

IDENTIFICATION OF DISORDERED EATING BEHAVIORS IN ADOLESCENTS WITH  
TYPE 1 DIABETES

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**Title**

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**DOCTOR OF NURSING PRACTICE**

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## ABSTRACT

Type 1 diabetes is a life-long chronic condition that typically presents in childhood, and approximately 193,000 Americans under age 20 are estimated to have either Type 1 or Type 2 Diabetes. Additionally, approximately 20-30% of adolescents with Type 1 diabetes have disordered eating behaviors or eating disorders. A common way disordered eating manifests in Type 1 diabetes is through manipulation of insulin dosages to promote hyperglycemia and subsequent weight loss. Disordered eating in diabetes can lead to short term complications such as diabetic ketoacidosis, severe hypoglycemia, and chronic long-term health conditions arising from complications of uncontrolled diabetes. Identification and screening for disordered eating in youth can lead to earlier intervention for those at risk and facilitate access to proper treatment.

The purpose of this practice improvement project was to educate providers in an urban midwestern pediatric endocrinology clinic on risk factors for disordered eating and implement a process workflow utilizing the Diabetes Eating Problems Survey-Revised (DEPS-R) screening tool. Descriptive statistics were used to determine the effectiveness of the screening tool into practice. Provider input was also evaluated regarding the implemented workflow and screening tool.

Following an education session with the clinic's providers, two out of three providers had perceived improvement in their knowledge about disordered eating behaviors in T1DM and felt the DEPS-R would be beneficial for practice. During the 6-week implementation process, 10.6% (n=5) of screened adolescents were detected as needing further evaluation for disordered eating behaviors. The post-project evaluation input from the providers indicated they felt the implemented workflow and DEPS-R process was helpful in detecting adolescents at risk for disordered eating behaviors.

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## LIST OF ABBREVIATIONS

DEB.....	Disordered Eating Behavior
T1DM.....	Type 1 Diabetes Mellitus
ADA.....	American Diabetes Association
IHT .....	Integrated Behavioral Health Therapist

## CHAPTER ONE: INTRODUCTION

Type 1 diabetes (T1DM) is a lifelong, chronic condition that typically presents in childhood. About 193,000 Americans under age 20 are estimated to have diagnosed Type 1 or Type 2 diabetes per the most recent estimates from the American Diabetes Association (Statistics about Diabetes, 2019). The ongoing maintenance of this disease can be overwhelming and stressful, with the primary focus for disease management consisting of counting the number of carbohydrates in food, current blood sugar, counting of precise insulin doses, along with the continual worry of hyper or hypoglycemia (King, King, Nayar, & Wilkes, 2017). Due to these constant worries, diabetes can lead to an increase in stress and anxiety in a child's life, leading to distress surrounding their diabetes (Goad, 2015). Approximately one-third of adolescents with T1DM experience significant distress about their diabetes, which includes dietary concerns, adherence to the regimen, or conflict with parents, leading to a worsening of their diabetes control (Hagger, Hendrieckx, Sturt, Skinner, & Speight, 2016). Similarly, the increased stressors with managing T1DM can lead to an increase in mental health disorders, with approximately one-third of adolescents reporting depression, anxiety, or disordered eating (Goad, 2015).

The SEARCH for Diabetes in Youth (SEARCH) is a significant National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) funded study, which launched in 2000 to study various aspects of diabetes management (SEARCH for Diabetes in Youth, 2020). There are currently over 27,000 participants in the study, from diverse racial backgrounds (SEARCH for Diabetes in Youth, 2020). The SEARCH study seeks to determine the prevalence of T1DM and T2DM in various age, sex, and ethnic groups and trends of diabetes in these groups (Hamman et al., 2014). SEARCH also examines the longitudinal effects of complications related to diabetes, including mental, physical, and social implications (Hamman et al., 2014). One

recommendation from the study is that the increasing trends of Type 1 and Type 2 diabetes in the United States require long-term follow-up to evaluate ongoing complications related to diabetes (Hamman et al., 2014).

Another condition that commonly affects adolescents in both the general population as well as those with T1DM is disordered eating. Research suggests that in the general population, children aged 9-14 years old, 7.1% of boys and 13.4% of girls have disordered eating behaviors (Treasure, Claudino, & Zucker, 2010). Common manifestations of eating disorders may include binge eating, fear of losing control over their eating, having guilt about eating, obsessively checking body weight, and dissatisfaction with body shape (Gagnon, Aimé, Bélanger, & Markowitz, 2012).

Per the most recent revision of the Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-V), there are four categories of disordered eating in the general population (American Psychiatric Association, 2013). The categories outlined are anorexia nervosa, bulimia nervosa, other specified feeding or eating disorder, and unspecified feeding or eating disorder. Per the DSM-V, anorexia nervosa is categorized by purposeful food restriction due to an extreme fear of weight gain with associated significant weight loss and disturbed self-image. Bulimia nervosa is associated with an affected individual feeling intense guilt or lack of control after eating large amounts of food, then subsequent elimination of the food through either vomiting, use of laxatives, fasting, or excessive exercise. Within the other specified feeding or eating disorder (OSFED) category, a person displays symptoms of a particular eating disorder but does not meet the full diagnostic criteria for that diagnosis, and the clinician communicates the specific reasons why the person does not meet standards. Diagnoses in the OSFED category could include atypical anorexia nervosa, bulimia nervosa, purging disorder, or night eating

syndrome. Finally, unspecified feeding or eating disorder describes feeding or eating disorders that cause distress and does not meet the full criteria for clinical diagnosis, and the clinician chooses not to communicate the reason why a person does not meet the requirements (American Psychiatric Association, 2013).

In Type 1 diabetes, there is an additional subtype that falls under OSFED; however, it has been colloquially identified as “diabulimia.” Diabulimia is a unique type of disordered eating in which an individual with diabetes will purposely restrict or omit insulin to cause hyperglycemia and subsequent glucosuria, which effectively creates a calorie deficit and weight loss (Doyle et al., 2017). Diabulimia or other disordered eating is present in approximately 30-40% of adolescents with T1DM (Larrangna, Docet, & García-Mayor, 2011). The abundance in available research demonstrates that disordered eating in T1DM is not a unique issue and spans multiple countries and cultures.

### **Significance of Proposed Project/Intervention**

The purpose of the practice improvement project was to educate healthcare providers at an urban pediatric endocrinology clinic on risk factors for adolescent youth with T1DM who may develop disordered eating behaviors (DEB) and implement a screening/referral process to more effectively identify and treat at-risk youth.

Per the recommendations in the 2019 American Diabetes Association Standards of Medical Care (“B” recommendation), eating disorders should be assessed in youth with T1DM between the ages of 10 and 12 using a validated screening tool, such as the Diabetes Eating Problems Survey- Revised (DEPS-R)(American Diabetes Association, 2019). Diabetes with co-morbid disordered eating behaviors can lead to short-term complications such as diabetic ketoacidosis, severe hypoglycemia, and chronic long-term health conditions arising from

complications of their uncontrolled diabetes. However, identification of DEB in people with diabetes may be difficult due to discomfort by the providers in approaching the topic of disordered eating and lack of experience in the identification of such practices (Tierney, Deaton, & Whitehead, 2009). The research by Tierney et al. (2009) provided in-depth interviews with practitioners who had experience in working with youth who have T1DM and DEB. The investigators suggested certain people with T1DM felt pressured to have “good” glycemic control and subsequently developed an extremely restricted diet leading to DEB. Interestingly, the study also revealed that providers were reluctant to approach eating behavior topics and desired a screening tool to identify those youth with inappropriate eating behaviors more adequately. Screening for disordered eating in adolescents with Type 1 diabetes through the use of a validated survey screening tool, such as the Diabetes Eating Problems Survey- Revised (DEPS-R), can lead to earlier identification for those at risk and facilitate access to proper treatment.

### **Project Objectives**

To better assess the extent of DEB in pediatric patients who have Type 1 DM and receive care at the participating endocrinology clinic, a practice improvement project was implemented with the following objectives:

1. Educate clinic staff regarding the risk factors for DEB in youth diagnosed with Type 1 diabetes.
2. Educate the clinic staff regarding the use of the Diabetes Eating Problems Survey- Revised (DEPS-R) screening tool.
3. Implement a DEPS-R workflow into practice during a 3-month span to identify youth aged 10-18 diagnosed with Type 1 diabetes who are at risk for DEB.

4. Develop referral strategies to behavioral health for further evaluation of youth who score positively on the DEPS-R screening tool.

## **CHAPTER TWO: REVIEW OF LITERATURE**

### **Background/Incidence of Type 1 Diabetes**

#### **Pathophysiology of Type 1 Diabetes**

T1DM is an autoimmune disease that affects pancreatic beta-cell function and causes a disruption in insulin production (Childs, Cypress, & Spollett, 2017). Insulin is a crucial hormone in the way the body uses glucose for essential metabolic functioning. As a result of insulin deficiency, glucose is unable to be utilized. Subsequently, glucose remains in the bloodstream and causes elevated blood sugar. A non-diabetic person's typical fasting blood sugar is 70-100 mg/dl, and peak level after eating is generally less than 140 mg/dl (Childs et al., 2017).

Guidelines for diagnosing T1DM is when a person's fasting blood sugar is higher than 126 mg/dl on two separate occasions, or when A1c, which measures a three-month average of blood sugars, is greater than 6.5% (Dimeglio, Evans-Molina, & Oram, 2018). When the blood sugar is chronically above these levels, the body's compensatory mechanism is to eliminate excess glucose through the kidneys and urine, leading to an increase in urination and, subsequently, thirst. Also, concurrent with that compensatory process, when an insulin deficiency is present, the body will begin a breakdown of fat for energy consumption, leading to weight loss (Dimeglio et al., 2018). Exogenous insulin administration is then required for glucose homeostasis (Childs et al., 2017).

#### **Prevalence and Incidence**

Currently, the worldwide prevalence of diabetes is 22.9 cases per 100,000 people, age 65 or younger; however, this figure is rising at approximately 2-3% per year (Dimeglio et al., 2018). In North Dakota, the prevalence is 14.8-18.0/10,000 person-years (Rogers, M., Rogers, B., & Basu, 2018). The incidence of T1DM in childhood continues to trend upwards and has risen



approximately 2.8%–4.0% each year over the last several years (Zysberg & Lang, 2015). The SEARCH study for diabetes, however, found after adjusting for age, sex, race, the annual increase was approximately 1.8% in the years of 2002-2012 (Mayer-Davis et al., 2017; American Diabetes Association, 2019). Currently, the incidence rate peaks between the ages of 10–14 years (Maahs, West, Lawrence, & Mayer-Davis, 2010). In 2011-2012, the number of children diagnosed with T1DM in the United States was 17,900 (Mayer-Davis et al., 2017).

## **Management**

T1DM must be managed through careful measurement of blood sugars, carbohydrate counting, and insulin administration. The landmark study, the Diabetes Control and Complications Trial (DCCT) stressed the necessity of intensive insulin therapy for lowering A1c for reduction of complications from diabetes and was instrumental in guiding current diabetes management guidelines (National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], n.d.; The Diabetes Control and Complications Trial Research Group, 1993).

Intensive therapy, defined as three or more injections of insulin per day, and monitoring of blood sugars at least four times a day, has been proven to reduce the risk of retinopathy, nephropathy, and neuropathy; however, with such intensive therapy, the risk for hypoglycemia is higher (The Diabetes Control and Complications Trial Research Group, 1993). Additionally, the addition of insulin can cause weight gain, with those in the intensive insulin group gaining an average of 10 pounds more than the traditional management group (Childs et al., 2017).

The risk of early death is reduced or eliminated with the maintenance of blood sugars in goal range (NIDDK, n.d.). The ADA recommends for children with T1DM that blood sugars prior to meals should be 90-130 mg/dl, or target A1c of 7.5% or less (American Diabetes Association, 2019). Frequent blood sugar monitoring provides a snapshot of the blood sugar at a

certain point in time and is influenced by recent food intake, level of activity, illness, or other multiple factors (Dimeglio et al., 2018). There have been technological advances to help ease the burden of fingerstick monitoring through continuous glucose monitoring (CGM).

Continuous glucose monitoring has been a tool used with increasing frequency to eliminate the need for frequent finger-sticks as it provides an updated blood sugar readout every five minutes to help the user detect hyper and hypoglycemia more readily (Childs et al. (2017). A person with T1DM must frequently think about and constantly be reminded about their current blood sugar to have appropriate control of their disease.

In addition to frequent blood sugar monitoring, precise carbohydrate counting, and insulin administration must be considered (Dimeglio et al., 2018). People with T1DM often administer insulin through multiple daily subcutaneous injections; however, many children and adolescents use an insulin pump to manage their blood sugars (Childs et al., 2017). A few of the tasks the child must consider before administering insulin are the current blood sugar, the number of carbohydrates to be eaten, and the last insulin dosing. These duties require complex calculations for accuracy, and miscalculation can lead to severe hyper or hypoglycemia (Childs et al., 2017). Therefore, to prevent complications from diabetes, a delicate balance must be maintained between a person's blood sugar, insulin intake, and the food consumed.

### **Common Adolescent Challenges**

Adolescence is a time of rapid change. The American Academy of Pediatrics: Bright Futures divides adolescence into three categories: early adolescence, middle adolescence, and late adolescence, each with common attributes for the individual stage. Early adolescence is defined age youth aged 11-14; middle adolescence encompasses youth age 15-17; and late adolescence is ages 18-21 (Hagan, Shaw, & Duncan, 2007).

In early adolescence, not only are physical changes beginning to manifest, psychological and social changes are also occurring. The early adolescent seeks to identify with their peers as well as gain independence from parental oversight (Hagan et al., 2007). The adolescent in this age group may engage in risky behaviors in an effort to impress friends. Diabetes may affect this cohort by causing embarrassment when doing insulin injections and refusal to perform diabetes self-management care to exert independence with their disease or conform to their peers. Early adolescents may also become upset with frequent reminders on managing their diabetes (Childs et al., 2017).

In middle adolescence, body image and appearance become more important to the adolescent. The adolescent may begin to engage in risky behaviors related to maintaining their health, such as questioning if a particular medication is necessary (Hagan et al. 2007). Middle adolescence is also a stage where there is a risk of developing mental health concerns, namely depression and anxiety or conduct disorders (Hagan et al. 2007). Concerning diabetes management, children in middle adolescence continue to become more independent in their management of their diabetes with less parental oversight; however, they may begin doing other risky behaviors, such as alcohol intake, which can affect their ability to manage their diabetes (Childs et al., 2017).

During late adolescence, physical changes have slowed, and the adolescent may have a more established idea of their self-identity. Children in late adolescence are beginning to transition further into adulthood and take on more adult responsibilities (Hagan et al., 2007). Some challenges the late adolescent cohort may experience include determining how to be fully independent with the broader aspects of diabetes management, such as making appointments to

see their provider. Additional tasks, such as ordering supplies for their diabetes management and managing college life along with their diabetes, are also common (Childs et al., 2017).

A common thread in adolescents with diabetes is a desire to “fit in.” Having diabetes can make the adolescent feel like they are abnormal or different (Chao, Minges, Murphy, Grey, & Whittemore, 2016). Some adolescents desired “forgetting” they had diabetes and wanted to “be the same as everyone else” (King et al., 2017, pg. 28). Adolescents who tended to have poorer management of their diabetes performed behaviors to avoid being viewed differently (Rassart et al., 2018).

In addition to the routine tasks of diabetes management, such as checking blood sugars regularly and injecting insulin, there is a prevailing feeling of always having to watch dietary intake. Adolescents felt it was difficult to determine what was “appropriate” to eat and felt that their intake was always observed (Chao et al., 2016). These daily reminders of feeling different from their peers, the constant day-to-day tasks, and the need to continually think about their diabetes lead to more low moods (King et al., 2017). As these low moods grow more frequent and cause increasing negativity towards their disease, the less likely youth are to be engaged in their diabetes management, leading to higher A1c levels (Goad, 2015). The poor moods can lead to ineffective strategies for managing their diabetes, as well as increased depression and anxiety.

There is also a struggle between gaining independence with their diabetes and how their management is perceived. As a child moves through adolescence, they are expected to accept additional tasks regarding their diabetes management (Rassart et al., 2018). Adolescents have varying levels of support as they age, and transition towards independence is not well understood (Zysberg & Lang, 2015). As adolescents gain more autonomy with their diabetes, there is a sense of pressure to have “perfect” control (Chao et al., 2016). Discussions with healthcare

providers often involve the parents, and the adolescent may not feel an active participant in their care (King et al., 2017). Distress about diabetes may then lead to strained relationships with both parents and healthcare providers (Rassart et al., 2018).

With these additional tasks and decreased parental oversight, there can be less focus on diabetes management by the adolescent (Hood et al., 2014). Interestingly, however, parents who become overly involved in their child's diabetes management can take away their confidence in managing their diabetes and cause increased parental conflict (Hagger et al., 2016).

Additionally, having a parent who is too controlling of a particular diet may disrupt the child's self-control and feeding behaviors (Conviser et al., 2018).

### **Psychological Disorders in Diabetes**

Since adolescence is a time of emerging independence, the addition of a chronic disease can lead to an increase in anxiety and depression surrounding the management of their disease (King et al., 2017). The age of onset of diabetes can impact coping with their illness (Dybdal et al., 2018). There is a risk of psychiatric disorders, increasing with each year from early to late childhood, with the highest risk seen in children diagnosed with T1DM between 10 to 14 years of age (Dybdal et al., 2018). Goad (2015) suggests approximately 50% of people with T1DM are diagnosed with a psychiatric condition within one year of diagnosis, with the most common co-morbidity being depression; however, Hood et al., (2014) found nearly 50% of adolescents were diagnosed with a psychiatric disorder within ten years of their T1DM diagnosis. Other psychiatric diagnoses that a child is at risk for may include anxiety, eating disorders, somatoform disorders, substance abuse, and personality disorders (Dybdal et al., 2018). Despite differing research on when co-morbid mental illness begins, there is a high risk of developing a psychiatric condition in T1DM.

Using data from the SEARCH for diabetes study, Hood et al. (2014) described that as psychological distress increased in adolescents within the first six years of their T1DM diagnosis, so did the worsening of their diabetes control. These children viewed diabetes as having a significant impact on their everyday life, in addition to disrupting their social life and academic performance. As the adolescent had increasing diabetes burden and increasing depression, less focus was placed on checking blood sugars, adjusting insulin, and troubleshooting unexpected glucose excursions (Hood et al., 2014).

Anxiety is another common psychological disorder present in T1DM. Currently, the lifetime risk of generalized anxiety disorder and co-morbid diabetes (Type 1 or Type 2) is approximately 19.5% (Young-Hyman et al., 2016). The anxiety a child may experience with the management of their diabetes can include real-life concerns regarding hypoglycemia. Hypoglycemia is a common fear in adolescents with T1DM and may cause the child to keep their blood sugars elevated to prevent hypoglycemia--despite them knowing they should keep their blood sugars in a recommended range (King et al., 2017).

### **ADA Recommendations**

Due to the prevalence of psychological distress in those with T1DM, the American Diabetes Association (ADA) has put forth recommendations for mental health care. In a position statement from 2016, the ADA suggests providers should partner with mental health providers, preferably those with expertise in diabetes, to care for those with the disease. Further, routine assessment of psychological disorders, including depression, anxiety, and DEB, should be performed for everyone with T1DM periodically, whether there is an identified issue or not. The ADA also suggests additional psychological assessment should be performed during significant life changes, including an intensification of diabetes treatment, or times of transition

(Young-Hyman et al., 2016). Times of transition may include adolescence or a shift into adult life.

### **Disordered Eating in Type 1 Diabetes**

DEB in T1DM has conflicting prevalence rates. Conviser, Fisher, & McColley (2018) suggests that elevated levels of disordered eating were most common in children with any chronic illness, with rates between 11 and 70% of subjects. Hanlan, Griffith, Patel, & Jaser (2013) suggest DEB are as common as 37.9% in females and 15.9% in males with T1DM. Other studies suggest that eating disorders problems are more common in adolescents with T1DM, as much as twice as common, compared with peers without T1DM (Young et al., 2013; Clery, Stahl, Ismail, Treasure, & Kan, 2017). Despite these varied prevalence rates, the research suggests disordered eating in diabetes is a pervasive problem, affecting at least a portion of this population.

### **Risk Factors for Disordered Eating in Diabetes**

Numerous risk factors may increase the development of disordered eating in T1DM, such as adolescent age, higher body mass index, and conflict in how a family copes with the diagnosis of diabetes (Hanlan et al., 2013; Doyle et al., 2017; Nip et al., 2019). Clinical suspicion must be aroused when these risk factors are present, along with clues of worsening diabetes control.

Pinhas-Hamiel et al. (2013, pg. 820) outline some clinical hints for intentional insulin manipulation, which include “a decrease in the frequency of daily glucose monitoring, forgetting to bring the glucometer to medical appointments, using several glucometers, changing dates and battery before the appointments, and refusing to be weighed.”

Technology has eased some of the burdens of managing diabetes care through continuous glucose monitors and insulin pumps. While these technological advances may improve diabetes

management with a constant readout of blood sugars and encouraging independent insulin administration, there is also a risk of misuse among those with DEB (Hanlan et al., 2013). Due to less parental oversight, a child may more easily manipulate how much insulin they receive with their meals. The child may also feel more confident with the constant blood sugar readout that they will prevent severe glucose excursions related to the manipulation of this insulin (Hanlan et al., 2013).

### ***Age***

Age can be a risk factor for the development of disordered eating patterns, as DEB often manifests in adolescence (Nip et al., 2019). The average age for disordered eating behaviors in the general population is between 10 and 19 (Treasure et al., 2010). Additionally, the age at which a child is diagnosed with diabetes can also influence the development of DEB. Hanlan et al. (2013) describe a study which found that females diagnosed with T1DM between the ages of seven and 18 years were at a significantly higher risk for developing an eating disorder, compared to those who were diagnosed with diabetes in either young childhood or early adulthood. The females also had a high chance of continuing into adulthood if left untreated. Bulimia nervosa and binge eating disorder are also more likely to have onset during adolescence (Goad, 2015).

### ***Family Stressors and Adjustment to Diabetes***

How a family copes, addresses, and manages a child's diabetes may also be a critical factor in the development of DEB in T1DM. A new diagnosis of diabetes can be very stressful for families, and there may be differing opinions in the family on how to manage day-to-day responsibilities. The need to manage the numerous aspects of diabetes is often a source of conflict among family members (Zysberg & Lang, 2015). A child may pick up on the tension



between family members, and this may present negatively in the management of their diabetes. The difficulty adjusting to the tasks of diabetes may lead to avoidance of conflict with healthcare providers and their family members (Young-Hyman, & Davis, 2010). Subsequently, avoidance behaviors may increase the risk of disordered eating (Conviser et al., 2018).

Family cohesion at mealtimes can also influence diabetes management surrounding insulin intake. Families who have disorganized or erratic eating patterns or families with a focus on weight and weight loss have nearly twice as high likelihood of having a child with DEB (Hanlan et al., 2013). The parent's focus on their personal eating habits, weight, and body shape may shape a child's thoughts on their body type (Conviser et al., 2018). In addition to critiquing their own body, parents may also critique their child's weight, and these negative comments concerning their body increase the risk of DEB (Conviser et al., 2018). Clearly, a child may be influenced by family members' behaviors towards weight and begin critiquing their own weight.

### ***Gender***

Studies have suggested that females are at higher risk of developing DEB in the general population; this is no different in studies comparing disordered eating in diabetes with the general population (Treasure et al., 2010; Nip et al., 2019). In female adolescents with T1DM, the risk of developing DEB is as much as twice as high as males with T1DM (Hanlan et al., 2013).

However, males with T1DM are also at risk for DEB, as much as twice as likely when compared with males without chronic illness (Markowitz et al., 2010). Males with T1DM who have higher BMIs and a desire for thinness are also at risk for the development of DEB (Young-Hyman & Davis, 2010). Thus, clinicians should have a high index of suspicion when they

encounter an emerging adult who is overweight and is in poor metabolic control, regardless of sex (Doyle et al., 2017).

### ***BMI***

Weight and desire for weight loss can significantly impact diabetes management. With insulin administration, a typical side effect is weight gain, which can lead to more considerable distress about body shape and increase the risk for DEB (Pinhas-Hamiel et al., 2013). A shared body type in adolescents with T1DM and DEB is a BMI in the overweight range (Young-Hyman, & Davis, 2010). Further, adolescents who scored positively on eating disorder screening tests typically do not have muscle wasting or fat loss, but actually have elevated BMIs with a correlating elevated A1c level (Doyle et al., 2017; Nip et al., 2019). Additionally, a frustration shared by some adolescents with T1DM is the need to treat hypoglycemia associated with exercise by eating, leading to the negating of the benefits of the activity (King et al., 2017).

### **Complications**

Complications related to diabetes are generally associated with poor diabetes management and may include short-term consequences and long-term effects. Acute complications are related to hyperglycemia (classified as a blood sugar level over 200 mg/dl), or severe hypoglycemia (blood sugar of less than 55mg/dl) (American Diabetes Association, 2019; Glaser, 2019). Severe hypoglycemia is an acute lack of glucose in the blood, which leads to a sudden deficiency of glucose for brain function. Hypoglycemia can lead to disorientation and confusion, seizure, or even death in severe cases. In all people with T1DM, hypoglycemia that is severe enough to warrant external assistance occurs at rates of 16-20 per 100 person-years (Dimeglio et al. 2018). Acute hyperglycemia can lead to hospitalization or death through diabetic ketoacidosis. In the pediatric setting, diabetic ketoacidosis requiring hospitalization

occurs at rates of 1-10 per 100 person-years (Dimeglio et al., 2018). Potential long-term complications of diabetes include macro and microvascular changes, which increase a person's risk of heart attack, stroke, blindness, amputations, or renal failure (Conviser et al., 2018).

There may be clinical clues present that are indicative of the physical manifestations of an eating disorder, which may include dizziness, degradation of tooth enamel, electrolyte imbalance, constipation or diarrhea, and decreased intestinal motility (Gagnon et al., 2012). Similar to the complications related to poor diabetes management, there are short-term and long-term consequences related to undetected disordered eating in diabetes. In addition to the variability in blood sugars, other short-term effects on a child with diabetes due to insulin restriction is dehydration, and risk of developing infections, such as urinary tract or mycotic infections (Larrangna et al., 2011). Other short-term consequences of T1DM-associated disordered eating include more frequent episodes of diabetic ketoacidosis (DKA) and hospitalizations (Clery et al., 2017).

If the DEB is chronic, the child is at risk for persistently elevated blood sugars and long-term complications of diabetes (Conviser et al., 2018). The typical long-term complications of diabetes may include kidney failure, eye disease, cardiovascular disease, and even death (Larrangna et al., 2011). Even more concerning, both Markowitz et al., (2010) and Larrangna et al., (2011) indicate there is a 3-fold increased risk of mortality when insulin restriction and subsequent hyperglycemia is used as a weight-loss measure. Life span may be shortened to an average age of death of 45 years, as compared to 58 years among those who take insulin as indicated (Larrangna et al., 2011).

## **Identification of Disordered Eating Behaviors**

Identification of DEB can be challenging in people with T1DM. Actions such as dietary restraint, precise carbohydrate counting, and regular exercise are prescribed components of diabetes care; however, when these behaviors are misused to encourage unhealthy weight loss, they are suggestive for DEB (Young et al., 2013). Risk factors for disordered eating can help narrow clinical suspicion when there is a worsening in blood sugar control. However, there may be other reasons for the omission of insulin. These reasons may include poor compliance, denial of the disease, avoidance of injecting insulin in social settings, as well as a fear of hypoglycemia (Pinhas-Hamiel et al., 2013).

Insulin manipulation for weight loss is only one part of a constellation of reasons for worsening diabetes control. A thorough history taking is essential to recognize concern for DEB. Gagnon et al. (2012) indicate that assessment is a vital tool in the early identification of disordered eating, as the adolescent may not have the foresight to realize their behaviors are disordered. Direct, non-judgmental questioning by the provider or the use of a screening tool can aid in identification for this group (Gagon et al., 2012).

Various validated screening tools for disordered eating behaviors are available. Questions involved in the screening questionnaires for DEB in the general population can include questions about the concern with body weight, appearance, and attitudes surrounding food. Markowitz et al. (2010) noted that while these scales help screen for DEB in the general population, they may not be appropriate for people who require special diets, such as those with T1DM. T1DM often requires a focus on food portions, types of foods consumed, and counting of carbohydrates or calories for successful management of blood sugars. Measurements meant for the general population may overestimate the prevalence of DEB in adolescents with diabetes

(Markowitz et al., 2010). Also, screening tools meant for the general population do not inquire about the manipulation of insulin and will miss patients with diabulimia (Doyle et al., 2017). Therefore, a tool designed specifically for the T1DM population is likely the most effective in detecting DEB in adolescents with T1DM.

### **Diabetes Eating Problems Survey-Revised (DEPS-R)**

The Diabetes Eating Problems Survey (DEPS) was developed to achieve the goal of identification of disordered eating in the diabetes population. When the DEPS was developed in 2001, it became a first step for the detection of DEB in diabetes; however, it was designed before the updated recommendations for intensive insulin therapy, and validation studies were only completed in the adult population Markowitz et al. (2010). Thus, Markowitz et al. (2010) developed the Diabetes Eating Problems Survey- Revised (DEPS-R) in 2010. The DEPS-R is a diabetes-specific screening tool tailored to encompass some of the typical day-to-day management of T1DM and can effectively include or exclude behaviors that would be considered a positive screen in the general adolescent population (Doyle, 2017). The DEPS-R screen tool (Appendix A), assesses practices that would be considered questionable regarding both food and insulin management. The tool is a 16 question Likert-scale survey, scored from zero to five, with zero being “never” and five being “always.” The DEPS-R tool scale was validated for use in individuals with T1DM, aged 10-19, and the adolescent can complete the survey in less than 10 minutes (Markowitz et al., 2010).

During the initial validation study of the DEPS-R by Markowitz et al., (2010), 112 adolescents aged 13-19 (mean age 15.1 +/- 1.2 years) with T1DM were screened for disordered eating. The study population consisted of 56% female participants and 44% male participants. The average length of time of life with T1DM was approximately 7.5 +/- 3.7 years, and they had

an average A1c of 8.7 +/- 1.7%. During the validation study, the DEPS-R tool demonstrated excellent internal consistency with a Cronbach alpha of 0.86. External validity was measured by comparing provider responses of adolescents identified as insulin restrictors and DEPS-R score of 20 or greater. There was also a correlation of DEPS-R scores with A1c levels, poor glucose monitoring, age, gender, BMI, and the adolescent's perceived diabetes burden. The results of this study demonstrated that those with the highest A1c levels and consistently missed or restricted their insulin typically scored 20 or higher on the DEPS-R tool (Markowitz et al., 2010). Furthermore, using a SEARCH for Diabetes in Youth cohort, Nip et al. (2019) examined the use of the DEPS-R tool in adolescents aged 10-25 with T1DM (n=2,156) and T2DM (n=149). Nip et al. (2019) determined the prevalence of DEB to be 21.2% of people with T1DM, with a mean DEPS-R score of 12.7 +/- 10.3. The highest positive scores were in the 15-19-year-old age group (24.9%), followed by 16% of those aged 10-14.

Several follow-up studies have also confirmed the validation for the use of the tool in the adolescent population in other countries. In a study done by Wisting et al. (2013), the DEPS-R was given to a larger population of 770 children and adolescents aged 11-19 years (mean age 14.6) with T1DM in Norway. The average DEPS-R scores were 11.0 for the total sample population, 7.7 for the males, and 14.2 for the female participants. Wisting et al. (2013) determined correlations between age, A1c, BMI, and DEPS-R scores, though the relationship was mixed between the variables. The study concluded that the DEPS-R demonstrated good validity with a Cronbach alpha of 0.89 and supported the use of the survey in screening adolescents.

## **Early Identification and Treatment**

Early identification of DEB in adolescents with T1DM is essential for facilitating treatment. If DEB develops in adolescence, there is a higher chance of it continuing into adulthood (Hanlan et al., 2013). Daily lifestyle and assessment of the emotional status of the child must be considered to achieve successful diabetes management (Young-Hyman et al., 2016). Further, assessment of and decreasing distress related to diabetes, as well as establishing healthy practices, may lead to better management of diabetes later in life (Rassart et al., 2018; Hagan, Shaw, & Duncan, 2007).

Research into effective treatments for adolescents who have co-morbid T1DM and disordered eating is limited; however, various therapies are available for the treatment of eating disorders in the general population. Intensive psychotherapy, including cognitive-behavioral therapy (CBT), family therapy, and medication therapy, have been used for the treatment of eating disorders. For those who have anorexia, there is moderate evidence for the use of family therapy (Treasure et al., 2010). Additionally, CBT and increasing parental involvement were most effective for improving psychosocial outcomes (Hagger et al., 2016).

Parallels can be drawn from this research to the utility of treatment for DEB in T1DM, even though there have been few treatments explicitly designed for those with T1DM and disordered eating (Hanlan et al., 2013; Gagnon et al., 2012). Inpatient hospitalization, CBT, and pharmacological seem to be proven interventions along with nutrition counseling with a dietitian (Hanlan et al., 2013). Gagnon et al. (2012) and Larrangna et al. (2011) also note that a multidisciplinary approach, including a mental health specialist, dietitian, and diabetes education team, tends to be the most effective treatment strategy. Family intervention may also be of benefit for treatment (Clery et al., 2017; Young-Hyman et al., 2016).

Unfortunately, eating disorders in the general population are typically refractive to treatment, with half of the persons with anorexia never recovering from their eating disorder (Harrington, Jimerson, Haxton, & Jimerson, 2015). In those with anorexia, the longer the disease is present, the more treatment is refractive to the therapy. (Treasure et al., 2010). For those with bulimia, pharmacological therapy, CBT had the most significant impact on treatment. People with binge eating disorder had positive responses to pharmacological treatment and CBT (Treasure et al., 2010). People with bulimia have slightly more favorable odds of recovery, with approximately 80% of patients achieving remission (Harrington et al., 2015). However, Gagnon et al. (2012) and Nip et al. (2019) note early intervention and implementation of therapy for DEB are associated with a better prognosis and remission, and Treasure et al. (2010) found that adolescents have the best response to treatment. In other words, early identification of DEB in adolescence is crucial for initial intervention and treatment.

## **Theoretical Framework**

### **The Plan, Do, Study, Act (PDSA) Model**

The Plan, Do, Study, Act (PDSA) model is a framework for change, developed by the Institute for Healthcare Improvement. This model guides nurses and other clinicians in making decisions about clinical and administrative practices that affect patient outcomes. Figure 1 outlines the steps that are included in this model, which include asking “What are we trying to accomplish?”, “How will we know that a change is an improvement?” and finally, “What change can we make that will result in an improvement?” (Langley et al., 2009). For the purposes of the practice improvement project, the PDSA will be used to determine whether provider knowledge was gained on DEB and the DEPS-R, results of the implementation of DEPS-R, and provider



evaluation on the practice improvement project. To use the PDSA model effectively for the practice improvement project, each of these questions will be addressed and answered.

### ***Plan***

The first step of this framework is developing a plan to test the change, including the questions “Who, What, When, Where, and What data need to be collected?” (Langley et al., 2009). These questions help to streamline a plan for the improvement project and narrow the focus for the project. The two groups identified for the project are providers who care for children with T1DM at a local pediatric endocrinology clinic and youth with T1DM who potentially have disordered eating patterns. In the selected clinic, there is no formal process for identifying adolescents at risk. Using current recommendations from the ADA, a plan was created to implement change into this clinic to begin screening for DEB in youth with T1DM using a validated screening tool, as well as creating a process for consistent referral to mental health services.

### ***Do***

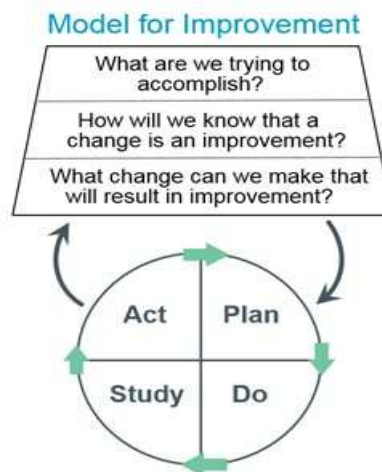
The next step in the PDSA model is Do, which includes implementation of the project, as well as observation of any barriers that may arise (Langley et al., 2009). In relation to the practice improvement project, this step included the development of the suggested workflow that was implemented into the clinic. An education session was held with staff regarding the risk factors for DEB and background/scoring of the DEPS-R survey. A post-education survey and post-project evaluation was administered to the providers to assess their thoughts regarding the implementation and evaluation of the DEPS-R survey and workflow. The Do step is further outlined in Chapter Three: Methodology.

## ***Study***

The Study step in the PDSA model includes an analysis of the collected data. Results from the provider post-education surveys, DEPS-R results, and post-project evaluation surveys were reviewed for provider input regarding the workflow process. The analysis of provider surveys and DEPS-R results aided in changes for the next cycle of PDSA, including studying of barriers to the project, limitations, and recommendation for future research. The Study step is further outlined in Chapters Four and Five: Results and Discussion, respectively.

## ***Act***

Finally, the Act step involves the synthesis of the information and recommendations for changes to the implemented workflow to be made. Areas of improvement, including barriers to the adolescent receiving the survey, were identified and the results of the project were shared with the clinic providers. Recommendations for the next PDSA cycle were also shared. Finally, the results were disseminated to the clinic's leadership through an executive summary.



*Figure 1. PDSA Model. From The Improvement Guide: A Practical Approach to Enhancing Organizational Performance (2nd edition) by Langley et al, 2009, San Francisco: Jossey-Bass Publishers. Reprinted with permission.*

## **Nursing Theory: Theory of Families, Children, and Chronic Illness**

The way a nurse interacts with their patients has been an area of considerable study and are guided by underlying principals and illustrated using theoretical models. One such theory, the mid-range Theory of Families, Children, and Chronic Illness, was developed by Dr. Maureen Frey, RN, Ph.D., and was derived from Imogene King's Theory Systems Framework. King's theory sought to explain the interacting systems on a child with a chronic illness and their family. According to Imogene King, there are three dimensions of systems: personal systems, interpersonal systems, and social systems (Frey, 1989). The personal system includes the individual, and the concepts of "self, perception, growth and development, time, personal space, and coping" (Sieloff, Frey, & King, 2007). Interpersonal systems may include the patient's interaction with others, such as a nurse or healthcare provider. Finally, the social system may consist of the family, religious areas, educational system, work, or healthcare system (Sieloff et al., 2007). These interacting systems influence a person's maintenance of health.

Taking this a step further, Dr. Frey developed her theory, the Theory of Families, Children, and Chronic Illness (Frey, 1989). Her theory tested King's theory and strived to explain the effects of stressors associated with chronic illness on a child and their family. Frey noted, "King's systems framework for nursing provides structure and function for understanding the complex interplay of factors that influence family and child health when the child has a chronic illness" (Frey, 1995). The Theory of Families, Children, and Chronic Illness is particularly unique to the care of children with diabetes, as Maureen Frey chose to specifically study the effect of Type 1 diabetes on the child and family.

In her theory, she outlines how illness factors, social support, family health, health actions, and child health interact with each other. Illness factors include the duration of the

chronic illness, age at onset, illness status, and child's perception of severity. Parental support and child support are interlinked and influence each other's general illness satisfaction.

Structure, coping skills, resource availability, and stressors all influence the family's health, which has a rebound effect on the child's general health and illness management. Finally, the child's health is shaped by role competence, school attendance and performance, perception of health, and physical/mental status. Frey noted, "predictors of child health for youths with IDDM [insulin-dependent diabetes mellitus] were general health and illness management behaviors, illness variables of age at diagnosis, and duration of illness, and, less frequently, the family health variables of cohesion and adaptability" (Frey, 1995, pg. 114). These same variables that interact with the child can influence the development of DEB in T1DM. The literature has shown that poor family cohesion and conflict can have a negative effect on the child; likewise, the child's mental status can affect their self-care.

Dr. Frey hypothesized and determined that social support when dealing with a chronic illness can have a significant impact on the health of the family, and as a result, the health of the child. Dr. Frey's perspective helps reinforce further support for the entire family can impact the overall health of a child with T1DM. Dr. Frey also emphasizes that chronic illness management in T1DM should not only include physical health maintenance, but also an assessment of mental health and stressors on the child, and what their perception of their health is (Frey, 1995). Dr. Frey's theory can guide the participating organization by incorporating a mental status assessment into their clinic and allowing for a more in-depth assessment of the child's social factors to improve the overall wellness of the child.

## **CHAPTER THREE: METHODS**

The overall goal of the project was to educate specialty diabetes providers about adolescents with T1DM who are at risk for DEB and implementation of the DEPS-R screening tool/workflow to aid in the identification of these youth. The literature suggests that disordered eating is pervasive in adolescents with T1DM, and early identification is vital for treatment. The Standards of Care in Diabetes 2019 suggests youth should have an initial screening for disordered eating between the ages of 10 and 12 using a validated survey, due to the long-term consequences that can accompany poor diabetes management (American Diabetes Association, 2019).

### **Setting and Population**

The goal to improve the identification of DEB and the facilitation of therapy services for adolescents with disordered eating behaviors speaks to the participating organization's values of improving overall health for all people they serve. The participating organization has demonstrated a particular interest in the management, treatment, and cure of Type 1 diabetes through ongoing clinical research in immunotherapy. The specific implementation site was a pediatric endocrinology clinic in a small urban city in the upper midwest. The clinic is a primary hub for specialty services for T1DM and serves patients from a tri-state area. Currently, the pediatric endocrinology clinic serves approximately 400 adults and children with T1DM. The clinic also provides outreach services to an outlying city within the state and another site in a neighboring state; however, outreach areas were excluded from the practice improvement project.

The study included two groups of participants. The first group of project participants were two physicians and one nurse practitioner who provide specialty care to youth and

adolescents with T1DM or T2DM. One physician is a board-certified endocrinologist in pediatric and adult populations; the other physician is a pediatrician and diabetologist.

The second group of participants are male and female adolescents with T1DM aged 10-18 who have had T1DM for at least one month. The age range for inclusion was 10 to 18 years, as the ADA guidelines suggest screening between the ages of 10 and 12 years. Adolescents often begin to transition to adult services after age 18; therefore, inclusion after this age may not be representative of the pediatric endocrinology population. Additionally, children with Type 2 diabetes and maturity-onset diabetes of the young (MODY) are often treated with oral medication and may not require multiple daily injections of insulin; therefore, this population was excluded. Furthermore, in the validation studies for the DEPS-R, only individuals with T1DM were included. Lastly, the management of Type 2 diabetes in children often requires dietary recommendations for limiting carbohydrate intake and weight loss, which may skew the results of the DEPS-R.

### **Project Design and Implementation**

An initial proposal meeting was conducted with members of NDSU's faculty who served on the project committee on September 20<sup>th</sup>, 2019. After receiving approval from NDSU for the proposed project, an additional proposal meeting was conducted with the participating facility's student review committee on September 25<sup>th</sup>, 2019.

After the initiation of the project, an initial education session was completed on December 16<sup>th</sup>, 2019, with clinic staff during a pediatric endocrinology departmental meeting. The staff in attendance included two physicians, one nurse practitioner, two diabetes educators, one dietitian/certified diabetes educator, one staff registered nurse, one staff licensed practical nurse, and one staff nurse assistant who are all employed in the pediatric endocrinology

department. Additionally, the subspecialty clinical chair, the integrated behavioral specialist, and the clinic director were present. An invitation to participate in the practice improvement project was provided to the staff (Appendix C). The presentation and subsequent discussion were approximately one hour in length and included background information regarding disordered eating in the pediatric T1DM population and risk factors for the development of DEB. The DEPS-R survey, scoring and proposed workflow were also introduced (Appendix G).

Following the education session, two physicians and a nurse practitioner took the post-education survey (Appendix D). The post-education survey was a five-question assessment, with Likert-scale responses, scored from one to five. A score of one indicates “poor,” and a score of five indicates “very good.” The first two questions on the post-education survey assessed responses to the previous level of perceived knowledge of DEB before the education session and perceived level of knowledge following the education session. Question three assessed the provider’s perception of understanding how to administer the DEPS-R. Question four assessed the provider’s confidence in approaching an adolescent who had a positive screen of greater than 20 and their belief on how they feel the DEPS-R will identify adolescents at risk for disordered eating in practice.

Prior to the project, the creators and copyright owners of the DEPS-R granted permission to use the DEPS-R survey (Appendix I). During the period of December 17<sup>th</sup>, 2019, to January 31<sup>st</sup>, 2020, the DEPS-R was administered to eligible patients, which included a convenience sample of children and adolescents aged 10-18 with T1DM. Per the suggested workflow (Appendix G), the rooming nurse approached adolescents and their guardians to complete the survey at the time of their scheduled appointment with their provider.

Once the adolescent completed the DEPS-R, the nurse who administered the survey reviewed and calculated the results. The results were then shared with the provider verbally and by the presentation of the hard copy of the survey. A score of 20 or greater on the DEPS-R initiated a referral to the Integrated Behavioral Health Therapist (IHT). The referral was entered into the chart by the rooming nurse and signed by the provider following provider discussion with the patient. The rooming nurse then entered the date of the survey, the score of the DEPS-R survey, and if a referral was entered as a “specialty comment” in the electronic health record for future provider follow-up. Following the visit with the provider, the IHT then immediately assessed the adolescent who scored positively on the DEPS-R to determine if further behavioral therapy was indicated.

The implementation of the project was approximately six weeks. On February 17<sup>th</sup>, 2020, a post-project evaluation survey was administered to the participating providers via a paper survey. The post-project evaluation survey (Appendix H) assessed provider attitudes towards the implemented workflow and recommendations for change through open-ended questioning. Other questions evaluated how DEPS-R impacted clinical practice, barriers encountered through the use of the DEPS-R, patient response to taking the DEPS-R, and interest in the continued use of DEPS-R.

During the data collection phase, the investigator kept all completed surveys, including the provider post-education surveys, DEPS-R responses, and project evaluation surveys in a locked drawer. Responses from both the providers and the participating adolescents were anonymous. Providers were identified only by “Respondent 1,” “Respondent 2,” and “Respondent 3.” Due to the small specialized nature of the provider cohort, no other demographic data was collected about the providers to preserve anonymity. The data collected



on the DEPS-R surveys included patient gender, age, and score of the DEPS-R. The investigator then transcribed the provider survey responses, DEPS-R data, and provider evaluation responses into an Excel spreadsheet on the investigator's personal computer. After the data transcription, the computer and survey data were password-protected, and the investigator shredded the hard copies of the surveys. After data collection, cohort data from the DEPS-R surveys were analyzed by an NDSU statistician. The statistician utilized statistical software, SAS, to determine the percentage of negative and positive responses per gender and age group.

### **Protection of Human Subjects**

There were two groups of participants in the practice improvement project: providers in a pediatric endocrinology clinic and the adolescents who took the DEPS-R survey. The risk for subjects participating in the practice improvement project was minimal. Providers received an invitation to participate (Appendix C), participation was voluntary, and the provider could withdraw from the project at any time. There was a risk of loss of confidentiality for the provider participants due to the small participant size, specialization area, gender, and years in practice. There were multiple potential benefits for providers who participated in the practice improvement project. Providers gained knowledge on DEB in T1DM, as well as the administration and scoring of a recommended screening tool. Their participation and input will also guide the future implementation of the screening tool and workflow into other departments.

The adolescents participating in the research were deemed as exempt from human research as there was no interaction with the adolescent by the investigators; therefore, a formal written consent process was not required per the IRB determination. The adolescent or guardian could verbally decline the DEPS-R when presented at the time of the office visit. A potential risk to adolescents was the risk of introducing thoughts of disordered eating behaviors to

adolescents that had not considered these behaviors. There was also a potential for increased emotional distress due to the sensitive nature of the subject. Benefits for participating in the practice improvement project included earlier identification and treatment referral to help improve overall blood sugar control, and potentially limit future complications from uncontrolled blood sugars related to DEB. The adolescent will also have had an opportunity for other mental health services that may be required.

### **Institutional Review Board Approval**

IRB approval through the participating facility was approved on November 7<sup>th</sup>, 2019. The IRB (#STUDY00001870) was reviewed as an Initial Study via Non-Committee Review and deemed Not Human Research (Appendix E). Following the facility's approval, IRB Protocol for Exemption: Primary Research (Protocol #PH20110) was submitted to NDSU on November 14, 2019 (Appendix F). The human research subjects were determined exempt via category #2(i) and category 4(ii). A protocol amendment request was submitted on February 13<sup>th</sup>, 2020, due to proposed question changes on the post-project evaluation survey for providers. The question changes included an evaluation of the implemented workflow, in addition to provider input on the DEPS-R survey.

The providers who participated in the practice improvement project were presented with an invitation to participate (Appendix C), outlining the risks and benefits of participation. The administration of the DEPS-R survey to the adolescent did not require any direct contact by the investigators and, therefore, determined exempt as human research. Data was collected from the DEPS-R survey such that no reasonably identifiable information was obtained. Evaluation

In conjunction with the PDSA framework, a logic model (Table 1) was used to help guide the evaluation of each objective. A logic model is a visual guide to identify the situations,

resources required, as well as track progress through a project and evaluation of its outcomes. A logic model organizes information, including the team participating in the practice improvement project, the activities that will be performed, and the goals of the project. The logic model then guides evaluation by ensuring all the activities have an outcome that is addressed (The Compass for Social and Behavioral Change, n.d.).

Following the provider education and completion of the post-education surveys, the survey scores were reviewed. A comparison of perceived learning was compared with pre-education and post-education and evaluated to determine whether the providers felt they had knowledge gain from the education session. The survey scores were also evaluated to determine knowledge gain regarding the administration of the DEPS-R survey prior to implementation in the clinic.

After the six-week implementation period, adolescent responses to the DEPS-R were reviewed and the number of positive responses determined. The number of positive responses was then broken into gender and age categories to provide insight and comparison to the literature for the utility of the DEPS-R into practice.

Finally, following the six-week implementation of the DEPS-R survey, qualitative responses were gathered using a post-project evaluation survey. The responses were then separated into categories relating to the implemented workflow or the DEPS-R survey and the successes, barriers, and impact to practice noted.

Table 1

*Logic Model*

Situation	Inputs	Outputs	Short-term outcomes (anticipated)	Short-term outcomes (actual)	Long-term outcomes (anticipated)
<p>Recommendation from ADA that youth should be screened for disordered eating in T1DM between the ages of 10-12</p> <p>Lack of current standard process for identifying youth with T1DM for disordered eating behaviors in the local clinic</p> <p>No current literature on provider attitudes towards DEPS-R or implementation into the clinic</p>	<p>Healthcare system</p> <p>Provider participation</p> <p>Youth/guardian participation</p> <p>Nurses</p> <p>DEPS-R survey</p> <p>Electronic health record</p> <p>DNP Student</p> <p>DNP Committee</p>	<p>Creation of workflow for screening/referral</p> <p>Administration of DEPS-R survey</p> <p>Administration of post-education survey</p> <p>Administration of evaluation survey</p> <p>Survey Analysis</p>	<p>Provider education of disordered eating behaviors</p> <p>Evaluation of workflow for the referral process for youth identified to have disordered eating behaviors</p> <p>Evaluation of implementing DEPS-R into practice</p>	<p>Perceived knowledge gained on disordered eating behaviors in T1DM by providers</p> <p>Satisfactory workflow implemented</p> <p>Improved coordination of care for the adolescent at risk for DEB</p> <p>Favorable response to the DEPS-R and provider desire to continue to use</p>	<p>Overall improved self-care strategies and diabetes management by the adolescent</p> <p>Prevention of long-term effects related to uncontrolled T1DM and disordered eating</p> <p>Better mental health for the adolescent who is at risk for disordered eating</p>
<p>External factors:</p> <p>Appointment date</p>					
<p>Assumption:</p> <p>Participation of the selected site</p> <p>Provider and child participation</p>					

## CHAPTER FOUR: RESULTS

### Objective 1: Educate Clinic Staff Regarding the Risk Factors for DEB in Youth Diagnosed with Type 1 Diabetes

All the providers employed by the pediatric endocrinology clinic participated in the education session on background and risk factors for DEB in T1DM and completed the post-education survey (N=3). The post-education survey was a Likert-scale rated from one to five, with one being “poor” and five being “very good.” Per the responses on the post-education survey, 66% (N=2) had perceived improvement from their baseline knowledge of disordered eating in T1DM (Figure 2), with one provider indicating a doubling in perceived knowledge. One provider rated their previous knowledge as very good, and therefore, there was no improvement in score. The increase in overall knowledge on the background of disordered eating in T1DM suggests that the provider’s perception was that they gained education.

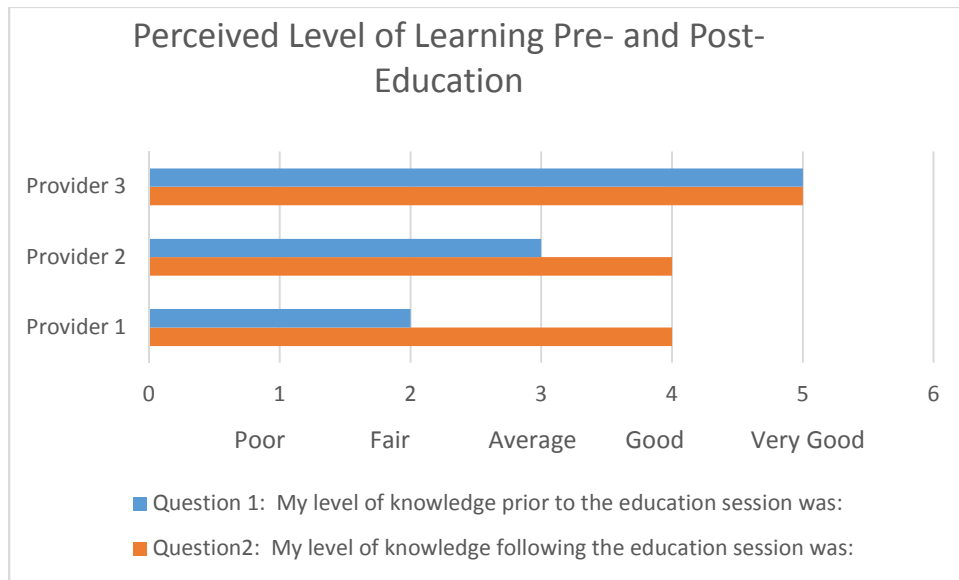


Figure 2. Increased Provider Knowledge of DEB Following Education.

## **Objective 2: Educate the Clinic Staff Regarding the Use of the Diabetes Eating Problems Survey-Revised (DEPS-R) Screening Tool**

The post-education survey (Appendix B) evaluated the provider's perception of the understanding of the DEPS-R. When evaluating their understanding of how to administer and score the DEPS-R after the training (Question 3), 66% (n=2) indicated "good," and 33% (n=1) indicated "very good" (Figure 3). The same two providers also felt "good" about approaching a youth who had scored 20 or greater on the survey. Thirty-three percent (n=1) provider rated their feeling as "very good." Question four assessed their confidence approaching and discussing DEB for the adolescent that scored 20 or greater on the DEPS-R; respondents 1 and 2 indicated "good," and respondent 3 indicated "very good." Lastly, question 5 measured how the provider believes the DEPS-R will help to identify at-risk adolescents for disordered eating in practice. One hundred percent of providers (N=3) indicated "good," or "very good." For additional comments, respondent 3 wrote "great."

The providers indicated that the education session was successful in how to utilize the DEPS-R and following steps in the workflow, should an adolescent score 20 or greater on the survey. Additionally, the DEPS-R was viewed as favorable for implementation into practice to assess DEB in the selected clinic.

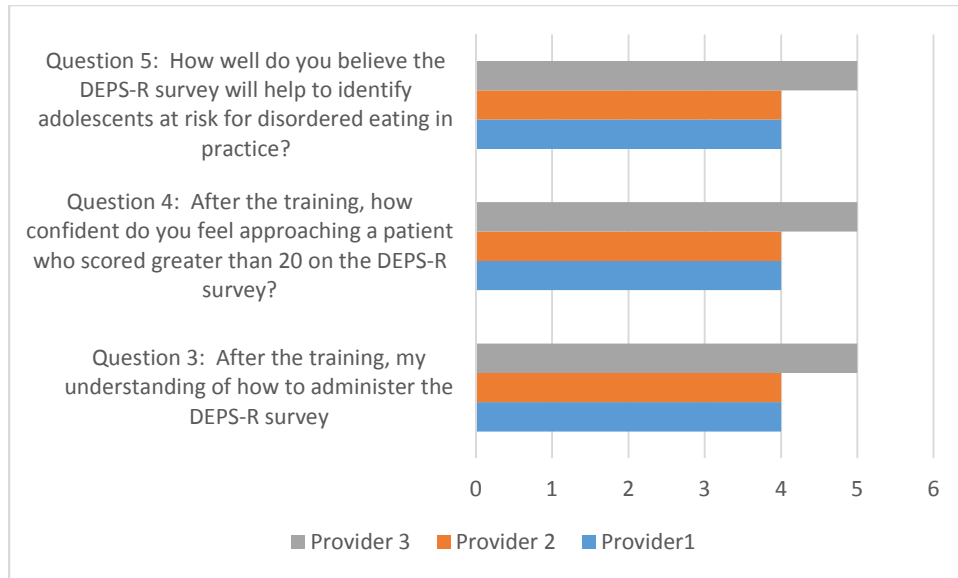


Figure 3. Post-Education Survey: Perceived Learning Regarding DEPS-R

**Objective 3: Implement a DEPS-R Workflow into Practice During a 3-Month Span to Identify Youth Aged 10-18 Diagnosed with Type 1 Diabetes Who Are at Risk for DEB**

A process workflow (Appendix G) was introduced and accepted during the education session. The suggested process began with the rooming nurse administering the DEPS-R during an office visit and calculating results, followed by a discussion with the provider about the results. The provider was then responsible for reviewing the DEPS-R response and entering the mental health referral for the IHT. Evaluation of the workflow process was assessed through open-ended questioning via a paper survey (Appendix H). No data was able to be obtained from the organization regarding referral rates before the implementation of the screening tool.

**DEPS-R Results**

The sample population of adolescents in the clinic completed a total of 47 DEPS-R surveys during a six-week timeframe. One response was discarded because the respondent did not supply their gender or age; therefore, the total survey response was 46 (N=46). A total of five participants scored 20 or higher on the DEPS-R for a total of 10.6% of the total sample

population. Twenty-six females (56.5%) and 20 males (43.48%) between the ages of 10-18 participated. The average age of the respondents was 14.3 years.

The average total score for the DEPS-R was 12, out of an overall possible score of 80. The higher the DEPS-R score, the more disordered eating behaviors are evident. Two of the five responses that were indicative of a positive DEPS-R were female (40%), and three of the five were male (60%) (Figure 4). Of the total sampled population, positive male responses represented 15% of the total sample population, and the positive female responses were 7.6% of the total sampled population. The DEPS-R results are further subcategorized into early adolescence, middle adolescence, and late adolescence, and cross-tabbed to gender.

### ***Early Adolescence***

Early adolescence was defined as participants aged 10-13. Nine females (19.5%) and ten males (21.7%) completed the DEPS-R, for a total of 19 respondents in this category. These 19 (of 46 participants) represented 41.3% of the total completed surveys of DEPS-R. Of the early adolescent participants, 47.3% were female, and 52.6% were male. The female participants in the early adolescence category represented 34.6% of the total sample size, and males in early adolescence represented 50% of the surveyed population. There were no positive responses for the DEPS-R in this category (Figure 4).

### ***Middle Adolescence***

Middle adolescence included adolescents aged 14-17. Eleven females (23.9%) and nine males (19.5%) in this category completed the DEPS-R, for a total of 20 out of 46 participants. These 20 participants represented 43.4% of the total sample population. For the participants in the middle adolescence category, 55% were female, and 45% were male. The female participants in middle adolescence represented 42.3% of the total sample size, and the males in



this category represented 45% of the total sample. Seventeen (85%) of the DEPS-R responses in this category had a score of less than 20, and three (15%) scored 20 or higher (Figure 4). All the positive responses in the middle adolescent (n=3) category were male. Additionally, of the cumulative total of positive DEPS-R responses (n=5), 60% (n=3) were in middle adolescence.

### ***Late Adolescence***

Late adolescence was defined as participants aged 18. Of this category, six females (13.0%) and one male (2.1%) age 18 completed the DEPS-R for a total of seven out of 46 respondents. These seven participants represented 15.2% of the total sample population. Of the late adolescence category, 85.7% were female, and 14.2% were male. The female participants in this category (n=6) represented 23.0% of the sample population, and the males in this category (n=1) represented 5% of the total sample population. Five (71.4%) of the DEPS-R surveys scored less than 20 in this category, and two (28.5%) scored higher than 20 (Figure 4). These two respondents in late adolescence were representative of 40% of the total positive sample (n=5). The two positive DEPS-R responses were both females.

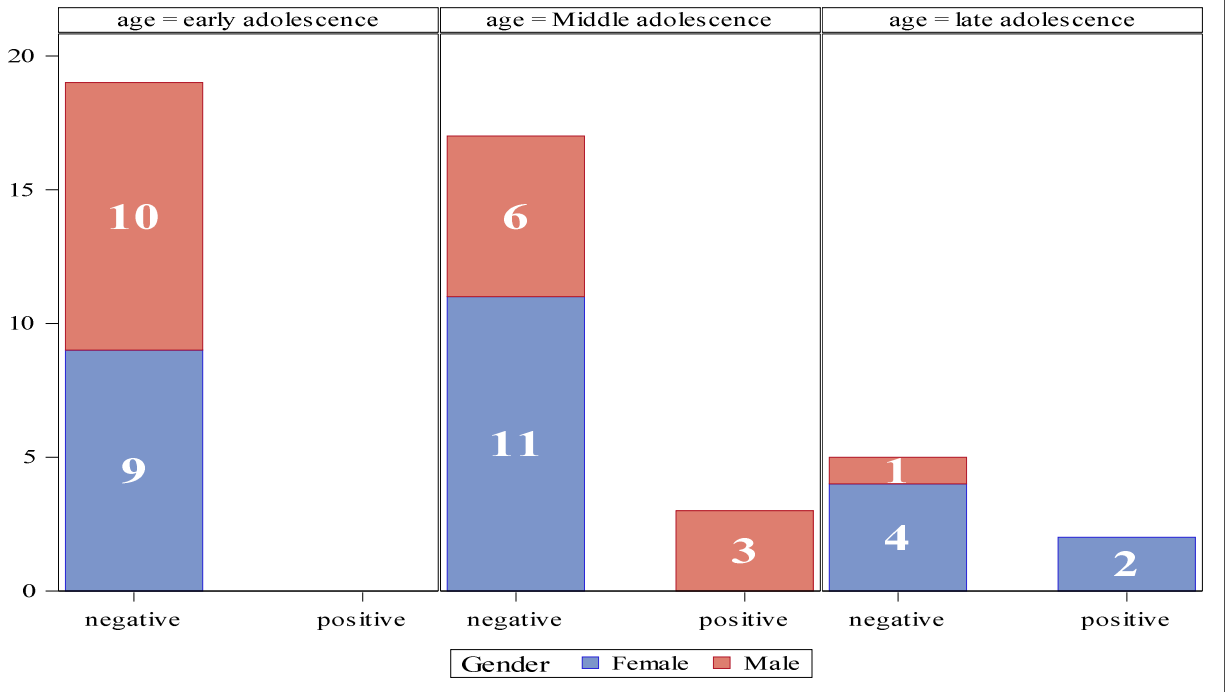


Figure 4. Positive/Negative Responses per Adolescent Age Group

**Objective 4: Develop Referral Strategies to Behavioral Health for Further Evaluation of Youth Who Score Positively on the DEPS-R Screening Tool**

Qualitative responses from the providers were reviewed and categorized into two groups: DEPS-R evaluation and implemented workflow evaluation. Multiple providers indicated they felt the DEPS-R helped identify youth who had not been suspected as having DEB. Two providers felt that some of the questions on the DEPS-R were difficult for younger adolescents to understand; however, all three providers surveyed indicated a desire to continue to use the implemented workflow and DEPS-R into practice. Data were unable to be obtained from the participating organization to evaluate the number of referrals placed for IHT.

**Post-Project Evaluation Surveys**

Post-project evaluation surveys (Appendix H) were administered to the providers in the clinic after the project (N=3). The evaluation surveys elicited provider input on the utilization of the DEPS-R and the implemented workflow. The two areas are described below (Table 2). A

theme that was present in all the post-evaluation surveys was that all the providers found the DEPS-R survey useful in identifying youth that they hadn't considered as being at-risk for DEB. Another theme that emerged was regarding the literacy of the DEPS-R questions, and that some questions were difficult to understand. Concerns regarding the workflow primarily centered around completing the DEPS-R if the rooming nurse failed to administer the survey.

Table 2

*Post-Project Evaluation Provider Response*

	DEPS-R	Implemented Workflow
Impact on Practice	<p>“It helped screen for eating disorders/concerns to be referred to along with my additional focus on diet and behavior.”</p> <p>“We've found a few patients with concerns who likely wouldn't have been picked up.”</p> <p>“Insightful”</p> <p>“Useful. Even in some not suspected.”</p>	<p>“It worked well except when CNA failed to do screen during rooming.”</p> <p>“Not always able to get it done during visit if not done prior.”</p>
Barriers	<p>“Younger kids had some difficulty answering or understanding the questions.”</p> <p>“Some commented that it was hard or tricky to answer some of the questions.”</p>	<p>“Referring them after an elevated score was a barrier d/t provider needed”</p> <p>“No barriers that I am aware of.”</p>
Recommendations	<p>“I would like a revised questionnaire that words the questions better.”</p> <p>“Easier to understand wording for younger kids- consider a parent version.”</p>	<p>“No recommendations.”</p>

## CHAPTER FIVE: DISCUSSION

The ultimate goal of the practice improvement project was to educate providers on the risk for DEB in T1DM, implement the DEPS-R into practice in the selected clinic to aid in the identification of youth with T1DM who may have DEB, and evaluate the created and implemented workflow into the chosen clinic. The selected clinic does not have a standardized process for identifying youth with DEB, and this project sought to evaluate whether educating providers, as well as implementing a standardized process and validated screening tool, would enhance the identification process of at-risk youth for DEB. A detailed discussion of the objectives is further outlined.

### **Objective 1: Educate Clinic Staff Regarding the Risk Factors for DEB in Youth Diagnosed with Type 1 Diabetes**

Education for the providers in the pediatric endocrinology clinic is an essential piece of identification of disordered eating in T1DM. The prevalence rates of disordered eating in T1DM in the literature indicate a substantial portion of this population is at risk. Providers who may not be familiar with the background knowledge may miss important clinical clues of disordered eating. The literature outlines the underlying characteristics of those who are at the highest risk, such as female gender, BMI, age, and level of family conflict. Should clinical suspicion arise, these characteristics can help indicate those who require a more in-depth assessment. Education regarding the complications of untreated eating disorders and its complications also helps reinforce the suggestion that early intervention is necessary to prevent the development of DEB. The co-investigator of the practice improvement project demonstrated that two of the three providers in the pediatric endocrinology clinic had an improvement in scores and rated their final perceived knowledge level as “good.” The results suggest that the providers gained knowledge

about DEB and recognizing risk factors that may be present. The perceived gain in knowledge may aid the provider in narrowing clinical suspicion for those they suspect of DEB and facilitate an earlier intervention with mental health services for further evaluation. As the providers are diabetes specialists, they have a particular interest in the information presented. They can also have a reinforcement of the information gained through repeated interactions with children with T1DM.

**Objective 2: Educate the Clinic Staff Regarding the Use of the Diabetes Eating Problems Survey-Revised (DEPS-R) Screening Tool.**

The post-education surveys assessed provider attitude towards the implementation of the DEPS-R into the clinic. All providers viewed the DEPS-R as a welcome addition to their practice as they all indicated “good” on whether the DEPS-R would be beneficial for detecting DEB. The providers all indicated they understood how to score and interpret the DEPS-R. All providers also felt “good” or “very good” about approaching an adolescent that scored 20 or greater on the DEPS-R. These results suggest that perceived knowledge was gained regarding the DEPS-R survey. The providers indicated that the education session was successful in how to utilize the DEPS-R and steps should an adolescent score 20 or greater on the survey.

**Objective 3: Implement a DEPS-R Workflow into Practice During a 3-Month Span to Identify Youth Aged 10-18 Diagnosed With Type 1 Diabetes Who Are at Risk for DEB.**

The results from the DEPS-R provided insight into the prevalence of disordered eating in the participating pediatric endocrinology clinic. While the prevalence was lower than what the literature suggests (Nip et al., 2019), approximately 10% of the sample population was identified as being at risk for DEB. While significant, the lower than expected rate of positive screens using the DEPS-R could be related to the limited sample population and the shortened

implemented time frame of 6 weeks. The planned timeline of three months for this objective was only partially met due to time constraints related to IRB review. An interesting observation was that the number of males who scored positively on the DEPS-R was higher than the females who scored positive. The literature consistently found that females typically had higher rates of DEB in T1DM (Hanlan et al., 2013). The results could potentially have been in line with the literature if the DEPS-R had been administered over a longer timeframe; further research would be required. While the result is not generalizable to the entire pediatric endocrinology clinic, the data obtained suggest males should continue to be assessed in the implemented clinic. Another interesting observation was that middle adolescents had the highest number of positive responses, followed by late adolescents. These results are comparable to the literature in which the highest rates of DEB were found in these categories (Nip et al., 2019). The number of positive responses in the middle adolescent group could be related to the adolescent in the middle adolescent stage having increased attention to body image (Hagan et al., 2007). While it is essential to screen for DEB at any age, particular attention and increased frequency of screening may be required for adolescents in middle and late adolescent age groups (Hagan et al., 2007).

For a more thorough evaluation of the use of the DEPS-R in practice, a comparison of rates before implementation and post-implementation of the number of adolescents who were detected as having DEB was requested from the participating facility. Unfortunately, the data was not obtainable. Therefore, a quantitative analysis was unable to be performed regarding whether the implementation of the DEPS-R improved identification from previous methods.

#### **Objective 4: Develop Referral Strategies to Behavioral Health for Further Evaluation of Youth Who Score Positively on the DEPS-R Screening Tool.**

The provider feedback through the post-project evaluation was valuable regarding the utility of the DEPS-R. All of the providers indicated that the DEPS-R was useful to incorporate into practice, and all felt the DEPS-R should be continued to use in their practice. The favorable attitudes towards the DEPS-R were congruent with the literature indicating that a screening tool is desired in identifying DEB and approaching the youth to discuss DEB (Tierney et al., 2009). However, some providers felt the questions on the DEPS-R were difficult for adolescents to understand. Misunderstanding of the questions on the DEPS-R by the adolescent could have an association with the number of zero positive responses in the early adolescent group of the sample population; however, the literature does suggest there is a higher incidence of DEB as the child moves through adolescence (Nip et al., 2019; Markowitz et al., 2010; Wisting et al., 2013).

While the support staff were crucial to the implementation of the project, the providers were targeted for the post-education and post-evaluation surveys as they were able to follow the workflow from beginning to end. The implemented process included providers ensuring the survey was completed, discussing the results of the survey with the families and potential referral, as well as ensuring the IHT met with the patient following the provider visit. Wider implementation and replication of the study would benefit by including thoughts from the support staff. Their unique perspective may include more areas of improvement, such as guardian involvement when the adolescent was taking the survey and input on whether an EHR reminder would be beneficial.

Some areas identified as a breakdown in the workflow included a failure of the rooming nurse to administer the DEPS-R to eligible patients. As a result, the provider felt obligated to

have the patient complete the DEPS-R during the visit, limiting the visit even further. Another breakdown in the workflow surrounded the use of the IHT. During the implementation phase, the IHT embedded in the clinic resigned from their position. The resignation was an unanticipated development during the implementation phase. A suitable replacement was identified for referral; however, they were not on-site and could not necessarily assess the adolescent that scored 20 or greater on the DEPS-R survey on the same day. Despite these barriers in the workflow process, the providers had no further suggestions for the improvement of the workflow. Data regarding the number of referrals to behavioral health would have aided the evaluation of the workflow; however, this information was not obtainable.

The literature is abundant about the DEPS-R's effectiveness in screening for DEB in T1DM but is scant regarding the implementation process of the DEPS-R. Also, only one literature article was found regarding how often the DEPS-R was administered to the youth; during the study, the DEPS-R was administered every three months (Luyckx et al., 2019). While the suggested referral process was overall perceived as a positive addition to the clinic's workflow, barriers were identified which could have impacted the response rate to the DEPS-R and referral to IHT. Multiple cycles through the PDSA are necessary for continued refinement of the workflow process for addressing literacy questions, barriers to administration of the survey, and the frequency the adolescent should be screened for DEB.

### **Repeating Plan-Do-Study-Act**

A recommended second cycle of PDSA would include identifying a project team leader, likely the clinical supervisor of the pediatric endocrinology clinic. The clinical supervisor would then recruit additional staff, including providers, nurses, dietitian, and IHT. A recommended aim for the next implementation cycle would include addressing barriers to completing the DEPS-R



survey. One barrier noted was that the rooming nurse did not always administer the DEPS-R to the adolescent. To study the identified barrier further, the project team could work with the information technology department to create best practice alerts in the EMR. The best practice notification would be initially set to alert for children with T1DM between the ages of 12-18 in the selected clinic at least once yearly. Data from the information technology department could then be sent to the project lead monthly to monitor completion rates for the DEPS-R survey, with a goal survey completion rate of at least 60%. Should completion rates be under 60%, the clinical supervisor/project lead would then discuss with the staff barriers for the adolescent to complete the DEPS-R.

### **Strengths of Practice Improvement Project**

Several positive outcomes arose from the implementation of the practice improvement project. There was a positive impact on the participating clinic and organization, with the providers becoming more aware of DEB in adolescents with T1DM. There was a perceived increase in knowledge on risks for DEB in T1DM, which enhances their care for this population. The perceived knowledge gained can also aid the provider in determining if the youth requires a deeper evaluation of DEB. The practice improvement project also implemented a screening process into a clinic that currently does not have a standardized process in place for identifying at-risk youth for DEB. The initial workflow can continue to be modified through repeated cycles of the PDSA model for further refinement and improvement.

Additionally, this project adds to the literature, which is limited regarding the implementation of a screening tool, DEPS-R, into practice. Finally, through the implementation of the DEPS-R and workflow process, five youth patients were identified as needing further assessment for DEB. The identification of additional services for these youth may help connect

these youth and their families to mental health services, which could have a positive impact on their long-term management of T1DM and family cohesion.

### **Limitations of Practice Improvement Project**

There are several limitations to this project. First, the planned implementation period of three months was shortened to six weeks related to the IRB approval process. Patients with T1DM in the selected clinic typically have appointments every three months; therefore, a portion of the population was unable to participate in the completion of the DEPS-R. The limited timeframe and convenience sampling lead to a small sample size that is not generalizable to the entire pediatric endocrinology population at the participating site. Additionally, the resulting evaluation measures were limited related to the inability to receive quantitative data on referrals from the participating organization.

Another identified limitation is that when the rooming nurse approached the adolescents to take the DEPS-R survey, their guardian was present. Having the guardian in the room could have led the adolescent to answer falsely on the DEPS-R to avoid conflict. Hanlan et al. (2013) suggest that to avoid the perceived conflict, it may be beneficial to have the adolescent take the DEPS-R while the guardian is out of the room. Future administrations of the DEPS-R could include having the guardian step out of the room while the youth is taking the survey; however, each adolescent should be assessed individually for the appropriateness of this intervention. Lastly, no identifying information on adolescents was collected, which included past medical or mental health history. Those who scored 20 or greater on the DEPS-R may have had pre-existing eating disorders and undergoing treatment which could have influenced the number of positive DEPS-R responses.

## **Dissemination**

The sharing of results is an essential step in advancing knowledge of DEB in adolescents with T1DM. The providers of the pediatric endocrinology clinic were presented with the results of the practice improvement project following its completion during a staff meeting.

Additionally, an executive summary was submitted to the participating organization's leadership regarding the results of the project. Further plans for dissemination of the information gained include submission to diabetes-specific scholarly journals. The project results and cohort data were also presented during a poster session at North Dakota State University in April 2020.

## **Recommendations**

### **Organizational Recommendations**

Applying the PDSA to the practice improvement project, action must be taken for continued improvement. The following recommendations have been identified to ensure continued use of the implemented workflow with the DEPS-R screening:

1. Obtain permission from the creators and copyright holders of the DEPS-R for permanent use in the organization.

The DEPS-R is not currently public domain, and permission must be obtained from the copyright holders for continued use. The participating facility's nursing supervisor was provided with contact information to initiate the permissions request. The organization will then be tasked to follow-up on the request.

2. Begin screening for DEB in the pediatric endocrinology clinic, starting at age 12, at least yearly.

The ADA has suggested screening for disordered eating in the T1DM population between the ages of 10 and 12 with a validated screening tool, to allow for early intervention; however,

the providers indicated younger adolescents did not always understand the questions on the DEPS-R. In the literature, the DEPS-R was administered to a variety of ages, from 10-25 years of age (Nip et al., 2019). Considering provider input and ADA recommendations, beginning screening at age 12 in the participating clinic would be reasonable. Further research by the organization could include an analysis of the literacy level of the DEPS-R survey. Additionally, the organization could also determine its own target age for initial screening or contact the copyright holders of the DEPS-R for permission to alter the survey.

Drawing from the current AAP recommendations that screening for disordered eating and adolescent perception of body image should occur yearly, an initial target of screening for DEB in T1DM yearly is suggested (Hagan et al., 2007). Starting at age 12 and performing yearly assessments can provide a baseline score and allow the provider to track scores over time. Should the provider suspect DEB outside of routine screenings, the DEPS-R can be administered as needed.

3. Continue the administration of the DEPS-R survey and implemented workflow in the pediatric endocrinology clinic and analyze data over a longer time frame.

Based on the providers' perception of the DEB workflow, no changes to the workflow are recommended. To enhance the distribution of the DEPS-R survey and ensure that all adolescents are being administered the DEPS-R, the participating facility should consider collaboration with their information technology support staff to create a best-practice notification beginning at age 12. The creation of the notification would alert the rooming nurse and the provider when a child becomes eligible to take the DEPS-R. Additionally, through the integration of the DEPS-R into the EHR, the provider can track trends in DEPS-R results each time it is administered. The incorporation into the EHR would also be beneficial for report

generation for further provider analysis of DEB trends in the clinic and referrals to IHT. The literature is scant regarding the frequency of administration of the DEPS-R; deeper analysis of trends and referrals to IHT could guide as to how often to screen for DEB in practice.

4. Implement the screening process into the outreach areas to capture youth at risk for DEB in outlying areas.

Currently, the pediatric endocrinology providers provide outreach services to two other moderately sized midwestern cities. Further dissemination of the screening workflow and DEPS-R would broaden the population who would benefit from early identification of DEB within the organization.

### **Implications for Future Research**

The selected screening tool (DEPS-R) and the implemented workflow were viewed favorably; however, there are opportunities for further research. Suggestions for further refinement of the practice improvement project could include new data collection, including a larger sample population, for a more thorough evaluation of the prevalence of DEB and referral rates to IHT in the selected clinic. Other data collected could also include information on whether an eating disorder diagnosis was confirmed following the initial screening process or if a different mental health condition was uncovered.

Additional research could also include implementation of the DEPS-R and workflow into other settings, such as primary care, student health, or other healthcare organizations. Implementation into the other healthcare setting would involve education about DEB in T1DM to the staff, which a DNP is suited to provide. An additional area of interest would consist of new research into how often the DEPS-R should be administered for the screening of disordered eating. Lastly, application into an adult setting is another intriguing area of research. Times of

transition, such as transition into an adult setting, can increase diabetes distress (Young-Hyman et al., 2016). Work is currently being undertaken to validate the DEPS-R in the adult T1DM population (Doyle et al., 2016).

### **Application to the DNP Role**

The impacts of implementing the practice change project would include benefits for both the nurse practitioner and the organization. By applying the practice improvement project, the DNP fulfills multiple roles as described by the American Association of Nurse Practitioners, such as educator, advocate, and interdisciplinary consultant. While the disordered eating workflow was piloted in a specialty area, nurse practitioners encounter adolescents with T1DM in several areas. They may need to assess beyond the basics of blood sugar management to provide holistic care. The DNP is suited to educate family and other providers on the risk of DEB in adolescents with T1DM and provide a tool in which to assess for concerns rapidly, such as the DEPS-R. Finally, acting as an interdisciplinary consultant, the DNP is collaborating with several other disciplines, including behavioral health. The DNP is also acting as an advocate for at-risk youth with T1DM to have a further assessment of their mental health. Referring to Dr. Frey's nursing theory, improving the child's diabetes management can lead to improved general health maintenance outcomes, the child's mental health, and enhance the health of the entire family.

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## APPENDIX A: DIABETES EATING SURVEY-REVISED

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**.

Age:    Gender:

	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

DEPS-R    Not to be reproduced without permission

Copyright © 2010 Joslin Diabetes Center

## APPENDIX B: DIABETES EATING SURVEY-REVISED SCORING

### **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, Antisdell 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 C: INVITATION TO PARTICIPATE

### **Title of Research Study: Identification of Disordered Eating Behaviors in Adolescents with Type 1 Diabetes**

My name is Heather Kranitz, and I am a DNP student at North Dakota State University. I am conducting a practice improvement project to improve identification of disordered eating behaviors in adolescents with Type 1 diabetes. By participating in this project, it is my hope that we will detect early signs of disordered eating and insulin manipulation and create a workflow to facilitate early intervention for mental health services.

As you are a provider who cares for adolescents with Type 1 diabetes, you will be invited to take part in this project. Your participation is completely voluntary, and you may withdraw from participating in this project with no penalty to you.

There is minimal risk to participants. The known risks may include: loss of confidentiality due to face-to-face participation. There is also a risk of emotional distress due to the sensitive nature of this topic. By participating in the project, you may benefit by learning more about disordered eating behaviors in adolescents with Type 1 diabetes as well as the screening tool to identify these youth. You may also help improve the process in aiding children with concerning eating behaviors to mental health services.

This study is anonymous. That means that no one, not even members of the practice improvement project team, will know that the information you give comes from you.

If you have any questions about this project, please contact me at [heather.kranitz@ndus.edu](mailto:heather.kranitz@ndus.edu), or contact my advisor Adam Hohman at [adam.hohman@ndus.edu](mailto:adam.hohman@ndus.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 research 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](mailto:ndsu.irb@ndsu.edu).

Thank you for your time and taking part in this practice improvement project,

Heather Kranitz

Email: [heather.kranitz@ndus.edu](mailto:heather.kranitz@ndus.edu)

Cell: 701-306-6401



**APPENDIX D: POST-EDUCATION SURVEY**

1. My level of knowledge prior to the education session was:

5	4	3	2	1
Very Good	Good	Average	Fair	Poor

2. My level of knowledge following the education session was:

5	4	3	2	1
Very Good	Good	Average	Fair	Poor

3. After the training, my understanding of how to administer the DEPS-R survey:

5	4	3	2	1
Very Good	Good	Average	Fair	Poor

4. After the training, how confident do you feel approaching a patient who scored greater than 20 on the DEPS-R survey?

5	4	3	2	1
Very Good	Good	Average	Fair	Poor

5. How well do you believe the DEPS-R survey will help to identify adolescents at risk for disordered eating in practice?

5	4	3	2	1
Very Good	Good	Average	Fair	Poor

Comments:

## APPENDIX E: PARTICIPATING ORGANIZATION IRB APPROVAL

### NOT HUMAN RESEARCH

November 7, 2019

Dear Heather Kranitz:

The IRB reviewed the following submission:

Type of Review:	Initial Study via Non-Committee Review
Title of Study:	Identification of DEB: Identification of Disordered Eating Behaviors in Adolescents with Type 1 Diabetes
Investigator:	Heather Kranitz
IRB ID:	STUDY00001870
Special Determinations:	None

The IRB determined, on 11/7/2019, that the proposed activity is not human research.  
IRB review and approval is not required.

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are being considered and there are questions about whether IRB review is needed, please submit a study modification to the IRB for a determination. You can create a modification by clicking **Create Modification / CR** within the study.

For questions, please contact the IRB Office: [eIRB@sanfordhealth.org](mailto:eIRB@sanfordhealth.org).

## APPENDIX F: NDSU IRB APPROVAL



December 9, 2019

Dr. Adam Holman  
School of Nursing

Re: IRB Determination of Exempt Human Subjects Research:  
Protocol #PH20110, "Identification of Disordered Eating Behaviors in Adolescents with Type 1 Diabetes"

Co-investigator(s) and research team: Heather Kranitz  
Date of Exempt Determination: 12/9/2019 Expiration Date: 12/8/2022  
Study site(s): Sanford Health Sponsor: n/a

The above referenced human subjects research project has been determined exempt (category #2(i), 4(ii)) 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 12/5/2019).

Please also note the following:

- If you wish to continue the research after the expiration, submit a request for recertification several weeks prior 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,

A handwritten signature in blue ink that reads "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\\_irb/](https://www.ndsu.edu/research/for_researchers/research_integrity_and_compliance/institutional_review_board_irb/). This Institution has an approved FederalWide Assurance with the Department of Health and Human Services: FWA00002439.

#### INSTITUTIONAL REVIEW BOARD

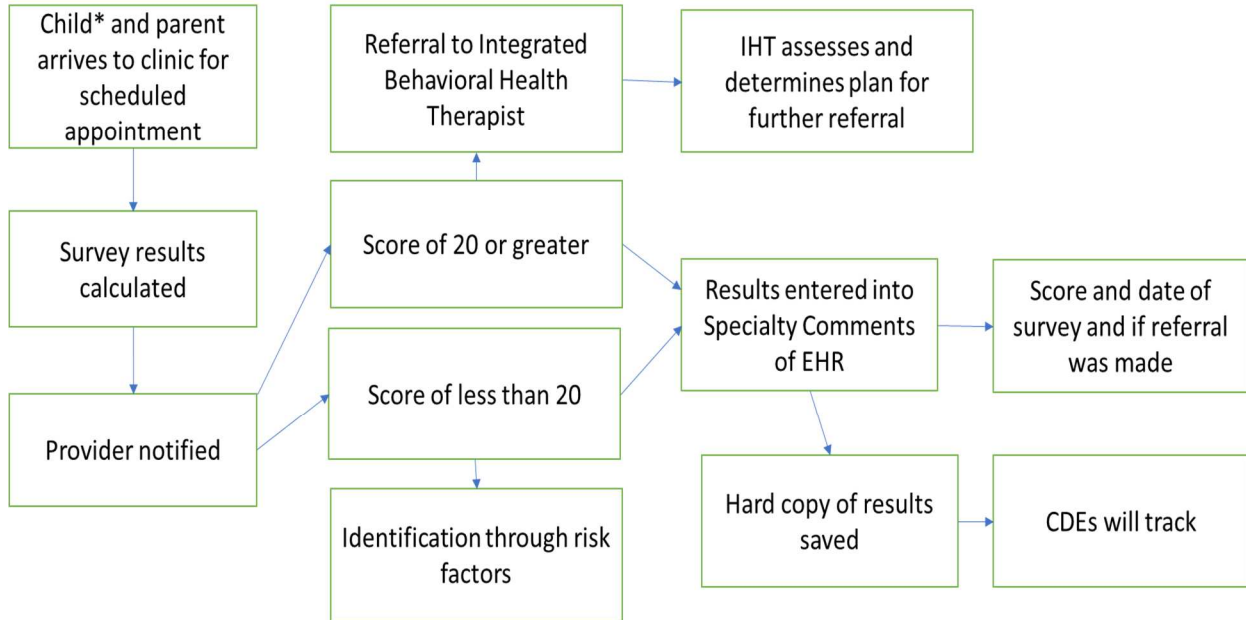
NDSU Dept 4000 | PO Box 6050 | Fargo ND 58108-6050 | 701.231.8995 | Fax 701.231.8098 | [ndsu.edu/irb](http://ndsu.edu/irb)

Shipping address: Research 1, 1725 NDSU Research Park Drive, Fargo ND 58102

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## APPENDIX G: IMPLEMENTED WORKFLOW

### Recommended Workflow



\*Child is aged 10-18, and has Type 1 diabetes for at least 1 month  
--Do not give to children with Type 2 diabetes or MODY

## APPENDIX H: POST-PROJECT EVALUATION SURVEY

1. How has the DEPS-R has impacted your practice?
2. How do you feel the implemented **workflow** helped in the identification of disordered eating behaviors in adolescents with Type 1 diabetes?
3. What barriers did you encounter with the use of the DEPS-R?
4. How was the DEPS-R received by your patients?
5. Do you have any recommendations for changing the **workflow** for identifying disordered eating behaviors in adolescents with Type 1 diabetes?
6. Do you anticipate continuing to use the DEPS-R in your practice?

## APPENDIX I: PERMISSION TO USE DEPS-R SURVEY

North Dakota State University  
1919 N University Dr. Dept 2670

### Fargo, ND 58108-6050 LICENSING AGREEMENT

This Licensing Agreement (the "Agreement") is by and between [redacted] Diabetes Center, Inc. (hereafter [redacted]) with its principal office at One [redacted] Place, Boston, MA 02215 and North Dakota State University, (hereafter collectively referred to as "University") located at 1919 N. University Drive, Dept. 2670.

WHEREAS, [redacted] has published and holds the copyright to a questionnaire entitled Diabetes Eating Problems Survey Refined (hereinafter the "DEPS-R");

WHEREAS University desires to license the right to use the DEPS-R as more specifically described below;

WHEREAS, [redacted] desires to license to University the rights to use the DEPS-R in accordance with the terms and conditions set forth below;

THEREFORE, in consideration of the mutual covenants, promises and obligations set forth herein, the Parties hereby agree as follows:

#### 1. LICENSE PURPOSE.

University is interested in using the DEPS-R in a project focusing on research and clinical care that will involve implementing the DEPS-R screening tool into a pediatric endocrinology outpatient clinic ("Study"). University has requested to license certain rights to use the DEPS-R solely in conjunction with the Study ("License Purpose").

#### 2. GRANT OF LICENSE.

[redacted] hereby grants to University, solely for the License Purpose, the nonexclusive, non-assignable, non-sublicensable, license to use the DEPS-R as it exists in the English language solely for the License Purpose.

#### 3. OWNERSHIP/CONTROL

3.1. The DEPS-R as used and distributed for the License Purpose in English will contain copyright notice and notice of University's license and permission to use the DEPS-R.

3.2. No title to, or ownership of, the DEPS-R or any derivative works thereof shall be transferred to University pursuant to this Agreement. [redacted] shall own all patent, copyright, trademark and other intellectual property rights in and to the DEPS-R, including without limitation, the right to distribute, market and license the DEPS-R to other parties. University shall have no rights in any scale, questionnaire, or instrument owned or controlled by [redacted] other than as specifically provided under this Agreement or in any subsequent agreement between the parties.

3.3. University may copy the DEPS-R subject to the terms hereof, only as necessary to support the authorized use of the DEPS-R. University may make the DEPS-R available to patients in the Study in an electronic format for Internet access on a secure server. University may reformat the DEPS-R solely to enable such electronic use, but shall obtain [redacted] prior

written approval for any substantive reformatting or rewriting thereof, and [redacted] will retain ownership of any such reformatted or rewritten version. University shall include without alteration [redacted] copyright notice on the DEPS-R and all copies thereof and any versions displayed on computer screens or otherwise accessed by patients via the Internet.

3.4. University shall not transfer or provide the DEPS-R, or any copies thereof, to any third party, nor allow any third party access to the Internet version of such DEPS-R, or maintain any electronic copy of the DEPS-R on a publicly-accessible server without password protection, without [redacted] prior written consent, except for persons or entities directly participating in the Study, and solely for their use therein.

3.5. All the rights whether now existing or which may hereafter come into existence, which are not expressly licensed in this Agreement are hereby reserved to [redacted]. This Agreement confers no rights to University to use and/or distribute the DEPS-R for any purpose other than the License Purpose.

#### 4. TERM

This Agreement will be effective upon the latest date of execution by a party hereto ("Effective Date") and will extend for a period of twelve (12) months from the Effective Date (the "Term").

#### 5. PAYMENT

There is no license fee for use of the DEPS-R as described herein.

#### 6. LIMITATIONS OF LIABILITY

6.1. The DEPS-R is provided to University on an "as is" basis. [redacted] makes no representations regarding their validity, reliability or other characteristics. [redacted] DISCLAIMS ALL WARRANTIES WHETHER EXPRESS OR IMPLIED, INCLUDING, WITHOUT LIMITATION, ANY WARRANTY OF MERCHANTABILITY AND FITNESS FOR A PARTICULAR PURPOSE. University, now and in the future, releases [redacted], its trustees, appointees, employees and agents from any liability in connection with the use of the DEPS-R or any derivative thereof produced by or for University.

6.2. (a) University shall indemnify, defend and hold harmless [redacted] and its trustees, officers, medical and professional staff, employees, and agents and their respective successors, heirs and assigns (the "Indemnitees"), against any liability, damage, loss or expense (including reasonable attorney's fees and expenses of litigation) incurred by or imposed upon the Indemnitees or any one of them in connection with any claims, suits, actions, demands or judgments arising out of any theory of product liability (including, but not limited to, actions in the form of tort, warranty, or strict liability) concerning the use or reproduction of the DEPS-R pursuant to any right or license granted under this Agreement even when other remedies are impossible, ineffective, or fail of their essential purpose.

(b) University agrees, at its own expense to provide attorneys reasonably acceptable to [redacted] to defend against any actions brought or filed against any party indemnified hereunder with respect to the subject of indemnity contained herein, whether or not such actions are rightfully brought.

(c) This Section 6 shall survive expiration or termination of this Agreement.

#### 7. USE OF NAME

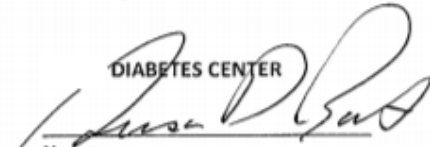
University may not use [redacted] name, logo or other proprietary marks in conjunction with any


promotional activities, advertising or marketing copy, proposals, studies, reports or media releases without prior written approval.

**8. MISCELLANEOUS**

- 8.1. **Governing Law; Jurisdiction.** The validity, performance, constitution and interpretation of this Agreement shall be governed by the laws of the Commonwealth of Massachusetts. Any claims or legal actions by one party against the other shall be commenced and maintained in a state or federal court located in Massachusetts, and both parties hereby submit to the jurisdiction and venue of any such court.
- 8.2. **Severability.** In the event that any one or more of the provisions of this Agreement shall for any reason be held to be unenforceable in any respect, such unenforceability shall not affect any other provision, but this Agreement shall then be construed as if such unenforceable provision or provisions had never been contained herein.
- 8.3. **Modifications.** This Agreement shall not be altered, modified or amended in any respect except by a writing signed by each party.
- 8.4. **Nonwaiver.** The failure of any party to enforce at any time any of the provisions hereof shall not be construed to be a waiver of the right of such party thereafter to enforce such provisions.
- 8.5. **Successors and Assigns.** All the terms and provisions of this Agreement shall be binding upon and inure to the benefit of the parties hereto, and their successors and assigns and legal representatives, except that neither party may assign this Agreement nor any rights granted hereunder, in whole or part (except in connection with a reorganization, merger or sale of such party's business or assets to a third party), without the other party's prior written consent, which shall not be unreasonably withheld.
- 8.6. **Headings.** The headings used in this Agreement are for convenience of reference only and shall not be interpreted or construed to modify or alter any of the terms herein.
- 8.7. **Entire Agreement.** This Agreement and any attached exhibits represent the entire agreement between the parties and supersedes all prior agreements and understandings with respect to all matters covered in this Agreement.

IN WITNESS WHEREOF, the parties hereto have caused this Agreement to be executed under seal by their duly authorized representatives as of the Effective Date.

**DIABETES CENTER**  
  
Name  
Steve Dir Business Affairs  
Title  
6-27-2019  
Date:

**NORTH DAKOTA STATE UNIVERSITY**  
  
Name  
Assistant Professor of Medicine  
Title  
6-17-19  
Date:



## APPENDIX J: PROTOCOL AMENDMENT REQUEST



### INSTITUTIONAL REVIEW BOARD

office: Research 1, 1735 NDSU Research Park Drive, Fargo, ND 58102

mail: NDSU Dept. #4000, PO Box 6050, Fargo, ND 58108-6050

p: 701.231.8995 f: 701.231.8098 e: [ndsuirb@ndsud.edu](mailto:ndsuirb@ndsud.edu) w: [www.ndsu.edu/irb](http://www.ndsu.edu/irb)

Date Received

2/13/2020

IRB Protocol #:

PH20110

### Protocol Amendment Request Form

Changes to approved research may not be initiated without prior IRB review and approval, except where necessary to eliminate apparent immediate hazards to participants. Reference: [SOP 7.5 Protocol Amendments](#).

Examples of changes requiring IRB review include, but are not limited to changes in: investigators or research team members, purpose/scope of research, recruitment procedures, compensation strategy, participant population, research setting, interventions involving participants, data collection procedures, or surveys, measures or other data forms.

#### Protocol Information:


Protocol #: PH20110 Title: Identification of Disordered Eating Behaviors in Adolescents with Type 1 Diabetes

Review category:  Exempt  Expedited  Full board

Principal investigator: Adam Hohman Email address: [Adam.Hohman@ndus.edu](mailto:Adam.Hohman@ndus.edu)  
Dept: Nursing

Co-investigator: Heather Kranitz Email address: [Heather.Kranitz@ndus.edu](mailto:Heather.Kranitz@ndus.edu)  
Dept: Nursing

Principal investigator signature, Date: Heather Kranitz via email 2/13/2020

 In lieu of a written signature, submission via the Principal Investigator's NDSU email constitutes an acceptable electronic signature.

#### Description of proposed changes:

- Date of proposed implementation of change(s)\*: 2/11/2020  
*\* Cannot be implemented prior to IRB approval unless the IRB Chair has determined that the change is necessary to eliminate apparent immediate hazards to participants.*
- Describe proposed change(s), including justification:  
**Adjustment of the post-project evaluation survey to be administered to the providers. The adjustment allows for more details to be obtained to evaluate the implemented project.**
- Will the change(s) increase any risks, or present new risks (*physical, economic, psychological, or sociological*)

to participants?

No

Yes: *In the appropriate section of the protocol form, describe new or altered risks and how they will be minimized.*

4. Does the proposed change involve the addition of a vulnerable group of participants?

Children:  no  yes - include the *Children in Research* attachment form

Prisoners:  no  yes - include the *Prisoners in Research* attachment form

Cognitively impaired individuals:  no  yes\*

Economically or educationally disadvantaged individuals:  no  yes\*

*\*Provide additional information where applicable in the revised protocol form.*

5. Does the proposed change involve a request to waive some or all the elements of informed consent or documentation of consent?

no

yes -  Attach the *Informed Consent Waiver or Alteration Request*.

6. Does the proposed change involve a new research site?

no

yes



**If information in your previously approved protocol has changed, or additional information is being added, incorporate the changes into relevant section(s) of the protocol. Draw attention to changes by using all caps, asterisks, etc. to the revised section(s) and attach a copy of the revised protocol with your submission. (If the changes are limited to addition/change in research team members, research sites, etc. a revised protocol form is not needed.)**

**Impact for Participants (future, current, or prior):**

1. Will the change(s) alter information on previously approved versions of the recruitment materials, informed consent, or other documents, or require new documents?

No

Yes -  attach revised/new document(s)

2. Could the change(s) affect the willingness of *currently* enrolled participants to continue in the research?

No

Yes - describe procedures that will be used to inform current participants, and re-consent, if necessary:

3. Will the change(s) have any impact to *previously* enrolled participants?

No

Yes - describe impact, and any procedures that will be taken to protect the rights and welfare of participants:

-----FOR IRB OFFICE USE ONLY-----

Request is: <input checked="" type="checkbox"/> Approved <input type="checkbox"/> Not Approved	
Review: <input checked="" type="checkbox"/> Exempt, category #: <u>2(i)</u> <input type="checkbox"/> Expedited method, category # ____ <input type="checkbox"/> Convened meeting, date: ____ <input type="checkbox"/> Expedited review of minor change	
IRB Signature: <u>Kristy Shurling</u>	Date: <u>1/13/20</u>
Comments:	

## APPENDIX K. EXECUTIVE SUMMARY

# Identification of Disordered Eating Behaviors in Adolescents with Type 1 Diabetes

### Background

Type 1 diabetes is a life-long chronic condition that typically presents in childhood, and approximately 193,000 Americans under age 20 are estimated to have diagnosed diabetes. The literature is varied, but it is estimated approximately 20-30% of adolescents with Type 1 diabetes have disordered eating behaviors. A common way disordered eating manifests in Type 1 diabetes is through manipulation of insulin dosages to promote hyperglycemia and subsequent weight loss.

Disordered eating in diabetes can lead to short term complications such as diabetic ketoacidosis, severe hypoglycemia, and chronic long-term health conditions arising from complications of their uncontrolled diabetes. Identification and screening for disordered eating in youth can lead to earlier intervention for those at risk and facilitate access to proper treatment.

The 2019 American Diabetes Association Standards of Medical Care has suggested that youth with type 1 diabetes should be screened for eating disorders between 10 and 12 years of age (American Diabetes Association, 2019). At this time, there is no formal practice in place at the proposed site for identification of disordered eating behaviors in adolescents with Type 1 diabetes.

### Purpose

- Educate clinic staff regarding the risk factors for disordered eating behaviors in youth diagnosed with Type 1 diabetes
- Educate the clinic staff regarding the use of the Diabetes Eating Problems Survey-Revised (DEPS-R) screening tool
- Implement a DEPS-R workflow into practice during a 3-month span to identify youth aged 10-18 with Type 1 diabetes who are at risk for disordered eating behaviors.
- Develop referral strategies to behavioral health for further evaluation of youth who score positively on the DEPS-R screening tool.

### Process

An education session was held with staff of an urban pediatric endocrinology clinic to educate providers on risk factors for disordered eating in Type 1 diabetes, the DEPS-R screening tool, and introduction of a workflow. Following the education session, a post-education survey was provided to evaluate perceived learning gained, and confidence on using the screening tool.

### RECOMMENDATIONS

- Obtain permission from the creators and copyright holders of the DEPS-R for permanent use in the organization.
- Begin screening for DEB in the pediatric endocrinology clinic beginning at age 12 per the American Diabetes Association guidelines.
- Continue the administration of the DEPS-R survey and implemented workflow in the pediatric endocrinology clinic and analyze data over a longer time frame.
- Create best practice alerts in the EMR to assist with consistent usage of the DEPS-R.
- Implement the screening process into the outreach areas to capture youth at risk for DEB in outlying areas.

The DEPS-R was then implemented for 6 weeks to children aged 10-18 with Type 1 diabetes to aid in identification of youth at risk for disordered eating in Type 1 Diabetes.

At the end of the 6 weeks, a post-project evaluation was given to the providers to evaluate their feelings about the implemented workflow and DEPS-R survey.

## Findings

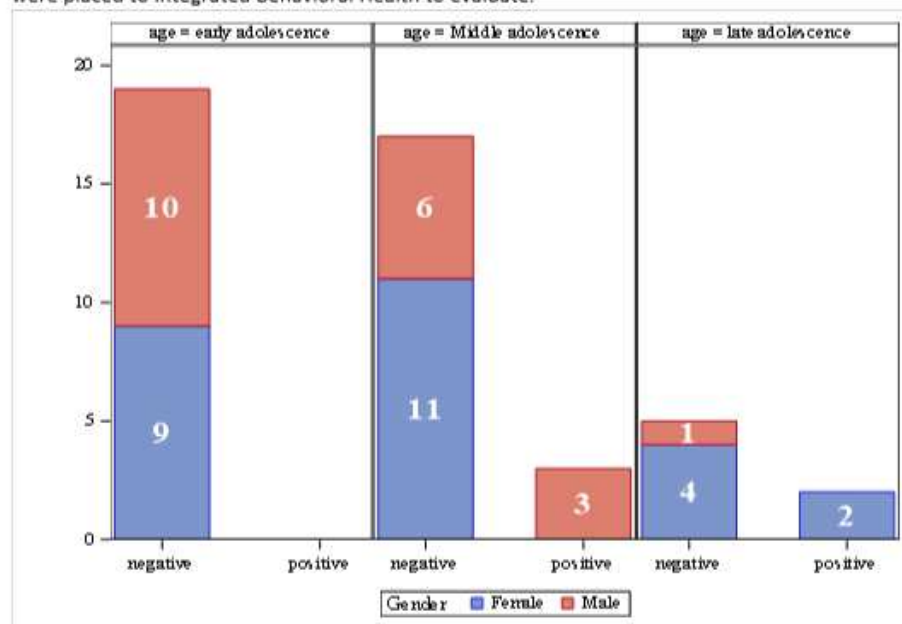
### Provider Survey:

2 out of 3 providers (66%) had a perceived gain in knowledge about disordered eating in Type 1 Diabetes. One provider (33%) felt their knowledge prior to education was "very good."

2 out of 3 providers felt "good" about how to administer the DEPS-R, approaching a patient who scored positive on the DEPS-R, and aiding in identification. One provider felt "very good" on all the above topics.

### DEPS-R Survey:

Five adolescents (10%) were identified as needing further screening for disordered eating behaviors, and referrals were placed to Integrated Behavioral Health to evaluate.



### Post-Project Evaluation Survey:

DEPS-R was valuable to practice as it helped detect issues in adolescents who wouldn't have ordinarily been picked up on.

Barriers included issues with failure of the rooming nurse to complete the survey.

Providers noted some concerns with the literacy or wording of the questions on the DEPS-R.