BARRIERS AND STRATEGIES TO OPTIMIZE DIABETES MANAGEMENT IN EMERGING ADULTS WITH TYPE 1 DIABETES

A Dissertation
Submitted to the Graduate Faculty
of the
North Dakota State University
of Agriculture and Applied Science

By

Bailee Catherine Sawyer

In Partial Fulfillment of the Requirements
for the Degree of
DOCTOR OF PHILOSOPHY

Major Program:
Exercise Science & Nutrition

October 2020

Fargo, North Dakota

North Dakota State University
Graduate School

Title

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The Supervisory Committee certifies that this ***disquisition*** complies with North Dakota State University's regulations and meets the accepted standards for the degree of

DOCTOR OF PHILOSOPHY

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ABSTRACT

Emerging adults aged 18 – 30 years with type 1 diabetes (T1DM) make unique lifestyle choices that can create complications for disease management. The objective of this study was to identify barriers and strategies for management of T1DM in young adults (YA). A non-experimental, causal-comparative, observational cross-sectional study using both quantitative and qualitative methods was utilized for the study. In May 2020, YA with T1DM (n = 115; mean age diagnosed 14 ± 7.23) aged 18 – 30 years (64% in age group 25 – 30 years) were recruited to complete the Managing Diabetes in Young Adults Survey. Participant self-reported biomarkers and demographics. The survey included: T1DM management questions from the Diabetes Empowerment Scale (DES), the Diabetes Self-Management Questionnaire (DSMQ), the Diabetes Eating Problems Survey – Revised (DEPS-R), and select questions from the Centers for Disease Control Youth Risk Behavior Surveillance System (YRBSS). Qualitative methods included a telephone interview. From the survey, 'good' glycemic control (GC) was associated with higher DSMQ overall scores (p = 0.0003) and the DSMQ glucose management subscale (p = 0.0027) compared to 'medium' and 'poor' GC. Participants with 'good' GC were observed to have higher eating disorder/disordered eating risk (DEPS-R score ≥ 20) than the 'medium' GC group (mean 28.60 ± 6.86 vs. mean 22.17 ± 2.56, p = 0.0320). Participants who drank more alcohol per session and per week were more likely to adjust dietary intake and insulin dosage: (F (1,114) = 9.52, $R^2 = 0.0770, \mathrm{p} = 0.0026$), (F (1,114) = 5.14, $R^2 = 0.0431, \mathrm{p} = 0.0253$). There was a weak negative association observed from the Spearman correlation coefficient (-0.0755; 95% CI -0.2665, 0.1154) for 'good' GC and those who are at risk for low blood glucose during physical activity. Qualitative examination exposed various barriers and strategies for T1DM management. From the survey completers, 21 volunteered for the telephone interview

(female = 19, male = 2) (diagnosed age: mean 15.00 ± 8.00). Barrier themes included physiology, environment, and insurance and subthemes, mental health, lack of social support and weather. Strategy themes included medical technology, social support, and physical activity; and strategy subthemes, supplies, compliance, social media and accountability.

ACKNOWLEDGEMENTS

First, this disquisition is dedicated to Stephanie Waletzko, whose journey in life ended too soon. Stephanie was an incredible friend, classmate, and woman of science. I am both honored to have known her and hope to continue her legacy in research pursuits. I would also like to thank all the staff and faculty at NDSU and my graduate department, Health, Nutrition, and Exercise Sciences. Additionally, I would like to show deepest gratitude to my graduate adviser, Dr. Sherri Stastny. Dr. Stastny has been not only an adviser, but also a mentor who has guided my ability to teach, research, and become a more disciplined, empathic individual. I acknowledge Dr. Barbara North, whose career and life has been an example to me during my academic endeavors for nutrition sciences. Lastly, I would also like to thank Qian Wen, NDSU graduate service assistant in statistics, for spending countless hours aiding the completion of statistics for the study.

This research could not have been completed without the Diabetes community and all the research participants. My father, Byron Sawyer, and cousin, Hunter Aycock, whose life with diabetes inspired the idea for this study. Thanks also goes to, Cullen Cooper, who has supported career goals, been a friend, and partner during my degree. I am deeply grateful to the rest of my family, Belinda Sawyer, Britton Sawyer, and Laura Sawyer as they have been supportive during this process. Finally, I would like to express gratitude to the Schultz family; Emily Jo and Steve, who provided me with a flexible part-time job. They were a constant support during stressful times, and pushed me to succeed.

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Body mass index (BMI) .....Body mass in kilograms divided by the square of height in meters; known to be associated with overall mortality (Garrow & Webster, 1985).

Carbohydrate (CHO) counting .....Technique for estimation of carbohydrate gram (g) total in the meal or snack (in portions of 12 – 15 g CHO per serving) (Gillespie, 2006).

Cardiovascular disease (CVD) .....Can refer to several of the following conditions; atherosclerosis, heart attack, ischemic and hemorrhagic stroke, congestive heart failure, and arrhythmia (McClellan et al., 2019).

Dual energy x-ray absorptiometry (DXA).....Means of measuring bone mineral density, lean muscle mass, and fat mass through two x-ray beams (International Society for Clinical Densitometry, 2013).

Emerging adults .....Proposed conception of development from late teens through twenties, with the focus age group 18 – 25 years of age; goal of age group is to establish independence (Arnett, 2000).

Estimated glucose disposal rate (eGDR) .....Equation for estimating insulin resistance (24.31 – [12.22xwaist-to-hip ratio] – [3.29xhypertension]-[0.57xA1C]) where the units were milligrams per kilogram per minute and hypertension status was 140/90 mm Hg (was controlled with medications); this is a validated clinical tool for estimating insulin sensitivity in T1DM; higher score correlates to less insulin resistance (Williams et al., 2000).

Fasting plasma blood glucose (FPG) .....Value of acute blood glucose level through a capillary reading during a fasted state (Barrett-Connor, 1980).

Glycated hemoglobin (A1C) .....Red blood cells that are glycated via venous blood draw; historical biomarker for glucose control to show amount of glucose in the blood stream for last 3 to 4 months (American Diabetes Association, 2019b).

Human leukocyte antigen	The region that encodes several molecules in deoxyribonucleic acid (DNA) that may play key roles in the immune system and is strongly associated with autoimmune diseases (Gough et al., 2007).
Hyperglycemia	Blood glucose measurement above 180 to 200 (10.0 to 11.1) milligrams per deciliter (mg/dL) (mmol/L) (American Diabetes Association, 2019b).
Hypoglycemia	Blood glucose measurement below 80 mg/dL (4.4 mmol/L) (American Diabetes Association, 2019b).
Insulin resistance	Increased requirement for greater amounts of insulin to decrease the amount of glucose in the blood stream post-prandial i.e. after a meal; calculated by the eGDR (Reaven, 1988).
Late onset type 1 diabetes	Autoimmune diabetes presents in adulthood with requirement of insulin to control hypoglycemia (Lasserson et al., 2012).
Objective binge eating	Binge eating large amounts of food at one time, comparative to participant subjective binge eating which is defined at eating large amounts of a specific food (Timmerman, 1999).
Oral glucose intolerance test (OGTT)	Two-hour acute plasma glucose (PG) value after ingestion of 75 g oral glucose (American Diabetes Association, 2019b).
Plasma glucose (PG)	Plasma glucose is the measurement of glucose value in the body that can be assessed quickly and is separated quickly without waiting for the blood to clot (about 15 minutes). Plasma glucose should be drawn in the morning because concentration of glucose may decrease in the afternoon due to glycolysis by the erythrocyte, white blood cells, and platelet (American Diabetes Association, 2019b).
Type 1 diabetes (T1DM)	Autoimmune disorder producing β-cell destruction in the pancreas, usually leading to absolute insulin deficiency (American Diabetes Association, 2019b).

Type 2 diabetes (T2DM) .....Lifestyle disorder that is progressive; an individual decreases the ability to secrete insulin (American Diabetes Association, 2019b).

CHAPTER 1. INTRODUCTION

Type 1 diabetes (T1DM) is an autoimmune disease clinically described as the destruction of insulin producing β-cells in the pancreas (American Diabetes Association, 2019b). Daily glycemic regulation is required through endogenously administered insulin and the balanced dietary intake for individuals with T1DM. Hypoglycemia and hyperglycemia can have short-term and long-term biomedical implications when T1DM is not managed properly. Short-term difficulties include weakness, confusion, seizures, ketoacidosis, and diuresis. Long-term complications can include retinopathy, renal disease, cardiovascular disease (CVD), immune suppression, neuropathy, autonomic nervous system dysfunction, and peripheral arterial disease (Lakey et al., 2013). Severe hypoglycemia affects 30% of individuals with T1DM each year (McCrimmon & Sherwin, 2010). Hypoglycemia can be avoided through the help of medical professionals by creating an individualized plan for daily glycemic regulation for patients with T1DM. Medical professionals, who work with T1DM, can include primary physicians, endocrinologists, nurse practitioners, physician assistants, nurses, certified diabetes care and education specialists, exercise specialists, pharmacists, dentists, podiatrists, mental health professionals, and registered dietitians.

Statement of the Problem

Type 1 diabetes among emerging adults (ages 18 – 30) may be difficult to manage due to lifestyle choices. Emerging adults with this chronic disease might be at risk for comorbidities. However, emerging adults with T1DM often must find new ways to navigate help from various medical professionals, during this life stage.

Purpose of the Literature Review

The purpose of this literature review was to assess current research related to barriers and strategies to manage diabetes among emerging adults with T1DM. To assist future research endeavors, it is important to identify tactics to manage T1DM among emerging adults. Also reviewing articles which involve emerging adults and others who are in danger of uncontrolled T1DM, possible eating disorders, and unbalanced lifestyle will be paramount in exploring research to ascertain the individual's risk factors.

CHAPTER 2. LITERATURE REVIEW

Data and Methodology

The literature review explored relevant research material on the topic of emerging adults with T1DM.

Databases

A literature search of online databases EBSCOhost (MEDLINE), Web of Science (via Thomas Reuters), and Scopus, from inception until November 2019 was conducted for potential research studies.

Search Terms

The literature review search included the terms T1DM, etiology, adolescent, young adult, emerging adult, exercise, physical activity, eating disorders, body composition, management, comorbidities, and qualitative methods. Records that contained irrelevant terms (e.g. rat, mouse, aged care, reaction, disease, illness, bacteria, and elderly) were excluded from the literature search using the Boolean search operator 'NOT'. One investigator (B.S.) independently screened potential research studies to identify relevant texts. Irrelevant titles were discarded. The remaining studies were systematically screened for eligibility by abstract and full text, respectively. In the end, one investigator (B.S.) made the final decision to include or discard research studies for the reference list.

Inclusion Criteria

Literature specific to T1DM, disease management, and how psychosocial skills might impact management of T1DM among emerging adults was limited. Therefore, the inclusion criteria were kept liberal. Studies included descriptive studies and qualitative/quantitative studies. There were no restrictions for sample sizes. Peer-reviewed journals as well as other

publications specific to T1DM and emerging adults were included. While the population focus of the review was emerging adults with T1DM, other publications with other T1DM age groups were evaluated for relevance in relation to disease management, life skills, long-term health, physical activity, and dietary choices.

Exclusion Criteria

There were limited criteria identified for exclusion due to the limited nature of literature specific to emerging adults with T1DM. Only articles not addressing at least one of the key terms were excluded. Articles including rat, mouse, aged care, reaction, illness, bacteria, and elderly were excluded from the review.

Emerging adults with type 1 diabetes

As defined by Arnett (2000), emerging adults are the age group (18 – 25 years) between adolescence and adulthood that are striving to establish independence. During this period of life, significant choices may be decided such as committing to a lifelong partner, attending college, determining a future career, and moving to a permanent home away from their original family unit (Arnett, 2000). Though this definition is established, the ages of 25 – 30 add additional insight into the adulthood transition of personal growth. Emerging adults are known to make risky decisions that can affect their future, financial stability, and overall well-being (Arnett, 2000). In addition, at age 26, many young adults are dropped from parent/caregiver's insurance plans. Individuals with T1DM in this age group find unique difficulties that create additional stress and affect self-efficacy.

Self-efficacy has been defined as the perceived ability to exercise sufficient performance over situations that affect personal lives (Bandura, 1994). Individuals with a strong sense of self-efficacy face challenges as a task to be completed rather than a threat to avoid (Bandura, 1994).

A diminished sense of self-efficacy can create personal struggles with difficult situations and decrease the capability of accomplishment, which can lead to failure and depression (Bandura, 1994). The American Diabetes Association has identified the age group 18 – 25 years to be at risk for target glycated hemoglobin (A1C) levels, a measurement directly correlated to diabetes management (2019f). Financial and/or social hardships may cause emerging adults to struggle with disease management (American Diabetes Association, 2019f).

Etiology of type 1 diabetes

Type 1 diabetes requires daily insulin administration and dependency can vary based on age of diagnosis and length of decline of the pancreas (American Diabetes Association, 2019b). For some individuals, the chronic disease T1DM requires exhaustive frequent medical attention. For others daily, self-monitoring is required. Evidence suggests there are genetic factors contributing to the risk of T1DM, which include the human leukocyte antigen region on chromosome 6p21, the insulin gene (Lawrence & Mayer-Davis, 2019). Since there are multiple pathways to β-cell destruction resulting in T1DM, environmental triggers for T1DM onset were reported as part of the Environmental Determinants of Diabetes in the Young (TEDDY) and include infections, probiotics, micronutrients, and the microbiome (Krischer et al., 2019). To advance environmental prevention strategies, these difficult to target triggers need to be mapped over time (Lawrence et al., 2019).

Insulin is created in the pancreas for shuttling glucose molecules from the blood stream to the rest of the body for both available and stored energy in the form of glycogen (International Diabetes Federation, 2017). When carbohydrates are consumed orally, the body breaks down the food product both mechanically and chemically to form glucose (Siddle, 2011). Once glucose is in the body, insulin is released and triggers the insulin receptor, tyrosine kinase (Siddle, 2011).

After this occurs, tyrosine kinase is then phosphorylated to signal activation of other metabolic functions in the body (Siddle, 2011). Insulin stimulates glucose uptake in the muscle via translocation of GLUT4 vesicles to the plasma membrane (Siddle, 2011).

In addition, insulin inhibits gluconeogenesis in the liver and induces fatty acid/cholesterol synthesis through the regulation of sterol regulatory element-binding protein transcription factors (Siddle, 2011). Lastly, insulin signaling promotes fatty acid synthesis through the activation of upstream stimulatory factor 1 and liver X receptor (Siddle, 2011). Insulin has other various physiological responses in the body but those listed above are the major roles in a normal functioning pancreas. The autoimmune disease of T1DM will cause insulin elimination and will require daily insulin injections into the blood stream since the pancreas produces little to no insulin to move glucose out of the blood stream (International Diabetes Federation, 2017). Blood glucose and diabetes management are controlled through insulin injections (American Diabetes Association, 2019b).

Prevalence of type 1 diabetes

Diabetes diagnosis is reported on a yearly basis in the United States for both T1DM and type 2 diabetes (T2DM) in both children and adult cohorts. In 2015, diabetes was the seventh leading cause of death in the United States (Centers for Disease Control and Prevention (CDC), 2017). An international review reported T1DM is 5-10% among those diagnosed with diabetes (International Diabetes Federation Report, 2017). Current United States data indicates a rise in T1DM in children, with a 3% annual increase or 1 in every 400 children (>13,000 annually) (CDC, 2017). In the United States, late onset T1DM is becoming increasingly prevalent (Lasserson, Fox, & Farmer, 2012). A survey showed an incidence of 15/100,000 in the 15 – 34 years age group with a 2.8% increase annually (Lasserson et al, 2012). In the multicenter

"SEARCH for Diabetes in Youth Study", five centers in the United States conducted research, on age, sex, and race/ethnicity. From 2002 to 2012 an adjusted annual increase in T1DM incidence of 1.8% was reported (Lawrence et al., 2019).

The North Dakota Public Diabetes Report (2014) shows the prevalence of diagnosed T1DM and T2DM; diabetes among adults (18 and older) increased more than 2.5 times over the past sixteen years, from 3.1% in 1996 to 8.6 %in 2012. In 2012, an estimated 45,232 adults in North Dakota were living with diagnosed diabetes, with an additional estimated 13,149 adults who had undiagnosed diabetes. According to the CDC, 35% of the American population has prediabetes, which translates to over 184,000 North Dakotans. There is no reliable source for data on the prevalence of either T1DM or T2DM among youth in North Dakota (North Dakota Department of Human Services, 2014). According to the North Dakota Public Diabetes Report (2014), sex is not an important risk factor for diabetes. However, race is a significant risk factor for diabetes among North Dakotans. For example, American Indians have a prevalence rate of diabetes that is nearly twice that of non-American Indian residents. Certain geographic regions of North Dakota have higher prevalence rates as well. Sioux and Rolette counties have the highest prevalence rates. Both Sioux and Rolette counties contain American Indian reservations. In contrast, Cass and Grand Forks counties have the lowest diabetes prevalence.

Diagnosis of type 1 diabetes

Type 1 diabetes is a heterogeneous disease in which clinical presentation for diagnosis and progression of diseased state may vary significantly (American Diabetes Association, 2019b). Years ago, the clinical diagnostic criteria for T1DM versus T2DM diabetes was age differentiation; insulin-dependent or juvenile-onset diabetes (≤ 18 years of age) was defined as T1DM and adult diabetes (≥ 18 years of age) as T2DM (American Diabetes Association, 2019b).

There are two forms of T1DM, immune-mediated (formerly insulin-dependent or juvenile-onset diabetes) and idiopathic (unknown cause for diabetes) (American Diabetes Association, 2019b).

Immune-mediated diabetes (previously juvenile-onset diabetes) accounts for 5-10% of T1DM and is due to cellular-mediated autoimmune destruction of the pancreatic β-cells (American Diabetes Association, 2019b). Autoimmune markers include islet cell autoantibodies and autoantibodies to glutamic acid decarboxylase insulin and the tyrosine phosphatases. Type 1 diabetes is determined by the presence of one or more of these autoimmune markers. Immune-mediated diabetes commonly occurs in childhood and adolescence but can occur at any age, even in middle age and up (American Diabetes Association, 2019b).

Idiopathic T1DM currently has no known etiology (American Diabetes Association, 2019b). These patients have permanent inability to produce insulin from the pancreas therefore are more likely to experience diabetic ketoacidosis. However, there is no evidence of β-cell autoimmunity. A small minority of patients diagnosed with this form are mostly of African or Asian ancestry. Many of these individuals may need absolute insulin replacement therapy (American Diabetes Association, 2019b). In the past, the triad symptoms of polyuria (excessive urination), polydipsia (excessive thirst), and polyphagia (excessive hunger), were utilized alongside blood glucose hyperglycemia as indicative results for T1DM (Atkinson, von Herrath, Powers, & Clare-Salzler, 2015). Children typically present symptoms of polyuria/polydipsia and approximately one-third exhibit diabetic ketoacidosis (National Diabetes Statistics Report, 2017).

The American Diabetes Association (2019b) recommends utilizing plasma glucose (PG) rather than A1C to diagnose acute diabetes onset in individuals with symptoms of hyperglycemia. Any screening for T1DM risk along with a panel of autoantibodies should only

be completed for research trials or individuals with first-degree family members with T1DM. Two or more autoantibodies predicts clinical diabetes and may create the need for intervention in a clinical trial setting (American Diabetes Association, 2019b). A healthcare provider may recommend A1C testing to determine how long a patient has had hyperglycemia (American Diabetes Association, 2019b).

Table 2.1 presents criteria for diabetes diagnosis from the American Diabetes Association (2019b). Any individual (not dependent on age) can be diagnosed with either disease state, T1DM or T2DM diabetes (American Diabetes Association, 2019b).

Table 2.1

Criteria for Diagnosis of Diabetes (American Diabetes Association), 2019b

T1DM Diagnosis Criteria	**Fasting Plasma Blood Glucose**	**Oral Glucose Tolerance Test**	**Hemoglobin A1C**	**Classic Symptoms of Hypoglycemia or Hyperglycemia Crisis**
Clinical Lab Value	FPG ≥ 126 mg/dL (7.0 mmol/L)	2-h plasma glucose ≥ 200 mg/dL (11.1 mmol/L)	A1C ≥ 6.5% (48 mmol/mol)	Random plasma glucose ≤60 mg/dL (3.3 mmol/L) or ≥200 mg/dL (11.1 mmol/L)
Test Requirements	Fasting is defined as no caloric intake for at least 8 h. *	Test should be performed as described by the World Health Organization (WHO), using a glucose load containing the equivalent of 75 g anhydrous glucose dissolved in water *	The test should be performed in a laboratory using a method that is National Glycohemoglobin Standardization Program (NGSP) certified and standardized to the diabetes control and complications trial (DCCT) assay	
Target values for individuals living with T1DM	80 – 120 mg/dL (4.4 – 6.7 mmol/L) = within normal limits (WNL)	N/A	<7.5% (< 58 mmol/mol)	

Note: *In the absence of unequivocal hyperglycemia, results should be confirmed by repeat testing.

Type 1 diabetes is medically diagnosed through three parameters based on plasma glucose criteria: fasting plasma glucose, two-hour plasma blood glucose value after ingestion of 75 g oral glucose tolerance test (OGTT), and A1C criteria (≥ 6.5% / 48 mmol/mol) (American Diabetes Association, 2019b). Unless there is a hypoglycemic crisis (plasma glucose ≤ 60 mg/dL) (3.3 mmol/L) or clinical hyperglycemia symptoms (plasma glucose ≥ 200 mg/dL) (11.1 mmol/L), a second test is needed to confirm diagnosis. The OGTT may not demonstrate the total rise in blood glucose level. The area under the curve was developed to quantify the total rise in blood glucose during an OGTT. The OGTT has been utilized to calculate the glycemic index (Cheng, Li, & Cheng, 2018). The area under the curve shows response versus time of the blood glucose shifts during the OGTT and was designed to resemble changes during fasting blood glucose testing (Cheng et al., 2018). The equation of the glycemic index is = (incremental area under the curve for the test food containing 50 g of available carbohydrate/incremental area under the curve of a standard food with an equal carbohydrate portion) × 100 % (Cheng et al., 2018).

The three stages of T1DM may aid in the overall diagnostic process in the clinical setting (American Diabetes Association, 2019b). Table 2.2 identifies the characteristics and diagnostic criteria for all three stages.

Table 2.2

Staging of Type 1 Diabetes (American Diabetes Association), 2019b

	Stage 1	**Stage 2**	**Stage 3**
Characteristics	• Autoimmunity • Normoglycemia • Presymtomatic	• Autoimmunity • Dysglycemia • Presymptomatic	• New-onset hypoglycemia • Symptomatic
Diagnostic criteria	• Multiple autoantibodies • No impaired glucose tolerance (IGT) or insulin-like growth factor (IGF)	• Multiple autoantibodies • Dysglycemia: IFG and/or IGT • FPG: 100–125 mg/dL(5.6-6.9 mmol/L) • 2-h PG 140-199 mg/dL (7.8-11.0 mmol/L) • A1C 5.7-6.4% (39-47 mmol/mol) or ≥10% increase in A1C	• Diabetes by standard criteria – explained in Table 2.1

These stages may lead in the progression of screening geared towards early detection in diagnosing T1DM. Stage one is confirmed by testing the first degree relative of an individual for autoantibodies. The second stage can be determined through increased fasting plasma glucose (FPG), 2-h PG, and A1C lab values. Lastly, stage three is identified through both the characteristics of new-onset hypoglycemia and diabetes standard criteria identified in Table 2.1 (American Diabetes Association, 2019b).

Hemoglobin is made of two globin dimers, each with an associated heme moiety (Gallagher, Le Roith, & Bloomgarden, 2009). The components of Hemoglobin A were identified by charge on the cation exchange resin, and named according to their order of elution (i.e. A1C) (Gallagher et al., 2009). In hyperglycemia, the highly permeable erythrocyte cell membrane allows exposure of hemoglobin to elevated intracellular glucose levels (Gallagher et al., 2009). On average, erythrocytes survive 117 days in men and 106 days in women (Gallagher et al., 2009). Although older erythrocytes are likely to have more exposure to hyperglycemia, younger erythrocytes are more numerous (Gallagher et al., 2009). Several genetic hematologic blood disorders effect hemoglobin A1C and illness related factors (Gallagher et al., 2009). The altered

relationship between A1C and glycemic values can occur from conditions such as sickle cell disease, pregnancy, glucose-6-phosphate dehydrogenase deficiency, human immunodeficiency, hemodialysis, recent blood loss, or erythropoietin therapy (American Diabetes Association, 2019b). If these relationship examples should occur, only plasma blood glucose criteria should be utilized to diagnose diabetes (American Diabetes Association, 2019b).

The American Diabetes Association recommends performing the A1C test using a method that is certified by the National Glycohemoglobin Standardization Program (2019b). The method should also be standardized by the Diabetes Control and Complications Trial reference assay. Point-of-care assays approved for diagnostic purposes should only be considered in settings licensed to perform moderate-to-high complexity tests (American Diabetes Association, 2019b).

Individuals diagnosed with T1DM are recommended to routinely undergo an A1C test every 3 months (American Diabetes Association, 2019b). The A1C test has distinct advantages over FPG and OGTT. Benefits include greater convenience (no fasting required), greater pre-analytical stability, less day-to-day disturbances from stress and illness, and it is a long-term measure (> 3 months). However, the advantages of this method may be disturbed by greater cost, limited availability for testing in certain regions, and an imperfect correlation between A1C and the average glucose in certain individuals (American Diabetes Association, 2019b). The A1C test has a diagnostic threshold of ≥ 6.5% (48 mmol/mol). However, data collected by the National Health and Nutrition Examination survey reveals individuals diagnosed using A1C accounts for only about 30% of diabetic cases when compared to FPG or 2-h PG (American Diabetes Association, 2019b). The A1C measure can be disturbed by HIV treatment, age, race/ethnicity, pregnancy status, genetic background, and anemia (American Diabetes Association, 2019b).

The A1C target values for adult individuals with T1DM is set at a level <7.5% for blood glucose control (American Diabetes Association, 2019). Data is unclear if this recommendation should be used for children or adolescent populations (American Diabetes Association, 2019). Therefore, fasting blood glucose values rather than A1C can determine T1DM diagnosis for children and adolescents with hyperglycemia and hypoglycemia symptoms (American Diabetes Association, 2019). Screening for T1DM risk can be completed through the diagnostic tools in Table 2.1. Patients with acute symptoms of T1DM and elevated blood glucose levels may be easily screened for the progression of the disease (American Diabetes Association, 2019). One-third of patients are diagnosed with T1DM by the detection of life-threatening diabetes ketoacidosis (American Diabetes Association, 2019b). Early detection of T1DM is critical and can be determined by A1C value, fasting blood glucose, and diabetes ketoacidosis.

Control and management of type 1 diabetes

The American Diabetes Association reports that in 23% of cases, uncontrolled A1C, blood pressure, and lipids were associated with poor prescribed medication compliance (2019b). Barriers to proper medication adherence may include patient related factors such as financial burden, negligence or disorganization, fear, depression, or personal health beliefs. The mean A1C nationally among individuals with diabetes declined from 7.6% (60 mmol/mol) in 1999-2002 to 7.2% (55 mmol/mol) in 2007-2010 based on the National Health and Nutrition Examination Survey, with younger adults less likely to meet treatment targets than older adults (American Diabetes Association, 2019b). However, only 33-49% of patients still did not meet general targets for glycemic, blood pressure, or blood lipid control, and only 14% met targets for all three measures (American Diabetes Association, 2019b). Emerging adults (aged 18 – 30),

patients with complex comorbidities, financial or other social hardships, and/or limited English proficiency may face barriers related to target goals (American Diabetes Association, 2019e).

Insulin needed to manage A1C can be divided into three categories: basal, bolus, and mixed (American Diabetes Association, 2019f). Insulin action times can vary with each injection; the timings listed in Table 2.3 are general guidelines only.

Table 2.3

Insulin Definitions and Identifications (American Diabetes Association), 2019f

Action of insulin	**Insulin name**	**Onset**	**Peak**	**Duration**
Bolus: rapid acting	Aspart (Novolog) Lispro (Humalog) Glullisine (Apidra)	5-15 min	30-90 min	< 5 h
Bolus: rapid acting	Regular	30-60 min	2-3 h	5-8 h
Basal: Intermediate	Isophane insulin (NPH)	2-4 h	4-10 h	10-16 h
Basal: long acting	Detemir (Levemir)	3-8 h	No peak	6-24 h
Basal: long acting	Glargine (Lantus) Glargine (Toujeo)	2-4 h 6 h	No peak No peak	20-24 h 24-32 h
Basal: long acting	Degludec (Tresiba)	30-90 min	No peak	42 h
Bolus + basal: Intermediate + rapid acting:	NovoLog mix 70/30 Humalog mix 75/25	5-15 min	Dual peaks	10-16 h
Bolus + basal: Intermediate + rapid acting	NPH plus regular combination 70/30 50/50	30-60 min	Dual peaks	10-16 h

Basal insulin is long acting or intermediate and is designed to provide a baseline amount of insulin (American Diabetes Association, 2019f). Most individuals are prescribed basal insulin through once-daily injection or via their personal insulin pump. Bolus insulin is utilized to optimize blood glucose levels when food is consumed or to correct hyperglycemia (American Diabetes Association, 2019f). Mixed is a combination of both insulin types and is normally prescribed for individuals in personal doses for T1DM.

The American Diabetes Association discusses two therapy methods for insulin injections (2019f). Multiple daily injections are a type of mixed therapy to mimic normal insulin secretion

in the body. The doses are timed during the day to provide basal and bolus to accommodate for food consumption and any necessary hyperglycemia correction throughout the day (American Diabetes Association, 2019f). In comparison, an insulin pump is a computerized device that is worn 24 hours/7 days a week and connected subcutaneously through a tiny catheter (American Diabetes Association, 2019f). Individuals who are provided the necessary education for the insulin pump may find precise management for blood glucose control (American Diabetes Association, 2019f). Insulin pumps are programmed to provide rapid acting insulin and small increments of basal insulin throughout the day. However, an individual who is switched from multiple daily injections to a pump will need to meet with a medical professional to adjust dose because insulin is absorbed at a faster rate with the pump than through injections (American Diabetes Association, 2019f). A major consideration in dosing is lifestyle and risk for the dawn phenomenon. The dawn phenomenon is when an individual continually has higher than normal blood glucose in the morning and will need a greater amount of basal insulin to start the day (American Diabetes Association, 2019f). The dawn phenomenon may occur around 2 a.m. due to the release of growth hormone, cortisol, glucagon, and epinephrine. This may not occur in every individual with T1DM but the review of nocturnal blood glucose can show evidence to suggest the dawn phenomenon (American Diabetes Association, 2019f).

Insulin sensitivity is the ability for the body to utilize insulin properly and promote glucose uptake (American Diabetes Association, 2019f). Insulin resistance is associated with greater vascular risk (Epstein et al., 2013). Researchers Epstein et al. (2013) utilized a cross-sectional study to assess the distribution of estimated glucose disposal rate (eGDR) in a multiethnic population of patients with T1DM. The association between measured eGDR and diabetes complications was also reviewed. The estimated glucose disposal rate (eGDR) is

calculated through A1C, presence of hypertension, and waist circumference (American Diabetes Association, 2019f). The eGDR is a validated tool to estimate insulin sensitivity in individuals with T1DM (American Diabetes Association, 2019f). Participants in the study included individuals (n = 207) with mean and interquartile age range of 43.0 (34.0-54.0), female sex (42%), (mean 26.5, interquartile range 23.5-30.2), insulin dose (U/kg/day) (mean 0.59, interquartile range 0.44-0.79), A1C (mean 8.1, interquartile range 7.2-9.4) with a clinical diagnosis of T1DM. The participants were recruited from the endocrinology clinics and faculty practices at the Montefiore Medical Center (Bronx, NY) (Epstein et al., 2013). The eGDR was calculated as eGDR (mg/kg/min) = 21.158 + (0.09 * waist circumference) + (- 3.407 * hypertension) + (- 0.551 + A1C). Hypertension was defined with (0 = no, 1 = yes), diagnosed by a physician, or receiving treatment with antihypertensive medication. After assessing normality assumptions, eGDR (mean ± standard deviation (SD) was determined for the overall sample as well for ethnic groups. One-way ANOVA with post hoc pairwise comparisons were used to contrast between ethnic groups. Continuous variables that did not meet normality assumptions were reported as a median and interquartile range, with medians being compared by category of race/ethnicity with the Kruskal-Wallis test. The entire sample was divided into tertiles of eGDR (<5.39, 5.39-7.75, and >7.75), with the lowest eGDR tertile representing the most insulin resistant and the highest tertile representing the most insulin sensitive.

From the results, ethnicity was significantly associated with eGDR; blacks had significantly lower eGDR (5.66 ± 2.34) than Hispanics (6.70 ± 2.29) and whites (7.20 ± 2.03) ($p<0.001$). Participants with the lowest eGDR compared to the highest had a significantly greater risk of any diabetes complications (OR: 3.0, 95% CI 1.2-8.1) contrasted with the least insulin-

resistant participants. The eGDR is a validated tool to estimate insulin sensitivity for multiple ethnic populations.

Managing blood glucose can be completed through self-monitored finger prick blood (i.e. capillary finger sticks) testing with an electronic monitor. The goal for fasting blood glucose is between 80 – 120 mg/dL (4.4 – 6.7 mmol/L), which can be monitored after arising in the morning and prior to dietary consumption or insulin dosing (American Diabetes Association, 2019d). This system is used to determine whether blood glucose is within normal limits (WNL) (between 80 – 120 mg/dL) (4.4 – 6.7 mmol/L). The levels outside WNL include hypoglycemia (low blood sugar <70 mg/dL) (3.9 mmol/L) or hyperglycemia (high blood sugar > 120 mg/dL) (> 6.7 mmol/L). Self-monitoring can be performed in a clinical or home setting throughout the day; either scheduled or as needed from blood samples (Marigliano et al., 2013). For physically active individuals, additional "as needed" (PRN) blood testing can guide insulin dose adjustments before, during, and after exercise, depending on volume and intensity. Table 2.4 is an example of self-monitoring for blood glucose values measured with finger sticks via capillary blood. Tracking blood glucose through this process can improve real-time control and allow for flexibility during the day (American Diabetes Association, 2019d).

Table 2.4

Blood Glucose and Insulin Dose Example Log for One Week

	Breakfast	Lunch	Dinner	Bedtime
	BG before/insulin dose	**BG before/insulin dose**	**BG before/insulin dose**	**BG before/insulin dose**
Monday	157/2	197/4	153/2	85/0
Tuesday	67/0	154/2	285/6	124/0
Wednesday	122/2	106/0	89/0	150/2
Thursday	115/0	200/4	98/0	168/2
Friday	330/8	87/0	112/0	134/2
Saturday	135/2	65/0	217/4	115/0
Sunday	101/0	336/8	110/0	119/0

Note: * Blood glucose is measured in mg/dL; insulin is in units

Table 2.5 provides an example of gram count of carbohydrate for each meal and snack to utilize insulin injections properly based on carbohydrate intake and current blood glucose value reading (American Diabetes Association, 2019d).

Table 2.5

Carbohydrate (grams) Count Example for One Week

	Breakfast	Snack	Lunch	Snack	Dinner	Snack
Monday	45g	15g	30g		60g	15g
Tuesday	45g		45g		45g	
Wednesday			45g	15g	45g	
Thursday	15g	30g		15g	45g	
Friday	30g	15g	45g		45g	15g
Saturday			30g		75g	
Sunday	60g				45g	15g

Self-monitoring may improve overall diabetes management and increase awareness of dietary intake, body weight, physical activity, insulin injections, and blood glucose levels. Table 2.4 and 2.5 show examples of how individuals track self-monitored values. Researchers completed a systematic review of current self-monitoring data with reference to body weight, obesity, and weight loss (Burke, Wang, & Sevick, 2011). From the search, 22 studies remained that met both the inclusion and exclusion criteria. Of the 15 studies that focused on self-monitoring diet and weight loss, about half of those used paper diaries only and the other studies

used a variation of electronic and/or paper diaries for food intake. Investigators from the studies that were extracted found more detailed (e.g. food amount, time of consumption, example of portion) completeness of the self-monitoring records were associated with greater weight loss. From three studies, researchers recommended body weight self-monitoring. Self-monitoring increased awareness of energy intake and consumption related to weight loss. Structured programs may result in the best outcomes for adherence to weight loss. The researchers found a positive relationship between self-monitoring and weight loss (Burke et al., 2011).

Self-report dietary methods may provide support for individuals with T1DM to improve daily management. However, self-report methods such as the three-day food diary, may be difficult to complete due to the complexity of dietary intake (Kirkpatrick et al., 2019). Three-day food diaries may be used for surveillance, but if the subject is asked to log too many days, or too many consecutive three-day food diaries, subject fatigue may occur. While dietary intake can be observed in person, in most settings this method is not feasible. Short-term dietary assessment such as 24-hour recall and food records for multiple days can show an average of long-term consumption, a form of random error that accounts for within-person variation. The random error may occur regardless due to limitations of truthful recording of intake. Biomarkers may provide insight during the self-report time and are relevant to validation of dietary assessment, however more research is needed to assess any error within a 24-hour period for this tool (Kirkpatrick et al., 2019).

Microvascular and macrovascular complications related to T1DM mismanagement can be prevented or slowed through self-care behaviors (Schmitt al., 2013). Psychosocial factors such as depression can impact self-care behaviors and reduced self-care can lead to elevated to A1C (Schmitt et al., 2013). As a result, assessing the relationship between self-care behaviors for

an individual with T1DM can help aid objective planning for improved A1C levels (Schmitt et al., 2013). The Diabetes Self-Management Questionnaire (DSMQ) was developed to quickly evaluate self-care behaviors for individuals with diabetes (Schmitt et al., 2013). The questionnaire is designed to assess behaviors associated with metabolic control within common treatments.

To test the DSMQ for reliability and validity, patients were recruited from the German Diabetes Center (Schmitt et al., 2013). After obtaining informed consent, the demographics for the individuals in the study were taken from electronic health records. The first study of the DSMQ evaluated the full 37-item questionnaire. The topics of the questionnaire were medication intake (4 items), diet adjustments (8 items), self-monitoring of blood glucose (4 items), physical activity (5 items), appointment adherence with health-care staff (4 items), self-recording of blood sugars (5 items), and judgement of self-care adequacy (7 items). There were 110 patients who were diagnosed with T1DM or T2DM included in the study. The demographics showed an average age of 51 ± 16 SD years old, BMI of 30 ± 7 SD, 46% with T1DM, diagnosed with diabetes for 16 ± 10 SD years, A1C 8.5 ± 1.8% SD, and 53% with other diabetes-related complications. Five psychologists, three endocrinologists, and a sample of fifteen patients with diabetes piloted the items in the first study for the 37-item survey before it was administered (Schmitt et al., 2013). Of the 27 items that assessed ‘dealing with hypoglycemic episodes’, ‘calculating carbohydrates’, ‘alcohol consumption’, ‘needed insulin devices’, and ‘weight control’, ten were negatively correlated to better overall A1C value and subsequently removed. Two items decreased internal consistency and 25 items had an alpha-coefficient 0.93 observed, which means the 25 items were related to the criterion variable. A principal component factor analysis was performed. A varimax-rotated factor loading evaluation showed six items were

below the threshold of 0.50 or higher. These items were removed from the questionnaire. Next, factors were interpreted and matched items were rated. Lastly, the remaining 18 items were analyzed for equal content and equal correlation. The items with lower correlation to A1C were removed.

After the first study, subscales were created for the sixteen items that had the best assessment of self-care (Schmitt et al., 2013). The subscales were 'glucose management' (5 items, 1, 4, 6, 10, 12), 'dietary control' (4 items, 2, 5, 9, 13), 'physical activity' (3 items, 8, 11, 15), 'health care use' (3 items, 3, 7, 14), and one item (16) that requests a rating of overall self-care (Schmitt et al., 2013). Each subscale was calculated by the 4-point scale of 'applies to me very much' to 0-point 'does not apply to me'. Then that score is divided by the total possible score and then multiplied by ten. This tool was then tested for reliability for good internal consistency with Cronbach's alpha coefficients. The reliability analysis revealed the Cronbach alpha was 0.77 for 'glucose management', 0.77 for 'dietary control', 0.76 for 'physical activity', and 0.60 for 'health-care use'. For the 'sum scale', an alpha coefficient of 0.84 was observed. A comparison was completed for known-group validity. The patient groups were split into 'good glycemic control' (A1C $\leq$ 7.5), 'medium glycemic control' (A1C 7.6 -8.9) and 'poor glycemic control' (A1C $\geq$ 9.0). The 'good glycemic control' group showed better ratings for all three subscales and had a higher sum scale score than 'poor glycemic control' group. However, when compared to the 'medium glycemic control' group the 'good glycemic control' group reported improved 'glucose management' and 'physical activity' but no differences in 'dietary control' and 'health care use'. This survey can be utilized to evaluate the relationship between self-care with related subscales of overall diabetes management and glycemic control. This tool can also be valuable to assess barriers to improved A1C.

A continuous glucose monitoring (CGM) system may be utilized for measurement through interstitial fluid every five minutes (Pickup et al., 2011). This system is composed of a glucose sensor implanted in the subcutaneous tissue utilizing a wireless transmitter and radio-frequency identification (RFID) microchip (American Diabetes Association, 2019f). After the glucose sensor is inserted in the subcutaneous tissue, the needle is retracted, and applicator is removed. Then the tiny electrode under the skin is connected to the wireless transmitter that allows readings to be submitted to the glucose sensor (American Diabetes Association, 2019f). In five minute intervals, blood glucose levels are then sent to the device of choice such as; smart phone, iPad, etc. (American Diabetes Association, 2019f). The device can be utilized to track trends and programmed to "red flag" concerns such as hypoglycemia and hyperglycemia. Patterns can be more easily identified because blood glucose is measured more frequently (American Diabetes Association, 2019f).

The continuous monitor system may be utilized as a tool for hypoglycemia prevention and to protect against dangerously low blood glucose values. A sample of older adults with T1DM were recruited using a snowball sampling technique from the Diabetes Online Community within Facebook to participate in one of the two online surveys focused on CGMs (Litchman & Allen, 2017). The snowball sampling technique is defined as chain-referral sampling and is a non-random group who are already interested in providing information for the topic (Lewis-Beck, Bryman, & Futing Liao, 2004). The first survey included individuals who were current CGM users. The second survey, that occurred a month later, examined individuals who were not currently using CGMs but had the desire to do so. The interview included two open-ended questions. The first open-ended question was focused on why participants were using or wanted to use CGMs. The second open-ended question was how the monitor affected

diabetes management and safety. Open-ended questions are prompt but allow the participant to provide a free-formed response (Lewis-Beck et al., 2004). The open-ended questions for the interview also addressed hypoglycemia, severe hypoglycemia episodes, and hypoglycemia unawareness. For this report, hypoglycemia was defined as blood glucose < 70 mg/dL (3.9 mmol/L), severe hypoglycemia was defined as a hypoglycemia episode requiring assistance from another person, and hypoglycemia unawareness was defined as occurring when an individual with diabetes was experiencing hypoglycemia but reported no symptoms. Participants were eligible for the study if they were ≥ 65 years, had been diagnosed with T1DM, and could read/write English. There were 22 participants (11 males, 11 females) and those using the CGM (n = 11) and those not using the CGM but desiring to do so (n = 11). The participants were white, mean age of 70 ± 4.7 years, diabetes duration of 59 ± 9.6 years, and identified as high technology users. Individuals who were wearing the CGM were less likely to experience severe hypoglycemia requiring assistance from another person from the results of the Fisher's exact test, run at a $p<0.05$ ($p=.02$). In the last year, there was a significant difference in non-monitor users who were more likely to have severe hypoglycemia resulting in a fall or inability to operate a vehicle (Fisher's exact test, $p<0.05$, $p=.01$). The study concluded participants demonstrate a greater feeling of safety for blood glucose control when utilizing CGM from the qualitative measures. The individuals using the CGM reported the system improves well-being. Lastly, the interviews revealed insurance approval as a barrier to access CGM (Litchman et al., 2017).

Individuals with T1DM may be concerned for the accuracy of the CGM system versus self-monitoring through means of a hand-held glucometer. One study compared the differences between glucose values of the CGM system and capillary readings in a real-world setting (Francescato, Geat, Stel, & Cauci, 2011). The researchers acquired venous blood samples from

eighteen participants (males = 10; females = 8) diagnosed with T1DM (35-65 years old, median 47 years) then followed by capillary measurement (Bayer Contour Link meter, Basel, Switzerland) and CGM readings (Medtronic Paradigm, Northridge, CA) were taken and analyzed. The demographic data included, diabetes duration mean 28 years (range 5 – 49 years), mean A1C 7.1% (range 5.2-9.2%, 33-771 mmol/mol) and BMI mean 25.3 kg/m² (range 20.1-30.2 kg/m²) (Francescato et al., 2011). Participants were recruited if they did not have acute or chronic diseases that would impact blood glucose levels. All participants were taking multiple daily insulin injections. After lab values were collected to compare both monitoring systems, a Clarke's Error Grid Analysis was subdivided into five zones. Linear regression was utilized to review error of both the self-monitoring capillary system and the CGM (Francescato et al., 2011). There was no statistical difference between the capillary and CGM readings, mean difference, (- 0.05 ± 1.06 mmol/mol and 0.10 ± 1.84 mmol/mol glucose). The absolute errors of the CGM device showed a direct correlation of the moderate level related to the rate of glucose change ($r = 0.598$, $p<0.001$). However, an error was found for both systems during hypoglycemic blood values (Francescato et al., 2011). The researchers recommend following the American Diabetes Association guidelines to initiate hypoglycemia treatment with a self-monitoring system that reads < 19 mmol/mol, although the reading was not associated with normal extreme low blood glucose symptoms (Francescato et al., 2011). Individuals with T1DM should be aware there is a margin of error with any blood glucose-monitoring device. Medical professionals need to educate and guide patients on monitoring tools to best improve blood glucose control and prevent diabetes complications.

Medical nutrition therapy to manage type 1 diabetes

As defined by the National Academy of Medicine, diabetes medical nutrition therapy is the process of treatment for diabetes through the modification of nutrient or whole food consumption (Evert et al., 2019). Medical nutrition therapy for individuals with T1DM promotes long-term health benefits (American Diabetes Association, 2019d). Ideally, a registered dietitian can aid to achieve treatment goals and should provide an individual medical nutrition therapy program. Medical nutrition therapy has been shown to help achieve specific goals, such as improved A1C values and should be adequately reimbursed by insurance providers (American Diabetes Association, 2019d).

One of the primary T1DM management goals identified by the American Diabetes Association is to promote and support healthy eating patterns. The pattern should focus on a variety of nutrient dense foods in appropriate portions. The eating patterns should achieve and help maintain body weight goals, attain individualized glycemic goals, blood pressure goals, and blood lipid goals. The eating patterns should delay, prevent, or slow the onset of complications from diabetes (American Diabetes Association, 2019d). Nutrition therapy should address behavior and culture and should otherwise be individualized or personalized for each patient. Food choices should also incorporate the pleasure of eating. The individual should be provided the correct tools, such as food portion examples, based on the appropriate eating pattern rather than focus on individual macronutrients, micronutrients, or single foods (American Diabetes Association, 2019d).

Researchers reviewed nutrient intake based on the Canadian dietary recommendations for T1DM (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, & Cheng, 2013). The Food Guide, Canada, (2016) and the Mediterranean diet pattern for

individuals with T1DM was utilized as a part of a cross-sectional study (Gingras et al., 2015). The primary hypothesis was that individuals who have a dietary pattern like the Mediterranean style would have a more favorable cardiometabolic profile than those who do not. The second was a greater number of nutrient recommendations for T1DM that would be associated with a better cardiometabolic profile for participants. The two sets of dietary recommendations were compared to the following measures: waist-to-hip ratio, blood pressure, lipid profile, physical activity, and insulin resistance. Of the 124 participants recruited, six were excluded for not completing the three-day food record. The study utilized n = 118 (men = 67, women= 51), mean age, 44.3 ± 12.3 years, with a mean diagnosis of T1DM aged 23.1 ± 12.6 years, and mean A1C was 8.0% ± 1.1%. Physical activity was measured with a motion sensor (SenseWear Pro 3 Armband; HealthWear Bodymedia, Portland, Oregon). A registered dietitian instructed participants on how to use the motion sensor device and how to complete a three-day food record. Truncal fat percentage was determined through the iDXA (dual x-ray absorptiometry) scan using a LUNAR Prodigy system (version 6.10.019; General Electric Lunar Corporation, Madison, WI). Truncal percentage can be utilized to predict possible implications of comorbidities. The Food Processor SQL (ESHA Research, version 10.8, 2011, Montreal, Canada) and the 2007 Canadian Nutrient File were used to estimate intake from the three-day food diaries. The Mediterranean diet score was calculated based on the Mediterranean diet pyramid of nutrient components (Gingras et al., 2015).

About half of the participants met the Canadian dietary recommendations for T1DM (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee et al., 2013) nutritional recommendations for protein (15% to 20% of total calories), total fat (20% to 35% of total calories), and carbohydrates (45% to 60% of total calories). Approximately one-third of the

participants met recommendations for dietary fiber (>25 g/day) and sodium (<2,300 mg/day). There was a significant difference ($p<0.001$) between men and women in total energy intake (kcal/day) ($p<0.001$) and sodium (mg/day) ($p<0.001$) when comparing descriptive statistics. There was a statistical difference ($p<0.05$) for participants who met daily Canadian dietary recommendations for carbohydrate intake. They had a lower truncal fat percentage (mean, 28.1±9.9), A1C (mean, 7.8±1.0), and higher eGDR (mean, 8.29±2.30) compared with individuals who did not meet Canadian dietary recommendations. However, the differences observed between participants who met the recommended Canadian dietary intake for carbohydrates or not were no longer significant after further adjustment for physical activity level in the general linear regression model. Lastly, the participants who had a higher Mediterranean diet score had a significantly lower BMI (mean, 25±4.3), waist circumference (mean, 86.1±11.3), truncal fat percentage (mean, 28.4±10.0), systolic blood pressure (mean, 112±12), diastolic blood pressure (mean, 69±8), and higher eGDR (mean, 8.33±2.12) ($p<0.05$) (Gingras et al., 2015). This study suggests adopting Canadian or Mediterranean dietary recommendations may decrease the risk of cardiometabolic prediction factors.

Carbohydrate contribution to dietary patterns

Dietary patterns are based on foods composed of various macronutrient and micronutrients. Because carbohydrate can directly influence insulin needs and because protein and fat can affect blood glucose spikes, patterns are first based on macronutrients (American Diabetes Association, 2019d). Then, micronutrient consideration is incorporated to assure nutrient density. Carbohydrates increase blood glucose levels in the blood stream and the insulin demand is increased (Brazeau et al., 2013). After carbohydrates are ingested, most individuals with T1DM require insulin injections to transport glucose molecules from the blood stream to the

liver, muscle, and brain (Atkinson et al, 2015). Carbohydrate intake and insulin doses directly correlate with postprandial plasma blood glucose values (Beck et al., 2017). Carbohydrate counting is the evaluation of carbohydrate gram total in the meal and/or snack (in portions of 12 – 15 g per serving) to calculate pre-meal and/or snack insulin dose (Gillespie, 2006).

The American Diabetes Association recommends utilization of insulin-to-carbohydrate ratios (carbohydrate counting) (2019d). As a means of controlling blood glucose, carbohydrate counting for three to six months decreased A1C from 0.4% to 1.6% among adults with T1DM or T2DM (American Diabetes Association, 2019d). Both individuals who take multiple daily insulin injections or continuous insulin pump therapy maintained a lower A1C value combined with carbohydrate counting for up to 44 months (American Diabetes Association, 2019d). The daily balance of carbohydrate intake and insulin dosage should be assessed for individuals with T1DM because carbohydrate counting is indicated as a successful means of controlling T1DM.

The American Diabetes Association does not recommend consumption of carbohydrates lower than 130g per day for teenagers and adults with T1DM (2019d). A plausible cause for initial weight loss with a low carbohydrate diet could be from decrease in fluid (American Diabetes Association, 2019d). A low carbohydrate diet is dangerous due to the extreme high risk of hypoglycemia and minimal consumption of B vitamins utilized for metabolism (American Diabetes Association, 2019d). Weight loss should be coordinated through the medical team which includes a registered dietitian (American Diabetes Association, 2019d). The most appropriate recommendation for weight loss and reduction of diabetic complications is through a balanced diet and prescribed exercise through means of total decreased energy expenditure (American Diabetes Association, 2019d).

There is a need for education on carbohydrate counting before using this technique to optimize glucose control (American Diabetes Association, 2019d). To help control blood glucose, insulin dosage, carbohydrate counting, and other lifestyle affecting choices, management must be intentional and planned. Table 2.6 lists examples of serving sizes for carbohydrate servings to utilize when calculating carbohydrate totals.

Table 2.6

Carbohydrate Counting Table (American Diabetes Association), 2009

Serving sizes for some carbohydrate foods (each has about 15 g of carbohydrates)	
Apple: 1 small (4 ounces)	Milk, fat-free or reduced fat: 1 cup
Bagel: ¼ large (1 ounce)	Orange juice: ½ cup
Banana: 1 extra small (4 ounces)	Pasta or rice (cooked): 1/3 cup
Bread: 1 slice (1 ounce) or 2 slices reduced calorie (1 ½ ounces)	Green peas: ½ cup
Cake (unfrosted): 2-inch square	Pinto beans or kidney beans (cooked): ½ cup
Cereal, unsweetened (ready-to-eat): ¾ cup	Popcorn (popped): 3 cups
Cereal, cooked: ½ cup	Potato, mashed: ½ cup
Cookies: 2 small (2 ¼ inches across)	Potato chips: ¾ ounce (about 9 to 13)
Corn: ½ cup	Pretzels: ¾ ounce
Crackers (saltines): 6	Rice: 1/3 cup
Fruit, canned (no added sugar): ½ cup	Sugar: 1 tablespoon
Hamburger bun: ½ bun (1 ounce)	Sweet potato: ½ cup
Ice cream (light): ½ cup	Taco shells: 2 shells (5 inches across)
Jam or jelly: 1 tablespoon	Tortilla, corn or flour: 1 (6 inches across)

The current stance on carbohydrate counting education from the American Diabetes Association states consistent carbohydrate intake with respect to time and amount can improve glycemic control and reduce hypoglycemia for those individuals using a fixed insulin dosage (2019d). Using carbohydrate counting may help individuals in tracking amount(s) and timing of carbohydrate intake. The current per feeding carbohydrate recommendations are defined as 15 g for a small meal/snack and 45 – 60 g for a large meal for an individual with T1DM (American

Diabetes Association, 2019d). This dietary plan may also vary depending on individual needs, daily physical activity and weight management goals.

The American Diabetes Association recommends carbohydrate choices that are nutrient dense options such as those high in fiber, e.g. vegetables, legumes, fruits, and whole grains; those high in vitamin E (e.g. nuts and seeds); and other micronutrients such as B vitamins (2019d). Individuals with diabetes should avoid sugar-sweetened beverages (when at a normal glycemic state) to control blood glucose and manage body weight. The risk of CVD and fatty liver disease can be reduced through the minimized consumption of foods with added sugar (American Diabetes Association, 2019d). The recommendation for carbohydrate intake percentage of total daily energy intake is a minimum of 50% to improve A1C values and decrease saturated fat consumption (American Diabetes Association, 2019d).

Individuals with T1DM may have a difficult time adhering to dietary recommendations for carbohydrate percent of total energy intake (Meissner et al., 2014). Researchers completed a cross-sectional study of participants ages (1 – 18 years) with their parents and compared data to their healthy peers. The comparison included associations between carbohydrate intake, BMI, lipid profile and glycemic control with the hypothesis that lower intake of carbohydrate would have a negative impact on the other factors (Meissner et al., 2014). Standard care in Germany and Austria for teaching patients and their parents for carbohydrate counting is 10-12 g per exchange. Patients and parents were educated on following the reference for carbohydrates. Participants were divided into quartiles for review of carbohydrate intake, BMI, lipid profile and A1C using a hierarchical mixed linear regression model. The quartiles were split based on adherence to nutritional recommendations, which were in relation to at least 50% carbohydrate of total energy intake of the German, Austrian, and Swiss Nutrition Societies (Meissner et al,

2014). The recommendation for carbohydrate percent of total energy as observation for this study included: The Institute of Medicine, 45 – 65%, American Academy of Pediatrics guidelines, 50% and European Food Safety Authority, 45 – 60%.

The study included 46,010 children and adolescents with T1DM from 332 clinical centers in Germany and Austria (Meissner et al, 2014). The EsKiMo-study, the nutrition module of the German Health Interview and Examination Survey for Children and Adolescents, compared the carbohydrate intake data from 2,506 healthy children aged 6 – 17 years, 51.8% male, median age 11.9 years and duration with diabetes was 4.3 years (Meissner et al, 2014). From the report, 15 to 18-year-old males and females had the lowest carbohydrate consumption with an average 57% and 56% of total energy (Meissner et al, 2014). There was an inverse association between carbohydrate intake and BMI-SDS in boys and girls with T1DM ($p < 0.001$ and $p < 0.001$) (Meissner et al, 2014). When participants consumed a lower amount of carbohydrate intake percent of total energy for the day, these individuals were more likely to have a higher BMI (Meissner et al, 2014). Participants with T1DM with the lowest carbohydrate intake (45.6 ± 5.35) had the highest total cholesterol ($p < 0.001$) and low-density lipoprotein (LDL)-cholesterol ($p < 0.001$) (Meissner et al, 2014). Among this sample, individuals with T1DM consumed less carbohydrates compared to their healthy peers, especially for older adolescent T1DM patients (Meissner et al., 2014). These findings can suggest the need for nutrition education, specific to carbohydrate intake as part of the total dietary pattern.

Protein contribution to dietary patterns

The USDA Dietary Guidelines for Americans 2015 – 2020 recommend dietary protein as protein gram per kilogram of body weight is 0.8 g/kg (2015). However, protein-rich meals may delay the glycemic response and require an increased amount of insulin postprandial (Paterson et

al., 2016). Protein alone may have a glycemic impact on postprandial blood glucose dose-response for varying amounts of total protein for individuals with T1DM (Paterson et al., 2016). In Australia, researchers reviewed amount of protein intake and glycemic response among individuals with T1DM aged 7 – 40 years in a cross-sectional study. The inclusion criteria was an A1C ≤ 8.5%, T1DM for ≥ 12 months and using either insulin pump therapy or multiple daily insulin injections for ≥ 6 months. Additionally, participants were included if they had a healthy BMI, defined as 18.50-24.99 for adults and ≤ 91st percentile for children and adolescents (Paterson et al., 2016).

Participants were contacted daily for one week by a diabetes care and education specialist to review blood glucose levels, ensuring 24-hour targets were met (Paterson et al., 2016). Participants were provided with pre-measured protein and glucose powders in sealed bags with 150 ml of water (Paterson et al., 2016). Protein loads were 0 kcal (0 g), 50 kcal (12.5 g), 100 kcal (25 g), 200 kcal (50g), 300 kcal (75 g), and 400 kcal (100 g); glucose loads were 10 g and 20 g. The glucose and water drinks were included in reference meals. Protein drinks were made using 100% pure whey protein isolate powder. Continuous glucose monitoring was used (Dexcom G4 Platinum, Inc., San Diego, CA). The primary outcome measure was the mean postprandial glucose over 60-minute intervals for 5 hours. Secondary outcomes included the mean time for blood glucose to reach maximal glucose levels within a 300-minute period and proportion of time the blood glucose level exceeded 10 mmol/mol. Differences in meal glucose excursions over each 60-minute interval were tested using generalized linear mixed models to account for repeated measurements on the same subject. Test drinks were administered in a randomized order 4-hours post evening meal, over 8 days, without insulin. The evening meal was standardized for the amount and type of carbohydrate, fat, and protein. Insulin was given as per

individual insulin/carbohydrate ratios. Participants fasted for 5 hours following test drinks and physical activity was standardized.

A total of twenty-seven participants (aged mean, 21.7 ± 11.7) with T1DM for 7.8 ± 6.8 years (A1C mean, 6.9 ± 0.8 (52 mmol/mol), BMI 21 ± 3.1) completed the protocol (male = 11, female = 16). Fourteen participants utilized insulin pump therapy and twelve used multiple daily insulin injections (Paterson et al., 2016). There was no significant difference between starting blood glucose values in all participants before the start of the study. The blood glucose testing for the control (0 g), 25 g, 75 g, and 100 g protein drinks resulted in significantly lower mean glucose responses between 60 and 120 minutes compared with the control ($p < 0.001$). There were significant differences in mean blood glucose excursions between 75 g and 100 g protein drinks, and control for 180 minutes. Glucose levels in the 180-240 minute and 240-300-minute intervals for 75 g and 100 g of protein had a similar response to that of 20 g glucose (all $p < 0.05$). However, there was an ongoing rise profile after 5 hours from the CGM compared to the 20 g of glucose.

The study demonstrated that > 75 g of protein consumed alone significantly increases the possibility of higher postprandial glycemic blood values between 3 and 5 hours compared with the control of water only (Paterson et al., 2016). As expected, 20 g of glucose had the quickest peak after consumption at 60 minutes and was sustained for 300 minutes. After consumption of 75 g and 100 g of protein there was a similar blood glucose response compared to 20 g of protein. However, after five hours, the CGM profile suggested an ongoing rise of blood glucose for the 75 g and 100 g protein intake compared to the 20 g protein consumption. The late, sustained glycemic excursion may indicate calculating large amounts of dietary protein and insulin dose to avoid long-standing high blood glucose (Paterson et al., 2016).

In another study, researchers reviewed how the same carbohydrate intake at mealtime differed when paired with either low-fat, low-protein or high-fat, high-protein (Bell, Toschi, Steil, & Wolpert, 2016). Bolus insulin was utilized for both meal components until target postprandial glycemic control was achieved. Utilized for the study were ten (nine males, one female) aged 18-75 years participants diagnosed with TID (mean 60.4 ± 11.3 year, BMI was 25.8 ± 3.5, A1C was 7.1 ± 0.8% (72 mmol/mol), and total daily insulin dose was 35.5 ± 14.8 U/day (range was 17 – 65 U/day) who were currently using an insulin pump and CGM. Each participant had T1DM for > 3 years, had used an insulin pump for > 6 months, with an A1C < 8.5% (69 mmol/mol). After 10 hours of fasting, participants were admitted to the Joslin Clinical Research Center (Boston, MA). On admission if any blood glucose measurements were outside target range (80 – 120 mg/dL) (4.4 – 6.7 mmol/L), a correction insulin dose or glucose tablets were provided and testing was delayed 2.5 hours.

For the first two study sessions, participants were randomly assigned high-fat, high-protein or low-fat, low-protein meals, with an identical insulin bolus calculated using their carbohydrate to insulin ratio (delivered as 50%/50% combination bolus over 2 hours) (Bell et al., 2016). On subsequent visits, participants repeated the high-fat, high-protein meal with an insulin dose estimated using the model predictive bolus algorithm. Visits were repeated four different times until the glucose criteria was achieved: ≤ 10 mg/dL (0.6 mmol/L) decreased from baseline during the first 2 hours, peak postprandial glucose ≤ baseline plus 80 mg/dL (4.4 mmol/L), 2 hours' postprandial glucose ≤ plus 40 mg/dL (2.2 mmol/L), and no hypoglycemia requiring treatment. Postprandial is the length of period after a meal. The meals consisted of a pizza base marinara sauce (low-fat, low-protein) or the same pizza base and sauce with added cheese (high-fat, high-protein). The two meals had identical carbohydrates (50 g), but varied in total calories,

fat, and protein. The low-fat, low-protein meal had 273 calories, 4 g of fat, and 9 g of protein. The high-fat, high-protein meal had 764 calories, 44 g of fat, and 36 g of protein.

The results were reported as changes in insulin dose and glucose incremental area under the curve. The results were assessed by repeated-measures ANOVA, with correction for multiple comparisons (Bell et al., 2016). Despite the same insulin dose, the blood glucose in the high-fat, high-protein group was more than double that of the low-fat, low-protein group ($p = 0.0013$), with a significant difference observed from 180 minutes onwards and > 100 mg/dL (5.6 mmol/L) differences in the blood glucose concentrations at 6 hours. To achieve target postprandial blood glucose control following a high-fat, high-protein meal, the dose of insulin needed to be increased by 65% ± 10% and needed to be delivered in a combination bolus with a 30%/70% split over 2.4 hours. While this provides insight to both fat and protein macronutrients and insulin dose during mealtime, neither of the macronutrients were isolated. The limitation of not having either fat or protein isolated may alter how the blood glucose shifts over two hours postprandial. However, this study suggests bolus insulin dose for optimal mealtime blood glucose may need to be based on meal composition and not just carbohydrates alone (Bell et al., 2016).

In a review of protein metabolism and insulin therapy, authors discuss how insulin can decrease the rate of muscle protein synthesis and prevent muscle protein breakdown in adults. Uncontrolled T1DM is associated with abnormalities in protein metabolism and utilization in muscle, leading to net protein loss (Caso & McNurlan, 2010). Inappropriate use of insulin injections has been shown to create a catabolic response and impact lean muscle mass (Caso et al., 2010). Insulin is involved in transcription of genes for oxidative phosphorylation and affects mitochondrial rates of protein synthesis in the myocyte (Hebert & Nair, 2010). Muscle protein

synthesis is unable to start if insulin is deprived in the body (Hebert et al., 2010). Lack of insulin in the body blocks the pathway for the transcription process to signal oxidative phosphorylation (Hebert et al., 2010). The longer metabolism continues without insulin, net loss of protein occurs (Hebert et al., 2010). There is limited research on protein metabolism and total protein loss due to the nature of T1DM and insulin dependency. Since protein metabolism is impacted due to insulin dosing, more research focused on insulin deprivation is needed. In addition, research related to muscle protein synthesis may be needed to comprehend relationships between dietary protein intake and T1DM.

Fat contribution to dietary patterns

The 2015 – 2020 USDA Dietary Guidelines for Americans (2015) recommends increasing polyunsaturated fatty acid consumption as a replacement for saturated fatty acids to help lower LDL cholesterol. Low-density lipoprotein (LDL cholesterol) contributes to atherosclerotic plaque development in the arteries (USDA, 2015). This contribution narrows the arteries and increases risk for CVD. Dietary recommendations were based on studies that show substitution of saturated fatty acids to polyunsaturated fatty acids reduce the occurrence of CVD events by 19% through lowering LDL in the diet (Mozaffarian et al., 2010). An increased dietary intake of processed carbohydrates is associated with increased blood triglycerides (Mozaffarian et al., 2010). Increased triglycerides in the blood stream, in combination with high LDL and low high-density lipoprotein (HDL) can increase risk for CVD (American Diabetes Association, 2019c). As individuals with T1DM age, more education may be necessary to guide ideal macronutrient balance in the diet. In addition, more research is needed for prevention of CVD risk factors for individuals with T1DM.

Complications of uncontrolled type 1 diabetes

Diabetic ketoacidosis can occur during a hypoglycemic event (American Diabetes Association, 2019e). This risk is associated with lifestyle factors such as imbalanced carbohydrate intake, inappropriate insulin injections, and physical activity. Since diabetic ketoacidosis can be triggered, but is not limited to, the three factors above, individuals with T1DM may fear hypoglycemia (Litchman et al., 2017). Hypoglycemia is defined as a blood glucose value lower than 70 mg/dL (3.9 mmol/L). The American Diabetes Association describes mild hypoglycemia symptoms as urgency to eat, nervousness, shakiness, and excessive perspiration (2019e). Hypoglycemia symptoms associated with blood glucose less than 55 mg/dL (3.1 mmol/L) include changes in mood, anxiety, restlessness, anger, confusion, difficulty concentrating, blurred vision, dizziness, low energy, poor coordination, slurred speech, and decreased communication (American Diabetes Association, 2019e). Severe hypoglycemia may occur when blood glucose is below 35 to 40 mg/dL (1.9 to 2.2 mmol/L). The individual may be too unresponsive for necessary hypoglycemic correction and may experience an altered state of consciousness, coma, seizures, or hypothermia. This extreme low blood glucose may require medical emergency assistance (American Diabetes Association, 2019e). These symptoms may vary among individuals and can be affected by the number of years since diagnosis, frequent low blood glucose, rapid decline in blood glucose, stress or depression, diabetic ketoacidosis within the previous 24 to 48 hours, and alcohol used the past 12 hours (American Diabetes Association, 2019e).

Nocturnal management of blood glucose can be challenging. One reason to plan proper blood glucose management before sleeping at night is to prevent nocturnal hypoglycemia (American Diabetes Association, 2019e). Researchers investigated post-dinner dietary intake and

its effect on nocturnal hypoglycemia (Desjardins et al., 2014). Participants (n = 100) [median interquartile range]: mean age 46.4 [36.0-55.8] year, mean A1C 7.9 (63 mmol/mol) [7.3-8.6%] (56 – 70 mmol/mol) using multiple daily insulin injections (n = 67) or insulin pump therapy (n = 33) completed a questionnaire to identify those with reduced awareness of hypoglycemia. During the first visit, a blinded CGM system was installed to analyze interstitial blood glucose values and a motion sensor was provided to assess physical activity. The blinded CGM system was connected to a monitor that tracks blood glucose values but does not provide the participant with information. The participants were educated on how to complete a food diary and insulin dosage logbook during the following 72 hours after the visit. During the second visit, the participants returned the equipment, logbook, and a registered dietitian reviewed the food diary with the participants using Food Processor (ESHA, Salem, OR). Univariate and multivariate analyses were completed to review associations among multiple variables and nocturnal hypoglycemia/hyperglycemia and morning hyperglycemia. The variables included were sex, duration of T1DM (in years), A1C, multiple daily insulin injections, BMI, post-dinner rapid-acting insulin use, post-dinner dietary intake, alcohol intake, and physical activity level.

Researchers discovered post-dinner dietary intake is a common habit for 63% of the participants (Desjardins et al., 2014). The univariate model ($p < 0.05$) showed risk for nocturnal hypoglycemia was associated with diabetes duration (OR=1.03, 95% CI=1.01-1.05, per year, p=0.0007). In addition, higher A1C was significantly associated with nocturnal hypoglycemia occurrence (OR= 0.76, 95% CI=0.59-0.98, per 1% increase, p=0.037). A higher total daily dose from basal insulin level was associated with hypoglycemia occurrence (OR=1.14, 95% CI=1.01-1.28, per 5% increase, 0.027). Lastly, the bedtime interstitial blood glucose value was inversely associated with nocturnal hypoglycemia (OR=1.14, 95% CI=1.04-1.24, per 1 mmol/mol

decrease, p=0.004). The multivariate analyses model showed risk for nocturnal hypoglycemia was positively associated with rapid acting insulin injections and caloric intake of post-dinner dietary consumption and carbohydrate intake (OR=1.16, 95% CI=1.04-1.29, per 5 g increase, p=0.0008) (Desjardins et al., 2014). Nocturnal hypoglycemic risk was inversely associated with protein intake without rapid acting insulin (OR=0.88, 95% CI=0.78-1.00, per 2 g increase, p=0.048). However, nocturnal hyperglycemic risk was associated with caloric intake after one post-dinner meal, carbohydrate consumption, dietary fiber, and fat intake without rapid acting insulin. The study determined nocturnal management was suboptimal; the testing resulted in nighttime hypoglycemia measured in 54% of the participants (Desjardins et al., 2014). Further research is needed to prevent nocturnal hypoglycemia as it relates to diet.

Financial burden of uncontrolled type 1 diabetes

The rising cost of diabetes as a disease continues to be a financial hardship to society and to individuals with T1DM. The American Diabetes Association reports the annual cost of overall diagnosed diabetes in 2017 was an estimated $327 billion, including $237 billion in direct medical costs and $90 billion in reduced productivity (2019d). After inflation, economic costs of diabetes increased by 26% from 2012 to 2017. The North Dakota Public Diabetes Report (2014) states medical costs for people with diabetes are twice as high compared to people without diabetes. The largest components of medical expenditures in order of highest percent are hospital inpatient care, prescription medications, antidiabetic agents and diabetes supplies, physician office visits, and nursing/residential facility stays.

Individuals diagnosed with diabetes incur average medical expenditures around $13,700 per year (North Dakota Public Diabetes Report, 2014). Care for individuals with diagnosed diabetes accounts for more than 1 in 5 healthcare dollars in the United States (North Dakota

Public Diabetes Report, 2014). In 2014, the estimated annual cost of diabetes in the state of North Dakota was $700 million. Individuals with T1DM have increased "up front" costs because of need for insulin injections. On average, the cost of one day of insulin costs $15 or almost $6000 per year per individual (North Dakota Public Diabetes Report, 2014). Additional costs are accrued to purchase and store insulin because it is perishable and must be refrigerated.

The Minnesota Department of Health reported young adults (ages 18-44) with T1DM were 3-5 times more likely to be hospitalized than older adults due to uncontrolled blood glucose values (Minnesota Department of Health, 2018). The report found young adults were also more likely to have high blood glucose values (Minnesota Department of Health, 2018). Many of the hospitalizations were due to diabetic ketoacidosis (Minnesota Department of Health, 2018). According to the CDC, 16% of the 300,000 Minnesotans who have diabetes are younger than 45 years of age (CDC, 2017). This age group is more likely to suffer from depression and be hospitalized for mental health issues (CDC, 2017). Younger adults were also less likely to check their blood glucose and reach out to a physician for managing T1DM (CDC, 2017). Insurance coverage and rising prices of insulin may contribute to loss of blood glucose control among young adults (CDC, 2017). The Minnesota Department of Health recommends addressing barriers to blood glucose testing and improve diabetes management and mental health care (Minnesota Department of Health, 2018).

The Forum of Fargo-Moorhead reported on one Minnesota State University-Moorhead sophomore with T1DM (Baumgarten, 2019). The student has worked to voice her support to draw attention with the U.S. Congress to reduce the cost of insulin by supporting the Minnesota assistance program (Baumgarten, 2019). The student is working on a campaign through social media called "The Gold Vial Project" to show that insulin is worth its weight in gold. This is to

bring awareness to the Emergency Access to Insulin Act that would improve the overall cost of insulin (United States Senate, 2019). The student discussed with The Forum that individuals are rationing their insulin because of the cost and some are even dying due to the insulin crisis of price (Baumgarten, 2019). There is still an insecurity for the affordability of insulin. Young adults with T1DM may struggle to financially support themselves as independents (Baumgarten, 2019).

Comorbidities associated with type 1 diabetes

Increased risk for cardiovascular disease (CVD), diabetic kidney disease, retinopathy, osteoporosis, and psychosocial/emotional disorders is associated with uncontrolled T1DM (Krishnan et al., 2012; Speight et al., 2014; Celik et al., 2015). Autoimmune diseases, cognitive impairment/dementia, pancreatitis, hearing impairment, low testosterone in men, and obstructive sleep apnea are also increased comorbidity risks for individuals with diabetes (American Diabetes Association, 2019c). Since T1DM is an autoimmune disease, these individuals are at a heightened risk for these comorbidities due to decreased immune support (American Diabetes Association, 2019c). Cardiovascular disease, a leading cause of death for adults in the United States., is accelerated in mismanaged T1DM (American Diabetes Association, 2016). The long-term effects of hyperglycemia increase the risk for CVD by development of vascular complications such as retinopathy and renal disease (Orchard, Nathan, & Zinman, 2015).

Individuals with T1DM are at risk for autoimmune diseases such as thyroid disease, primary adrenal insufficiency, celiac disease, autoimmune gastritis, autoimmune hepatitis, dermatomyositis, and myasthenia gravis (American Diabetes Association, 2019c). The reason the immune system fails to protect against autoimmune diseases is the inability to self-tolerate specific peptides within target organs (American Diabetes Association, 2019c). Type 1 diabetes

is associated with higher risk for osteoporosis. Bone mineral density is lower for individuals with T1DM and may increase risk for hip and other fractures (American Diabetes Association, 2019c). In addition, hearing loss is increased for both high and low frequency and risk is increased twice compared to individuals with diabetes than without diabetes (American Diabetes Association, 2019c). The cause of hearing loss is unknown.

Metabolic syndrome may affect individuals with T1DM as a comorbidity, due to the variables involved in the risk. The variables include large waist circumference, elevated fasting blood glucose, increased triglyceride values, low HDL, and high blood pressure (Alberti et al., 2009; Mottillo et al., 2010; Benjamin et al., 2017; Carroll, Kit, Lacher, Yoon, 2013; HealthFinder.gov, 2018). Emerging adults with T1DM may not be at risk for metabolic syndrome since risk increases with age. Metabolic syndrome shows that waist circumference has an increased association to risk over BMI and can increase risk for CVD (Alberti et al., 2009). In addition, individuals with uncontrolled T1DM may be at increased risk since higher triglyceride values and fasting blood glucose is associated with inappropriate consumption of carbohydrates. Screening for metabolic syndrome should be completed yearly as individuals with T1DM age.

One significant comorbidity associated with uncontrolled diabetes is CVD. Even with management of blood glucose, CVD is a leading origin of morbidity and mortality for individuals with T1DM (Fox et al., 2007). A North Dakota Diabetes Report states individuals with T1DM and T2DM are two to four times more likely to have CVD than individuals without diabetes (ND HHS, 2014). Chronic high blood glucose levels can increase risk for CVD due to secondary medical complications with increased blood pressure and kidney damage (American Diabetes Association, 2019c). Impaired kidney function that occurs with high blood glucose progressively increases blood pressure to chronically high rates. High blood pressure causes

vascular damage that increases risk for stroke, heart failure and other cardiac related problems (American Diabetes Association, 2019c).

One study reviewed risk for CVD through a cardiometabolic risk profile, which includes dyslipidemia, hypertension, and insulin resistance (Leroux et al., 2015). There were markers observed among 124 adult participants with T1DM (mean, 44.0 ± 12.5 years of age), (49% women, 51% men). The mean A1C was 8.0 ± 1.1% (64 mmol/mol) and mean daily insulin dose was 0.67 ± units/kg. Nine participants were excluded for not completing one of the study variables. The researchers aimed to determine the prevalence of adults with T1DM who adopted a healthy lifestyle, including regular physical activity, a good quality diet, non-smoking habits, and how the relationship of a healthy lifestyle correlated to the cardiometabolic profile (Leroux et al., 2015). Inclusion criteria for study included treatment with continuous insulin pump therapy or multiple daily injections regimen with rapid and basal insulin analogs for T1DM.

Participants were tested at two sessions, one week apart. At the first session body weight (kg), height (cm), waist and hip were measured. Waist-to-hip ratio and BMI were calculated. Resting blood pressure and heart rate was measured three times and the mean values were calculated. A fasting blood sample was drawn to measure blood glucose value and lipids (total cholesterol, HDL-cholesterol, non-HDL-cholesterol, and triglycerides). The participants then wore a portable motion sensor to measure physical activity for 72 hours after the clinic visit. They were then asked to complete a three-day food record and insulin dosage logbook while maintaining their daily routine. At the second visit, the participant returned the motion sensor and a registered dietitian reviewed the food record and insulin dosage logbook with the participant. Fat mass percentage was measured through dual energy x-ray absorptiometry (DXA) and the participant completed a questionnaire to obtain smoking data, insulin dosage therapy,

ethnicity, marital status, education level, and household income. Insulin resistance was calculated using estimated blood glucose disposal rate (eGDR) and insulin dose was calculated from the three-day insulin dosage logbook. An endocrinologist collected medical history and a medication list. Physical activity level was calculated by dividing total energy expenditure by the estimated resting energy expenditure. The ratio of physical activity level to total energy expenditure of ≥ 1.7 corresponded to the recommended threshold defining an active lifestyle (Leroux et al., 2015).

A registered dietitian using the Food Processor SQL (ESHA Research, Salem, OR, version 10.8) analyzed food records. The mean intake of the three days was calculated for each participant for energy, macronutrients, fiber, cholesterol, and sodium intake. Diet quality was assessed using the Canadian-Healthy Eating Index (Shatenstein, Nadon, Godin, Ferland, 2005). The maximum score on the index was 100; a score of over 80 represents a "good" diet quality; score between 51 and 80 is "needs improvement'; and lower than 51 score represents "poor" diet quality. The participants were categorized according to the number of "healthy lifestyle" habits adopted, ranging between 0 and 3. Criteria were met if there was a regular physical activity level to ratio of energy expenditure of ≥ 1.7, good diet quality with a Canadian-Healthy Eating Index score over 80 and, never-smoking status. Mean values ± standard deviation of each cardiometabolic risk profile of participants divided according to the number of healthy lifestyle habits adopted were computed. Lifestyle habits were compared between men and women using t-tests for continuous variables and by chi-square for categorical variables ($p<0.05$). Pearson's correlation coefficients between individual lifestyle habits (diet quality score and physical activity level) and variables of the cardiometabolic risk profile were computed.

The Canadian-Healthy Eating Index score and the physical activity level had a strong negative correlation with BMI, waist circumference, body fat percentage (total and central) and non-HDL-cholesterol ($p< 0.05$). The Canadian-Healthy Eating Index score had a strong positive correlation with eGDR and negatively with A1C, systolic, and diastolic blood pressure. Physical activity level positively correlated with eGDR and negatively with triglycerides, systolic and diastolic blood pressure; but those correlations were attenuated after further adjustment for BMI ($p< 0.05$). Researchers found that only 11% of participants practiced an active lifestyle, good diet quality, and non-smoking status. Whereas 49% of the participants had, a diet quality classified as "good", 69% did not reach the recommended physical activity, and nearly half of the participants were current or former smokers. These data suggest the potential benefit to adapt a healthy lifestyle to improve the cardiometabolic risk profile for individuals with T1DM (Leroux et al., 2015).

Mental health with type 1 diabetes

Adults with T1DM are four times more likely to have prevalence of depressive symptoms in adults than their healthy peers (Roy & Lloyd, 2012). Difficulty with metabolic control may be associated with additional depressive symptoms (Roy & Lloyd, 2012). Bächle et al. (2015) sought to find associations between depressive symptoms and glycemic control among individuals (aged 18 – 21 years old) diagnosed with T1DM. The hypothesis of the study included that individuals with depressive symptoms would have different associations with metabolic control and there would be varying results by sex. There were 211 (males= 85, females= 126) participants mean age 19.4 (± 0.9) years, diagnosed with diabetes for 15.7 (SD = 1.0) years who completed the comprehensive questionnaire. All were early-onset (diagnosed between ages 0 to 4 years) T1DM (duration at least 10 years) (Bächle et al., 2015). The Patient Health

Questionnaire-9 (PHQ-9) which uses a 4-point scale from (0 = not at all) to (3 = nearly every day) was utilized to assess depressive symptoms, over the previous two weeks. The screening is for key depressive symptoms including anhedonia (in ability to feel pleasure), dysphoria (generalized dissatisfaction in life), sleep difficulty, lethargy, and overeating/poor appetite, feelings of worthlessness, difficulties concentrating, psychomotor retardation, and suicidal ideation. The screening tool was the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Health-related covariates in the review included insulin regimen, most recent self-reported A1C, smoking status and self-reported height and weight for BMI. Socioeconomic status and family structure/residence was identified as well. For statistical analysis, each depressive symptom, total number, and proportion of positive screens for depression was determined. The mean A1C levels among those who screened positive and negative for depression were compared via t-test. This procedure was repeated for the total PHQ-9 score, applying either F-tests or Pearson's chi-squared test. Young adult men smoked less frequently, had higher socioeconomic status, and lived with their biological parents more than women. The mean A1C value was significantly higher in women than men (8.6% vs. 8.0%) (70 vs 64 mmol/mol) ($p = 0.026$) (Bächle et al., 2015). One-third of young men and two out of five women screened positive for at least one depressive symptom. Sleeping difficulties was mentioned the most from the questionnaire (21.8%), followed by lethargy and overeating/poor appetite (17.3%) (Bächle et al., 2015). Overeating/poor appetite was significantly associated with higher A1C value in both sexes. Among men, higher A1C was associated with sleeping difficulties ($p = 0.012$), overeating/poor appetite ($p < 0.001$) and lethargy symptoms ($p < 0.001$). Women had higher A1C, increased psychomotor retardation symptoms ($p = 0.019$), and overeating/poor appetite ($p= 0.002$) (Bächle et al., 2015).

From these data, there is a high prevalence of depressive symptoms reported among individuals with T1DM. This response was similar for both those who were early-onset and for long-duration of T1DM. There was a strong association between higher A1C value and disordered eating symptoms, followed by lethargy, and total PHQ-9 score (Bächle et al., 2015). One research limitation was the review of glycemic control through A1C values. There are other methods to assess glycemic control as this can vary per individual based on personal goals. Diabetes management goals can center around fasting blood glucose, physical activity, and dietary targets. Worse control of blood glucose can be the result of other underlying depressive symptoms, such as diabetes distress (Bächle et al., 2015). This study illustrates the need for screening of depressive symptoms to prevent long-term complications of glycemic control among young adults diagnosed with T1DM.

Mental health difficulties may affect quality of life, especially for individuals with T1DM (Stahl-Pehe et al., 2014). Researchers reviewed adolescents with early-onset T1DM and mental health problems compared to general population peers in Germany. They also reviewed if adolescents with early-onset T1DM differed in quality of life assessment versus their peers. There were 629 children and adolescent individuals with T1DM that fulfilled the inclusion criteria of being diagnosed between ages 0 to 4 years and who participated in the questionnaire for the age group 11 - 17 years. A total of 6,813 children and adolescents and parents fulfilled the inclusion criteria for the comparison group and participated for the age group 11 to 17 years. The Strengths and Difficulties Questionnaire (Goodman, 1997) was used to assess the overall distress and social impairment of the child. The self- and parent-report versions of the questionnaire consist of 25, 3-point Likert-scaled items referring to the past six months. The questions were grouped in subscales including emotional symptoms, hyperactivity-inattention, peer-problems,

conduct problems, prosocial behavior, and impact on T1DM management. Higher scores indicate greater difficulties, except for prosocial behavior, where a higher score indicates strengths for mental health. Quality of life was assessed through the self-report version of Revised Children's Quality of Life Questionnaire (Ravens-Sieberer & Bullinger, 1998).

Several covariates were included in the analyses: age, sex, socioeconomic status, immigrant background, region of residence in Germany, family structure, informant of the proxy report, BMI, and hospitalization in the past 12 months (Stahl-Pehe et al., 2014). Both univariate and multivariate regression analyses were applied to identify differences between the patient and reference group. The participants were diagnosed at the mean age of 2.7 years (± 1.1, range 0.6 – 4.9 years), mean duration with diabetes 12.5 years (± 1.6, range 10.0 – 16.5 years), and mean hemoglobin A1C of 8.3% (67 mmol/mol) (± 1.3, range 5.6 – 14.4%) (38 – 134 mmol/mol). Based on the self-reports, the group diagnosed with T1DM had higher total abnormal difficulties scores from the Strength and Difficulties Questionnaire than the comparison group (4.4% versus 2.9%, $p = 0.036$). While the results were comparable for other covariates, there was an association to difficulty of quality of life and mental health. This association to quality of life and mental health should be considered in clinical practice for individuals with T1DM.

Disordered eating and eating disorders with type 1 diabetes

Disordered eating/eating disorders such as binge eating is common among individuals with T1DM (Moskovich et al., 2019). Besides binge eating, caloric restricting, self-induced vomiting, and the unique ability to restrict insulin for weight loss purposes are all associated with individuals who are diagnosed with T1DM (Moskovich et al., 2019). Disordered eating/eating disorders may be more prevalent among individuals diagnosed with T1DM due to diabetic distress (i.e., emotional distress of living with diabetes). Current research shows that diabetic

complications, such as poor glycemic control, can occur with disruptive eating patterns even when full diagnostic criteria for an eating disorder is not met (Moskovich et al., 2019).

Objective binge eating is defined as the loss of control over eating and consuming a large amount of food at one time (Moskovich et al., 2019). Consequences of binge eating disorder for individuals with T1DM may have a long-term medical impact, such as chronic uncontrolled blood glucose and risk of mental health disorders (Moskovich et al., 2019). One study examined real-time precursors and consequences of objective binge eating in adults with T1DM using ecological momentary assessment methods (Stone & Shiffman, 1994). The ecological momentary assessment method refers to a collection of methods by which a research participant repeatedly reports symptoms, affect, behavior, and cognitions close in time to experience and in the participant's natural environment (Stone & Shiffman, 1994). The researchers concluded negative emotion and diabetes distress is a predictor of objective binge eating disorder. Also, negative emotion and diabetes distress decreases glycemic control and increases binge eating episodes (Moskovich et al., 2019).

The assessment of disordered eating/eating disorders is critical in a clinical and research setting to improve care for individuals at risk for this comorbidity in T1DM. The original Diabetes Eating Problems Survey (DEPS) (Antisdel, Laffel, Anderson, 2001) was designed before insulin pumps and CGM's were developed. This was a 28-item diabetes-specific self-report measure of disordered eating behaviors. This was previously validated against a clinical diagnosis of eating disorders in adult patients with T1DM. The items were answered on a 6-point Likert scale (0 = never, 1 = rarely, 2 = sometimes, 3 = often, 4 = usually, 5 = always), higher scores indicating greater eating disorder pathology. This previously demonstrated excellent internal consistency (Cronbach's Alpha= 0.95) and was significantly correlated with diabetes

specific distress ($R = 0.83$, $P < 0.001$). Most recently, the 16-item Diabetes Eating Problems Survey – Revised (DEPS-R) (Appendix F) has been reviewed as a reliable and valid tool for assessment of psychometric properties for eating disorder/disordered eating risk for children and adolescents (Markowitz et al., 2010). The predetermined cut-off score for disordered eating is empirically established at twenty or above for the DEPS-R (Markowitz et al., 2010).

In a cross-sectional study, participants (n = 112) (aged 13 – 19, 15.1 ±1.2 years) with T1DM duration 7.5 ± 3.7 years were followed at a tertiary care center (Kuczmarksi et al., 2000). The mean zBMI (age- and sex- adjusted BMI) was 0.8 ± 0.7. The majority of participants were treated with multiple daily insulin injections or received insulin pump therapy, 62% and 26%, respectively. The eligibility criteria were T1DM for > 1-year, English speaking, no other major medical or psychiatric disorders, stable living environment and resident of the northwest U.S. During a regular scheduled medical visit, each child and parent met with a trained research assistant who gathered demographic information and administered surveys (Markowitz et al., 2010). Information collected included frequency of blood glucose monitoring, A1C, height, weight, Tanner staging, and total daily insulin dose from the medical record. The research assistants also assessed treatment adherence through a modified scale developed by Jacobson et al. (1990). The validated questionnaires administered included the DEPS (Antisdel et al, 2001), the Diabetes Family Conflict Scale (Hood, Butler, Anderson, Laffel, 2007), the Blood Glucose Monitoring Communication Questionnaire (Hood et al, 2004), the Problem Areas in Diabetes Survey-Parent version (Varni, Seid, Rode, 1999), and the Diabetes Quality of Life for Youth Questionnaire (Antisdel, 2001).

As part of this study, the DEPS was revised by eliminating any items with low face validity (those that did not appear to specifically measure disordered eating) (Markowitz et al.,

2010). Any questions that were found to be duplicate and had higher item-to-total correlation were taken out of the survey. Of the seven questions removed, four questions concerning participants feelings about insulin were omitted. The researchers kept the same 6-point Likert scale for survey measurements for a final 16-item tool DEPS-R. Statistics included unpaired t-tests and Pearson and Spearman correlations. Analyses included the entire sample of males and females, as well as females only.

The sixteen item DEPS-R demonstrated internal consistency in this sample of youth with a Cronbach's Alpha of 0.86 overall and .87 for females. (Markowitz et al., 2010). The DEPS-R is typically completed in less than 10 minutes. The score can range from 0 to 80. The revised survey also demonstrated construct validity through comparison areas that would present signs and symptoms of disordered eating. The DEPS-R correlated positively with youth *z*BMI ($r = 0.24$, $p = 0.01$), age ($r = 0.25$, $p = 0.01$), A1C ($r = 0.30$, $p = 0.001$), youth and parent report of diabetes-specific family conflict ($r = 0.37$, $p < 0.0001$), youth report of negative affect related to blood glucose monitoring ($r = 0.36$, $p = 0.001$), youth score on the eating subscale of the Diabetes Quality of Life for Youth Questionnaire ($r = 0.59$, $p < 0.0001$), and parent report of diabetes-specific burden ($r = 0.39$, $p = 0.0005$). Lastly, the survey presented external validity for the participants who answered 'yes' to missing or restricting insulin. These participants scored significantly higher on the DEPS-R (mean, 17.7 ± 13.7) than other youth (mean, 10.2 ± 8.1, $p = 0.009$). More than half of youth (52%) who self-reported missing or restricting insulin scored $\geq$ 20 on the DEPS-R. Females scored significantly higher on the DEPS-R (14.1 ± 11.0) than males (9.3 ± 8.7, $p = 0.02$). The researchers observed the DEPS-R correlated positively with age, which is supported by current diagnostic criteria. Eating disorders are more likely to occur more often in late adolescence, early adulthood and among females (Markowitz et al., 2010). Individuals

with a score ≥ 20 may be at a higher risk for eating disorder behaviors such as omission or restriction of insulin, as well as significant weight control (noted from BMI). This self-administered tool can be useful for youth with T1DM for screening for disordered eating and eating disorders.

One study aimed to investigate validation of the DEPS-R for utilization of eating disorder/disordered eating screening in adults (Wisting, Wonderlich, Skrivarhaug, Jorgensen, & Ro, 2013). Patients were recruited from the Norwegian Diabetic Centre, which is an outpatient clinic for adults for T1DM. There were 282 participants ages 18 – 79 years (mean 42.1 ± 15.2) included. Mean age of onset was 15.1 years (± 11.2), mean A1C was 7.8% (± 0.9) (62 mmol/mol), mean T1DM duration was 27.1 years (± 14.4), and mean BMI was 26.0 (± 4.1). A score of DEPS-R ≥ 20 indicates a level of disordered eating warranting need for attention. Correlation analyses were performed to investigate the association between the DEPS-R and variables such as age and BMI. Effect size > 0.2 were interpreted as small, > 0.5 as medium, and > 0.8 as large. The Cronbach's alpha of the survey was greater than 0.70 (0.84), suggesting good internal consistency. The survey correlated significantly with BMI in both sexes, with moderate correlations (female = 0.33, $p < 0.001$, male = 0.35, $p < 0.001$). In addition, A1C had a weak correlation with the screening tool among females (0.27, $p < 0.01$). The reduction of diabetic complications and eating disorders is crucial in the clinical setting. The psychometric properties of the DEPS-R provide reliability and validity to screen eating disorder/disordered eating risk for adult populations (Wisting et al., 2019).

Individuals with T1DM may be at a greater risk of developing eating disorder behaviors due to the heightened focus on dietary habits. Eisenberg et al. (2018) examined risk of eating disorder development among adolescents with T1DM. The researchers reviewed the association

between dietary intervention, increase of disordered eating behavior and the association between disordered eating behavior and the decline of glycemic control. The observation was completed through the examination of biomarkers of glycemic control and variability in both treatment and control participants for 18 months. The participants (n = 89) were at least 13 years of age, mean age of 13.7 years, diagnosed with T1DM for ≥ 1 year with a daily insulin dose ≥ 0.5 units/kg. The English-speaking participants most recent A1C ranged between 6.5-10.0% (48 – 86 mmol/mol). The participants insulin regimen included three or more injections daily or use of the insulin pump and at least one visit to the diabetes clinic in the past year. Nine in-person intervention sessions were designed to be led by trained research personnel and included behavioral techniques. Additionally, the sessions included educational content to increase the consumption of fruits, vegetables, whole grains, and legumes. Sessions also included motivational interviewing and goal setting. Motivational interviewing is a participant-centered method for enhancing intrinsic motivation to change health behavior by exploring and resolving ambivalence (Resnicow, Davis, & Rollinick, 2006).

The first six sessions occurred monthly and were the "core" of the intervention. Then the final three sessions occurred at months 9, 10, and 15, and were the "booster" sessions (Eisenberg et al., 2018). The dietary intervention focused on a healthful eating approach including completion of food records and CGM feedback reports, rather than weight-based food restriction. These sessions targeted difficulties specific to social eating, meal planning, and food environment. The control group was designed to match healthy outcomes but not focus on the dietary intervention. The intervention did not focus on weight loss or prevention of disordered eating. Glycemic control was obtained at baseline and at month 6, 12, and 18 using a laboratory assay standardized to the Diabetes Control and Complications Trial (reference range: 4-6%)

(Nathan, 2014). A three-day blinded CGM was obtained using the Medtronic iPro Continuous Glucose System (Boston, MA). The participants completed the Diabetes Management Questionnaire (Mehta et al., 2015) and DEPS-R. Anthropometric measurements were completed for each participant. A linear mixed-effects model was utilized to analyze the data. High DEPS-R scores were associated with poorer glycemic control over time as indicated by A1C ($p = 0.001$) and DEPS-R scores were also associated with higher mean sensor glucose ($p = 0.001$) and percent of sensor glucose values > 180 mg/dL (10.0 mmol/L) ($p < 0.001$).

In another study, adult participants (ages 18 to 65) were recruited from two medical centers located in the southeast part of the United States (Moskovich et al., 2019). The surrounding area was also included as a part of a larger study investigating eating disorder symptoms among individuals diagnosed with T1DM. There were 83 (female, 88%, white 87%, and mean age 41.9 ± 12.43, range 18-68) individuals, including 63 participants who scored ≥ 20 on the DEPS-R. Participants completed three days of ecological momentary assessment of mood and eating behavior using a telephone-based survey system. Interstitial blood glucose levels were monitored throughout the assessment period using blind CGM (Medtronic CGMS iPro™ or iPro2™, Durham, NC). To be eligible for the study the participants were required to self-report that they were without hypoglycemic awareness. Individuals in the study also tested for cognitive abilities that could interfere with independent individual diabetes management. The Gold Method, used to measure personal hypoglycemia awareness is a 7-point Likert scale that poses the question “do you know when you are in a hypoglycemic state?” with one on the scale representing “always aware” and seven, “never aware” (Gold, MacLeod, Frier, 1994). A score of ≥ 4 implies impaired awareness of hypoglycemia. Individuals who were assessed for having a clinically significant eating disorder were recruited first. Then enrollment was opened to

individuals with DEPS-R scores below 20 to capture full range of eating disorder symptoms. After initial assessments, individuals presented in the lab on two separate days to complete self-report measures of illness history and blood was drawn to determine A1C. They had a CGM placed and were trained on momentary assessment and survey entries for meals and snacks. Participants were prompted to rate momentary affects including level of diabetes distress and report on eating episodes (Moskovich et al., 2019). A random telephone call from IfByPhone, an automated telephone system, was at the rate of 1-2 times an hour between hours 8am and 10pm. At each call, using the scale of one to six based on 'How do you feel?", participants completed brief surveys (taking 1-2 minutes) on their current mood or emotion, eating, and T1DM management behavior. Participants were also asked to call the survey system to report any meals or snack right after consumption. At each call, the participants were asked to provide momentary ratings of their affective state (e.g. happy, sad, frustrated, angry, anxious/nervous, guilty/disgusted with yourself). Current level of diabetes distress was assessed by the following question: "How upset do you feel about your diabetes or diabetes management?" (1 = not at all, 6 = very much). For calls reporting food consumption, participants were asked to indicate the time they started eating and behavior. The first eating disorder question was, "Did you eat a large amount of food, more than would be typical of others in a similar situation?" and the second was "Did you experience a loss of control over your eating?". The first response was (1 = Yes, I ate a large amount of food or 2 = No). For the second question (loss of control), participants responded with (1 = Yes, loss of control or 2 = No). Objective binge eating was determined by a response of yes to both questions. Individuals received training specific to "large amount of food" and "loss of control overeating" as defined by the Diagnostic and Statistical Manual of Mental Disorders – 5 (American Psychiatric Association, 2013). The study coordinator reviewed

the definitions with all the participants by provided examples, and a handbook to refer to as needed during the three-day assessment (Moskovich et al., 2019).

Multi-level modeling was used to examine between- and within-person effects of momentary increases in emotions (Moskovich et al., 2019). This was to review prior to eating on the likelihood of objective binge eating and the impact of objective binge eating on postprandial blood glucose (Moskovich et al., 2019). Generalized linear mixed models examined whether change in post-meal effect differed between objective binge eating and non-objective binge eating episodes (Moskovich et al., 2019). From the results of the three-day ecological assessment period, 8% of the eating episodes were characterized by objective binge eating. The between-person effect for negative emotion (frustrated, angry, anxious/nervous, guilty/disgusted with yourself, upset about diabetes) 60 minutes prior to meal predicting objective binge eating (OR = 1.93, p = 0.02, 95% CI = 1.09, 3.41), indicated a 93% increase risk of binge eating with a higher negative emotion. The odds ratios showed that with every one-point increase of negative effect in survey score, the odds of objective binge eating nearly doubled. Blood glucose at 120 minutes postprandial was higher for objective binge eating (mean = 213 mg/dL (11.8 mmol/L), 95% CI = 191, 234) than for non-objective binge eating episodes (mean = 188 mg/dL (10.4 mmol/L), 95% CI = 179, 198), (p = 0.03). Between-person effects were significant for guilt, frustration, and diabetes distress (OR=1.48-1.77). Mean change in post-meal negative effect was significantly greater for objective binge eating order relative to non-binge eating disorder episodes ($p<0.001$). Females were less likely to cope with the negative emotions of diabetic distress with eating disorders/disordered eating (Moskovich et al., 2019). The survey for binge eating showed 45-80% of young women with T1DM reported binge-eating behavior (Moskovich et al., 2019). Dietary patterns for proper glycemic control and insulin distribution may be interrupted during

binge eating episodes (Moskovich et al., 2019). Female individuals with T1DM are more likely to practice objective binge eating disorder when compared to their peers.

One limitation to the study was the overall review of carbohydrate intake during objective binge eating and insulin to compensate for overeating (Moskovich et al., 2019). Consequently, the study was limited in ability to access exact serving sizes of carbohydrate intake during binge eating and overeating episodes since the three-day food diary was self-reported. However, these data suggest better methods of coping skills are needed for negative emotions and diabetic distress to increase management of glycemic control, especially among female individuals.

The reason individuals with T1DM are more likely to have an eating disorder/disordered eating can be difficult to determine. Qualitative methods in the form of interviews may provide insight. A study reviewed eating disorder risk and eating disorder diagnosis utilizing a qualitative approach among 35 female participants (23 – 30 years old) with T1DM (Balfe et al., 2013). This study included six female participants who considered themselves to have a past eating disorder. A past eating disorder was determined through coding of phrases such as, "weight concern, eating concern". Interviews were conducted and lasted 15 to 20 minutes. For individuals without an eating disorder, the interview focused on body composition control as a means of diabetes management. For individuals who identified with having an eating disorder disease condition, the interview focused on T1DM in connection to the current or previous eating disorder.

Interviews were analyzed with open coding, with three themes determined after the content was reviewed. The themes included 'general weight loss concerns', 'eating disorders', and a 'hidden problem of eating disorders'. The participants without an eating disorder were concerned about their weight in the past but did not want to disrupt diabetes management and

control. Participants who coded for ‘present eating disorder’ reported behaviors of omitting insulin injections, lack of knowledge of relationship between body weight and insulin, and positive feelings towards omitting insulin at the beginning of T1DM diagnosis. When insulin is omitted, weight loss occurs quickly; however, extremely high blood glucose (>300 mg/dL) (16.7 mmol/L) may occur and could result in emergency medical care in patients with T1DM (Balfe et al., 2013). After the study was conducted, the researchers explained in the discussion section the need for further investigation for adult women with T1DM and risk for eating disorders (Balfe et al., 2013).

Transition into adulthood may be associated with disordered eating behaviors and increased risk for diabetes complications among young adults diagnosed with T1DM. Researchers utilized a longitudinal study (one year) to review how disordered eating behaviors, diabetic difficulties, and depressive symptoms may increase in youth to adult ages (Luyckx et al., 2019). The study was designed to examine the variables focusing on sex differences and subgroups such as high disordered eating behaviors versus low. The participants were split into four different intervals throughout the year based on the DEPS-R score of < 18. The four groups were divided based on measured disturbed eating behaviors from DEPS-R score: < 18 at the first two intervals, < 18 at the first interval and >18 at the second interval, > 18 at the first interval and < 18 at the second interval, lastly the persistent < 18 for both intervals. The researchers investigated the disparities between those subgroups considering self-management, glycemic control, diabetes distress, and depressive symptoms over time (Luyckx et al., 2019). Participants (n = 300) were aged 14 – 25 years (mean 20.80 ± 3.31) and without cognitive impairment. The study implemented a self-management assessment using the 14-item Self-Care Inventory (La Greca, 2004). This questionnaire addressed blood glucose testing and monitoring, insulin and

food regulation, exercise, and emergency precautions. Diabetes distress was observed with the Problems Areas in Diabetes Scale (Welch, Jacobson, & Polonsky, 1997), and measured difficulties related to diabetes in four domains (emotions, food, self-management, social support). Depressive symptoms were measured with the 20-item Center for Epidemiologic Studies Depression Scale (Radloff, 1977). Using a three month before or after the questionnaire span, glycemic control was assessed by A1C value by contacting treating physicians. Statistical analyses were calculated using Pearson correlations, and mixed analysis of variance (ANOVA) conducted with time as within-subjects factor, sex as between-subjects factor, and disturbed eating behaviors at the first interval and the second interval as dependent variable. The interaction effect (Time X Sex) was entered to examine differential change over the year for males versus females. In addition, cross-lagged analysis was used to review changes over time of behavior. The year-long study, n=300, mean A1C 7.4 (± 0.95) (57 mmol/mol) showed higher disordered eating screening score(s) had a positive relationship to diabetes distress, depressive symptoms, and increased value of A1C. From the data, 83.0% of the sample were living with their parent(s) and 61.3% had a college degree or were currently going to college. Females scored higher during the year for disordered eating behaviors based on the DEPS-R than males ($p < 0.001$). The mixed ANOVA indicated that mean disturbed eating behaviors remained stable ($F(1,294)=0.714$; $p=.399$) from T1 (mean 13.15 ± 10.43) to T2 (mean 12.71 ± 9.87). The Time X Sex interaction was not significant ($F(1,294)=2.078$; $p=.150$). Both males and females remained stable over time, with females (T1: mean 16.53 ± 11.34; T2: mean 15.57 ± 10.49) scoring substantially higher on diabetes eating behavior scores $F(1,294)=48.661$; $p<.001$; $\eta^2=.142$) than males (T1: mean 8.71 ± 6.97; T2: mean 8.96 ± 7.51). A healthy weight range for BMI showed low diabetes eating behavior scores. The study group reported 63.7% never restricted insulin,

21.0% almost never restricted insulin, and 15.3% at least sometimes restricted insulin (Luyckx et al., 2019).

The researchers did discuss limitations in the study (Luyckx et al., 2019). While the study was prospective, it would be beneficial to observe disordered eating behaviors for individuals transitioning from youth to adulthood. Also, the addition of short-term diaries to the current methodology would help identify possible factors relating to disordered eating behaviors (i.e. food diaries, insulin logs). Data on hospital admission rates related to disordered eating behaviors may increase insight to diabetes distress. This study provides clinical relevance to include disordered eating behaviors assessment in population age groups of adolescents and emerging adults (Luyckx et al., 2019). The DEPS-R may be an effective method to assess eating disorder risk/disordered eating for adults (aged > 18 years) (Luyckx et al., 2019).

Body composition and physical activity

A study reviewed the pathophysiology of CVD and body composition as it relates to T1DM among adolescents (Krishnan et al., 2012). Researchers recruited 29 individuals (aged 13 to 20 years) diagnosed with T1DM and 37 healthy controls without T1DM. Body composition was measured with DXA and a pulse wave estimated arterial elasticity. Statistical analyses utilized were t-tests with $p< 0.05$ for statistical significance. The study revealed female participants with T1DM have more centrally located adipose tissue than their male equivalents ($p<0.01$) (Krishnan et al., 2012). There was no sex difference among any other CVD risk factors in adolescents either with or without diabetes. The researchers noted that an increase in central body fat percentage might contribute to higher risk of CVD.

Body composition and blood glucose control can influence insulin resistance and risk for CVD in T1DM. Researchers attempted to identify a relationship between blood glucose control

and body composition 12 to 18 months' post T1DM diagnosis (Davis et al., 2012). During a one-year period, researchers analyzed 30 newly diagnosed children (boys, n = 18, girls, n = 12) with T1DM (aged 0-18 years) and 14 control (no T1DM) participants (boys, n = 8, girls, n = 6) in a prospective study. Inclusion criteria for participants included within one week of diagnosis of T1DM and post correction of dehydration and metabolic alteration. Body composition and blood pressure measurements were made after diagnosis, at six weeks, and at one year. Measures of height, weight, and waist circumference were completed. Body composition was measured using DXA and pubertal status was assessed in all participants through clinic observation or self-report at baseline. Hemoglobin A1C was measured at diagnosis and at each visit, with measurements of high sensitivity C reactive protein, fibrinogen, total triglycerides, and HDL and LDL cholesterol made after 1 year of diagnosis. Age and sex matched controls were selected using best friends or siblings who underwent anthropometric and body composition measurements on two occasions, one year apart. Controls and test subjects were compared to detect BMI difference > or = 0.5 or difference in 3% body fat by DXA between groups and within groups over time. Anthropometric and body composition measurements were compared between groups using unpaired t-tests and within groups using paired *t*-tests. Univariate analysis was used to compare markers of CVD risk and changes in body composition. Current research defines categories of <1, 1-3, and 3-10 mg/l to define high sensitivity C reactive protein indicative of low, moderate or high CVD risk respectively. Based on the defined categories, non-parametric tests and Chi-squared tests were used. Correlations were performed using bivariate correlation and Pearson's correlation coefficient with two-sided significance. At baseline children newly diagnosed with T1DM had a lower BMI ratio and percentage of body fat than the controls. The researchers discussed the possibility of insulin deficiency prior to diagnosis to cause a catabolic state. Unlike the control

group, the BMI standard deviation of girls with T1DM was lower than boys at time of diagnosis. Among participants diagnosed with T1DM, higher body fat percentage and greater waist-to-hip ratio were correlated with risk for CVD along with high blood pressure and high LDL cholesterol values (Davis et al., 2012). Females with T1DM demonstrated higher insulin resistance when compared to their male peers with T1DM ($p<0.05$) (mean 1.00 ± 0.30) =female versus (mean 0.82 ± 0.18) =male). The female participants also had higher total cholesterol (mean 4.30 ± 0.45) =female versus (mean 3.79 ± 0.050) =male) and A1C values at one year (mean 8.8 ± 1.2) (73 mmol/mol) =female versus (mean 7.8 ± 1.0) =male(62 mmol/mol) (Davis et al., 2012). Children with T1DM should be screened for CVD and insulin resistance risk to decrease clinical complications, especially among females.

Physical activity helps lower blood glucose without the use of insulin. The body completes this physiological process by increasing the muscle's ability to take up and use blood glucose (American Diabetes Association, 2019d). The physiological process is possible since AMP kinase is activated during exercise by the influence of muscle contraction. After AMP kinase is activated, blood glucose transporters (GLUT-4) are translocated to the cell membrane and blood glucose can enter the muscle cells without an insulin injection (Stanford & Goodyear, 2014).

Physical activity and daily exercise are important for individuals with T1DM to maintain a healthy BMI and waist-to-hip ratio, which can decrease CVD risk (American Diabetes Association, 2019d). There are three types of structured exercise, including aerobic, strength training, and flexibility/balance. Aerobic exercise is defined as continuous movement of large muscle groups. The benefits of aerobic training for individuals with T1DM include weight loss, increased insulin sensitivity, reduced A1C levels, improved blood pressure, blood lipids, total

triglycerides, and blood glucose levels (American Diabetes Association, 2019d). Strength training is characterized by working against resistance to develop strength and endurance in specific muscles. Benefits from strength training include prevention of diabetes-related decline in muscle strength and functional status. In addition, strength training improves glycemic control, insulin sensitivity, blood pressure, and cardiovascular health (American Diabetes Association, 2019d). Lastly, strength training can improve body composition by increasing lean muscle mass, reducing body fat, and increasing basal metabolic rate (American Diabetes Association, 2019d). Flexibility and balance training are described by the ability to control the center weight of individual body mass. Flexibility and balance exercises include yoga and simple stretching. Benefits include improved joint mobility, better quality gait, and reduced risk of falls (American Diabetes Association, 2019d). All three types of physical activity/exercise, especially aerobic and strength training improve glycemic control (American Diabetes Association, 2019d).

The current American Diabetes Association physical activity recommendations for adults with diabetes are a minimum of 150 minutes of physical activity per week (2019d). This includes moderate-intensity aerobic exercise (50% to 70% of maximum heart rate) spread over at least three days per week with no more than two consecutive days without exercise. It is also recommended to incorporate resistance training at least twice per week and reduce sedentary time by breaking up extended amounts of time with no physical activity (more than 90 minutes) (Colberg, Laan, Dassau, & Kerr, 2016). Resistance/strength training can include using free weights, exercise machines, body weight or elastic bands. Any prolonged sedentary behavior should be interrupted every 30 minutes for blood glucose benefits (American Diabetes Association, 2019d).

One study reviewed the effects of exercise on untrained males diagnosed with T1DM (n = 21, mean age: 37 years, diabetes duration: 23 years, mean A1C 7.4% (57 mmol/mol)) (Wróbel et al., 2018). The participants were split into two groups of aerobic training or resistance training twice a week for three months. At baseline and after the intervention, echocardiography, an electrocardiogram, blood pressure, lipid profile, and blood lactate were assessed for all participants. For the resistance-training group, five exercises were completed at a 50% 1RM load, 10-15 repetitions, 5 sets, and 2-minute rest interval. The aerobic training group completed a 5-minute warm-up, a 50-minute main session, and 5-minute cool down. The intensity of the exercise was set at 75% of the lactate threshold determined from an endurance test. The normality of distribution was examined by the Shapiro-Wilk test. The results were normally distributed. Student's t-tests for dependent and independent variables were used to assess differences with statistical significance defined as $p<0.05$. The two groups did not differ at baseline in A1C ($p=0.84$), nor was there a statistical difference in mean A1C after three months. However, there was a downward trend in A1C for the aerobic training group after the intervention protocol (decrease to 7.1 %) (54 mmol/mol) ($p=0.07$). The researchers noted a small number of hypoglycemic events in the resistance training group. The aerobic training group daily insulin requirement decreased significantly after 3 months compared to baseline (75U/day initially vs. 68U/day after three months, $p<0.05$) (Wrobel et al., 2018). The insulin requirement per kg of body weight was also reduced (0.84kg vs. 0.75/kg, $p<0.05$). In the resistance training group, there was an upward trend in the final load (VO2max), with no change in the maximum heart rate. These training adaptations may suggest benefits to the cardiovascular system for resistance training. This reduction in daily insulin can support the benefits of aerobic training for individuals with T1DM.

Avoiding hypoglycemia during exercise can be difficult due to the various physical activity types, duration, and intensity among individuals diagnosed with T1DM (Colberg et al., 2015). Activity type, duration, and intensity can alter blood glucose values due to fluctuation in exercise-based hormone levels, utilization of blood glucose from the muscle, and need to administer carbohydrates during physical activity (Colberg et al., 2015).

Before exercise, carbohydrate servings should be planned based on pre-exercise blood glucose level. During training, regulation of blood glucose level and proper administration of carbohydrates may be necessary to avoid hypoglycemic encounters. Higher intensity physical activities can have a greater impact on outcome of blood glucose due to counter regulatory hormones such as epinephrine and glucagon.

Metabolic pathways are mediated by hormonal reaction during exercise (Karpinski et al., 2017). When exercises begin, catecholamine's epinephrine and norepinephrine are released. This release then triggers other metabolic hormones including glucagon, growth hormone, and cortisol (American Diabetes Association, 2019d). Insulin is a storage hormone that facilitates fuel to the cells to be utilized as immediate energy or stored in the liver. Fuel storage is facilitated by insulin since the uptake of amino acids and fatty free acids can occur and begin the process of glycogen synthesis, protein synthesis, and lipogenesis (American Diabetes Association, 2019d).

Researchers have identified the need for higher insulin dose as a barrier to an active lifestyle for individuals with T1DM (Leroux et al., 2015). Higher daily insulin dose may increase the risk of hypoglycemia. Insulin pumps may have a more reliable delivery system and quickness in method but can still have a wide variation of blood glucose values during exercise, and should be monitored closely (Colberg et al., 2015). Individuals with T1DM need to be aware that

physical activity may cause hypoglycemia if doses of insulin and/or carbohydrate ingestion are not adjusted (Karpinski et al., 2017). Blood glucose monitoring and tracking of blood glucose patterns must be utilized to exercise safely (Beck et al., 2017).

Medical professionals should create an individualized plan, especially for new exercisers with T1DM. Blood glucose should be checked before, during, and after exercise (American Diabetes Association, 2019d). Monitoring methods, such as CGM and finger prick allow the individual to adjust oral intake of carbohydrates or injection of insulin for critical exercise sessions (American Diabetes Association, 2019d). The Sports, Cardiovascular, and Wellness Nutrition professional group of the Academy of Nutrition and Dietetics recommends goals for management of blood glucose before, during, and after exercise (2016). Before beginning exercise, delaying activity and consuming carbohydrates is suggested if blood glucose is less than 100 mg/dL (5.6 mmol/L). A blood glucose between 100 - 120 mg/dL (5.6 – 6.7 mmol/L) is the optimal level to begin exercise. If blood glucose is over 250 mg/dL (13.9 mmol/L) before, during, or after exercise, urine should be checked for ketones to prevent extended hyperglycemia. During exercise, individuals are recommended take breaks during timeouts to check blood glucose. For endurance events over 60 minutes, it is suggested to consume 15 – 30 g of carbohydrates every 30 – 60 minutes within 15 minutes of exercise, unless blood glucose is high at the beginning of exercise. After exercise is completed, blood glucose should be checked immediately and consume carbohydrates according to blood glucose levels. Lastly, replenishing both carbohydrates and protein is recommended to restore muscle and liver glycogen, and initiate muscle protein synthesis.

Regardless of blood glucose state, proper monitoring should take place through either self-monitoring or continuous monitoring (American Diabetes Association, 2019d). During

exercise, it is recommended to have a strict range for blood glucose (100 – 120 mg/dL) (5.6 – 6.7 mmol/L) (since there is a faster uptake of glucose from the working muscle (American Diabetes Association, 2019d). When blood glucose is trending under 100 mg/dL (5.6 mmol/L), one serving of carbohydrate is essential to increase the blood glucose back to WNL. The American Diabetes Association (2019d) recommends a simple carbohydrate serving, such as fruit juice, for fast breakdown via metabolism to the blood stream. However, if blood glucose is trending upwards over 120 mg/dL (6.7 mmol/L), blood glucose should be monitored since insulin may be needed. If blood glucose continues to increase or decrease, exercise may need to cease to bring blood glucose back to normal levels (American Diabetes Association, 2019d).

Emerging adults with type 1 diabetes

Any individual would be challenged to maintain healthy living with T1DM, but especially emerging adults. Obstacles to management of T1DM while entering emerging adulthood may be difficult due to various alterations in lifestyle, living situation, and new independence. Emerging adulthood can be a challenging time for self-regulation of behavior, habits, and wellness (Findley, Cha, Wong, & Faulkner, 2015). Arnett (2000) defined this period of the lifecycle through human developmental theory as ages between 18 and 25. The leading cause of death for individuals in the United States ages 20 – 44 years old is unintentional injuries; 38.9% for males and 30.0% for females (Heron, 2019). These data can suggest risky behavior occurs past the age of 25 and therefore a larger age demographic of 18 – 30 years old is needed to expand insight for this age group (Heron, 2019).

There are three areas identified that distinguish emerging adults (Arnett, 2000). These areas are demographics, participant perceptions, and identity explorations. The ‘demographic’ definition of emerging adulthood can be difficult to explain since the age 18 to 25 range is very

broad. Individuals in this age group may be married, single, in or out of school, with or without children, and may or may not live at home as a dependent (Arnett, 2000). 'Participant perceptions' include how emerging adults view themselves in the world, such as denial of the self as an adolescent or as an adult (Arnett, 2000). This can be a time when many individuals in this age group are trying to determine their own personal identity (Arnett, 2000). 'Identity explorations' includes love, career field, and worldview (Arnett, 2000).

For this population, Arnett identified three characteristics that matter in attaining adulthood. The three characteristics include accepting responsibility for one's actions, making independent decisions, and financial stability. In contrast, the average U.S. adult might define adulthood from the following examples: completing school, marriage, parenthood, and settling into a career. Arnett explains the most important characteristic to this demographic is being a self-sufficient person (Arnett, 2000). One significant area of concern for this life stage is the enhanced risk behavior(s) these individuals exhibit. These behaviors can include unprotected sex, substance abuse, poor judgement, and risky driving at high speeds with or without substance intake (Arnett, 2000). Emerging adulthood is a period in which there may be unique circumstances for behaviors to become negative lifestyle choices or patterns.

Emerging adults with T1DM may face certain challenges which can be explored through the lens of identified themes of behavioral development. The risk behaviors discussed above can alter self-efficacy for this population. Self-efficacy is defined as an individual's belief in control over performance in one area of life that can influence themselves and others (Bandura, 1994). Figure 2.1 identifies the development of self-efficacy for goals, behaviors, sociocultural factors, and expectations of self-efficacy.

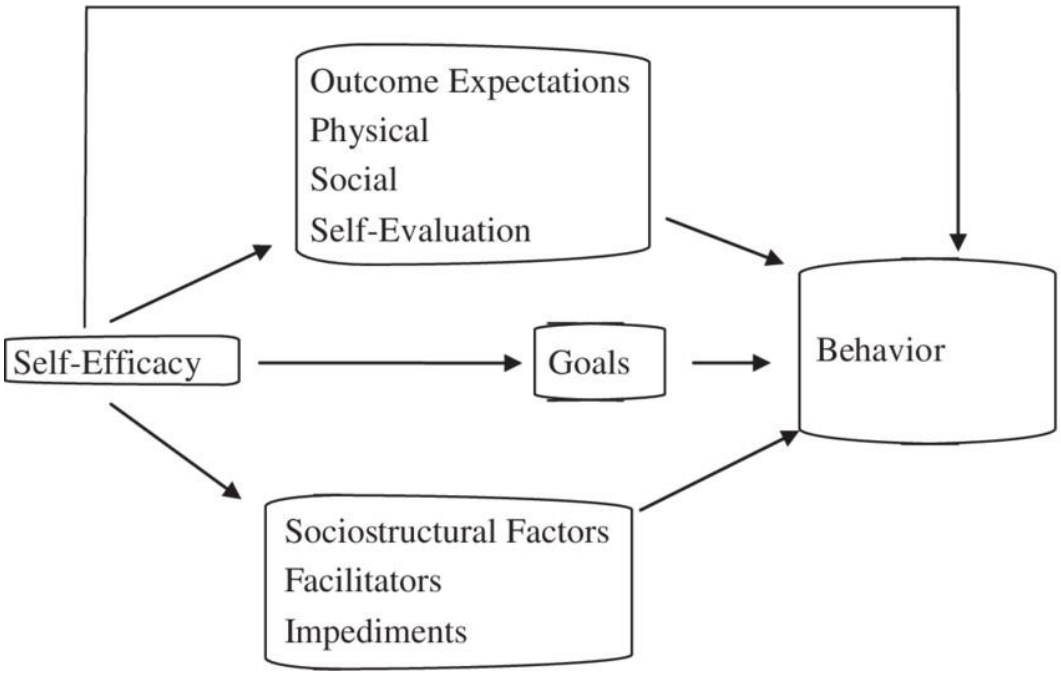

Figure 2.1. Paths of influence for self-efficacy (Bandura), 2004.

Each of these areas have an impact through the main source of self-efficacy as defined by Bandura (2004). Self-efficacy is the focal point because it can directly affect behavior and can be influenced by the other determinants (Bandura, 2004). The stronger the perceived self-efficacy the higher the expectations and commitment to the set goals. With lower perceived self-efficacy, the individual believes any effort will bring about a poor outcome or exhibits apathy. Outcome expectations are influenced by the costs and benefits for healthy habit choices. Goals are plans and strategies for both expected outcomes for health and the sociocultural impact for realizing the set goals. Sociocultural factors influence those who have both low and high self-efficacy. Individuals will be either provided with the needed support from facilitators to achieve a certain behavior or will be impeded and swayed from any effort to pursue a behavior change due to lack of support(s) (Bandura, 2004).

One study reviewed self-efficacy for T1DM through the creation of the Diabetes Empowerment Scale (DES) (Anderson, Fitzgerald, Funnel, & Marrero, 2000). The pilot version

of the Diabetes Empowerment Scale (DES) (Appendix D) had eight subscales that were major components of patient empowerment and education. From the pilot version, only three of the eight subscales had internal consistency scores (coefficient $\alpha \geq 0.80$). The wording of each question was also reviewed for diabetes-specific self-efficacy. Researchers used the Diabetes Care Profile (Fitzgerald, Davis, Conell, Hess, Hiss, 1996) to observe correlations to attitudes of having diabetes and A1C to assess levels of diabetes control. The study was completed from the review of previous participants from a larger study through the Michigan Diabetes Research and Training Center outreach programs; n = 375, ages 50.4 ± 15.8, participants with T1DM (n = 25).

A principal components factor analysis yielded six factors with Eigen values ≥ 1.0. From the factor analysis, the researchers determined a 3-factor solution to be best. This method for factor extraction aims to reveal relationships among items until there is no variance remaining (Bartholomew, Steele, Galbraith, Moustaki, 2008). The three subscales tested were 'Managing the Psychological Aspects of Diabetes' (coefficient $\alpha = 0.93$), 'Assessing Dissatisfaction and Readiness to Change' (coefficient $\alpha = 0.81$), and 'Setting and Achieving Diabetes Goals' (coefficient $\alpha = 0.81$). The internal consistency for each subscale was estimated to be $\alpha \geq 0.80$. These factors were identified as subscales for the DES. The first subscale, 'Managing the Psychosocial Aspects of Diabetes' contains nine items related to social support, self-motivation, and diabetes care decisions. The second subscale 'Assessing Dissatisfaction and Readiness to Change' has nine items to assess readiness in changing and the patients' ability to recognize self-management changes. Finally, the third subscale, 'Setting and Achieving Diabetes Goals' has ten items that identify self-efficacy to achieve goals and overcome barriers that could influence the planned goals. There was a test-retest reliability correlation (0.79) from the previous pilot of the

Diabetes Empowerment Scale (Anderson et al., 1995). The final version of DES has 28 questions and three subscales.

The study supports validity by a positive and negative relationship identified for the DES and the three subscales when compared to the Diabetes Care Profile - Attitude Scale (DCP) (Anderson et al., 2000; Fitzgerald et al., 1996). The DCP has ten questions, five questions that are self-rated for a positive attitude and five questions that are self-rated as a negative attitude. The DCP scale is a 5-point scale from 'strongly disagree = 1, disagree = 2, neutral = 3, agree = 4, and strongly agree = 5'. An example of a negative attitude question is 'I am afraid of my diabetes' and an example of a positive attitude question was 'I feel satisfied with my life'. The 'Managing the Psychosocial Aspects of Diabetes' subscale had a 0.59 correlation to the positive questions of the DCP and a – 0.59 correlation to the negative questions. The 'Assessing Dissatisfaction and Readiness to Change' subscale had a 0.32 correlation to the positive DCP questions and a – 0.38 correlation to the negative questions of the DCP. The 'Setting and Achieving Diabetes Goals' subscale had a 0.42 correlation to the positive questions of the DCP and a – 0.45 correlation to the negative questions of the DCP. Lastly, there was a test-retest reliability correlation (0.79) from the pilot study of DES (Appendix D) between the instrument that was administered to the same group at the beginning and end of the 6-week no-treatment control period. The researchers found the DES is a valid and reliable tool for the review of psychosocial self-efficacy for individuals with T1DM (Anderson et al., 2000).

The DES was been shortened to be utilized as eight questions and not 28 questions to form the Diabetes Empowerment Scale – Short Form (DES-SF) (Anderson et al., 2003). The DES-SF has been utilized to assess empowerment along with the measurement of diabetes-related distress. A cross-sectional study in Brazil was designed to determine levels of

empowerment and document diabetes-related distress associated with glycemic control (Silveria et al., 2019). The study also documented the frequency of clinical depression and depression symptoms. The participants were at an outpatient clinic, with inclusion criteria of > 18 years of age (mean 31.5 ± 8.9 years old) and diagnosed with T1DM for at least 6 months (n = 63, 23 = male (36.5%). The diagnosis of major depressive disorder was completed by the senior author based on the Diagnostic Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013). Evaluation of depressive symptoms was made with the depression subscale of the Hospital Anxiety and Depression Scale (American Psychiatric Association, 2013). The Diabetes Distress Scale was utilized to assess diabetes-related distress (Polonsky et al., 2005). Lastly, the empowerment scale for the study was the DES-SF. Chronic microvascular complications of diabetes were assessed through a medical record review. Statistics were completed to analyze group differences with the Mann-Whitney test for numerical variables, and chi-square test or by Fisher's exact test for categorical variables. The association of major depressive disorder and other variables on glycemic control were assessed by linear and multivariable regression analysis, using stepwise criteria. All analyses were undertaken using SAS version 9.2 for Windows. Statistical significance was set at 0.05.

Of the 63 participants, the mean A1C was 10.0% (± 2.0%) (86 mmol/mol) and 62 participants utilized multiple daily insulin injections, one using a pump (Silveria et al., 2019). Also, 80.9% reported a low socioeconomic status (based on Brazilian wage measurements). From the sample, 34.9% reported major depressive disorder, 34.9% had depressive symptoms, and 57.0% were identified with diabetes-related distress. Lower empowerment and high diabetes-related distress were significantly associated with higher A1C, according to the linear regression analyses. Higher A1C was associated to lower empowerment levels (p = 0.01) and

higher diabetes-relates distress ($p = 0.03$). In the multivariate analyses, lower empowerment levels were linked to better glycemic control (beta – 1.11; r-partial 0.09; $p = 0.0126$). The study showed major depressive disorder, increased depression symptoms, high diabetes-related distress, and low levels of empowerment for this population of low socioeconomic class of individuals diagnosed with T1DM in Brazil. The researchers suggested measurements of diabetes control alone will not suffice for diabetes management. Screening and assessment, and education focused on empowerment and depression level are necessary in the clinical setting for overall medical care (Silveria et al., 2019).

In a study conducted by Bowen, Henske, & Potter (2010), medical transition was defined as "purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems". There are developmental alterations of physical, emotional, and mental states during adolescence into emerging adulthood. Medical transition was identified as critical to decrease diabetic distress and complications (Bowen et al., 2010). Approximately 11-24% of adolescents with T1DM fail to follow up in the adult health care system (Bowen et al., 2010). Young adults who have less than one follow-up appointment per year after transfer from pediatric care to adult care have higher A1C, increased hospitalization, and increased diabetic complications (Bowen et al., 2010). Longitudinal follow-up of individuals with T1DM show higher obesity rates, increased tobacco use and alcohol consumption within 8 years of transfer from pediatric care to adult care (Bowen et al., 2010).

Plans for transition into an adult-oriented healthcare provider system should have clear goals for both providers of the medical team, patient, and the family/caregiver (Bowen et al., 2010). Transition models for this population group varies among individuals. Unlike their peers,

the transfer of individuals with T1DM to an adult-oriented provider system should be based on patient readiness rather than age (Bowen et al., 2010). Structured transition that allows the patient to meet the new providers before transfer occurs increases patient satisfaction and engagement with adult provider (Bowen et al., 2010). Young adults have voiced the need for flexible availability of providers, such as weekends and evenings to accommodate their work and school schedule. One difficulty for this population is feeling out of place in the adult care system and emerging adults may need education and training that is age appropriate (Bowen et al., 2010). Furthermore, the medical team may benefit from additional programming related to the emotional, developmental, and social needs of the emerging adult with T1DM (Bowen et al., 2010). Programming surrounding specific needs to address the disease of T1DM and alcohol, tobacco, sex education, recreational drug use, stress management, financial matters, and healthy cooking may be necessary for this transition (Bowen et al., 2010).

One barrier to this new transition is the long-standing relationships built among the medical team, adolescent, and family/caregiver after years working through the disease (Bowen et al., 2010). Additionally, lack of cost-effective insurance is an obstacle for young adults. Providers need to address this issue with the individual to prevent any major complications related to insurance coverage and be proactive in planning these needs (Bowen et al., 2010). After the age of 26, young adults are forcibly dropped from their parent's insurance. In conclusion, this age group is better transitioned when the previous medical team communicates in person with the patient and introduces the individual to the new team multiple times (Bowen et al., 2010). While this may require increased provider time with each individual during the transition, the outcome promotes compliance and prevents future complications that could increase medical cost (Bowen et al., 2010).

A review of the current state of transitional care for emerging adults with T1DM included adolescents (14 – 18 years) and emerging adults (ages 19 – 29) for both qualitative and quantitative studies conducted (Findley, Cha, Wong, & Faulkner, 2015). From the search, the researchers identified 31 articles that reported the clinical transitional care from pediatric to adult health. The transition normally occurs between ages 14 – 25 years with a median transition age of 20.1 years (Findley et al., 2015). Of those aged 14-25 years and diagnosed with TID, 34% reported a six-month gap in which there was no medical care. Also, there was reported to be less support staff for the primary care physicians at the adult-care level. Patients described the care received in negative terms (Findley et al., 2015). The review suggested it could take up to two years for an adult to be acquainted with a new provider. Adults did mention the transition of care was 'shocking'. Emerging adults reported feeling invisible in adult care and significantly judged when working to achieve optimal glycemic control values. The timing of transitional care influences diabetic outcomes; those individuals who stayed in pediatric care longer, or until an older age, demonstrated better self-care and controlled A1C than those who did not (Findley et al., 2015). The review suggested individual readiness was not associated with controlled A1C, rather more structured program showed improvement of glycemic control after one year of transition. Emerging adults who were using insulin pumps rather than daily injections had greater perceived control ($p < 0.001$). Researchers found that 10% of emerging adults were hospitalized for T1DM related complications with four years of their transition in providers. This hospitalization was also significantly related to post-transition as compared to pre-transition ($p = 0.03$). Lastly, emerging adults going to college found significant difficulty in this transition. Continued research is needed in this area to promote clinical prevention programming for the transition process for emerging adults with T1DM.

Assessing risky behaviors for this age group (i.e. excess alcohol consumption, recreational drug use, unhealthy sleep habits, and lack of physical activity) is needed during this life stage. The CDC Youth Risk Behavior Surveillance System (YRBSS) was designed to describe prevalence of health risk in youth in the United States, compare national, state, and local data, and evaluate/improve policies and programs related to health-risk behaviors (Appendix G) (Brener et al., 2013). The CDC then developed the YRBSS to create a data source of ongoing surveys and specific methods within the system. The ongoing survey focuses on grades 9 – 12 in the United States from various regions and districts for the national, state, territorial, tribal, and local level. In addition to risky behaviors such as unsafe recreational drug and alcohol use, the CDC also assesses topics such as risky sexual choices and violence. The survey is conducted biennially, is self-administered, and students can respond on computer-scannable questionnaires or booklets. The survey is conducted between February and May each odd-numbered year.

The health-risk behaviors were determined in 1988 through the review of the leading causes of morbidity and mortality for youths and adults (aged 1 – 24 years) (Brener et al., 2013). From these data in 1988, 68% of all deaths included motor vehicle accidents (MVA), other unintentional injuries, homicide, and suicide. Then in 2008, 72% of deaths were related to those four causes. In 2008, approximately 34% of deaths were related to cardiovascular disease and 23% were related to cancer so the CDC focused on assessing risky behaviors, rather than determinants of health since the risk-taking behaviors e.g. MVA's had higher occurrence (Brener et al., 2013). The six behaviors that were determined to be the leading causes of morbidity and mortality included, 1) unintentional injuries and violence, 2) sexual behaviors, 3) tobacco use, 4) alcohol and recreational drug use, 5) unhealthy dietary behaviors, 6) physical inactivity. The risky behaviors that are addressed in the YRBSS are associated with educational and social

outcomes, such as poor academic achievement. In 2013, education and health agencies in all 50 states, seven territorial agencies, and 31 educational agencies were able to receive funding to conduct the surveys. Each even year cycle, the survey is revised by experts both inside and outside the CDC regarding questions that need to be changed, added, or deleted from the survey.

The CDC has conducted two test-retest reliability studies, one in 1992 and one in 2000. In 1992, a convenience sample (n = 1,679) was utilized for grades 7-12 and administered on two occasions, fourteen days apart (Brener et al., 2013). The responses from students in grade 7 were different than students in grades 9-12, which suggest the questionnaire needs to be more developmentally appropriate for 7th grade participants. There was no significant difference observed between both times the questionnaire was administered. Then in 2000, a convenience sample of high school students (n = 4,619) were administered the questionnaire in a similar fashion two weeks apart. There were ten questions (14%) determined to be statistically significant from the two different survey administrations. These questions were then revised or deleted for later versions. No study has been conducted to determine validity of all self-reported behaviors. However, in 2003 a review of current literature to evaluate cognitive and situational factors related to validity of self-reporting of behaviors measured in the questionnaire, was conducted. The CDC concluded that though self-reports of behaviors are affected by cognitive and social factors, this did not threaten the validity of the type of behavior equally. Lastly, in 2000, the CDC conducted a study to assess validity of self-report for height and weight with a sample of high school students (n = 2,965). Students were weighed and measured for height after they completed the questionnaire two weeks apart. The study observed students on average more likely to over report their height by 2.7 inches and under report their body weight by 3.5 pounds,

which may have indicated the CDC YRBSS may have under reported overweight and obesity in adolescent populations.

Qualitative methods for studies of type 1 diabetes

The approach of qualitative research is utilized to analyze data in the form of natural language (i.e. words) and expressions of experiences (e.g., social interactions) (Levitt, Bamberg, Creswell, Frost, Josselson, & Suárez-Orozco, 2018). These data may be from fewer sources (i.e. participants) than quantitative but may be rich, detailed, and provide deeper descriptions from each resource (Levitt et al., 2018). This methodology may enhance the understanding of social aspects of living with chronic diseases, such as T1DM (Carlsund et al., 2018). Semi-structured interviews are a type of qualitative method in which the interviewer and respondents engage in a formal interview. The interviewer develops an 'interview guide' with a pre-set list of topics and questions to be conducted in a certain order during the conversation (Bernard, 1988). This structure can develop an observational understanding of certain topics, create a guide for further research, and generate questions prompted during the conversation (Bernard, 1988).

Thematic analysis is a qualitative method utilized to analyze large data sets. There are a variety of approaches to thematic analysis including grounded theory, phenomenology, and framework analysis. Grounded theory methodology is an approach whereby the analysis is based on the data within the text. Phenomenology focuses on a common lived experience or circumstance within a group. The research may conclude a deeper phenomenon from the meaning of the experience (Blair, 2015). Lastly, framework analysis is utilized by identifying themes and issues of the data and then placing the identified themes into a framework to be interpreted (Blair, 2015). Framework analysis guides the researcher through the data to create themes from the source (Blair, 2015). There are different techniques for coding qualitative data

to utilize for the analysis process and create themes from the interviews (Blair, 2015). Open coding is a technique drawn from grounded theory methodology. This coding generates a participant 'theory' and template for framing data in a coherent concept through the application of an established 'language' (Blair, 2015). The stages of open coding are illustrated in Table 2.7.

Table 2.7

Stages of Open Coding or Thematic Analysis (Elo and Kyngäs), 2008

	Method	**Description of method**
Stage 1.	Open coding	Notes and headings are written in the text while reading it several times
Stage 2.	Creating categories	The headings are transferred from the margins into coding sheets, ordered into subcategories aiming to collapse data
Stage 3.	Abstracting	Subcategories with similar content are grouped into two or more main categories

In one qualitative study, researchers observed effective routes to introduce and improve diabetes management among individuals with T1DM. A sample of 23 women and 12 men ranging in age from 19 to 70 (mean age 36.54 ± 16.65) were enrolled in the study (Freeborn et al., 2017). Age at diagnosis of T1DM ranged from 2 to 35 years (mean 15.06 ± 9.84) and time since diagnosis of T1DM ranged from one to 54 years (mean 21.46 ± 12.87). The participants were interviewed twice. Each interview began with questions such as "tell me about growing up and living with T1DM…". The researchers utilized guidelines by Denzin and Lincoln (1999). Transcripts of the interviews were analyzed line by line for codes that revealed major and minor themes (Freeborn et al., 2017). After the interview process, seven major themes emerged. The themes included; 'diabetes is not who you are', 'don't let it limit you', 'get diabetes support', 'it's going to be OK', 'teach them', 'don't scare them', and 'don't single kids out'. Investigators reported the importance of education in a 'matter-of-fact' manner based on finding from the study. In addition, the researchers suggested avoidance of a focus on clinical obstacles of the

mismanagement of T1DM (Freeborn et al., 2017). There is a need for individualized support for daily diabetes management including education (Freeborn et al., 2017).

Comparable to their peers, adolescents with T1DM may experience significant life changes in a short amount of time. In another qualitative study, eighteen adolescents with T1DM were recruited (Serlachius et al., 2012). The researchers were concurrently conducting a psychosocial program to improve coping skills for this population with T1DM. The program was adapted from the Best of Coping (Frydenberg & Brandon, 2007). This program is theory driven and has been shown to improve the coping skills of adolescents with disabilities (Frydenberg et al., 2007). Through the program, the researchers hypothesized a clinical improvement in glycemic control, which could then improve long-term diabetes management (Serlachius et al., 2012). Eligibility criteria included being diagnosed with T1DM for at least six months and aged between 13 to 17 years. Thirteen participants attended four focus groups (n = 9 male and n = 4 female), but five failed to attend all the sessions. The participants were separated into age-appropriate focus groups (13 – 14 and 15 – 17 years). The mean age for the 13 participants was 15.4 ± 1.7 years and mean time since diagnosis was 5.8 ± 3.9 years. The most recent A1C was recorded (mean 8.1 ± 1.2 %) (65 mmol/mol).

A semi-structured interview process was developed to guide group discussions based on the research questions. Interviews were directed to find out: ‘What are some things that you find stressful or worry you now?’ and ‘What else would you like to see included in this program?’. The transcripts were coded and analyzed using thematic analysis (Serlachius et al., 2012). There were five main themes identified: ‘parental/adolescent conflict’, ‘balancing self-management’, ‘health concerns’, ‘benefits of social support’, and ‘importance of diabetes specific information and skills’. The participants acknowledged diabetes control decline since diagnosis and concern

about future obstacles to diabetes control. Participants explained the struggle with daily medical and nutritional requirements. One example was, “I find it sometimes a bit hard to fit in all my injections, like sometimes I’m worried about missing them…if I’m at school and its lunch time and I know that we’re all meeting up at the oval or something, sometimes it’ll worry me if can’t find time to take my insulin (Girl, 14 year)”. They also indicated a desire for carbohydrate counting education to be able to increase daily physical activity (Serlachius et al., 2012). Another quote was, “Like maybe a second education meeting, where you can ask questions. I remember when I got educated for the first time; I was totally lost (Boy, 17 years)”. This study provides guidance on psychosocial programs to address specific stressors that may occur for this age group with T1DM. The participants identified the desire to have social support through peers with a coping program, specifically peers who also have T1DM. The researchers concluded that participants in a coping program learned and retained disease-specific information and skills (Serlachius et al., 2012).

In another qualitative focus group study, the researchers sought to identify psychosocial challenges of adults with T1DM (Trief et al., 2013). There were two groups (n = 9 and 7) and two partner/married groups of (n = 7 and 7). Inclusion criteria including T1DM diagnosis from group 1 and being a partner with someone in group 1 to include in group 2. Group 1 and group 2 were paired in comparison. The pairs were separated to increase contribution of participant interaction during the study. The mean age was 48.3 years (patients) and 45.6 years (partners). Eleven (68.8%) patients and five (35.7%) partners were women and all couples were married. The mean reported recent A1C was 7.6% (60 mmol/mol) for the participants with T1DM. For participants diagnosed with T1DM, reported complications were hypertension (n = 6), stomach problems (n = 4), retinopathy (n = 3), kidney disease (n = 2), and depression (n = 2), and one

reported heart disease, neuropathy, stroke, and/or memory problems. Each study meeting lasted 1.5 – 2 hours and dinner was served for the group sessions.

Two broad questions were asked to begin the group study to create room for open-ended responses from the participants. The first was "What are the emotional and interpersonal challenges you have (your partner has) experienced because your partner has diabetes?". The second question was "How does the fact that you have (your partner has) T1DM affect your relationship?" The principal analytic tool was constant comparison to code similarities and differences from the recorded group meetings (Stirling, 2001). Constant comparison is the data-analytic process whereby each interpretation and finding are compared with existing findings as it emerges from the data analysis (Lewis-Beck, Bryman, Liao, 2004). There were four major domains identified: 'impact on relationship', 'impact of hypoglycemia', 'stress of potential complications', and 'benefits of technology'. The general tone from the patients on understanding the impact of a diabetic ketoacidosis episode was that an episode creates a sense of 'helplessness and anxiety'. Participants in the partner group responded with worry as well since they 'feel the burden' to 'constantly manage' or prevent hypoglycemia. These burdens include the daily task of carrying snacks, observing for signs and symptoms of low blood glucose and prearranging for emergencies (Trief et al., 2013). The possibility of diabetic ketoacidosis can create daily emotional and physical difficulties on individuals with T1DM and their partners (Trief et al., 2013).

A qualitative study utilizing semi-structured interviews recruited participants from an Irish support group for young adults (aged 23 to 30 years) with T1DM was designed to measure quality of life (Balfe et al., 2013). The enrolled participants (n = 29, female, n = 6, male), mean age 26.7 ± 2.67, number of years with T1DM 11.5 ± 5.6, and A1C 8.0 ± 0.76% (64 mmol/mol)

were recruited to study factors of distress living with T1DM for emerging adults. There were similar themes in both the female and male participants and therefore the data were reported together. Semi-structured interviews were conducted in person and over the telephone lasting 34 to 86 minutes. The participants were given information about the project, the approximate time the interview would take, and the different questions during the session.

The interviews were thematically analyzed by 'open coding' and each section of the transcript was given a specific 'code' if a theme was distinguished. There were eight main themes observed in the study and the participants reviewed the article for inconsistencies. The eight themes identified were, 'struggles with the health care system', 'pregnancy', 'day-to-day management', 'type 2 diabetes', 'stigma', 'complications/future', 'media representations of T1DM', and 'limited daily activities' (Balfe et al., 2013). Researchers recommended healthcare professionals intervene with this age group due to the emotional struggles related to life with T1DM (Balfe et al., 2013). Quality of life is difficult to measure but self-reported quality of life can aid insight to living with T1DM.

Carlsund & Söderberg (2018) aimed to review difficulties emerging adults face with T1DM using qualitative methods. Individual, semi-structured interviews were conducted with participants (n = 12, women = 8) between the ages of 19 and 30 years. The participants (mean age 23 years) had lived with the disease between 3-14 years (mean 9.5) and diagnosis age between 3-14 years (mean 9.5). Eight lived in a joint household, four lived alone, eight participants had a high school education, and four had university education. Individual interviews were performed and lasted between 40-70 minutes (mean 44). Participants were asked the following questions: "Describe experiences of getting sick and living with the long-term illness?" and "How others accepted long-term illness issues?". During the interview, other

clarifying questions were additionally asked such as, “What happened next?”, “Can you give an example?” and, “How did you feel then?”. The interviews were recorded and later transcribed. Each interview was given a number to represent each participant. Interviews were analyzed by a hands-on qualitative content analysis guide designed for the study. The analysis revealed two main categories ‘handling the situation’ and ‘dealing with the different opinions’. Each main category had the following five subcategories including ‘managing daily life’, ‘emotional rollercoaster’, ‘general attitudes’, ‘own views and apprehensions’, and ‘ignorance and lack of motivation’. The participants expressed a significant need for planning and structure for both physical and mental stability. Participants explained managing diabetes as stressful, sometimes attributable to the misunderstandings of T1DM from the public; or related to low blood glucose, being anxious of losing control of blood glucose and the possibility of death during hypoglycemia. Many of the participants did not feel the need to hide their illness; however, in a few situations, such as hypoglycemic and hyperglycemic events, they were embarrassed to ask for help. The participants reported an avoidance of assistance during daily situations. One circumstance example was intentionally keeping blood glucose higher than normal values (>120 mg/dL) (6.7 mmol/L) during certain situations to prevent hypoglycemia. All the participants expressed lack of motivation to manage the disease and in some cases completely ceased insulin injections for special occasions (Carlsund et al., 2018). This qualitative data suggests the need for proper guidance from medical professionals to improve emerging adult physical and mental health support. The improvement of professional support can increase management of T1DM by further understanding mental, emotional, and physical aspects to daily life.

Speight et al., (2014) interviewed individuals who had been diagnosed with T1DM for > 10 years and completed a qualitative review of their reported severe hypoglycemia. Exploratory

semi-structured interview techniques were used to investigate participants' experiences of hypoglycemia through open and non-directive discussions about symptom awareness and experience, severity and progression. The participants self-reported an awareness of the symptoms, self-monitoring of blood glucose, and an intervention plan to prevent hypoglycemia. There were 17 adults (aged 46 ± 11 years, diagnosed with T1DM for 26 ± 14 years) who were recruited for the study. Non-directive discussions, i.e., avoidance of leading questions (Lewis-Beck et al., 2004) we used for all interviews, twelve of the seventeen (71%) conducted in a private room at the hospital, and 5 (29%) via telephone. Mean interview length was 52 minutes, and health psychologists, with no prior relationship to the participants, conducted the interview. Participants' most recent A1C (mean 7.7% ± 0.8%) (61 mmol/mol) was obtained from their medical records. Each interview was guided by pre-set questions, informed by literature, and professional experience (Speight et al., 2014). All interviews were digitally audio-recorded and transcribed verbatim, using the Adapted Grounded Theory approach to analysis, to explore themes from experiences (Burnard, 1991). In the previous year, 15 of the 17 participants had at least one episode of severe hypoglycemia.

Researchers recommended frequent self-monitoring of blood glucose and better knowledge of self-control to raise blood glucose and to prevent severe hypoglycemia which may be necessary for future treatment of T1DM (Speight et al., 2014). Participants experienced mild cognitive deficiencies before severe hypoglycemia occurred. Therefore, it was difficult for the participants to have awareness of their decreased blood glucose. Since the cognitive deficiencies were mild, the individual was at risk if they did not identify any alteration in blood glucose. The data from the interviews illustrate complexity in experiencing hypoglycemia including compromised cognitive capacity and the importance of having an action plan that may be needed

to treat low blood glucose. Proper early intervention may be the best way to prevent severe hypoglycemia (Speight et al., 2014).

Conclusion

As a chronic autoimmune disease, T1DM affects about 5-10% of individuals in the United States population and creates health complications (American Diabetes Association, 2019a). Medically appropriate dietary and physical activity recommendations can prevent comorbidity disease difficulties and risk factors for future additional comorbidities (Leroux et al., 2015; Gingras et al., 2015). Current research provides evidence to support the need for planned medical programming for emerging adults with T1DM to promote disease management.

Research Questions

1. What is the current self-rated level of self-efficacy and self-management among emerging adults, aged 18-30 with T1DM? Does compromised self-efficacy lead to loss of control of T1DM? Moreover, does a loss of control lead to increased risk for comorbidities?
2. Is disordered eating behavior a risk factor to diabetes management among emerging adults (aged 18 – 30 years) with T1DM?
3. Do lifestyle risky behavior choices (e.g. drunk driving, recreational drug use, lack of sleep, lack of physical activity) predict non-compliance of needed choices to manage T1DM?
4. Do emerging adults aged 18 to 30 who have difficulties managing their T1DM have decreased capabilities to be physically active? If so, why?
5. What are successes and difficulties with managing T1DM identified among emerging adults (18 – 30 years) with T1DM?

CHAPTER 3. METHODS

Identifying tactics to manage T1DM among emerging adults is important. The following methods were designed to identify both successes and difficulties related to diabetes management. A survey was designed to concentrate on self-efficacy, self-management, and eating disorder/disordered eating risk related to T1DM. The survey also focused questions on risky behaviors prevalent in this age group (aged 18 – 30). The survey results were then utilized for a second study, utilizing a qualitative approach, to deepen understanding of strategies and obstacles to diabetes management among emerging adults.

Research Design

A non-experimental causal-comparative observational cross-sectional design using a mixed methods approach was utilized to identify barriers and strategies to management of T1DM among emerging adults (aged 18 – 30). The first study included survey tools to assess diabetes control, self-efficacy, self-management, eating disorder/disordered eating risk, and risky behaviors. A second study, informed by the survey results, used an open-ended telephone interview approach to qualitative data and was designed to allow a deeper understanding of experiencing T1DM among emerging adults. One $200 Amazon gift card was provided as incentive to participate in the survey to a randomly drawn survey participant, among the first 100 participants. Then, one $100 Amazon gift card was provided as incentive to participate in the telephone interview to one of the first randomly drawn 20 interview participants.

Participants

During the spring of 2020, English speaking emerging adults with T1DM (aged 18-30) were recruited to participate in an electronic survey via email, NDSU listserv, and social media portals (e.g. Facebook and Instagram) using a scripted message (Appendix C). Both Facebook

and Instagram have pages and groups available online for T1DM support. Interested participants received the information about the study and informed consent via email (Appendix A). As part of the survey, the participant could indicate interest in the telephone interview. If so, the participant received a second informational email and informed consent (Appendix B) and was contacted to schedule an interview. Application and approval to the Institutional Review Board of NDSU was completed before recruitment (Appendix J).

Instrumentation

Survey instrumentation

A study-specific electronic survey (Qualtrics, Provo, UT), Managing Diabetes in Young Adults Survey (Appendix I) included questions borrowed with applicable approval from other questionnaires and surveys. First, questions related to diabetes control were selected to point out information for medical management, such as A1C range, age diagnosed and fasting blood glucose range. Three research instruments included as part of the Managing Diabetes in Young Adults Survey were a self-efficacy questionnaire, the Diabetes Empowerment Scale (DES) (Appendix D, Anderson et al., 2000), a questionnaire on self-management, the Diabetes Self-Management Questionnaire (DSMQ), (Appendix E, Schmitt et al., 2013), and a survey for eating disorder/disordered eating risk, the Diabetes Eating Problems Survey – Revised (DEPS-R) (Appendix F, Markowitz et al., 2010). Lastly, an adapted version of the CDC Youth Behavior Risk Surveillance System (YBRSS) relevant to emerging adults with T1DM was included (Appendix G, Brener et al., 2013). The DES, DSMQ, and DEPS-R were included in their entirety so that validated coding keys could be utilized. The DES, DSMQ, and DEPS-R include 28, 16, and 16 questions respectively for a total of 60 questions.

The DES questions included a Likert scale with options of 'never = 1, rarely = 2, sometimes = 3, often = 4, usually = 5, always = 6' (Anderson et al., 2000). The numerical values for a set of items in a particular subscale (for example: items 5-14 in the "Goal Setting" subscale) were added and the total was divided by the number of items (in this case 10) in the subscale (Anderson et al., 2000). The result value was the score for that subscale. An overall score for the DES was calculated by adding all the item scores and dividing by 28 (Anderson et al., 2000). The range of overall possible scores for the DES was 1 to 6.

The DSMQ questions included a Likert scale with the selection of 'applies to me very much = 3, applies to me a considerable degree = 2, applies to me to some degree = 1, and does not apply to me = 0' (Schmitt et al., 2013). For questions: 1, 4, 6, 10, and 12 there was an option of 'diabetes medication/insulin is not a part of my treatment' or 'blood glucose measurement is not a part of my treatment'. If the participant selected this option for question 1, 4, 6, 10, and 12, this question was left out for the DSMQ overall score (Schmitt et al., 2013). If participants did not select this option, the questions were scored. The sum score for the DSMQ could be in the range of 0 to 21. There were seven positive and nine reverse ordered questions (Schmitt et al., 2013). The questions that were reverse ordered included items: 5, 7, 10, 11, 12, 13, 14, 15 and 16 (Schmitt et al., 2013).

Lastly, the DEPS-R survey had a Likert scale with selected responses for 'never = 0, rarely = 1, sometimes = 2, often = 3, usually = 4, and always = 5' for the 16 questions. The scores could range from 0 to 80. For the YRBSS, only 18 of 99 total questions were selected from this survey (e.g. risk behaviors and demographic questions). The questions focused on alcohol consumption, sleep habits, recreational drug use, physical activity and socioeconomic status. Body mass index (BMI) was calculated by converting self-reported weight without shoes

in pounds to kilograms by dividing by 2.2, then converting height in feet and inches to meters. The converted weight (kilograms) was divided by height squared (meters).

A pilot of the Managing Diabetes in Young Adults Survey was used to (1) time the length of the survey for participants in minutes; (2) assess face validity of the questions as written (i.e. questions measure what they are intended to measure); and (3) check for clarity. The pilot test was completed from April to May 1, 2020 by 14 individuals. The survey was pilot tested with dietetic students, who were within the age range of 18-30. Individuals diagnosed with T1DM who were outside of the study age range also participated and were assumed to be informed participants. Dietitians, as medical professionals, partook in the pilot survey test as well. The total survey time took an average of 23 minutes for each participant. At the end of the survey the participants were asked for feedback. The recommendations included clarification of any misunderstood questions and then clearing up any confusion as to meaning or intent of a question. The survey originally asked the participants to provide their insulin regimen in a table form. The table was a required part of the survey and was reportedly very lengthy to fill out. The pilot survey participants suggested to change the table to 'optional' and to shorten it for ease of response. Another recommendation from the pilot test was to provide choices for 'I don't wish to respond' on questions that could be considered too personal. Examples of these questions were 'race' identification, 'sex' selection, and 'level of income'.

Interview instrumentation

The researcher wrote the telephone interview questions for the qualitative data with approval by the research team (Appendix H). The interview questions were pilot tested among two non-study participants who completed the pilot survey. One of the participants was a dietetic student who had a chronic disease and another was an individual with T1DM outside of the age

range of 18-30. Both individuals participated in the pilot telephone interview to test timing and understandability of the questions. To record the pilot telephone interview, the iPhone telephone application, called Rev – Call Recorder was utilized. Each interview question was asked or repeated if the pilot test participant did not understand the question. The pilot test interviews took ~ 45 minutes on average. The pilot interview testers suggested each question be read once for clarity, with a long pause to wait for a response. Another suggestion was to rewrite words such as, 'diabetes self-efficacy' and 'compliance' to, respectively, 'diabetes management' and 'habits' as those terms were more user friendly to the testers. Pilot interview suggestions were implemented as part of the final study procedures.

Procedures

The survey began immediately after pilot testing and was available for two weeks, May 1 to 15, 2020. The survey link was available via Qualtrics and was provided through NDSU email, Instagram, Facebook and the snowball effect. No reminders were sent for recruitment. The participants who indicated interest in the study were emailed the link to the Managing Diabetes in Young Adults Survey (Appendix I). At the end of the survey, the participants were asked if they would like to participate in a telephone interview (Appendix H). If the participant was interested, a telephone interview was scheduled by providing a follow-up email.

All identifiable information was kept strictly confidential between the members of the research team. All data collected from the study was kept on password protected computers or otherwise conforming to NDSU ITS standards of security. No names were stored on computers, only subject numbers. Only the research team had access to these electronic folders. In addition, the file connecting the participant numbers to the names were encrypted using standard Microsoft Excel. During the telephone interviews, a number identified participants. The

participants who volunteered for the telephone interview had email/contact information retained until after the telephone interview data was analyzed. After the data was analyzed, any links to names/contact information were destroyed.

Data Analysis

Quantitative data related to diabetes management, self-efficacy, self-management, eating disorder risk/disordered eating risk, risky behaviors and demographics were analyzed using parametric and non-parametric statistics. Each individual survey (DES, DSMQ, and DEPS-R) was scored separately to be used as variables. The means and SDs were calculated to compare diabetes management (self-reported A1C range) to survey scores and responses from the DES (Appendix D), DSMQ (Appendix E), the DEPS-R (Appendix F) and selected questions on risky behaviors from the YRBSS (Appendix G). Descriptive statistics were used for self-reported data for age group comparisons. Glycemic control (A1C range) to indicate level of diabetes management was used for group comparisons based on: 'good' (< 7.5%) (58 mmol/mol), 'medium' (7.5 – 8.5%) (58 – 69 mmol/mol), and 'poor' (> 8.5%) (> 69 mmol/mol) control, similar to Schmitt, et al., 2013 and following ADA recommendations (American Diabetes Association, 2019b). Similarly, blood glucose used for group comparison had three assigned levels: 'good' 80 – 120 mg/dL (4.4 – 6.7 mmol/L), 'hypoglycemia' < 80 mg/dL (< 4.4 mmol/L) and 'hyperglycemia' > 120 mg/dL (> 6.7 mmol/L) (American Diabetes Association, 2019b). The BMI was coded as 'underweight' (< 18.5 kg/m^2), 'normal' (18.5 – 24.9), 'overweight' (25.0 – 29.9) and 'obese' > 30 kg/m^2 (Garrow & Webster, 1985). The A1C value was converted from % into estimated mmol/mol and blood glucose was converted from mg/dL to mmol/L for international comparisons (Nathan et al., 2008).

A one-way analysis of variance (ANOVA) and chi-square were utilized to assess variable comparisons. A cumulative logistic regression with stepwise variable selection was used to evaluate relationships between A1C groups, age diagnosed, age range, DES overall score and the subscales, Managing the Psychosocial Aspects of Diabetes Management, Assessing Dissatisfaction and Readiness to Change, Setting and Achieving Diabetes Management Goals, DSMQ overall score, and the subscales, Dietary Control, Glucose Management, Physical Activity, and Physician Contact and DEPS-R overall score. A cumulative regression with stepwise variable selection was used to evaluate relationships between A1C groups, age diagnosed, age range, DSMQ overall score, DSMQ subscales, and risky behaviors (i.e. amount of sleep, alcohol days per week, alcohol drinks per session, recreational drug use in the past 30 days, and amount of physical activity or sedentary behavior). Lastly, a Spearman correlation coefficient was utilized to observe the relationship between those who responded 'yes' to low blood glucose during exercise and A1C groups. An alpha of 0.05 was used to indicate statistical significance. Statistical analysis was completed with SAS version 9.4 (Cary, NC).

Qualitative data was audio recorded, transcribed, and analyzed for themes by the researcher. After the data was transcribed, the researcher verified the transcription twice compared to the audio recording for mistakes. Transcription was first checked with listening and checking word-by-word for typos and other errors. Then the second time listening was completed with thematic analysis via open coding by writing out notes and headings from the recordings while reading the interviews several times. After that, categories were created in the margins of the transcriptions and then into subcategories of data. After the categories were created, subcategories with similar content were grouped into two or more main categories using methods developed by others (Elo & Kyngäs, 2008).

CHAPTER 4. MANUSCRIPT 1 – SELF-EFFICACY, SELF-MANAGEMENT, AND RISKY BEHAVIORS AMONG YOUNG ADULTS WITH TYPE 1 DIABETES

Abstract

Purpose: The purpose of this study was to evaluate emerging adults (aged 18 – 30) with type 1 diabetes (T1DM) for self-efficacy, self-management, eating disorder risk and risky behaviors related to diabetes control.

Methods: A cross-sectional design with a quantitative approach was utilized for a volunteer sample of emerging adults (n = 115, 94% female) with T1DM in May 2020. The Managing Diabetes in Young Adults Survey was comprised of the Diabetes Empowerment Scale survey (DES), Diabetes Self-Management Questionnaire (DSMQ), Diabetes Eating Problems Survey – Revised (DEPS-R) and select questions from the CDC Youth Risk Behavior Surveillance System (YRBSS).

Results: There were no significant associations between glycemic control and the DES overall score nor the three subscales although the subscale "Psychosocial Aspects of Diabetes Management" approached significance (F (2,108) = 2.30, $R^2 = 0.0415, \mathrm{p} = 0.1056$), (F (2,108) = 2.52, $R^2 = 0.0454, \mathrm{p} = 0.0850$). 'Good' glycemic control was associated with higher DSMQ overall scores (p=0.0003) and the DSMQ glucose management subscale (p=0.0027) compared to 'medium' and 'poor' glycemic control (F (2,108) = 8.63, $R^2 = 0.1400, \mathrm{p} = 0.0003$), (F (2,108) = 6.28, $R^2 = 0.1059, \mathrm{p} = 0.0027$). Participants with 'good' glycemic control were observed to have a risk for an eating disorder (DEPS-R score ≥ 20) than the 'medium' glycemic control group (F (2,29) = 2.82, $R^2 = 0.1726, \mathrm{p} = 0.0320$). Participants who drank more alcohol per session and per week were more likely to adjust dietary intake and insulin dosage (F (1,114) = 9.52, $R^2 = 0.0770, \mathrm{p} = 0.0026$), (F (1,114) = 5.14, $R^2 = 0.0431, \mathrm{p} = 0.0253$).

Conclusions: Self-management can improve personal glycemic control. Future research surrounding compromised self-efficacy and glycemic control, especially with psychosocial aspects to diabetes management is necessary. This age group is at risk for eating disorders, screening is important to prevent chronic complications. Addressing alcohol consumption in a risk reduction manner may improve emerging adults success with glycemic control.
Keywords: eating disorders; disordered eating; insulin adjustment; physical activity; emerging adults

Introduction

Type 1 diabetes is an autoimmune disease clinically described as the destruction of insulin producing β-cells in the pancreas, which requires complete insulin therapy (American Diabetes Association, 2019b). This disease entails daily blood glucose measurement and measured insulin injections or use of an insulin pump (American Diabetes Association, 2019b). Acute blood glucose can be measured through a continuous blood glucose monitor (CGM) or capillary blood finger prick (American Diabetes Association, 2019d). Chronic glycemic control can be measured through A1C (%) (mmol/mol), usually a three-month average of blood glucose measurements (American Diabetes Association, 2019d). In addition, carbohydrates are required to be counted in portion sizes since insulin is required to breakdown this macronutrient into glucose, after dietary intake (American Diabetes Association, 2019b). Microvascular and macrovascular complications related to T1DM mismanagement can be prevented or slowed through self-care behaviors (Schmitt et al., 2013). If mismanaged, an individual can lose glycemic control and increase risk for other medical complications. Complications of chronic uncontrolled T1DM may be comorbidities such as cardiovascular disease, stroke, neuropathy and the short-term difficulties such as hyper- or hypoglycemia, diabetes seizure, or diabetes

ketoacidosis (American Diabetes Association, 2019d). These acute and chronic complications may require medical intervention through hospitalization (American Diabetes Association, 2019d).

Diabetes management can be impacted through work schedule and social events since management is very strenuous. Emerging adults as defined by Arnett (2000) as the age group between adolescence and adulthood (18 – 25 years) that are striving to establish independence. During this period of life, significant choices may be decided such as committing to a lifelong partner, attending college for a future career and/or moving to a permanent home away from their original family unit (Arnett, 2000). Though this definition is established, the ages of 25 – 30 may add additional insight into the adulthood transition (Bowen et al., 2010; CDC, 2017). Of paramount importance, at the age of 26, dependents are dropped from their parents' or guardians' medical insurance and must obtain that insurance through an employer, the government, or pay for an individual policy (Bowen et al., 2010; CDC, 2017).

Emerging adults are known to make risky decisions that can affect their future, financial stability, and overall well-being (Arnett, 2000). Emerging adults are also known to be at a higher risk for mismanagement of diabetes (American Diabetes Association, 2019f). The American Diabetes Association has identified the age group (18 – 25 years) to be at risk for inappropriate A1C levels that directly correlate to diabetes mismanagement (2019f). Emerging adults may struggle with disease management due to financial and/or social hardships, such as an inadequate medical insurance (American Diabetes Association, 2019f).

Perceived self-efficacy can influence confidence towards overall self-care (Bandura, 2000). Self-efficacy is defined as a person's confidence in performing well in one area of life for the benefit of self or others (Bandura, 1994). One way to assess self-efficacy for individuals with

T1DM is with the Diabetes Self-Empowerment Scale (DES) (Anderson, Fitzgerald, Funnel, & Marrero, 2000). The subscales for the DES include, 'Managing the Psychosocial Aspects of Diabetes Management', 'Assessing Dissatisfaction and Readiness to Change', and 'Setting and Achieving Diabetes Management Goals'. These subscales align with attributes outlined by Bandura to measure self-efficacy (1994). The Diabetes Self-Management Questionnaire (DSMQ) was developed to quickly evaluate self-care for individuals with diabetes (Schmitt et al., 2013). The subscales for the DSMQ include 'Dietary Control', 'Glucose Management', 'Physical Activity', and 'Physician Contact'. These subscales are measurements identified for various aspects of self-management of diabetes (Schmitt et al., 2013). Transition into adulthood may be associated with eating disorder behaviors (Luyckx et al., 2019). Emerging adults with T1DM may need to be screened for eating disorders/disordered eating because of increased risk for this comorbidity (Moskovich et al., 2019). The Diabetes Eating Problems Survey – Revised (DEPS-R) has been reviewed as a reliable and valid tool for assessing psychometric properties for eating disorder/disordered eating risk among children, adolescents and adults (Markowitz et al., 2010). The predetermined cut-off score for eating disorder risk is empirically established at 20 or above (Markowitz et al., 2010). Assessing risky behaviors for this age group (i.e. excess alcohol consumption, recreational drug use, poor sleep habits, and lack of physical activity) is important because T1DM may be increasingly difficult to manage given increased risky behaviors. The CDC Youth Risk Behavior Surveillance System (YRBSS) was designed to identify prevalence of health risk in youth in the United States. The selected questions from the YRBSS were utilized to assess risky behaviors relevant to this age group (Brener et al., 2013). Identification of levels or occurrences of self-efficacy, self-management, eating disorder/disordered eating risk, and risky behaviors related to diabetes control are necessary to

create future programming geared towards T1DM, age and disease specific curriculum (Bowen et al., 2010).

Research Design

Aim

The first aim was to observe the current self-rated level of self-efficacy and self-management among emerging adults, aged 18-30 with T1DM. The second was to assess if compromised self-efficacy leads to loss of control of T1DM. Next, the researchers reviewed if loss of glycemic control leads to increased risk for comorbidities. Then participants were screened to assess if eating disorders/disordered eating behavior was a risk factor to diabetes management among emerging adults (aged 18 – 30 years) with T1DM. The study was designed to assess if lifestyle risky behavior choices (e.g. excess alcohol consumption, recreational drug use, lack of sleep, lack of physical activity) predicted non-compliance of choices to manage T1DM. Lastly, the study assessed if emerging adults aged (18 to 30) who have difficulties managing their T1DM have decreased capabilities to be physically active.

A non-experimental causal-comparative observational design was utilized to assess barriers and strategies to management of T1DM among emerging adults (aged 18 – 30). A survey was used to gather information concerning diabetes control, self-efficacy, self-management and risky behaviors. One $200 Amazon gift card was provided as incentive to participate in the survey to one of the first randomly drawn 100 survey participants.

Participants

During May 2020, English speaking emerging adults with T1DM (aged 18-30) were recruited to participate in an electronic questionnaire via email, university listserv, and social media portals (e.g. Facebook and Instagram) using a scripted message. Both Facebook and

Instagram have pages and groups for support for individuals with T1DM. Once the participant indicated interest in the survey they received information about the study and informed consent via email. Application and approval to the Institutional Review Board of North Dakota State University, Fargo, ND, was completed before recruitment, approval #HE20244.

Survey instrumentation

A study-specific electronic survey (Qualtrics, Provo, UT), the Managing Diabetes in Young Adults Survey (Appendix I) included questions used from other surveys and questionnaires. First, questions related to diabetes control were included to screen for information related to medical management, such as A1C range, age diagnosed, and fasting blood glucose range. There were also questions in this section for medical training related to diabetes management. An example was, 'What educational topics would improve your diabetes management?', 'What gets in the way of you managing your diabetes?' and 'Who helps you with management of your diabetes?'. These questions had the option for, 'choose all that apply'. The other research instruments included as part of the Managing Diabetes in Young Adults Survey included the DES (Appendix D, Anderson et al., 2000), the DSMQ, (Appendix E, Schmitt et al., 2013), and the DEPS-R (Appendix F, Markowitz et al., 2010). Lastly, an adapted version of the YRBSS relevant to emerging adults with T1DM was included (Appendix G, Brener et al., 2013). Only 18 of 99 total questions were selected from the YRBSS (e.g. risk behaviors and demographic questions) for the Managing Diabetes in Young Adults Survey. The DES, DSMQ and DEPS-R were included in their entirety so that validated coding keys could be utilized with 28, 16, and 16 questions respectively for a total of 60 questions. All questionnaires are available for public access, except the DEPS-R. Permission was obtained to use this tool (Appendix F, Markowitz et al., 2010).

The DES questions include a Likert scale with options of 'never = 1, rarely = 2, sometimes = 3, often = 4, usually = 5, always = 6' (Anderson et al., 2000). The numerical values for a set of items in a subscale (for example: items 5-14 in the "Goal Setting" subscale) are added and the total is divided by the number of items (in this case 10) in the subscale (Anderson et al., 2000). The resulting value is the score for that subscale. The subscales for the DES are Managing the Psychosocial Aspects of Diabetes Management, Assessing Dissatisfaction and Readiness to Change, and Setting and Achieving Diabetes Management Goals. An overall score for the DES can be calculated by adding all the item scores and dividing by 28 (Anderson et al., 2000). The range of overall possible scores for each subscale and the overall score for DES is 1 to 6, with higher scores indicating higher self-efficacy.

The DSMQ questions include a Likert scale with the selection of 'applies to me very much = 3, applies to me a considerable degree = 2, applies to me to some degree = 1, and does not apply to me = 0' (Schmitt et al., 2013). For questions; 1, 4, 6, 10, and 12 the option of 'diabetes medication/insulin is not a part of my treatment' or 'blood glucose measurement is not a part of my treatment' are left out if checked by the participant (Schmitt et al., 2013). If participants did not select this option, the questions were not scored. There are nine of sixteen reverse scored questions including items: 5, 7, 10, 11, 12, 13, 14, 15 and 16 (Schmitt et al., 2013). The subscales for the DSMQ are Dietary Control, Glucose Management, Physical Activity, and Physician Contact. The range of overall score could have been 0 to 21 and subscale scores could have been 0 to 6 for Dietary Control, 0 to 9 for Glucose Management, 0 to 3 for Physical Activity, and 0 to 3 for Physician Contact. A higher DSMQ score indicates improved diabetes management.

The DEPS-R survey contains a Likert scale with selected responses for ‘never = 0, rarely = 1, sometimes = 2, often = 3, usually = 4, and always = 5’. The scores could range from 0 to 80, 20 or above “at risk” for disordered eating/eating disorders. The YRBSS, questions selected were chosen to help identify risky behaviors and to standardize demographic questions. The “risk” questions focused on alcohol consumption, sleep habits, recreational drug use, and physical activity. Lastly, there was an optional insulin regimen table for participants to fill in daily insulin dosing. Body mass index (BMI) was calculated by converting self-reported weight without shoes in pounds to kilograms by dividing by 2.2 and converting self-reported height in feet/inches to cm. The converted weight (kilograms) was divided by height squared (meters).

A pilot of the Managing Diabetes in Young Adults Survey was used to (1) time the length of the survey for participants in minutes; (2) assess face validity of the questions as written (i.e. questions measure what they are intended to measure); and (3) check for clarity. The pilot test was completed during April to May 1, 2020 by 14 individuals. The survey was pilot tested with dietetic students, who were within the age range of 18-30. Individuals diagnosed with T1DM who were outside of the study age range also participated, and were assumed to be informed participants. Dietitians, as medical professionals, partook in the pilot survey test as well. The total survey time took an average of 23 minutes for each participant. At the end of the survey the participants were asked for feedback. The recommendations included clarification of any misunderstood questions. Other suggestions included clearing up any confusion as to meaning or intent of a question. The survey originally asked the participants to provide their insulin regimen in a table form. The table was a required part of the survey and was reportedly lengthy to fill out. The pilot survey participants suggested to switch this part to optional and to be shortened for ease of response. Another recommendation from the pilot test was to provide choices for ‘I don’t

wish to respond' on questions that could be considered too personal. Examples of these questions were 'race' identification, 'sex' selection, and 'level of income'.

Methodology

The survey began immediately after pilot testing and was available for two weeks, ending May 15, 2020. The survey link was available via Qualtrics and was provided through NDSU email, Instagram, Facebook and the snowball effect. No reminders were sent for recruitment. The participants who indicated interest in being in the study were emailed a link to the Managing Diabetes in Young Adults Survey (Appendix I).

Nominal and ordinal data related to diabetes control, self-efficacy, self-management, eating disorder risk, risky behaviors and demographics were analyzed using non-parametric statistics. Each individual survey (DES, DSMQ, and DEPS-R), and applicable subscales were scored separately to be used as variables. The means and SDs from the survey were calculated to compare glycemic control (A1C) to scores and responses from the DES (Appendix D), DSMQ (Appendix E), the DEPS-R (Appendix F) and selected items for risky behaviors from the YRBSS (Appendix G). Descriptive statistics were used to report data for age-group comparisons. Group comparisons for glycemic control (A1C % range) (mmol/mol) were divided into 'good' (< 7.5%) (< 58 mmol/mol), 'medium' (7.5 – 8.5%) (58 - 69 mmol/mol), and 'poor' control (> 8.5%) (> 69 mmol/mol). Group comparisons for fasting blood glucose were divided into 'good' (80 – 120 mg/dL) (4.4 – 6.7 mmol/L), 'hyperglycemia' (> 120 mg/dL) (> 6.7 mmol/L), and 'hypoglycemia' (< 80 mg/dL) (4.4 mmol/L). The A1C value was converted from % into estimated mmol/mol and blood glucose was converted from mg/dL to mmol/L for international comparisons (Nathan et al., 2008). A one-way analysis of variance (ANOVA) and chi-square were utilized to assess dependent survey variables (DES, DSMQ, DEPS-R) and independent

variable glycemic control comparisons. Glycemic control was an independent variable for the ANOVA test since the ANOVA model works for continuous dependent variables with a categorical independent variable.

A cumulative logistic regression with stepwise variable selection was used to evaluate relationships between A1C groups (dependent variable), and independent variables age diagnosed, age range, DES (overall total and all three subscales), DSMQ (overall total and all three subscales), DEPS-R, and risky behaviors (i.e. amount of sleep, alcohol days per week, drinks per session, recreational drug use in the past 30 days, and amount of physical activity or sedentary behavior). Glycemic control was a dependent variable, in the cumulative logistic regression with stepwise loaded variables, since this response on the survey was categorical. Lastly, a Spearman correlation coefficient was utilized to observe the relationship among those who responded to difficulty with low blood glucose during exercise and applicable A1C groups. An alpha of 0.05 was used for statistical significance. Statistical Analysis System (SAS) version 9.4 (Cary, NC) computer software was used for analysis.

Results

There were originally 118 participants. Three participant surveys were removed for having identical responses to each question. Key descriptives of the participants (n = 115; mean age diagnosed 14 ± 7.23) are listed in Table 4.1.

Table 4.1

Diabetes Management in Young Adults Survey Demographic and Diabetes Management Results

Characteristic	**Category**	**Survey (n=115)**
Age (yrs)	(18 – 20)	9
	(21 – 24)	32
	(25 – 30)	74
Sex	Male	6
	Female	108
	No answer	1
BMI (kg/m^2)	Underweight (<18.50)	1
	Normal (18.5 – 24.9)	50
	Overweight (25.0 – 29.9)	37
	Obese (>30)	27
A1C (%) (mmol/mol)	Good (< 7.5) (< 58 mmol/mol)	85
	Medium (7.5 – 8.5) (58 – 69 mmol/mol)	17
	Poor (> 8.5) (> 58 mmol/mol)	6
	Do not know	7
Fasting Blood Glucose (mg/dL) (mmol/L)	Hypoglycemia (< 80) (< 4.4 mmol/L)	3
	Good 80 – 120 (4.4 – 6.7 mmol/L)	67
	Hyperglycemia > 120 (> 6.7 mmol/L)	19
	I don't know	25
	I do not wish to disclose	1
Age at time of diagnosis (yrs)	< 10	41
	10 – 15	31
	15 – 20	22
	> 20	21

Socioeconomic status, ethnic and racial categories are presented in Table 4.2.

Table 4.2

Diabetes Management in Young Adults Survey Socioeconomic Status, Ethnic and Racial Categories

Characteristic	Category	Survey (n=115)
Race Identification	White	97
	Hispanic or Latino	6
	Black or African American	4
	Asian	3
	Other	5
Annual income (estimate per year)	< $15,000	32
	$15,000 - 30,000	15
	$30,000 - 45,000	13
	$45,000 – 60,000	18
	> $60,000	22
	I do not wish to disclose	15
Education Level	High school graduate or equivalent	5
	Trade school or vocational school	3
	Some college	22
	Associates degree	9
	Bachelor's degree	54
	Graduate or professional degree	22

Participant response to educational topics, barriers to management and social support are presented in Table 4.3. Participants were able to respond to multiple choices in each category.

Table 4.3

Diabetes Management Social Support, Educational Topics and Barriers

Characteristic	Category	Survey Percent
Educational Topics	None	3%
	Meal planning	42%
	Dining out	22%
	Exercise	43%
	Blood sugar monitoring	13%
	Taking medications	4%
	Dealing with high or low blood glucose	13%
	Managing diabetes when you are sick	30%
	Foot and skin care	13%
	Preparing for pregnancy	47%
	Impotence/sexual dysfunction	15%
	Dealing with stress	57%
	Other	3%
Barriers to Management	Nothing	17%
	Stress	71%
	Work	35%
	Friends	3%
	Emotions	42%
	Money	20%
	Health problems	7%
	Lack of time	33%
	Lack of knowledge	7%
	Family	12%
	Other	9%
Social Support	Me	77%
	No one	7%
	Family	47%
	Co-workers	5%
	Healthcare provider	63%
	Support group	10%
	Other	14%

DES, DSMQ, and DEPS-R

The results for the three surveys and subscales for the means and the SDs for the participants are presented in Table 4.4.

Table 4.4

Self-Efficacy, Self-Management, and Eating Disorder Risk Survey Scores

Survey	Possible Total Score	Mean (SD)	Range
DES overall score	1 - 6	4.79 (0.79)	2.57 - 6.00
1. Managing the Psychosocial Aspects of Diabetes Management	1 - 6	4.70 (0.93)	1.78 - 6.00
2. Assessing Dissatisfaction and Readiness to Change	1 - 6	4.89 (0.75)	4.22 - 6.00
3. Setting and Achieving Diabetes Management Goals	1 - 6	4.75 (0.88)	2.70 - 6.00
DSMQ overall score	0 - 21	10.88 (4.82)	0.00 - 20.00
1. Dietary Control	0 - 6	2.45 (1.40)	0.00 - 6.00
2. Glucose Management	0 - 9	7.28 (1.77)	2.00 - 9.00
3. Physical Activity	0 - 3	1.58 (0.96)	0.00 - 3.00
4. Physician Contact	0 - 3	2.51 (0.76)	0.00 - 3.00
DEPS-R	0 - 80	14.73 (9.30)	0.00 - 44.00

DES, DSMQ, DEPS-R and glycemic control

'Good' glycemic control (dependent variable) was significantly predicted by shorter age diagnosed, higher DSMQ overall score, and lower DSMQ dietary control score (predictor or independent variables) shown in Table 4.5. The independent variables in the cumulative logistic regression with the stepwise variables included current age, age diagnosed, DES overall score, DES subscales, DSMQ overall score, DSMQ subscales, and DEPS-R overall score. The variables DES overall score, DES subscales, and DEPS-R did not have a predictive significance. As age diagnosed increased (e.g. age 15 – 20, > 20 versus age < 10 , 10 – 15) better glycemic control was predicted from the regression results.

Table 4.5

Cumulative Logistic Regression with Stepwise Variable Selection for Glycemic Control

	Estimate	**SE**	**p-value**
A1C <7.5% (<58 mmol/mol)	-0.3929	0.7413	0.5961
A1C 7.5-8.5% (58-69 mmol/mol)	1.7067	0.8310	0.0400
Age diagnosed	0.0842	0.0404	0.0373
DSMQ overall score	0.4617	01441	0.0014
DSMQ dietary control	-0.6107	0.2410	0.0113

Note: A1C <7.5% (<58 mmol/mol) =glycated hemoglobin, good glycemic control; A1C 7.5-8.5% (58 – 69 mmol/mol) =glycated hemoglobin, medium glycemic control; DSMQ=Diabetes Self-management Questionnaire

DES and glycemic control

There was no significance between glycemic control (independent variable) and the DES overall score nor the three subscales (dependent variables) (Table 4.6) although the subscale 'Psychosocial Aspects of Diabetes Management' approached significance, (F (2,108) = 2.30, $R^2 = 0.0415, \mathrm{p} = 0.1056$), (F (2,108) = 2.52, $R^2 = 0.0454, \mathrm{p} = 0.0850$).

Table 4.6

Comparison of the DES in Participants with A1C < 7.5% (< 58 mmol/mol), 7.5-8.5% (58 – 6.9 mmol/mol), and > 8.5% (> 69 mmol/mol)

Survey	**A1C < 7.5% (<58 mmol/mol)**	**A1C 7.5 - 8.5% (58-69 mmol/mol)**	**A1C > 8.5% (>69 mmol/mol)**	**ANOVA P-value**
DES overall score	4.88(0.76)	4.70(0.80)	4.22(0.79)	0.1056
1. Managing the Psychosocial Aspects of Diabetes Management	4.83(0.90)	4.56(0.93)	4.06(0.95)	0.0850
2. Assessing Dissatisfaction and Readiness to Change	4.95(0.75)	4.87(0.75)	4.50(0.69)	0.3437
3. Setting and Achieving Diabetes Management	4.85(0.86)	4.67(0.92)	4.12(0.84)	0.1121

Note: Data are mean ± SD. Tests were one-way ANOVA and Tukey Kramer Test for post-hoc group comparisons. DES; Diabetes Empowerment Scale; A1C , glycated hemoglobin; ANOVA, Analysis of Variance.

DSMQ and glycemic control

There was a significance between glycemic control (independent variable) and DSMQ overall score and the DSMQ glucose management subscale (dependent variable) shown in Table 4.7, (F (2,108) = 8.63, $R^2 = 0.1400, \mathrm{p} = 0.0003$), (F (2,108) = 6.28, $R^2 = 0.1059, \mathrm{p} = 0.0027$).

Table 4.7

Comparison of the DSMQ in Participants with A1C < 7.5% (< 58 mmol/mol), 7.5-8.5% (58 – 69 mmol/mol), and > 8.5% (> 69 mmol/mol)

Survey	**A1C < 7.5% (<58 mmol/mol)**	**Sign. [a]**	**A1C 7.5 - 8.5% (58-69 mmol/mol)**	**Sign. [b]**	**A1C > 8.5% (>69 mmol/mol)**	**Sign. [c]**	**ANOVA P-value**
DSMQ overall score	5.55(2.12)	*	4.06(2.79)	ns	2.22(2.19)	†	0.0003
1. Dietary Control	2.45(1.45)	ns	2.79(1.44)	ns	1.67(0.82)	ns	0.2423
2. Glucose Management	7.62(1.58)	*	6.63(1.83)	ns	5.67(1.37)	*	0.0027
3. Physical Activity	1.63(1.00)	ns	1.47(0.84)	ns	1.50(0.84)	ns	0.7911
4. Physician Contact	2.60(0.73)	ns	2.42(0.69)	ns	2.00(1.26)	ns	0.1439

Note: Data are mean ± SD. Tests were one-way ANOVA and Tukey Kramer Test for post-hoc group comparisons. Tukey Kramer significance is expressed: * P < 0.05; † P < 0.01; ‡ P < 0.001; ns, not significant. DSMQ; Diabetes Self-management Questionnaire; A1C, glycated hemoglobin; ANOVA, Analysis of Variance. [a] regards comparison between the first and second group. [b] regards comparison between the second and third group. [c] regards comparison between the third and first group.

DEPS-R and glycemic control

Participants with ‘good’ glycemic control (independent variable) were observed to have a higher DEPS-R risk score (≥ 20) (dependent variable) than ‘medium’ glycemic control (A1C 7.5 – 8.5%) (58 – 69 mmol/mol) (independent variable) (mean 28.60 ± 6.86 vs. mean 22.17 ± 2.56, p = 0.0320) shown in Figure 4.1. The ‘poor’ glycemic control was less than ‘good’ glycemic control but there was not a relationship detected (mean 26.33 ± 5.19), which could have been related to low group size (n= 6).

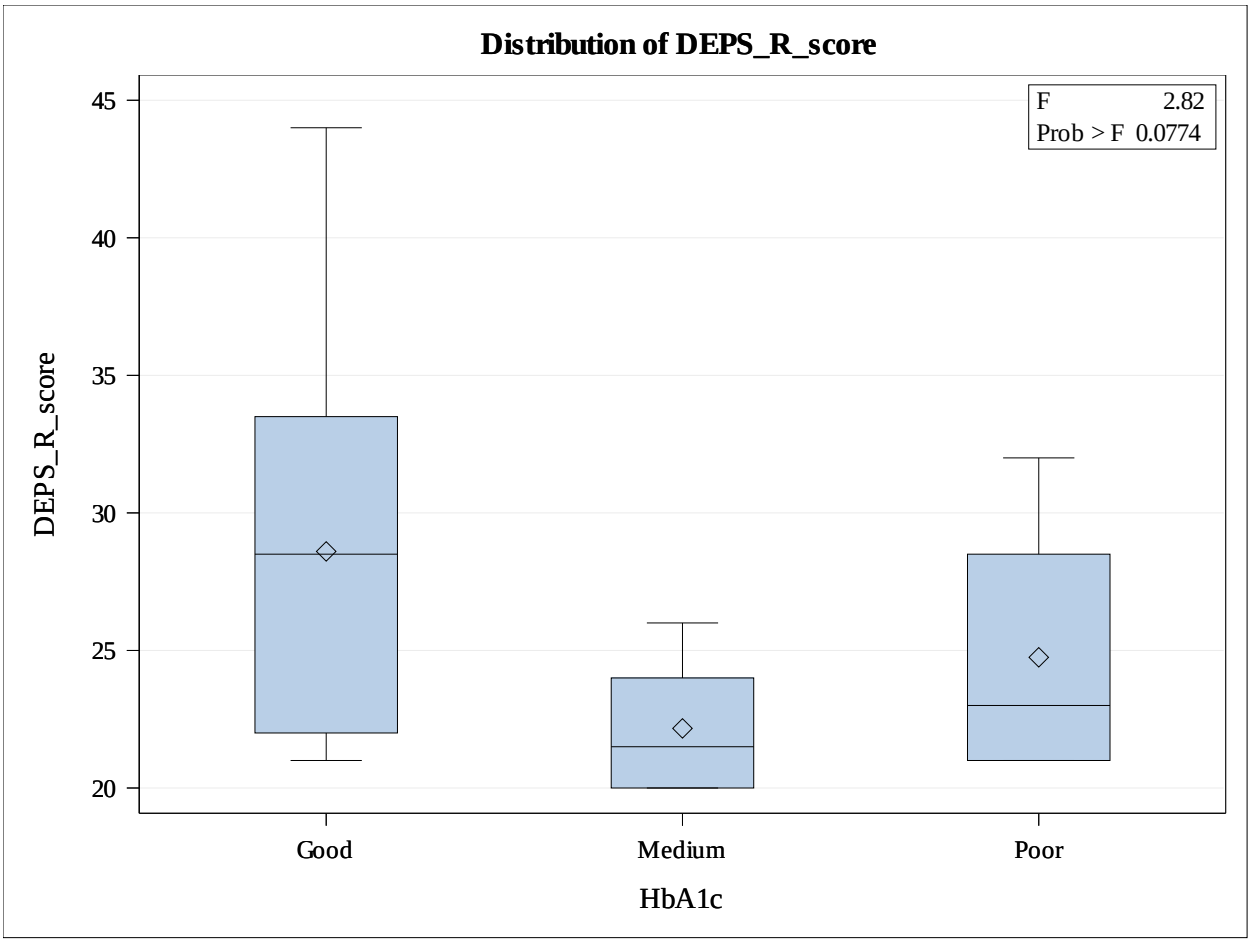

Figure 4.1. Glycemic control and Diabetes Eating Problems Survey-Revised (score ≥ 20)

DEPS-R, age, anxiety, and depression

The middle 20's age group (aged 21-24) (independent variable) had higher DEPS-R risk scores (≥ 20) (dependent variable) than the older 20's age group (aged 25-30) (independent variable) (mean 34.86 ± 9.82 vs. mean 30.51 ± 7.34, p = 0.0174) shown in Figure 4.2. There was no significant association found between age diagnosed, depression, and anxiety (independent variables) and DEPS-R risk score (≥ 20) (dependent variable).

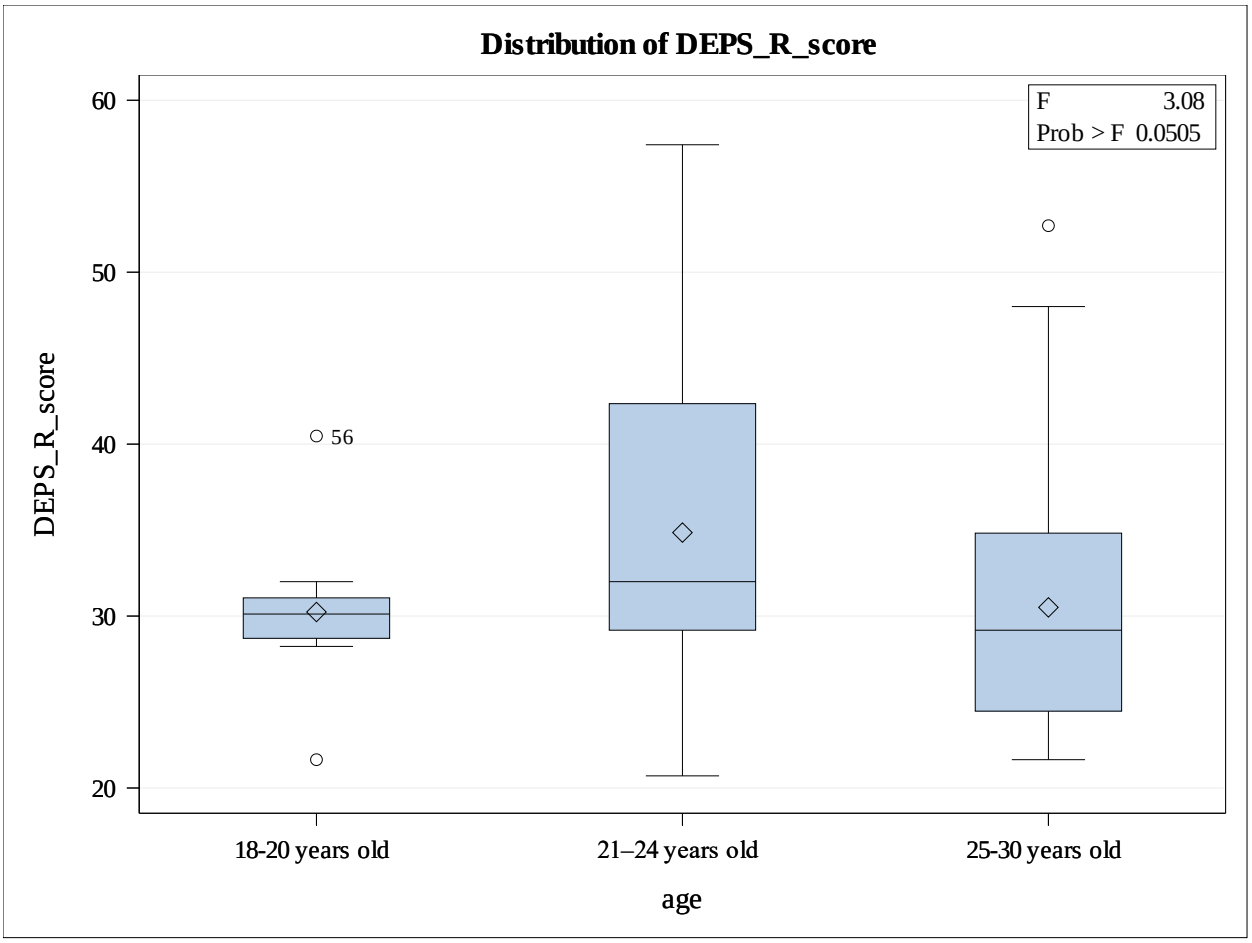

Figure 4.2. Age groups and Diabetes Eating Problems Survey-Revised (risk score > 20)

Comorbidities and glycemic control

There was no significance observed for glycemic control (A1C range) (independent variable) and total number of comorbidities (dependent variable). Glycemic control (A1C range) and average number of total comorbidities were similar among the three levels; 'good' glycemic control (mean comorbidities 1.65), 'medium' glycemic control (mean comorbidities 1.58), and 'poor' glycemic control (mean comorbidities 1.83).

Risky behaviors

Risky behaviors (i.e. excess alcohol consumption, recreational drug use in the past 30 days, lack of sleep or physical activity, or too much sedentary behavior) were self-reported from

emerging adults with T1DM. The recommended amount for physical activity from the American Diabetes Association is at least 150 minutes per week with at least 3 days of moderate to vigorous activity. The behaviors were split into responses and a percentage was calculated for comparison of total participants, shown in Table 4.8.

Table 4.8

Diabetes Management in Young Adults Survey Risky Behaviors

Characteristic	**Category**	**Survey (n=115)**	**Percent**
Alcohol Consumption (days per week)	4 or more days	9	7%
	2 – 3 days	15	13%
	1 – 2 days	42	37%
	0 days	49	43%
Alcohol Consumption (drinks per session)	< 2 drinks	42	37%
	2 drinks	26	23%
	3 or more drinks	13	11%
	I do not drink	34	30%
Recreational drug use (last 30 days)	None	103	90%
	Have used	12	10%
Sleep (hours per night)	> 8 hours	8	7%
	8 hours	40	35%
	7 hours	42	37%
	6 hours or less	25	23%
Physical activity (days per week)	None	9	8%
	1 – 3 days	62	54%
	4 or more days	44	38%
Physical activity (moderate to vigorous per week)	None	10	9%
	1 – 3 days	66	57%
	4 or more days	39	34%

Note: Alcohol higher risk (days per week/drinks per session) = > 2 days, > 2 drinks; Recreational drug use (last 30 days) = have used; Lack of sleep (hours per night) = 6 hours or less; Sedentary risk (physical activity days per week/moderate to vigorous per week) = none.

Alcohol consumption/recreational drug use and diet or insulin adjustment

From the cumulative logistic regression with a stepwise variable selection, there was no significant prediction observed between the dependent variable of glycemic control (A1C range) and the independent variables of all risky behaviors (i.e. alcohol consumption, recreational drug use for the past 30 days, sleep, and physical activity or sedentary behavior), age, age diagnosed, and DSMQ (overall score and the four subscales). Those who consumed more alcohol per week

were more likely to adjust diet or insulin dose to be able to consume alcohol shown in Figure 4.3, (F (1,114) = 9.52, $R^2 = 0.0770, \mathrm{p} = 0.0026$).

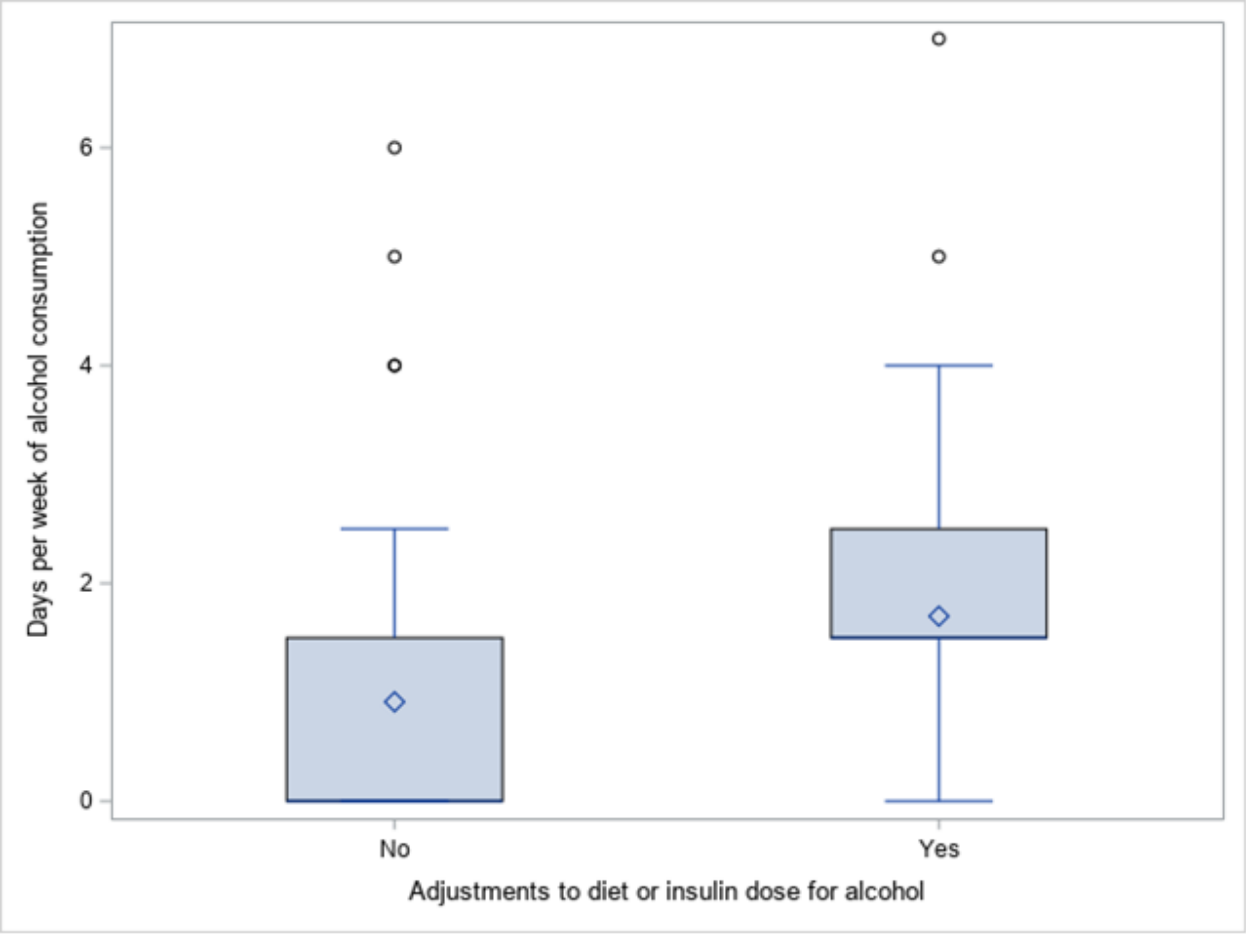

Figure 4.3. Adjustments to diet or insulin dose for alcohol consumption and total days of alcohol consumption per week.

Participants who consumed more alcohol per drink session were more likely to adjust diet or insulin dose to be able to drink alcohol shown in Figure 4.4, (F (1,114) = 5.14, $R^2 = 0.0431, \mathrm{p} = 0.0253$).

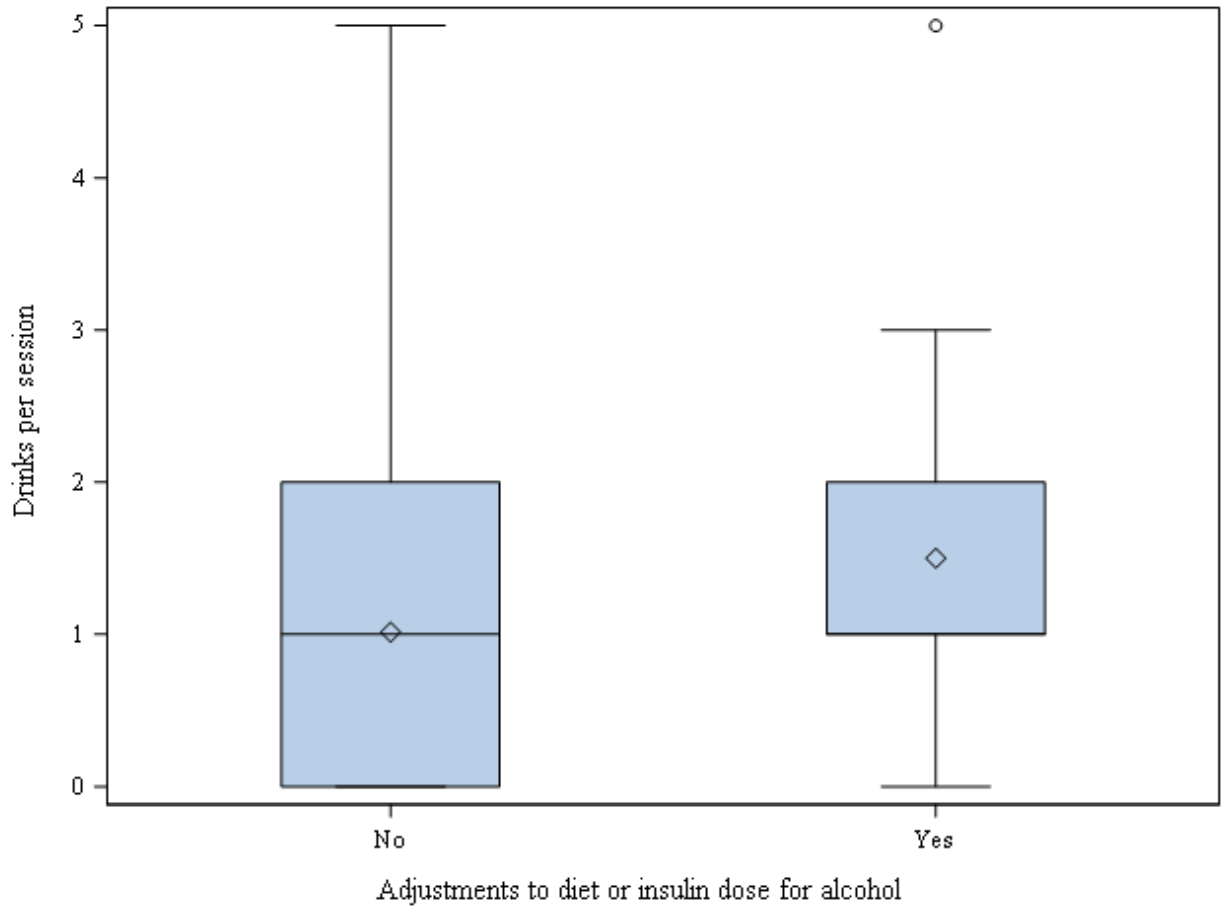

Figure 4.4. Adjustments to diet or insulin dose for alcohol consumption and total days of alcohol consumption per session.

There were a few quotes from those who responded 'yes' in the open-ended option to adjusting diet or insulin for alcohol consumption. One participant stated, "If I drink alcohol, I always eat food with it, but only bolus for half if I'm drinking hard liquor". Another said, "If I'm drinking beer, I bolus as normal, and usually have to take more later in the night".

Physical activity and hypoglycemic risk

Physical activity was selected by over half of the participants (51%) for 'topic to improve management'. There was a negative, weak association observed from the Spearman correlation coefficient (-0.0755; 95% CI -0.2665, 0.1154) for individuals who responded 'yes' to 'Do you

have problems with exercise-related low blood glucose reactions?' and 'good' glycemic control, shown in Figure 4.5.

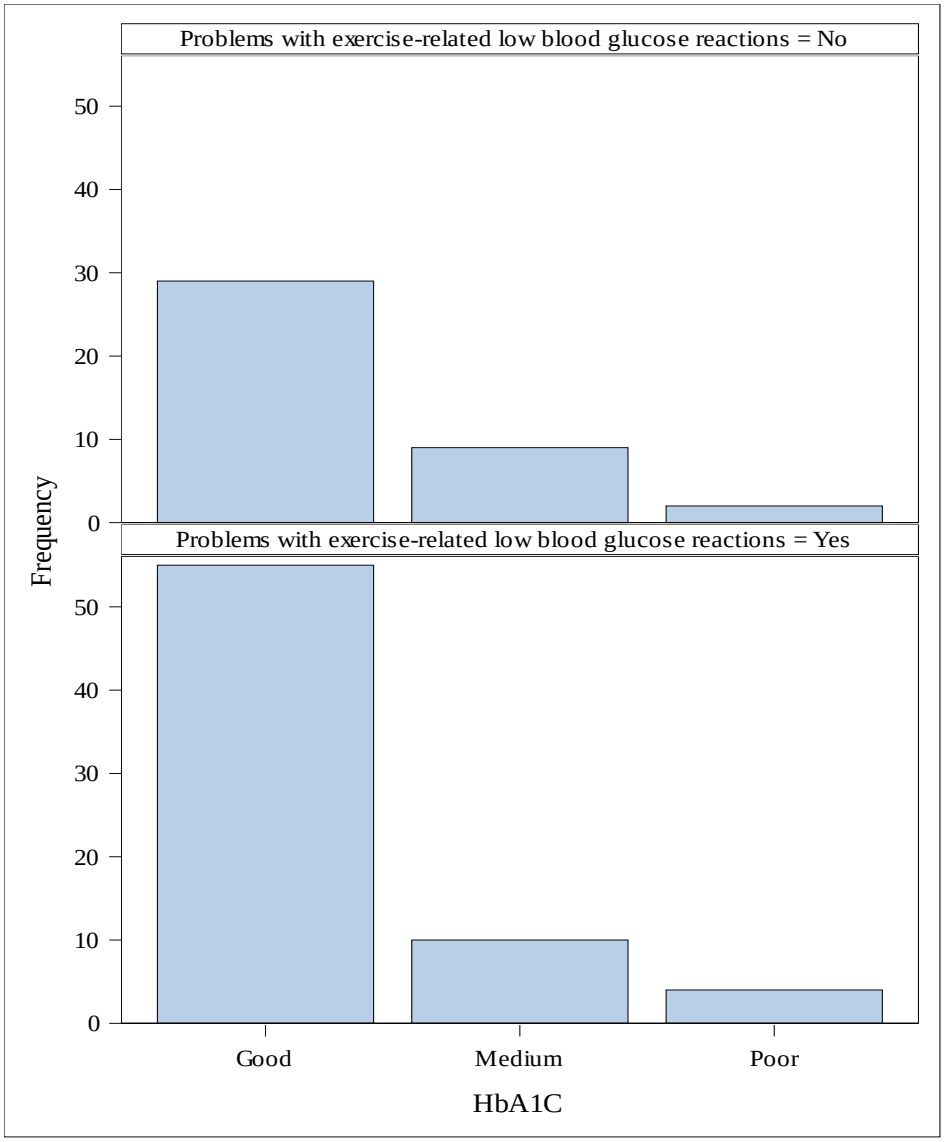

Figure 4.5. Glycemic control and individuals who have problems with low blood glucose reactions during exercise.
Note: A1C; Good = < 7.5% (< 58 mmol/mol), Medium = 7.5 – 8.5% (58 – 69 mmol/mol), Poor = > 8.5% (> 69 mmol/mol); Frequency = number of participants

However, there was no significance between individuals who responded 'yes' or 'no' to 'Do you have problems with exercise-related low blood glucose reactions?' and total days of physical activity or days of higher intensity. There were a few open-ended responses from those

who selected ‘yes’. One participant reported, “During cardio my blood sugar will drop. During weight lifting my blood sugar increases”. Another commented, “I have to consume about 30 carbs before exercising, even when starting with high (160+) sugars. I have to stop exercising when my sugar drops too low. Drinking juice helps bring my sugars back to normal, but I can’t keep exercising because at this point I feel nauseous”.

Over half of the participants (56%) were hospitalized in the last year. When asked the question, ‘What gets in the way of you managing your diabetes?’ a total of 71% participants chose ‘stress’ and 42% of the participants selected ‘emotions’. In addition, 57% of participants selected ‘stress management’ for an ‘educational topic’. A total of 47% of the participants completed the insulin fill-in table. There were comparable participant numbers for the voluntary insulin regimen fill-in table; 23 participants who use the pen (insulin injections) and 28 participants who use the insulin pump; 82% of participants who use a CGM and 16% who use the finger prick method for blood glucose monitoring. When asked ‘How often do you have low blood sugar?’, 45% of the participants selected at least once a day. The range of diabetes diagnosis was between ages 1 to 29 years and the median diagnosed age was 13 years old. A little less than half of the participants (40%) diagnosed under twelve years old responded with the open-ended choice of ‘other’ to ‘How often do you check your blood sugar?’. The most common open-ended response to ‘other’ was the CGM checked blood glucose. Similarly, 50% of participants who were diagnosed thirteen years and older responded with the open response of ‘other’ and the ‘CGM’, ‘Dexcom (brand of CGM)’, or ‘constantly through CGM’ checked blood glucose. Lastly, almost half of the participants (43%) who utilized the CGM had ‘good’ glycemic control.

Conclusions

During the time this research was conducted, this was the only known study to review barriers and strategies of diabetes control related to self-efficacy, self-management, eating disorder/disordered eating risk, and risky behaviors among emerging adults diagnosed with T1DM (18 – 30 years). The average response from the participants show self-efficacy was rated between 'often and usually'. This response was to example questions such as 'In general I believe that I know what part(s) of taking care of my diabetes that I am satisfied with' and 'In general, I believe that I can choose realistic diabetes goals'. However, this study did not find any relationship for a lower DES score, low DES subscale scores and 'poor' glycemic control. The higher measured self-efficacy was previously discovered to be associated with lower glycemic control (Anderson et al., 2000). In addition, lower self-efficacy has been previously correlated to diabetes distress and depression (aged mean 31.5 ± 8.9 years old) with T1DM in Brazil (Silveria et al., 2019). There may have been no relationship between self-efficacy and glycemic control since individuals with T1DM typically are self-critical (Anderson et al., 2000).

The self-management tool identified barriers and strategies to diabetes management for emerging adults. Measured diabetes self-management was associated with 'good' glycemic control. However, prediction of glycemic control was not found for the subscales of dietary control, physical activity, and physician contact. The relationship to the subscale of dietary control and 'good' glycemic control is an interesting finding. This age group may have rated themselves lower in self-management for the dietary control subscale questions since the questions relate to 'over consuming food items'. For example, the two negative dietary questions were 'Occasionally I eat lots of sweets or other foods rich in carbohydrates' and 'Sometimes I have real 'food binges' (not triggered by hypoglycemia)'. The 'good' glycemic group was at a

higher risk for eating disorders/disordered eating risk (DEPS-R ≥ 20). The participants in the 'good' glycemic group may rate themselves at a lower level for dietary control (Luyckx et al., 2019), so the lack of a relationship may be related to typical management difficulties for this age group. In addition, participants may have responded lower to the physical activity subscale as the negative physical activity questions related to the age group difficulties, such as time management. For example, one of the negative physical activity questions from the self-management survey was 'I avoid physical activity, although it would improve my diabetes' and 'I tend to skip planned physical activity'.

Physician contact can be a barrier for emerging adults since change of or lack of insurance impacts medical care, and individuals are dropped from parental/guardian insurance at age 26 (Bowen et al., 2010). Young adults also have a difficult transition from pediatric to adult medical care, termed "medical transition" (Bowen et al., 2010; Findley et al., 2015). In addition, this age group can struggle to create a schedule surrounding recommended dietary habits and daily capabilities for physical activity (American Diabetes Association, 2019e; Bowen et al., 2010). Researchers have previously found 'good' glycemic control and higher DSMQ overall score for middle aged adults (aged 51 ± 16 SD) with T1DM when compared to 'medium' and 'poor' glycemic control (Schmitt et al., 2013). The same study discovered 'good' glycemic control was associated with a higher DSMQ glucose management subscale when compared to 'medium' and 'poor' glycemic control (Schmitt et al., 2013). However, the current study identified a unique prediction for better glycemic control and older aged diagnosed (e.g. age 15 – 20, > 20 versus age < 10 , 10 – 15), higher self-management score, lower self-management dietary control score when compared to in the regression to self-efficacy score and disordered eating/eating disorder score for emerging adults with T1DM. Individuals from all glycemic

groups had similar ratings of self-efficacy, which may be the reason there was no prediction shown for the regression. The median age of diagnosis for this study was 13 years. Individuals who are diagnosed past early onset (0 – 4 years) may have better self-management and improved glycemic control. This study did not find a significance between early onset and depressive symptoms. However, there was a previous study which discovered individuals with early onset diagnosis for T1DM typically have higher depressive symptoms and diabetes distress (Bächle et al., 2015).

Moreover, the current study aimed to identify if a loss of glycemic control leads to increased number of comorbidities. There was not an association between loss of glycemic control and number of comorbidities. This finding is unique since uncontrolled T1DM can increase risk for comorbidities such as CVD, kidney failure, and other autoimmune diseases (Krishnan et al., 2012; Speight et al., 2014; Celik et al., 2015). Regardless of blood glucose control, all individuals with T1DM may be at risk for multiple comorbidities. However, this study only viewed the total number of comorbidities compared to glycemic control. While the survey did distinguish the type of comorbidity, there was no statistical test run for the category of comorbidity with glycemic control. Typically, difficulties with the leading causes of morbidity (i.e. CVD, stroke, etc.) occur later in life (Krishnan et al., 2012; Speight et al., 2014; Celik et al., 2015). Comorbidities related to the leading causes of death typically increase with advanced age (Krishnan et al., 2012; Speight et al., 2014; Celik et al., 2015). Despite this observation, the American Diabetes Association recommends that young adults with T1DM be screened during any medical appointment for comorbidities since T1DM decreases autoimmune support (2019c). Screening and monitoring test results for comorbidities can prevent future complications (American Diabetes Association, 2019c).

The ‘good’ glycemic control group and higher DEPS-R risk score association suggest those individuals with tight regulation of glycemic control may be overly focused on dietary intake and glucose measurements. Tight regulation of blood glucose related to eating disorders/disordered eating can create acute and chronic medical complications. These complications can include acute hypoglycemia and chronic hypoglycemia which can lead to cerebrovascular disease, neurocognitive dysfunction and can possibly be fatal (American Diabetes Association, 2019d). Screening for eating disorders/disordered eating for all emerging adults with T1DM is important as evidenced by this current study’s relationship between glycemic control and DEPS-R score ≥ 20. The DEPS-R has been previously validated, any score ≥ 20 indicated “at risk” for eating disorders/disordered eating (Markowitz et al., 2010). The difference in score of DEPS-R between the lower score for older 20’s (age 25 – 30) and higher score for middle 20’s (age 21 – 24) may suggest individuals who are transitioning into independence are at a greater risk for eating disorder/disordered eating. Life stress can increase during this time by graduating from college, solidifying a first-time job, and/or moving away from the comfort of a supportive university setting, for example (Arnett, 2000). Eating disorder/disordered eating risk screening should be conducted since transition into adulthood creates a greater risk for diabetes complications (Luyckx et al, 2019). A similar study found that the disordered eating screening score had a positive relationship to increased diabetes distress, more depressive symptoms, and increased value of A1C (Moskovich et al., 2019). However, for the current study there was not an association observed between depression, eating disorder/disordered eating risk, anxiety, and glycemic control when compared in a regression with all independent variables.

The current study aimed to assess if risky behavior choices such as: excessive alcohol consumption, sleep deprivation, use of recreational drugs, and inappropriate intake of alcohol in one sitting predicted non-controlled glycemic management. Individuals who drank more alcohol during the week and drank more drinks per session were more likely to adjust medical management or dietary intake. While these participants consumed over the recommended amount of alcohol, these participants are not necessarily consuming alcohol in a reckless manner. If there would have been a positive relationship between 'no' adjustment and consumption per week/drinks per session, then individuals would seem to be ignoring T1DM. Alcohol consumption can affect hypoglycemic response within 12 hours of a drinking session (American Diabetes Association, 2019e). Individuals who drink more times per week and more drinks per session may have to manage insulin and dietary adjustments more precisely than those who consume less. As reported by Bowen et al., during the medical transition age range, there was a higher rate of alcohol consumption, as part of their longitudinal study (2010). Specific educational programming related to risky behaviors are suggested for emerging adults. This age group will most likely participate in risky behaviors so therefore require tools, resources, and training related to these habits (Bowen et al., 2010). The WHO defines 'risk reduction' as "measures designed either to prevent hazards from creating risks or to less the distribution…" (2007). One previous study observed college-aged participants had increased motivation to drink less in high-risk situations if they were in an alcohol 'risk reduction program'. The participants were less likely to report heavy drinking and negative alcohol consequences with program participation (Bock et al., 2016). Behavior 'risk reduction' programs may benefit individuals with T1DM. Lastly, the hospitalization response was similar with previous findings in Minnesota, whereas this age group is more likely to be hospitalized than older individuals with

T1DM due to uncontrolled blood glucose (Minnesota Department of Health, 2018). However, this study did not question specifics for reason of hospitalization.

The relationship between participants who responded ‘yes’ to problems with low blood glucose during exercise and better glycemic control is a unique finding. This negative relationship may suggest tighter regulation of blood glucose may increase risk for physical activity complications for lower blood glucose. Individuals who are more physically active may have increased utilization of glucose in the muscle (Wrobel et al., 2018; Karpinski & Rosenbloom, 2017). A little over one-third of the participants reported completion of over the recommended amount of physical activity per week originally suggested from Colberg et al. (2016). The recommended amount for physical activity from the American Diabetes Association is at least 150 minutes per week with at least 3 days of moderate to vigorous activity. The participants who completed the weekly recommended amount of physical activity had better chronic glycemic control. However, the participants with better chronic glycemic control had difficulties with acute blood glucose regulation during physical activity. The current study did not have an option for participants to select what type of physical activity they partook in throughout the week. There may have been an association between ability to exercise and blood glucose control if participants were asked type of exercise (i.e. strength, cardiovascular and flexibility). In addition, the type of insulin regimen utilized may affect blood glucose response during exercise, such as an insulin pen or pump. In comparison, an insulin pump is a computerized device that is worn 24 hours/7 days a week and connected subcutaneously through a tiny catheter (American Diabetes Association, 2019f). The dose of insulin is absorbed at a faster rate with the pump than through injections (American Diabetes Association, 2019f). Therefore, a medical professional may need to assist in strict regulation of blood glucose for

those individuals with an insulin pump during physical activity (American Diabetes Association, 2019f). In addition, a previous study identified that type of exercise (i.e. strength, cardiovascular, and flexibility) can have an impact on blood glucose fluctuations (Colberg et al., 2015; Leroux et al., 2015).

One of the limitations of the study was the lack of participation diversity of the survey. In addition, all data was self-reported and due to the cross-sectional study design, no causality can be determined. Lastly, the survey was completed during the coronavirus (COVID-19) pandemic. The pandemic local, state, and national regulations could have increased the response of anxiety and/or depression since many individuals were locked-in at home and could not participate in their normal routine. In addition, the pandemic could have decreased the ability for participants to meet with their medical team due to COVID-19 restrictions. A strength of the study was the inclusion criteria only included a requirement of age and diagnosis of T1DM. An additional strength of the study was there were no restrictions to length of T1DM diagnosis.

Type 1 diabetes is a complex autoimmune disease with significant health complications. This disease can be more difficult to manage for the emerging adult age group (18 – 30) due to lifestyle choices. From this study, individuals who rate themselves higher in self-management are more likely to have better glycemic control, speaking to the usefulness of the DSMQ for screening. Future research surrounding compromised self-efficacy and glycemic control, especially with psychosocial aspects to diabetes management is necessary. Higher self-rated self-efficacy may prevent long-term psychosocial issues, such as diabetes distress. On the other hand, those who scored lower for dietary control were in the ‘good’ glycemic control group. This age group is at risk for eating disorder/disordered eating and should be screened yearly. This age group appears to participate in risky behaviors, especially alcohol consumption (per days and

drinks per session) and adjust diet or insulin to be able to drink. Therefore, improved health programming based on a risk reduction model may improve diabetes control for the emerging adult age group. Participants with ‘good’ glycemic control are at a higher risk for low blood glucose during exercise than the ‘medium’ and ‘poor’ glycemic control group. Lastly, participants who partake in regular physical activity according to recommended guidelines both tend to have better control of chronic glycemic control but less control over acute blood glucose during exercise.

Conflicts of interest

There are no conflicts of interest.

Ethics declaration

The host university’s Institutional Review Board for the protection of human participants approved all procedures.

CHAPTER 5. MANUSCRIPT 2 - BARRIERS AND STRATEGIES FOR TYPE 1 DIABETES MANAGEMENT AMONG YOUNG ADULTS: A QUALITATIVE STUDY

Abstract

Purpose: Individuals in the emerging adult age group with type 1 diabetes (T1DM) (aged 18 – 30) have unique medical and social necessities. The purpose of this study was to observe barriers and strategies to diabetes management for emerging adults with T1DM.

Methods: Open-ended interviews (iPhone telephone application, Rev – Call Recorder) from a cross sectional study were utilized to assess barriers and strategies for management of T1DM among emerging adults (aged 18 – 30). The participants were English speaking and from a female and male larger survey volunteer participant group in the May 2020 and were asked to complete the interview (n = 21, female = 19, diagnosed age: mean 15.00 ± 8.00). The data was analyzed for cohesive themes using ground theory.

Results: Interviews indicated three main barrier themes (physiology, environment, and insurance). Three main strategy themes to diabetes management were recognized (medical technology, social support, and physical activity). There were three barrier subthemes (mental health, lack of social support and weather). There were four strategy subthemes (supplies, compliance, social media and accountability). Almost half of the participants (n = 10) were approved through insurance to have both an insulin pump and a continuous glucose monitor. All identified insurance as a barrier and suggested medical technology and physical activity as a strategy to T1D control.

Conclusions: Social support, such as social media support groups and medical technology improve overall diabetes management. However, insurance and environment, for example lack of social support and weather are identified to be barriers to disease self-care.

Keywords: anxiety; environment; physical activity; stress

Introduction

Type 1 diabetes is an autoimmune disease clinically described as the destruction of insulin producing β-cells in the pancreas, which requires complete insulin therapy (American Diabetes Association, 2019b). This disease requires daily blood glucose measurement and precisely dosed insulin injections (American Diabetes Association, 2019b). Blood glucose can be measured through a continuous blood glucose monitor (CGM) or finger prick. Long term glycemic control can be measured through glycated hemoglobin (A1C) (%) (mmol/mol), which gives an indication of average blood glucose levels over the previous three months. In addition, individuals must carefully count dietary carbohydrates in order to properly dose the insulin needed for blood glucose absorption (American Diabetes Association, 2019d). If mismanaged, an individual can decrease glycemic control and increase risk for other medical complications (American Diabetes Association, 2019d). Diabetes management can be hindered by work schedule and social events since management is very strenuous. The long-term complications of poor management may be comorbidities such as cardiovascular disease, stroke and neuropathy. The short-term difficulties can be hyper- or hypoglycemia, diabetic seizure, or diabetic ketoacidosis (American Diabetes Association, 2019d). These acute and chronic conditions may require medical intervention through hospitalization.

An emerging adult as defined by Arnett (2000) is an individual between adolescence and adulthood (18 – 25 years) striving to establish independence. During this period of life, significant decisions arise which include: committing to a lifelong partner, attending a college for a future career and/or moving to a permanent home away from their original family unit (Arnett, 2000). Although “emerging adult” is a well-defined term, including the ages of 25 – 30 in this

definition may add additional insight into the adulthood transition (Bowen et al., 2010; CDC, 2017; Findley et al., 2015). Of paramount importance, at the age of 26, individuals are no longer eligible to remain as a dependent on a parent's or guardian's medical insurance. Thus, they must procure this insurance through an employer, the government, or an individual plan (Bowen et al., 2010; CDC, 2017).

Emerging adults are known to make risky decisions that can affect their future, financial stability, and overall well-being (Arnett, 2000). These individuals are at a higher risk for mismanagement of diabetes (American Diabetes Association, 2019f). The American Diabetes Association has identified emerging adults to be at risk for not meeting target A1C goals (2019f). Emerging adults may struggle with disease management due to financial and/or social hardships (American Diabetes Association, 2019f). Previous researchers have identified that social support can impact glycemic control among young adults. In addition, qualitative studies have suggested how social support can affect diabetes management (Serlachius et al., 2012; Trief et al., 2013; Bächle et al., 2015). Individuals whom feel socially support from family, medical professionals, and friends/significant others have improved self-care (Serlachius et al., 2012; Trief et al., 2013; Bächle et al., 2015). This age group is at a high risk for clinical depression and diabetes distress can add to depression symptoms (Stahl-Pehe et al., 2014; CDC, 2017; Roy & Lloyd, 2012). Diabetes supplies are expensive and may be difficult to afford even with a full-time job (Litchman et al., 2017; Bowen et al., 2010). Young adults with T1DM have extensive difficulties related to diabetes management. Observing barriers and strategies to management may provide insight for future implications to overall improved self-care for individuals with T1DM.

Research Design

Aim

The goal of this study was to identify barriers and strategies to diabetes management as informed by the lived experiences of emerging adults with T1DM. A non-experimental causal-comparative observational design using a qualitative approach was utilized to assess barriers and strategies to management of T1DM among emerging adults (aged 18 – 30). An open-ended approach to qualitative data with a telephone interview was designed to allow a deeper understanding of the T1DM experience among emerging adults. Application and approval to the Institutional Review Board of North Dakota State University, Fargo, ND was completed before recruitment, approval #HE20244.

Participants

During May 2020, emerging adults with T1DM (aged 18-30) were recruited through targeted messaging using both a convenience sample and word-of-mouth. An electronic questionnaire via email, university listserv, and social media portals (e.g. Facebook and Instagram) was utilized for recruitment. The questionnaire included a scripted message, including informed consent, to recruit participants. After completing the survey regarding T1DM (reported elsewhere), interested participants received a second email and informed consent to be contacted for a telephone interview. The sample participants had no relationship to the researcher prior to the beginning of the study.

Methodology

Data Collection

The researcher wrote the telephone interview questions with approval of the research team, including three registered dietitian/PhDs. The interview questions were pilot tested with

two non-study participants chosen from those who completed the diabetes related survey. A dietetic student who had a non-T1DM chronic disease and another individual with T1DM who was outside of the study age group participated in pilot testing. For the pilot, an iPhone telephone application (Rev – Call Recorder, San Francisco, CA) was utilized to record the interview. The testing interviews took ~ 45 minutes on average. Based on pilot testing feedback the following changes were made: each question was read once with a long pause to wait for a response; and the terms 'diabetes self-efficacy' and 'compliance' were revised to 'diabetes management' and 'habits'.

Participants were contacted via email to schedule a time for the telephone interview. During the scheduled time, the RA contacted the participant using the Rev – Call Recorder. The interview lengths on average were similar to the pilot interviews (~ 45 minutes each). Telephone interviews were conducted using a semi-structured format with scripted questions. However, the research assistant conducting the interviews, could add prompts she felt were needed based on her expertise in T1DM.

All identifiable information was kept strictly confidential between the members of the research team. Each participant was assigned a unique identifier for the phone interviews. The participants who volunteered for the telephone interview had email/contact information retained until after the telephone interview data was analyzed. After the data was analyzed, any links to names/contact information were destroyed. Field notes were data processed by the RA during the telephone interview and saved by participant number to guide the data analysis.

Data analysis

Telephone interviews were audio recorded, transcribed, and analyzed for themes and patterns by the RA using grounded theory, an inductive approach (Brown, 2011). Recorded

interviews were transcribed twice. The first transcription included a word-by-word approach to capture exactly what participants stated. The second transcription was completed to check for missed words and assure completeness. The next step was thematic analysis via open coding. This process included writing out notes and headings from the recordings. These notes and heading were grouped in various subcategories. Subcategories with similar content were grouped into two or more main categories using methods similar previous qualitative research (Elo & Kyngäs, 2008).

Results

Ninety percent (90%) of the participants completing phone interviews were female (n=21) and had been diagnosed at 25.85 ± 3.20 years of age which was older than the diagnosis age for those participating only in the survey (15.00 ± 8.00).

Figure 5.1 lists the main themes and subthemes for barriers and strategies in managing diabetes. Three themes, one contained two subthemes, were identified for barriers and three themes, two of which included two subthemes, were identified for strategies.

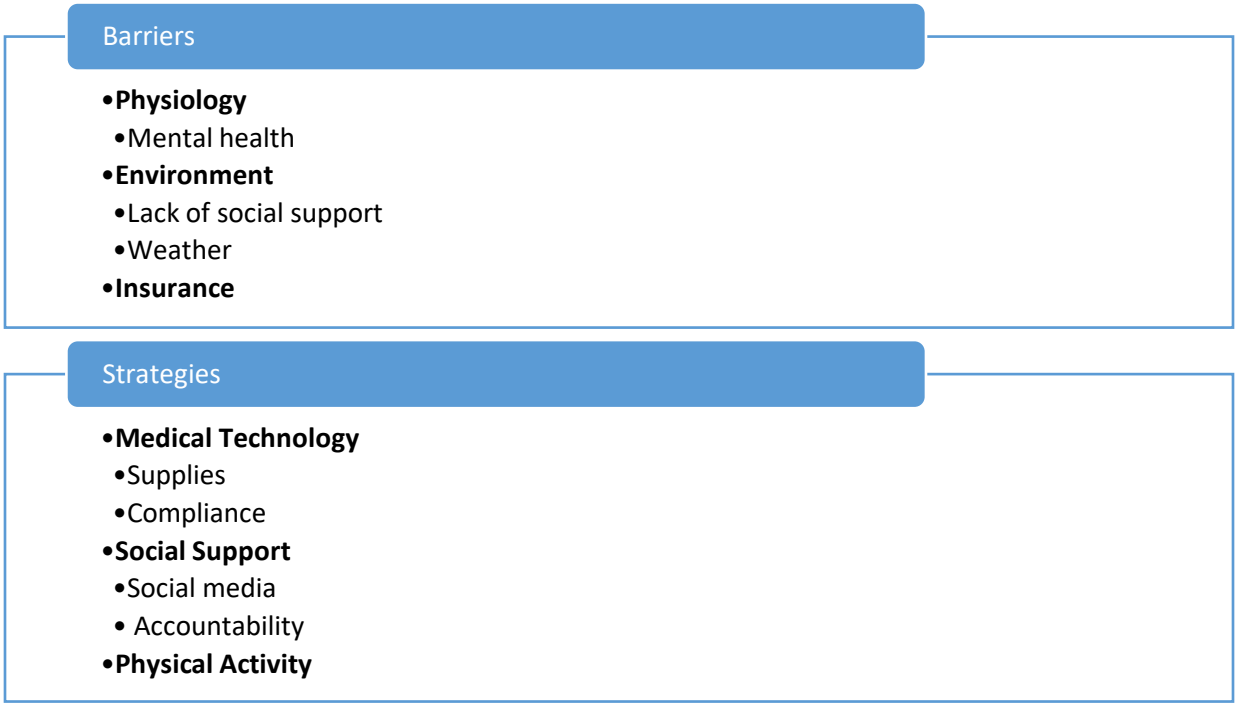

Figure 5.1. Identified barriers and strategies to diabetes management from telephone interview.

Barrier themes

There were three main barrier themes: physiology, environment, and insurance. Additionally, physiology and environment subthemes: mental health for physiology; and lack of social support and weather for environment.

Physiology

Physiology, an aspect of biology that pertains to the normal function of the body, was a challenge for young adults with diabetes. All indicated challenges with managing alterations in metabolism. The time of day influenced metabolism, as evidenced by many participants habitually waking up with upward trending blood glucose. Hyperglycemia in the morning is common for some individuals with T1DM, which may influence work schedule, morning routine, and meal consumption (Desjardins et al., 2014). High blood glucose in the morning may also affect responsibilities, such as parenting, work, and school class schedules. There is

typically no medical reason for morning hyperglycemia, but a trend some individuals encounter (Desjardins et al., 2014). Waking up with high blood glucose meant participants would choose to consume a later mid-morning breakfast until blood glucose normalized. Adjusting insulin dosage based on blood glucose values may be a challenge to manage because of frequent metabolic shifts. Several participants described this experience by stating the following:

> "I could eat the same food, the same time, with the same insulin units, and my blood glucose readings could still be an extreme difference", 26-year-old female, diagnosed 16 months old.
>
> "Taking medication and counting carbohydrates is an easy part, but the management of blood glucose is much more than that", 22-year-old female, diagnosed 20 years old.
>
> "I wish someone could observe what was happening in my body and fix the problem before it started", 28-year-old female, diagnosed at 13 years old.
>
> "Since I have not been approved (for continuous blood glucose monitoring by medical insurance), I have a really hard time sleeping. I am very fearful of going too low and having no one at home to notice", 22-year-old female, diagnosed 20 years old.
>
> "I wish my wife understood diabetes better. There are days where my blood glucose is really high for no reason and I can't get it to come down with insulin. She doesn't understand why I am so upset and moody", 24-year-old male, diagnosed 19 years old.
>
> "Spring and summer can be tricky, like going to the beach or the pool and trying to figure out where to put my pump", 30-year-old female, diagnosed at 18 years old.

Participants suggested daily living seemed to be demanding because each minute could be different. Try to predict how the body would respond was difficult and created a sense of

anxiety. Many participants suggested the daily variation was the most challenging aspect of diabetes management.

Mental health

Mental health is a unique aspect of physiology. Mental health can affect stress hormone response in the body, which may induce difficulties for insulin dosing, blood glucose levels and increase A1C ((Bächle et al., 2015; Stahl-Pehe et al., 2014). This subtheme was observed as a barrier to diabetes management. The inability to self-motivate and mental burnout were hindrances to diabetes management. Several participants shared examples:

> "I know what I am supposed to do, but this doesn't always mean I have the motivation to actually do it", 27-year-old female, diagnosed 6 years old.
>
> "The worst part of the pandemic is I always used time and a busy schedule as an excuse to management, but now since I am home and have plenty of time, the problem is me and not time", 27-year-old female, diagnosed 2 years old.
>
> "Burnout is a major issue in diabetes management and known in the community. It is the exhaustion of having to do everything perfect all the time to be healthy that you finally just say, 'I don't care anymore", 30-year-old female, diagnosed 10 years old.
>
> "Sugars can get in the way of life. A very frustrating part is the ups and downs of blood sugars, the rollercoaster can make things very difficult", 30-year-old female, diagnosed age 18 years old.

There were participants that did seek regular sessions with a professional counselor whose expertise was chronic diseases. A large portion of the participants explained they had struggled with various forms of depression in the past.

Negative emotion is a branch of mental health and may increase the physiological response of stress hormones and alter T1DM lab values. Participants who consistently have

negative emotion are at a higher risk for disordered eating/eating disorders and decreased ability for diabetes self-management (Moskovich et al., 2019). Emotional health is reaction and 'feeling' to a life circumstance (Nikolaidis 2013). Continual difficulty with negative emotion and emotional health can lead to depressive symtoms and eventually depression (Stahl-Pehe et al., 2014). The negative 'feeling' about disease control, blood glucose readings, insulin dosing, and physical activity was observed to decrease motivation for many participants. The word 'guilt' was used numerous times to explain how participants 'felt', explaining they knew exactly how to better manage their diabetes but did not have the drive or energy to feel inspired. Others described their experiences with emotions with the following quotes:

> "I typically feel guilty, especially now quarantined, that I don't want to tighten my diabetes control", 28-year-old female, diagnosed 19 years old.
>
> "While medical technology helps with control, there is also a feeling of 'I'm not good enough', because you can see on a graph how my blood glucose control could be tighter", 30-year-old female, diagnosed 15 years old.

Environment

Environment was referenced for time, place, and outside temperature as an obstacle for diabetes control. There were two subthemes included with this barrier: lack of social support and weather. Adapting to a new environment with T1DM appeared to be a challenge for many individuals.

Lack of social support

Lack of social support suggest a participant living alone, with family/guardian, or partner affected how they personally managed diabetes. The subtheme, lack of social support, was identified as a factor that created a barrier to diabetes management. Absence of social support removed accountability and created stress for participants which impacted management.

Participants who lived alone relied heavily on technology for blood glucose monitoring in daily activities, even sleeping at night. Participants who lived with a partner explained that they were supported but identified self-isolation as an issue. Others explained that living with their family into adulthood was not a personal concern but felt the parent/guardian was supportive and offered a shoulder to lean on during difficult times, such as examples listed here:

> "Dosing changes a lot throughout the year for me. I eat differently when I am at home versus when I am at college. I am also more active in the summer so that changes dosing. Even though I have had my pump for a year, when my schedule changes I have to readjust dosing and food intake", 21-year-old female, diagnosed 10 years old.
>
> "When I lived with roommates I was able to voice my day with diabetes, now living alone I really don't have anyone to tell. Sometimes it's just nice to have someone to be around and talk about diabetes with", 25-year-old female, diagnosed 12 years old.

Living with people who supported diabetes management seemed to improve blood glucose management. While on the other hand, participants that experienced loneliness or isolation struggled with daily management when living alone.

Weather

An interesting barrier was weather, specifically temperature or season of the year. Participants explained that season of the year affected control by increasing difficulty for physical activity or daily walks. Temperature is perceived and observed by participants who have signs (like altered blood glucose levels) and symptoms of changing blood sugar. Participants identified seasonal changes that impacted daily living with T1DM in the examples listed here:

> "Summer is a tough season. The heat really changes my sugars. They will shoot up really high for no reason in the heat but then when I come inside they will drop fast", 28-year-old female, diagnosed 18 years old.

> "I think winter is a hard time of year. Not only are you around holiday events with lots of food, but since I live in the upper East coast, it's too cold to be physically active outside", 28-year-old female, diagnosed 18 months old.

The participants explained the high outside temperature increases blood glucose naturally but then once indoors blood glucose would typically drop.

Insurance

Health care insurance was an identified barrier, specifically regarding coverage for supplies and appointments. Participants explained family/individual insurance may or may not cover medical supplies such as insulin, a CGM or even primary care appointments with the medical team. All participants stated at some point during diagnosis, insurance would either improve or decrease ability to management diabetes. The participants expressed annoyance and dread when discussing insurance as a barrier to T1DM control. Examples are included here:

> "I feel like if I could get a Dexcom (continuous blood glucose monitor) a lot of my stress would decrease and I would be much more controlled", 21-year-old female, diagnosed 20 years old.
>
> "If you don't know how to talk to insurance companies, it can be really tough to get approved for what you actually need", 27-year-old female, diagnosed 6 years old.
>
> "At some point, even for those who have had diabetes for a long time, you are going to run into issues with insurance. It's just insane to me, it's not my fault I have an autoimmune disease that I need medication to survive everyday", 30-year-old female, diagnosed 15 years old.

> "A struggle for me is taking insulin and making sure I take my blood sugar. I don't have insurance right now, so I can't afford all the fun stuff like the pump and CGM, so we are going with what we got", 21-year-old female, diagnosed age 15 years old.

One participant, a dual Canadian and American citizen, indicated that living in Canada with diabetes is much easier due to the availability of medical services. The participant explained health care in Canada is designed so individuals who have an autoimmune disease, such as T1DM, can meet with their medical team more frequently. For example, CGM's are more accessible for personal use, and insulin is more affordable.

Strategy themes

There were three main strategy themes which influenced overall diabetes health. These three themes comprised medical technology, including two subthemes of supplies and compliance, social support, including two themes of social media and accountability, and physical activity.

Medical technology

The advancement of technology for items such as the CGM allowed participants to have better 'real' time control of diabetes. Almost half of the participants (n = 10) were approved through insurance to have both an insulin pump and a CGM. These two devices can record blood glucose, and register insulin dosing throughout the day automatically. Participants who were diagnosed with diabetes at an earlier age explained that the progression in medical technology helped decrease anxiety and fear of the future.

> "My diabetes did not like the pump. I could never get the insulin settings correct, especially for physical activity. Switching to the pen (insulin injections) created a lot more freedom and I can still connect to my Dexcom that tracks everything really well.

> The best part about the pen or pump is it will tell you how much insulin you still have in your blood stream so you don't over dose", 21-year-old female, diagnosed 12 years old.
>
> "The Dexcom continues to improve. The more research is done the more accurate the readings are. I still use the finger prick morning and night, but I am confident in what my Dexcom says", 26-year-old female, diagnosed 13 years old.

Many participants suggested technology improved management by observing trends in blood glucose and automatic, responsive insulin dosing. In addition, a few participants switched from an insulin pump to insulin injections explaining the change created a sense of freedom. Participants predicted that as technology increased in reliability, then management of their T1DM would be successful or at least less stressful.

Supplies

Type of supplies, such as the CGM, insulin pen, or insulin pump were strategies to diabetes management improvement. The participants who had access to these supplies explained that ability to manage the disease improved for both laboratory measures of management and feeling of personal achievement. Understanding how to use these items correctly was a strategy for improved management as well. Once approved through either a medical professional or insurance, participants would receive training on the tools from a diabetes care and education specialist or endocrinologist.

> "The easiest part about diabetes for me is using all my supplies, I know how to insulin dose, count carbs, and read my blood glucose monitor well", 24-year-old female, diagnosed 18 years old.

Compliance

Compliance or following directions in a recommended manner, was coded as a strategy for successful diabetes management. Participants described the best way to improve T1DM

health was to take insulin, calculate dietary carbohydrate intake, and record and interpret blood glucose trends. Some of the participants who had diabetes for a longer duration were not expressively different in medical management responses.

> "Even if you have not had diabetes very long, the teaching for diabetes (insulin, pump, monitor etc.), is pretty simplistic", 24-year-old female, diagnosed 18 years old.
>
> "I love my sweets, I love my candy so making sure I am checking my blood sugar and dosing correctly helps me still enjoy those foods", 21-year-old female, diagnosed 15 years old.
>
> "The training for carbohydrate counting and insulin dosing were and still are the easiest part of diabetes" 21-year-old female, diagnosed age 10 years old.

Social support

Social support was identified as a strategy for diabetes health. Participants who had support from family or healthcare providers reported overall better management.

> "My pediatric diabetes care and education specialist became a family friend; I always felt welcome like she understood what I was going through. She was available for quick check-ups if my endocrinologist was busy", 27-year-old female, diagnosed 6 years old.
>
> "Both my parents have always been really supportive of my diabetes. I still feel like even in adulthood they help. I had a lot of independence with my diabetes at around 8th grade, taking my own shots and dosing insulin myself. But my mom still went with me to appointments to make sure she knew what was going on", 26-year-old female, diagnosed 13 years old.

Many participants explained their peers who also had T1DM understood the daily challenges of diabetes on a deeper level, creating a sense of comradery, instead of the scientific theory, which came from the medical professional.

Social media

Social media (i.e. Twitter, Instagram, Facebook, and Snapchat) was selected as a strategy for improved management. All participants discussed 'Instagram icons' or admired professional athletes, who have T1DM, as role models for management support and motivation. Quick access to a community for T1DM seemed to improve motivation and outlook, and decrease anxiety for participants who felt alone:

> "This is really silly but I look up to Nick Jonas. He is very outspoken about his diabetes. When I see him able to perform and tour, I say to myself *'If he can do all these things, so can I'*", 24-year-old female, diagnosed 18 years old.
>
> "I was going through a really tough time with burnout. I was able to find the Diabetic Therapist (Instagram account). She had an online therapy training that was 6 weeks. I've never met her in person but I was able to work through a lot of struggles online and be trained to handle obstacles", 27-year-old female, diagnosed 16 years old.
>
> "I used to be part of an online chat group through diabetes camps that was connected through email. You could log in and respond to other people through the chat group. Once that closed I joined a bunch of Facebook groups to reconnect with others", 21-year-old female, diagnosed age 10 years old.
>
> "When I first got diagnosed I started following diabetes hashtags (on Instagram) then I just started following accounts that were cool. I have reached out to a few accounts and found support or ideas", 30-year-old female, diagnosed 22 years old.

> "Pregnancy and diabetes is scary. The Facebook group of moms with diabetes has been really supportive", 26-year-old female, diagnosed 24 years old.

Many participants discussed Facebook groups for daily management skills or topics. Participants explained they would direct message Instagram accounts for support. Many participants developed personal relationships with others whom they had never met in person. A new social media application, Snapchat, was supportive for many individuals. Participants sent videos or pictures about daily management. One participant, quoted above, stated Nick Jonas was a role model for diabetes. Nick Jonas is a 24-year-old singer, songwriter, producer, and actor with T1DM (diagnosed at 13 years old) (Medline Plus, 2017). According to a medical magazine article, Nick shares similar T1DM experiences with the participants in this study. These experiences include "being independent, but wanting familial support" and "being frustrated with the unpredictable day-to-day changes" (Medline Plus, 2017).

Accountability

Accountability, or a sense of responsibility, was identified as a strategy for diabetes control. While participants each explained independence in diabetes care, external support provided confidence. Study participants who could identify a person in their life, who asked about topics such as blood glucose levels, insulin injections, physical activity, weight management, medical appointments, etc., stated they had better overall health outcomes. Accountability partners included romantic partners, social media friends, family members or medical professionals.

> "My parents keep me accountable, especially my mom. She tracks my blood sugars from my Dexcom on her phone and checks in with me throughout the day", 26-year-old female, diagnosed 13 years old.

> "My friends from diabetes camp are really supportive. We check in with each other on our group Snapchat and compare Dexcom graphs. It really helps when you are having a rough day and don't feel motivated", 21-year-old female, diagnosed 10 years old.
>
> "My husband is my mentor. He will always encourage me to go on a walk with him when he knows I am high. Especially since we have been working together for two years for me to be super controlled and get pregnant, he knows how important it means to me", 25-year-old female, diagnosed 1 year old.
>
> "One of my friends was diagnosed a year before I was in high school became my role model and we would ask each other during the day or between classes how insulin and blood sugars were going", 21-year-old female, diagnosed at 15 years old.

Physical activity

Physical activity was identified as a strategy to diabetes management. All participants discussed how leisure, moderate, and vigorous physical activity improved blood glucose levels. There was not a guided question on type or level of physical activity during the telephone interview, however participants chose to describe the level and type of physical activity on their own. Participants daily routine included scheduled physical activity (based on blood glucose) such as a run or resistance training and late afternoon/evening walks. Participants were able to use less insulin, noticed benefits for A1C, and expressed feeling better overall if they chose to be physically active during the day. All participants discussed that both a morning and evening walk improved normal fluctuations in blood glucose levels. However, physical activity also increased awareness or concern for blood glucose fluctuations.

> "Physical activity is the best way to control my sugars. It makes me feel better, even if it's just a 10-minute walk", 30-year-old female, diagnosed 10 years old.

> "I tend to plan my school and work schedule around exercise. I really like running and know that will keep my blood sugar under control. When my hemoglobin A1C hit under 6 that was a big goal for me and I know exercise really helped", 23-year-old female, diagnosed 13 years old.
>
> "I really wanted to get fit, even with diabetes. Since I was diagnosed going into sophomore year (as a college basketball player) I just kinda let things go and ate what I want. Now I have physical goals (for weight lifting) and how I want to be in shape, knowing that it will help my diabetes control too", 28-year-old male, diagnosed 19 years old.
>
> "From since I was diagnosed, I had the mindset that things would be different but I wasn't going to let diabetes stop me from doing the things I love, like being physically active and traveling", 30-year-old female, diagnosed 18 years old.

Physical activity was a part of the daily schedule or utilized to bring a high blood glucose down without taking insulin. Being active and exercising seemed to improve overall mental health and well-being for participants.

Conclusions

Successes and difficulties for T1DM management for emerging adults were observed through qualitative measures with a telephone interview. A unique finding of this study was that participants identified environment as a barrier to diabetes management. Environment included lack of social support and weather. Unlike their peers, emerging adults with T1DM have to be aware of external temperature and be selective with who they access social support from. In comparison, social support was noted to improve diabetes management. Other research supports the importance of social support. In another study, participants from this age group (18 – 30

years) indicated that community integration plays a crucial role in diabetes management (Serlachius et al., 2012). Researchers from a parallel qualitative study reported social support influenced blood glucose control (Trief et al., 2013). Another study demonstrated that men were more likely to live at home with a primary care giver/parent and have lower A1C values (< 7.5%)(< 58 mmol/mol) (Bächle et al., 2015). However, this current study had a limited number of male participants (n = 2).

Inadequate blood glucose control can result from underlying depressive symptoms, such as diabetes distress (Bächle et al., 2015). Depression and anxiety are two of the most commonly reported mental health issues among those with T1DM and emerging adults (Stahl-Pehe et al., 2014). Emerging adults are more likely to be hospitalized with depression concerns (CDC, 2017). Adults with T1DM are four times more likely to have prevalence of depressive symptoms than their healthy peers (Roy & Lloyd, 2012). Researchers have previously found T1DM may create increased mental health distress compared to healthy controls (Stahl-Pehe et al., 2014). Though this current study did not compare depression, anxiety, and mental health among participants with and without T1DM, participants with T1DM experienced management barriers related to mental health concerns. This may have been related to diabetes distress and anxiety.

Similar to the telephone interview participants in this study, a previous qualitative study discovered CGM was effective in preventing hypoglycemia but insurance was a barrier to obtaining the needed equipment (Litchman et al., 2017). In one U.S. state, the average cost to an individual for one day of insulin is $15 or almost $6000 per year (North Dakota Public Diabetes Report, 2014). This does not include the costs incurred for proper insulin storage (insulin must be refrigerated). Emerging adults lose parental or guardian healthcare insurance at the age of 26. They may qualify for Medicaid with T1DM as a disability. However, earned income must fall

below a certain threshold to qualify. For example, an individual in North Dakota with income above $17,609 or above $16,970 in Minnesota are not eligible for this vital assistance.

In the United States, individuals over age 26 may apply for individual health insurance through HealthCare.gov during 'Open Enrollment'. However, the coverage for an individual with T1DM may be costly and only cover emergency medical services, such as diabetic ketoacidosis. This coverage may or may not cover preventative items such as insulin or any glucose monitoring system (finger prick or CGM). The monthly premium may not cover deductibles for primary care appointments or specialty appointments, such as a certified diabetes care and education specialist or registered dietitian. If the individual misses the deadline to apply during 'Open Enrollment', then specific criteria must be met for eligibility for this health insurance. The 'Special Enrollment' period allows individuals to apply for health coverage if the following criteria are met: lost health coverage within 60 days, birth, marriage, death in immediate family, gained a dependent, change in income, had a change in residence, denied Medicaid, gained citizenship, or released from incarceration. Lack of health coverage can hinder insulin usage since the cost of insulin continues to rise (CDC, 2017). In addition, the transition period for young adults from pediatric to adult medical care can be stunted if lack of insurance coverage for appointments is a barrier (Bowen et al., 2010). Additionally, the longer the transition occurs the more likely A1C will climb to unhealthy levels (Findley et al., 2015). There are government bills waiting approval in the U.S. legislature aimed at altering insulin cost for emergency coverage. Emergency coverage is intended for periods when an individual has lost employment or is transitioning between insurance companies. One example is the Minnesota assistance program (Baumgarten, 2019).

One of the limitations of this study was the lack of participation diversity of the interview. The telephone interview was completed during the coronavirus (COVID-19) pandemic. The local, state, and national pandemic regulations could have increased level of participant anxiety and/or depression since due to isolation and disruptions in normal routine. In addition, the pandemic could have decreased the ability for participants to meet with their medical team due to COVID-19 restrictions. A strength of the study was the inclusion criteria for the survey and the interview only included a requirement of age, English speaking, and diagnosis of T1DM. An additional strength of the study was there were no restrictions to length of T1DM diagnosis. Not limiting the time of diagnosis may have allowed for a variety of responses and participants who were well versed in living with diabetes.

Emerging adults with T1DM have significant daily management challenges in avoiding intensive medical interventions. To circumvent dangerous disease management complications, this study identified three main strategies to improve self-care, including medical technology, social support and physical activity. However, there were barriers also identified that hinder management. Future educational programming for this age group with T1DM may include areas for peer social support. In addition, diabetes management training for family, relations and an increase is resources for mental health would be beneficial to diabetes control. Future research designed to compare sex and age groups among emerging adult comparisons coping with T1DM may be necessary to improve glycemic control and assess social support. Lastly, public policy targeting affordable insurance that significantly improves access to insulin and other diabetes management supplies and professionals will benefit diabetes management for this age group.

Conflicts of interest

There are no conflicts of interest.

Ethics declaration

The host university's Institutional Review Board for the protection of human participants approved all procedures.

CHAPTER 6. CONCLUSIONS

Type 1 diabetes is a complex autoimmune disease with significant health complications. This disease can be more difficult to manage for the emerging adult age group (18 – 30) due to lifestyle choices. From this study, participants who rate themselves higher in self-management are more likely to have 'good' glycemic control. However, regardless of glycemic control, this age group is at risk for eating disorder/disordered eating and should be screened yearly. Participants with 'good' glycemic control were at higher risk for low blood glucose during physical activity. This age group appears to participate in risky behaviors, especially alcohol consumption (per days and drinks per session) and adjustment with diet or insulin for consumption of alcohol. Therefore, improved health programming designed based on a risk reduction model may improve diabetes control for the emerging adult age group. In addition, to circumvent mismanagement choices, this study has identified three main strategies to improve self-care. The tactics to diabetes management participants suggested included social support, medical technology and physical activity. However, there were barriers implied to affect management. The obstacles participants identified included physiology, environment and insurance. Future implications for this age group with T1DM may include programming that will relate to daily life as an emerging adult.

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APPENDIX A. EMAIL GREETING/ ASSUMED INFORMED CONSENT FOR DIABETES MANAGEMENT IN YOUNG ADULTS SURVEY

North Dakota State University (NDSU)
Department of Health, Nutrition, and Exercise Sciences
E. Morrow Lebedeff Hall 316H: NDSU Dept. 2620
PO Box 6050
Fargo, ND 58108-6050

Barriers and strategies to diabetes management in young adults with type 1 diabetes.

My name is Bailee Sawyer, RD, LRD. I am a doctoral student in the Department of Health, Nutrition, and Exercise Sciences at North Dakota State University and I am also an experienced licensed, registered dietitian. I am conducting a research project which includes a *survey* to assess successes and barriers to diabetes management among young adults with type 1 diabetes. It is our hope, that with this research, we will learn more about a glimpse in the daily life for an individual aged 18 to 30 years who is diagnosed with type 1 diabetes. Your participation is entirely your choice, and you may change your mind or quit participating at any time, with no penalty to you.

By taking part in this survey, you may benefit by studying your own self-management and confidence for managing your type 1 diabetes by reading and answering the various questions that are part of the study. Also, the survey in itself may intrigue you to learn more about this topic. However, you may not get any individual benefit from being in this study. Benefits to others and/or in the unique community among young adults with type 1 diabetes are likely to include advancement of knowledge in this area of research.

It should take about 25-30 minutes to complete the questions about successes and barriers to management of type 1 diabetes. We will keep private all research records that identify you. Your information will be combined with information from other people taking part in the study. We will write about the combined information that we have gathered. You will not be identified in these written materials. We may publish the results of the study; however, we will keep your name and other identifying information private. After the completion of the survey, the *first 100 respondents* will have the opportunity to provide their e-mail addresses for a chance to win one **$200** Amazon.com gift card. The e-mail addresses provided will not be connected to the survey question answers. Additionally, after survey completion, you may sign up to participate in an *optional telephone survey* to help explain what it is like living with type 1 diabetes.

If you have any questions about this project, please contact me, Bailee Sawyer, RD, LRD, at (325)374-6185 or bailee.sawyer@ndsu.edu , or contact my faculty advisor, Dr. Sherri Stastny, PhD, RD, CSSD, LRD, Professor in Health, Nutrition, and Exercise Sciences at (701) 238-0633 (cell phone during study) or sherri.stastny@ndsu.edu. You have rights as a research participant. If you have questions about your rights or complaints about this research, you may talk to the researchers or contact the NDSU Human Research Protection Program at 701.231.8995, toll-free at 1-855-800-6717, or by email at ndsu.irb@ndsu.edu. Thank you for your taking part in this research.

Please complete the survey by Friday, May 15th and feel free to share with other young adults with type 1 diabetes.

To access the survey, please click on the link below: diabetes management survey

APPENDIX B. EMAIL GREETING/ ASSUMED INFORMED CONSENT FOR DIABETES MANAGEMENT INTERVIEW

North Dakota State University (NDSU)
Department of Health, Nutrition, and Exercise Sciences
E. Morrow Lebedeff Hall 316H: NDSU Dept. 2620
PO Box 6050
Fargo, ND 58108-6050
701.231.7479

Barrier and strategies to diabetes management in young adults with type 1 diabetes.

My name is Bailee Sawyer, RD, LRD. I am a doctoral student in the Department of Health, Nutrition, and Exercise Sciences at North Dakota State University and I am also an experience licensed, registered dietitian. Thank you for filling out our survey. It is our hope, that with this research, we will learn more about a glimpse in the daily life for an individual aged 18 to 30 years who is diagnosed with type 1 diabetes. We now ask that you participate in a brief telephone interview. Your participation is entirely your choice, and you may change your mind or quit participating at any time, with no penalty to you.

You may find it interesting and thought provoking to participate in the interview. If, however, you feel uncomfortable in any way during the interview session, you have the right to decline to answer any question(s), or to end the interview. It should take about 30 – 45 minutes to complete the interview. We will ask you about glimpse in the daily life for an individual aged 18 to 30 years who is diagnosed with type 1 diabetes. The interview will be audio recorded. We will keep private all research records that identify you. When the interview is transcribed, you will be assigned a number, and other potentially identifying information will be left out of the transcripts. In any written documents (including publications) regarding the study, only the number and not your name will be used.

At the completion of the interview the first 20 participants will have the opportunity to provide their e-mail addresses for a chance to win one $100 Amazon.com gift card. The e-mail addresses provided will not be connected to the survey question answers.

Audio files will be stored in a password protected file on a computer that is only accessible to the principal investigator and co-investigators. Electronic copies of the interview transcripts will be saved and protected in the same fashion. After the data has been analyzed, the audio recordings will be deleted. If you have any questions about the study, please contact me at (325) 374 –6185 or bailee.sawyer@ndus.edu or contact my advisor Dr. Sherri Stastny at (701) 238-0633 (cell phone) or sherri.stastny@ndsu.edu. You have rights as a research participant. If you have questions about your rights or complaints about this research, you may talk to the researcher or contact the NDSU Human Research Protection Program at 701.231.8995, toll-free at 1-855-800-6717, by email at ndsu.irb@ndsu.edu, or by mail at: NDSU HRPP Office, NDSU Dept. 4000, P.O. Box 6050, Fargo, ND 58108-6050.
Thank you for your taking part in this research. To sign up for an interview, click this link https://doodle.com/meetme/qc/znDuIwsc19 and choose the slot (CST) that best matches your schedule. As part of signing up, you will be asked to provide a phone number.

APPENDIX C. SOCIAL MEDIA POST

Attention Young Adults with Type 1 Diabetes:
Please participate in a brief survey on barriers and strategies for diabetes management with type 1 diabetes as a young adult. A doctoral student Bailee Sawyer, RD, LRD from North Dakota State University (NDSU) is conducting this survey. You will receive an email to complete the survey by clicking https://1drv.ms/w/s!At_8F0cABpNVcse3DWCoJoNkNRE.

The instructions will be in the email. Your identity is not shared with anyone. Your completion of the survey will be very much appreciated and will contribute to this area of research.

After the completion of the survey, the first **100 respondents** will have the opportunity to provide their e-mail addresses for a chance to win one **$200 Amazon.com gift card**. The e-mail addresses provided will not be connected to the survey question answers.

APPENDIX D. DIABETES EMPOWERMENT SCALE (DES)

University of Michigan Diabetes Research and Training Center

DIABETES ATTITUDE QUESTIONNAIRE

PLEASE ANSWER THE FOLLOWING QUESTIONS

Diabetes Empowerment Scale – (DES)

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
In general, I believe that I:					
1. ...know what part(s) of taking care of my diabetes that I am **satisfied** with. ( )	( )	( )	( )	( )	( )
2. ...know what part(s) of taking care of my diabetes that I am **dissatisfied** with. ( )	( )	( )	( )	( )	( )
3. ...know what part(s) of taking care of my diabetes that I am ready to change. ( )	( )	( )	( )	( )	( )
4. ...know what part(s) of taking care of my diabetes that I am <u>not</u> ready to change. ( )	( )	( )	( )	( )	( )
5. ...can choose realistic diabetes goals. ( )	( )	( )	( )	( )	( )
6. ...know which of my diabetes goals are **most** important to me. ( )	( )	( )	( )	( )	( )
7. ...know the things about **myself** that either help or prevent me from reaching my diabetes goals. ( )	( )	( )	( )	( )	( )
8. ...can come up with good ideas to help me reach my goals. ( )	( )	( )	( )	( )	( )
9. ...am able to turn my diabetes goals into a workable plan. ( )	( )	( )	( )	( )	( )

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
In general, I believe that I:					
10. ...can reach my diabetes goals once I make up my mind. ( )	( )	( )	( )	( )	( )
11. ...know which **barriers** make reaching my diabetes goals more difficult. ( )	( )	( )	( )	( )	( )
12. ...can **think** of different ways to overcome barriers to my diabetes goals ( )	( )	( )	( )	( )	( )
13. ...can try out different ways of overcoming barriers to my diabetes goals. ( )	( )	( )	( )	( )	( )
14. ...am able to decide which way of overcoming barriers to my diabetes goals works best for me. ( )	( )	( )	( )	( )	( )
15. ...can tell how I'm feeling about **having** diabetes. ( )	( )	( )	( )	( )	( )
16. ...can tell how I'm feeling about **caring** for my diabetes. ( )	( )	( )	( )	( )	( )
17. ...know the ways that having diabetes causes stress in my life. ( )	( )	( )	( )	( )	( )
18. ...know the **positive** ways I cope with diabetes-related stress. ( )	( )	( )	( )	( )	( )
19. ...know the **negative** ways I cope with diabetes-related stress. ( )	( )	( )	( )	( )	( )

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
In general, I believe that I:					
20. ...can cope well with diabetes-related stress.	( )	( )	( )	( )	( )
21. ...know where I can get support for having and caring for my diabetes.	( )	( )	( )	( )	( )
22. ...can ask for support for having and caring for my diabetes when I need it.	( )	( )	( )	( )	( )
23. ...can support myself in dealing with my diabetes.	( )	( )	( )	( )	( )
24. ...know what helps me stay motivated to care for my diabetes.	( )	( )	( )	( )	( )
25. ...can motivate myself to care for my diabetes.	( )	( )	( )	( )	( )
26. ...know enough about diabetes to make self-care choices that are right for me.	( )	( )	( )	( )	( )
27. ...know enough about myself as a person to make diabetes care choices that are right for me.	( )	( )	( )	( )	( )
28. ...am able to figure out if it is worth my while to change how I take care of my diabetes.	( )	( )	( )	( )	( )

Thank you very much for completing this questionnaire.

Survey Scoring Key

Robert M. Anderson, Ed.D.
University of Michigan Medical School
G1116 — Towsley Center — 0201
Ann Arbor, MI 48109-0201

Diabetes Empowerment Scale (DES)

Scoring Key
The DES measures the patient's
Self-efficacy related to:
Subscales & Items

I. Managing the psychosocial aspects of diabetes (18,20–27) (9 items)

.

II. Assessing dissatisfaction and readiness to change (1-4,15-17, 19, and 28) (9 items)

III. Setting and achieving diabetes goals (5–14) (10 items)

The scoring of the DES is straightforward and is based on completed items. An item checked "strongly agree" receives 5 points; "agree" – 4 points; "neutral" – 3 points; "disagree" – 2 points; and "strongly disagree" receives 1 point. The numerical values for a set of items in a particular subscale (for example: items 5-14 in the "Goal Setting" subscale) are added and the total is divided by the number of items (in this case 10) in the subscale. The resulting value is the score for that subscale. An overall score for the DES can be calculated by adding all of the item scores and dividing by 28.

APPENDIX E. DIABETES SELF-MANAGEMENT QUESTIONNAIRE (DSMQ)

The following statements describe self-care activities related to your diabetes. Thinking about your self-care over the **last 8 weeks**, please specify the extent to which each statement applies to you. Note: If you monitor your glucose using continuous interstitial glucose monitoring (CGM), please refer to this where 'blood sugar checking' is requested.	applies to me very much	applies to me to a consider-able degree	applies to me to some degree	does not apply to me
1. I check my blood sugar levels with care and attention. ☐ *Blood sugar measurement is not required as a part of my treatment.*	☐3	☐2	☐1	☐0
2. The food I choose to eat makes it easy to achieve optimal blood sugar levels.	☐3	☐2	☐1	☐0
3. I keep all doctors' appointments recommended for my diabetes treatment.	☐3	☐2	☐1	☐0
4. I take my diabetes medication (e. g. insulin, tablets) as prescribed. ☐ *Diabetes medication/insulin is not required as a part of my treatment.*	☐3	☐2	☐1	☐0
5. Occasionally I eat lots of sweets or other foods rich in carbohydrates.	☐3	☐2	☐1	☐0
6. I record my blood sugar levels regularly (or analyse the value chart with my blood glucose meter). ☐ *Blood sugar measurement is not required as a part of my treatment.*	☐3	☐2	☐1	☐0
7. I tend to avoid diabetes-related doctors' appointments.	☐3	☐2	☐1	☐0
8. I do regular physical activity to achieve optimal blood sugar levels.	☐3	☐2	☐1	☐0
9. I strictly follow the dietary recommendations given by my doctor or diabetes specialist.	☐3	☐2	☐1	☐0
10. I do not check my blood sugar levels frequently enough as would be required for achieving good blood glucose control. ☐ *Blood sugar measurement is not required as a part of my treatment.*	☐3	☐2	☐1	☐0
11. I avoid physical activity, although it would improve my diabetes.	☐3	☐2	☐1	☐0
12. I tend to forget to take or skip my diabetes medication (e. g. insulin, tablets). ☐ *Diabetes medication/insulin is not required as a part of my treatment.*	☐3	☐2	☐1	☐0
13. Sometimes I have real 'food binges' (not triggered by hypoglycaemia).	☐3	☐2	☐1	☐0
14. Regarding my diabetes care, I should see my medical practitioner(s) more often.	☐3	☐2	☐1	☐0

15. I tend to skip planned physical activity.	☐3	☐2	☐1	☐0
16. My diabetes self-care is poor.	☐3	☐2	☐1	☐0

DSMQ – United Kingdom/English - Original version
DSMQ_AU1.0_eng-GBori

Questionnaire Scale Description and Scoring Guide

Scale structure (original 16-item version)

a. The **total score** is a global measure of diabetes self-management; it comprises all 16 items (reverse-scored items: 5, 7, 10, 11, 12, 13, 14, 15 and 16)
b. **4 or 5 subscales**

- **Dietary control** on diabetes-related dietary management behaviors; comprising items 2, 5, 9, and 13 (5 and 13 are reverse-scored)
- **Glucose management** on blood glucose monitoring and medication adherence; comprising items 1, 4, 6, 10 and 12 (10 and 12 are reverse-scored)
    - **Glucose monitoring** (items 1, 6, 10; 10 reverse-scored)
    - **Medication adherence** (items 4, 12; 12 reverse-scored)
- **Physical activity** on activity/exercise as means of diabetes management; comprising items 8, 11, 15 (11 and 15 reverse-scored)
- **Physician contact** on adherence to diabetes-related doctors' appointments; comprising items 3, 7, 14, (7 and 14 reverse-scored)

Item scoring

4-point Likert scale: 'Applies to me very much' = 3 points/ 'Applies to me to a considerable degree' = 2 points/ 'Applies to me to some degree = 1 point/ 'Does not apply to me' = 0 points
If '…is not required as a part of my treatment' is stated in an item, that item should not be scored.

Scale scoring (original 16-items version):

The DSMQ contains 7 positively and 9 negatively keyed items (with view to effective self-management); negatively keyed items have to be reverse-scored so that higher values indicate more effective self-management before summing to scale scores.

Scale score = actual sum of items / maximum possible sum of items x 10

APPENDIX F. DIABETES EATING PROBLEMS SURVEY – REVISED (DEPS-R)

DIABETES EATING PROBLEM SURVEY – REVISED (DEPS-R)

Living with diabetes can sometimes be difficult, particularly regarding eating and diabetes management. Listed below are a variety of attitudes and behaviors regarding diabetes management. For each statement, choose the ONE answer that indicates how often this is true for you during the PAST MONTH.

	Never	Rarely	Some-times	Often	Usually	Always
1. Losing weight is an important goal to me.	⓪	①	②	③	④	⑤
2. I skip meals and/or snacks.	⓪	①	②	③	④	⑤
3. Other people have told me that my eating is out of control.	⓪	①	②	③	④	⑤
4. When I overeat, I don't take enough insulin to cover the food.	⓪	①	②	③	④	⑤
5. I eat more when I am alone than when I am with others.	⓪	①	②	③	④	⑤
6. I feel that it's difficult to lose weight and control my diabetes at the same time.	⓪	①	②	③	④	⑤
7. I avoid checking my blood sugar when I feel like it is out of range.	⓪	①	②	③	④	⑤
8. I make myself vomit.	⓪	①	②	③	④	⑤
9. I try to keep my blood sugar high so that I will lose weight.	⓪	①	②	③	④	⑤
10. I try to eat to the point of spilling ketones in my urine.	⓪	①	②	③	④	⑤
11. I feel fat when I take all of my insulin.	⓪	①	②	③	④	⑤
12. Other people tell me to take better care of my diabetes.	⓪	①	②	③	④	⑤
13. After I overeat, I skip my next insulin dose.	⓪	①	②	③	④	⑤
14. I feel that my eating is out of control.	⓪	①	②	③	④	⑤
15. I alternate between eating very little and eating huge amounts.	⓪	①	②	③	④	⑤
16. I would rather be thin than have good control of my diabetes.	⓪	①	②	③	④	⑤

SCORING INSTRUCTIONS

DIABETES EATING PROBLEM SURVEY – REVISED (DEPS-R)

Survey attributes

- 16 items
- Response options: 6-point scale from 0 to 5 (0=never, 1=rarely, 2=sometimes, 3=often, 4=usually, 5=always)
- Possible total score: 0 to 80
- Higher total score indicates: more disordered eating behaviors

Scoring instructions

1. Calculate the mean of all non-missing items.
2. Multiply this value by 16.

Citation for publications/presentations

Please cite the following article in all publications/presentations related to the use of the Diabetes Eating Problem Survey – Revised:

> Markowitz JT, Butler DA, Volkening LK, Antisdel JE, Anderson BJ, Laffel LM. Brief screening tool for disordered eating in diabetes: Internal consistency and external validity in a contemporary sample of pediatric patients with type 1 diabetes. Diabetes Care 2010;33:495-500.

APPENDIX G. CDC YOUTH RISK BEHAVIOR SURVEILLANCE SYSTEM (YRBSS)

Please answer the following questions:
How old are you? ___
Male ___
Female ___
Do not wish to answer ___
Are you Hispanic or Latin?

a. Yes
b. No

What is your race?

a. American Indian or Alaska Native
b. Asian
c. Black or African American
d. Native Hawaiian or Other Pacific Islander
e. White

How tall are you without your shoes on? ____ ft _____ in
How much do you weigh without your shoes on? ____ lbs
How often do you wear a seat belt when riding in a car driven by someone else?

a. Never
b. Rarely
c. Sometimes
d. Most of the time
e. Always

During the past 30 days, how many times did you ride in a car or other vehicle driven by someone who had been drinking alcohol?

a. 0 times
b. 1 time
c. 2 or 3 times
d. 4 or 5 times
e. 6 or more times

During the past 30 days, how many times did you drive a car or other vehicle when you had been drinking alcohol?

a. I did not drive a car or other vehicle during the past 30 days
b. 0 times
c. 1 time
d. 2 or 3 times
e. 4 or 5 times
f. 6 or more times

During the past 30 days, on how many days did you text or e-mail/use social media apps while driving a car or other vehicle?

A. I did not drive a car or other vehicle during the past 30 days
B. 0 days
C. 1 or 2 days
D. 3 to 5 days
E. 6 to 9 days
F. 10 to 19 days
G. 20 to 29 days
H. All 30 days

During the past 30 days, on how many days did you carry a weapon such as a gun, knife, or club?

a. 0 days
b. 1 day
c. 2 or 3 days
d. 4 or 5 days
e. 6 or more days

During the past 12 months, how many times were you in a physical fight?

a. 0 times
b. 1 time
c. 2 or 3 times
d. 4 or 5 times
e. 6 or 7 times
f. 8 or 9 times
g. 10 or 11 times
h. 12 or more times

Have you ever been physically forced to have sexual intercourse when you did not want to?

a. Yes
b. No

During the past 12 months, how many times did anyone force you to do sexual things that you did not want to do? (Count such things as kissing, touching, or being physically forced to have sexual intercourse.)

a. 0 times
b. 1 times
c. 2 or 3 times
d. 4 or 5 times
e. 6 or more times

During the past 12 months, how many times did someone you were dating or going out with force you to do sexual things that you did not want to do? (Count such things as kissing, touching, or being physically forced to have sexual intercourse.)

a. 0 times
b. 1 times
c. 2 or 3 times
d. 4 or 5 times
e. 6 or more times

During the past 12 months, how many times did someone you were dating or going out with physically hurt you on purpose? (Count such things as being hit, slammed into something, or injured with an object or weapon.)

a. I did not date or go out with anyone during the past 12 months
b. 0 times
c. 1 time
d. 2 or 3 times
e. 4 or 5 times
f. 6 or more times

During the past 12 months, have you ever been bullied at school or work?

a. Yes
b. No

During the past 12 months, have you ever been electronically bullied? (Count being bullied through texting, Instagram, Facebook, or other social media.)

a. Yes
b. No

During the past 12 months, did you ever feel so sad or hopeless almost every day for two weeks or more in a row that you stopped doing some usual activities?

a. Yes
b. No

During the past 12 months, did you ever seriously consider attempting suicide?

a. Yes
b. No

During the past 12 months, did you make a plan about how you would attempt suicide?

a. Yes
b. No

During the past 12 months, how many times did you actually attempt suicide?

a. 0 times
b. 1 time
c. 2 or 3 times
d. 4 or 5 times
e. 6 or more times

If you attempted suicide during the past 12 months, did any attempt result in an injury, poisoning, or overdose that had to be treated by a doctor or nurse?

a. I did not attempt suicide during the past 12 months
b. Yes
c. No

Have you ever tried cigarette smoking, even one or two puffs?

a. Yes
b. No

How old were you when you first tried cigarette smoking, even one or two puffs?

a. I have never tried cigarette smoking, not even one or two puffs
b. 8 years old or younger
c. 9 to 10 years old
d. 11 to 12 years old
e. 13 to 14 years old
f. 15 to 16 years old
g. 17 years old or older

During the past 30 days, on how many days did you smoke cigarettes?

a. 0 days
b. 1 or 2 days
c. 3 or 5 days
d. 6 to 9 days
e. 10 to 19 days
f. 20 to 29 days
g. All 30 days

During the past 30 days, on the days you smoked, how many cigarettes did you smoke per day?

a. I did not smoke cigarettes during the past 30 days
b. Less than 1 cigarette per day
c. 2 to 5 cigarettes per day
d. 6 to 10 cigarettes per day
e. 11 to 20 cigarettes per day
f. More than 20 cigarettes per day

Have you ever used an electronic vapor product?

a. Yes
b. No

During the past 30 days, on how many days did you use an electronic vapor product?

a. 0 days
b. 1 or 2 days
c. 3 to 5 days
d. 6 to 9 days
e. 10 to 19 days
f. 20 to 29 days
g. All 30 days

During the past 30 days, how did you usually get your own electronic vapor products?

a. I did not use any electronic vapor products during the 30 days
b. I bought them in a store such as a convenience store, supermarket, discount store, gas station, or vape store
c. I got them on the internet
d. I gave someone else money to buy them for me
e. I borrowed them from someone else
f. A person who can legally buy these products gave them to me
g. I took them from a store or another person
h. I got them some other way

During the past 30 days, on how many days did you use chewing tobacco, snuff, dip, snus, or dissolvable tobacco products, such as Copenhagen, Grizzly, Skoal, or Camel Snus?

a. 0 days
b. 1 or 2 days
c. 3 to 5 days
d. 6 to 9 days
e. 10 to 19 days
f. 20 to 29 days
g. All 30 days

During the past 30 days, on how many days did you smoke cigars, cigarillos, or little cigars?

a. 0 days
b. 1 or 2 days
c. 3 to 5 days
d. 6 to 9 days
e. 10 to 19 days
f. 20 to 29 days
g. All 30 days

During the past 12 months, did you ever try to quit using all tobacco products, including cigarettes, cigars, smokeless tobacco, shisha or hookah tobacco, and electronic vapor products?

a. I did not use any tobacco products during the past 12 months
b. Yes
c. No

How old were you when you had your first drink of alcohol other than a few sips?

a. I have never had a drink of alcohol other than a few sips
b. 8 years old or younger
c. 9 or 10 years old
d. 11 or 12 years old
e. 13 or 14 years old
f. 15 or 16 years old
g. 17 years old or older

During the past 30 days, on how many days did you have at least one drink of alcohol?

a. 0 days
b. 1 or 2 days
c. 3 to 5 days
d. 6 to 9 days
e. 10 to 19 days
f. 20 to 29 days
g. All 30 days

During the past 30 days, on how many days did you have 4 or more drinks of alcohol in a row, that is, within a couple hours (if you are female) or 5 or more drinks of alcohol in a row, that is, within a couple of hours (if you are a male)?

a. 0 days
b. 1 day
c. 2 days
d. 3 to 5 days
e. 6 to 9 days
f. 10 to 19 days
g. 20 or more days

During the past 30 days, what is the largest number of alcoholic drinks you had in a row, that is, within a couple hours?

a. I did not a drink alcohol during the past 30 days
b. 1 or 2 drinks
c. 3 drinks
d. 4 drinks
e. 5 drinks
f. 6 or 7 drinks
g. 8 or 9 drinks
h. 10 or more drinks

During the past 30 days, how did you usually get alcohol you drank?

a. I did not drink alcohol during the past 30 days
b. I bought it in a store such as a liquor store, convenience store, supermarket, discount store, or gas station
c. I bought it at a restaurant, bar, or club
d. I bought it at a public event such as a concert or sporting event
e. I gave someone else money to buy it for me
f. Someone gave it to me
g. I took it from a store or family member
h. I got it some other way

During your life, how many times have you used marijuana?

a. 0 times
b. 1 or 2 times
c. 3 to 9 times
d. 10 to 19 times
e. 20 to 39 times
f. 40 to 99 times
g. 100 or more times

How old were you when you tried marijuana for the first time?

a. I have never tried marijuana
b. 8 years old or younger
c. 9 or 10 years old
d. 11 or 12 years old
e. 13 or 14 years old
f. 15 or 16 years old
g. 17 years old or older

During the past 30 days, how many times did you use marijuana?

a. 0 times
b. 1 or 2 times
c. 3 to 9 times
d. 10 to 19 times
e. 20 to 39 times
f. 40 or more times

During your life, how many times have you used synthetic marijuana?

a. 0 times
b. 1 or 2 times
c. 3 to 9 times
d. 10 to 19 times
e. 20 to 39 times
f. 40 or more times

During your life, how many times have you taken prescription pain medicine without a doctor's prescription or differently than how a doctor told you to use it?

a. 0 times
b. 1 or 2 times
c. 3 to 9 times
d. 10 to 19 times
e. 20 to 39 times
f. 40 or more times

During the past 30 days, how many times have you taken prescription pain medicine without a doctor's prescription or differently than how a doctor told you to use it?

a. 0 times
b. 1 or 2 times
c. 3 to 9 times
d. 10 to 19 times
e. 20 to 39 times
f. 40 or more times

During your life, how many times have you used any form of cocaine, including powder, crack, or freebase?

a. 0 times
b. 1 or 2 times
c. 3 to 9 times
d. 10 to 19 times
e. 20 to 39 times
f. 40 or more times

During your life, how many times have you used heroin (also called smack, junk or China White)?

a. 0 times
b. 1 or 2 times
c. 3 to 9 times
d. 10 to 19 times
e. 20 to 39 times
f. 40 or more times

During your life, how many times have you used methamphetamines (also called speed, crystal meth, crank, ice, or meth?

a. 0 times
b. 1 or 2 times
c. 3 to 9 times
d. 10 to 19 times
e. 20 to 39 times
f. 40 or more times

During your life, how many times have you used ecstasy (also called MDMA)?

a. 0 times
b. 1 or 2 times
c. 3 to 9 times
d. 10 to 19 times
e. 20 to 39 times
f. 40 or more times

During your life, how many times have you taken steroid pills or shots without a doctor's prescription?

a. 0 times
b. 1 or 2 times
c. 3 to 9 times
d. 10 to 19 times
e. 20 to 39 times
f. 40 or more times

During your life, how many times have you used a needle to inject any illegal drug into your body?

a. 0 times
b. 1 time
c. 2 or more times

During the past 12 months, has anyone offered, sold, or given you an illegal drug on school/work property?

a. Yes
b. No

Have you ever had sexual intercourse?

a. Yes
b. No

How old were you when you had sexual intercourse for the first time?

a. I have never had sexual intercourse
b. 11 years old or younger
c. 12 years old
d. 13 years old
e. 14 years old
f. 15 years old
g. 16 years old
h. 17 years old or older

During your life, with how many people have you had sexual intercourse?

a. I have never had sexual intercourse
b. 1 person
c. 2 people
d. 3 people
e. 4 people
f. 5 people
g. 6 or more people

During the past 3 months, with how many people did you have sexual intercourse?

a. I have never had sexual intercourse
b. I have had sexual intercourse, but not during the past 3 months
c. 1 person
d. 2 people
e. 3 people
f. 4 people
g. 5 people
h. 6 or more people

Did you drink alcohol or use drugs before you had sexual intercourse the last time?

a. I have never had sexual intercourse
b. Yes
c. No

The last time you had sexual intercourse, did you or your partner use a condom?

a. I have never had sexual intercourse
b. Yes
c. No

The last time you had sexual intercourse, what one method did you or your partner use to prevent pregnancy (Select only one response.)

a. I have never had sexual intercourse
b. No method was used to prevent pregnancy
c. Birth control bills
d. Condoms
e. An IUD (such as Mirena or ParaGard) or implant (such as Implanon or Nexplanon)
f. A shot (such as Depo-Provera), patch (such as Ortho Evra), or birth control ring (such as a NuvaRing)
g. Withdrawal or some other method
h. Not sure

During your life, with whom have you had sexual contact?

a. I have never had sexual contact
b. Females
c. Males
d. Females and males

Which of the following best describes you?

a. Heterosexual (straight)
b. Gay or lesbian
c. Bisexual
d. Not sure

How do you describe your weight?

a. Very underweight
b. Slightly underweight
c. About the right weight
d. Slightly overweight
e. Very overweight

Which of the following are you trying to do about your weight?

a. Lose weight
b. Gain weight
c. Stay the same weight
d. I am not trying to do anything about my weight

During the past 7 days, how many times did you drink 100% fruit juices such as orange juice, apple juice, or grape juice? (Do not count punch, Kool-Aid, sports drinks, or other fruit-flavored drinks.).

A. I did not drink 100% fruit juice during the past 7 days
B. 1 to 3 times during the past 7 days
C. 4 to 6 times during the past 7 days
D. 1 time per day
E. 2 times per day
F. 3 times per day
G. 4 or more times per day

During the past 7 days, how many times did you eat fruit? (Do not count fruit juice)

a. I did not eat fruit during the past 7 days
b. 1 to 3 times during the past 7 days
c. 4 to 6 times during the past 7 days
d. 1 time per day
e. 2 times per day
f. 3 times per day
g. 4 or more times per day

During the past 7 days, how many times did you eat green salad?

A. I did not eat green salad during the past 7 days
B. 1 to 3 times during the past 7 days
C. 4 to 6 times during the past 7 days
D. 1 time per day
E. 2 times per day
F. 3 times per day
G. 4 or more times per day

During the past 7 days, how many times did you eat potatoes? (Do not count French fries, fried potatoes, or potato chips)

a. I did not eat potatoes during the past 7 days
b. 1 to 3 times during the past 7 days
c. 4 to 6 times during the past 7 days
d. 1 time per day
e. 2 times per day
f. 3 times per day
g. 4 or more times per day

During the past 7 days, how many times did you eat carrots?

a. I did not eat carrots during the past 7 days
b. 1 to 3 times during the past 7 days
c. 4 to 6 times during the past 7 days
d. 1 time per day
e. 2 times per day
f. 3 times per day
g. 4 or more times per day

During the past 7 days, how many times did you eat other vegetables? (Do not count green salad, potatoes, or carrots)

a. I did not eat other vegetables during the past 7 days
b. 1 to 3 times during the past 7 days
c. 4 to 6 times during the past 7 days
d. 1 time per day
e. 2 times per day
f. 3 times per day
g. 4 or more times per day

During the past 7 days, how many times did you drink a can, bottle, or glass of soda or pop such as Coke, Pepsi, or Sprite? (Do not count diet soda or diet pop.)

a. I did not drink soda or pop during the past 7 days
b. 1 to 3 times during the past 7 days
c. 4 to 6 times during the past 7 days
d. 1 time per day
e. 2 times per day
f. 3 times per day
g. 4 or more times per day

During the past 7 days, how many times did you drink a can, bottle, or glass of a sports drink such as Gatorade or Powderade? (Do not count low-calorie sports drinks such as Propel or G2.)

a. I did not drink sports drinks during the past 7 days
b. 1 to 3 times during the past 7 days
c. 4 to 6 times during the past 7 days
d. 1 time per day
e. 2 times per day
f. 3 times per day
g. 4 or more times per day

During the past 7 days, how many times did you drink a bottle or glass of plain water? (Count tap, bottled, and unflavored sparkling water.)

a. I did not drink water during the past 7 days
b. 1 to 3 times during the past 7 days
c. 4 to 6 times during the past 7 days
d. 1 time per day
e. 2 times per day
f. 3 times per day
g. 4 or more times per day

During the past 7 days, how many glasses of milk did you drink? (Count the milk you drank in a glass or cup, from a carton, or with cereal. Count the half pint of milk served at school as equal to one glass).

a. I did not drink milk during the past 7 days
b. 1 to 3 times during the past 7 days
c. 4 to 6 times during the past 7 days
d. 1 time per day
e. 2 times per day
f. 3 times per day
g. 4 or more times per day

During the past 7 days, on how many days did you eat breakfast?

a. 0 days
b. 1 day
c. 2 days
d. 3 days
e. 4 days
f. 5 days
g. 6 days
h. 7 days

Are there any foods that you have to avoid because eating the food could cause an allergic reaction, such as skin rashes, swelling, itching, vomiting coughing, or trouble breathing?

a. Yes
b. No
c. Not sure

During the past 7 days, on how many days were you physically active for a total of at least 60 minutes per day? (Add up all the time you spent in any kind of physical activity that increased your heart rate and made you breathe hard some of the time.)

a. 0 days
b. 1 day
c. 2 days
d. 3 days
e. 4 days
f. 5 days
g. 6 days
h. 7 days

During the past 7 days, on how many days did you do exercises to strengthen or tone your muscles, such as push-ups, sit-ups, or weight lifting?

a. 0 days
b. 1 day
c. 2 days
d. 3 days
e. 4 days
f. 5 days
g. 6 days
h. 7 days

On an average day, how many hours do you watch TV?

a. I do not watch TV on an average day
b. Less than 1 hour per day
c. 1 hour per day
d. 2 hours per day
e. 3 hours per day
f. 4 hours per day
g. 5 or more hours per day

On an average day, how many hours do you use a screen for something that is not school/work related? (Count time spent playing games, watching videos, texting, or using social media on your smartphone, computer, Xbox, PlayStation, iPad, or other tablet.)

a. I do not use a screen for something that is not school/work related
b. Less than 1 hour per day
c. 1 hour per day
d. 2 hours per day
e. 3 hours per day
f. 4 hours per day
g. 5 or more hours per day

In an average week, on how many days do you go to fitness classes?

a. 0 days
b. 1 day
c. 2 days
d. 3 days
e. 4 days
f. 5 days

Have you ever been tested for HIV, a virus that causes AIDS? (Do not count tests done if you donated blood.)

a. yes
b. no
c. not sure

During the past 12 months, have you been tested for a sexually transmitted disease (STD) other than HIV, such as chlamydia or gonorrhea?

a. Yes
b. No
c. Not sure

During the past 12 months, how many times did you use an indoor tanning device such as a sunlamp, sunbed, or tanning booth? (Do not count getting a spray-on tan.)

a. 0 times
b. 1 or 2 times
c. 3 to 9 times
d. 10 to 19 times
e. 20 to 39 times
f. 40 or more times

When you are outside for more than one hour on a sunny day, how often do you wear sunscreen with an SPF of 15 or higher?

a. Never
b. Rarely
c. Sometimes
d. Most of the time
e. Always

When was the last time you saw a dentist for a check-up, exam, teeth cleaning, or other dental work?

a. During the past 12 months
b. Between 12 and 24 months ago
c. More than 24 months ago
d. Never
e. Not sure

Has a doctor or nurse ever told you that you have asthma?

a. Yes
b. No
c. Not sure

On an average night, how many hours of sleep do you get?

a. 4 or less hours
b. 5 hours
c. 6 hours
d. 7 hours
e. 8 hours
f. 9 hours
g. 10 or more hours

Because of a physical, mental, or emotional problem, do you have serious difficulty concentrating, remembering, or making decisions?

a. Yes
b. No

APPENDIX H. DIABETES MANAGEMENT TELEPHONE INTERVIEW SCRIPT

Participant is introduced as participant No. ____

Thank you for filling out the Diabetes Survey. My name is Bailee Sawyer, RD, LRD and I am a graduate student at NDSU. I would like to learn more about your diabetes. Is this a good time to chat?
Yes, proceed.
No,
Would you like to schedule another time.

Do you mind talking with me for a few minutes to answer some questions?
No. Discontinue interview.

Yes. OK. We are going to talk about living with type 1 diabetes, such as successes and difficulties. Please feel free to stop me and ask questions at any time. If you need me to repeat a question, I'm happy to do so.

Let's start.

1. Would you mind telling me your age? Yes/No
2. Would you like to define your sex? Yes/No
3. On a scale of 1 to 10 with 1 being easy and 10 being difficult, how capable do you feel when managing diabetes
   1 2 3 4 5 6 7 8 9 10

   a. What part is easy for you?

   b. What part is a struggle?

4. Think about where you grew up and who helped you with self-care (if you had diabetes as a child, how they helped with management skills) in your family.
   Describe how your family helped with self-care and/or diabetes management.

   Prompts:
   a. Self-care
   b. Diabetes Management

5. Is there any times of the year or special events when it is more difficult to manage your type 1 diabetes?

   If yes, tell me about them.
   Prompts:
   Tell me about when these events occur (family holidays, special occasions, etc.)
   a. Is there food involved?
   b. How are you involved?

6. Do you feel you have had positive role models for diabetes management?
    a. Yes
    b. No
    c. Maybe
    If yes, who? Why is that person your role model?

7. Think about where you live now and your diabetes management habits. Think about yesterday. Thinking about after you woke up in the morning – what was the first thing you did?

About what time was that?
What did you do next?
About what time of the day was that?
{Continue until the whole day is discussed}

What made you choose what you did?

8. What things prevent you from making proper diabetes management choices?

9. What are 2 or 3 things that would help you manage diabetes better?

10. How could you deal with _____ {things they mentioned as barriers}?
List all

11. Describe a time you learned something about making diabetes management choices that really stuck with you.

Where (or from whom) did you learn it?

12. When it comes to learning, how do you prefer to learn?
    a. Large lecture hall
    b. Regular classroom
    c. Small group
    d. One-on-one with just the teacher
    e. Other

How about when it comes to your diabetes?

13. Do you have confidence in your ability to control your level of motivation, behavior, or discipline to make smart lifestyle and social choices?

14. How does your level of confidence in your abilities to control your choices impact the management of your diabetes?

15. What is your current living situation?
    A. at home with parents or family
    B. Shared housing with others, not parents
    C. Live alone
    D. Other

    If not living with parents, then Now that you are living outside of the home you grew up in, you may learn some "non-school" skills that could help you in life.

If you would like to participate in the random drawing for the $100 Amazon.com gift card please provide an email: _____

APPENDIX I. MANAGING DIABETES IN YOUNG ADULTS SURVEY

The following survey will inquire about life as a young adult and being a young adult living with type 1 diabetes. The survey will also ask about living with type 1 diabetes. The questions will be about self-management, self-efficacy, and certain eating behaviors for young adults living with type 1 diabetes.

At the *completion* of the survey, the first 100 respondents will have the opportunity to provide their e-mail addresses for a chance to win one $200 Amazon.com gift card. The e-mail addresses provided will not be connected to the survey question answers.

The entire questionnaire contains 108 questions and will take you about an hour to complete (TBD by pilot test). Most of the questions are very brief. You must answer each question before moving on to the next question. This is set up in this manner to assure that all questions are answered to help us understand what it is like living with type 1 diabetes. We urge you to complete the entire survey to help us understand what it is like living with diabetes.

1. How old are you?
    a. Under 18 (survey stops)
    b. 18 – 20
    c. 21 – 24
    d. 25 – 30
    e. older than 30 (survey stops)

Please answer the following questions in reference to life with type 1 diabetes. This section is 33 questions and will take you approximately _tbd___ minutes.

2. Check any of the following medical complications you may have: (check all that apply)
    - ☐ alcoholism/drug abuse
    - ☐ asthma
    - ☐ arthritis
    - ☐ cancer (type: _____)
    - ☐ depression
    - ☐ anxiety
    - ☐ bipolar
    - ☐ suicidal
    - ☐ emphysema
    - ☐ (COPD)
    - ☐ heart disease
    - ☐ high blood pressure (hypertension)
    - ☐ high cholesterol
    - ☐ hypothyroidism/thyroid disease
    - ☐ renal (kidney) disease
    - ☐ migraine headaches
    - ☐ stroke
    - ☐ irritable bowel syndrome/Crohn's/bowel problem
    - ☐ celiac disease
    - ☐ retinopathy

- Skin ulcer with diabetes
- overweight/obesity

3. Do you have any food intolerances/allergies?
   - Lactose intolerance
   - Other food allergy/intolerance (please explain: _____)
4. What is the level of your hemoglobin A1C within the past 3 months?
   a. 6.0% or less
   b. between 6.0 – 7.5%
   c. 7.5 – 8.5%
   d. > 8.5%
   e. Do not know
   f. Do not wish to disclose
5. What is the level of your fasting blood glucose within the past 3 months?
   a. < 80 mg/dL or less
   b. 80 – 110 mg/dL
   c. 110 – 120 mg/dL
   d. > 120 mg/dL
   e. Do not know
   f. Do not wish to answer
6. Which blood glucose monitor system do you currently use?
   a. Finger prick
   b. Continuous Monitor
   c. None
   d. Other: _____
7. How often do you check your blood glucose?
   a. I do not check my blood glucose
   b. Once a day
   c. Twice a day
   d. Every meal
   e. Every meal, fasting morning, and bedtime
   f. Other: _____
8. What is your target blood sugar range?
   a. Between 80 – 110 mg/dL
   b. 110 – 120 mg/dL
   c. > 120 mg/dL
   d. Do not know
   e. Do not wish to answer
   f. Other: _____
9. Can you tell the symptoms of a low blood sugar?
   a. Yes
   b. No
10. Have you had any low blood sugar symptoms in the past month?
    a. Yes
    b. No

11. If yes, how often have you had a low blood sugar?
    a. More than 4 times a day
    b. Once a day
    c. Never
    d. Do not know
    e. Do not wish to answer
    f. Other: _____

If you have had symptoms associated with low blood sugar, please identify applicable symptoms from the following list:

Please check all that apply:

- □ Trembling or shaking
- □ Light headedness or dizziness
- □ Headache
- □ Hunger
- □ Numb lips or fingers
- □ Sweating
- □ Weakness
- □ Crying
- □ Irritability
- □ Lack of concentration or behaving strangely
- □ Other: _____

12. How do you treat low blood sugar?
    - □ I do not know
    - □ Drink juice
    - □ Take a glucose supplement or gel
    - □ Eat candy
    - □ Eat food
    - □ I choose to not treat my low blood sugar
    - □ Other: _____
13. Can you tell when your blood sugar is too high?
    a. I do not know
    b. Yes
    c. No
14. What do you do when your blood sugar is too high?
    - □ Nothing
    - □ Drink water
    - □ Drink broth
    - □ Exercise
    - □ Take medication
    - □ Call the doctor
    - □ Other: _____
15. In the past year, have you had an eye exam?
    a. Yes
    b. No

16. In the past year, have you had a dental exam?
    a. Yes
    b. No
17. In the past year, have you had a flu shot?
    a. Yes
    b. No
18. What educational topics would improve your diabetes management?
    - None
    - Meal planning
    - Dining out
    - Exercise
    - Blood sugar monitoring
    - Taking medications
    - Dealing with high or low blood glucose
    - Managing diabetes when you are sick
    - Foot and skin care
    - Preparing for pregnancy
    - Impotence/sexual dysfunction
    - Dealing with stress
    - Other_____
19. Do you follow a meal plan for diabetes?
    a. Yes
    b. No
20. Tell us about your meal plan: _____
21. Please provide information concerning your daily insulin(s) regimen.

	Time of Injection and Units	Time of Injection and Units	Time of Injection and Units	Time of Injection and Units	Time of Injection and Units
Insulin 1					
Insulin 2					
Other					

22. Age of diagnosis of type 1 diabetes: _____
23. Do you make any adjustments to your diet or insulin dose to be able to drink alcohol?
    a. Yes
    b. No
    c. If yes, please explain: _____
24. Do you have problems with exercise-related low blood glucose reactions?
    a. Yes
    b. No
    c. If yes, please explain: _____

25. What are symptoms of diabetes that you have had in the past 4 weeks?
    - None
    - Excessive thirst
    - Frequent urination
    - Weight loss
    - Blurred vision
    - Nausea or vomiting
    - Stomach bloating
    - Numbness of feet
    - Leg cramps
    - Leg pains when walking
    - Leg pains when resting
    - Fatigue
    - Chest pain
    - Shortness of breath
    - Numbness of hands
    - Other: _____
26. What gets in the way of you managing your diabetes?
    - Nothing
    - Stress
    - Work
    - Friends
    - Emotions
    - Money
    - Health problems
    - Lack of time
    - Lack of knowledge
    - Family
    - Other: _____
27. Who helps you with management of your diabetes?
    - Me
    - No one
    - Family
    - Co-workers
    - Healthcare provider
    - Support group
    - Other: _____
28. Have you had any low blood glucose reactions lately?
    a. Yes
    b. No
        a. What times of day? _____
        b. Have you ever passed out or had a seizure due to low blood glucose?
            i. Yes
            ii. No

29. Have you had any problems with infections?
    a. Yes
    b. No

    Check all that apply:
    - ☐ Acne
    - ☐ Burning on urination
    - ☐ Frequent colds
    - ☐ Itching in groin
    - ☐ Feet
    - ☐ Boils
    - ☐ Other: _____

30. Have you been hospitalized for your diabetes?
    a. Yes
    b. No

Most recent (in last year) date of hospitalization(s): _____
31. Why were you hospitalized? _____

Please provide information concerning your attitude about living with type 1 diabetes. This section is 27 questions and will take you approximately _tbd___ minutes.
This section will be set up as a table in Qualtrics

32. In general, I believe that I know what part(s) of taking care of my diabetes that I am **satisfied** with.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
33. In general, I believe that I know what part(s) of taking care of my diabetes that I am **dissatisfied** with.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
34. In general, I believe that I know what part(s) of taking care of my diabetes that I am ready to change.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always

35. In general, I believe that I know what part(s) of taking care of my diabetes that I am <u>not</u> ready to change.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
36. In general, I believe that I can choose realistic diabetes goals.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
37. In general, I believe that I know which of my diabetes goals are **most** important to me.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
38. In general, I believe that I know the things about **myself** that either help or prevent me from reaching my diabetes goals.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
39. In general, I believe I can come up with good ideas to help me reach my goals.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
40. In general, I believe that I am able to turn my diabetes goals into a workable plan.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always

41. In general, I believe I can reach my diabetes goals once I make up my mind.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
42. In general, I believe I know which **barriers** make reaching my diabetes goals are more difficult.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
43. In general, I believe that I can **think** of different ways to overcome barriers to my diabetes goals.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
44. In general, I believe that I can try out different ways of overcoming barriers to my diabetes goals.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
45. In general, I believe that I am able to decide which way of overcoming barriers to my diabetes goals works.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
46. In general, I believe I can tell how I'm feeling about **having** diabetes.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always

47. In general, I believe I can tell how I am feeling about **caring** for my diabetes.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
48. In general, I believe I know the ways that having diabetes causes stress in my life.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
49. In general, I believe I know the **positive** ways I cope with diabetes-related stress.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
50. In general, I believe I know the **negative** ways I cope with diabetes-related stress.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
51. In general, I believe that I can cope well with diabetes-related stress.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
52. In general, I believe that I know where I can get support for having and caring for my diabetes.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always

53. In general, I believe that I can ask for support for having and caring for my diabetes when I need it.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
54. In general, I believe that I can support myself in dealing with my diabetes.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
55. In general, I believe that I know what helps me stay motivated to care for my diabetes.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
56. In general, I believe I can motivate myself to care for my diabetes.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
57. In general, I believe I know enough about diabetes to make self-care choices that are right for me.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
58. In general, I believe that I know enough about myself as a person to make diabetes care choices that are right for me.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always

59. In general, I believe that I am able to figure out if it is worth my while to change how I take care of my diabetes.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always

The following statements describe self-care activities related to your diabetes. Thinking about your self-care over the last **2 months,** please specify the extent to which each statement applies to you. This section is 15 questions and will take you approximately __tbd__ minutes.
Note: If you monitor your glucose using continuous interstitial glucose monitoring (CGM), please refer to this where 'blood sugar checking' is requested.

60. I check my blood sugar levels with care and attention.
    a. Applies to me very much
    b. Applies to me a considerable degree
    c. Applies to me to some degree
    d. Does not apply to me
    e. Blood sugar measurement is not required as a part of my treatment.
61. The food I chose to eat makes it easy to achieve optimal blood sugar levels.
    a. Applies to me very much
    b. Applies to me a considerable degree
    c. Applies to me to some degree
    d. Does not apply to me
62. I keep all my doctors' appointments recommended for my diabetes treatment.
    a. Applies to me very much
    b. Applies to me a considerable degree
    c. Applies to me to some degree
    d. Does not apply to me
63. I take my diabetes medication (e.g. insulin, tablets) as prescribed.
    a. Applies to me very much
    b. Applies to me a considerable degree
    c. Applies to me to some degree
    d. Does not apply to me
    e. Diabetes medication/insulin is not required as a part of my treatment.
64. Occasionally I eat lots of sweets or other foods rich in carbohydrates.
    a. Applies to me very much
    b. Applies to me a considerable degree
    c. Applies to me to some degree
    d. Does not apply to me

65. I record my blood sugar levels regularly (or analyze the value chart with my blood glucose meter).
    a. Applies to me very much
    b. Applies to me a considerable degree
    c. Applies to me to some degree
    d. Does not apply to me
    e. Blood sugar measurement is not required as a part of my treatment.
66. I tend to avoid diabetes-related doctors' appointments.
    a. Applies to me very much
    b. Applies to me a considerable degree
    c. Applies to me to some degree
    d. Does not apply to me
67. I do regular physical activity to achieve optimal blood sugar levels.
    a. Applies to me very much
    b. Applies to me a considerable degree
    c. Applies to me to some degree
    d. Does not apply to me
68. I strictly follow the dietary recommendations given by my doctor or diabetes specialist.
    a. Applies to me very much
    b. Applies to me a considerable degree
    c. Applies to me to some degree
    d. Does not apply to me
69. I do not check my blood sugar levels frequently enough as would be required for achieving good blood glucose control.
    a. Applies to me very much
    b. Applies to me a considerable degree
    c. Applies to me to some degree
    d. Does not apply to me
    e. Blood sugar measurement is not required as a part of my treatment.
70. I avoid physical activity, although it would improve my diabetes.
    a. Applies to me very much
    b. Applies to me a considerable degree
    c. Applies to me to some degree
    d. Does not apply to me
71. I tend to forget to take or skip diabetes medication (e.g. insulin, tablets).
    a. Applies to me very much
    b. Applies to me a considerable degree
    c. Applies to me to some degree
    d. Does not apply to me
    e. Diabetes medication/insulin is not required as a part of my treatment.
72. Sometimes I have real 'food binges' (not triggered by hypoglycemia)
    a. Applies to me very much
    b. Applies to me a considerable degree
    c. Applies to me to some degree
    d. Does not apply to me

73. Regarding my diabetes care, I should see my medical practitioner(s) more often.
    a. Applies to me very much
    b. Applies to me a considerable degree
    c. Applies to me to some degree
    d. Does not apply to me
74. I tend to skip planned physical activity.
    a. Applies to me very much
    b. Applies to me a considerable degree
    c. Applies to me to some degree
    d. Does not apply to me
75. My diabetes self-care is poor.
    a. Applies to me very much
    b. Applies to me a considerable degree
    c. Applies to me to some degree
    d. Does not apply to me

Living with diabetes can sometimes be difficult, particularly regarding eating and diabetes management. Listed below are a variety of attitudes and behaviors regarding diabetes management. For each statement, choose the ONE answer that indicates how often this is true for you during the PAST MONTH. This section is 16 questions and will take you approximately __tbd__ minutes.
This section will become a table in qualtrics.

76. Losing weight is an important goal for me
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
77. I skip meals and/or snacks.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
78. Often people have told me that my eating is out of control.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always

79. When I overeat, I don't take enough insulin to cover the food.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
80. I eat more when I am alone than when I am with others.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
81. I feel that it's difficult to lose weight and control my diabetes at the same time.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
82. I avoid checking my blood sugar when I feel like it is out of range.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
83. I make myself vomit.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
84. I try to keep my blood sugar high so that I will lose weight.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always

85. I try to eat to the point of spilling ketones in my urine.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
86. I feel fat when I take all of my insulin.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
87. Other people tell me to take better care of my diabetes.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
88. After I overeat, I skip my next insulin dose.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
89. I feel that my eating is out of control.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always
90. I alternate between eating very little and eating huge amounts.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always

91. I would rather be thin than have good control of my diabetes.
    a. Never
    b. Rarely
    c. Sometimes
    d. Often
    e. Usually
    f. Always

Please provide information about behaviors and activities you experienced during the past month. This section is 17 questions and will take you approximately __tbd__ minutes. Before moving to the next question, you will need to provide an answer for the current question.

92. What sex do you identify with?
    a. Male ___
    b. Female ___
    c. Do not wish to answer ___
93. What is your race?
    a. American Indian or Alaska Native
    b. Asian
    c. Black or African American
    d. Native Hawaiian or other Pacific Islander
    e. White
    f. Hispanic or Latin
    g. Other _____
94. How tall are you *without* your shoes on? ____ feet _____ inches
95. How much do you weigh *without* your shoes on? ____ pounds
96. How many days a week do you drink alcohol?
    a. 7 days
    b. 6 days
    c. 5 days
    d. 4 days
    e. 2 to 3 days
    f. 1 to 2 days
    g. 0 days
97. How many drinks a session?
    a. Less than 2 drinks
    b. 2 drinks
    c. 3 drinks
    d. 4 drinks
    e. 5 drinks
    f. 6 or more drinks
    g. I do not drink
98. How many times during the last month have you used recreational drugs?
    a. None
    b. 1 time
    c. 2 to 3 times
    d. 4 to 5 times
    e. More than 5 times

99. How many days this week have you been physically active (exercised)?
    a. None
    b. 1 day
    c. 2 days
    d. 3 days
    e. 4 to 5 days
    f. 5 to 6 days
    g. 7 days
100. How many days this week did you participate in an activity that made your heart beat faster and/or breath heavier and/or break a sweat?
    a. None
    b. 1 day
    c. 2 days
    d. 3 days
    e. 4 to 5 days
    f. 5 to 6 days
    g. 7 days
101. On average, how many hours of sleep do you get a night?
    a. Greater than 8 hours
    b. 8 hours
    c. 7 hours
    d. 6 hours
    e. 4 to 5 hours
    f. 2 to 3 hours
    g. Less than 2 hours
102. What is your employment status (choose all that apply):
    a. Student
    b. Employed full time
    c. Employed part time
    d. Not employed, but looking for work
    e. Not employed, not looking for work
    f. Retired
    g. Homemaker
    h. Other: _____
103. How do you learn best?
    a. Listening
    b. Reading
    c. Observing
    d. Doing
    e. Other: _____

104. What is your level of education:
    a. Some high school
    b. High school graduate or equivalent
    c. Trade or vocational degree
    d. Some college
    e. Associate degree
    f. Bachelor's degree
    g. Graduate or Professional degree
    h. Other: _____
105. What is your current yearly salary?
    a. Below $15,000
    b. $15,000 - $30,000
    c. $30,000 - $45,000
    d. $45,000 - $60,000
    e. $60,000 - $75,000
    f. $75,000 - $100,000
    g. above $100,000
    h. Do not wish to disclose
106. Who do you currently live with?
    a. Alone
    b. With a roommate(s)/spouse
    c. With primary care giver/parent(s)
    d. With children and spouse
    e. Other: _____

Please click submit to finish the survey: SUBMIT
Next page:
If you would like to be placed in the drawing for the $200 Amazon.com gift card please provide an email _____.
Please reenter your email address here to assure that each character is correct
_____
Next page:
Help improve the future of diabetes research! Please provide an email to be interviewed about life with type 1 diabetes. _____
Please reenter your email address here to assure that each character is correct
_____
Thank you! Bailee Sawyer, RD, LRD

APPENDIX J. IRB APPROVAL

NDSU NORTH DAKOTA STATE UNIVERSITY

April 15, 2020

Dr. Sherri Stastny

Health, Nutrition & Exercise Sciences

Re: IRB Determination of Exempt Human Subjects Research:

Protocol #HE20244, "BARRIERS AND STRATEGIES TO DIABETES MANAGEMENT IN YOUNG ADULTS WITH TYPE I DIABETES"

Co-investigator(s) and research team: Bailee Sawyer

Date of Exempt Determination: 4/15/2020 Expiration Date: 4/14/2023 Study site(s): NDSU, online and via phone Sponsor: n/a

The above referenced human subjects research project has been determined exempt (category #2(iii) in accordance with federal regulations (Code of Federal Regulations, Title 45, Part 46, Protection of Human Subjects). This determination is based on the revised protocol submission (received 4/15/2020).

Please also note the following:

If you wish to continue the research after the expiration, submit a request for recertification several weeksprior to the expiration.
The study must be conducted as described in the approved protocol. Changes to this protocol must be approved prior to initiating, unless the changes are necessary to eliminate an immediate hazard to subjects.
Notify the IRB promptly of any adverse events, complaints, or unanticipated problems involving risks to subjects or others related to this project.
Report any significant new findings that may affect the risks and benefits to the participants and the IRB.

Research records may be subject to a random or directed audit at any time to verify compliance with IRB standard operating procedures.

Thank you for your cooperation with NDSU IRB procedures. Best wishes for a successful study. Sincerely,

Kristy Shirley

Kristy Shirley, CIP, Research Compliance Administrator

For more information regarding IRB Office submissions and guidelines, please consult https://www.ndsu.edu/research/for_researchers/research_integrity_and_compliance/institutional_review_board_i rb/. This Institution has an approved Federal Wide Assurance with the Department of Health and Human Services: FWA00002439.

INSTITUTIONAL REVIEW BOARD
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