulties in communicating with staff members, impacting the care she receives. Furthermore, Mickey stated: *“the [CCDC] helped me as far as part of it is hearing. Not being able to communicate with the people that I need to, is the most frustrating part...and actually the nurse here [at the CCDC], the social worker here, they’re learning how to deal with me, because*

*they've never run into this situation ... So they are bring me back more often, because they can't pick up the phone and do an over the phone interview type of thing... I'm might be coming back every 2 to 3 weeks so that they can check up with me. But in the resource of coming here, the gas money to get here."*

The quality of care received may differ based on patient's disability and life situation, which impact diabetes management. Clearly, the staff at CCDC are attempting to accommodate Mickey, however, this necessitate more visits to the clinic by Mickey. Moreover, the marginalization Mickey currently experiences coming from a lower SES, intensifies by attempting to receive care. Patients, such as Mickey, lack the financial resources to visit the health clinics like the CCDC more frequently. As a result, these patients are forced to deplete monetary funds in order to comply with recommended reoccurring visits to clinics.

#### 5.4.1.4.2 The CCDC experience: Increased hours of service

Currently, the CCDC program requires a referral from a primary healthcare provider. However, the CCDC is temporary and only accessible on certain days and hours of the week. One participant stated that the hours of operation at the CCDC can sometimes be inaccessible or inconvenient, especially for individuals who work or have competing priorities. Moreover, inaccessible hours of operation places a strain of low incomes patients, who are forced to take time of work, placing further financial burden on the family household income. As previously described, Gracie who wealthy and manages irritable bowel syndrome in addition to diabetes, stated: "*... okay the CCDC they're great ... like everybody here [at the CCDC] they help you deal with what's going on. [They've got] diabetic workshops, like all those little things they have – well they should have a diabetes centre. .... [They've] got something in the Lakeridge Health Centre [the CCDC] that runs 2-4 every Wednesday. Sometimes people are working, sometimes you have a question and you just need to just pick up a phone and talk to somebody. They don't have anything like that...."*

Even though participants view the CCDC as a life line in terms of diabetes management, Gracie highlights that more needs to be done. This is especially true

when it comes to increasing patient access to care. Increased patient hours and time of contact may be needed in managing complex diabetes due to a person juggling multiple ailments, and is vital in improving overall health and quality of life. Moreover, increased access is needed to patients with complex diabetes who require unique and often quite substantial care and follow-up to manage their disease and associated conditions.

#### 5.4.1.4.3 The CCDC experience: Education and information

Information regarding diabetes prevention and management is vital, especially for people at increased risk. All participants expressed confusion in regards to understanding what their diabetes diagnosis entailed and how they should comply with dietary demands. Participants also stated that information distributed by healthcare professionals can sometimes be inconsistent, resulting in misunderstanding and low compliance with management recommendations. This is evident especially when it comes to certain foods that person with diabetes should abstain from.

Gracie related earlier her belief that diabetes care needs to be tailored to the individual, and consistent across various healthcare providers. In her experience, this was evident while attending diabetes management workshops. Often times the information dispersed via workshops and received at the CCDC left Gracie highly perplexed. For example, she exclaimed: *“[When] I came there [diabetes workshop] they said well you can’t [have] bacon and eggs. I come to the CCDC oh you can have bacon and eggs, that’s good, that’s a good meal for yah.....It is conflicting information.”*

Conflicting information can become an obstacle for persons with complex diabetes, deterring efforts to implement effective eating habits, and may lead to frustration and poor recommendation compliance. Although diabetes education and workshops are a vital part of the Ontario Diabetes Strategy, consistent information needs to be dispersed, to insure preventative interventions are effective.

In opposition to Gracie's experience, Victoria valued her diabetes education and strongly believed that diabetes education needs to occur sooner than later. As mentioned earlier, Victoria currently struggles to adhere to dietary recommendation due to economic restraints and cultural eating patterns. Victoria stated: *"... My only thing I wish it had been available to me earlier. That's the only thing, at the time I was diagnosed, all that was offered to me was the workshops, which I was grateful for and I took, because they gave me a much better understanding of what I was trying to cope with. So yah the only thing I would say is that intervention needs to happen right away. If we want to prevent or be proactive about diabetes, then that, that intervention needs to happen when you are diagnosed."*

Although the information regarding diabetes is slowly being distributed, all participants strongly believe that interventions such as the CCDC needs to happen sooner. Unlike many other diabetes clinics, the CCDC attempts to individualize care and coach patients in self-managing diabetes. Participants in this study viewed this type of intervention as vital in preventing the development of diabetes complications and deteriorating health conditions.

## **5.5 Narrative Composites: a compilation of participants experience**

This study utilized the compilation of narrative composites, which are fictional accounts derived from participant's life experiences. The following composites are examples of collective participants' stores. This was done to convey and express the many realities people living with complex diabetes encounter on a day-to-day basis, and barriers that currently exist in accessing healthcare (Wertz, Nosek, McNiesh, & Marlow, 2011).

### **5.5.1 Zara's story: composite**

I grew up in a small town, forty-five minutes outside of Toronto. I can say I definitely had a normal childhood, both parents working, playing outside with my sibling till the street lights were turned off. Happy times. When I was twenty-five I got married to my high school sweetheart. A few years later we had two daughters. During my time at home, I tried to finish my education and got my certification in Business Management. I was able to secure an entry level position in administration, but given my family responsibilities, I only was able to manage part-time work outside the home through most of my life.

In my marriage there were ups and downs like any marriage. One day I woke up and my ex-husband decided he wanted to leave us. For no reason it seemed he was just leaving. I was now alone, by myself, with the responsibility of raising two girls. I'd never been alone before I was married, you see I was living with my parents. I was never really on my own. But there I was in my late thirties, on my own, no one around to help. Sure my parents pitched in and did what they could. But when your younger one keeps on asking, "Mummy where is Daddy," what do I say? It's hard you know, you see all of your friends with their families, what you once dreamt of having is taken away from you. Now I'm forced to play both mother and father. In addition to the change, with limited income, it was struggle. Struggling to keep the lights on, to put food on the table, the stress of it all really took a toll on me. I was alone and depressed, but had to put all of that aside for the sake of my children.

A year later, an old knee injury started acting up, I was also feeling stiffness at the back of my neck and getting frequent headaches that weren't going away. So I decided to check in with my family doctor. Upon discovery I had high blood pressure, which was followed with the diagnosis of diabetes. My dad had diabetes, so I wasn't surprised. You know, they do all this talking about not being overweight, and stuff, but if it's in your blood, it's only a matter of time till you get it. But I also think, the personal stress of what I was going through, my body just hit ground zero. I had no support, especially with the finances. So a lot of times it was cheap quick-to-prepare meals, a lot of pasta, grilled cheese, you know you're not getting all the nutrients you need. But what can you do?

The more I think about it, my diabetes spiralling out of control was also due to my own ignorance of what diabetes was, and how I was supposed to manage it. Now I've got hypertension, dyslipidemia, and I'm a big person, but I've always been on the thicker side. I think for everyone it's only a matter of time until you're on the pills, so dietary control is basically out the window. When I was diagnosed with diabetes, you're pushed to attend these classes where they are throwing information at you. There's just no personalized care. Some of the information conflicts with the stuff they are recommending at the Diabetes Clinic, which just leads to more frustration.

When it comes to getting medication it's a struggle. I mean I have two mouths to feed at home, I'm the sole provider. And everywhere you go, its pay for parking. And it's not like I need one pill, its many pills to control all the stuff I'm dealing with. My doctor usually tries and gets me samples. Or I come here and they try to help me. But if I have to choose between caring for my family and buy meds, I'd make sure my family is fed with the lights on.

### **5.5.2 Zara's story: analysis**

Three out of five female participants consisted of mothers in this study. Zara's story was formulated in efforts to convey and portray the social and caring giving responsibilities women carry in their social spheres, in addition to managing complex diabetes. All female participants in this study was charged in

one form or another in fulfilling family roles, whether this be care of children or aging parents with health issues. Many also experienced a lack of social support networks. As a result, these participants neglected their own well-being and health, in order to comply with the demands of their social surroundings and circumstances. As a consequence, health complications such as complex diabetes developed due to a lack of social support, economic resources, and lifestyle habits.

For example, after Zara's husband left, she neglected her own needs and sense of well-being in order to care for her children. Now a single parent, Zara was now the primary bread winner, where the well-being of her family was priority. Zara's divorce not only signified a loss of social support, and partnership, but financial security.

As discussed earlier, another common theme among participants, was the lack of financial security and time its association to accessing necessities such as food, shelter, and medication. For example, being single parent like Zara, can be very time-consuming, especially when there is little additional support. This means having time to exercise, preparing meals, going to appointments can become very difficult.

Likewise, low income persons living with diabetes are often caught in a vicious cycle where they are forced to choose between survival and improving their health. The struggle to attain medication and comply with prescribed recommendation becomes exacerbated when diabetes care is not centered on the needs of the individual and their current access to resources, and inconsistent diabetes information.

### **5.5.3 Darrell's story: composite**

I grew up on farm. There was seven of us kids, and we were responsible for helping out every day after school. My dad worked for a company, my mom stayed at home running the house. I'd say my childhood was normal. Didn't have much time to do school work because you'd be doing farm work from the time you came home until you went to bed. I got married when I was twenty-three, and had two boys, one with special needs. I was working in the electrical business for

a while and got laid off. I decided to open my own company, and was quite successful.

We were blessed enough to always have, never lacked anything. We've got a house paid off for. Ten years ago, I was getting some angina problems. After dragging myself around, I decided to retire. My mother also had some heart problems and died from it, which hit me like a rock. The diabetes happened following the angina. I've had a by-pass, but was never worried about it. I knew it just had to be done. Diabetes runs in my family. My grandfather had it and so did my dad. In fact four of my brothers got it to, and the other three siblings their doctors got them testing for it because of the family history.

My wife is currently sick with many health problems and uses a wheel chair, so it's quite difficult getting her around. She's got some surgeries coming up. So I frequently have to take her back and forth from the doctors every week. Our son is also in a special needs residential home, so we try and visit him often. At the age of 65 you realize your body is quite limited in what it can do. My other son had taken over the business due to my health, so he's got his hands full. But it can be challenging, I have to rearrange my insulin dose schedule. I try and take it at night, but I also have to take my wife to the clinic. So I just do the best I can. When it comes to affording medication or supplies, we are pretty good on the financial side. But it's safe to say, I've got my hands pretty full now. I was referred to the diabetes clinic by my specialist to help me get my blood sugar under control, currently it is all over the place.

#### **5.5.4 Darrell's story: analysis**

Social responsibilities and demands often influences diabetes self-management. Darrell's story is a reflection and collective portrayal of participants who are caregivers living with complex diabetes. As depicted in Zara's story, family responsibilities often rank priority over personal well-being and taking care of one's health condition. Darrell who is a senior living with complex diabetes, must manage his wife's health complications in addition to his own, and tend to his special needs son. As a result Darrell's insulin doses are inconsistent.



Darrell's inability to adhere to diabetes management guidelines is a consequence of juggling various responsibilities with little support. Although financially secure, Darrell lacks the social support and guidance, which can have a negative impact on his health and quality of life.

Mirroring the experience of participants in this study, Darrell's story depicts the social attributes that influence management of complex diabetes. Moreover, though financial security places treatment and medication within a person's reach, diabetes self-management efforts may still be inhibited due to a lack of social support, and coaching. Competing priorities often place restraints on diabetes management, causing diabetes management efforts to be nullified and ineffective, as personal family needs coincide with demands of one's health. As mentioned prior, perceived diabetes to be affiliated to family history attributes. Subsequently, this perception may influence implementation of preventative measures, and as a result may lead to the onset of complex diabetes.

#### **5.5.5 Todd's story: composite**

I grew up in Calgary, I didn't grow up in the most affluent neighborhood, just average middleclass folks, but we always had enough through the generosity of people. Shortly, my family moved to Ontario, and I attended university and got my certificate in construction, got married, had a kid. I was excited to be in the field that I was in, but I found myself not being able to find work.

Sometimes weeks would go by and the phone wouldn't ring. Finding work was hard, which had a direct impact on the household economics. If worse came to worse, we could always call some friends up and they'd have us over for dinner. After my divorce, I remarried, and my wife currently helps me manage my health conditions. We've got a daughter.

A few years back, I had a work accident, which left me on disability, but currently my health condition is declining, so I try and stay positive and spend enough time with my family. The stress of it all is really taking a toll on my wife, there seems to be no support from the system for her.

I've had diabetes for over twenty years now. I've got high blood pressure, dyslipidemia, and some kidney problems. It's just one thing after another. No one in my family had diabetes, so it was a shock, but I think its years of poor eating, and not exercising. Maybe some of these problems could have been prevented, if the follow up they have now, was implemented back then. But nothing is for certain.

Over the years, my wife and I developed a frugal lifestyle, but finances are still a struggle. Being seventy-four years old and not being able to work and help the household is hard. So all it rests on the shoulders of my wife, so financially we're not doing so well. The diabetes with all the other health issues leave me with a lot of side effects, it's sometimes very depressing. I'm in a lot of pain and on a lot of medication, so I just try and sleep it off.

#### **5.5.6 Todd's story: analysis**

Like three participants in this study, Todd did not have the most affluent upbringing. Unlike Todd, one participant in this study revealed that due to hard times he was force to drop out of school. This resulted in limited career options, and many years of economic hardship.

Moreover, Todd's story goes onto disclose his perception that a lifetime of insecure and unstable work, lead to financial problems. Todd also underwent personal turmoil through the breakdown of his marriage, and work injuries, which render him physically disabled and unable to work. The by-product of insufficient social and economic resources can lower a person's health capabilities to improve health conditions. This is elucidated as Todd is no longer to work, which directly impacts his household income, and his ability to institute measures for improving his health.

As a consequence of complex diabetes and its side effects, two participants were unable to care for themselves and depended on their partner. This is portrayed in Todd's experience to convey the various social and physical changes that may occur when living with complex diabetes. This often include various side effects from the interaction of multiple medication and living with the disease

itself. Furthermore, undergoing this transition restricts a person from fulfilling family roles, and thus transfers responsibilities to Todd's wife.

In addition to experiencing various side effects, one side effect mentioned by a participant was depression. With stringent social and financial resources, health conditions may be depleting influencing a person's perspective on their health. Analogous to Todd's perspective, participants in this study also expressed that complex diabetes rendered feelings of confinement, restriction, frustration and was another add to their other health conditions.

## **5.6 Summary**

In conclusion, this chapter explored five overarching themes from semi-structured interviews (figure 8), in which participants living with complex diabetes reflected and expressed as they recounted various difficulties and challenges they encountered throughout their lifetime. In addition to economic restraints and deteriorating health conditions, participants also disclosed various social circumstances thought to have influenced the onset and course of health complications. This included social factors such as: family stress (e.g. being a caregiver and having diabetes), lifestyle choices, and dealing with various forms of loss (e.g. divorce, death, and job loss).

Furthermore, when discussing issues of accessing care within the healthcare system and barriers prohibiting positive diabetes management, the overall consensus among participants was the inaccessibility to quality care when it was needed the most (e.g. access to healthcare professionals) and out-of-pocket costs for diabetes medication and equipment. Participants also spoke very positively about the support, care, and access to various health professional at the CCDC. However, some participants expressed that in order to ensure optimal diabetes care is being delivered, improvements can be made. These improvements at the CCDC include: having more accessible operational hours, and increased professional training and development for providing care for individuals with disabilities such as persons with hearing impairment.

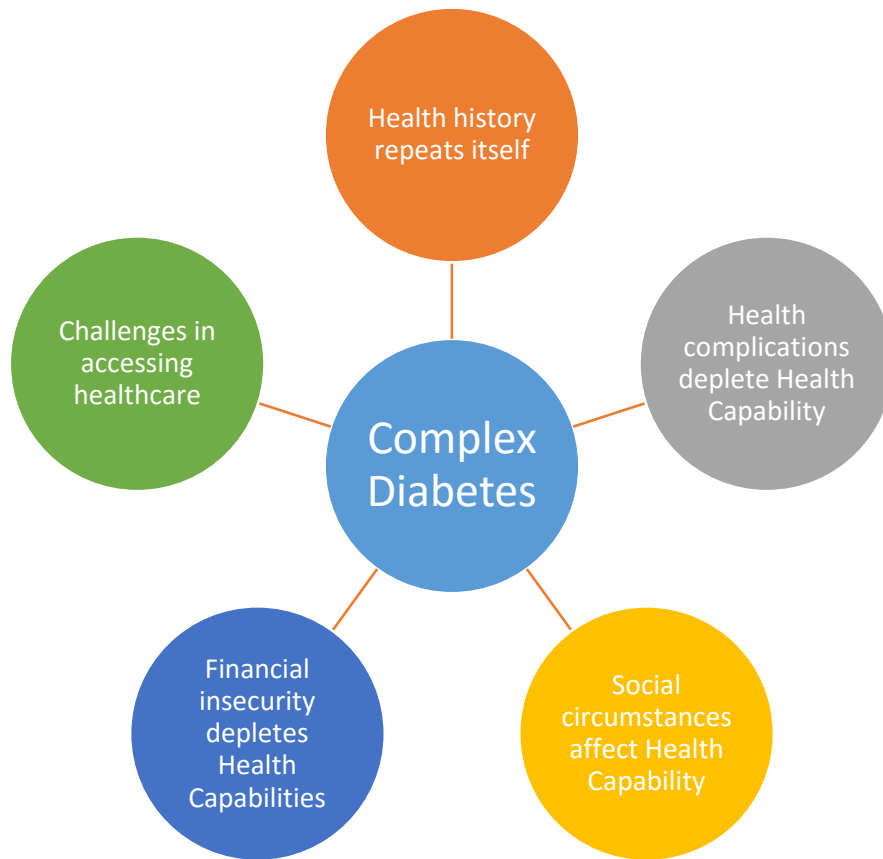


Figure 8: Summary of five overarching themes

## **6. Chapter Six: Discussion and Conclusion**

### **6.1 Introduction**

This chapter include a summary discussion of findings and the emerging themes in accordance with health capabilities and syndemics approach.

Additionally, emerging themes of this study will be used to not only described the multitude of health conditions and complications patients with complex diabetes live with, but also the social burden of everyday life which aid in initiating and sustain a vicious downward cycle of illness. Finally, discussion of various limitations and future implications of this study will follow.

The purpose of this study was to understand how social environment help shape the health, well-being, and experience of those who live with complex diabetes. Furthermore, this study aimed to explore the perceived challenges people with complex diabetes encountered, when interacting with the healthcare system.

### **6.2 Summary of Findings**

The findings from this study reveal that there are various factors within the social environment that shape the health, well-being, and experience of those who live with complex diabetes. Additionally, the participants' perspectives sheds light on the many challenges encountered when interacting with the healthcare system.

The analysis of interview transcripts followed by the compilation of composites based on the life experiences of participants, support the syndemic and health capabilities frameworks, and extend understanding of the experience of living with complex diabetes. These two frameworks describe how fundamental contextual and social factors foster an environment that encourages clusters of diseases to synergistically interact.

Furthermore, the in-depth, semi-structured interviews exposed the crisis many individuals with complex diabetes face, as they struggle to manage a plethora of health conditions, in addition to the stress of everyday life. Reflecting on their life experiences and what brought them to the CCDC, many study participants spoke candidly about various life experiences that may have sabotaged their ability to attain improved health. Some of these experiences

included experiencing food insecurity during childhood and adulthood, inability to improve health conditions due to financial constraints, perceptions of the etiology of diabetes, as well as dealing with various stresses from social circumstances.

As discussed in chapter four, nine out of eleven study participants perceived the etiology of their diabetes to be directly linked to their biology. With this belief in tandem with lifestyle behavioural patterns, participants often viewed preventative measures as ineffective. Furthermore, people in this study also regarded their complex health conditions to be a consequence of uncontrolled diabetes and the by-product of various forms of stress from their social roles and responsibilities and from experiencing significant losses of support persons.

In addition to personal responsibilities and stresses from everyday life, individuals living with diabetes are expected to follow through with rigorous prescribed lifestyle changes, which also demand time and resources. For many individuals already struggling to keep up with everyday life, instituting the demands of diabetes care was not feasible, and for some, the financial resources and social support was simply just not there. Moreover, as individuals look to healthcare professionals for guidance and support, some were left in dismay, after having negative experiences with staff or denied access to care. Individuals with disabilities (and other patients with particular needs) often encounter difficulty when accessing care. This is because most healthcare professionals are not equipped or trained to facilitate care and meet the needs of patients with disabilities (particularly patients with specific needs) (Pharr & Chino, 2013).

Some participants had access to viable financial resources and were able to access medication, supplies, and implement a diabetes management regimen but lacked social support. This was especially true among participants who were also caregivers. These participants were not only charged to manage their own health complications, but was accountable for managing and caring for children or sick family members. As a consequence to mounting social responsibilities and demands, diabetes management was often not priority.

In addition to diabetes, the majority of participants were living with injuries, multiple chronic conditions and comorbidities, and experienced various

side effects produced by medication interaction. As a result, juggling multiple health conditions often hindered positive diabetes management. This is because compared to diabetes, illness with more severe side effects was prioritized and often demanded more resources. Furthermore, majority of participants expressed that because of their socioeconomic circumstance, their capability to improve health conditions was out of their control, which resulted in worsening health complications.

### **6.3 Conceptualization**

This study combines syndemic and health capabilities approaches to understanding complex chronic illness, both of which offer a theoretical framework for making sense of perceptions and experiences of those living with complex diabetes. Seen in the stories of many participants, a person's socioeconomic predisposition within the social strata, can often discourage and counteract health improvement efforts. For some in this study, implementing various preventative measures was simply not plausible due to financial constraints and opposing priorities, such as the stress and demands of family life, work, and other comorbidities.

The goal of this study was not to merely understand the etiology of complex diabetes, but to explore and understand the social and psychological facilitators that support the synergistic interaction between diabetes and other comorbidities, and to examine the various barriers individuals encounter when interacting with the healthcare system.

The ability to lead a healthy lifestyle is dictated by opportunities which provides available choices based on individual's life changes (Cockerham, 2005). The pursuit of health and well-being hinge on individuals' access to economic, social and cultural resources and opportunities. Following Bourdieu (1986; and Weaver, et al., 2014), economic resources are transformed into social and cultural resources that become integrated and expressed as distinctive social classes and lifestyles reproduced over time through the process of socialization.

In turn, these resources may be transformed into health-related resources that enable maintenance or improvement of overall health and well-being (Abel, 2008; Abel and Frohlich, 2012; Ruger, 2010b; Weaver et al., 2014). As a consequence, overall health and health choices are also impacted by health agency, and shape one's health capability. This can be seen, as poor health lowers an individual's health capabilities, which in turn may contribute in developing or worsening further morbidities. Conversely, good health bolsters existing capabilities, enabling further health. For example, co-morbidities such as depression can reduce a person's capacity to work and participate in physical activities, and impede motivation to improve health, which inevitably can result in increased BMI, deteriorating health conditions, and job loss. Poor health not only decreases health capabilities, but may place restraints on financial resources needed to improve health conditions.

The syndemic framework describes how adverse social realities (e.g., poverty, food insecurity and oppressive social relationships) converge in not only shaping an individual's illness experience, but also the distribution of disease among populations (Mendenhall, 2012; Singer 1996, 2009a, 2009b; Singer and Clair 2003). Furthermore, the syndemic approach integrates social, cultural, psychological, and biological elements that congregate to cultivate experiences observed in this study (Mendehall 2015).

Forged on the belief that social and economic inequalities are both the root and result of disease interaction and associated morbidities and mortality, the syndemic approach pin points to this negative biosocial feedback loop at work. Contributing significantly to this negative feedback loop, the social context and social conditions coalesce to increase the epidemiology of health conditions among populations (Mendenhall, 2012). At the forefront, structural violence or structural inequality uphold the social conditions (e.g. access to economic and social resources) that encourage clustering of various ailments (Singer, Pg. 140-141).

Building upon the health capabilities model (Ruger, 2010), and the principles of the syndemic approach, this study suggest that based on the attributes



of the study population, the structure of resource allocation (e.g. access to economic and social resources) may be seen as a key factor in initiating this negative biosocial feedback loop, as described in the health capabilities model. As seen in this study population, structural inequality often times dictates access to economic and social resources, which in turn can be translated to health related resources to improve one's health capability.

The attributes of participants in this study mirrors that to a syndemic population. That is, individuals in study were suffering with various morbid conditions, and were situated in social environments which may have helped foster worsening health outcomes, while lowering health capabilities.

Moreover, people's access to resources may influence and help cultivate the environment in which they inhabit, which as a result can impact's a population's natural defense. The environment which one inhabits helps to orchestrate and facilitate an individual's life chances/ opportunities through socialization, and thus may influence a person's health capabilities. In turn, this study builds upon the findings of Weaver et al., (2014) and suggests that how high or low an individual's health capabilities are, correlates with two paths that dictates the possibility of an individual achieving optimal health, or a diminishing of health conditions, such as clustering of comorbid conditions.

In one path (Figure 9: Path 1), as health conditions improve, this cycles backs into increased ability to acquire ample resources. For example, a person who is able to work, increases household earnings which then increases health capabilities and supports conditions that are vital in improving health. An example of this would be the five participants in this study who were able to financially afford the demands of diabetes, such as medication, food, and therapy if needed. As a result of financial security, access to healthy food, diabetes medication, and other health services were not viewed as a barrier by participants who were economically secure. As opposed to financial security, many of these participants view a lack of social and healthcare support as an obstacle in diabetes self-management.

However, for some individuals (Figure 9: Path 2) there is much bleaker outcome. This is because, a person's ability to acquire much needed resources is hampered as comorbid conditions begin to cluster, and may furthermore inhibit an individual's capability to implement measures to improve health conditions. This then sets the course of a vicious negative feedback loop, which was observed in the lives and perspectives of many participants in this study. Furthermore, barriers within the healthcare system may also impede on an individual's capability to acquire resources. This can be illustrated by restricting access and not facilitating to the needs of minority populations, such as individuals with disabilities.

This model is also reflected in the stories of various individuals in this study. For example, as a person experiences various forms of access to resources which is built into the social structure, which can further act to help increase or decrease their health capabilities, and ultimately their health outcome. As seen in the perspectives of many participants with a lower SES such as Mickey and Victoria, a lack of economic and social due to structural inequality aided in lowering their health capabilities in improving health conditions. Due to limited resources, many were forced to choose between surviving and improving health conditions (e.g. choosing between purchasing medication/ medical supplies and buying food). As health capabilities were lowered, this often resulted in worsening health conditions. As health conditions continued to worsen, prospects of increasing household income quickly diminish because of the inability to work, which in turn cycles back to limited resources, lower health capabilities, and degrading health outcomes. For some in this study, this process was quite the opposite, where it was observed that not all participants has equal health capabilities, due to increased access to resources that was utilized to improve health conditions and well-being.

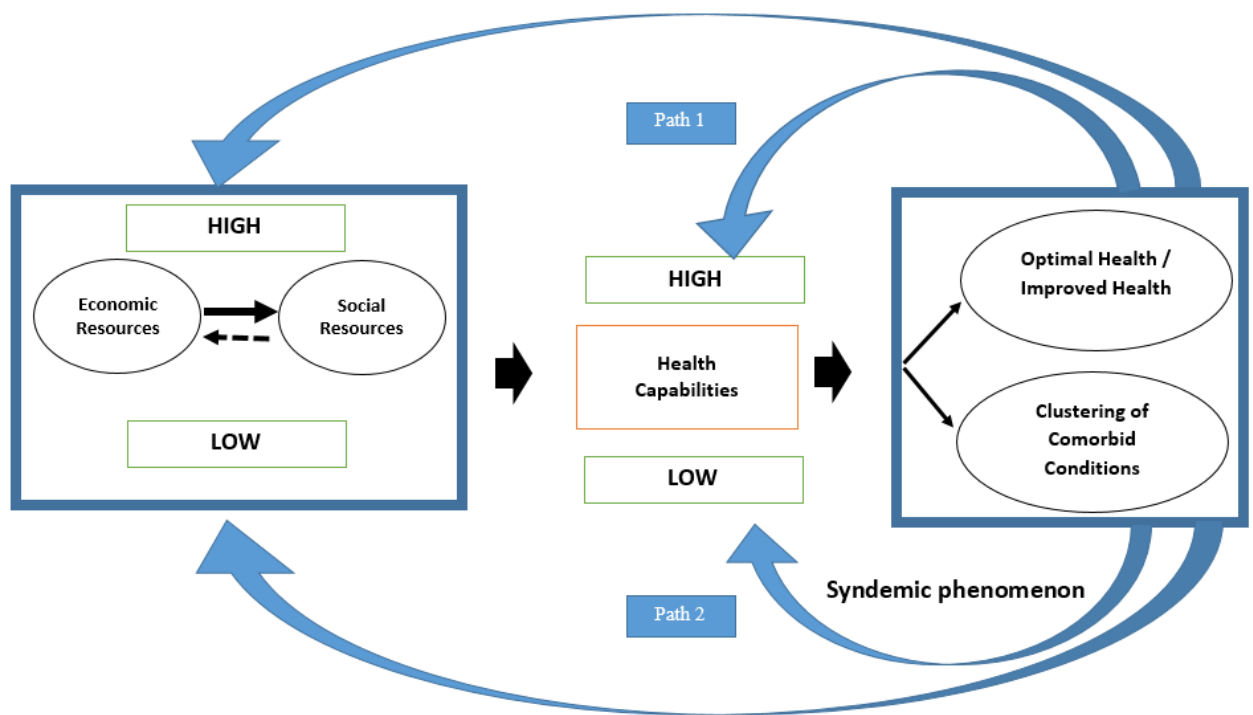


Figure 9: Syndemic and Health Capabilities Model

#### 6.4 Study Limitation

While the exploration of individuals' perceptions and experiences of complex diabetes suggests how resources shape vicious pathways toward improved or worsening health, one should remain cautious about over-interpreting these results. For instance, the sampled population was limited to those with complex diabetes yet the most severe cases were excluded from the study. Although we suspect that their inclusion would bolster the association between resources, health capability, and health, whether and how strongly this relationship might be made remains uncertain. Moreover, the limited sample size and demographic variation of participants enabled more in-depth exploration into each individual's experiences with complex diabetes, the extent to which the results apply to other populations requires additional investigation.

For instance, the sample lacked the inclusion of various ethnic minorities who, we suspect, would face additional obstacles that were not uncovered in the current study. In 2011 approximately 26% of Ontario's total population was comprised of visible minorities, while various immigrant populations that are at an

increased risk of type 2 diabetes (e.g. South Asian, Chinese, and African origins) also call Ontario home (Canadian Diabetes Association, 2015). Due to the immigrant population in Ontario on the rise, immigrants also impacts the epidemiology of diabetes in the overall population of Ontario (Peel Public Health, 2013; Ontario Ministry of Finance, 2016). The risk of type 2 diabetes may also increase to due to ethnic composition of community, nutrition transition, change in physical activity levels, and stress (Peel Public Health, 2013). Therefore, in order to determine if the phenomenon of complex diabetes described in this study might how a larger syndemic patter, a broader sample that includes various visible/ ethnic minorities is needed. This may be because, certain ethno-cultural groups may encounter difficulties when accessing care (e.g. language barrier, dietary barrier when implementing recommendations), which may have long-term health implications.

Additionally, there may have been some form of selection biased in the recruitment phase of this study. This is because the CCDC staff had an active role in selecting individual's best fit to participate, due the nature and personal in-depth questions involved in this study. Moreover, participant's responses in regards to questions about their experience at the CCDC may have been slightly skewed. For example, some participants may have perceived that their responses would impact the quality of care they were receiving at the CCDC.

## **6.5 Implications and Future Directions**

Part of the Ontario Ministry of Health and Long –Term Care: Ontario Diabetes Strategy (ODS) initiative, the CCDC acts as the last resort to refer patients living with complex diabetes. Granting individuals with access to specialized inter-professional teams, the CCDC works-hand-in-hand with primary care providers to help individuals' health. However, as illustrated by the findings of this study, the social sphere many live in greatly impacts an individual's ability to attain viable health, and improve current health conditions. Competing priorities and life circumstances often force individuals to sacrifice their own health concerns in favour of other pressing demands (e.g., children's needs,

housing, food). The frustration of having access to limited socioeconomic resources and living diabetes and its array of complications, makes diabetes management exasperating. This experience is further compounded by healthcare professionals who may overlook the everyday realities many with chronic diabetes must confront.

This study and other studies (e.g., Beverly, et al., 2011; 2014) challenge the traditional biomedical approaches that focus on physical aspects of disease, neglecting social and emotional facets that shape illness experience. For example, a cross-sectional study across thirteen countries conducted by Peyrot and colleagues (2005), revealed diabetes adherence was poor, more importantly 41% of patients had poor psychological well-being, while 10% of patients reported receiving psychological treatment. Furthermore, worldwide psychosocial problems appear to be common among patient living with diabetes. Similar to the findings of this study, another study led by Stuckey et al., (2014) reported that 72% of 8,569 participants were living with diabetes and some form of complication or comorbidity. Moreover, findings of this study found that people have negative psychosocial experiences with diabetes, and often include emotional reactions such as: anxiety/ fear, depression, and negative moods/ hopelessness coupled by discrimination at work or public misunderstanding (Stuckey et al., 2014).

This study also suggests the utility of syndemic and health capabilities models for examining macro-level political-economic factors and micro-level social stresses at work, that lower health capabilities while encouraging clustering of comorbid conditions.

Findings of this study and other studies suggest that healthcare providers need to take account of a person's social context when conducting assessments, to better treat individuals with complex diabetes. Such accounts illuminate psychosocial conditions that shape health and health management (Lynch, Waite, & Davey, 2013; Brayeman & Barclay, 2009).

Lastly, although there are several traditional types of diabetes education programs and care, the context in which people live with diabetes continues to

have a significant impact on diabetes self-management and also on the present healthcare system. However, in order to accomplish optimal diabetes care, ongoing collaboration between person with diabetes, family members, community, and healthcare teams is vital (Peyrot et al., 2013). Currently, how care is organized and delivered, tends to place expectations on the individual while neglecting the social reality lived by many. These expectations may aid in forming barriers which are often difficult to overcome, and thus can make the current system ineffective in supporting self-management. Additionally, the structural inequality many endure should be acknowledge, and further social services need to be made available for individuals living with multiple chronic illness, if health conditions are to improve.

Future research may focus on examining structure of social inequality, and its impact on access to food, medication, meaningful social connection, health outcomes, and healthcare. Also, the landscape of diabetes care should move towards preventative intervention occurring right after diagnoses. For example, many participants often voiced that interventions such as the CCDC needs to happen right after diagnosis, as opposed to after development of chronic complications. By moving to an upstream approach, where individuals are able to receive diabetes education and support, may help improve health conditions, and decrease negative health outcomes. In conclusion, maintaining one's health presupposes one's health capability. Health capability is shaped by social context. The failure and insecurity of social context are part and parcel of a syndemic phenomenon that is associated with complex diabetes.

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## 8. Appendix A

- **Ethical Consideration:** With participant's permission, all interviews were audio recorded and took place in a confidential room at the CCDC, located in Whitby. To protect patient's identity, participants were addressed/ referred to by a pseudonym throughout the interview. All Audio recording files were individually encrypted and transferred to an encrypted electronic drive (e.g. encrypted USB), using a secure Lakeridge Health computer.
- Any data collected during this study was kept confidential, and stripped of any patient identifiers. To ensure confidentiality and anonymity, a continuum of numerical codes and pseudonyms was used to protect participant's identity. All physical and electronic data collected was kept safe and locked in a UOIT office (e.g., the Principal Overarching Investigator's office: Dr. Robert Weaver), where only the primary investigator (Elisabeth Ramdawar) and the Faculty advisor/ Principal Overarching Investigator (Dr. Robert Weaver) had access to the collected data.
- It is important to note, that before and during each new stage of the study (e.g. administration of survey and commencement of interview), participants were made aware and verbally reminded that they are volunteering and had the right to withdraw from the study at any time and they will still receive a \$20 Tim Hortons gift card. Participants were also be verbally reminded that may choose to pass during the interview on any question that are uncomfortable and will still receive a \$20 Tim Hortons gift card. It is also important to note that, five years from study completion date all collected data will be destroyed.
- **Insulin** is a polypeptide hormone secreted by beta cells of the pancreatic islets of Langerhans (Walsh, 2009). The primary role of insulin is to regulate blood glucose levels to normal; therefore, insulin is secreted by the pancreas when blood sugar levels are elevated (McKee & McKee, 2009). Insulin receptors are expressed on a variety of cells in the body (Walsh, 2009). However, insulin predominantly binds to target cells such as: skeletal muscle fibres, hepatocytes, and adipocytes (Walsh, 2009). Here, insulin acts as an inhibitor to glucagon (Walsh, 2009). Glucagon is a hormone produced by alpha cells of the pancreatic islets of Langerhans, which promotes an increase of glucose when levels are low) (Walsh, 2009). The binding of

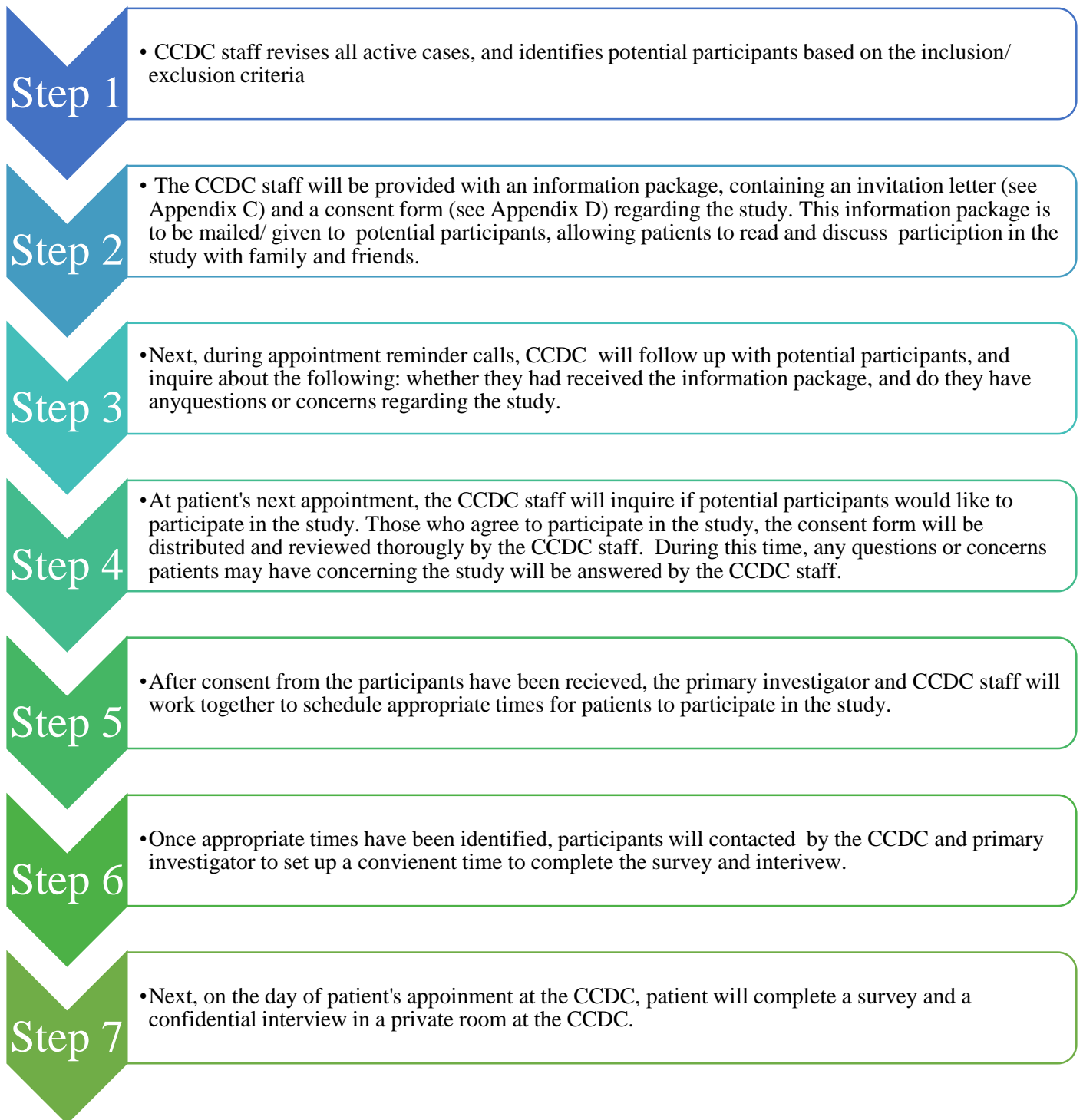
insulin stimulates the transportation of glucose, amino acids, potassium ions, and other nutrients across the plasma membrane (Walsh, 2009). Insulin also helps promote glycogen synthesis, inhibition of catabolic pathways and stimulates protein and DNA production (Walsh, 2009). The common forms of diabetes are Type 1 (T1DM) and Type 2 (T2DM) diabetes mellitus (Sizer, Whitney, & Piché, 2012).

- **Type 1 diabetes (insulin-dependent diabetes mellitus)**: is known as the less common form, occurs when beta cells of the pancreas which produce the hormone insulin, are destroyed due to T-cell mediated autoimmune process, causing insufficient amounts of insulin to be secreted (Sizer, Whitney, & Piché, 2012). This occurs predominantly in genetically predisposed individuals (Sizer, Whitney, & Piché, 2012; Walsh, 2009; and McKee & McKee, 2009). The symptoms of T1DM are not at first obvious, but are apparent once all insulin producing ability has been destroyed (Cox & Nelson, 2008). The destruction of pancreatic beta-cells appears to transpire over numerous years via an inflammatory process (Cox & Nelson, 2008). Although cells are severely depleted in glucose, blood glucose levels continue to rise after a meal due to the pancreas's inability to synthesize insulin (Sizer, Whitney, & Piché, 2012).
- **Type 2 diabetes mellitus (non- insulin-dependent diabetes mellitus)**: is the most prevalent form of diabetes mellitus is. The hallmark of T2DM is the progression of insulin resistance in muscle, adipose, and liver cells (Whitney & Rolfes, 2008). With reduced sensitivity in these cells, the beta cells in the pancreas increase the amount of insulin it secretes to carry out a biological effect, which usually requires a lower amount of insulin in a normal health state (Whitney & Rolfes, 2008; Cox & Nelson, 2008). Insulin resistance occurs when insulin receptors are improper or defective, leading to the down regulation of insulin receptors (McKee & McKee, 2009). With an increased request for insulin, the beta cells of the pancreas become exhausted (McKee & McKee, 2009).

- The process of beta cells from the pancreas secreting insulin is exacerbated, impairing insulin secretion and reducing plasma insulin concentration (Cox & Nelson, 2008). Failure to produce adequate insulin is reflected in the body's inability to regulate blood glucose levels. It is important to note that, in contrast to T1DM, where blood glucose levels are elevated, in T2DM blood insulin levels are also elevated (Sizer, Whitney, & Piché, 2012). Furthermore, in T2DM glucose does not enter the cells, but instead accumulates in the blood (Whitney & Rolfes, 2008). Such phenomena can lead to both acute and chronic problems. Continual elevated blood glucose can modify glucose metabolism in cells, sometimes converting excess glucose to sugar alcohols, exhibiting a toxic effect and cell distention (Whitney & Rolfes, 2008).
- **Syndemics:** The term “*syndemic*” combines two concepts, *synergy* and *epidemic*, and highlights the synergistic interaction between two or more epidemic diseases or disorders, and the socioenvironmental contexts (such as poverty) that endorse such interactions (Singer, 2009).
- **VIDDA Syndemics:** First coined by Mendenhall (2012a), the VIDDA syndemic model, emphasize the influence of political-economic and social forces. It also describes how these combined forces shape the clustering of depression and diabetes among Mexican immigrant women in Chicago (Mendenhall, 2012a, Mendenhall & Jacobs, 2012; and Mendenhall, Fernandez, Alder, & Jacobs, 2012). The VIDDA syndemic model encompasses the five core facets of health and social well-being that formulate diabetes and depression, which are: **V**iolence (e.g., structural, symbolic, and every day); **I**mmigration and feelings of social **I**solation (e.g., relationship factors); **D**epression; **T**ype two **D**iabetes (e.g., sociocultural factors); and interpersonal **A**buse (Mendenhall, 2012b, pp. 23-24,105-106; and Weaver & Mendenhall, 2014). As the stress of interpersonal abuse, structural violence, poverty, and immigration merge, they synergistically produce distress among individuals, prompting health conditions to deteriorate (Mendenhall, 2012b, pp. 23-24,105-106). Similarly, the clustering of diabetes and depression is also shaped by a fusion of macro and micro forces (Mendenhall & Jacobs, 2012).

- **SAVA Syndemics:** Developed by Singer et al., 2006, to describe the AIDS epidemic, substance abuse, violence, and AIDS (SAVA), embodies a triangulation of dynamic health-related problems, which interact with one another (Singer, 2009). This synergistic interaction is illustrated in the simultaneous presence of drug use, AIDS, and violence. These three factors feed off each other and produce a multiplicative effect which deteriorates health conditions (Singer, 2009). Additionally, *SAVA syndemics* are shaped by the instituted structure of social contexts imposed on disadvantaged populations (Singer, 2009).
  
- **Central East Centre for Complex Diabetes (CCDC):** The CCDC is located at Lakeridge Health Whitby, and is a regional diabetes care delivery program, that supports patients with diabetes who have complex needs. The CCDC offers assistance, support, education, treatment, and transition/ discharge to patients with complex diabetes, using an intensive case management approach. To be referred to the CCDC, individuals must have Type 1 or Type 2 diabetes, be 18 years of age, and have more than one chronic/ comorbid conditions (e.g., inadequate glycemic control, serious mental health issues, etc.) barriers in accessing health care, facing other and determinants of health issues. The CCDC is composed of CCAC Care coordinator, Nurse Practitioner, nurse, dietitian, Social worker, and a pharmacist. (CCDC, 2014).

## 9. Appendix B: Process Map



## 10. Appendix C: Study Invitation Letter



Centres for Complex Diabetes Care (CCDC) at Lakeridge Health Letter mailed to  
potential participants

January 16<sup>th</sup>, 2015

Frist and Last Name  
Address  
Durham, ON, Postal Code

Dear Mr. /Mrs. \_\_\_\_\_,

The CCDC clinic staff are partnering with researchers at UOIT (The University of Ontario Institute of Technology) to look at how the healthcare system has enhanced/ not enhanced patient illness experience throughout your lifetime, and how social factors (e.g. education, income, family background, access to food) throughout a person's lifetime may contribute to their diabetes. We hope that what we learn from this study will help us better serve diabetes patients at the CCDC.

The UOIT researchers would like to invite you to participate in this study. This study involves you completing a survey (asking you about your age, sex, income, occupation) followed by a one-on-one interview with a UOIT researcher. It is hoped that the interview will give patients an opportunity to voice their personal experiences regarding diabetes, management, life experiences, and interaction with the healthcare system. During the interview, personal questions regarding diabetes management, life experiences, family history, and interaction with the health care system will be asked. The interview will take place in a private room, and should take approximately 1- 1 ½ hours. What you share at the interview will be kept confidential. Upon completion of the interview, participants in the interview will receive \$20 Tim Hortons gift card, as a token of appreciation for their time.

You may choose to participate or decline. It is important to remember that this study is separate from the CCDC, and is being conducted by independent researchers. Your choosing to decline or participate in this study will not in any way affect the services or care you receive from the CCDC. Participation in this study is completely voluntary, and there are no consequences for not participating.

If you do choose to participate in the study, you may choose to pass any questions being asked during the interview or withdraw from the study at any time.



If you are interested in taking part in the study, attached to this letter is a copy of the consent form, describing the study, so that you may review it with family and friends prior to your next appointment. At your next appointment the CCDC staff will thoroughly review the consent form with you and answer any questions you may have. If you decide to participate in the study, the clinic staff will assist you in completing the consent form, and thoroughly review the consent form with you. Next, the UOIT research will then contact you to set-up a time convenient for you to complete the survey and interview.

If you have any questions or concerns about the study, please feel free to call the CCDC clinic at (905) - \_\_\_\_\_ - \_\_\_\_\_.

Thank you,

Elisabeth A Ramdawar

## 11. Appendix D: Study Consent form

Centre for Complex Diabetes Care (CCDC), Lakeridge Health, Whitby



**Lakeridge  
Health**



**Title of Study:** Examining complex diabetes and patient illness experience, utilizing a syndemic approach

**Principal Overarching Investigator:**

Dr. Robert Weaver, PhD, Professor and Associate Dean  
Faculty of Health Sciences  
University of Ontario Institute of Technology (UOIT)  
2000 Simcoe Street North, Oshawa, Ontario, Canada, L1H 7K4  
Telephone: (905)-721-8668 ext. 3705

**Lakeridge Health Site Lead:**

Christina Vaillancourt, MHSc, RD, CDE  
Lakeridge Health Patient Care Manager, Diabetes and Nephrology Research/ Professional Development/ Inter-professional Collaboration and Lakeridge Health Principle Investigator  
300 Gordon Street, Whitby Ontario, Canada, L1N 5T3  
Telephone: (905)-242-8711 ext. 3161

**Primary Investigator/Graduate student:**

Elisabeth-Abigail Ramdawar, BSc (Hons),  
Graduate student at the University Of Ontario Institute Of Technology (UOIT)  
2000 Simcoe Street North, Oshawa, Ontario, Canada, L1H 7K4  
Telephone: (905)-926-2175

You are being asked if you wish to participate in a research study. Please take your time to review this consent form and discuss any questions you may have with the study staff. You may take your time to make your decision about participating in this study and you may discuss it with your friends, family or (if applicable) your doctor before you make your decision. This consent form may contain words that you do not understand. Please ask the study staff to explain any words or information that you do not clearly understand.

**Purpose of Study**

The purpose of this research study is to critically assess how complex diabetes care can be improved by the healthcare system, and to analyze the role social factors play in complex diabetes. This research also how explores how the healthcare system has enhanced/ not enhanced patient illness experience throughout their lifetime.

Objectives/ Aims of this study to:

1. Explore how patients with complex diabetes perceive the causes and consequences of their current medical condition
2. Identify the social attributes or characteristics, background, and current circumstances that are associated with the onset of complex diabetes
3. Critically examine the perceived challenges persons with complex diabetes encounter when interacting with the health care system.

You are being asked if you wish to participate in this study because of your membership with the Central East Centre for Complex Diabetes Care (CCDC) and health characteristics. A total of 10-15 participants will participate in this study.

### **Study Procedures**

Your participation in this study is completely voluntary and you may withdraw at any time. This study will take place from January to March 2015. In this study you will be required to take part in a survey (which will take approximately ten minutes), followed by a one-on-one interview (please note one interview per individual participant) lasting approximately 1-1 ½ hour.

Before individuals participate in this study, this consent form will be mailed to you, allowing you time to review and discuss it with family and friends. Next, this consent form will be reviewed and explained to you by the CCDC staff. It will also be made known, that your participation in this study is voluntary, and you may withdraw from this study at any time. This will also be verbally stated before and throughout the administration of the survey and during the interview.

Once the consent form has been read, verbally explained, and signed, you will be contacted by the CCDC team and the UOIT researcher to set up a time convenient for you to complete the survey and the interview. With participant's permission, each interview will be audiotaped. To ensure that no attribution will be made to you in relation to anything you might say during the interview, and to protect your identity, with your permission you will be assigned and referred to during the interview by a pseudonym (e.g. a false name). In addition to a pseudonym, each participant will be given a numeric code to maintain participant anonymity.

During the interview, you may choose not to answer any question that makes you uncomfortable, and withdraw your participation at any time without. Your decision whether or not to participate in or withdraw from this study will not affect the care you receive from the CCDC at Lakeridge Health.

After the interview, you will be verbally thanked for your participation in this study. You will also receive a \$20 gift card to Tim Hortons as a token of our appreciation. Individuals who choose to withdraw from the study will also receive a \$20 gift card to Tim Hortons as a token of our appreciation. Once the study has been completed, an executive summary will be made available; you may request a copy by phoning the primary investigator (905.926.2175). It is important to note that the results of this study will be used for both academic and community publication and presentation, and other academic means.

### **Risks and Discomforts**

If you are uncomfortable or feel distressed with the questions presented, you are free to pass and may discontinue the interview at any time if need be, or may speak with a member of the CCDC team. It is important to note, that if you choose to withdraw from this study, you will still receive a \$20 Tim Hortons gift card as a token of our appreciation for your participation.

### **Benefits**

While there will be no direct benefit to you, participants will receive a \$20 Tim Hortons gift card for their participation in the study. However, the overall aim is to use the findings of this study to improve understanding of the issues associated with complex diabetes and identify programs and services to address these issues. A long term aim of this study is to influence public policy change to better address the needs of individuals with complex diabetes, and the challenges they face when interacting with the healthcare system.

### **Costs**

All the procedures, which will be performed as part of this study, are provided at no cost to you.

### **Confidentiality**

All the information collected during this study will be kept confidential. Each interview will be audio recorded, and a continuum of numeric codes will be used to maintain anonymity and protect your identity. Interview scripts, recordings, and any other data collected will be kept in a confidential UOIT office, where only the primary investigator (Elisabeth Ramdwar; contact: 905.926.2175) and Principal Overarching Investigator/faculty advisor (Dr. Robert Weaver; contact: 905.721.8668. ext.3705) will have access to the collected data. Protecting your privacy and confidential information is of utmost importance to us. Therefore, the collected data will only be used for this current study and will not be shared without your permission, unless required by law.

Information gathered in this research study may be published or presented in public forums; however your name and other information involving your identity will not be used or revealed. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law.

The Lakeridge Health Research Ethics Board may review records related to the study for quality assurance purposes, as it oversees the conduct of this study at Lakeridge Health.

### **Voluntary Participation / Withdrawal from the Study**

Your participation to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time, and all information you have provided will not be used and will be destroyed. Your decision not to participate or withdraw from the study will

not affect your care at the CCDC. If the study staff feels that it is in your best interest to withdraw from the study, they will remove you without your consent.

You may withdraw at any time a statement from the interview or withdraw completely from this study at any time by contacting the CCDC or the primary investigator (Elisabeth Ramdawar via 905-926-2175). However, it is important to note that five years from the study's completion date all collected data will be destroyed. If you choose to withdraw from this study you will still receive a \$20 gift card as a token of our appreciation.

You will be informed as soon as possible if changes are made to the study, or new information that might affect your health, welfare, or willingness to continue in the study becomes available.

### **Medical Care for Injury Related to the Study**

In no way does signing this consent form waive your legal rights nor does it relieve the investigators or involved institutions from their legal and professional responsibilities.

### **Questions**

You are free to ask any questions that you may have about your treatment and your rights as a research participant.

Should you have any questions or concerns regarding your rights as a participant in this research study, or if you wish to speak with someone who is not related to this study, you may contact the Chair of the Lakeridge Health Research Ethics Board at (905) 576-8711.

Also, if you would like to inquire about your rights as a participant in this study, you may also contact the Compliance Officer at the University of Ontario Institute of Technology: 905.721.8668 ext. 3693, or via email at: [compliance@uoit.ca](mailto:compliance@uoit.ca).

### **Statement of Consent**

I have read this consent form. I have had the opportunity to discuss this study with *Elisabeth A Ramdawar* and/or the CCDC staff. I have had my questions answered by them in language I understand. The risks and benefits have been explained to me. I understand that I will be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

By signing this consent form, I have not waived any of the legal rights that I have as a participant in a research study.

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Participant Signature

---

Date

---

Participant Printed Name

I, the undersigned, attest that the information in the Consent Form was accurately explained to and apparently understood by the participant or the participant's legally authorized representative and that consent to participate in this study was freely given by the participant or the participant's legally authorized representative.

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Witness Signature

---

Date

---

Witness Printed Name

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

---

Printed Name

---

Date

---

Signature

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Role in the Study

## 12. Appendix E: Sociodemographic Survey

The Centre for Complex Diabetes Care (CDCC) at Lakeridge Health, Whitby is collaborating with researchers at the University of Ontario Institute of Technology on a project entitled: *Examining complex diabetes and patient illness experience, utilizing a syndemic*. The aim is to learn how social factors contribute to the onset of complex diabetes and how complex diabetes care can be improved by identify gaps within the health care system. This study is being conducted, to gain a better the understanding of complex diabetes which will help the CCDC and others better serve you and other diabetes patients. It is important to note that this study is an independent study; your choosing to participate or not participate in this study will not in any way affect the care you receive from the CCDC.

The survey will take approximately 10 minutes to complete. There are no known risks if you do choose to complete the survey. There are no penalties if you decide not to participate; your decision to participate in this study is completely voluntary. You may refuse to answer any questions you do not wish to answer. Further, the questionnaire does not ask for your name, so none of your answers can be traced to you. The questionnaire is completely *anonymous*, and your specific responses will be kept confidential. Raw data from the survey will remain in a secure location at the University and will not be shared with anyone besides the researchers. Protecting your privacy and confidential information is of uttermost importance to us. Therefore, the collected data will only be used for this current study and will not be shared without your permission, unless required by law. The collected data will be retained until study is fully completed, published, and presented. After, all documents, data collected, and numeric codes will be destroyed after five years. Once the study is completed, upon request, an executive summary regarding the study will be available by contacting the primary investigator at 905.926.2175.

The results of this study will be used for both academic and community publication and presentation, and other academic means.

This study has been reviewed and received Ethics approval through the Research Ethics Board at UOIT (#REB \_\_-\_\_), and the Lakeridge Health Ethics Board as of \_\_\_\_, 2014. If you may have any questions concerning the research study, or experience any discomfort related to the study please contact the researcher(s) at 905-621-7621. Any questions regarding your rights as a participant, complaints may be addressed to Research Ethics Board through the Ethics and Compliance Officer at 905.721.8668 ext. 3693, or via email at: [compliance@uoit.ca](mailto:compliance@uoit.ca).

**NEXT PAGE →**



**Lakeridge  
Health**



**Study:** *Examining complex diabetes and patient illness experience, utilizing a syndemic.*  
Please **do not write your name** on this questionnaire so your answers will remain strictly  
***anonymous.***

1) Please provide the following <i>demographic</i> information			
1. Age: _____		2. Sex/Gender: ____ Female ____ Male	
3. Education (highest degree earned):	____ less than high school	____ college diploma	____ graduate degree
	____ high school diploma	____ university degree	other (specify): _____
4. Ethnicity (specify): _____			
5. What country were you born in: _____			
6. What city/ town do you reside in? How long have you been living there? _____; _____			
7. What is your occupation: _____			
8. Current household annual income:	____ less than \$25,000	____ \$25,000 to \$34,999	
	____ \$35,000 to \$49,000	____ \$50,000 to \$74,000	
	____ \$75,000 to \$99,999	____ \$100,000 to \$149,999	
	____ \$150,000 to \$199,999	____ \$200,000 to \$249,999	
	____ \$250,000 or more		
9. Marital Status:	____ married	____ widow	
	____ separated/divorced	____ single (never married)	
10. Do you have children:	____ Yes, I have _____ children		
	____ NO		
11. How many people live in your household? _____			
12. Do you rent or own: house		____ I rent ____ I own a condominium ____ I own a	



### 13. Appendix F: Open-ended interview questions

#### Open-ended participant interview questions<sup>1</sup>

##### **Background:**

- Tell me about your childhood?
  - What about where you grew up?
  - Can you tell me about your family?
    - What about your parents, what did they do for a living?
    - What was it like living in your neighbourhood?
- Where did you go to school?
  - What was it like?
  - What was the last school you attended?
- So tell me, would you say while growing up you had a lot of opportunities in life?
  - What about challenges? Have you encountered situations or stressful circumstances that were hard to overcome?
  - How about life chances? Would you say you've had a lot of those?
- What about now? What about your current family/ living situation, what's that like?
- Have you ever been married?
  - What was your age when you first got married?
  - Can you tell me about your relationship?
  - Tell me about your family, do you have children?

##### **Health:**

- What about your health history, can you tell me a bit about that?
  - What caused your diabetes? What do you see as the reason why you got diabetes?
  - Is there any family history?
  - What about managing diabetes, does anyone help you manage your diabetes?
- Was diabetes the first health issues to develop?
  - How did diabetes play a role in the development of other current health issues (conditions)?
- What would you say are the barriers to managing diabetes?
  - What makes it difficult?
  - What do you think causes these difficulties?
- Tell me about feelings of depression; have you experience feelings like hopelessness?
- How about emotions, do any emotions affect your diabetes?

##### **Healthcare System:**

- How has the health care system helped or not helped your health?
  - What are some issues you have encountered regarding access to services?
    - For example, access to services regarding diabetes
  - Tell me, how do you think the healthcare system has failed you?
  - What would you say can be improved?
  - How about the CCDC, can you tell me about your experience here?
    - What do you think can be improved?

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<sup>1</sup> Several sub-bulleted points represent probative questions that will be ignored when answered in the more general, higher-level question above.