

FOOD INSECURITY AND DIABETES IN HALTON REGION

M.A. Thesis – Rebecca Burns, B.A.; McMaster University – Anthropology of  
Health

“IF THEY FUND PEOPLE WITH GOOD FOOD, MAYBE THEY DON’T END UP ON  
THE MEDICAL END OF THINGS...”: FOOD INSECURITY AND TYPE 2  
DIABETES AMONG PEOPLE RECEIVING FOOD ASSISTANCE IN HALTON  
REGION, ONTARIO

By: REBECCA BURNS, B.A.

A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of  
the Requirements for the Degree Master of Arts

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TITLE: “If they fund people with good food, maybe they don’t end up on the  
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Lay Abstract:

This study looks at how individuals from Halton Region, Ontario maintain their health while living with type 2 diabetes and reduced access to healthy, fresh food. The project uses interview data from 18 one-on-one interviews to demonstrate how people with low income suffer from poorer overall health. Specifically, five conditions affected the study participants' health: type 2 diabetes, reduced access to healthy food, low income, poor mental health, and reduced financial or physical access to exercise or activities of daily living (activity limitation). To combat these conditions, this study suggests an approach to health and diabetes care that looks at the whole person. Evidence and participant suggestions indicate a diabetes health care centre that screens and offers care for other common conditions that occur such as the elements listed above, and also provides nutrition care, physical activity, and social support to patients.

Abstract:

The present study investigates the self-care and health maintenance strategies undertaken by individuals from Halton Region, Ontario living with type 2 diabetes and receiving assistance from food acquisition services such as community food re-distribution centres and food banks. This qualitative research project pulls narrative and thematic interview data from 18 semi-structured one-on-one interviews analyzed with syndemic theory and social determinants of health frameworks to demonstrate how clustering non-communicable diseases and social conditions disproportionately affect those in the lowest income category, and interact with each other to exacerbate the negative health effects of each condition alone. The contributions of this study are theoretical and applied. Theoretical contributions augment existing evidence for the study of non-communicable diseases using a syndemic model. The study participants demonstrated syndemic clustering of five conditions: type 2 diabetes, food insecurity, low income, poor mental health, and activity limitation. Further, this study suggests an applied element to the syndemic model through an approach to health and diabetes care that incorporates the whole person as opposed to a single disease as a unit of care. As suggested through the findings of research participant testimony, a diabetes health care centre, in addition to traditional diabetes care, would ideally screen and offer care for the other common clustered conditions listed in the syndemic elements above. Thus, the centre would provide nutrition, physical activity, mental health, and social supports to patients. As well, it is recommended that future research contributes to prevention and treatment of non-communicable diseases through social, political, and economic in form of increasing government and healthcare supports for people living with low-income and food insecurity.

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Declaration of Academic Achievement:

Rebecca Burns, in partial fulfillment of the requirements for the degree Master of Arts: created the research proposal, wrote the application to the McMaster Research Ethics Board, conducted the research including participant observation and one-on-one interviews, and wrote the content of this thesis. Dr. Tina Moffat provided guidance, content edits, and copy edits, and Dr. Ann Herring completed copy edits.

# Chapter 1: Introduction

## 1.0 Introduction

This thesis is an investigation of people living in food insecure households who use the services of the community-based organization Food for Life (<https://www.foodforlife.ca/>) and who are living with type 2 diabetes. The research is community-based in that it was affiliated with a community-based organization and the research questions are relevant to the community of concern.

The thesis is based on 18 one-on-one, semi-structured, qualitative interviews with clients of the Halton region community-based food distribution organization, Food for Life. Inclusion in the research study was limited to people who have been diagnosed and are living with type 2 diabetes and who volunteered to be participants in this study. In this thesis, I analyse these qualitative findings using social determinants of health and syndemics frameworks. Participants display food insecurity through reduced access, utilization, and stability of food. Diabetes management often influences participants' food choices; however, due to reduced income it is not always possible to follow a diabetes diet. Most participants in this study live on a fixed income, and their income goes to rent and bills before food. Non-communicable diseases (NCDs) can also be managed through exercise, but activity is limited for most participants due to reduced financial means to travel to and pay for exercise facilities, and physical mobility problems. Any of these conditions can influence mental health through stress and stigma. For these and other reasons, which are described at length in the thesis, I propose a cluster of the five conditions: food insecurity, type 2 diabetes, low income, mental illness, and activity limitation, which combine as a syndemic to create an increased health burden on those affected.

This project was of interest to me because I worked closely with people with type 2 diabetes and other chronic illnesses throughout my undergraduate and graduate education. Before beginning the project, I was employed as a pharmacy assistant and as clerical support at a diabetes education centre. As a pharmacy assistant, I gained “insider” information about government benefits for low income earners, old age, or disability support, and I assisted in educating patients about benefits applications. At the diabetes education centre, I prepared information packages for group education sessions, including basic information for newly diagnosed diabetics, learning to make diabetes meal plans, foot care, and other aspects

of diabetes self-care. During graduate school I worked at a residential care facility where many residents took diabetes medication, regularly checked their blood sugar, and asked for help in recording or interpreting their results using doctor-prepared guides. I feel that these combined experiences allowed me a more informed lens within which to frame my interview questions and enabled me to relate to my participants during one-on-one interviews, and to interpret their narratives as they described navigating the pharmacy system, social services, and diabetes self-care.

## 1.1 Research Context

### 1.1.1 Food Insecurity

The studies on food insecurity often include individuals living with low income, poor health, and chronic diseases, or those marginalized by other social conditions such as low educational attainment, immigration status, or minority status. Food security is most frequently defined as “a situation that exists when all people, at all times, have physical, social, and economic access to sufficient, safe and nutritious food that meets their dietary needs and food preferences for an active and healthy life,” (World Food Summit, 1996). The absence of these conditions equates to food insecurity. In order for an individual or family to be food secure, three pillars of food security must exist: availability, access and utilization. Food may be available to consume, but that does not mean that it is either accessible or sufficiently utilized. Food accessibility, which is determined by income, cost of food, travel to places of food procurement, demand, and prevailing tastes within the community. Food utilization requires that it be of good nutritional quality, prepared in safe and sanitary conditions by someone with adequate knowledge of food preparation; nutrients must be readily absorbed and not hindered by chronic illness or deficit. When one or more of these pillars is not met, a household may be food insecure, and may have to resort to food types or food acquisition strategies that are culturally inappropriate, of less nutritional quality, or reduce consumption all together (Barrett, 2010).

In Canada, food insecurity is measured as marginal, moderate, or severe. Marginal food insecurity represents financial constraints or barriers to food security, such as worry over running out of food or not having money for food, and may include limiting selections of foods for financial reasons. Moderate food insecurity is a reduced variety or quantity of food, and severe food insecurity is an overall interruption in food consumption such as reduced food intake, missing meals, or so far as going one or more days without food (Tarasuk, Mitchell, & Dachner, 2016). Food insecurity is cyclical

in nature, where a household will go through cycles of food availability and scarce resources periodically throughout the year (Barrett, 2010). In addition, food insecure households often face external or internal stigma, live with increased social isolation, and this can have implications for food acquisition and management strategies. Both the cyclical nature of food security and the stigma faced by food insecure populations are discussed throughout this review.

### 1.1.2 Type 2 Diabetes: Pathology and Etiology

Type 2 diabetes mellitus (henceforth called diabetes) is a metabolic disorder categorized by insulin resistance, hyperglycemia and pancreatic beta cell dysfunction. Thus, the body cannot use the insulin it produces or does not make enough insulin. Sugar builds up in the blood and may cause damage to other tissues including blood vessels, nerves, and other organs (Diabetes Canada, 2017d; Nolan, Damm, & Prentki, 2011). Prediabetes is diagnosed when there are elevated blood sugar levels through elevated fasting glucose levels or decreased glucose tolerance, but these levels do not reach diabetic levels. Prediabetes can lead to incident diabetes, and there is some research that states that elevated glucose levels present in prediabetes may contribute similar complications as diabetes (Diabetes Canada, 2017d; Nolan et al., 2011). There are many risk factors contributing to diabetes including genetics and epigenetics, overweight and obesity, overnutrition, and lack of exercise, to name a few (Nolan et al., 2011). An important measure of diabetes management is the level of glycosylated hemoglobin, HbA1c, where levels less than or equal to 7% are considered well-managed in diabetic patients, but levels above 8% could indicate a higher risk of complications. These levels are measured through blood testing, and controlled through medication and lifestyle modifications. These medications as well as diet and exercise plans are made with the assistance of dietitians, diabetes educators, and physicians. Some sources now suggest that healthcare professionals incorporate individualized plans that take into account the patient's levels of food security (Nolan et al., 2011; Rendle et al., 2013; Seligman, Laraia, & Kushel, 2010).

Importantly, one method of managing blood sugar levels is through following a strict diet and gauging the effect of foods on diabetes and blood sugar through the Glycemic Index. The Glycemic Index is measured against a standard food, which is glucose or white bread, and describes how quickly or drastically a food can elevate blood sugars. Foods with a low Glycemic Index raise blood glucose less drastically and can help control appetite, thus are

better than starchy foods, and foods with a high Glycemic Index, which raise the blood sugar quickly. For example, vegetables, most fruits, low-fat milk products, or 100% whole wheat bread in general have a low glycemic index, while white bread, Russet potatoes, some processed crackers and short grain rice have a high glycemic index (Diabetes Canada, 2017c). Another dietary strategy relevant to those who are living with low income or are using food acquisition services is to reduce salt intake. The recommendation from Diabetes Canada is to choose vegetables, fruits and whole grains and reduce consumption of packaged foods, including canned vegetables (with salt), canned soups or pastas, instant hot cereals, crackers, frozen dinners, and processed meats and cheeses, which are high in sodium to maintain freshness and safety (Diabetes Canada, 2017b).

To measure blood glucose levels diabetics are eligible to receive a free glucometer, or a device that measures blood glucose levels, when they purchase blood glucose test strips. The cost of the glucometer is absorbed by the pharmaceutical company with the purchase of 100 or more test strips. These test strips are paid for by the Ontario Drug Benefit (ODB), private insurance, or the cost is out-of-pocket if the diabetic is ineligible for either of these. This is often the case for low wage earners who are ineligible for either ODB or private insurance. The test strip is placed in the glucometer, a finger is pricked with a device with a small needle called a lancet, and the drop of blood is placed on the indicated area of the test strip. The glucometer gives the current blood glucose concentration, and most devices now store the results for a certain number of days for interpretation with the assistance of a healthcare professional. Other supplies used by diabetics may be needles or syringes, if that individual has been prescribed insulin injections. It is important to know that lancets and needles are not covered by some private healthcare plans and at the time of the interviews many of these supplies were cited by participants as not covered by benefits for low income, old age, or disability.

### 1.1.3 Low Income Measurements in Canada & Social Assistance in Ontario

Low income cut-offs (LICOs) are the most widely accepted Canadian low-income measurements. They are an estimate of an income threshold above which a family will spend 20 percent more than average families on necessities such as shelter, food, and clothing; families below this cut-off are spending more of their financial resources on necessities. Families are classified by the number of members and community size, and if a family is

below the cut-off then all persons in the family are considered low income (Statistics Canada, 2015b).

Further measures of income include Dissemination Areas and Quintile of Annual Income Per Person Equivalent (QAIPPE). A Dissemination Area has a population of approximately 400 to 700 people and is the smallest geographic area for which Canadian census data is analyzed. QAIPPE is an average income of every person in a Dissemination Area, and the areas are split into fifths, so that 20 percent of those with the highest income are designated as “5” and the lowest 20 percent are designated as “1” (Halton Region Health Department, 2012; Statistics Canada, 2015a).

Ontario Disability Support Program (ODSP) provides income and employment support to persons with a disability who need assistance with living expenses. It provides financial assistance as well as benefits such as prescription medication or vision care, as well as employment services that assist persons with disabilities to find or keep a job or advance their careers (Ontario Ministry of Community and Social Services, 2015b). To be eligible for ODSP income support a person must be over the age of 18, in need of financial assistance (living expenses are more than income and assets), and have a disability. A disability is defined as a mental or physical impairment verified by a medical professional, and expected to last more than a year, resulting in a restriction to work, care for self, or the ability to participate in the community (Ontario Ministry of Community and Social Services, 2015a).

Ontario Works (OW) is a similar program to ODSP except eligibility includes the need for financial assistance with living expenses. It also requires that those taking financial assistance participate in employment support programs (Ontario Ministry of Community and Social Services, 2016).

Old Age Security (OAS) is a Canadian financial benefit for which legal residents over the age of 65 years are eligible, and is based on number of years of residence in Canada (Government of Canada, 2016b). Additional Guaranteed Income Supplements (GIS) are available to recipients of OAS whose annual income is lower than a predetermined maximum annual threshold (Government of Canada, 2016a). Ontario Guaranteed Annual Income System (GAINS) is a support additional to OAS and GIS for Ontario residents who are 65 or older whose incomes do not meet the threshold level determined by the Ontario government (Ontario Ministry of Finance, 2016).



Finally, the Ontario Drug Benefit (ODB) provides coverage for prescription medication and some products used to test and monitor diabetes, including diabetes test strips. Persons that are eligible include those age 65 or older, those living in long-term care, special care, OW, and ODSP. There is also the Trillium Drug Program, which is for Ontario residents who spend approximately three to four percent of their after-tax income on prescription medications. The co-payment for the Trillium Drug Program is calculated by the government and will be either \$6.11 or \$2.00 (or less depending on fees waived by individual pharmacies) per prescription (Ontario.ca, 2017a, 2017b).

#### 1.1.4 Community-Based Research

The original impetus for this project was to assist a team of healthcare professionals and volunteers in their creation of a diabetes education program that was intended to meet the specific needs of clients of Food for Life. I was to assist through provision of research materials relevant to the Food for Life population and then to evaluate the program, once it was established, and to incorporate these elements into my MA thesis as per my educational requirements. As the scope of Food for Life's community goals changed in 2015, the thesis project itself became less applied and more research-based, but was still designed to meet the needs of the community. Community here includes both the Food for Life Organization and the clients they serve. The research participants receiving food assistance were assumed to be living with low income and/or depending on social assistance.

Community-based research is community situated, collaborative, and action-oriented. This means that the research is practically relevant to the community in which it takes place, community members and researchers share research design, implementation and dissemination, and the results of the research are useful to the community and may drive social change (Centre for Community Based Research, 2007). A researcher engaging in community-based research must recognize the power imbalances between themselves and the community in which their research is situated, and understand that community members have expertise that should be recognized and used in research question formation. The research itself must be driven by creating positive social change, respect for the community, and adaptation of the project as the needs of the community are investigated (Centre for Community Based Research, 2007). The final product of the research must be shared with community members, and thus a summary will be provided to the community partner, Food for Life, as well as the study

participants. Efforts, moreover, will be made to disseminate results to relevant Halton Region health and social service providers.

## 1.2 Study Location

All participants lived in Halton Region, in Southern Ontario, Canada. The research recruitment sites were in the cities of Oakville, Burlington, Milton, and Georgetown (a part of Halton Hills). Most of the 18 participants were recruited through the community partner, Food for Life. The research itself took place at Food for Life sites, and local coffee shops or community hubs near the residences of the study participants. Maps of Halton Region may be seen in Figures 1 and 2, which show the Region in the context of major nearby cities including Toronto and Hamilton, and the satellite view gives a

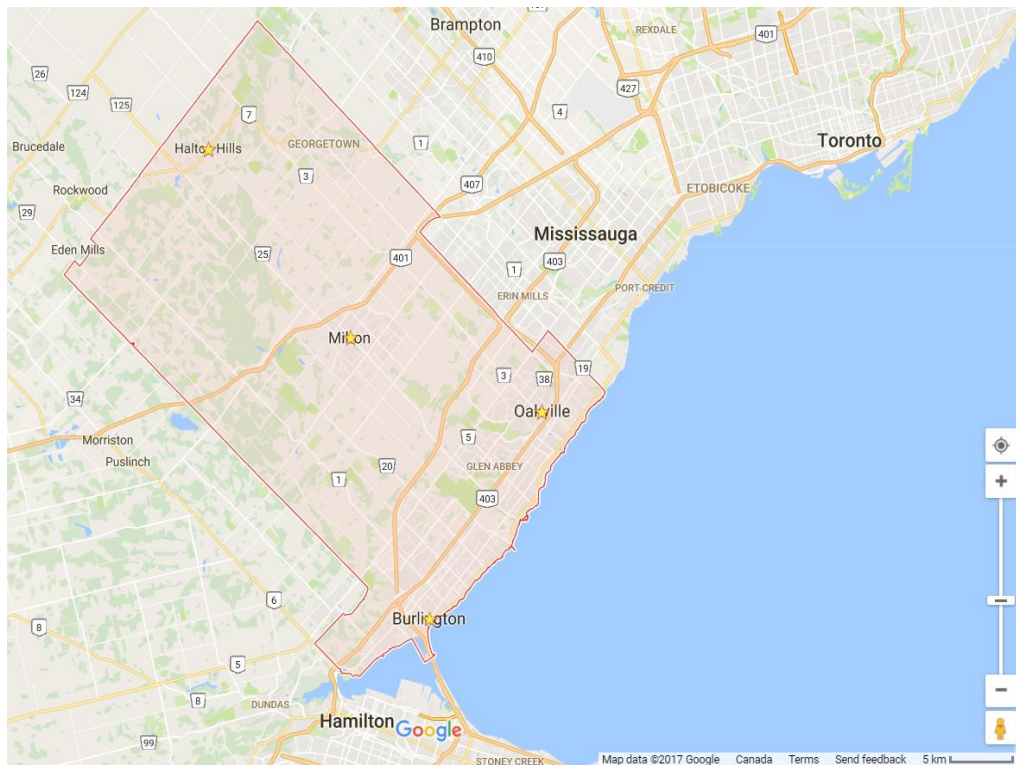


Figure 1: Map of Halton Region. Includes nearby urban centres: Toronto to the east and Hamilton to the west (Google Maps, 2017a).

better idea of the relative degrees of urbanization in the cities discussed throughout the paper.

### 1.2.1 Halton Region: Demographics and Health

Halton Region is west of Peel Region and east of Hamilton. The total population of Halton was 439,256 persons in 2006<sup>1</sup> (Halton Region Health Department, 2012). Burlington and Oakville are the more densely populated, southern cities, while Milton and Halton Hills (of which Georgetown is a part) are further north, and have less development, as can be seen in Figure 2: Map of Halton Region: Satellite View (below).

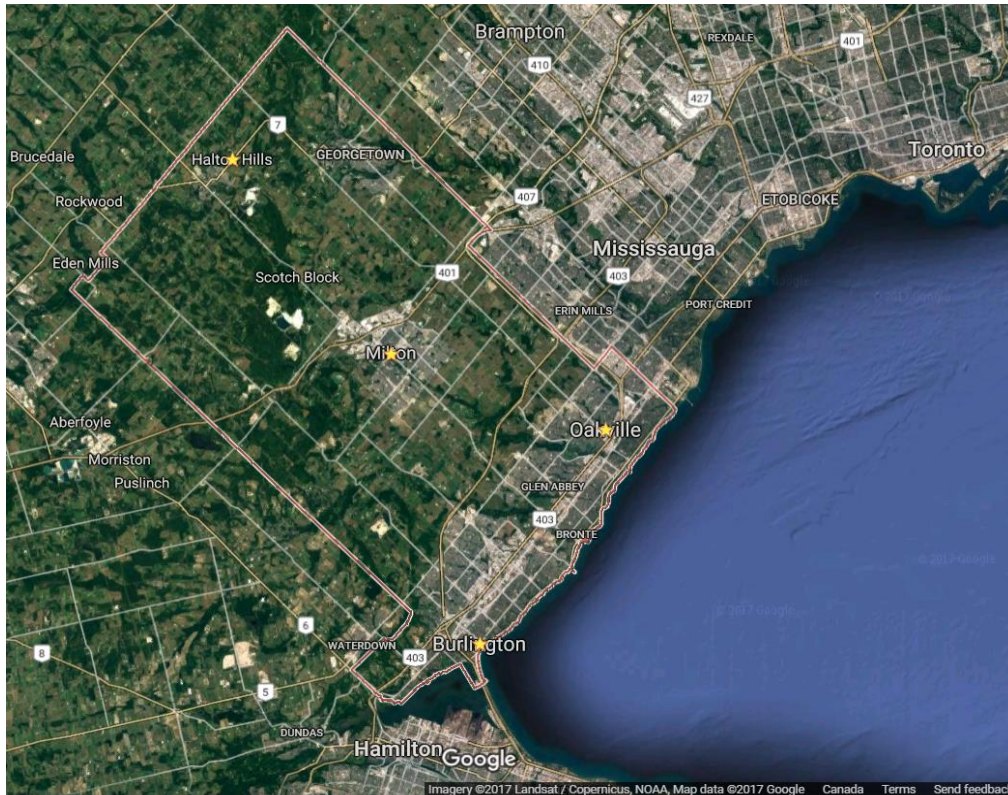


Figure 2: Map of Halton Region, Satellite View. Satellite view gives a visual representation of urbanization (Google Maps, 2017b).

Halton Region has a very high proportion of high income earning families as measured by Quintile of Annual Income Per Person Equivalent (QAIPPE). In 2006, Halton had 312 of 662 quintiles (45.0%) in the highest (5) category and 179 quintiles (32.6%) in the second-highest income category compared to 15 quintiles (2.4%) in the lowest (1) and 56 quintiles (7.6%) in the second lowest categories. QAIPPE distribution can be seen in Figure 3.

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<sup>1</sup> This is the date of the most recent census at the time of the research project.

For the lowest income QAIPE quintile, important statistics include the highest rate of lone parent families (27.8%), immigrants (34.2%), recent immigrants (10.1%), and visible minorities (23.9%), most people renting their home (73.3%), spending over 30% of their income on housing (41.4%), and living below the LICO after tax (24.5%). Further, income-related health inequalities are prevalent in Halton Region. Notably, self-rated health and self-rated mental health, chronic disease risk factors, physical activity in males, diabetes in persons aged 65 and older, activity limitation, hospitalizations, all-cause mortality, circulatory mortality, among others show a gradient across income categories. Interestingly, overweight and obesity, physical activity, alcohol intake, fruit and vegetable intake, and diabetes in those aged 18-64 did not show a statistically significant income-related gradient. That being said, some of these measures showed poor results across income categories, as 39 percent of Halton women and 69 percent of Halton men are overweight or obese, and less than 50 percent of Halton adults overall consumed fruits and vegetables at least five times daily (Halton Region Health Department, 2012).



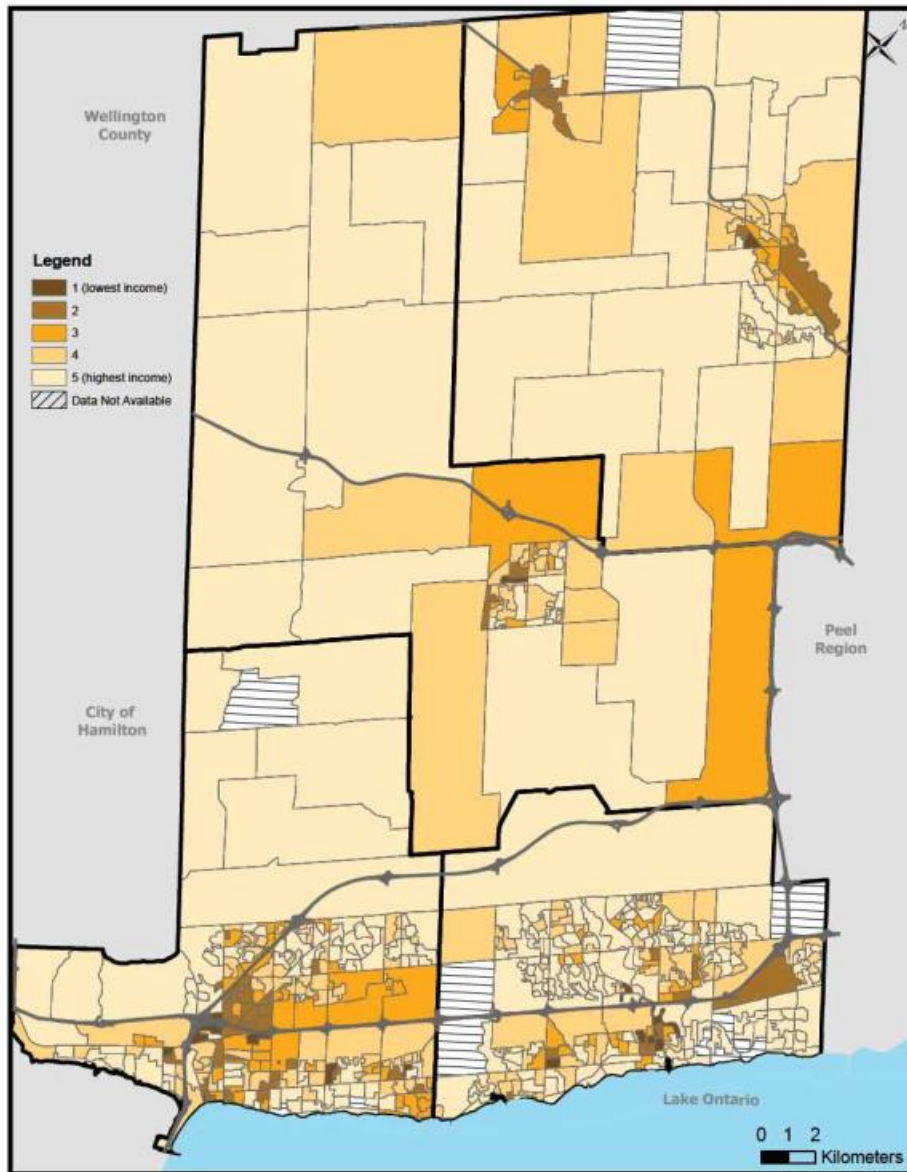


Figure 3: Income Group Map of Halton Region, QAIPE by Dissemination Area, 2006. (Halton Region Health Department, 2012, p. 13). The southern Dissemination Areas are Oakville (east) and Burlington (east) with Georgetown in the northeast, Acton the furthest north, and Milton in the middle.

### 1.2.2 Food for Life

Food for Life is a not-for-profit food distribution program that delivers fresh foods to low-income neighbourhoods in Halton Region, and surrounding area. The primary goal of Food for Life is to deliver donated food from grocery stores and other food stores from stock that is not purchased by day's end and thus unsaleable, but still nutritious, edible, and safe. It

includes fresh and frozen produce, grain products, shelf-stable canned or boxed goods, and occasionally dairy or meat products. A secondary goal of this program is to increase social cohesion among clients while at food distribution centres (<https://www.foodforlife.ca/>).

### 1.3 Research Objectives & Questions

The research objectives are the following:

- 1) To investigate interconnections between diabetes and household food insecurity using qualitative, community-based research methods.
- 2) To aid healthcare practitioners, educators, and policy makers in understanding the barriers and challenges faced by people living with type 2 diabetes and household food insecurity.
- 3) To document the use and possible need for education and support programs. This includes participant ideas about whether modifications to existing programs or additional support programs are required.

The research questions are as follows:

- 1) How does the dual burden of diabetes and food insecurity affect overall health? In particular, is there a relationship between mental health, food insecurity and diabetes?
- 2) What are the cultural narratives or lay explanations of type 2 diabetes etiology?
- 3) Do people living with food insecurity and type 2 diabetes practice compensatory strategies, trade-offs, or financial spending hierarchies?
- 4) Is a syndemics approach to understanding the relationship between type 2 diabetes and food insecurity useful?

One of the main findings of this study includes suggestions for a new syndemic framework of food insecurity and type 2 diabetes. Further, the study participants provide suggestions for policy and healthcare changes to break this syndemic cycle. These are summarized in the Discussion and Conclusion of the thesis.

### 1.4 Chapter Outline

Chapter 2 reviews current literature about diabetes, obesity, food insecurity, low-income, their interconnectedness and relationship with physical and mental health, and then describes the two theoretical frameworks used in this thesis: social determinants of health and syndemics theory.

Chapter 3 details the methodology used to complete qualitative research including participant observation and one-on-one semi-structured interviews, and the approaches used to perform the data analysis.

Chapter 4 summarizes the results of the study, beginning with evidence for participants' experiences of food insecurity, moving to diabetes illness narratives, to living with mental illness, and then the resilience that participants showed in the face of overwhelming barriers and struggle. The chapter closes with participants' ideas for the types of mental and physical health supports they would like to see to help them manage their illnesses, summarized within one facility that incorporates chronic illness, mental illness, and peer support.

Chapter 5 provides a discussion of the syndemic cluster involving type 2 diabetes, food insecurity, mental illness, activity limitation, and low income. The chapter describes pathways and mechanisms of interaction between these five elements, from epidemiological, to longitudinal, to physiological pathways, to qualitative evidence, all incorporated with study participant narratives. The chapter closes by continuing the discussion of the participant-proposed diabetes centre that incorporates participant ideas for centralized care that addresses their overall health and wellness that is physical, mental, and social in nature.

# Chapter 2: Background & Literature Review

## 2.0 Introduction

Food insecurity and diabetes both cause serious health consequences and place a large impact on the Canadian healthcare system. This chapter reviews definitions and current Canadian statistics of food insecurity, diabetes, and obesity. These statistics are interwoven with the qualitative and anthropological research on the personal and interpersonal effects that these conditions have on the individual lives of those affected. From there I move into a review of the state of the social determinants of health in Canada and Ontario, including published perspectives from healthcare professionals. The review is summarized through a short section on theoretical perspectives that were used in the completion of this research project.

## 2.1 Food Insecurity: Canadian Statistics

The most recent statistics regarding food insecurity in Canada were published in 2016 using 2014 data from the Canada Community Health Survey (CCHS) (Tarasuk et al., 2016). The CCHS is a cross-sectional survey of approximately 60,000 Canadians representative of the provinces and territories, and excluding individuals who are full-time members of the Canadian Armed Forces, those living on First Nations reserves or Crown Lands, in prisons, in care facilities, the homeless, and those living in Région du Nunavik and Région des Terres-Cries-de-la-Baie-James in Québec (Statistics Canada, 2016). Not all provinces or territories chose to participate in the food security questionnaire in 2014 as it was not mandatory for that year; thus national numbers are not available in the 2014 report (however Ontario's responses are part of the calculations). The report considers all ranges of food insecurity, from marginally food insecure to severely food insecure, whereas other reports, such as Statistics Canada only include moderate and severe food insecurity. Finally, the nature of the CCHS likely underestimates food insecurity, as those that are at the highest risk, such as the homeless, are excluded from the study (Tarasuk et al., 2016).

In Canada in 2012 (the most recent complete national sample) food insecure households included 4 million individuals, or nearly 13% of households (Tarasuk, Mitchell, & Dachner, 2014). The 2014 survey indicated that 12.0% of households, or 3.2 million individuals experienced food



insecurity in the past 12 months. Further, in 2014 5.5% and 2.7% of households were moderately and severely food insecure, respectively (Tarasuk et al., 2016). The authors noted that while the rate of food insecurity slightly declined between 2013 and 2014, this decline was not statistically significant, and is still substantially high when compared to 2008 levels of food insecurity (Tarasuk et al., 2016).

In 2012 Ontario had an 11.7% rate of food insecurity, which rose to 12.5% in 2013 and then dropped to 11.9% in 2014. That is the equivalent to 571,300 households in 2012, and 594,900 in 2014. Of those households, 141,800 were severely food insecure in 2014 (Tarasuk et al., 2014, 2016).

One of the most important interpretations of the CCHS data involves understanding the characteristics of the households that are food insecure. In 2014 food insecurity was most prevalent in households with children under 18 (15.6%) with increased vulnerability in households with children supported solely by a female lone parent (33.5%). Also of note was the rate of food insecurity in households led by a female lone parent with children at or above 18 years of age (13.8%), households with individuals unattached, living alone, or living with others (15.7%) (Tarasuk et al., 2016). In addition, income was a major determinant of food security, with increased likelihood of severe food insecurity with decreased income compared to Statistics Canada's Low Income Measure<sup>2</sup> (Tarasuk et al., 2016). Other characteristics of households that were food insecure included those that rented (24.5%) versus owned (6.2%) their homes, recent immigrants to Canada (15.2%), and those self-identifying as Aboriginal (25.9%) or Black (29.4%). Rural households reported less food insecurity (10.3%) than urban households (12.4%), but this difference was not statistically significant (Tarasuk et al., 2016).

Further findings indicated that of households reliant on social assistance in Ontario, 64.0% were food insecure. Further, in Canada, of those whose household income was reliant on social assistance, nearly one-third, or 29.4% of households were severely food insecure. This brings to light the fact that social assistance is not meeting the needs of this vulnerable population (PROOF Food Insecurity Policy Research, 2017). Of the food insecure population itself, most households were reliant on wages or salaries from employment (62.2% in both 2012 and 2014) (Tarasuk et al., 2014, 2016),

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<sup>2</sup> Low Income Measure is used in Canada as an indication of poverty. It is 50% of household income adjusted for household needs such as family size. It is the most commonly used low income measure used internationally (Statistics Canada, 2015c).

meaning that these individuals and families likely did not have stable or adequate employment or access to extended health benefits or welfare that could provide additional support (Pilkington et al., 2011; Raphael et al., 2003). Other demographics included those on senior's income (13.3%), other or no income (6.3%) and employment insurance or workers compensation (2.5%) (Tarasuk et al., 2016). A final important note made by the authors of the report is that since 2005, when monitoring of household food insecurity began, the problem of food insecurity has either persisted or grown, despite monitoring (Tarasuk et al., 2016).

Literature published before the regular reports on household food insecurity in Canada highlight the history of the research on food insecurity in Canada (Tarasuk, 2005) as well as the issues regarding the stigmatization of food insecurity and the inadequacy of current measures for combatting it (Kirkpatrick & Tarasuk, 2009; Tarasuk, 2005; Vozoris & Tarasuk, 2003). A valuable point made by Kirkpatrick and Tarasuk (2009) is that charitable food programs, such as food banks, are perceived to be effective and to reach everyone in need, when in fact they are underutilized by food insecure populations and do not adequately address the social and economic issues that lead to food insecurity. Food banks, breakfast programs, community kitchens and other charitable programs are associated with stigma, often poor quality food, and do not adequately deal with issues of low income and other social determinants of health (discussed later in this review, as well as in Raphael et al., 2003; Raphael et al., 2012). There are, however, some key aspects of these types of programs that could be beneficial and should be considered. In particular stress and social isolation associated with food insecurity can have very negative health and social consequences (Hamelin, Habicht, & Beaudry, 1999; Mendenhall, 2012; Pilkington et al., 2011). Some of the authors who have criticized, for example, breakfast programs for children or community kitchen programs, (Kirkpatrick & Tarasuk, 2009; Tarasuk, 2005) have not considered the potential stress relieving effects or reduced social isolation that may be positive outcomes of these programs. In addition, these charitable food programs can be improved by the inclusion of fresh foods and produce, which could contribute to a more balanced diet for food insecure households by improving micronutrient (vitamins and minerals vital to body function and health) intake. I have not found research that has documented these potential positive outcomes, and thus there is a gap in the literature.

## 2.2 Diabetes & Obesity: Canadian Statistics

### 2.2.1 Diabetes

The prevalence of diabetes in Canada in 2016 was 3.5 million people, or 9.2% of the population, and the prevalence of diabetes and prediabetes together was 11 million individuals, or 29%. This is estimated to rise to 4.9 million or 11.6% by 2026 for people with diagnosed diabetes, and 13.9 million or 33% for prediabetes and diabetes combined. The magnitude of the problem of diabetes in Canada is further illustrated through the estimated 72% increase in diabetes prevalence between 2006 and 2016, and the further 41% estimated increase in diabetes prevalence between 2016 and 2026. For context, the cost of diabetes to our healthcare system was \$3.4 billion in 2016, which is estimated to increase to \$5 billion by 2026 (Canadian Diabetes Association, 2016).

Some authors have noted that the presence of diabetes was 4.14 times higher in the lowest income category compared to the highest, and that the obese population was 4.96 times more likely to have diabetes than those who are not overweight. Other groups with higher rates of diabetes included immigrants, those who rented their house, had less education, were widowed, and were less physically active (Dinca-Panaitescu et al., 2011). These results show that there are similar risk factors for diabetes as for food insecurity.

### 2.2.2 Obesity

Historically, policy makers discredited claims of hunger and food insecurity in the low income population because of the high prevalence of overweight and obesity in low income or diabetic populations (Adams, Grummer-Strawn, & Chavez, 2003; Olson, 1999; Townsend, Peerson, Love, Achterberg, & Murphy, 2001). However, studies of overweight and obesity among food insecure households have found similar results in that those with food insecurity are more likely to be overweight or obese, and this trend was more likely to hold true for women than men. Olson (1999), using survey data and multiple linear regression analysis, found that women in households with food insecurity were approximately two BMI (Body Mass Index) units heavier than those in households that were food secure. Townsend et al. (2001) found a relationship between increased overweight in food insecure women but not men; however, the study used only one question to measure food insecurity and thus may not have accurately represented the prevalence of food insecurity in the study population, bringing into question the reliability of the results. Adams et al. (2003) found that for non-Hispanic White women

the presence of obesity increased with food insecurity, but did not increase further as food insecurity became more severe; while for women of other ethnicities the prevalence of obesity increased with increasing food insecurity.

One of the main concerns with these studies is that they do not include any sort of measure of micronutrient sufficiency or deficiency status for their study populations. While they do make brief mention of social and health outcomes for these individuals, such as mental health status in children of food insecure households (Olson, 1999), they do not note how deficiencies in micronutrient status brought on by the inability to afford nutrient dense foods can have a negative effect on health and well-being. Also worth mentioning is that different authors used slightly different methods and slightly different categorizations of overweight and obesity. A review of how the understanding and measurement of obesity has changed over time is available in McNaughton (2013).

In Canada, in 2014, 5.3 million adults 18 years of age or older, or 20.2% of adults, self-reported height and weight that classified them as obese. In addition, 40.0% of men and 27.5% of women self-identified height and weight that classified them as overweight (Statistics Canada, 2015d). Overweight and obesity are important risk factors for type 2 diabetes mellitus as they contribute to insulin resistance, and when paired with chronic overnutrition, or susceptible  $\beta$  cells, can lead to diabetes (Nolan et al., 2011). insecurity.

## 2.3 Living with Low-income, Food Insecurity, and Chronic Conditions

### 2.3.1 Food Insecurity and Diabetes

Drewnowski and Specter's (2004) review provides insight into the relationship between food insecurity and obesity, which can also be related to other health outcomes. The authors examine the relationship between obesity and diet quality, dietary energy density, and energy cost. They find that foods with lower shelf lives have higher water content, and are more expensive. The less expensive foods are generally energy dense and more deficient in nutrients. The authors also discuss laboratory studies showing that once one is on a diet that is high energy, and often quite palatable due to salt, fat and sugar content, it is more difficult to switch to fresh fruits and vegetables. This means that an individual or household that is used to energy dense and nutrient poor food consumption is more likely to continue to eat

these same foods during times of food security (Drewnowski & Specter, 2004).

Food insecurity and financial restriction are often cyclical in nature and thus families experience times of scarcity and times where acquisition of food is not as much of an issue. This cyclical nature of food insecurity also leads to a pattern of restricted eating followed by overconsumption (Adams et al., 2003; Rendle et al., 2013), and as previously mentioned, during times when adequate food consumption is possible, a diet that may cause or exacerbate diabetes is likely to be consumed due to palatability (Drewnowski & Specter, 2004) or due to rewarding oneself for overcoming the stress of paying all necessary bills (Rendle et al., 2013). This suggests that interventions that interrupt the cyclical nature of food insecurity could be effective in preventing diabetes onset.

Using the 2005 cycle of the Canada Community Health Survey (CCHS), Gucciardi et al. (2009) found that the overall rate of household food insecurity was higher among those with diabetes than without diabetes. The authors, moreover, found that a higher proportion of individuals with diabetes living in food insecure households reported being diagnosed at an earlier age, having unmet healthcare needs, being hospitalized overnight during the last year, being current smokers, living with the effects of a stroke, and having a mood disorder (Gucciardi, Vogt, DeMelo, & Stewart, 2009). Gucciardi et al. (2009) also found that individuals living with diabetes and food insecurity were less likely to rate their satisfaction with life, health, mental health, or stress levels positively (Gucciardi, Vogt, DeMelo, & Stewart, 2009). Similarly, Vozoris and Tarasuk (2003) found that poorer health rating, restricted activity, poorer functional health, multiple chronic conditions, major depression and diabetes and poor social support were all associated with food insecurity. In addition, they found that physical, mental and social health were all affected by food security status. These outcomes all point to unequal access, as opposed to availability, of healthcare, healthy food resources, and social support to combat feelings of isolation and stress. Thus, the inability to properly manage diabetes and other chronic diseases and access to adequate food, coupled with stress and the stigma of food insecurity are all associated with one another, leading to negative biological and social outcomes.

A key source for the study of diabetes in relation to food insecurity is Seligman et al.'s (2007) evaluation of the risk of diabetes according to mild or severe food insecurity. Using the National Health and Nutrition Examination

Survey (NHANES), (a US National Statistical study similar to the CCHS, discussed above) from 1999 to 2002, the authors found that the prevalence of diabetes was 10.0% and 16.1% in the mildly and severely food insecure populations respectively, compared to 11.7% in food secure populations. They found similar determinants of food insecurity and diabetes as the previously mentioned in Canadian studies (Tarasuk et al., 2016), such as racial and ethnic minority groups, low income, less education, and decreased level of physical activity, but they also mention the very important risk factor of family history of the disease. Tracking family history of diabetes using the CCHS may provide useful information, as in the American samples. Seligman et al. (2007) highlight a limitation of this type of study in that food insecurity is a household measure while diabetes is an individual measure, thus these statistics are difficult to directly compare.

Seligman and Schillinger discuss chronic disease alongside hunger and socioeconomic disparities. They importantly point to compensatory behaviours that people undertake when their food resources are lacking, and how this can have a negative effect on chronic disease management outcomes (Seligman & Schillinger, 2010). Another study also found that food insecure adults were less likely to have control over their diabetes, and mean HbA1c level was higher in food insecure than food secure populations (Seligman, Laraia, et al., 2010). These studies are located in the US, and thus while some findings, such as chronic disease diagnosis among the food secure versus food insecure populations are significant, they are not as applicable to Canada, where health care access is not as severe a barrier to disease diagnosis (Pilkington et al., 2011; Raphael et al., 2012).

A final important link between food insecurity and diabetes is the risk of hypoglycemic, or severely low blood sugar episodes, which at best decrease quality of life, and at worst cause death (Seligman et al., 2010a; Seligman et al., 2011). Food insecurity can contribute to this problem in two ways. First, the cost of food can compete with the cost of blood sugar testing supplies, and thus people might be unaware of their blood sugar levels until they get severe symptoms of hypoglycemia. Second, food insecurity can lead to the household running out of food, or not having supplies of fast sugar (sources of sugar that quickly raise the blood glucose level to prevent symptoms of hypoglycemia), both of which can lead to a hypoglycemic episode (Seligman et al., 2011; Seligman, Davis, Schillinger, & Wolf, 2010). This problem is relevant to Canada, as often the working poor, who make up the majority of the food insecure population (Tarasuk et al., 2014), do not have extended

health coverage, and blood sugar testing supplies that are part of welfare benefits only, are not covered by universal health care benefits such as OHIP (Pilkington et al., 2011; Raphael et al., 2012). Thus, the need to purchase these supplies may compete with food needs.

The main limitations of the studies conducted by Seligman and colleagues are their cross-sectional nature, which don't capture the changes in food security and health status of their population over time (which came first, food insecurity or disease?), and the small sample sizes of diabetic survey participants, especially food insecure diabetic survey participants, relative to those who are food secure.

One thing that Seligman and colleagues attempt, which other authors do not, is a way to explain the biological connections between food insecurity and type 2 diabetes. Unfortunately, they propose unsubstantiated use of evolutionary explanations without full explanation of these theories. There is potential for these theories to be deterministic, and sometimes replace the use of the social determinants of health in understanding these disease inequalities. A mechanistic explanation that could replace evolutionary explanations is provided by the theory of epigenetics. Epigenetics is a relatively new approach within biomedicine, reviewed recently by Waterland and Michels (2007). Methylation determines epigenetics, with methylation referring to a methyl group attached to a cytosine DNA nucleotide residue. Increased methylation will decrease DNA transcription (silence the gene) through tighter histone packing. It is proposed that methylation is sensitive to environmental and nutritional stimuli. Inadequate micronutrient supply can decrease the supply of molecules necessary for sufficient methylation. Hormonal environment may upregulate or downregulate the transfer of DNA methylation from parent to daughter strands of DNA through altered enzymatic activity. Environmental stimuli for the developing fetus is considered the intrauterine environment, which receives hormonal, including insulin and stress hormone, signalling from the mother (Waterland & Michels, 2007). Epigenetics also refers to the transfer of gene expression information that is not strictly genetic, as in the methylation of certain genes as described above. DNA methylation in the early embryo sets up the epigenetic profile of open and closed, or expressed and non-expressed, chromatin states. Once these are set up, they are generally maintained with high fidelity throughout life, thus altering the offspring phenotype (Waterland & Michels, 2007). This is specifically relevant to type 2 diabetes, because a hyperglycemic environment may influence DNA methylation in

offspring, leading to insulin resistant, hyperglycemic, obese, or type 2 diabetic phenotypes in the offspring (McLean, Chipps, & Cheung, 2006; Waterland & Michels, 2007).

A discussion of epigenetics in relation to diabetes and food insecurity is relevant because it provides an explanation that encompasses environment, socioeconomic status, stress, and family history. Some of these factors are modifiable, which shows that there is the potential for a phenotype modification in future generations, for better or for worse. Continuing along a trajectory that ignores these epigenetic or social determinants of health factors could potentially increase obesity or diabetic phenotypes; however the evidence shows that improving these factors may mitigate the current rise in diabetes. The hypothesis would be that with improved food security, better nutrition, and improved environmental factors, the offspring of parents with these phenotypes may have better health outcomes or healthier phenotypes, which could benefit public health and public health spending. Further, epigenetics fits nicely with the syndemic model (see 2.5 below for a full discussion of the syndemic model), which also looks at the interrelationship among environmental and social factors. The similarities of these two frameworks offer a common ground between disciplines, leaving room for collaboration across specialties or inclusion of evidence from multiple disciplines. Epigenetics is further discussed in the Lancet series on syndemics (Mendenhall, Kohrt, Norris, Ndeti, & Prabhakaran, 2017).

### 2.3.2 Food Insecurity, Diabetes, and Mental Health

As previously stated, stress and social isolation can have negative impacts on diabetes management, through elevated blood glucose levels and decreased self-care practices. Schoenberg and colleagues (2005) did a qualitative study with a multiethnic cohort to discover ways that stress can affect disease management and outcomes. Their study is unique because, “interviewers did not inquire about stress; rather, the fundamental place of stress within lay diabetes narratives emerged as a central thematic construct during analytic procedures,” (Schoenberg, Drew, Stoller, & Kart, 2005, p. 178). The results of the interviews show that within lay discourses a stressor can directly or indirectly cause diabetes (“proximate” or “distal” mechanisms), and diabetes pathogenesis can be acute or long-term (“sudden” or “protracted” onset). They also find that stress or stress-like emotions can exacerbate diabetes pathology, undermine self-care regimens, and importantly lay persons feel that stress can be both a precursor to, and a consequence of diabetes pathology (Schoenberg et al., 2005). These lay



discourses are important because they provide alternative definitions from the biomedical model of explanations and understandings of stress and diabetes etiology. This type of research has the potential to assist physicians and health care providers to screen for additional risk factors for diabetes onset, as well as assist in counselling for better glucose management (Schoenberg et al., 2005). Finally, this type of research, especially alongside other research on diabetes management habits and self-care, food insecurity, social isolation, and other barriers to good health, (Hamelin et al., 1999; Mendenhall, 2012; Pilkington et al., 2011; Raphael et al., 2012; Rendle et al., 2013) can assist physicians in understanding the unique situations of low-income patients and avoid reductionist models that blame the disease and poor management of it to “poor compliance”<sup>3</sup> (Schoenberg et al., 2005).

## 2.4 Theoretical Perspectives

Social determinants of health (Pilkington et al., 2011; Raphael et al., 2003, 2012) and syndemics (Singer, 2009; Singer & Clair, 2003) frameworks were used in this study to examine health, illness and health care from a critical perspective. These frameworks allow for an in-depth analysis of social, cultural, economic and policy barriers to food security and successful diabetes prevention and treatment. A syndemics approach, as conceived by Singer and Clair (2003) and Singer (2009), was used to understand the simultaneous and synergistic effects of diabetes, food insecurity, and stress related to living in poverty. Syndemics theory describes the interplay of a multitude of burdens: biological synergism of more than one disease, social barriers, structural barriers, environmental factors, other social determinants of health, and structural violence (Farmer, 2004; Raphael et al., 2003), resulting in an additional disease load on those affected. Previously Syndemics has described coexistent disease epidemics, such as Singer’s (2009) discussion of tuberculosis and HIV, or Mendenhall’s (2012) study of diabetes, depression and violence among Mexican immigrant women living in Chicago. Singer and Clair (2003) discuss that syndemics applies to health consequences because of biological interactions among health conditions, thus I would argue that it is applicable to diabetes and food insecurity. Food insecurity can lead to a range of health issues, not limited to malnutrition, poor rating of overall health or psychological health, and overweight and obesity (Adams et al., 2003; Olson, 1999; Ramsey, Giskes, Turrell, & Gallegos,

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<sup>3</sup> Quotations around “poor compliance” in this instance refer to the author’s hesitance to use the term, as people who are low income or on social assistance often have less control over their “compliance” habits.

2012; Seligman, Laraia, et al., 2010; Townsend et al., 2001; Vozoris & Tarasuk, 2003), and it has been proven to contribute to the poor management of diabetes (Gucciardi et al., 2009; Ramsey et al., 2012; Seligman et al., 2011; Seligman, Bindman, Vittinghoff, Kanaya, & Kushel, 2007; Seligman, Davis, et al., 2010). It has also been suggested that diabetes or poor diabetes self-management may contribute to increased food insecurity through increasing morbidity and decreasing participation in the work force (Nelson, Cunningham, Andersen, Harrison, & Gelberg, 2001; Seligman et al., 2007; Seligman, Laraia, et al., 2010). I will demonstrate how this disease and this social determinant of health interact dynamically, with each condition making the other worse to contribute to increased diabetes morbidity and devolving social circumstances. For these reasons syndemics in addition to a social determinants of health approach is a useful theoretical framework for the investigation of food insecurity and diabetes.

Finally, the concept of culture is used to attempt to access lay discourses of diabetes etiology and symptomology. Dinca-Panaitescu et al. (2011) mentioned that little work has been done regarding culture, the social determinants of health, and diabetes. Contrarily, Ferzacca (2012) calls for the end of the use of culture when talking about diabetes, due to its misuse by the general public, and its potentially damaging misuse in other disciplines as an all-encompassing blanket explanation as to why diabetes prevalence is higher in one population over another, instead of looking to deeper social issues. Culture is sometimes part of peoples' explanatory models of diabetes pathogenesis, such as Mexican immigrant women in Mendenhall's study who blame the onset of diabetes on chronic stress and a "bad case of nerves". Nerves is recognized as an illness in Mexican culture (2012). Thus, if culture is used appropriately, it can be an effective tool for accessing someone's experience with and perspectives on diabetes.

#### 2.4.1 Food Insecurity, Diabetes, and Social Determinants of Health in Canada

Hamelin et al. (1999) examine the social and familial implications of household food insecurity. This is an excellent article that provides reference tables of such implications, as well as detailed analyses of findings at the micro (familial) level. The authors find that food insecurity consequences include physical impairment, such as hunger, illness, or lack of concentration at school or work, psychological suffering due to stress or practicing food procurement strategies that go outside their perceived norms, and sociofamilial perturbations such as the loss of the family meal and disrupted

household dynamics. The authors also suggest that such impaired learning, loss of productivity, decrease of participation in social life, and the loss of transfer of knowledge at mealtime could have broader implications of slowing social and economic development, feeding into socioeconomic inequalities (Hamelin et al., 1999). While this study was done with a Quebec (Francophone) study population, which could have different perspectives on the symbolism of food that may not represent the general Canadian population, I believe that these fears of the loss of the family meal and the school and workplace implications can be applied more broadly. In addition, the authors mention that this could contribute to socioeconomic disparity, which is echoed by other authors (Ramsey et al., 2012) when they discuss that food insecurity and associated depression and general decreased health may lead to decreased participation in the work force, contributing to increased food insecurity. Another way to examine this issue is by looking at the social determinants of health that could play a role in the propagation, or if modified, alleviation of health inequalities.

Social determinants of health are the political, economic, and other social factors that make the necessities for life, such as income, food, and shelter, more or less available to populations, communities, families or individuals (Pilkington et al., 2011; Raphael et al., 2003, 2012). Each article reviewed here expresses similar views with regard to the lack of social support available for Canadians in the lowest-income groups, the unsustainability of the necessity of exhausting all forms of income and savings before social assistance becomes available, and the lack of knowledge and awareness of these factors by the general public. Specifically, Pilkington et al. (2011) looked at community healthcare providers' views of the social determinants of health. Through focus groups, this study identified that these healthcare providers are well aware of the compounding effects that poverty, generalized insecurity, lack of personal control, and chronic stress can have on an individual's health. They also identify the need to counter isolation, to provide long-term as opposed to short-term solutions for providing health supplies (such as syringes and lancets for diabetic patients, as those are not covered by any form of government assistance), and the need to integrate primary healthcare, public health and social services while making social policy changes. These providers are frustrated that they do not have the time for social advocacy under constraints imposed by the current health care system, which forces them to focus on the quantity of patient visits rather than quality; it also appears to the authors that health advocacy does not

seem to be a part of healthcare providers' jobs, as they never mention it in their focus groups (Pilkington et al., 2011).

Two articles authored by Raphael et al. (2003; 2012) discuss how social exclusion, food, housing and employment insecurity, and public policy supporting lifestyle interventions to improve disease outcomes leave Canadians in the lowest income category without support, leading to negative health outcomes. To better access the needs of these underserved populations, Raphael et al. (2012) conducted research through qualitative, semi-structured interviews. The current model of “lifestyle approaches” to diabetes management is based on diet, exercise and medications, all three of which can be inaccessible to low-income populations. Instead, the authors call for a shift in public policy that focuses on social programs to create safe outdoor spaces and indoor meeting places to reduce isolation and increase social cohesion and the feeling of safety while exercising, as well as improving welfare benefits, which currently place people that use those services below Canada's cut-off measure of poverty, which at the time the articles were written was the Low Income Cut-Off (Raphael et al., 2003, 2012).

The Social Determinants of Health model could be improved by linking these factors to biologically recognized physiological processes, so that doctors and other health professionals may be better equipped, or even more inspired to advocate social change. If social and demographic evidence can be linked with physiological disease outcomes, a stronger case to promote policy change could be made, placing us in a better position to demonstrate that by spending more money on social assistance, less money will be spent on emergency and chronic healthcare.

#### 2.4.2 Syndemics Framework

A central goal of medical anthropology is to evaluate the interaction of social, psychological, and biological influences on health across cultures and time. One method with which to do so is through syndemic theory (Weaver & Mendenhall, 2014). Syndemics is a term coined by Merrill Singer, initially used in medical anthropology, but now cited across disciplines including epidemiology, medical sociology, public health, and most recently biomedicine. This section will review the components of a syndemic framework, with specific examples from research involving diabetes. Syndemics occur when two or more health conditions or diseases interact, along with social conditions, to cause an even greater negative health effect than any individual disease, health condition, or social condition alone. They

involve all health conditions including infectious diseases, non-communicable diseases, mental illness, malnutrition, toxic exposure, and behavioural conditions, and most often occur among those with the poorest social conditions because this is where these types of health conditions tend to cluster. For this reason, syndemics moves beyond simple comorbidity to look at a larger picture of cause and consequence, as social conditions can influence illness distribution, (Mendenhall, 2012, 2016; Singer, 2009). Management of a syndemic requires an intervention that is multifaceted and spans across professions (Singer, Bulled, Ostrach, & Mendenhall, 2017) bringing together multiple fields, including medicine, health systems and human rights, as these fields work towards understanding and alleviating suffering in vulnerable populations (Mendenhall et al., 2017). To identify a syndemic, five conditions must be met: a “clear account of the diseases and health conditions, examination of the pathways or mechanisms of disease-disease interaction, a clear description of the socioenvironmental conditions and how they are experienced by human minds and bodies as adversity, examination of the pathways of effect from socioenvironmental conditions to biological or psychological states, [and] evidence of greater health burden because of interaction” (Singer et al., 2017, p. 941).

Recently there has been a major infusion of syndemic thinking within the literature on NCDs, specifically diabetes (Mendenhall, 2012, 2016; Mendenhall et al., 2017; Mendenhall, Seligman, Fernandez, & Jacobs, 2010; Weaver & Mendenhall, 2014). Specifically, Mendenhall and colleagues argue that NCD syndemics show the complexities of interactions between social, psychological, and biological factors that influence health, epidemiology, and experiences, and that these local complexities, once discovered, can assist in creating health interventions specific to the populations studied (2016; 2017). Studying individual experiences can demonstrate social problem clustering, how experiences differ, and how this can manifest in depression or symptomology within a syndemic (Mendenhall et al., 2017). A syndemic approach would suggest treating individuals that suffer from syndemic interactions as a single unit instead of dealing separately with one of their conditions or diseases at a time, thus attempting to tackle major comorbidities and social conditions simultaneously (Mendenhall et al., 2017).

A prime example of a syndemic approach to NCDs is exemplified in Mendenhall’s 2012 book, *Syndemic Suffering: Social Distress, Depression, and Diabetes among Mexican Immigrant Women*, as she provides the most complete review on diabetes as it relates to the social determinants of health,

as well as social-cultural, individual, and interpersonal factors that play into diabetes pathogenesis and management. The book centres around the experiences of first and second generation Mexican immigrant women in Chicago, Illinois. Mendenhall adopted Singer's syndemics approach to describe what she calls the VIDDA Syndemic: Violence, social Isolation, Depression, Diabetes, and interpersonal Abuse. Violence is described by structural violence, symbolic violence (men and women not being able to fulfill their culturally understood traditional roles), and everyday violence. Isolation describes the women's longing for friends and family back home, the inability to acquire political or legal help due to fear of deportation for self or other family members, and the inability to seek mental health care. Interpersonal abuse: sexual, physical, verbal and emotional, often from a very young age, cause women to harbour very negative emotions that increase chronic stress. Diabetes and depression play off one another, as chronic stress can increase blood sugar, depression can make diabetes self-care a difficult task, and fear of diabetes complications often plays back into the women's depression and anxiety. Mendenhall allows the women, her study participants, to define what is important for her research, and through this learns that her informants often link their social and emotional distress with somatic (body) symptoms. Diabetes was not identified as a major stressor in most women's lives, wherein diabetes was not an endpoint, rather it was just one piece of their narratives of distress. The interaction of these five factors clustered to create increased morbidity in study participants and other members of their community. Mendenhall uses the term "syndemic suffering" to describe the lived experience of syndemics in her participants (Mendenhall, 2012, 2016).

A final noteworthy point is that syndemics pushes for social change to alleviate poor health outcomes, and this is supported by social justice and international human rights. In the *Lancet*, "According to international human rights standards, all people have an equal right to the highest attainable standard of physical and mental health, which includes access not only to health care, but also to the underlying determinants of good health," (Willen, Knipper, Abadía-Barrero, & Davidovitch, 2017, p. 964). When looking at human health rights through a medical anthropological lens, we must look at "(1) the role of power and inequality in structuring vulnerability; (2) the complex and multilayered nature of local contexts (historical, structural, environmental, social, economic, political); and (3) the subjective impact of disease, illness, and injury on individuals and their families and communities," (Willen et al., 2017, p. 968). In the syndemics approach we can

recognize upstream factors that influence health, how some communities or individuals are more at risk than others, and how we can intervene through these upstream channels to positively influence health at the point of the individual or clinical interaction.

Some important criticisms of syndemics exist, found within (Tsai, Mendenhall, Trostle, & Kawachi, 2017). Firstly, there is weak empirical evidence for the success of multicomponent interventions. Another criticism of modern syndemics work is that many papers use a sum score of exposures as the unit of syndemic measurement, which does not prove causality or interaction. Finally, if at the core of syndemics is the interaction of two or more diseases or conditions, then it has been suggested that a single-component intervention should suffice to interrupt a syndemic interaction (Tsai et al., 2017), although I would argue that this point of view dismisses the social conditions aspect of syndemics theory.

This thesis research project does not use a sum score of exposures, but rather utilizes the unique lens of perspectives from study participants to demonstrate interactions between clustered conditions to provide practical suggestions to mitigate the diabetes and food insecurity syndemic that I propose these participants and many in their community are experiencing.

## 2.5 Summary

Though research on food insecurity and type 2 diabetes is scarce, there are some good indications from several Canadian and US sources that there is an important link between the two conditions. Tarasuk and colleagues (2016) found that a significant proportion of the Canadian population is food insecure (11.9% in 2014), and that the majority of these food insecure households rely on wage earnings, meaning that these families do not have access to extended health benefits to pay for diabetes medication and supplies (Pilkington et al., 2011; Raphael et al., 2003, 2012). Furthermore, in Ontario, 64% of households reliant on social assistance in 2014 were food insecure (Tarasuk et al., 2016), and those on social assistance can include individuals on disability for diabetes-related complications. Food insecurity is associated with both obesity (Adams et al., 2003; Olson, 1999; Townsend et al., 2001) and diabetes in American (Seligman et al., 2007) and Canadian (Gucciardi et al., 2009) studies. Further, it is also associated with increased hypoglycemic episodes in diabetic patients (Seligman et al., 2011; Seligman, Davis, et al., 2010). These studies are limited due to their cross-sectional nature, and thus qualitative studies can better access the lifecourse

narratives and lived experiences of individuals living with food insecurity and diabetes.

Mendenhall (2012) looked at how stress, social isolation and violence can exacerbate diabetes symptoms in Mexican immigrant women using a syndemics model. Stress and social isolation can reduce self-care and cause increases in blood glucose (Mendenhall, 2012; Rendle et al., 2013; Schoenberg et al., 2005). Unfortunately, blame for “non-compliance” often falls on the patient for not following prescribed regimes or eating correct foods, even though access to these resources is limited. This can, in turn, reduce communication in the clinical setting (Rendle et al., 2013). In Canada, there is a lack of funding and policy supporting the social determinants of health. Further, policies geared toward “lifestyle approaches” to health coupled with the necessity to exhaust all monetary funds before welfare is provided leads to poorer health outcomes (Pilkington et al., 2011; Raphael et al., 2003, 2012).

Both the social determinants of health and syndemics approaches are used in this thesis to analyse and interpret the narratives and perspectives of participants discussing their experiences living with type 2 diabetes, household food insecurity, and, in many cases, social isolation.



## Chapter 3: Methodology

### 3.0 Introduction

In this study, I employ community-based, qualitative research methods and narrative analysis to understand the challenges and barriers to healthy living for adults living with type 2 diabetes in Halton Region, Ontario. As mentioned in the Introduction (Chapter 1), the inception of my research was in line with the goals of community-based research. Namely, this research was meant to be practically relevant to the community in which it takes place through collaboration with community members to strive towards positive social change within the community.

Qualitative research methods allow research participants to describe what is important to them, and gives them a voice to describe their histories, challenges, and successes with their illnesses. Qualitative methodology is integral to the study of diabetes in the context of food insecurity and low income because it allows informants to tell researchers from their own perspectives the biggest challenges and barriers they face in their daily lives, and how they affect their health, food, employment, and housing security among other aspects of their lives.

Narrative analysis, specifically, keeps these histories, challenges, and successes intact for each participant so that their voices remain their own, while making analytical connections between narratives. The proceeding section details methods of participant sampling and recruitment at food distribution centres in the Halton Region, data collection through one-on-one interviews, and manual as well as software-aided data analysis.

### 3.1 Sampling and Recruitment

Participants for this research were recruited with the permission and assistance of Food for Life site managers and volunteers. After receiving permission to complete my research project with Food for Life from Executive Director Brenda Hajdu, she contacted the Food for Life food services throughout Halton Region to ask for their permission for me to attend their weekly food services so that I might recruit participants for the study as well as observe and volunteer my assistance. Overall, three Halton Region sites welcomed me: Halton Hills/Georgetown, Milton, and Burlington. In addition, I received permission from Kerr Street Missions in South Halton, Oakville to recruit participants. Kerr Street Missions runs independently of Food for Life administration, and therefore I received separate permission

from them to proceed with research at that location (see Figure 1: Map of Halton Region, and Diagram 2: Recruitment Sites in Halton Region). With all community-based research, it is important that the researcher and the community maintain a mutually beneficial relationship; thus, while recruiting participants for research I arrived early to all sites on the days of their food services and I volunteered my time under the direction of volunteers and site managers. I assisted in preparation, before clients arrived, occasionally while food was being distributed, and with clean-up of the venue. This allowed me an inside look and better understanding of Food for Life services, the kinds of foods donated by retailers, and the Food for Life client base as a whole. In total, I spent two to five weeks volunteering, recruiting, and interviewing at each location. Active recruitment began June 25<sup>th</sup>, 2015 and ended August 4<sup>th</sup>, 2015.

A total of 18 participants for this study were recruited as a convenience sample (Bernard, 2011). Participant inclusion criteria included being over 18 years of age, currently receiving food from Food for Life, food banks or other food donor services, and having received a diagnosis of type 2 diabetes mellitus from a medical doctor. Recruitment included posting information on bulletin boards and in high traffic areas, announcements made to clients by myself and by Food for Life volunteers, and one-on-one conversations with Food for Life clients. Thirteen participants contacted me independently after hearing or seeing advertisements about my study, and another five participants were recruited through snowball sampling (Bernard, 2011). The concept of qualitative “saturation,” or reaching a point where additional interviews would not create additional insight into research questions (when similar information is seen multiple times over), is not well defined in that there are no universally accepted guidelines to determine when interview data has reached saturation (Guest, Bunce, & Johnson, 2006). In a qualitative thematic coding methodological study, researchers found that the majority of their codes or metathemes were found within the first six interviews ( $n = 80$  codes, 73%), and near full saturation ( $n = 20$  codes, 92%) of codes were found by 12 interviews. With the addition of 6 more interviews for a total of 18 interviews, only 5 more codes were added. As they analyzed more interviews, novel data was discovered far less frequently, leading the authors to suggest that 12 interviews reached data saturation (Guest et al., 2006). This study supports my use of 18 participant interviews as sufficient to answer research questions. It is also worth noting that the acceptable number of interviews was also in part determined by the research budget for

interview compensation and travel cost to and from recruitment and interview sites.

While convenience sampling was used, an effort was made to ensure an equal number of men and women, and representation of participants from both North and South Halton. This proved difficult as women represented 61% of the participants (n = 11) even with special announcements that more men were needed for the study. At the Halton Hills/Georgetown site in North Halton nobody self-identified as having diabetes. This skewed the data participants to be overrepresented by women living in South Halton. Given that Type 2 Diabetes is a non-communicable disease that usually occurs in later life, most of the participants were older. Participants age range was 40 to 76 at the time of the interviews.

### 3.2 Data Collection

The recruitment and interviews for this project took place between June and August 2015. Eighteen one-on-one, semi-structured interviews were conducted in person, and lasted between 35 minutes and two hours. Participants were asked to pick a location that was comfortable and convenient for them for the interview. Most of the interviews were conducted off the Food for Life/Kerr Street Mission location, most commonly at coffee shops. While all efforts were made to protect the confidentiality of participants, due to participant mobility and accessibility considerations, time, and financial constraints, and because of participant preference, some interviews were conducted in private rooms at Food for Life service sites. The study was cleared by the McMaster Research Ethics Board. As part of the ethics protocol, before the interviews participants were provided verbally and in written documentation a statement about their confidentiality as well as the purposes of the research project. They were reminded that they were welcome to decline to answer any question or section of the interview, and they were welcome to withdraw from the study at any time. No participants declined to answer any questions or withdrew from the study.

Interviews were recorded using a small digital voice recorder with participants' consent and transcribed verbatim. Each participant was given a \$20 grocery gift card to a local grocery chain in appreciation for their time. This gift card was funded through graduate studies academic scholarships provided by the School of Graduate Studies and the Department of Anthropology, McMaster University.

The interview guide (see Appendix 1: Interview Guide) was designed to access information pertaining to the research questions while allowing participants to provide their own experiences or come to their own conclusions about their social situations, food insecurity, diabetes, mental health, and the interaction among these factors. This was done to reduce researcher bias and the influence of theoretical frameworks such as syndemics theory, as well as the researcher's knowledge of findings from previous studies. Only if participants asked for clarity, examples of answers, or did not answer the question asked, did I make the question more specific with interview probes. Each interview included basic demographic questions, questions about diabetes, food insecurity, mental health, and diabetes supports and services.

In addition to conducting interviews, I attended a diabetes education session ("Just the Basics") delivered by a nurse and a dietitian at the Oakville Diabetes Education Centre to learn about the resources and recommendations provided to people with diabetes in Canada. Further, I had a nurse contact, Cathy Benbow-Pleues, and she provided direction to diabetes resources as necessary. These resources are cited throughout, with the author as "Diabetes Canada," the new re-branded name of the Canadian Diabetes Association. I also learned about these resources through my previous employment as a pharmacy assistant and at a diabetes education centre (as previously stated in 1.0 Introduction).

In addition to volunteering for Food for Life by unloading trucks, setting up food distribution tables, preparing lunch or light snacks for clients, assisting in the distribution of food, and cleaning at the end of the day, I was able to engage in some participant observation to gain further understanding of how participants use Food for Life services to obtain food on a regular basis. The knowledge was incorporated into the interviews I conducted with participants, rendering me a more informed interviewer with knowledge about their regular activities connected to acquiring food.

### 3.3 Data Analysis

Once complete, interviews were transcribed *verbatim*, with the assistance of InqScribe, a free downloadable transcription software that allows the input of keyboard hot keys in the place of a transcription pedal.

I chose a qualitative, narrative thematic analysis for this project. Riesmann says that "narratives are strategic, functional, and purposeful" (Riessman, 2008, p. 8). Narratives are used to accomplish certain ends, and narratives,

in how events are told, are part of identity. Narratives make meaning, create order, contain emotions, and tell truths about human experience. Finally, and most importantly to this research, narratives are told in a way that can allow the reader or researcher to enter the perspective of the story-teller and possibly inspire that audience into action (Riessman, 2008). I chose the narrative thematic approach because it allows me to work with complete narratives or whole pieces of a biography or story while also comparing common themes across participants. I wanted to represent the research participants not only as a group of people sharing demographic characteristics but as individuals, each with their own histories, struggles, and resistances to the challenges they faced. This aligns with the narrative thematic approach because when using it, authors make a strong effort to maintain a unit of analysis as a complete story or biographical account. As well, they look at what is told rather than the act of telling, and interpret the narrative data in light of themes (Riessman, 2008) using inductive (informed by the research narratives themselves as theory emerges) and deductive (informed by the literature and prior theory) approaches (Bernard, 2011; Ryan & Bernard, 2003). The narratives that are discussed within the thesis are not statistically representative, but instead assist in creating a theoretical model (Bernard, 2011).

In keeping with this approach, during each interview transcription I kept notes of possible themes, using verbal intonation and emphasis of the participants as a guide for their idea of thematic importance. Once the interviews were transcribed, I read through each of them as a whole, noting emergent themes using a highlighter and hand-written notes. During both of these passes I used questions from the interview guide as basic guides for possible themes, as noted by Bernard and Ryan (2003) from Coffey and Atkinson (1996, p. 34). Once every interview was re-read, I created a map of themes and subthemes, informed by the theory in the literature and the data itself. I entered the interviews into NVIVO 10, and used the theme map as a nodal starting point for coding. As I read through the interviews again this map developed as the themes developed. In keeping with the narrative thematic approach, as I coded passages with NVIVO, I highlighted complete paragraphs, stories and biographies instead of small fragments of passages to keep the account as a complete story. Once this was done, the individual thematic nodes were examined individually, again using highlighters and hand-written notes to cross-compare participants' discussions of challenges and barriers to their health and their resistance to their setbacks. When

necessary I referred to the original interview transcription to maintain a complete understanding of the case I was studying.

### 3.4 Summary

The goals of community-based research informed this project. Food for Life, the community partner, aided in the recruitment of research volunteers and my participant observation at the Centre allowed a window into the food resources and acquisition strategies of participants. Research participants used food acquisition services (re-distribution services from Food for Life, or food from food banks), were living with Type 2 Diabetes, and resided throughout Halton Region, Ontario. Data acquired included 18 one-on-one interviews, which were subsequently transcribed *verbatim* and then coded for themes manually and through NVIVO10 data analysis software, informed by a narrative approach. The results of this study are reported in the proceeding chapter.

## Chapter 4: Results

### 4.0 Introduction

I begin this chapter by introducing the sample population and then move on to a presentation of the key findings of the research. Participants faced a multitude of daily financial, physical, and social burdens while attempting to maintain food security, healthy levels of activity, medication doses, and stay overall physically and mentally well. Many participants believed that their inability to afford healthy, fresh foods exacerbated their diabetes, but often did not make explicit references to food insecurity causing their diabetes or diabetes leading to food insecurity. They also talked about the connections between diabetes and worsening mental health, in particular related to stress and stigma, and in some cases depression. An important aspect of their mental health was also social isolation, as they managed the challenges that accompany chronic illness, which they said their social networks were unable to understand, or when they did not have the financial means with which to actively participate in having a social life. Many of the participants' quotes are presented within each thematic finding. Pseudonyms are used in order to protect the confidentiality of the participants.

### 4.1 Participant Demographic Profile

A total of 18 participants were interviewed. The majority of participants were women (n = 11), lived on a fixed income (n = 15), and had at least some postsecondary education (n = 14). In addition, most participants had a known family history of diabetes (n = 13) and lived with some mobility, physical health, or mental health comorbidity. A detailed table of participant demographics is available in Appendix 2: Participant Characteristics.

Table 1: Summary of Participant Demographic Information

Characteristic		Number (n =)	Percentage (%)	
<b>Gender:</b>	Men	7	(39)	
	Women	11	(61)	
<b>Age:</b>	Under 65	15	(83)	
	Over 65 <sup>4</sup>	3	(17)	
<b>Area in Halton:</b>	South	12	(67)	
	North	6	(33)	
<b>Country of Origin:</b>	Born outside of Canada	4	(22)	
<b>Education:</b>	No high school	1	(5)	
	High school	3	(17)	
	Some postsecondary	14	(78)	
<b>Income Type:</b>	Fixed:	Disability	10	(56)
		Ontario Works	1	(5)
		Old age or pension	3	(17)
		Unspecified	1	(5)
	Employ:	Part-time employment <sup>5</sup>	2	(11)
		Full-time employment	1	(5)

## 4.2 Food Insecurity

All but five participants were recruited through their attendance at Food for Life. The five participants who were recruited through word of mouth (snowball technique), one of whom was using Food for Life services, lived on a fixed income from a pension or disability. As stated previously in Chapter 2: Background and Literature review, “food security exists when all people, at all times, have physical and economic access to sufficient, safe and nutritious food that meets their dietary needs and food preferences for an active and healthy life,” (World Food Summit, 1996). Thus it follows that for an individual to be food secure food must be physically available<sup>6</sup>, economically and physically accessible, individuals or households must be able to utilize this food correctly, and previous three determinants must be consistently

<sup>4</sup> The age at which old age benefits, including Ontario Drug Benefit (ODB) begins

<sup>5</sup> One participant was employed part-time while receiving Ontario Disability Support Program (ODSP)

<sup>6</sup> The physical availability of food has to do with national production of food or trade and supplying sufficient food of quality (FAO’s Agriculture and Development Economic’s Division, 2006; FAO, 2008). Availability is thus outside the scope of this project.



stable (FAO's Agriculture and Development Economic's Division, 2006; FAO, 2008). Of these four determinants of food security, the study participants demonstrated a lack of one or a combination of: accessibility, utilization, and stability, as will be described in the following three sections.

#### 4.2.1 Access

Individuals and households must be able to have physical and economic access to safe, nutritious food and foods that are culturally important (Dietitians of Canada, 2005; FAO's Agriculture and Development Economic's Division, 2006; FAO, 2008), and so it follows that this food must be obtained through culturally acceptable methods. Access is a multidimensional concept, encompassing social, economic, and cultural factors. In regard to food accessibility, the value of qualitative research is that it allows participants to describe their own specific experiences, without researchers and academics struggling to describe or quantify the concept.

A common narrative among participants, regardless of income type, was that to eat healthy was expensive and difficult. For example, Lily said she was buying "*not always the best food*" but "*belly stickers*" such as pastas, potatoes and rice when purchasing food for herself or her family because "*it's the cheapest food you can find.*" This sentiment was shared by Hammond who said he was "*on a fixed income... so is very hard when you pay you know your accommodation and then very little left money for you[r] food, so you[re] buying you know junk.*" John buys in bulk and food that will last for more meals, as opposed to buying foods that would align with a diabetes diet.

*"...If I'm given 10 bucks to go get some food, I'm going to go to Food Basics, I'm going to buy a packet of 20, 20 Jamaican patties rather than a thing of salad and a piece of chicken. Because that 20 thing is going to last me a week. Rather than a meal, then I'm not worrying about what I am getting a meal tomorrow."*

Others complained about the price of "healthy" snacks compared to junk food type snacks.

When specifically asked about the access to fresh food in her neighbourhood, Gina, from North Halton, said, "*No, there's lots of availability [referring to "access" in the defined terminology], we have a farmer's market on Saturday mornings downtown, and um, but I don't go to the farmer's market, fruits and vegetables are twice as expensive as the grocery store.*"

While physically accessible, these grocery options were not financially accessible to her.

Conversely, some residents of Acton, a city in North Halton, complained that the only two grocery stores were beside each other and on one side of the town, which meant that those who lived far from the stores and those who had no personal transport had less access to fresh groceries. To further compound the issue of distant grocery stores, some participants' mobility issues made public transit and walking or cycling to the stores difficult or impossible, thus increasing this barrier to access to fresh and healthy foods. Mobility issues are discussed later in this chapter.

Participants also had strong opinions about the food made accessible to them through Food for Life and other more traditional food banks. Food for Life food was received very well by participants, who were grateful for more accessible fresh produce. They also liked that they were able to choose the foods they would like to eat and utilize within their dietary requirements. Some participants used the selection to make complete meals, and some used it to supplement their diet. Julianna used Food for Life to supplement her meals, saying she was *"...going to the food bank to fill a void... I mean the food you get from them isn't going to 100% feed you on the table, but it's kinda something you can build. You know you can take this stuff home and you can build a meal around it. You know, if nothing else, you can make homemade soup!"* Further, while many participants went as often as possible, some did not. Lily described her Food for Life use as such: *"I didn't use it every week... So if I have a day... I'll take advantage of it because I know it's there and it's a little extra boost right for me. Especially next week's pay day and not this week."*

While it was acknowledged that there were unhealthy options available at Food for Life, such as sweet or savoury pastries, this was not seen as an issue, as other healthy options were made available. The main concern participants shared was that the amount of fresh food offered during winter months might decline.

Participants did not favourably discuss food banks. They criticized them for providing unhealthy foods, or foods that do not benefit someone on a diabetes diet. Hammond did not know canned food was unhealthy, and since he did not know how to cook, he ate canned food from the food bank as an easy meal. Other participants avoided traditional food banks entirely because of their canned, boxed, and unhealthy offerings.

There is some evidence that receiving food from a food bank was seen as culturally and socially unacceptable or stigmatized by some participants or their acquaintances. Two participants knew people who could use help accessing food, but they would not use a food bank or accept help with food if they knew it came from a food bank. Another participant saw an acquaintance at a food bank, and the acquaintance was surprised that she used the service. Further evidence of potential stigma or cultural unacceptability of using food banks and Food for Life as charitable services surfaced as participants referenced their volunteering with these services. They stated that their volunteering was the reason that they did not feel bad about accepting food.

Another method of obtaining food besides Food for Life and food banks was accepting food gifts from family members. Three participants made references to having family members help them afford adequate nutrition. Some participants reported that they took part in free community meals, but faced difficulty when attempting to find food that met their dietary needs.

#### 4.2.2 Utilization

For food to be properly utilized it must be properly prepared and sufficiently biologically utilized. Food must be varied and diverse, and all members of the household should receive adequate nutrition (FAO's Agriculture and Development Economic's Division, 2006; FAO, 2008).

Participants in the study already face a utilization issue as some foods that are more economically accessible such as pastas, rice, and potatoes, are not appropriate in large amounts for their dietary needs and will not be appropriately utilized by their bodies. As Gina said, when I asked her what she does when her diet is heavily laden with starchy foods, *"Well, the one thing is the protein, make sure I have a protein with it, or eat less, but you don't always have a choice. So, all you do is just hope it doesn't do too bad and then test your sugars and just see it way up there and then kick yourself for eating it. But you had to because that's what was there today."* Another aspect of this issue is that there is likely a lack of variety in the diets of the study participants, or there may be reduced options for daily meals, and participants end up eating the same thing frequently, leading to a lack of some micronutrients. As Theresa said, *"...so that's [quinoa] what sometimes I just have for supper... But after a while when it's just, blah. And I'm looking at it I'm thinking 'geez I wish I had some nice fresh vegetables in there' what'd be really nice."*

With their diabetes, participants had to be careful of the amount of sugar that was in products they consumed. Two participants discussed problems with labels on food packaging. One participant said that the sugar content labelling on food packaging was not transparent enough, and another participant had an issue with label “suggested serving” sizes, as they did not reflect what a person would normally eat or consider a serving, thus potentially misleading consumers. These two issues could be problematic for those with restricted carbohydrate diets.

Further, many participants faced physical comorbidities along with their diabetes (see Appendix 2b Participant Chronic Illnesses) that made their diets more specific, and in some cases eating according to a doctor recommended diet was simply not possible. For example, Theresa had multiple comorbidities including thyroid problems that were difficult to treat, and she could not afford the doctor recommended diet for her conditions. To further compound this issue, she was attempting to follow her personal recommendations while also shopping for a kidney diet for her husband, even though these two diet recommendations were in direct competition with one other. The above example demonstrates a utilization aspect of food insecurity, as a member of her household other than herself was determining the type of food that she eats (that is, food distribution). While she had some money budgeted to food, it was not put towards options that would benefit her personal dietary requirements. In another example, Gina specifically mentioned the difficulties of combining cardiac diet with diabetes diet, and it is possible that many other participants with varying diseases under the metabolic syndrome spectrum also had this problem. Finally, one participant had undergone gastric bypass surgery and so many foods were no longer an option for her as her body could not process those foods.

As previously stated, another way that an individual or household might make proper utilization of the foods to which they have access is through food preparation and cooking. One participant regularly reminded me that he did not know how to cook, which significantly limited his ability to follow his prescribed diet. Two participants attended cooking classes or community cooking sessions and were excited to learn how to use new ingredients and recipes in unfamiliar or ethnic styles. Three other participants discussed looking for ways to learn about easy, budget-friendly, diabetes diet style recipes, or strategies for incorporating healthy food into already familiar meals, but could not find the resources to do so. When discussing ways of

accessing this information, John pointed out that the grocery stores with in-house dietitians that could provide some assistance with proper shopping or food preparation were more expensive. *“I think you gotta look at the demographics too. You know stuff like Superstores and Metros, or Whole Foods... those are your pricier things. And mostly the people that need help are the people that need to go to the Food Basics, you know this area where it’s low income, rather than mid- to high-.”*

Another issue that came up frequently when participants were talking about food utilization was cooking for one or living alone (n = 5). This was discussed in a multitude of ways: not having a monitor or conscientiously making food choices to ensure healthy foods are consumed and unhealthy foods are limited (contributing to initial disease onset); losing motivation to cook for oneself; difficulty portioning recipes correctly; and being easier to pick up a single meal from a fast food restaurant instead of preparing a meal for oneself (as opposed to preparing a meal for more than one person, which is seen as having more purpose). This concept of cooking and the labours of meal preparation tie in with mental health and food security: one participant discussed how hard it was to get out of bed, let alone prepare a meal when her mental health was poor, thus contributing to her elevated blood sugar levels when she ate unhealthy meals or “comfort foods”.

Regardless of cooking skills or knowledge, reduced access to proper cooking facilities will severely limit food utilization options. One participant did not have full-time access to the full kitchen in his home, and another participant discussed his “small” stove and fridge in a senior’s residence.

#### 4.2.3 Stability

In order to be food secure, availability, accessibility and utilization must be consistent and stable. Specifically pertaining to the study participants, food security should not be threatened by economic instability or job loss, rising food costs, or seasonal availability of food or work (FAO’s Agriculture and Development Economic’s Division, 2006; FAO, 2008).

One participant displayed instability or temporary food insecurity because he was on a fixed income but had to double his rent payments after a hospital stay. He was using food banks temporarily to help with his financial situation. This example also shows the necessity of food bank programs for those who experience temporary set-backs or as fall backs due to instability of food access.

Participants were in tune with the unstable nature of their food resources. Francine mentioned the seasonality of available foods through Food for Life, saying she was picturing the winter months when there were more “*comfort type foods*” and less fresh food available through the service. Another participant used her daughter as a food safety net, because she said food prices went up and down regularly. Paula was subject to predictable transitory food insecurity, or food security that is short-term and temporary caused by a sudden drop in food availability or access (FAO, 2008). “*And it seems like the first couple weeks of the month I’m fine because I have money, but when it gets to the middle of the month I’m depending on the food bank and... you have to eat more pasta and stuff, and I find that my sugar goes a little higher.*”

A couple of participants mentioned the cyclical nature of chronic food instability and chronic food insecurity. These participants talked about how food insecurity in one generation can lead to food insecurity and poor health in the next generation, for example in this quote from Hammond:

*When you go, just, you know to the store and buy 50 dollars is nothing today. Believe me. ...and when you have the family, children whatever, how they can, how they supposed support this? I mean then the family going the food bank and the food bank even just only you know not perishable... not healthy at all. And they feed you know the family. Yeah. So is the circle you know because this kids will be... overweight, will be sick, you know then they will be the problem on the government to... healthcare and everything. This whole cycle, we should break the cycle.*

This concept is particularly relevant to a syndemic framework for studying food insecurity and diabetes, specifically, and chronic disease generally. As Julianna said,

*I mean I understand them not wanting to put a lot of money on peoples' cheques, some people aren't very um what's a nice way of putting it... but if they funded food banks, and like, did food stamps or something like that, where's the harm? If you don't need it, you don't use it. They need it they got it. Because anybody in their right mind knows there's not enough money on that cheque. So they need to step up in some other direction and stop going ahead like a bunch of ostriches and realize that this is necessary you know, because in reality if they fund people*

*with good food, maybe they don't end up on the medical end of things where it costs a hell of a lot more money.*

These ideas are important and will be covered more in Chapter 5 (Discussion) when I talk about how these study participants demonstrated a syndemic model.

### 4.3 Diabetes

This section begins with a discussion of participants' ideas of their own diabetes etiology, including life circumstances at the time of diagnosis, the symptoms participants linked to the onset of their diabetes, and a discussion of the reasons they felt they had diabetes. It then moves into a discussion of the unique challenges participants face when attempting to manage their diabetes and conduct proper self-care techniques including the management of their comorbidities, exercise, financial situation, and trade-offs. These challenges are faced with resilience and resistance from the participants as they manage their health through knowledge of the self and putting great effort into their diabetes management and learning new skills. Following this section is a discussion of how participants managed their mental health and its potential effects on their diabetes and other aspects of their physical health. This section is followed by a summary of participants' suggestions of ways to better support the health, chronic illness, and food security in their neighbourhoods.

#### 4.3.1 Etiology

One of the first questions I asked the participants in the study was, "when did you first think you might have had diabetes?" as a way of assessing cultural or lay discourses for diabetes onset. Peoples' responses varied but fell within two camps: 1) They did not think they had diabetes and were surprised by their diagnosis after a regular visit at their clinician's office; or 2) They had a long history of symptomology leading them to test their blood on a family member's blood testing machine, or they sought out a clinician for diagnosis. If participants did not describe why they thought they had diabetes after the initial prompt, the follow-up question was, "why do you think you have diabetes?" When investigating the reasons participants thought they had diabetes, their responses could be classified as either a family history explanation, a lifestyle explanation, or a combination of the two.

This subsection includes participants' diabetes diagnosis narratives, including typical and atypical symptomology, as well as common experiences

across multiple narratives. It then moves into explanations participants gave for why they think they have diabetes, namely family history and lifestyle explanations of disease etiology.

#### 4.3.1.1 Symptomology

Some participants did not feel any irregular symptoms leading them to seek medical attention; they were told of their diagnosis at a regular visit with a physician, or at a follow-up with a physician for another health issue. Some participants were told of their diagnosis after a severe health event, most often a cardiac event. John said:

*I was just out having a walk and I started having shortness of breath and not feeling good and getting dizzy and my doctor's office was right there, and they pushed me to go to the hospital and the doctor at the hospital had mentioned that I had something like an angina attack but not an angina attack and then they mentioned how long I've had diabetes for, and I kinda looked at him. 'I don't have diabetes' and then that's when he looked up, 'yes you do'.*

Similarly, Gina simply said, *"I had a heart attack, and then I was told that I had type 2"*.

About a third of participants (n = 6 explicit references) were diagnosed with diabetes when a "routine test" or "routine blood test" revealed elevated blood sugars, before the participants experienced diabetes symptomology. This could be indicative of the effectiveness of the healthcare system in the area. For example, Julianna described her doctor's long-term monitoring of her health conditions, *"The doctor started telling me quite a while ago that I was pre-diabetic. I have been diabetic now for probably 15 years?... So I would say easily 20, 25 years ago the doctor had started telling me that my sugars were elevated. And eventually it worked into the point that it's time to put you on the medication!"*

Participants who did experience symptoms such as blurry vision, thirst, dizziness, tiredness, and who *"just didn't feel right"*, as Francine put it, and subsequently sought medical attention, demonstrate a knowledge of their own bodies, one that many people with diabetes possess. [See section 4.5 Resistance.] The above symptoms are typical symptoms experienced by those with diabetes.

Participants also discussed symptoms less often mentioned in the literature such as anger or mood swings and "shocks". Theresa explained a



symptom that had been abnormal for her. *“...I flipped out one day and I got mad at my husband and I threw something at him... Then I knew something was wrong so I went down to the hall and got my mom's tester and it was 29.6.”* This is an ongoing symptom for this participant as it is for several others in the study and is connected to the mental health issues discussed more completely in section 4.4.

Alice reported experiencing “shocks”.

*No, actually I uh, I was having a feeling that I was getting shocks in my head and I had never had that before. And I was visiting my mother at the time and I said "you know something's not quite right" and I just wonder if it's diabetes. And I said, I wanna test on your monitor. So I did, and my sugar was 16. So I went back to my family doctor and said I tested there so he sent me to the clinic and I had a proper workup done and yeah.*

A commonality between these narratives is that each individual remembered the number<sup>7</sup> they saw when they initially suspected they had diabetes. This is demonstrated through many narratives, including Xavier's, *“Okay um, with the diabetes right, I was first diagnosed in Guelph, right?... I was 39.1. ... Yes. It was just phenomenal.”* These individuals clearly show that the very high blood sugar numbers at the time of diagnosis is important to their illness narratives, and something important to share as part of their histories.

Though some of these narratives were shocking and severe, the entire study sample did not experience such extreme symptoms associated with diabetes; in fact some remain nearly symptom-free, such as Dierdre. *“I never thought I had diabetes, I still uh, I don't feel like I have diabetes, uh, but this is about 8 years ago I think as a routine blood test, my diabetes test whatever it was, came up not severely high, but high enough that my doctor had some concerns so she put me on some diabetic medication.”* Some participants did not experience extreme symptomology and were well-managed through their medication and regular contact with their physicians.

#### 4.3.1.2 Diabetes Onset

Participants were asked about their suspected reasons for their disease etiology, in part to discern whether food insecurity was as an antecedent of diabetes and also to augment a clinical literature for when diabetes testing

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<sup>7</sup> “number” or “reading” are colloquial terms used by diabetics to represent a blood glucose measurement, as seen on the screen of their glucometer.

might be merited for a Canadian population that faces food insecurity or low income. However, results also surfaced showing the stereotypes that the participants internalised from media and an older medical literature focusing on lifestyle explanations as opposed to social determinants of health explanations for chronic disease onset.

### Family History

When asked when and why they thought they might have first developed diabetes, many people brought up their family history of diabetes, whether confirmed or suspected (n = 13/18 participants). Not everyone who thought their own diabetes was linked to a family history of the disease could confirm their family history, but they suspected it through an understanding of their own symptomology. As Alan said: *“I- there is probably um a family history of it, I had a grandfather who died of a heart attack, when he was um, in his late 50s or early 60s, rather tragically, back in that, those times they didn’t really do, know a lot about diabetes... my grandmother would always say that grandfather, his feet were always bleeding, so I’m gonna assume that he probably had uh neuropathy just like I did.”* Similarly, Lily said, when talking about her father: *“I mean in reality he had been sick for a long time, and the doctor didn’t pick up on it, you know what I mean? And uh, he just dropped dead.”* When a family history could not be confirmed, it was common for participants to justify their suspicions by explaining that diabetes was not as well-known “back then”.

Within their narratives, people spoke of their family history of diabetes in three ways: as their reason for having diabetes, as a source of distress over what might happen to them in the future as their disease progresses, or in contrast, as something that normalized their disease, reducing shock or anxiety about new medications, blood testing, and insulin administration.

When asked the question “is there any reason why you think you got diabetes?”, many people responded directly by citing either a family member relationship, or simply saying “family history”. Some even went as far as to describe their diagnosis as “inevitable” (Gina), because of their family history, or made links between their phenotype and that of their parents. For example, Alice said *“...my mother was diabetic, um, I’m so identical to her in looks in size and you know other, other medical conditions, that this, having diabetes is not a surprise”*. Some saw their family history as a contributing factor to their diabetes onset, as did Alan, *“...you know you asked me, you know, what do I think you know caused it well that’s probably family, a*

*combination of different things, you know like perfect storm kind of thing of family history and poor diet choices.”*

As the participants continued to discuss their family history, some divulged that it made their perceptions of their prognosis worse or better, depending on what they witnessed with their close family members. Alice described how she watched her mother pass away from complications of diabetes, and the effect this has on her now as her disease progresses: “...no matter how controlled you are, no matter how careful you are about what your intake is, your diabetes will be progressive. You just can't do anything about it.” When asked if the concept of disease progression scares her, she said,

*It absolutely terrifies me. My, I tell you why, my mother, my mother's kidneys failed and she was 85 at the time and she was approved for dialysis... the doctor thought she was a good candidate and that she could tolerate it and she did for a long time. But when she was 88, going on 89, she called me and she said 'you should come down now' I said 'why' she said 'because I'm going I'm- I went off dialysis and I'm going to die on Sunday' and I sat with her in palliative care until she died and it was horrible. So, yes it scares me.*

### Lifestyle Explanations

Another common explanation for diabetes onset was that of lifestyle. This approach stresses poor diet and lack of exercise as the predominant determining factors for diabetes onset. The most common “lifestyle explanation” offered by participants had to do with consuming foods (in the past or present) with heavy emphasis on meat and starchy foods, with very few vegetable or fruit options consumed. This style of eating was often brought back to “how I was raised” and the food choices and meal options served in their households growing up. As Daniela said, “...I think it's the way we were brought up too... say the dad or the mom or whatever was only a meat and potatoes kind of person, then you're only going to and, they weren't brought [up] on vegetables, then you're going to stick on peas and corn. Right? And I think that's what it is...”

Lily provides an exemplary narrative that displays the complexities of making food choices: cultural influences from her household diet growing up are amplified in her adulthood as an individual that is food insecure.

*Um but [my father] had you know, hardening arteries, and high blood pressure and diabetes, and cancer. So being brought up*

*on the good old British diet, you know fish and chips, egg and chips, beans and chips, you know, butter and toast, bacon and eggs... you know, like, that kind of diet... Sunday was probably the only time some vegetables, some frozen veggies on a plate, some peas and carrots, or something you know? A little salad and sometimes some white mayonnaise on it, you know?*

The beginning of this narrative demonstrates that she was aware of her “British diet” and the health consequences associated with it. Her food choices were influenced by her upbringing. A little later in her interview, however, she then described how this upbringing affected her food choices when she moved out of her parents’ house and lived on her own, raising her son as a single mother.

*...so I'd gone to [my doctor] for a work up... and he'd been checking my A1C and I guess it was borderline at that time and he said... 'if you don't stop doing what you're doing now, make changes, you will be a diabetic.' And it scared me right? Well at the time I was like living on my own, I would have had my son, so, I was doing everything for him so nothing really changed. Working, you know, food, and worrying about him, and Pampers and diapers and the whole thing, no support from his dad, right? And then in the blink of an eye six years is gone, right? My dad used to say 'the older you get, time flies' and it's so true right? Well you know I was diabetic, and I was like 'oh my god, what do I do now?'*

This narrative demonstrates many elements of a lifestyle explanation to disease onset, but also many problems with such a simple and narrowly focussed explanatory model. While it is true that this participant was eating a diet associated with morbidity and chronic disease, she was also a single mother raising an infant with a low-paying job, no support from the child’s father, and facing stigma from her own family for being a single, unwed mother. She understood the consequences of her “lifestyle” and wanted to be able to make changes, but with the conditions she had, it was not only difficult to afford healthy food, but there was little time to prepare healthy foods, and resources were focused on the child’s needs instead of her own health.

In addition, some narratives were heavily laden with self-blame, with many participants describing their disease as their own fault, either directly or indirectly. This sometimes came from their admission to having a

comfortable upbringing in a middle-class family, and often it came from their description of their eating habits and food choices. Alan was raised in a middle-class family and described himself as “*comfortable growing up*”. When I asked him if there was a reason he thought he got diabetes, his initial response was, “*What, aside from the fact that my diet had a lot of sugar in it?*” and laughed. After some more prompting he told me of his suspected family history through a grandfather. As he describes it,

*Alan: ...I think a lot of it too, uh looking back uh throughout my childhood, there's probably like a lot of sugar consumption as well that didn't help any, and a complete lack of knowledge and, and things like, it's not that I had a particularly horrible diet or nothing, I mean we had meat, potatoes, vegetables for dinner every night and all that sort of stuff but, I had lots of snacks too... I was overweight in high school.*

*Interviewer: Okay, um, but you know that doesn't necessarily say that everyone who does that gets diabetes but if there's a family history.*

*Alan: No, but your chances of getting, your chances of getting diabetes, being overweight and having... extracurricular snackage (chuckles) is, is doesn't help any.*

He completed this part of his story by saying, “*I mean... you know you asked me, you know, what do I think, you know, caused it, well that's probably family, a combination of different things, you know like perfect storm kind of thing of family history and poor diet choices.*”

This narrative is demonstrative of an individual who grew up eating a particular way, and these habits continued into adulthood. Looking through his narrative more, this individual relied on Ontario Student Assistance Program (OSAP), a government loan program for students to pay for their post-secondary education. This was cut-off before his fourth year and he did not have the opportunity to complete his degree. This, combined with his description of his eating habits, and the knowledge that he was currently attending a food bank made me curious to probe how heavily his food “choices” and lifestyle “choices” were influenced by his financial status. While I preferred discussions that related limited income to limited food choices to come up organically within the conversation, when they did not I gave prompts to investigate this direction of inquiry. One of my questions asked

whether participants were on a lower income at the time they had diabetes or when they were first experiencing diabetes symptoms.

*Alan: ...I mean by this, by this time I was out of school, and um, I was, I was working, um and not doing terrible but not doing great... you know um, again my diet choice probably wasn't that great.*

*Interviewer: Now was that by choice or was that because you didn't have a lot of money?*

*Alan: Probably a little from column A, a little from column B.*

While this admission was heavily prompted and therefore was likely influenced by my questioning, it is indicative that it is not common for people to link their income and their food spending habits with their eating habits. The more common connection is “I don’t eat well therefore I am unhealthy”. I suggest that it might be more representative and correct to say, “I don’t have many financial options for my food purchases, therefore I don’t eat well, and because of both of these things I am unhealthy.” This lack of connection between spending habits in regard to food is discussed more fully with spending hierarchies [See: 4.3.2. Challenges to Management & Self-Care].

Other participants indicated that significant life events or other health problems acted as precipitating circumstances leading to diabetes onset, such as the death of a spouse, heart problems, injury, or an extended stay in the hospital. As John told me, “*I was a professional wrestler for 25 years, I got a spine injury, I put on a ton of weight, and became diabetic.*” As we discussed the circumstances that surrounded his diagnosis, when I asked him if he had an explanation for why he had diabetes, he replied with “*no, just wildly overweight.*” As he continued his narrative, he described his lifestyle:

*I had a hard lifestyle. ...in the restaurant management stuff I used to run a bad movie theater here... so I worked a lot of nights. And long days, summertime, 16 hours a day easily wouldn't be unheard of. So trying to control diabetes in that type of sense is impossible. Because you know obviously you got to be in bed at a certain time to control your diabetes, you got to take your medications by... you know [long acting insulin] has to be before bed well, you're not going to bed until 3:00 in the morning, you know you're up by noon to get back to work, it was very difficult to try and control that. And then the eating problem. Because you're always on your feet, and you take a*

*little bit here, a little bit here, a little bit here and just, and the cost of food, it's unrealistic for someone like myself to eat healthy. Nobody really, you know... you're not going to spend 7 bucks on a box of granola bars. If you're only getting 6 of them. Easily.*

Thus while this participant originally told me that the reason he has diabetes is because he is “wildly overweight”, as he described his financial struggles and challenging work more fully it became clear that it was connected to the etiology of his illness. Nevertheless, as John discussed the etiology of his illness, he expressed the blame he felt was solely resting on himself and his choices:

*“...for the most part I mean, from what I understand I agree with, I think the majority of people that have this crappy disease, we've done it to ourselves. So I can't really feel sorry about, but I can't, I feel bad asking for handouts from the government for helping us when I did it to myself. It wasn't like I was born with it, or it wasn't like I had a car accident or I developed cancer or something, it's a disease for the most part that can be corrected... it's mainly because we're overweight and our diet's crap.*

These narratives were not only laden with blame and stigma, but the terminology used was heavily self-critical. Julianna was described earlier in the context of her doctor monitoring her pre-diabetes and its eventual progression to diabetes. In the quote provided, she said, *“So I would say easily 20, 25 years ago the doctor had started telling me that my sugars were elevated. And eventually it worked into the point that it's time to put you on the medication! (laughs) Because I wasn't a good girl I didn't change my eating habits, so.”* In this narrative, the blame is evidently self-directed as the participant equates “good” with undescribed, but seemingly universally understood “proper” eating habits. She expresses this even though she is on a fixed income and later talks about growing up on a low income, being a single mother to her son and putting his needs before her own.

Some participants described their difficulties with carrying this burden of blame and stigma. Lily told me that she appreciated that the diabetes educators attempted to remove some of the blame and stigma that their diabetic patients have:

*Yeah so it was like you know you get, you get blamed, I feel like you get blamed for everything, and even your health you get blamed for, and even in the diabetes classes they would say like*

*'it's not your fault' like sure things can accumulate, but you probably have like a genetic disorder there... Or there could be you know something wrong with the pancreas, you know, in the first place, or you know so they take the blame off you which is nice, because all the time you think 'oh my god I'm overweight'.*

#### 4.3.2 Challenges to Management & Self Care

People who are on a fixed or low income and those who use emergency food services face unique barriers to managing their diabetes. They often do not have the resources to correctly perform “self-care” behaviours that are outlined by diabetes medical professionals. Self-care refers to routines and habits that are supposed to be done by individuals with diabetes. The main points in self-care include eating meals with fewer carbohydrates and sugars and many vegetables, exercising regularly, with emphasis put on walking more often, taking medications correctly, and testing blood sugar as often as recommended by their healthcare providers (Diabetes Canada, 2017a, 2017c).

Participants narratives revealed themes of balance, struggles, and frustration when healthcare providers did not understand the unique challenges they faced. When participants commented on the questions: “Is there anything that makes your diabetes worse?” or “Is there anything that makes your diabetes better?” most participants revealed attempts to follow recommendations as closely as they were able. They put much effort into managing their health care, but that effort that did not always show positive results. Thus, they continued to experience large fluctuations in blood sugar levels.

When discussing self-care and habits for managing their diabetes, the participants most commonly mentioned exercise, maintaining even levels of blood sugar levels with regular testing, and taking medications properly. Also mentioned, though less frequently, was the need for adequate sleep, quitting smoking, and getting away from a stressful job. While the words were not often explicitly expressed, many participants lived a balancing act. To manage this range of chronic diseases that many participants faced, along with fewer resources with which to manage them, careful balance was important. Hannah told me,

*You know, it is up to the individual to say 'okay this is what I need to do. You are limited to a budget but there is always other options so I have always, I always think okay what is it that I need to do to sustain myself in the situation that I am in, which*



*is I'm diabetic, I, you know, high blood pressure, the whole getup that goes with the diabetes. So you sit down and you say okay, I have this... my plan... what am I gonna eat my snacks, what am I gonna eat in the morning, what am I gonna do in the evening, how late do I eat or I snack at, because for diabetics that is so important.*

This mindset of “What am I going to eat and when?” is important to recognize, because to maintain proper blood sugar levels, diabetes education recommends that people with diabetes eat breakfast, lunch and dinner, with small snacks in between each meal, both in an effort to curb hunger but also to ensure that they do not experience hypoglycemia. Julianna made two references to “balance”, the first in reference to managing competing needs for her health and other financial responsibilities, “*You know, sitting there and counting out my needles to make sure I've got enough to do the month, to make sure I put that money to that. So, you gotta get good at balancing,*” and similarly when she talked about managing her health itself as a balance:

*Well I think it's a balancing game, it's keeping everything balanced, you know, it's, you know I personally think since I've started injections my life has gotten easier. 'Cause it's not, I'm not so stressed about getting up in the morning and checking my blood and having a high reading and thinking 'well what did I eat last night that did this to me' and realizing it really wasn't anything I ate, my body just isn't doing what it used to. You know? When your pancreas starts shutting down, it starts shutting down.*

Julianna was resistant to starting insulin, but when her blood sugar remained uncontrolled with medication she took the advice of her endocrinologist and started on insulin. To her, making this change allowed her to get back to her “balance” between her competing health needs and financial responsibilities.

#### 4.3.2.1 Comorbidities

For the purposes of this research, a comorbidity is a disease for which a participant had a diagnosis or is receiving treatment from a medical professional, aside from their diabetes. While it was previously argued that food insecurity is a piece of the syndemic described in this project, this section is referring to illnesses or diseases as diagnosed by a physician. These comorbidities were classified into physical and mental comorbidities. Of the 18 participants interviewed, 16 disclosed at least one physical comorbidity, the vast majority of which were within the metabolic spectrum (heart

problems or high blood pressure for example), or musculoskeletal or joint issues that limited mobility. One participant disclosed his severe neuropathy and retinopathy, both of which are directly related to diabetes, whereas one to two other participants described symptoms similar to neuropathy and connected these symptoms to their diabetes, but did not have an official diagnosis from a medical professional. Further, 11 of the 18 participants disclosed a mental health comorbidity, the most common of which were depression and schizophrenia.

Many participants understood their comorbidities as a whole, with each condition interacting with diabetes. For example, Hammond said, *“I have... high (tri)glycerides I have diabetes like I said right, I have asthma, I have problem with the heart, high blood pressure, so I have many issues no? And the doctor can't help me out because you know you have to do it one thing but then it's chain, chain, and it's very hard you know...”* Similarly, Lily said: *“Um, I have high blood pressure, and I know they say that's due to part of diabetes because your heart's working harder... because it affects every single organ right? So, you know my diabetes is the worst [condition]... you're tired. Like you're so tired 'cause the medicine makes you exhausted right? And I just got diagnosed with sleep apnea.”* As mentioned in this quote, medications were an important part of narratives as people sometimes understood their comorbidities as caused by their prescription medications.

Some participants understood their illnesses as linked because when they were diagnosed with diabetes they were not only prescribed medications for diabetes, but they were given medications for common diabetes comorbidities, as with Alice. *“Well I think as soon as you're diagnosed as being diabetic the doctor will put you on blood pressure medication, cholesterol medication, um, what else. I think those were the only things. Daily Aspirin, low dose Aspirin.”* Similarly, Julianna told me about her varying medications that she was on as preventative measures. *“I mean a lot of the medications I'm on control things that might potentially be a problem. Like because I'm diabetic they keep me on [a drug] which protects my kidneys.”*

Some participants described their diagnoses of comorbidities as a chain reaction, such as Hammond above; another participant had an infectious disease that would not clear up, which led to tests and diagnostic imaging that brought out a host of illnesses that she is now learning to handle. On the other hand, some participants felt that all of their comorbidities came on at once. Theresa is an exemplary case, demonstrated through her response when I asked her if she had any comorbidity diagnoses since her diabetes

diagnosis. *“Since then? I had my knee replaced, I had uh cervical cancer, gall bladder, my husband become a diabetic. A lot of stress you know, 'cause he had quadruple bypass surgery, 6 multiple brain stem strokes and his kidneys are failing.”* She described the timeline at which her comorbidities occurred, *“Everything. Everything's, you know, it just seemed to all of the sudden, when I turned 40 everything hit. And I'm allergic to the medication for the thyroid so we can't even go there.”*

The fact that so many participants described multiple factors interplaying with their health and with each other is important to syndemic theory. Syndemic theory is articulated nicely by Daniela who discusses not only the physical comorbidities but also her social isolation:

*I think, sometimes I think a lot of that all plays in together, um, you know because there's the blood pressure... although the doctor did tell me that I wasn't taking the blood pressure pills for the blood pressure itself, it's for the veins, yeah. Because it's, mine's [my diabetes is] usually under control, um, the only thing I did have... at one point I'm having water retention on my ankles, I had that, but then I took the water pills and it went away. But I think all the factors of uh, you know, being by yourself, having to eat by yourself, all of that kind of stuff, I think that plays a part in it, so, um, so yeah.*

Stress was a frequently mentioned comorbidity, as many participants experienced chronic stress that would synergistically impair their physical health, including diabetes. Alice said, *“Well any illness, a cold, or an infection or anything like this will make the sugar go up... And uh I think if I'm stressed, I find that will make it a little higher.”* This interacted with her daily life. *“I'm more cautious I think. I'm careful about what I do, um I avoid people who are sick because I don't want to catch anything. I, for some reason and I don't know if I can blame diabetes for this, I don't rebound from that quickly, and, so I tried to, to not put myself in harm's way you know?”* In addition, she said she would test her blood more often if she were unwell.

#### 4.3.2.2 Exercise

When asked about changes in lifestyle since their diagnosis, or things that make their diabetes better or worse, most people mentioned exercise, most commonly walking. For example, when I asked Max to give me some examples of healthy behaviours he said, *“Try and get a good night's sleep, you know, I try and walk every day.”* Or Francine, *“I can't think of anything other than trying to eat sensibly, trying to eat healthy, trying to get in exercise.”*

*Basically just that.*” Other common activities were biking or swimming, especially for those who had difficulties walking or who lived close to an exercise facility. A few individuals worked out at a facility such as the YMCA, but many people discussed barriers to this type of workout, and these are discussed below. A barrier to exercise, for the purposes of this research, is a condition, whether physical or social, that reduces access to or availability of exercise, or discourages an individual from participating in exercise.

In my sample, 14 of the 18 participants disclosed a musculoskeletal or mobility impairment, including various types of arthritis, neuropathy of the feet or legs, or injury or surgery leading to long-term impairment. For example, when I asked Max how far and long he walked, he replied, “...*not long, because my knees. I walk maybe 10-15 minutes, couple times a day.*” Alan has neuropathy in his feet and legs, which causes varying degrees of pain and numbness depending on the day, “*And even just like walking here [to Food for Life] is, is, uh can be a task sometimes. Some days is better than others, like today it's not so bad, I can almost walk normally, I can still feel pain, but most days it's really painful to walk around, but I have to walk around anyways because I have to get some exercise.*” This demonstrates not only a barrier to exercise, but also a knowledge of healthy habits associated with diabetes and a determination to fulfil those health requirements. Some participants simply associated their chronic pain with diabetes, such as Hannah, “...*people who have chronic pain living in diabetes because diabetes does affect your joints...*”

Swimming was considered a low-impact exercise that meant participants could be active when higher impact activities or walking weren't an option. This was discussed by five participants. Theresa: “*When uh my daughter had a pool I was out there every day, I didn't do a lot of swimming but I did a lot of moving around, I could do exercise in the pool and it didn't hurt. So that was good.*” One of the biggest problems faced by those looking to swim was that public pools cost money and are not always located conveniently, thus reducing access to those who need them the most, that is to say, those who do not have the advantage of walking for exercise or walking as a form of transportation.

A final physical health barrier to exercise mentioned by participants, but not included in the count of musculoskeletal and mobility impairments, was breathing impairments such as asthma or chronic obstructive pulmonary disease (COPD). These comorbidities make it dangerous to participate in outdoor activities on extremely hot days, or complete aerobic activity that would significantly increase the breathing rate.

Participants also discussed barriers to exercise aside from physical body impairments. One of the best and easiest ways to exercise more is to incorporate walking into your daily activities. The ability to complete errands and tasks on foot, within a reasonable amount of time over a reasonable distance is termed walkability. Rural neighbourhoods, such as those found in the north of Halton Region, have low walkability, meaning that vehicular transportation is necessary for most tasks. As Christine said, *“I used to [walk the dog] when I lived in Brampton. We used to take him out on the lead and take him around the parks, but where I am now [in rural Halton] it's making you just lazy.”* I asked about sidewalks in the area, or places to walk to. Christine told me, *“Not where we live... well there's 7/11 but that's like down the road and up a hill and down the hill that's there and that's a different story... But there's no encouragement to walk much, you get in the car.”*

Another issue with lack of walkability is the time constraint getting to and from places to complete their errands. These complaints can be echoed by those who live in urban and suburban areas. Lily has a full-time job with a significant commute and rotating shift work hours, and she is a single mother whose son lives at home. She finds it hard not only to find time to walk, but also to have the energy to exercise once she has made time for all of her regular responsibilities. *“...the walking thing, you have to walk, at least 30 minutes, you have to walk, right? And I'm thinking well there's no time, and they're like ‘well what about your lunch’ I get a half hour lunch.”*

Further, the costs associated with exercise can be another barrier. Gyms and the YMCA require memberships or admission fees, as Julianna said, *“I mean you know, the government wants us to be out and be healthy and be active, where's the money coming from? You know? I mean you can't go out and blow, you know ten bucks going recreational skating or recreational swimming or that, you might need that ten bucks later on in the month for food...!”* In addition, there are often travel costs associated with getting to and from these places, for example gas money or bus passes. *“[My sister] says ‘come and swim anytime’ right? But it's all the way in [another city]...So it's like oh that would be so nice because it's good exercise for me and everything, and then um, but it's like, you know, 40-minute drive, and then you have to get gas...”* When she found classes that were affordable to her, there were few options that were accessible because of her full-time work schedule. *“I looked into tai chi, after taekwondo because that's too much now for me, and it's like same thing! It's like working hours, you know? ...they don't like have anything for people that are working.”*

Psychological factors present further barriers to exercise. One participant wanted exercise classes or facilities that were more welcoming to those who are older or overweight. This connects to the blame and stigma that participants felt for their diabetes or overweight, as discussed earlier. They felt that there is a culture where negative connotation is placed on those who are overweight or perceived to be unhealthy by current societal standards.

*And people like me. You know, I don't want a skinny bean pole, you know, you know all muscled up guys, and you know Barbie doll calendar girls, with someone like me, you know I want real people like me, you know, I want other 52 year olds, you know, because you always say fat and 40, right? ...I'm 52 and fat... So, and part of that too is the fear of getting out there and exposing yourself, especially in a gym situation or something? To all these beautiful bodies and you're like 'oh look at you', you know, it's like... A lot of that is the mental. Getting the confidence, getting your, um not being afraid to try new things.*

This psychological barrier speaks to the need for spaces and exercises that are friendly to those who are less fit, older, or have mobility impairments or otherwise those for whom high intensity or high impact exercise are unsafe.

A final psychological barrier to exercise complements both the desire for accessible exercise classes and the discussion of the psychological aspects of physical activity. One participant mentioned that it was hard for her to motivate herself to exercise because of loneliness. She wanted a partner or group of people with whom she could look forward to exercising as an added motivation to try new exercise forms or learn new skills.

These barriers to physical activity are important because people often discussed exercise as a way to “burn up” sugar or calories, or otherwise reduce blood sugar numbers, for example as Paula said, “*I try and walk a lot to burn off the calories too, but also to burn off the sugar,*” or Alice, “*...our walks [with the dog] can be really long. You know we could be out for a half an hour, 45 minutes. And although I'm not, it's not a brisk walk because you know stop and go as a dog, it's still enough to burn up some sugar you know and it helps. It's a little bit of exercise that helps.*” Thus it was understood that exercise was important for keeping blood sugar levels under control. It was not a lack of understanding or laziness that kept participants from exercising, but various physical and psychological barriers that made accessing exercise a challenge.

#### 4.3.2.3 Finances

Participants discussed their financial situation in specific ways. Three trends emerged from the interviews: participants worked hard for the money that they earned and worked hard to budget these funds, regardless of whether it was wage earnings or governmental support; special diets require careful budgets, medications place a financial strain on these budgets; and participants felt that the social support systems on which they relied were taken away very quickly in the event that their income improved.

Participants worked very hard to ensure they received adequate income. When her son was younger, Lily said that she usually worked two or three jobs to support him, and similarly, Julianna, also a single mother, worked a job that paid poorly and where she received less than her male coworkers because she was provided medical benefits, and the hours were steady so she could have her son in day care. *“So you know, I worked for 10 or 15 years in shipping and receiving and never made more than 12 bucks an hour doing it while the men were making 15, 20 bucks an hour.”* Others who received disability support and employment services income worked hard through claiming as many of their health-related expenses as possible, including their insulin and blood testing supplies, healthy food subsidies and bus passes. Even with claiming these expenses budgeting became difficult, as Alan described.

*I've lived on OW [Ontario Works] for like the last uh 5 or 6 years and you know when... you're only getting... 5, 600 dollars a month, it's, you know, and that's get pay all your bills and your food on top of that and yeah I was getting the special diet allowance and I was getting other things, bus pass money, all that stuff, but I had to provide receipts for all that stuff... I mean my total cheque may have been about 850 dollars, which still isn't a lot of money, but you know a good, you know 250 to 300 dollars of that was spoken for and I had to provide receipts for it so the rest of it was what I had leftover.*

Paula provided another example of this type of budgeting. After discovering she was receiving less for diabetes supplies from ODSP than a friend of hers, she was in communication with her ODSP worker to figure out why. In another example, Lily and Connor avoided increased expenses by living in the same apartment buildings for many years, as they had minimal, if any, rent increases year to year. There are many other examples of participants' knowledge of budgeting and expressing financial frustration and difficulties.

As Julianna said, *“I mean because it's only once a month that you get money, you gotta get really good at figuring out everything you need for the month.”* ODSP and many social supports only give out cheques once a month, so participants who were on this type of income (n = 15/18 on fixed, monthly income) had to be very good at budgeting or else go with less towards the end of the month. Paula explicitly expressed her difficulties attaining healthy, fresh foods towards the end of the month. Most participants, if they talked about budgets in reference to food and special diets, discussed general difficulty budgeting for the foods they required.

Many participants did not explicitly talk about food and healthy diets in terms of self-care when asked what makes their diabetes worse, and rarely “eating healthy” was mentioned when participants were asked if there was anything that made their diabetes better. Alternatively, people talked about food in reference to budgeting their monthly expenses. Many participants or their families were on special diets for varying reasons, including gastric bypass, kidney diets, or cardiac diets, aside from attempting to follow a diabetes diet. As Theresa said, *“It's just hard. You know because when you're trying to manage three people, and two of them are sick, and one has to have a diabetes diet, and one has to have both a diabetes and a kidney diet, it gets stressful,”* or Francine, when I asked about whether she finds it hard to buy fruits and vegetables, she replied, *“Very much so... Number one financially it's difficult, number 2 a lot of times I'm not at home so it's harder to, even though you could pack the fresh veggies, whatever, but I can't eat raw broccoli,”* which she gave as an example of her diet restriction after her successful gastric bypass. Gina is working through her recent diabetes diagnosis and cardiac problems, and was finding it quite difficult to manage her food budget while newly on fixed income after being employed for many years, and attempting to eat better than before her health complications were diagnosed. *“I'm combining cardiac diet as well as diabetes... it's an added expense you didn't have before... and it's so hard to be disciplined, you're you know, whatever you have to get is three times more expensive and you've never had it before so it's not in your budget. So, yeah, it's a lot of juggling around.”*

Some participants simply indicated that there was a sum of money they had for food for a period of time, and they employed whatever strategies they could to ensure they had food to eat. As John said, *“...you go to try and eat right but when you don't have the proper money to eat right its easier for somebody like myself and my wife to go and buy \$50 worth of groceries and buy bulk rather than, you know, buy a bunch of stuff that will last a week rather*



*than buy a few tiny packs that will last for a dinner.*” Lily mentioned shopping clearance sections or using the food bank when she could make it there, and Julianna mentioned skipping out on social and recreational activities, or even eating less food when budgets were short.

Another strain on monthly budgets was the cost of medication. While healthcare is free in Ontario, only people who are receiving social assistance (OW or ODSP) or are over the age of 65 have their medications paid for. Those who are working and do not receive employment benefits must pay for their medication. In Ontario, there is a program to subsidise the cost of medication, Trillium, but it still requires users to pay a co-payment every month, and this can be difficult for some people to pay, especially when the monthly cost of medication is high. The author is unaware of other public subsidies to medication, and the participants did not mention other programs. John answered my question, “Is there anything that makes your diabetes worse?” directly with the answer “medications”. His reasoning was thus: *“Um I find medications can be, make it, well not worse, but I guess worse because I can't always afford medications... That's a big part is medication is super expensive... And we don't have a drug plan and it's difficult to get Trillium and because [even if you get Trillium] you're still expected to, to spend x y z dollars...”* Lily had private benefits through her job, and she experienced a similar issue with her co-payments being high because her monthly medications were so expensive. Further, some medications are not covered at all regardless of the support system used, as Theresa expressed when she was talking about the healthcare cost burdens due to her husband’s illness. Also of note, over-the-counter medications are paid out-of-pocket and some participants used these to assist with their chronic pain.

The same physical comorbidities that reduce mobility for exercise as discussed in the previous section [4.3.2.2 Exercise] can also make it difficult to complete certain self-care practices, pushing participants to seek paid services. Many participants had issues checking their feet, an important aspect of diabetes care, and paying someone to perform foot care can strain small budgets further. Theresa told me, *“...I just can't bend to do my feet. I have somebody come in.”* With a husband that is also diabetic and has many comorbidities, she often put him first when it came to foot care. *“Well I have a woman come in for him for sure. Sometimes I don't have to go a little while longer than a month to two and then I can get mine.”*

Some participants faced challenges after acquiring new or better employment that provided better income. They found that as soon as this

income was acquired, they stopped receiving their disability support or subsidised housing, putting them in more precarious positions than before they were employed in these better positions. This issue happened to Lily a number of years ago when she first found full-time employment.

*...I managed to get in there [a subsidized housing program]. Brand new apartment... beautiful, two bedroom... And then, I was paying like 200 and something a month. And then when I got my job at the [current employment], which is where I am now, they jacked it up like 600 dollars. So I went from 200 to 6, I'm like 'I can't afford this' right? And I made some overtime and they jacked it up, and then they jacked it up again right? And I had to live, I had to move out, you know. And [my son] had the best babysitter at that point, you know, I had, I was really lucky I had subsidized day care. So lucky right?... But then they jacked up the rent so high.*

After she improved her employment and income, Lily lost both her housing and child care supports.

Tyler also expressed his frustrations with trying to find employment while he was on ODSP, in that most employment he found was part-time with hours that varied weekly. He said he wished that ODSP did not take so much money off his cheque when he tried to go back to work because it discouraged him and others from finding work. I also asked for clarification from Tyler if he received less money when he was working than when he was on ODSP, and while it depended on what type of work he had at the time, he told me that sometimes he was making less while employed than when he was on ODSP.

Participants worked very hard to earn money from employment, manage their budgets, and ensure they had adequate financial assistance when they couldn't work. Causes of financial worry included acquiring food resources for special diets, budgeting for medication co-payments, and governmental supports and subsidies disappearing at the time they acquired better employment or financial resources.

#### 4.3.2.5 Resource Management

##### Trade-Offs

During interviews, I described a trade-off to participants: "Some people describe trade-offs between managing their diabetes and other things that need to get done such as paying bills, buying food, buying medication, or

caring for a family member.” Participants were asked if this ever happened to them, and if so were asked to elaborate on these experiences. Ten of the 18 participants interviewed explicitly mentioned performing trade-offs when balancing their budgets. For example, Gina learned about the health benefits of flax seeds and flax meal, so she told me *“because it not only benefits the diabetes and the heart, and I have a family history of both... I give up something to make sure I have that to sprinkle on everything I can.”* One participant described these types of decisions in full. She made multiple references to trade-offs that had to be made on a monthly basis to ensure that all expenses were covered and there was food on the table.

*Well you see, you definitely don't get to have a social life. There's no money for a social life, there's no, you know, you scrape and die. You're counting every penny, you're, and I know social lives aren't physically necessary but I think sometimes they're mentally beneficial?*

*Plus, you know, I mean it, like, you know, trying for Christmas or gifts or stuff like that, 'What do you want for Christmas?' 'Gift Card'. You know, that way I can put a few gift cards together and get myself something I've been wanting all year, so there's no, you know, saying 'oh the cheque's coming in I'm gonna go spend myself a hundred dollars on a pair of jeans' no. You tend to go to places like Good Will and you know look for the deals... Um, I mean as, as a mom, even though my son is an adult, he's still, his needs, you know you're, you're scrimping together everything you possibly can for something nice for him...*

*Yeah I, it's, it's really financially hard to eat that balanced meal because you don't have the money to do it. When money's tight something's gotta give, and that's what's gonna give. You know. I mean with the price of fresh produce, it's awfully hard to go out and have fresh vegetables and salad and meat. And meat's you know, it's not so easy to cut back on the meat because you didn't have that much money to spend on the meat in the first place.*

In these pieces of her narrative, Julianna describes cutting corners, compromises, abandoning the idea of a social life, borrowing money from her son, and her difficulties with eating a balanced meal while managing her limited finances, all in an effort to ensure the money goes far enough to pay for her living expenses, food and unexpected finances that come up during

the month. Most importantly she describes that the aspect of her budget that will take the largest hit when financial difficulties arise is her food budget. This is important to recognize as this narrative is repeated: although healthy food is important for managing diabetes and overall health, and this is understood by all of the participants, the food budget is what most often takes a hit when money is tight.

Some of these participants described these trade-offs as “sacrifices,” in terms of sacrificing one necessity for another, such as Hammond, *“Oh yeah for sure sometimes you have to sacrifice right? You need something whatever you know which is uh over the counter to buy you know you're sick whatever you have to sacrifice. You have to buy this, milk, or you have to buy this right? So you have to sacrifice right.”* Julianna said: *“I think I'm fortunate to have ODSP because I don't have to sacrifice my medications.”* This understanding of “sacrifice” as a choice between one necessity and another within lay terminology can be a valuable addition when navigating discourses of diabetes care.

Likely because it was within the letter of information and consent as one of the topics that would be pursued within the interview, many participants gave their stories of choice between buying their medication or buying food. Many participants on ODSP felt very lucky that they did not have to make this decision, as their ODSP covered their medication expenses. There was a similar response to those over the age of 65, as that is the age that senior benefits begin and medication is covered by the government. Thus, those on ODSP and those over the age of 65 did not have to make a decision to pay for medication or pay for food. There was one notable exception to this: Theresa's husband did not have all of his rare and expensive medications covered by the government and so his medications were financed out of pocket and this put considerable strain on their finances. She did qualify this by saying that the diabetes centre was very understanding of this situation and helped them by providing supplies that would normally cost them money.

Participants who worked or were not on ODSP or old age benefits did have to make the choice between medication and food. As Lily put it, *“Do you buy food or do you buy medicine? Well, I've gone without my medicine because I have to buy food, right? You know, and it's not always the best food...”* At the time, she was making these choices she didn't have the option to charge her medicine to any insurance or benefits program.

### Compensatory Strategies

A compensatory strategy is defined here as an action that a participant undertakes to ensure they correctly manage their blood sugar and prevent it from becoming elevated. These strategies are mindful of the limited financial resources of this population; thus some of these actions may not be sanctioned by the medical community.

Many participants described regularly managing their carbohydrate and sugar intake by no longer eating sweets, treats, or baked goods. This narrative of reducing sugar intake can be quite empowering to participants as some of them mentioned losing weight, and still others described their quests to not have to take their medication. Hannah said,

*I have done very well staying away from candies for about 8 months and that has benefitted me in many ways to take, to be off certain medications... I think it's an individual yes, we do slip down into eating junk food, um, when it's available and it's always available, um, but it's your discipline: okay do I want to live with this disease, how am I gonna manage my life with this disease, and how am I going to do it on my limited budget.*

Some instead looked at this reduction of simple sugars as a balancing act, choosing when to indulge or when to refrain from partaking in offered goods. They were very cognizant of the decisions they had to make to manage their sugars, minding that they did not always eat as their healthcare professionals were recommending. For example, Alan said, *"I mean my doctor keeps telling me, he says 'well it's not that you don't, it's not that you can't have sweets, it's just that you have to severely limit' and I said well here's my problem. My diet consists of a lot of carbs. So if I have sweets that's just gonna compound the problem more."* Christine would refuse sweets and treats earlier in the day so that she could see what was available for dinner or dessert and only partake in one heavier carbohydrate or treat a day. Daniela gave the example of choosing between a baked good or an iced chai latte at the café where we conducted the interview. In order to manage portions, Theresa kept the small cups from the sherbet given to her husband while he was in the hospital to measure the amount of treat that they're allowed to have. John cut out simple sugars, as opposed to all carbohydrates, from his diet and found that was sufficient to manage his blood sugar. For all of these narratives managing blood sugar was a balancing act. As demonstrated above, for some participants eating with moderation was key to their blood sugar

management, as was explicitly mentioned by Christine, Julianna, and Alan. Some others, such as Alan above, could not eat everything in moderation, due to the food choices available to them. Still others, such as Connor, mentioned these strategies as “common sense”.

Compensatory strategies performed by study participants that would not be sanctioned by medical professionals had to do with medication and diabetes supply use. These strategies involve using needles or lancets more than once before discarding, or picking which medications will be purchased for the month. As one participant put it *“I’ve gone through periods when I haven’t been able to buy my pills and I’ve just stuck with the insulin or vice versa right, which is dangerous you know.”* Using only one type of medication is dangerous because blood sugar can become out of control or unmanaged, and diabetes can become mismanaged if that individual does not tell their health care provider they are not taking all medications as prescribed. Still other participants are using the same instrument to puncture their skin multiple times, such as this participant: *“...I just don’t use one [lancet] and then switch to the next one because you get, you get a little drum that has like 6 of them on there. I’ll use the same one about 6 or 7 times and then I’ll switch to the next one so you know I’ve got a drawer full of these things so luckily I haven’t had to worry about that right now...”* These instruments can become dull or contaminated with multiple uses. Still others use their insulin needles multiple times, *“...they’re like \$60 for a box... so actually I’ve actually been using, this is bad, I’ve been using the same needle head between the two insulins for about 6 weeks.”*

### Spending Hierarchies

A spending hierarchy is the budgetary priority of spending when income is received. For those on a fixed income, there is one pay period per month, so careful budgeting is needed. When I asked people how they budgeted or in what order they paid for necessities, the priority was always rent, then utilities, or more generally bills. One participant described having to reduce cable service as the price kept increasing and he couldn’t keep up with the cost. Theresa, Hammond and Paula respectively discussed their spending hierarchies,

*Rent’s first, medication second, food’s third, maybe...*

*I’m on a fixed income you know when you are on you know on the welfare so even less than what I’m getting right now so is very hard when you pay you know your accommodation and*

*then very little left money for your food, so you're buying you know junk,*

*Bills come first. And then um whatever else I've got leftover I spend on food like I say by the middle of the month I'm short so I have to depend on the food bank there.*

These narratives all mention food as the lowest item on their priority list; they buy food with whatever is left over after covering all of their other expenses. As previously mentioned, this can have major health consequences, especially for those with diabetes.

When asked if she had to make trade-offs, Hannah responded with “*I don't buy the trade-offs.*” She used her spending hierarchies, carefully budgeting to manage herself and her spending, so she did not have to make trade-offs. Her main tool to accomplish this is “discipline.” She took advantage of multiple free budgeting and cooking programs offered in varying locations near her, and she created a comfortable position for herself.

*I learned how to manage my money quite well, um, because of this program that was offered here... so there's a percentage that I allocate for the food. There's a percentage that I allocate for my living expenses, and there's a percentage that I allocate for my roof over my head. So if you do the way they teach you, if you do this correctly, I mean obviously I'm not saving anything... the way they taught us was uh, you do have a bank account in case you have an emergency.*

She demonstrates this work multiple times over when she discusses her daily habits for ensuring she sticks to her budget and has enough for her monthly expenses, without making trade-offs.

*...it's the effort that you put in. And I don't, I refuse to make a trade-off. I know that I have to do this, this, this and this, and in the beginning it is extremely difficult to do it, but that word 'no'... Because it is tempting when you go out in the store. and you go in with a list and you buy certain things, and for instance I shop at certain days when I know that it's the end of the sale at Christmas...*

In their spending hierarchies, participants indicated that they came last when choosing how to spend their money. Five participants made explicit references to putting the needs of their children, grandchildren and spouses before their own. These participants spent money on the food, special diets,

necessities, healthcare costs, and medication of their family members before they spent money on those same necessities for themselves.

### 4.3.3 Medical Care

#### 4.3.3.1 Barriers to Healthcare Access

Participants were asked about how they accessed their medical appointments, clinic visits, and recommendations for managing their diabetes. Directly in response to these questions, but also organically through conversation, they relayed many reasons they found it difficult to attend appointments or follow recommendations for exercise and diet. Participants mentioned being reprimanded or talked down to by a diabetes healthcare professional (n = 3), receiving different information and recommendations from different clinics (n = 1), a dislike of a group setting where you had to go at the pace of the member with the most questions or least understanding (n = 1), having many appointments with different clinicians in different locations (n = 1), not having Internet access or a personal computer from which to do their own research (n = 2), and a lack of physical accessibility due to geography, walkability, or affordable, direct<sup>8</sup> transit available in a neighbourhood (n = 5). This analysis is in reference to participants who stay in Halton Region for their diabetes care, as others traveled out of the region and faced other barriers such as parking and gas costs.

Participants explained their reasons for finding it difficult to attend their appointments, such as a lack of direct or reliable transit and not having a car. Participants from Oakville and Burlington (the south of Halton region, more established in terms of services) more often discussed taking a bus, biking, or walking to their appointments and for necessities such as groceries, whereas those from Milton or Acton (the north of Halton Region, with areas that are still rural, and with more poorly developed public transit and fewer services) had a problem getting where they needed to go, since many of Halton Region's services are in the Oakville/Burlington area, but there is little if any public transit that runs north-south. Inaccessible services and public transit is compounded for those with mobility and musculoskeletal comorbidities, as these two factors dually burden those who try to access healthcare services, safe exercise facilities, and basic necessities such as groceries. Further, public

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<sup>8</sup> By "direct" I am referencing that Halton Region does not have transit from North Halton to South Halton and vice versa. If you want to go from Milton to Oakville you have to travel to Toronto first, thus costing exorbitant amounts of time and money.



transit is an added and increasing expense for those on limited budgets (n = 3), paying out of pocket for their transportation to health appointments.

#### 4.3.3.3 Diabetes Education

Participants learned about diabetes and diabetes management from Diabetes Education Centres, medical doctors including family doctors and specialists, other people with diabetes, and occasionally the Internet. Every participant (n = 18) stated that they attended diabetes education classes or one-on-one sessions. Most participants expressed that they in some way received sufficient diabetes education for their medication and blood testing from a licenced practitioner. For the most part participants were very satisfied with the education and medical services provided to them, with a couple vocal exceptions.

#### Doctors & Pharmacists

When participants mentioned their doctors during the interviews, the majority of references were positive. Five participants were very happy with their doctors keeping them on a regular check-up schedule complete with blood tests for their diabetes. One participant went into detail about her visits, which were complete with lab work and discussion of how her medications were working for her. She liked that the consistency kept her on track and “stops the cheating.” Contrarily, one participant mentioned that she was unhappy with her doctor, since she was the person that made reminders that she needed her A1C checked, and she thought that should have been the doctor’s job. Another participant mentioned his displeasure over doctors’ agendas, saying that he did not like that they received a side income from big drug companies for “*pushing certain medications.*” To contrast this view, some participants mentioned their doctors going above and beyond what one would normally expect from a physician. Three participants made reference to doctors finding supplies of expensive medications such as new pills or expensive insulin for them for free. Doctors were giving their own supply of medications or and providing drug cards (provided by the pharmaceutical company) that would allow them to be covered. Another participant mentioned that his doctor, who practices in a low-income neighbourhood, helps to provide food to his patients and helps with a bicycle program so he could get his patients bicycles.

For some participants, pharmacists played a key role in influencing their health. Pharmacists are eligible to provide diabetes education to their patients who need assistance with medication or glucometers. Three participants expressed frustration or safety issues dealing with a certain big

chain pharmacy and were much happier with pharmacies where the pharmacists worked regular hours, remembered them and their medications, and slowed down to take the time to make sure they had a proper understanding of their medications and other items received from the pharmacy.

### Diabetes Clinics

Every participant had attended some form of education at a diabetes clinic, whether in group education, a classroom setting, or in a one-on-one session with a diabetes nurse or dietitian. From the narratives provided it was clear that their opinions of the classes varied. Over half of the participants found the education content helpful and accessible and generally had good experiences with their educators. They liked that the educators were understanding of their low-income situation and helped them with diabetes supplies when possible, liked the pamphlets and information provided to take home and review, found tours of grocery stores that included information on label reading and shopping strategies very helpful, and liked tips on portion control when plating food. Julianna thought this information should be offered on a “rotational basis”; diabetes education should be offered regularly after a few years, since advances in management occur frequently. She gave the example of the food education model changing, from policing what patients ate to more of a balancing act. Another participant who liked diabetes education and the programs associated with it, such as exercise groups, found these programs and groups relatively inaccessible as they take place during working hours.

About a third of participants did not like their diabetes education (n = 5). As one participant, Alan, described it,

*I'm not gonna say that they played the blame game on you... like you're the small child and they're the adult, they look down, I wouldn't say they look down on you but you know, just in their tone, their tone is, is, is very uh 'well you know you should be doing this and that' and the other end instead of... like that, they should be you know, alright well you've made these choices so let's you know, let's, let's forget about what you've done, let's work on things you should work, you know, be a little more supportive and positive rather than repeating, because every appointment was the same thing over and over. And that's another thing too, it's not really counselling so much, you go in and it's, they bring out the little props, they bring out a plate with like a little piece of meat and a little tiny piece of*

*potato and a big huge chunk of vegetable, which I don't like...  
Because in my opinion, in my opinion it, it's, I don't even know  
the word for it. I just feel as though I'm being looked down  
upon.*

This participant felt like he was not being spoken to with respect and instead suggested that once you've learned the basics of diabetes, the dietitian should act as a consultant and be friendly towards the client as opposed to being "clinical" (his description). This participant also did not like that some of the practitioners at the clinic engaged in habits that were unhealthy, such as smoking, which he felt meant that they shouldn't be in a position to judge him for his eating habits. Another participant told me that in theory his dietitians might have knowledge but practically the dietitians were "useless" because they were "fat". He didn't think he could learn from his dietitian for that reason. In addition, yet another participant found that education centres were not consistent between locations or between educators in the same location. He also found that group education was not individual enough, since his own health complications were difficult to manage using the general education information. Similarly, another participant took a class with others who had attended education before and felt she "*fell through the cracks*", since she did not feel the education went into sufficient detail and was aimed at the more advanced knowledge of her classmates. She also felt that the information provided was not in laymen's terms. Others mentioned this; one participant who liked the information provided found that advancing through material at others' paces proved frustrating.

One of the main topics of focus during diabetes education is eating habits that allow patients to manage blood sugar. A main tool that educators use to demonstrate these habits is the Diabetes Plate (Figure 4).

## Plan for healthy eating



- Eat more vegetables. These are very high in nutrients and low in calories.
- Choose starchy foods such as whole grain breads and cereals, rice, noodles, or potatoes at every meal. Starchy foods are broken down into glucose, which your body needs for energy.
- Include fish, lean meats, low-fat cheeses, eggs, or vegetarian protein choices as part of your meal.

Figure 4: Plan for Healthy Eating from "Just the Basics," a guide provided to participants (Canadian Diabetes Association, 2013, p. 2).

Participants had varying views of the plate: some found it to be a useful tool and liked the visual aspect of it; some just “knew” it and didn’t put extra effort into portioning and it became natural to them over time; and some did not like it and found it difficult to follow. Three participants explicitly expressed that they did not have sufficient food budgets to follow the Diabetes Plate, as did Daniela: *“It gets me because I can’t afford to do that.”* When I told Max that I was trying to figure out why people were not following a Diabetes Plate model, he said: *“I don’t know. I don’t have enough food.”* Two other participants alluded to the fact that they found it difficult to eat a balanced diet because of their financial situations. A couple of other participants also mentioned that they did not like or did not use this guide because it did not fit with their diets, because of their competing health needs, and one found it frustrating that food plans created with diabetes educators were not made with his specific food needs in mind. These narratives show that the education falls short for those who have very strict food budgets and have greater difficulty affording a complete meal, as outlined by their educators and Diabetes Canada (formerly the Canadian Diabetes Association).

### Non-Medical Teachers & the Internet

Family members were a valuable source of information and education for participants. In previous sections it was discussed that some participants

used a family member's glucometer to test their own blood sugar before their diagnosis of diabetes, and it has also been discussed that some individuals were comfortable using blood testing tools since they had seen their family members use the supplies often and without issue or complication. To further this point, some participants who are parents are adamant about teaching their children about diabetes and changing lifestyle habits within their control to prevent or delay onset of disease. As Deirdre said, *"And I will warn my daughters, like my husband actually had diabetes, so now there's me, so I will talk to them about it, like they need to be careful. You know that kind of thing a little bit. And not a lot because they're all bright intelligent women so they know their own consequences."* Some participants looked to their parents or to their friends who had been successful at managing their weight or coming off some medications as role models, or as a source of knowledge for their own management. Paula found her mother to be a valuable resource. *"...I talk to my mom a lot too because she's been through it for years so she's got a lot of knowledge on it yeah... when she got it and you now um and how she ended up losing so much weight and that's how she ended getting it under, very rarely, under control. And how she went off a lot of meds."*

Gina, who felt that she *"fell through the cracks"* of diabetes education and with less than a year since her diagnosis still has a lot to learn, explained to me how she is learning about diabetes management and listening to her body's symptoms with the help of her neighbour. *"I'm also working with a neighbour who was diagnosed around the same time as me, and we kind of talk to each other to see carbs make us tired, too many carbs, and in her case if she goes low she gets the shakes. I don't tend to go low. So physiological symptoms that we're trying to match up with food choices."* She also goes on to explain to me why talking to people about her condition is so important for her. *"And you kinda go through two phases where you know you're right into it for a month or two and you don't come across anything new or different, it's a lot of repetitive, so you're frustrated, and back off, and then somebody says something and then you look into that! You need triggers from other people."* She went on to explain how this could work in a medical setting.

*Personally, I think that one-on-one from someone with experience, like who has it, who went through it, who got it under control, that would be the most useful to me. Um, group education is too general, trying to look it up yourself is very frustrating, and I'm sure there's things I'm missing, and so I just feel like I'm doing, you get depressed, you get 'quit' attitude, it's 'well I can't win', you're always defeated, so, so I, one-on-one.*

*Like I said I'm working with my neighbour, because she's more of um, thinker about 'how I feel'. I don't always necessarily trigger that, you know, when I'm lethargic, it's because I've had too much carbs. Where that came from her. So, we help each other. I can help her with the quantities and the food groups and things like that. So someone with experience definitely, pairing up with someone newly diagnosed would be much easier.*

Julianna also pointed out a psychological benefit of learning to manage diabetes with someone else would allow you to feel less isolated and allow people to be there for each other and help each other out where they can, even though “they are low-income”.

One final source of education that some participants used was the Internet. Three participants used the Internet to find their own information and education, and one of these three referenced that she had to use library computers, as she did not own a personal computer.

#### 4.4 Mental Health

I introduced the topic of mental health in interviews by letting participants know that “mental health is a large topic of research right now, especially in relation to diabetes and diabetes management.” Most participants agreed with this statement; however when they were asked questions about taking care of themselves when “unwell”, for the most part they only mentioned their physical health or asked for elaboration. Sometimes they made references to feeling “drained,” their “attitude,” “denial” over their condition, or not testing their blood because they did not want to “face it”, but they did not make explicit references to their mental health as a distinct aspect of their wellness. This could be because lay understandings of mental health are different from the understandings of those within academia or biomedicine.

Some participants were invested in reflecting on how they looked at their situation and trying to look at positives as their “attitude”, while still others reflected on the fact that when they felt “drained” they did not want to do anything but sleep, lie down, or potentially eat comfort foods. As Theresa put it, *“I want to sleep a lot... And that's not good. I don't want to do anything. I just want to curl up and go into my bed and never come out... Sounds stupid, but it's the truth. I just don't want to be bothered.”*

Gina described how a diabetes diagnosis can affect how one feels about oneself:

*[When you're an] independent, strong woman... it knocks you down a few notches, so makes you I think that it makes you look like you're weaker and you don't want to outwardly show that, when you're supposed to be tough. (laughs) Dumb thinking... you go through, I don't know if there is such a thing as, you know, stages of, of, since, from diagnosis, like there is, you know, the stages of death, but definitely you go through a whole slew of things and depending on... how long you dwell on something, yeah.*

Similar to Gina, Deirdre mentioned an emotional hit when someone is diagnosed with diabetes. She wanted to give feedback on my interview, and said that I should have asked her how it feels emotionally to be a diabetic. This was a potential indication of a lay understanding of mental health that might have reached more participants.

*[You could have asked] 'how does it, how does it feel mentally or emotionally to be diabetic?' And I think it had an effect, way more of an effect on my husband than on me. So I'd like to say it affects men more than women. I think women are more accepting, just my own personal experience... well not easily, but accept it, but I think for my husband anyway it was a sign of weakness and now I can't do this, now I can't climb a ladder without drinking a glass of orange juice, you know that sort of stuff. I think the emotional part of it would be a really, a really good question to ask. 'How does this affect you emotionally?'... But um, I think that that since sometimes I will say 'gee I wish I had never got' like I got heavier when my husband passed away, maybe this wouldn't have happened. Maybe this wouldn't have happened. You know, like maybe this... but who cares. I'm taking a, my legs aren't affected, nothing else is affected that I'm aware of. So um, but I think that's the only feedback I would say, 'how does it affect you emotionally' and sometimes I don't like to say I'm a diabetic either.*

To complete the overview of general mental health, stigma must be revisited. Stigma and blame for being overweight or having diabetes was already discussed in the context of using “lifestyle explanations” for diabetes onset, as well as fear of stigma and judgement for weight preventing participants from accessing exercise facilities. Aside from this, stigma can negatively affect mental health, whether coming from an internalization of a lifestyle explanation for disease, “I feel like you get blamed for everything, and

*even your health you get blamed for,”* or from comments from family members, *“So even with your family, they stigmatize you, not stigmatize you, but they want you to do well, right?”* Lily, along with multiple others, found that they had family members questioning or monitoring their food choices, especially when they took part in a small indulgence. While for the most part they understood that these questions came from a place of love and concern, the situation still caused frustration and anger for the participants, who know how to manage their health.

#### 4.4.1 Depression

Depression affected a significant proportion of the participants. Five people mentioned explicitly that they were currently or had been in the past “depressed” or had either experienced or were experiencing “depression”. One other participant mentioned thoughts of self-harm related to other illness but did not discuss any mental health care or diagnosis of depression. One participant described her experience and the way she saw her diabetes as interacting with her depression:

*...I think mostly what it was is, is um, because of being that way, the way the depression went, like I was always put down, always. And um, so, what I would do is, is I would just go into my room, in the dark, and wouldn't shower for days, and just 'nobody talk to me,' I couldn't handle it. 'Cause when you're down... So, um, so I think more so with that is, is that you're not eating, you're not eating at all. And if you are it's that big bag of chips and a big thing of uh, dip, and just, eating it up. And that's basically what it was. And I think that's, I think that is pretty much it in a nutshell I think. You just don't eat right. Yeah. ...and that's another thing too I guess, too, because I um, if, if I did, like I mean a plate of spaghetti would be a plate of spaghetti.*

Of the participants who mentioned depression, three of them discussed that during the period of time when they were depressed they were dealing with many issues within their family and personal life, and also dealing with multiple health diagnoses; all this this was occurring while they attempted to manage their diabetes.

#### 4.4.2 Social Isolation

When social isolation came up during interviews, it related to talking to family and friends about diabetes, or in relation to taking part in social activities. Having diabetes did not seem to be an issue participants had



difficulty discussing with friends or family, although when a family member could not understand why someone was having a “bad day” related to their chronic illness, participants reported that this could cause some distress. A small subset of participants lived within the same residence building and each of these participants mentioned that they received support from each other, as they talked about their chronic conditions, the different ways they all felt that it was affecting their lives, and even occasionally making jokes. These social interactions can be important for reducing social isolation, as Gina said, *“I’m trying to get out of the rut now, but initially I was diagnosed [date] so I didn’t know anyone else diagnosed until [4 months later]. So the initial period was isolation...”* The rut she mentioned was somewhat alleviated when she found someone else who was recently diagnosed with diabetes and she began sharing her experience with that individual, and they worked through their diabetes problems together. *“You walk through it together so there’s a lot of emotional support about not quitting and not getting depressed, and you know, definitely a big benefit.”* Another participant wished for a “buddy system” to help keep her motivated to participate in healthy behaviours, and expressed that these healthy behaviours became that much more difficult to achieve when you are lonely. Similarly, one participant reported that now that she was without her social and diabetes clinic support, her blood sugars were increasing.

Participants also talked about isolation in reference to their social lives, or to being unable to participate in social activities. Some mentioned that social activities revolving around food were difficult, whether it was a family member not being able to understand repeated rejections of offers of sugary foods, family members monitoring what the participant was eating and making comments in the style of “haven’t you had enough of that”, or other events such as church socials centred around food or a meal. In these circumstances participants expressed frustration that their social circles did not understand diabetes food choices.

Another barrier to participation in these social activities was a lack of finances. Participants for the most part could not afford to eat out or have a social life, which could potentially be embarrassing to admit to those who invite them, or was isolating if invitations to participate ceased. One participant would like to have a group of people she could talk to about her diabetes that could be there for each other, but because she had a low income she said *“And it’s really hard because people on low incomes don’t have a lot of money for helping somebody out by driving them to the doctor or, you know...”*

In summary, diabetes diagnoses make social events with food challenging, and forming social networks is challenging when limited by financial constraints.

#### 4.4.3 Stress

The participants mentioned many potential stressors throughout their interviews. While these stressors were not always linked with the word “stress,” participants used words such as: hard, struggle, frustrate or frustrating, depressed, bad, worry, worries or worrying, sacrifice, challenge, stigma, “just another thing,” and defeat or defeated. These words could be considered the participants’ idioms for the stress or distress they faced while living with low income, food insecurity, and chronic illness. The topics that were mentioned most frequently by the participants as a group, or by a single or couple of participants with the most emphasis, are shown in the figure below. For example, diabetes progression as a source of distress was mentioned by many participants and thus it was added to the graphic. Most participants were diagnosed with diabetes too far in the past to remember if or how their daily lives changed immediately after their diagnosis, but those that were diagnosed more recently frequently mentioned the changes they were making to their diets and activities, and how they felt about those changes. Fewer people talked about these potential stressors; nevertheless, they are still included as a part of the map.

Stress affected participants’ lives by increasing their feelings of isolation, affecting their sleep or time spent in bed, or causing them to feel defeated. Stress has physiological interactions with body systems and chronic disease, moreover, as was outlined in Chapter 2, and once again in the Discussion.

One of the most frequently discussed stressors was the fear of diabetes symptom progression, or the development of secondary symptomology (n = 6) such as amputations, blindness, or kidney failure as a result of neuropathy, retinopathy, and nephropathy. This was also discussed in terms of the progressive nature of diabetes.

The stressors and how they synergistically contribute to the disease are displayed in Figure 5. From the graphic it is clear that there are many other potential stressors that these participants could face. However, they also discussed many ways by which they manage their stress. Some participants talked about learning to listen to their body cues and knowing when it was time to take a break, rest, or go to sleep. One participant told me she was leaving her job because she could not manage it on top of the other stressors

and health problems she was managing. While she was going to miss the money, to her it was not worth the stress that came with the job. Some participants used physical activity, such as swimming or yoga, or other activities such as breathing exercises, visualization, or reflecting on their attitude to deal with the stress they felt. When asked what makes her diabetes better, one participant told me that *“attitude is a big part of it”*. When I asked her to elaborate, she said *“like if you go at it with you know ‘I’m defeated’ or that ‘this is just a hurdle I have to jump over and get under control.’”* Similarly, another participant read about people who had gained control over their diabetes. Some talked about how their ideas around food as a tool for stress relief changed. Some only ate when they were hungry, but still others indulged in a favourite treat, but not to excess. One participant used to bake but now does not see that as an option for her. These de-stressing strategies are important to share because they are accessible to most low-income or food insecure people and sharing strategies for success was one point for which participants showed a lot of interest when they learned about my research project.

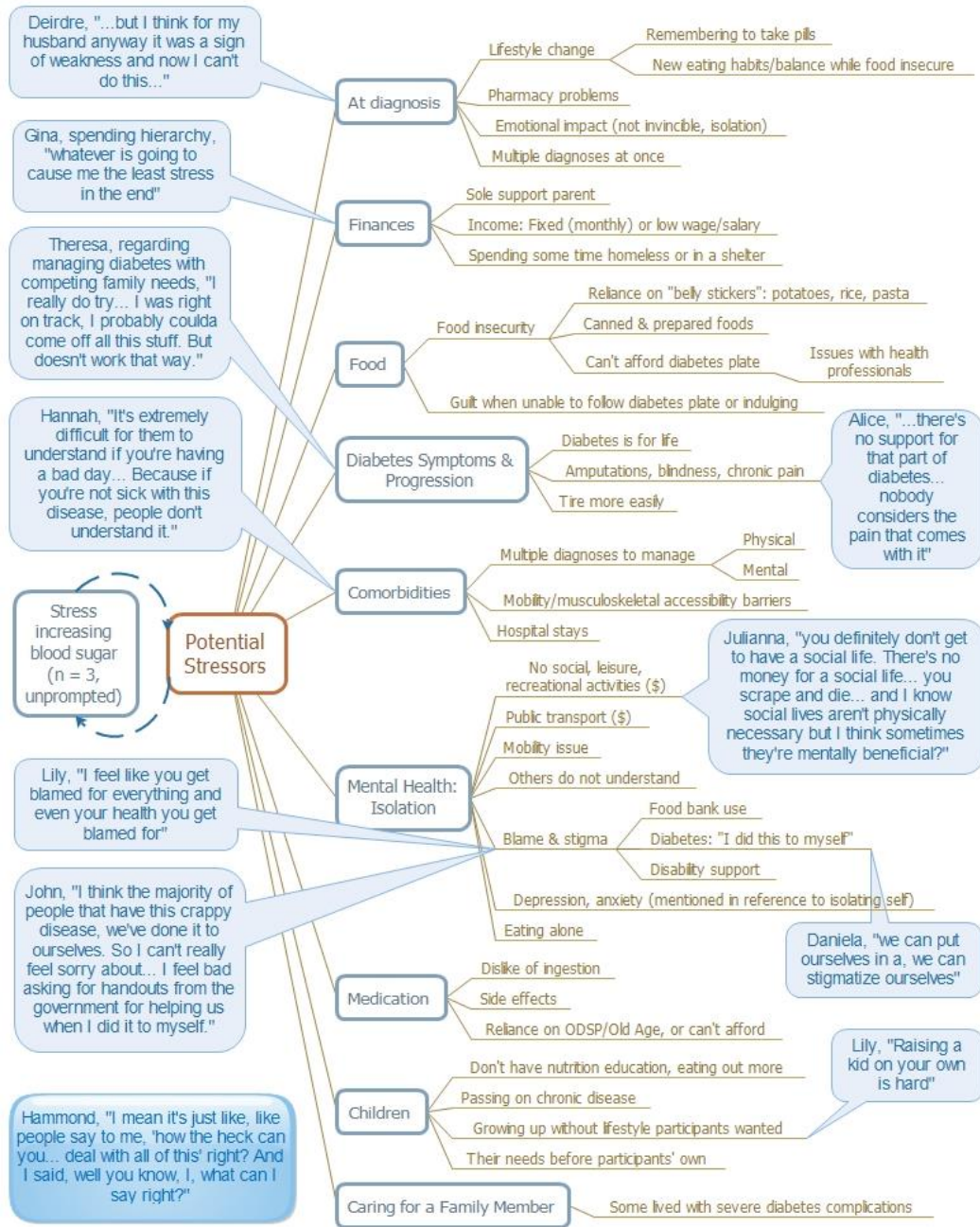


Figure 5: Map of Potential Stressors

## 4.5 Resilience: Diabetes Management, Skills Learning, & Self Knowledge

### Effort Put into Diabetes Management

After diabetes diagnosis, participants did not mention particular lifestyle changes that would be specific to having a low income, compared to someone with diabetes with a middle income. Food choice changes, exercise changes, and medication changes are challenges every individual faces when they are diagnosed with diabetes. From the examples already provided it is clear that participants are knowledgeable about health maintenance and management of finances and resources.

One oft-repeated word mentioned by participants when discussing the work they put into maintaining diabetes was “try”. They would say “*try to get a good night’s sleep, you know, I try and walk every day,*” (Max), or “*I can’t think of anything other than trying to eat sensibly, trying to eat healthy, trying to get exercise,*” (Francine), or “*I try and walk a lot to burn off the calories too, but also to burn off the sugar,*” (Hammond). This could be an indication of the knowledge and effort that this study population demonstrated, but also of the difficulty that they faced when following their diabetes guidelines.

Participants were for the most part very active in their healthcare management. They took their medication as prescribed when financially able to do so, and they made regular visits to varying healthcare professionals. For example, Gina said, “*So I’m a little anal about watching for things. Changes that I can visually see to try to be on top of it.*” This participant’s narrative was one of a “learning curve”, exemplified by her comment on foot care clinics. “*Ideally I’d like to attend one [a foot care clinic], and then understand what differences there are [for foot and nail care] because of the diabetes. Because then I can take over myself.*” She frequently demonstrates her desire to learn more about her disease, such as, “*...so I’m always looking. We have a dietitian at the Loblaws Supercentre and we tell her we’re diabetic; she’ll walk you through the diabetic side of it all. So, very good.*” Her desire to always be learning and to manage her condition as best as possible is exemplified:

*...and if I get the diet fully in check, maybe I could get off the metformin, but they’re [others she has met] thinking is ‘oh I’m stuck with this I might as well go out and eat and I’ll pop a bunch of pills’. Doesn’t make sense to me, they just find it easier. Now mind you, they probably got 20 years on me, I’m, I look at*

*it as quitting. Quit, give up, go ahead and get me I'm done, you know? No uh, I'll have to try everything else first.*

Participants were also active in seeking out healthcare from varying professionals. If participants were having problems checking their feet, did not like checking their blood sugar, or faced any other barriers as such, they often relied on their primary healthcare physicians to look after these aspects of their disease. Participants knew that their diabetes could affect their eyes so they sought out regular examination from optometrists. Some participants also had excellent relationships with their pharmacists and learned about medication and blood testing from them. One participant even went so far as to get involved in a small group support and study headed by a pharmacist. Still others became involved with dietitians at their diabetes centres or at local grocery stores and learned how to shop, read labels, and cook with a diabetes diet.

Hannah was very well educated on diabetes and local community programs geared toward financial assistance for low-income people and those living with chronic illness. Her high level of academic education may have contributed to her acuity, however she also put an immense amount of effort into her disease management, had a strong determination to be on as little medication as possible, and strictly manage her few financial resources. She has the potential to be an amazing community resource, if she can share her knowledge with her peers, healthcare professionals, community professionals, and researchers.

*I have taken programs on how to manage um my income at the present time here at Kerr Street, they're, they're offer it and I'm hoping that people do take advantage of it um, and I worked very hard on and yes in the beginning it's a little difficult but there's so many options in the community. Um, you have Kerr Street, you have, I'm, I'm sure that there are other places that I know that for instance we have a group called the Tomato Ladies that come in and they teach you how to cook for an individual as well as a family, all of the items that you receive at the market here.*

This individual also had knowledge of different financial resources, such as healthy food subsidies, available to those on ODSP living with chronic disease. Her narrative was one of emphasis upon putting effort into your health and managing what resources you have.

*But there's so many, and I have to put the emphasis on this, there's so many free programs in the community that just boggles the mind. I took uh, a program, um, a 6 weeks program at the Y, it was offered at the Y because the facility is free, and is through I how, again I through, Halton Diabetic, and it, it addresses issues of how you live with chronic diseases, how you manage, how you keep the food diary... which when I meet with the dietitian at Halton we go through the stuff, and you really, you know, it becomes a second nature after a while. In the beginning it's very hard, but we all have tendencies, we all have weaknesses, after all we are all human, but going back to that, that there are so many programs available for people and the emphasis is they are free, there's educational material, there are little things that you can do to follow up on it, but again, the onus is on you.*

This individual was very willing to share her knowledge and experience with her peers at the location from which I recruited her for research. She also was very willing to share her knowledge with me, partly for my own research goals, but also in an attempt to find ways to spread her knowledge into the community so that others in a similar situation to herself can benefit from her efforts.

### Knowledge of the Self

Many individuals are knowledgeable about how diabetes affects their bodies. They learned through experience and through shared knowledge how different foods affect participants' blood sugars differently. For example, Alan told me that he'd love to be able to eat fruit. When I inquired further he told me, *"well it's full of sugar. God I had, I had an apple a couple weeks ago, my blood sugar went up to like 12... And it's just like a small apple I'm like 'woah dang' what if I wanted something really sweet like a banana or mango or something,"* whereas other participants did not have trouble managing their blood sugar when eating fruit. Some participants were fine eating carbohydrates, and as long as they didn't ingest simple sugars they found they didn't experience high blood sugar numbers. As Julianna said, *"...I mean sometimes other peoples' experiences... I think all these diseases are totally individual with every person, there are some common things, but there are also, like there's foods that affect me that wouldn't affect somebody else. You know there are foods that I eat that make my sugar go way through the roof but somebody else can eat it and it's probably not going to affect them the same."*



Similarly, participants were knowledgeable of how their bodies are affected by high and low blood sugars, for example Deirdre told me, *“I usually have a protein bar or something in my purse. Because I can feel myself...”* or Francine saying, *“my face would go like really beet red, and I’d feel really hot,”* in reference to managing low and high blood sugar episodes. Participants also described typical symptoms of high and low blood sugar episodes. Further, some talked about trying to match symptoms to what foods they were eating. Finally, participants were interested in sharing knowledge about how to listen to their bodies and as a method for learning new strategies for disease management.

#### 4.6 Diabetes, Nutrition, and Social Supports: Study Participants’ Suggestions

Fifteen participants were asked or explicitly answered the question “Do you think that there is a need for more diabetes support,” and of those participants, 12 answered strongly in the affirmative, one replied with *“I guess,”* one said to *“make people more aware of Type 2,”* and one said no she does not believe that there is need for more diabetes support because, *“There’s so much of it... I think, to be quite honest there are some, some of these programs are doubled up.”* This participant did go on to explain that her area of Oakville is old and has services that were very well established, including medical care, food provision, and exercise facilities. She was also very capable at researching her options for finding the cares she needed, saying all she did was *“pick up the phone and just do whatever you need to.”*

Those who answered the question in the affirmative were asked to expand beyond a simple “yes” and explain what kinds of supports were needed or desired. Their answers were mostly related to food, diabetes education, and diabetes expenditures. Their ideas are summarized here:



Table 2: Suggested Improvements to Current Diabetes Systems

Category	Improvement	Number of participants
<b>Food</b>	Subsidized or more accessible fresh food; food that was applicable to diabetes diets at the food banks	7
<b>Education</b>	More space in diabetes clinics or more accessible education	3
	More non-traditional education including cooking classes or support groups	4
	Better, more centralized system, resource, or “flag as soon as you’re diagnosed” for diabetes education and other resources	2
	Diabetes programs with hours that were more accessible to those with full-time working hours	1
	Peer-mentoring or one-one one counselling with other diabetics	N/A
<b>Financial</b>	Financial support for those with low- or fixed income for related expenses such as vision care or foot care	1
	Better subsidies for medication, test strip, lancet, or other supply support for those who are low-income	2
	Reducing fees such as parking for those of low- or fixed income	1
	A better way to get in contact with pharmaceutical companies to apply for medication support	2
	Acknowledging the cost of over the counter products to manage diabetes chronic pain	1
	Free or subsidized exercise facilities or sports programs	2
	Improving ODSP programs to encourage people to work	1

#### 4.6.1 A “Trigger” Support

Some participants wished for a more immediate, streamlined responses when they were initially diagnosed with diabetes. They wished not only for a more immediate direction to the correct resources, but also a single common resource or information source, such as an information package, to which they could refer while they were navigating their first year after diagnosis. For example, Gina said, *“I think there needs to be some kind of flag as soon as you're diagnosed, to get you educated if you're open to it... I was had, I put my*

*prescription in [at the pharmacy] and nobody said or did anything.”* This participant only found out months later about pharmacist-provided education for medication, devices, and receiving sharps containers. Thus, she concluded that her ideal diabetes support would look like,

*A big, big communication from the moment of diagnosis, contacts for help with food if you have financial issues, help with um peer conversations, or you know someone who's been there, we should be connected to all the branches we need to... And right away with training on the meter, and strips and lancets and where to get them and how to get them, and what to do with them, physically actually showing you everything.*

This idea was expanded upon well by Alice, who said,

*It would be helpful if an information sheet was provided, telling you where to get financial assistance for your, for the items you have to have. What items you purchase that you should keep your receipts for because they're tax deductible... you know, what things are taken care of by um, city associations like the Rotarians, the Lyons Club... But I would like to see an information sheet that, that tells you about things like this and you know you can say 'oh okay this is what I have to do.'*

This participant went on to comment that services for chronic illness, not just diabetes, were, “*not easy and centralized... and you have to pick and pull every little piece.*” John reiterated this point when he said that a lot of people do not know about all of the “cares” that are available to diabetics. A good example of why this type of communication might be useful to someone who was newly diagnosed with chronic illness is:

*When I first had it I was kinda like 'meh it's diabetes' and I wasn't educated in it, didn't do anything about it, I kinda left it alone... [I] started having um, issues, I started having um a lot of ups and downs, I started having a lot of anger problems, which I never used to have, and eventually I found out that it was all due to diabetes and my numbers were incredibly high. They were really bad.*

#### 4.6.2 Ideal Centralized Diabetes Care

During this section of the interview, participants were asked to describe their ideas for new diabetes supports, and their ideal support system or

program for diabetes. While the answers varied, there were many commonalities between the answers, and they reflected the answers provided in Table 2: Suggested Improvements to Current Diabetes Systems. Here I describe a hypothetical program, amalgamated from participants' ideas:

*Table 3: Ideal Centralized Diabetes Care: Participant Ideas*

<b>"A Diabetes Centre with Everything You Need"</b>
➤ Food aligning with a diabetes diet
➤ Cooking classes and facilities
➤ Exercise facilities (subsidized)
➤ Direct contact with employees who know services and entitlements for diabetics, those on fixed income, and those with low-income
➤ Formal diabetes education
➤ Pharmacy
➤ The centre itself as a place of social support
➤ Community feel. Examples: community meals, shopping trips (with transportation)

As inspiration for a centralized location, some participants had attended clinics for other health concerns such as cardiology clinics, and marveled at the way one facility provided all diagnostic tests and medical appointments in one location where their medical files were communicated between all healthcare professionals in their circle of care. These individuals wondered why they had not experienced the same with their diabetes care. At the described clinic the rooms were private and all the facilities were clean and inviting, and it was all covered by OHIP. Lily thought something like that would work well for diabetes.

*So if they had centres like that for diabetes I think more people wouldn't be afraid to go, and they would use the medication, and they wouldn't... you know, 'cause you're scared anyway, right? And then you can go get your test done there, your bloodwork done, and talk to someone, get your education. I think a centre, a diabetes centre would be, like said all, like I think people would go, and they, what else is [reduce] the stigma to diabetes...*

The idea of a “spa-like” centre, even where clinicians did not wear medical uniforms was suggested as a way make the centre more welcoming. Also this centralized location should be accessible by public transit.

It was suggested that the diabetes centres would employ not only healthcare professionals typical to diabetes education centres (such as nurses and dietitians) but it was implied that a doctor should be present for medical appointments. There should be an individual who was knowledgeable about benefits to which people on a low or fixed income were entitled, and that there should be an advocate to represent the needs of the diabetic community to a larger audience, such as Diabetes Canada (Canadian Diabetes Association) and the government. A few participants mentioned professionals, such as a chef, who could work in the kitchen and teach cooking classes. One participant also suggested that the centre would offer care or assistance from individuals who spoke multiple languages and understood cultural aspects of diabetes from viewpoints other than clinical biomedicine. Some participants were interested in hearing from individuals who had learned to get their diabetes under control or had “defeated” their disease. Some participants were interested in this centre having partnerships with researchers so they have access to new and evolving medications, or even having representatives from pharmaceutical companies coming in to talk to them, since they were aware of programs that those big companies offered to help diabetics who cannot afford expensive medication.

One participant said that all facilities within the centre should be accessible to those with mobility issues. The facilities mentioned by all participants included medical rooms like those already included in diabetes education centres. In addition, a pharmacy with a pharmacist, especially knowledgeable of diabetes medications and supplies should be present.

The centre should include exercise facilities and a swimming pool that are free or affordable, possibly operating on a sliding scale according to income. Participants suggested that this centre could include many different food resources such as a community kitchen or a kitchen for cooking lessons, possibly a food bank or a room where something like Food for Life could set up, but with a special focus on providing healthy and fresh foods as opposed to prepared or canned foods. Francine made an excellent point describing why a set-up such as this would be beneficial:

*You listen to all this information, you listen to it, but if you're actually hands on with it and you see 'okay this is the food that*

*we have, this is what we're cooking tonight, this is good not only for your diabetes but your blood pressure, it's good for your health overall' then they can put the two pieces of the puzzle together and they can say 'okay yeah, yeah I can make this, this is easy enough to do' because I think you might look at a recipe and think 'I gotta chop up onion, I gotta chop up this, I gotta chop up that, I gotta do all this I gotta do all that, what's the point I might as well grab a bag of chips' right? So I think if they see how easy it is and how convenient it is, and you're with a bunch of people that are participating and cooking the food I think that would be a good idea.*

Many participants were looking for a community and group support atmosphere in this described diabetes centre. This community atmosphere was said to come from cooking together in the kitchen, and working out together in any group classes offered at the exercise facility. Some participants were especially excited by this idea, because they lived alone or were single and had a hard time staying motivated to take part in healthy activities on their own. Similarly, participants were excited about cooking in new ways, and learning from other diabetics from different cultures.

Participants thought that the diabetes centre also could act as a community centre where individuals of all ages could form sports teams and leagues in an effort to stay active. Some suggested that sports leagues and education could also reach out to younger demographics, preferably at reduced or no cost, as a preventative measure for diabetes onset.

Finally, participants were very concerned about the financial aspects of their diabetes care. Many participants mentioned finances or providing a possible program for people with low wages or fixed incomes. They were most interested in being able to access healthy food options, receiving supplies such as test strips or lancets at reduced cost or free of charge, and not charging a lot, if anything, for participation in cooking classes or gym memberships. One participant suggested that the centre might be able to reach out to companies or businesses and ask for specific donations for ingredients for community meals or cooking classes, or offer part-time jobs or volunteer hours to students to work at the gym. It was important to her and other participants that no one has to make the choice between medication and food, as they had before.

Participants' ideas about an ideal centralized diabetes centre revealed a significant theme: they see health and chronic illness management as

multifaceted and must be approached from multiple points of view, in a social setting. Participants were interested in improving the medical system in place, but they also wanted education resources, lifestyle change support, and most interestingly social support. Their health requires medical, nutritional, physical, financial, and social support.

#### 4.6.3 Support Groups

Participants were asked “if you could, would you meet with one or more people in your area so you could have peer support, solve diabetes problems, or even just get together to talk?” Participants who thought it was a good idea (n = 10) gave reasons that included sharing information and ideas that worked for them, learning from peers, and receiving emotional or mental health support and reducing feelings of isolation. Two participants said they would try a support group, but if they found it was not helpful they would not return. Some participants said they would not go (n = 5), because they were already managing well on their own, had experienced past frustrations when trying to share ideas with others, or they were already part of some sort of social or support program.

Alan had an excellent idea about why support groups could be so influential in supporting people with diabetes as they make healthy choices:

*I like the idea of a uh, diabetes clinic, it's great for people who uh just learning they're getting diabetes... But for people who've had diabetes and heard their song and dance for a long time, they should have something else. You, you know, um, kind of the way that alcoholics anonymous works, but for people with diabetes... If you could have a buddy that you could call, you'd be like 'well I came into Tim Horton's to get a diet soda, but man those oatmeal cookies look real good' you know? Or, or even just having weekly meetings, discussing all this stuff, and getting, and even though you're saying the same things over and over again 'oh I wish I could have this'... which is fine and everything, but just talking about it... And I think if they had a meeting of people who were serious, just to talk with you, just a support thing, even if they became I wouldn't say friends, but like, uh friendly acquaintances, that you know they could if they pass each other on the street they could stop for 5 minutes and catch up and say 'hey how's it going' you know stuff like that, you know, who you could call and say 'Oh I'm having a real tough time now I have a real craving for a bag of chips,'... If they had if it was moderated by... somebody who was a little*

*more, um a little more versed within the scope of um, a support group type setting, I think that would be really good... A new person needs to hear the clinical person... Once you get past that stage you get tired of hearing that same thing over and over and over again but that's all the province has...*

Some participants saw support groups as being more effective in a more casual setting than the previously mentioned diabetes centre, but some wanted them integrated into the diabetes centre itself. Regardless, participants did not want the support group to have a clinical feel. Participants saw a support group as a way to meet more people, find people with whom to cook, walk, or take part in exercise, as a source of new and helpful information, and as a way to stay mentally well.

#### 4.6.4 Other Supports

While the previously mentioned supports were overwhelmingly the most frequently discussed types of support systems, it is also worth mentioning that two other ideas came up. One participant wanted a support that was a type of “occupational therapy”, where people could learn a skill involving their hands, such as knitting, to reduce the desire to snack with idle hands while reading or watching television. Another couple of participants described in detail what they would like to see in a cookbook: inexpensive, healthy, diabetes-friendly meals with simple instructions, as a source of learning new ways to cook that supported their dietary needs. Finally, a couple of participants mentioned that they would like to see a co-op environment make a resurgence. In a co-op, people take ownership of their shared apartment building together and are part of a community that eats together, takes turns cooking or cleaning the common areas, and generally look out for each other and help each other out. Some participants felt this would be a good way to combat some elements of mental illness, food cost and preparation, and a way to ensure everyone in the community is well taken care of.

#### 4.7 Summary

A total of 18 people from the north and south of Halton Region, Ontario participated in this study. Of note, most participants are on a fixed income (n = 16), and only three participants are employed full- or part-time. Participants experience food insecurity through reduced access to healthy, fresh foods, ability to utilize food through metabolic changes due to chronic illness or insufficient cooking tools, or the cyclical nature of instability for acquiring their food resources due to unstable employment or reduced

financial resources towards the end of pay periods. Participants provide explanations for their diabetes aetiologies that extend back through their family histories, their lifestyle while growing up, or their lifestyle as an adult. Participants take part in varying trade-offs and compensatory strategies to manage their finances, such as paying for rent and utilities before all other expenditures including food, and severely limiting social expenditures. Activity limitation, including physical challenges to walking, cycling, or accessing public transit, or financial restriction to accessing exercise facilities or use of public transit limited participants' abilities to perform diabetes self-care including exercise, and made it more difficult for them to travel to medical appointments or the grocery store. Activity limitation, financial restriction, and food insecurity contribute to stress in participants' lives, influencing their mental health. Many participants also manage chronic mental illness alongside their chronic physical ailments. To deal with these confounding determinants of health, participants suggest a holistic approach to health that incorporated medical, pharmacy, nutrition, musculoskeletal, exercise, and mental health experts together at once facility designed to manage diabetes, the issues that accompany it, allow easier access to healthy diabetes management behaviours and resources, and increase the social cohesion of sufferers.



## Chapter 5: Discussion

### 5.0 Introduction

Using the syndemics theory and social determinants of health frameworks discussed in Chapter 2: Background & Literature Review and the data discussed in Chapter 4: Results, I propose a syndemic theory that includes type 2 diabetes, food insecurity, mental health, activity limitation, and low income. Using Singer’s framework (Singer et al., 2017) I provide evidence of the five conditions required for the identification of a syndemic. I then move into a discussion of an intervention for this syndemic interaction, namely a diabetes centre (as discussed by study participants) provide suggestions for future research, and finally discuss the strengths and limitations of the current study.

### 5.1 Food Insecurity and Diabetes Syndemic

Syndemics occur when two or more health conditions or diseases interact, along with social conditions, to cause an even greater negative health effect than any single disease, health condition, or social condition alone. To identify a syndemic, five conditions must be met: a “clear account of the diseases and health conditions, examination of the pathways or mechanisms

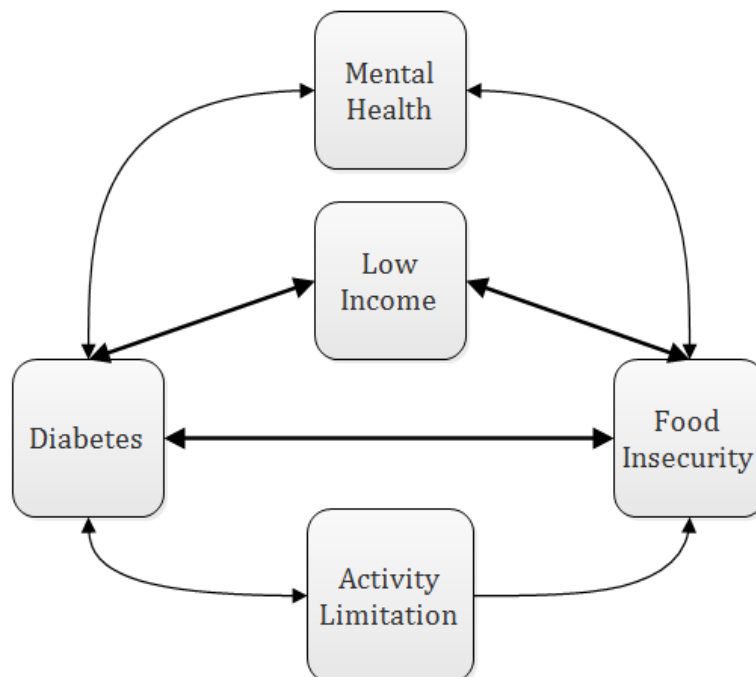


Figure 6: Syndemic Interaction

of disease-disease interaction, a clear description of the socioenvironmental conditions and how they are experienced by human minds and bodies as adversity, examination of the pathways of effect from socioenvironmental conditions to biological or psychological states, [and] evidence of greater health burden because of interaction” (Singer et al., 2017, p. 941).

### 5.1.1 Diseases and Health Conditions Involved

Based on the narratives of participants living in Halton Region, Ontario, I propose a syndemic involving food insecurity, Type 2 Diabetes, low (including low fixed) income, activity limitation, and mental health conditions. All participants involved in the study had diabetes. The measure of food insecurity for this thesis was self-description of use of food acquisition services or emergency food services, and all but four participants used these services. All four of those participants were on fixed pension or old age income. Most participants (n = 14) disclosed a musculoskeletal condition or barrier to mobility, and this combined with financial constraints led to activity limitation. Many participants lived on fixed disability support (n = 10), two part-time workers (with one participant on disability while working part-time), one full-time worker, one participant with no income at the time of the interview, one with an unspecified fixed income, and the rest of participants were on old age security or pension (see 4.1, Participant demographics). Finally, more than half of the participants (n = 11) disclosed having a current or past mental illness. It should be noted however, that near the Oakville site there is support centre for individuals with schizophrenia and this may have caused overrepresentation of those living with schizophrenia in the sample (n = 2). Even for those who did not explicitly identify living with mental illness, as discussed above in Results, Section 4.4.3 Stress, living with diabetes, low income and food insecurity gives rise to stress and stigma, which can directly feedback synergistically into the diabetes-food insecurity syndemic.

#### 5.1.1.1 Food Insecurity

For an individual or a household to be food secure they must be able to access, both physically and economically, safe and nutritious food. The majority of the study participants, by virtue of their fixed or low income, their participation in Food for Life or other food banks, and their choice of foods that were purchased by their own dollar did not have economic access to nutritious food at least, or sufficient amounts of food at worst. Food for Life played an important role in providing nutritious foods in many participants' diets. For some participants, especially in North Halton, physical access to

food was another issue that was faced due to geographic distance from fresh food retailers. Food resource utilization issues were common among the study participants. These individuals faced burdens of diabetes with possible comorbidities, low or fixed income, heavier reliance on cheaper foods (such as those that come in cans or boxes or high in starch and sugar), fewer skills and resources with which to manage their diet, and fewer available resources geared toward their demographic group. Finally, food insecurity was clear through the unstable nature of participants' food acquisition. Before the next paycheque is received, whether from low-wage employment or from fixed income, budgets are often stretched and food options are reduced.

Some of the participants said that receiving food from a food bank was seen as culturally and socially unacceptable or stigmatized by some participants or their acquaintances. Two participants knew people who could use help accessing food, but they would not use a food bank or accept help with food if they knew it came from a food bank. Another participant saw an acquaintance at a food bank, and the acquaintance was surprised that she used the service. Further evidence of potential stigma or cultural unacceptability of using food banks and Food for Life as charitable services surfaced as participants referenced their volunteering with these services. They stated that their volunteering was the reason that they did not feel bad about accepting food. This has been shown in larger surveys of people using food banks in Toronto, where stigma and cultural inappropriateness of using emergency food services or charity was cited by participants as a reason to avoid using a food bank (Loopstra & Tarasuk, 2012).

Finally, while food banks do not solve the issues that cause food insecurity, two participants were transiently food insecure during the research period, namely the participant who was doubling up on his rent after a hospital stay, and the other participant who uses Food for Life only during non-pay weeks. In these cases Food for Life and food banks addressed the stability aspect of their food insecurity, but it did not address the larger social issue which put these participants into these situations in the first place. Another stability issue with Food for Life was the seasonal or cyclical availability of healthy, fresh foods. While Food for Life makes efforts to provide these foods through the use of community gardens, these foods are only available in large quantities in the summer months. This means that food choices at Food for Life or food banks are insufficient for consuming a healthy diet for any person, let alone those with non-communicable diseases.

#### 5.1.1.2 Diabetes

Participants were diagnosed with diabetes either after a regular visit to their clinician's office or after a long history of symptomology leading them to seek care. About a third of participants were diagnosed with diabetes after a routine screen, possibly indicating the efficacy of the local healthcare systems. It is important to note that while sometimes participants experienced typical diabetes symptoms leading up to their diagnosis, some experienced symptoms not typically discussed. For example, some participants could not identify the cause of their feelings of malaise or "not feeling right", one participant experienced "shocks" and other participants experienced mood swings. Not only does this exemplify participants' knowledge of their own bodies, it shows that while there are typical symptoms of which to be aware for diabetes, others are atypical but should still lead to the appropriate tests for diabetes diagnosis.

More than half of participants either could confirm or suspected a family history of diabetes in the development of their own illness ( $n = 13$ ). This is an important piece of diabetes intervention. Subsequent generations may inherit the genotype from a parent but this is not deterministic. Interrupting the cyclical nature of diabetes before subsequent generations are diagnosed, or at the very least appropriately managing diabetes immediately after onset so that good care is learned by the next generations, could be more effective at managing the chronic illness than after it has been diagnosed.

The other element of diabetes etiology, either combined with family history or on its own, is the lifestyle explanation of chronic illness. Participants talked about poor eating habits or exercise habits, sometimes linking back to their childhood family eating habits. Even when participants blamed themselves or their poor decisions their narratives were laden with conditions that did not allow for healthier choices to be made, low paying jobs, high stress, and single motherhood, to name a few examples.

Some participants also talked about precipitating circumstances before their diabetes diagnosis such as emotional trauma, other illness diagnoses, or injury. This multitude of burdens could be indicators of the need for blood sugar monitoring, and is definitely something that should be managed in a syndemic health system [see 5.3.1 Diabetes Centre: A Syndemic Approach to Illness Treatment]. Diabetes was also frequently associated with other physical illnesses, such as kidney problems, cardiac ailments or other metabolic problems such as high cholesterol, high blood pressure, high

triglycerides, and other illnesses. Sometimes these illnesses were understood as a chain reaction with each piece interlinked.

When participants describe the precipitation of illnesses or conditions and the circumstances leading to their diabetes it shows that participants understand syndemic theory, without saying it in so many words.

#### 5.1.1.3 Mental Health

One of the most common “comorbidities” that accompanied diabetes was mental health problems, the most frequent of which was stress. Stress was characterized with words such as difficulty, frustration, worry, sacrifice, challenge, and defeat to name a few. Stressors included diabetes symptom progression, the required diet and lifestyle change that was sometimes unattainable, the emotional impact of a chronic illness, managing multiple comorbid diseases, feeling isolated, side effects of medication, and taking care of family members to name a few. Figure 5: Map of Potential Stressors [4.4.3 Stress] gives a more complete picture of participant stressors. Participants often did not make explicit references to their mental health in relation to their diabetes or food insecurity, but they often spoke of feeling “drained”, discussed their attitude, their denial of their diagnosis, or the frequent stressors they face. Some participants made references to physician diagnosed depression or feeling depressed (n = 5), which is proven to interact with diabetes (see next section). Social isolation was an issue because participants felt they lacked networks of support from other diabetics, or that their friends did not understand what it was like to manage a chronic illness and the daily monitoring or pain that accompanied it. Further, social isolation was exacerbated because participants could not afford to go out with friends or felt pressure when attending events centred around food. Participants also faced a great deal of stigma for their condition. They recounted feeling blamed for having diabetes or being overweight, from the ways their families talked with them about their food, and because of the “lifestyle explanations” for their condition.

#### 5.1.1.4 Activity Limitation

Activity limitation is a major determinant of exercise and food access in the study sample. Most participants (n = 14) described a musculoskeletal or mobility impairment such as neuropathy, arthritis, injury, or surgery leading to long-term impairment. Breathing problems such as asthma or COPD were not included in this number. Participants desired the ability to exercise through walking but could not walk for an extended time, and often low-impact exercise, for example swimming, which took into account their

impairment, was not financially accessible as the programs cost money, and travel to pools was either too far to walk or the cost of transit did not fit into budgets. To compound these issues, participants were not aware of any exercise programs geared toward their impairment, low-impact, overweight, or working hours needs. These issues are more severe in a diabetic population because exercise is one way to help control blood sugar levels.

#### 5.1.1.5 Low Income

Given their limited and fixed income, participants had to work very hard to manage their finances and balance their budgets. Their spending hierarchies meant that they paid for shelter and bills first, and food was purchased with what was left over. Participants enlisted many strategies to ensure their resources lasted. Participants put time and effort into counting needles or lancets, choosing between trade-offs and spending hierarchies to ensure they had shelter and utilities first before they could worry about food, and ensured their children's needs were met so they could be healthy. Income was also an issue for those who use social services, in that they found their benefits were drastically reduced immediately when they improved their employment or financial situations, and this would put them back into their previous precarious situation.

#### 5.1.2 Pathways and Mechanisms of Disease-Disease Interaction

The interaction of the five elements of this syndemic have been discussed at length in the previous sections. Figure 7: Pathways of Interaction summarizes participant ideas about how their food insecurity, low income, diabetes, activity limitation, and mental health interact and impact their overall health. These findings add to the existing evidence in the literature connecting elements of the syndemic. This section draws connections between the syndemic element interactions as discovered in the interview data and evidence from the literature from large studies including high-level meta-analyses and systematic reviews.

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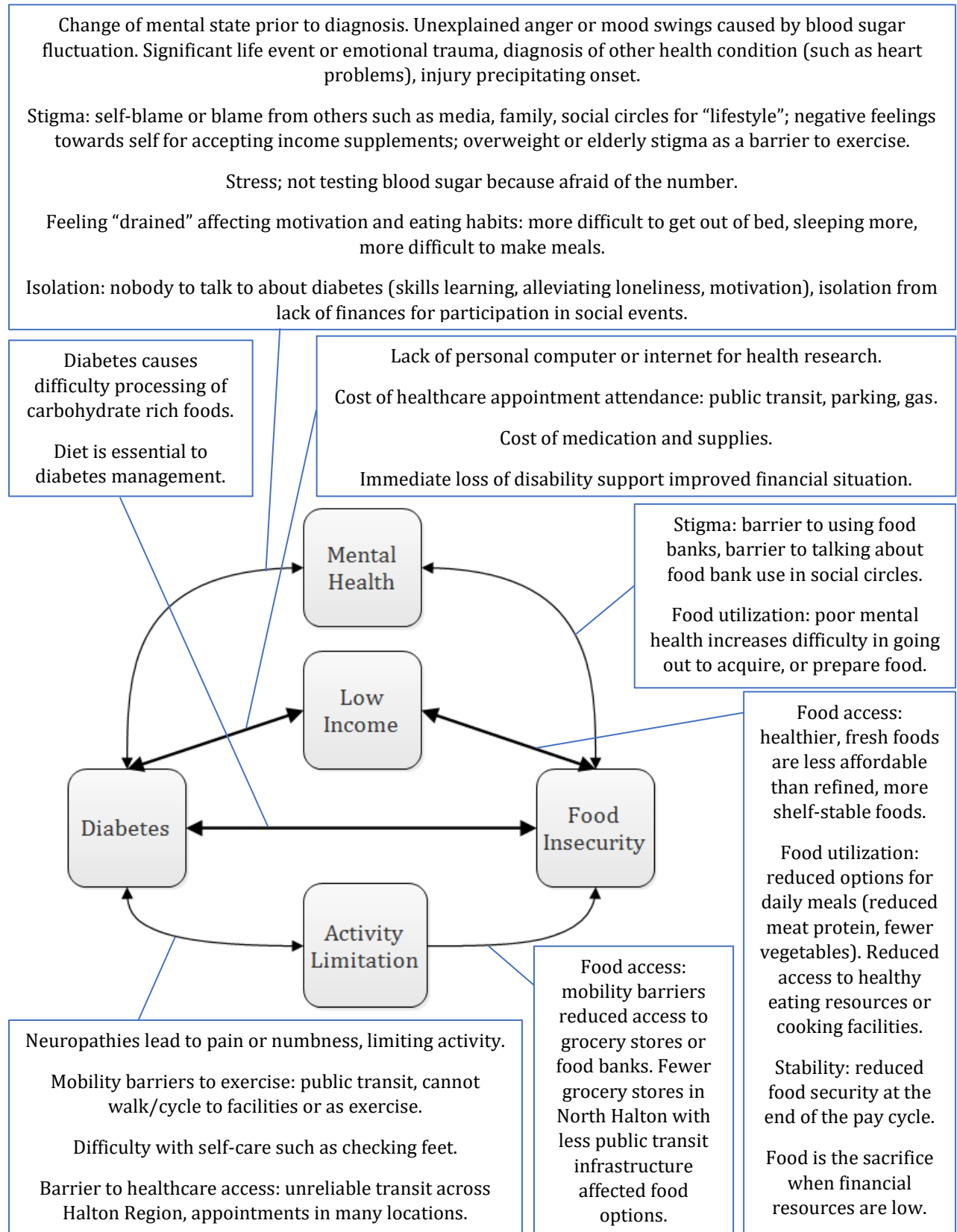


Figure 7: Pathways of Syndemic Interaction

There is mounting evidence within the literature of the association between depression and diabetes. Firstly, in a large, ethnically diverse study of persons aged 45-86 years, a bidirectional association was found between depressive symptoms and diabetes such that the incidence rate of type 2 diabetes was 22.0 compared to 16.6 per 1000 person-years for those with and without elevated depressive symptoms. Additionally, after adjustment, the risk of diabetes increased as the scale of depression increased (Golden et al., 2008). One of the most frequently cited reviews about comorbid depression and diabetes showed that the odds of depression were two times higher in diabetic groups compared to non-diabetic comparison groups (Anderson, Freedland, Clouse, & Lustman, 2001), similar to another study that found that the prevalence of depression was almost twice as high in people with diabetes compared to non-diabetics (Roy & Lloyd, 2012). This link has been evident since 1988, as an older review of depression and diabetes in adults showed an at least three-times increased prevalence of depression in adults with diabetes compared with the general population (Gavard, Lustman, & Clouse, 1993).

Some studies have aimed to ascertain a direction of association between diabetes and depression, for example a 2006 meta-analysis of longitudinal studies found that depressed adults have a 37% increased risk of developing diabetes (Knol et al., 2006). Evidence for pathophysiology in the other direction comes from study findings that individuals with diabetes were 24% more likely to develop depression compared to non-diabetic controls (A Nouwen et al., 2010). Similarly, a recent longitudinal Canadian study found that nearly half of patients with diabetes experienced at least one episode of subthreshold depressive symptoms over the duration of the study, and after adjustment the risk for poor function or impaired-health related quality of life was 2.86 times higher for participants with four or more of such episodes compared to participants with few or no depressive symptoms, suggesting a dose-response relationship (Schmitz et al., 2014). Anxiety was also associated with hyperglycemia in diabetic patients (Anderson et al., 2002), providing literature support to lay discourses on stressors elevating blood glucose levels in the study sample (see section 4.4.3 Stress).

Possible mechanisms for interaction of diabetes and depression include adults with depression showing poorer glycemic control leading to hyperglycemia or higher HbA1C levels in both cross-sectional and longitudinal analyses (Fisher et al., 2010; Lustman et al., 2000; Seligman, Laraia, et al., 2010). Fisher et al. also found that the relationship between



depressive symptoms and diabetes distress was greater than either relationship was to major depressive disorder. This contributes to the narratives of stress, stigma, or fear of diabetes complications contributing to poorer mental health and diabetes management. Further supporting these narratives, a meta-analytical study showed that depression was associated with diabetes complications such as neuropathy, nephropathy, retinopathy or cardiovascular complications (de Groot, Anderson, Freedland, Clouse, & Lustman, 2001), and depression is significantly associated with diabetes treatment nonadherence or poor self-care behaviours such as reduced physical activity, poorer diet, and lower adherence to medications (Gonzalez et al., 2008; Lin et al., 2004). Treatment non-adherence and poor self-care behaviours in turn can contribute to diabetes symptom progression, and this progression can contribute back into depression, thus self-perpetuating a positive feedback loop worsening the symptoms of both diseases and demonstrating the interconnectedness of the conditions. These studies back up participant narratives about the difficulty of completing self-care routines when experiencing depressive symptoms or diabetes distress, stories of their distress contributing to high blood sugar levels, and poor mental health outcomes associated with diabetes symptomology progression.

The aforementioned studies merely show association as opposed to biological mechanisms or pathways of effect connecting diabetes and depression. There are many proposed pathways: coincidental diabetes and depression due to similar life circumstances precipitating the diseases, the psychological burden of living with a chronic illness with physical symptoms, epigenetic DNA methylation and low weight at birth that can lead to premature metabolic aging or depression, innate immunity and inflammatory pathways, the hypothalamic-pituitary-adrenal (HPA) axis, insulin resistance and secretion, circadian rhythm, antidepressants, and environmental factors (Holt, de Groot, & Golden, 2014; Mezuk et al., 2013; Moulton, Pickup, & Khalida, 2015).

Evidence for a psychological association of diabetes and depression comes from a study that found that diabetes diagnosis, and not impaired glucose metabolism or undiagnosed diabetes increases the risk for depression in adults (Arie Nouwen et al., 2011).

Reviews of the literature on diabetes and depression have shown that increased cellular inflammatory response has been linked to incident diabetes, metabolic syndrome, pancreatic beta cell apoptosis (cell death), and insulin resistance. There is also some evidence for inflammation's role in

depression, and in people with increased cellular oxidative stress, reduced serotonin levels. Further, anti-inflammatory agents may improve glycemic control (Holt et al., 2014; Moulton et al., 2015).

HPA axis dysfunction can lead to increased levels of cortisol in the body (cortisol is the hormone related to long-term stress), which can affect the body's cortisol rhythm, increase free fatty acids, and contribute to insulin resistance. Low levels of cortisol have been linked with impaired glucose metabolism and increased inflammation (Holt et al., 2014; Moulton et al., 2015). There also evidence that depression can interfere with normal functioning of the HPA axis (Moulton et al., 2015).

The circadian rhythm, which plays a roll in the sleep-awake cycle, is disrupted in both diabetes and depression. Diabetes disrupts the sleep cycle as sleep apnea is a common side effect of the disease, and there are increased inflammatory markers in people with depression who sleep for long periods of time. Further, environmental cues such as light, food intake and social cues all may be disrupted with either condition, and these can affect the sleep cycle as well (Moulton et al., 2015). Poor sleep quality or altered circadian rhythms may increase insulin resistance and thus may affect susceptibility to diabetes (Holt et al., 2014).

As stated in Chapter 2: Background & Literature Review, the Canadian and American literature states that the overall rate of household food insecurity is higher for those with diabetes compared to those without diabetes, and those with diabetes and food insecurity were less likely to be satisfied with life, and more likely to have high levels of stress and poor mental health (Gucciardi et al., 2009). Conversely, the prevalence of diabetes was higher in severely food insecure compared to food secure populations (Seligman et al., 2007). Similarly, food insecurity was linked to restricted activity, higher rates of major depression and diabetes, and poorer social health (Vozoris & Tarasuk, 2003). These findings contain all elements of the current syndemic cluster.

### 5.1.3 Socioenvironmental Conditions and Adversity

For diabetes and depression, it can be argued that “environment” may refer to intra-uterine environment in the case of epigenetics, neighbourhood (physical environment), or social environment (Holt et al., 2014). For example, in a study of 336,340 adults in Sweden, high compared to low rates of neighbourhood deprivation accounted for a 1.66 odds ratio of diabetes (Mezuk et al., 2013). The pathways linking diabetes and depression, as

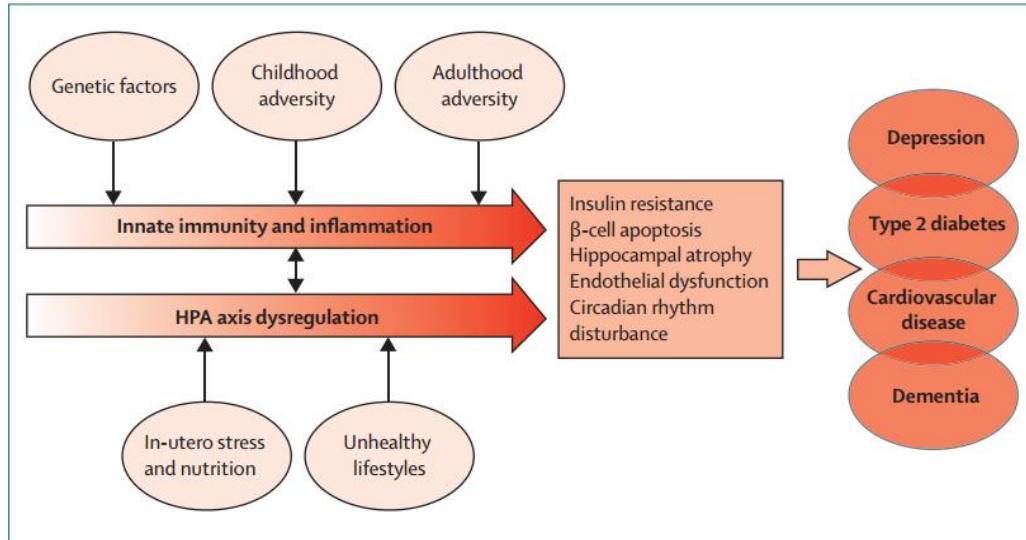
suggested in the previous section, are linked to socioenvironmental conditions and adversity through stress-mediated inflammatory pathways, and changes to the circadian rhythm. Further, low income, as a social determinant of health, is also highly implicated in socioenvironmental conditions experienced as adversity by individuals that experience syndemic clustering. Food security may be compromised through compensatory behaviours undertaken by low-income individuals (Seligman & Schillinger, 2010).

A qualitative study showed that stress can affect non-communicable disease outcomes through exacerbation of diabetes pathology or altered self-care regimens, and that stress can be both a precursor to and a consequence of diabetes pathology (Schoenberg et al., 2005). These sentiments were shared by the participants of this study as some experienced emotional trauma prior to their diabetes diagnosis, and many experienced stress as a consequence of their diabetes management. Many of these stressors were related to environment: food accessibility, reliance on social assistance, social isolation, or inaccessibility of grocery stores or exercise facilities, for example.

#### 5.1.4 Pathways of Effect from Socioenvironmental Conditions to Biological or Psychological States

There is evidence that stress during in-utero development may cause alteration in some areas of the brain that are highly sensitive to glucocorticoids, a class of hormones of which cortisol is associated. Further, stress during childhood can alter HPA axis function to increase an individual's responses to stress, increase inflammation, and is related to higher rates of depression and risk of diabetes in adults (Moulton et al., 2015). This is similar to evidence presented in section 2.3.1 Food Insecurity and Diabetes that suggested that epigenetic DNA methylation may pass phenotypes for chronic illness or metabolic syndromes from parent to offspring (McLean et al., 2006; Waterland & Michels, 2007). The interaction between environment, social conditions, and their effect on the physiology of

the biological and psychological implications can be summarized in the chart pictured in Figure 8.



**Figure 3: Summary of shared biological pathways contributing to pathogenesis of depression and type 2 diabetes throughout the life course**  
HPA=hypothalamic-pituitary-adrenal.

*Figure 8: Socioenvironmental Conditions Leading to Biological and Psychological States (Moulton et al., 2015, p. 466)*

### 5.1.5 Evidence of Greater Health Burden

Evidence for increased health burden comes from the participants' narratives describing their social determinants of health including their low income and environment, the interaction of their chronic physical and mental illnesses, and the impact these have on their daily lives. For some participants, something the general population may see as simple such as attending medical appointments or cooking meals are activities filled with challenges because of physical or financial mobility barriers, financial restriction reducing food options, and the mental strength required to overcome stress, stigma, distress, or depressive symptoms. The evidence of greater health burden comes from witnessing stories of illness, barrier, and resilience in the face of challenges.

## 5.2 Multifactorial Issues Require Multifactorial Interventions

### 5.2.1 Diabetes Centre: A Syndemic Approach to Illness Treatment

Study participants called for an inclusive diabetes centre that would treat their multiple conditions and treat their health from a multifaceted approach, from medical to pharmaceutical, to mental, to social systems (Section 4.6: Diabetes, Nutrition, and Social Supports: Study Participants' Suggestions). This concept is echoed in the literature,

*“Such an approach would view patients as one unit as opposed to diseases as one unit [patient-centred care]. Syndemic care would provide a clinic where, even if you go there for testing for one disorder, such as... diabetes, clinicians would employ a holistic approach. This would include testing for major comorbidities... alongside a general mental health assessment. One’s mental health has a direct effect on how people adhere to long-term treatment regimens. Because physical diseases are most likely to be chronic, mental health states will affect other chronic care conditions. Once comorbidity profiles are formulated, then the treatment of that patient would be holistic. Syndemic care would ensure task-sharing across the health system... After the general health assessment screening, each patient would meet with a counsellor and clinician as they set up their care plan. The clinic would serve as a place of diagnosis, treatment, and receipt of medicine.”* (Mendenhall et al., 2017, p. 956)

For example, when a patient comes in for diabetes testing or treatment (or after referral from a family physician), they would be screened for each element of the syndemic. They would be screened for living with food insecurity, mental illness such as depression, given the option of self-identifying as low-income or on disability, and screened for barrier to activity such as physical or financial activity limitation. A multidisciplinary team could carry out these varying screens, for example a mental health nurse would perform the mental health screen. A social worker knowledgeable of the different programs and services available to people living with chronic illness or low income would work on site and be available to consult regarding accessing these programs and services, and as another point of information communication between clinic patients and their disability workers, for example. Dietitians and nurses would provide diabetes

education and offer specialized consultation to individuals that are on low or fixed income. Diabetes cooking classes would be offered by these professionals or chefs so that participants had hands-on experience cooking healthy, fresh foods and the idea of changing one's cooking habits is not a major barrier to overcome. Participants are interested in incorporating into this facility an exercise facility with classes geared towards their mobility, overweight, or chronic illness needs. A pharmacy would be in site where the pharmacist was well-versed in programs such as Trillium and ODSP, as well as the common and less common pharmaceutical interventions for mental and chronic illnesses. In addition they would offer diabetes services on site for one-on-one education about diabetes supplies. The facility would also include meeting rooms where group or one-on-one peer mentoring could take place to help combat social isolation and share diabetes management strategies. A professional experienced in facilitating such discussions would be available to help train peer mentors or oversee group sessions. Through incorporation of all elements of the syndemic, patients would receive person-centred care instead of fractured disease-specific care, and thus may receive attention for conditions such as mental illness that might be missed during a more traditional approach to care. This has the potential to ensure fewer people "slip through the cracks" as some participants in this research study felt had happened to them. They would experience greater cohesion with other people in similar situations to them to help reduce social isolation, stress, or stigma. Patients could feel more assured that their health team is communicating and looking at all aspects of their health and well-being.

### 5.2.2 Future Research

Participants were asked whether their diabetes predated their food insecurity, or if the opposite was true. Participants often had no answer for this question, sometimes because their diabetes was diagnosed so long ago. Often they thought the conditions emerged simultaneously. There is evidence in this research project that food insecurity exacerbates diabetes, as seen when participants described their difficulties attempting to eat healthy, fresh foods or follow a diabetes diet. Further, there is evidence in the literature that food insecurity can lead to metabolic changes that contribute to chronic illness and obesity, as shown in the links between Canada's residential school program and the illness suffered by survivors and descendants of the survivors (Mosby & Galloway, 2017). This link must be studied further to better understand the causes and consequences of food insecurity and chronic physical and mental illness.

Similarly, aside from syndemic or epigenetic phenotypes that are inherited, watching a parent or close family member experience diabetes may have profound effects on younger generations' experiences with diabetes, or their psychology when dealing with diagnosis or management. For example, Deirdre suggested I ask my participants how diabetes affects them emotionally. Alice experienced distress when watching her mother die of complications of her chronic illnesses. Alternatively, a family member's positive or empowered experience of successfully managing their chronic illness could also positively effect someone who is newly diagnosed. Future research should continue to study the psychology of experiencing the chronic illness of a close family member, and further link this into a holistic framework, such as syndemics theory.

Food insecurity moreover is measured at the household level, while diabetes is measured individually (Seligman et al., 2007). I have not found any studies that compare the number of members in a household diagnosed with diabetes compared to food security status, income level, or other barriers to healthcare. Further, because food insecurity is a household measure, it does not access potential gendered stratification of food allocation. There is potential gendered access to food resources because women, but not men, have increased obesity in relation to food insecurity (Adams et al., 2003; Olson, 1999; Townsend et al., 2001). There are potential reasons for this gender trend, including mothers giving their children the healthiest food options, or women having restricted access to the healthiest food options. It is something worth investigating in future research.

Research should continue to investigate the possible mechanisms of interaction between the different elements of this syndemic, especially between diabetes and depression and other elements of mental health, as research regarding biological pathways is still in the preliminary stages for many of these proposed mechanisms. While the social sciences have long investigated the links between the social determinants of health (such as low income) and infectious or non-communicable diseases, the medical and biological sciences should research these pathways at the cellular, biochemical, and physiological level. Together, these fields can contribute to each others' evidence to promote health and find new and effective ways of intervening in syndemic interactions.

Future research should make clearer the links between the social determinants of health, food insecurity, and diabetes, including the biological and physiological pathways and mechanisms of disease pathogenesis and

poor disease outcomes. In addition, an effort should be made to investigate individual explanatory models of illness onset, to assist doctors and healthcare practitioners to determine when someone may be at high risk for diabetes pathogenesis.

### 5.3 Study Strengths & Limitations

This research project used a convenience sample (Bernard, 2011), and while the researcher made efforts to recruit a diverse sample the ratio between men and women, across age ranges, and countries of origin was not balanced. Further, due to language barriers non-English speakers could not be recruited. It is possible that this narrowed the lens of the data.

This study did not use formalized or validated measures of food insecurity, depression, or diabetes distress and instead relied on participant reports of common markers of food insecurity and self-reports of disease diagnoses from their medical doctors. This could introduce bias or misreporting into the data set.

The evidence used to show the interaction between the elements of the syndemic theory was largely cross-sectional in nature, however a benefit of this evidence is that they are supported by high order evidence, namely systematic reviews and meta-analyses.

### 5.4 Concluding Remarks

More public awareness should be made regarding inequality of access to social determinants of health, the inadequacy of food banks and other such donation-based food services for addressing food insecurity, and to reduce the victim blaming of overweight and obese individuals, so that these people face less discrimination and feel more comfortable seeking medical care. In particular we need to start recognizing syndemic models for food insecurity and diabetes, as seen in the Lancet series published in March 2017 (Mendenhall et al., 2017; Singer et al., 2017; Tsai et al., 2017) and in this current research project. This should also extend to including activity limitation and mental illness as either catalysts or by-products of living with these two conditions. No matter which element of the syndemic arises first, eventually as they progress they all synergistically interact to worsen the syndemic. Through working toward better equality in access to the social determinants of health, and reduced discrimination, health outcomes for those who live in the most difficult situations can improve.



## Chapter 6: References

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## Appendices & Diagrams

### Appendix 1: Interview Guide

**As a reminder, I am a researcher from McMaster University and I am looking into diabetes and the challenges that people who use Food For Life face every day. Do you have any questions about the research process, or what I am looking at?**

I will then go through the consent script

**Before I ask you about your diabetes I would like to ask a few questions about your everyday life. You may choose to not answer any one of them.**

**How old are you?**

**Were you born in Canada?** If not, when did you come to Canada and from where?

**What is your highest level of education?**

**Is there anything important you feel I should know about you?**

**Who do you live with?**

**Please do not tell me any numbers. Do you or does someone in your house work? What are your sources of income?** [Ontario Works, Ontario Disability Support Program, subsidized child care, Pension/Old Age Security, etc...]

**I am very interested to learn about different peoples' experiences with diabetes and I was wondering if you might be able to tell me a little about your life?**

**When did you first think you might have diabetes? When did the doctor tell you that you had diabetes?**

**Why do you think you got the disease?**

**Was there something that came first? Was there not a lot of money to buy food and then you found out you had diabetes? Or did you find out you had diabetes and then something happened that meant you didn't have a lot of money anymore?**

**Do you feel you have another illness that is related to your diabetes, or is made worse by your diabetes?**

**Is there anything that you feel makes your diabetes worse? Anything that makes it better?**

**Because everyone has a different situation, I am trying to find out how different people manage taking care of their diabetes and not having a lot of money or food resources.**

**Some people describe trade-offs between managing their diabetes and other things that need to get done, such as paying bills, buying food, buying medication, or caring for a family member. Does this ever happen to you?**

**When you don't have a lot of money, do you ever choose between diabetes medications or supplies [test strips, lancets, syringes, prescriptions] and food or other necessities? Which do you choose to buy first? Do you ever do without diabetes supplies/medications or food or other necessities?**

**I would like to ask you about whether diabetes has changed your life or made you feel different.**

**Has your diabetes impacted your family life? Work life?**

**Do you feel like there are things [about your diabetes] that you can't talk about with your friends, your family, or someone else close to you?**

**Do you notice any changes in your diabetes or how you take care of your diabetes (self-care) when you are unwell?**

**Finally, I am looking for your opinion as to whether there is enough support, education and programs for people with diabetes in your area.**

**Please describe what you eat and explain why you make those food choices. [What do you eat that you think is healthy?]**

**Do you know about the diabetes plate? Please describe it to me.**

**If yes, what do you think of the plate? Do you think it's hard to eat the diabetes plate? Are there foods that aren't on the diabetes plate that**

**you would like to eat? Are there any “healthy foods” that are not on the diabetes plate that you think should be?**

**If no, what do you know about what you should be eating with your diabetes? Are you able to achieve eating this way? Why or why not?**

**What are some reasons you might find it difficult to get foods on the diabetes plate or these healthy foods?**

**If there is not enough money to buy these foods, what do you do to help your blood sugar (keep it lower)?**

**Do you know about diabetes self-care from anyone? [HCP, friends, family]**

**Do you find it hard to do the self-care routines that your [whomever] talked about? [Examples: diabetes food plate, medication, foot care, testing blood sugar]? Why or why not?**

**Are there some other behaviours that you think are healthy? [Examples: exercise, walking, having children enrolled in sports activities, cooking own meals] Are you able to [do these activities]? [Why or why not? Prompts to access barriers and Social Determinants of Health that these individuals face]**

**Have you ever received formal diabetes education? What did you think of it?**

**Do you think that there is a need for more diabetes support? In what way? [education, meds support, healthy eating, community kitchens, affordable/safe places to exercise]**

**If you could create a diabetes program that would help you and people like you what would it look like? What would it include?**

**Groups? Activities?**

**A prompt: If you could, would you meet with one or more people in your area to have peer support to work through diabetes problems, cook, or simply get together and talk? Would this help you? If so, how?**

**Is there anything else important that you feel I should know about diabetes, anything to do with your experience of having diabetes, or anything else you feel is important to this research?**

**Thank you very much for your help today. Please contact me if you have any questions about my research or if you decide later that you don't want your answers in my study. If you want a copy of my work once it is**

**done, I will make it available to you through the address or contact  
method you provided me on the consent form. Have a good day.**

## Appendix 2: Participant Characteristics

### Appendix 2a: Participant Demographics

<b>PARTICIPANT NAME</b>	<b>GENDER</b>	<b>AGE, YRS</b>	<b>AREA IN HALTON</b>	<b>COUNTRY OF ORIGIN</b>	<b>LEVEL OF EDU.<sup>9</sup></b>	<b>EMPLOYMENT STATUS</b>	<b>INCOME TYPE</b>	<b>OTHERS IN HOME</b>
<b>LILY</b>	Woman	45-54	North	Canada	Some college	Employed FT <sup>10</sup>	Employed	Children
<b>TYLER</b>	Man	35-44	South	Canada	Some college	Unemployed	Disability	Spouse
<b>ALAN</b>	Man	45-54	South	Canada	Some university	Unemployed	Disability	Parent
<b>DIERDRE</b>	Woman	75+	South	Canada	Some college	Unemployed	Pension/ Old Age	None
<b>ALICE</b>	Woman	65-74	South	Canada	High school	Unemployed	Pension/ Old Age	None
<b>THERESA</b>	Woman	55-64	South	Canada	High school	Employed PT <sup>11</sup>	Employed	Spouse
<b>HAMMOND</b>	Man	65-74	South	Elsewhere	No high school	Unemployed	Pension/ Old Age	None
<b>MAX</b>	Man	55-64	South	Elsewhere	Some college	Unemployed	Disability	Other
<b>FRANCINE</b>	Woman	45-54	South	Canada	Some university	Unemployed	Disability	Children
<b>PAULA</b>	Woman	55-64	South	Canada	Some college	Unemployed	Disability	None
<b>GINA</b>	Woman	55-64	North	Canada	Some college	Unemployed	Ontario Works	Children
<b>DANIELA</b>	Woman	45-54	North	Canada	Some college	Unemployed	Disability	None
<b>CHRISTINE</b>	Woman	55-64	North	Canada	High school	Unemployed	Disability	Children
<b>JOHN</b>	Man	35-44	South	Elsewhere	Some college	Unemployed	None	Spouse
<b>JULIANNA</b>	Woman	55-64	North	Canada	Some college	Unemployed	Disability	Children
<b>CONNOR</b>	Man	55-64	North	Canada	Completed college	Unemployed	Disability	Children
<b>XAVIER</b>	Man	55-64	South	Canada	Completed college	Employed PT	Disability	None
<b>HANNAH</b>	Woman	55-64	South	Elsewhere	Some graduate level	Unemployed	Fixed, not specified	Parent

<sup>9</sup> Education

<sup>10</sup> FT = full-time

<sup>11</sup> PT = part-time

Appendix 2b: Participant Chronic Illnesses

<b>PARTICIPANT NAME</b>	<b>FAMILY HISTORY OF DIABETES</b>	<b>TIME SINCE DIAGNOSIS</b>	<b>MSK OR MOBILITY COMORB.<sup>12</sup></b>	<b>PHYSICAL COMORB.</b>	<b>MENTAL COMORB.</b>	<b>PHYSICAL &amp; MENTAL COMORB.</b>
<b>LILY</b>	Yes	5-10 years	Yes	More than one	Other	Yes
<b>TYLER</b>	Yes	Undisclosed	None Disclosed	None Disclosed	Schizophrenia	No
<b>ALAN</b>	Yes	10+ years	Yes	Other	Depression	Yes
<b>DIERDRE</b>	No	5-10 years	None Disclosed	None Disclosed	None Disclosed	No
<b>ALICE</b>	Yes	10+ years	Yes	More than one	None Disclosed	No
<b>THERESA</b>	Yes	Undisclosed	Yes	More than one	None Disclosed	No
<b>HAMMOND</b>	ND <sup>13</sup>	5-10 years	None Disclosed	MetS <sup>14</sup> Spectrum	None Disclosed	No
<b>MAX</b>	No	10+ years	Yes	More than one	Schizophrenia	Yes
<b>FRANCINE</b>	Yes	5-10 years	Yes	MSK or other mobility	Depression	Yes
<b>PAULA</b>	Yes	5-10 years	Yes	More than one	Other	Yes
<b>GINA</b>	Yes	Within last year	None Disclosed	MetS Spectrum	None Disclosed	No
<b>DANIELA</b>	Yes	10+ years	Yes	MSK or other mobility	Depression	Yes
<b>CHRISTINE</b>	Yes	Undisclosed	Yes	More than one	None Disclosed	No
<b>JOHN</b>	Yes	5-10 years	Yes	More than one	Depression	Yes
<b>JULIANNA</b>	Yes	10+ years	Yes	MSK or other mobility	Past, not current	No
<b>CONNOR</b>	Yes	Undisclosed	Yes	MSK or other mobility	Memory	Yes
<b>XAVIER</b>	No	10+ years	Yes	Other	Other	Yes
<b>HANNAH</b>	ND	Undisclosed	Yes	MSK or other mobility	None Disclosed	No

<sup>12</sup> Comorbidity

<sup>13</sup> Not disclosed

<sup>14</sup> Metabolic Syndrome Spectrum: including cardiovascular disease, hypertension, type 2 diabetes, high triglycerides, high cholesterol, etc.