

**PREDICTORS FOR ACCEPTANCE OF SERVICE SEEKING IN YOUTH WITH  
DIABETES AND MENTAL HEALTH SYMPTOMATOLOGY**

by

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### **Abstract**

There is a large number of children living with chronic health conditions. Endocrine disorders, particularly Type 1 Diabetes Mellitus (T1DM), are the most common among American children. Children with chronic disorders often experience psychological symptoms. This is particularly true for children of minority status. Given that help-seeking among youth and minorities is low. It is important for caregivers to be involved.

The aim of this study was to identify possible predictors for acceptability of service recommendations among youth with endocrine disorders. In study 1, participants included youth ages 13-17 with at least one parent (45 child-caregiver dyads). Adolescents' mental health symptoms were measured using the Beck Youth Inventory-Second Edition (BYI-2) and the computerized version of the National Institute of Mental Health Diagnostic Interview Schedule for Children, Version 4 (NIMH DISC IV-TR or C-DISC). Parents' perceived barriers and acceptability of a referral were measured. Study 2 included 102 caregivers of children ages four to 20, who completed an anonymous survey at an endocrine clinic. The survey inquired about demographic characteristics, endocrine diagnosis, mental health problems, services, barriers to mental health services for their child.

Results from Study 1 found a correlation between internalizing symptoms and parent endorsement of acceptability of a referral, but not for externalizing problems. Supplemental analysis found that those who accepted a referral were less surprised by the child's mental health evaluation results. Additionally, recognizing their child in the feedback provided to them was also correlated with understanding the services needed to help with the problem. Study 2 did not find a significant relationship between help-seeking and endorsement of barriers, when looking at negative past experiences and minority status.

Caregivers play a key role when it comes to their child receiving services. A disconnect exists between intention to help-seek and action taking that needs further exploration. Facilitating help-seeking for minors and providing caregivers with support to help reduce identified barriers are areas for future investigation.

## **Chapter 1: Introduction**

This chapter covers background information on chronic illnesses in youth, focusing on endocrine disorders, particularly type 1 diabetes (T1DM). Additionally, this chapter will review mental health problems in children and adolescents and how these issues may manifest in youth with endocrine conditions and T1DM. Caregiver's perspective of treatment seeking is examined. Of particular concern are help-seeking and barriers in minority youth with endocrine disorders. The chapter concludes with the purpose of this study, the research hypotheses, and some definitions of key terms.

### **Overview of Endocrine Conditions**

The number of children living with a chronic health condition is significant. A chronic medical condition, or chronic illness, is a permanent disease, persisting over an extended time (Illinois Disability and Health Program, 2017; Sendra et al., 2017; Seth & Maheshwari, 2013). In the United States, 26.6% of youth live with a chronic medical condition (Kish et al., 2018). Most common medical conditions in children include respiratory disorders (e.g., asthma and allergies), endocrine disorders (e.g., diabetes), mental health disorders (e.g., depression, anxiety, and ADHD), nervous system (e.g., epilepsy), and obesity (Abbott et al., 2018; Kish et al., 2018; Sendra et al., 2017). Studies have shown that children's response to their illness is affected by the characteristics of the illness, personal factors, and caregiver and environmental variables (Cauce et al., 2002 Guo et al., 2015).

### ***Endocrine System***

In children, common types of chronic illnesses are those found in the endocrine system. The endocrine system is a complex regulatory system that involves several systems in the body with varying rhythmic schedules; these include the metabolic axis, the hypothalamic-pituitary-

adrenal (HPA) systems, the reproductive organism, and other combined systems (Zavala et al., 2019). Given that so many endocrine structures are at play, the number of problems and disorders involving the endocrine system are numerous. Most commonly, problems in the endocrine system are due to abrasions and the over or underproduction of hormones (Kamboj, 2008). Environmental factors and treatment for other ailments can also cause endocrine dysfunction. Treatment for childhood cancer, including chemotherapy and radiation, can cause later endocrine disorders in adults (Sklar et al., 2018). Endocrine disorders often affect growth and puberty, and can lead to later difficulties with reproduction (De Sanctis et al., 2014).

**Common Endocrine Disorders.** One common childhood endocrine disorder is that of thyroid dysfunction. Hypothyroidism occurs when there is an insufficient formation of the thyroid hormone (Seth & Maheshwari, 2013). Hormones play a significant part in the growth and development of children. A deficit in the thyroid hormone can affect children's growth and cognitive development.

Growth, both in stature and puberty, can also be affected when there is an endocrine dysfunction. A child's stature depends on several factors, including nutrition, environment, and genetics; however, hormones also play a significant role (Seth & Maheshwari, 2013). If there is a deficit in hormone production, this can affect a child's height and cognitive development (De Sanctis et al., 2014). The thyroid hormone, glucocorticoids, and sex steroids can all affect a child's growth and development (Schnell & Bannard, 1991). Dysfunctional hormone production can also lead to a disruption in puberty. Puberty may develop prematurely (precocious puberty-PP), or it can become delayed (De Sanctis et al., 2014). Both early and delayed puberty can have emotional and developmental consequences.

Cancer can contribute to endocrine disruption. Not only can cancer itself cause lesions or deregulate hormone production, but the treatments used to treat cancer can have immediate or delayed effects on the endocrine system. Research shows that children treated for cancer with chemotherapy or radiation can later develop endocrine-related symptoms. These disruptions include excessive hair growth (e.g., hirsutism), overproduction of hormones (e.g., hyperparathyroidism), delayed puberty, and infertility (Kamboj, 2008; Nakhaei-Moghadam et al., 2016).

Type 2 diabetes is a metabolic syndrome that occurs when one's body creates insulin, but the body does not use it the way it should; this is a form of insulin resistance. Because of this, the body attempts to make more insulin, leading to the buildup of sugar in the blood and leading to hyperglycemia (Olokoba et al., 2012). This form of diabetes has a substantial environmental factor but can also have a genetic component (Dabelea et al., 2014). One's sedentary lifestyle and poor diet significantly contribute to type 2 diabetes. Since this type of diabetes is highly dependent on one's lifestyle, it has previously been more predominant in adults than in children. However, recent reports indicate a rise in type 2 diabetes in children (Mayer-Davis et al., 2017). While there are several problems in children that can occur within the endocrine-metabolic system, the most common is T1DM.

**T1DM.** The most common endocrine disorder in children is T1DM (Barthel et al., 2018). Diabetes is a lifelong, debilitating, and daily struggle, particularly insulin-dependent diabetes, which is an autoimmune condition. Diabetes affects all aspects of children's and adolescent's lives: youth have to manage their symptoms daily and make decisions about their treatment (Blanz et al., 1993; Burns et al., 2018). Diabetes affects about 1.25 million American youth (Al-Haidar, 2006; Dabelea et al., 2014; Korbel et al., 2017).

T1DM is a chronic disease for which the pancreas does not produce enough insulin. Insulin is a type of hormone in the body that oversees clearing glucose and ketones from the blood (Al-Haidar, 2006). Insulin-dependent diabetes requires multiple insulin injections a day, close monitoring of glucose levels, adjustments on their diet, and requires enhanced physical activity (Cohen et al., 2004). The routine of daily management and self-care is essential to prevent crisis episodes. Two common emergencies that occur due to poorly managed diabetes are diabetic ketoacidosis (DKA) and hyperglycemic hyperosmolar state (HHS; Kitabchi et al., 2001). Children with diabetes need to pay close attention to their physical health, yet an emphasis also needs to be made on their mental health (Burns et al., 2018). This is particularly true for minority youth with T1DM, as they are at increased risk for poorer prognosis (Redondo et al., 2018)

### **Mental Health in Youth**

Individuals with a medical ailment often experience psychological disturbances. Hysing and her colleagues (2007) found that 20% of children with chronic illness had more significant symptoms of mental or behavioral health disorders versus 11% of children without a chronic disease. Given the close tie between mental health and physical health, pediatric care settings started recognizing the importance of children's overall medical, psychological, and behavioral health (Manderscheid, et al., 2010; Muther et al., 2016). Understanding what mental illness is, the prevalence it presents in youth, and the psychological and behavioral symptoms it can produce is important to understand the overall effects it can have in children, especially children with hormonal imbalances.

For children, mental health disorders are a public health crisis given that one in three to four school-aged children has a notable mental health disorder (Merikangas et al., 2010; NAMI,

2013; Olsson & Kennedy, 2010). A mental health condition is a medical condition or group of symptoms that disrupt a person's thinking, feeling, mood, ability to relate to others, and daily functions (NAMI, 2013). Two types of categories for psychological symptoms include internalizing symptoms, such as depression, anxiety, and compulsiveness, and externalizing symptoms, such as aggression, hyperactivity, and delinquency (Blanz et al., 1993; Hilliard et al., 2017; Hysing et al., 2007). In early childhood the two most common disorders to develop are attention-deficit/hyperactivity disorder (ADHD) and anxiety (Merikangas et al., 2010). Yet symptomology across even the most common conditions can vary.

### *Sociocultural Context*

Mental health disorders can differ across sex, ethnicity, socioeconomic status (SES), education level, and age (NAMI, 2013; Narendorf et al., 2018). Research has shown that minority children have higher numbers of mental health disorders (Georgiades et al., 2018; Wight et al., 2005). Youth with foreign-born parents also show higher levels of depressive symptoms (Zychinski & Polo, 2012). Low-income minorities also reveal a more significant susceptibility to mental health illness. Not only does falling within a specific demographics population create a higher vulnerability to develop psychological symptoms, but a mental disorder can also co-exist with a chronic medical condition such as T1DM (Blanz et al., 1993; Cohen et al., 2004; De Wit et al., 2008).

### *Manifestation*

**Manifestation in Youth with Endocrine Disorders.** Psychological symptoms exist in individuals with endocrine disorders. Najafi et al. (2015) investigated hypothyroidism and depression symptoms in adults. They found that depression symptoms decreased after only twelve weeks of treating subclinical hypothyroidism. Additionally, Shoib and colleagues (2016)

set out to find if there was comorbidity between psychiatric symptoms and endocrine disorders. The study consisted of adolescents, young adults, and older adults with a mean age of 35. They found that depression and anxiety symptoms were present in individuals with endocrine disorders, particularly thyroid disorders and diabetes mellitus (Shoib et al., 2016).

De Sanctis and his colleagues (2014) presented an argument for the need for overall care in adolescents with endocrine disorders. Given that hormonal disorders can significantly affect a youth's physical and emotional state, a child's endocrinological care should involve assessing all areas, including psychological symptoms (De Sanctis et. al., 2014; Geffken et al., 1998). Several endocrine dysfunctions were reviewed, from stature to hirsutism to puberty, all of which can directly affect a youth's overall well-being. They concluded that issues seen by pediatricians and those seen by endocrinologists can differ considerably. This difference leads to the need for regular check-ups, more in-depth assessment, and referrals to appropriate specialists (De Sanctis, 2014).

**Manifestation in T1DM.** Literature has shown the co-occurrence of medical and mental health disorders in children (Hilliard et al., 2017; Horowitz & Garber, 2006; Kowalenko et al., 2005; Merikangas et al., 2004). When looking at youth with T1DM, the burden of diabetes management is significant. Diabetes management has added stress that can lead to psychological symptomatology (Merikangas et al., 2009). Blanz and colleagues (1993) found that 33.3% of adolescents with T1DM had a moderate or severe degree of a psychiatric disorder when compared to 9.7% of the non-diabetic youth. Similarly, Northham and colleagues (2004) found that 37% of youth with T1DM met the criteria for a DSM-IV psychiatric disorder. Not only do youth need to learn to manage their chronic illness, but they also deal with their mental health.

Nonadherence to diabetes care in the pediatric population is very common (Cohen et al., 2004). The lack of follow-through in care is even more significant when looking at minorities (Gross et al., 2005). Emotional and behavioral symptoms increase noncompliance with diabetes care (De Wit et al., 2008; Hilliard et al., 2017; Manderscheid et al., 2010). Glycemic dysregulation often occurs in children with externalizing symptoms, while non-adherence to diabetes treatment is common in children with internalizing disorders (Cohen et al., 2004).

Although moderate to severe psychological symptoms can exist in youth with diabetes, this does not necessarily indicate poorer glycemic control (Blanz et al., 1993). Yet, the stress in children and adolescents can influence glycemic control and adherence to treatment, particularly when stress is related to family dysfunction (Al-Haidar, 2006; Cohen et al., 2004). Dealing with the management of diabetes is burdensome enough, but the co-occurrence of mental health symptoms makes it even more difficult for youth. The weight of dealing with a medical and mental illness has a bearing on the youth's life, especially when it comes to help-seeking behaviors.

Given that adolescents carry a large burden when diagnosed with T1DM, which may affect mental health, it is crucial to become aware of early symptoms and assessment in all areas. The American Diabetes Association (ADA; 2020) has recently updated its Standards of Medical Care to highlight this exact issue. The ADA suggests that care of patients with diabetes should involve a multidisciplinary approach. These Standards of Care mean that the need for frequent screening and assessment is becoming more apparent and with it, the need to refer to other care providers. The recognition that mental health providers play a key role and should be a part of diabetes care is key in maintaining the overall wellbeing of the individual. However, there is limited research examining factors that contribute to families' willingness and actual follow-

through with referrals to address their child's mental health needs. In this regard, it is important to understand factors that predict the outcomes of the recommendations and the barriers that exist in following through with referrals to behavioral health services.

### **Help-Seeking**

Help-seeking refers to the behavior of actively searching for help and accepting or being willing to accept treatment (Narendorf et al., 2018). Research has shown that adolescent help-seeking behaviors are comparatively lower than their actual need for services (Kim & Zane, 2016; Roeg et al., 2015). When looking at children and adolescents who fall into a minority group, the likelihood of seeking treatment decreases significantly (Garcia et al., 2011; Guo et al., 2015). Additionally, the youth's lack of awareness that a problem exists and their difficulty in recognizing the signs of mental illness also makes help-seeking less likely to occur as well (Wright et al., 2007).

### ***Help-Seeking for Mental Health***

One study aimed to assess adolescent's ability to identify mental health problems and their willingness to seek help from a friend (Olsson & Kennedy, 2010). Youth read hypothetical scenarios to see if they could positively identify mental health symptoms. Only 27.5% of adolescents identified anxiety symptoms whereas depression symptoms were identified 42.4% of the time as being a mental health disorder (Olsson & Kennedy, 2010). Participants were most likely to choose a professional for support when they identified a mental health problem. The ability to correctly identify psychological symptoms in adolescents increases their help-seeking behavior.

Another factor that may impact pursuing help and treatment for mental health problems is the severity of negative symptomatology, although this is not always the case. Kim and Zane

(2016) found that the need for service delivery did not always meet the severity of symptoms. They used the health belief model (HBM) and found that the perceived severity of symptoms, the perceived benefit of getting help, and the potential barriers significantly affected help-seeking by minorities. Roeg and colleagues (2015) found that merely displaying severe symptomatology did not indicate help-seeking; however, when presented with support and resources, individuals engaged in services. Another limiting factor for minority youth is the lack of knowledge of resources by them and their family (Guo et al., 2015).

**Help-Seeking in Caregivers.** Parents are often the gatekeepers to their child receiving services (Reardon et al., 2017). Caregivers tend to be the first to know that something is off in their child's behavior or emotions. This sense in a caregiver is particularly true for behavioral issues, while teachers tend to recognize emotional problems before parents (Boulter & Rickwood, 2013). Ofonedu and colleagues (2017) examined factors that led to a lack of parental involvement in their child's mental health treatment. They found that the severity of the youth's depressive symptoms led to parents showing less engagement in their child's treatment. Maiuolo and colleagues (2019) also found that higher psychological distress predicted lower help-seeking. The burden of caring for a child or adolescent with mental health problems and chronic illness is more significant and may cause additional stressors.

Research has examined parental characteristics that predict help-seeking behavior. Being female has been shown to increase help-seeking behavior (Boulter & Rickwood, 2013). An authoritative parenting style along with a parent-child relationship that showed social support also increased intentions of help-seeking behavior, although obtaining actual services was not affected by these characteristics (Maiuolo et al., 2019). Maiuolo and colleagues (2019) also found that higher parental psychological distress correlated with actual help-seeking, versus just

anticipated help-seeking. Parents are a significant support for children to receive professional mental health treatment, but barriers often keep them from furthering support.

**Barriers to Help-Seeking.** Several factors exist that limit help-seeking behaviors for caregivers. Previously noted barriers include time, affordability, availability, and transportation (Harris et al., 2016; Perfect et al., 2011). Earlier negative experiences using professional providers can affect the utilization of services as well (Rastogi et al., 2012). The number of adults living in the household was also a barrier to caregivers seeking treatment (Ofonedu et al., 2017). Barriers specific to minorities (e.g., language, cultural values, and structural barriers) continue to exist (Rastogi et al., 2012).

A review of the literature showed that the most often reported barriers for services was waiting time and difficulty getting referral (Reardon et al., 2017). A different review found less of an emphasis of wait time as a barrier, and more of stigma and negative attitude towards mental health services (Aguirre Velasco et al., 2020). In a study by Perfect and colleagues (2011), half of the refusals to seek mental health services came from minorities. Caregivers often report language as a barrier by caregivers for seeking treatment for their child (Garcia et al., 2011). Another obstacle often identified by parents is stigma (Rastogi et al., 2012). Hispanic youth with diabetes and their caregivers are less likely to seek help for mental health problems and to follow through with diabetes care (Hyunsung et al., 2018). There has been some research that has attempted to predict help-seeking by viewing parent characteristics, but little research has examined youth characteristics among those who also suffer from a chronic medical disorder (Maiuolo et al., 2019).

**Help-Seeking Model.** Limited research is available on theoretical frameworks for help-seeking. Studies have tended to focus on formal forms of help-seeking, rather than informal

(Rickwood & Thomas, 2012). Liang and her colleagues (2005) sought to identify individual, family, economic, and socio-cultural factors that influenced help-seeking behavior for women who experienced domestic violence. In drawing from general models, they focused on the individual's internal and cognitive process, which included the following three stages: problem recognition and definition, the decision to seek help, and the selection of a help provider, or person or persons to request support from. Although this model focused on women experiencing partner violence, many of the same ideas can be used when examining the help-seeking of youth and their caregivers.

### **Purpose of the Study**

In summary, diabetes is one of the most prevalent medical conditions among children. Several publications have demonstrated that youth with chronic illness or diabetes are at significant risk for mental health difficulties that contributed to or are exacerbated by managing their condition (Blanz et al., 1993; Hagger et al., 2017). Hysing et al., 2007). The willingness to consider recommendations for mental health services and the perception that these services may be accessible, meaningful, and effective has been largely unexplored in this population. Further, very little research has reflected the experiences of individuals with diabetes and other endocrine disorders with various psychosocial services, including mental health treatments. Moreover, although studies have documented barriers to treatment among youth with endocrine disorders and youth with mental health disorders, limited research exists on anticipated barriers by caregivers or youth with endocrine disorders and psychological symptoms. Therefore, it is essential to examine which characteristics best predict openness to recommendations or willingness to seek mental health support in youth and caregivers. The study sought to determine the relative contribution of the sociodemographic characteristics and mental health

symptoms that predict caregivers' acceptability of treatment for youth with diabetes.

Additionally, this study investigated if any mental health symptoms best predicted help-seeking behaviors. Lastly, this study examined whether past experiences in help-seeking among minorities related to anticipated barriers and willingness to seek help. The following are the research questions examined in the study:

### *Research Questions*

**Research Question 1.** What is the relative contribution of mental health symptoms and demographic characteristics in youth with T1DM that predict caregiver acceptability of recommendations regarding mental health services?

**Hypothesis 1.1.** Youth with T1DM with higher levels of mental health symptoms with accompanying impairment will significantly predict a caregiver's intent to accept a mental health referral.

**Hypothesis 1.2.** Certain adolescent socio-demographic characteristics (e.g., SES, racial and ethnic minorities) will predict a greater likelihood that caregivers accept referral about mental health symptoms and referral to mental health services regardless of mental health impairments in youth.

**Research Question 2.** Which mental health symptoms in children predict anticipated barriers to participation in mental health services by caregivers of children with diabetes?

**Hypothesis 2.1.** Caregivers of youth who have mental health symptoms associated with behavioral issues (e.g., ODD, disruptive behaviors, anger) will be more likely to perceive more barriers to services.

**Research Question 3.** Which caregiver characteristics or demographic information predict help-seeking by caregivers of children with endocrine disorders?

**Hypothesis 3.1.** Past negative experiences in seeking treatment will negatively impact anticipated help-seeking by caregivers of children with endocrine disorders.

**Hypothesis 3.2:** When comparing White caregivers to caregivers who identify as a minority, minority caregivers will be more likely to note past negative experiences as a barrier to seeking treatment for their child.

**Research Question 4.** Do anticipated barriers to seeking treatment reported by Non-White participant caregivers of children with endocrine disorders differ from their White caregiver counterparts?

**Hypothesis 4.1.** Barriers that are related to resource (i.e. financial situation, no transportation, not aware of available resources, and not finding adequate childcare) and stigma (i.e. possibility of label and possibility of family and friends finding out about treatment seeking) are more likely to be stated as barriers by caregivers who identify themselves as minority when compared to their White caregiver counterparts.

These questions and hypotheses will be examined by analyzing data that comes from a larger study called *Integrating Medical and Psychological Services for Adolescents with Diabetes* (Institute for Mental Health Research [IMHR] #2008PM803). Study 1's data focused on mental health screening, assessment, and referral among youth with T1DM and mental health symptoms, whereas Study 2's dataset utilized caregivers' reports of youth with endocrine disorders who completed a survey about their experiences with and needs for various psychosocial services. The results of both Study 1 and Study 2 will provide further insights into the potential challenges associated with youth obtaining the recommended mental health or other services geared toward addressing and supporting their mental health needs. The ultimate goal is to reduce mental health symptoms by making the initiation and engagement of treatment

manageable and feasible for youth and their caregivers, especially in minority groups. From here on out, each dataset will be referred to as study 1, which refers to the screening, assessment, and referral study, and study 2, which refers to the caregiver study.

### **Definition of Terms**

The terminology used within the text may include interchangeable words noted below.

**Barriers:** factors that impede access to services (Rastogi et al., 2012).

**Chronic Disease:** (chronic illness; medical condition; medical ailment): A disease that persists over an extended period (Illinois Disability and Health Program, 2017).

**Diabetes Mellitus:** (type 1 diabetes; T1DM, insulin-dependent, juvenile diabetes): is a chronic disease where the body does not produce enough insulin (Al-Haidar, 2006; Hagger et al., 2017).

**Help-Seeking:** The recognition of a problem and intention to follow through with help from an external source. (Tomczyk et al., 2020).

**Help-Seeking Behavior:** The act of or behavior of actively seeking help or accepting treatment (Narendorf et al., 2018).

**Mental Health:** (psychological health): the overall psychological well-being of an individual (Manderscheid et al., 2010).

**Mental Illness:** (mental disorder; mental health disorder; mental health symptoms; psychological issues, psychological problems; psychological symptoms): a medical condition, or group of symptoms that disrupt a person's thinking, feeling, mood, ability to relate to others, and daily functions. It is a medical condition that results in the inability or lessened capacity to cope with ordinary demands of life (NAMI, 2013; the stated phrases will be used to describe the same concept).

**Mental Health Services:** any service provided to address someone's mental health in a positive manner.

**Stigma:** the worry or fear of being socially rejected or shunned, leading to the prevention of certain behaviors (Aguirre Velasco et al., 2020).

## **Chapter 2: Literature Review**

The following chapter provides a review of relevant literature, beginning with a general overview of chronic diseases, narrowing on endocrine disorders. Specifically, the prevalence of diabetes and how it affects minority groups and mental health. Additionally, chapter two reports on help-seeking behaviors by youth and their caregivers. The last section will also include reported barriers to help-seeking treatment. Of particular interest are these issues as they relate to minority groups, particularly Hispanic youth.

### **Chronic Disease**

A disease that persists over an extended period is said to be chronic. A common misconception of chronic illness is that if symptoms are not present the individual is free from the disease, yet chronic illnesses vary in onset, development, and severity (Kish et al., 2018). Demographics of chronic diseases suggest that anyone can be affected, which means that children and adolescents are not an exception. One of four US adolescents is growing up with a type of chronic illness (Weitzman et al., 2019).

Abbott and colleagues (2018) investigated the characteristics of chronically ill individuals, their behaviors, and the perception of the care they received. Their study found that 75% of participants reported low medical adherence, although those diagnosed with diabetes expressing the most adherence to treatment. They also found comorbidity as a factor in those with a long-lasting illness. Mental health issues, such as depression and alcohol use, were reported by participants. Another characteristic of this study included that those with higher levels of education reported lower perceptions of their quality of care. Overall, this study found the need to address additional factors in chronic illness that affect adherence, quality of care, and co-occurring illnesses (Abbott et al., 2018).

Another study investigated how youth with chronic illness dealt with their disease, particularly with substance use (Weitzman et al., 2019). Youth completed qualitative interviews that studied their decision-making when it came to substance use. The age of the participants ranged from 16-19 years of age, with a variety of chronic illnesses that including T1DM, inflammatory bowel disease, juvenile idiopathic arthritis, and asthma, along with other diseases. Weitzman and her colleagues (2019) found that adolescents identified the use of substance use, particularly marijuana, as a self-directed method to reduce their medical symptoms and treatment side effects. This study highlights how chronic disease can lead youth to develop additional coping mechanisms for their illness. Childhood chronic illnesses are particularly debilitating since the youth will have to deal with the disease for the rest of his or her life. In addition to managing their illness, children also have the burden of trying to fit in, developing independence, and establishing friendships (Al-Haidar, 2006; De Wit et al., 2008). Although the majority of substance use is still illegal, changes in the law are legalizing marijuana use for medical purposes. However, longitudinal studies have yet to show the appropriateness, risk, or benefits in youth.

### ***Endocrine Disorders***

One of the most common forms of chronic illnesses in youth is endocrine disorders. Endocrine disease is a disorder of the endocrine system. An endocrine dysfunction can occur due to a lesion, hormone imbalance, side effects of treatment, and environmental factors (Kamboj, 2008). There are many types of endocrine disorders. Endocrine disorders occur in childhood, others in adulthood, and some at both stages. Some forms of endocrine disorders in children include T1DM, precocious puberty, hirsutism, hypocalcemia, and many more (De Sanctis et al.,

2014). Endocrine disorders affect approximately 5% of the U.S. population, with T1DM being the most prevalent in children (Golden, et al., 2009).

De Sanctis and his colleagues (2014) investigated the importance of endocrine check-ups for adolescents. Attention focused on growth (abnormal stature) and endocrine disorders that included puberty-related disorders, hirsutism, and hypoglycemia. Pediatricians do not regularly complete examinations of these areas. Given the differences between adults and children, pediatric endocrinologists need to attend to different needs than do adult endocrinologists. Specialized services for children is especially true since certain risk factors, such as early puberty, are linked to more severe health conditions in later adulthood, such as cancer (De Sanctis et al., 2014). Understanding, screening, and treating endocrine is essential for youth, especially since these disorders are often chronic and lifelong.

Although endocrine disorders can be precursors to other health problems, endocrine dysfunction can also be affected by a pre-existing medical condition or the treatment of chronic illness (Kamboj, 2008). Nakhaei-Moghadam and colleagues (2016) investigated 96 participants with a childhood diagnosis of cancer. Treatment for cancer includes chemotherapy, chemotherapy and radiation, and radiation and surgery. Hyperinsulinemia was the most common endocrine disorder development by individuals after childhood cancer treatment. Other endocrine disorders included vitamin D deficiency, dyslipidemia, and type 2 diabetes. Gender differences were also found, with females at higher risk for developing hypothyroidism and thyroid nodules. This study identified the need to view both endocrine disorders as a primary illness, but also as a secondary dysfunction.

**Diabetes.** The most common endocrine disorder is T1DM (Perfect et al., 2011). Diabetes is a life-long chronic disease that affects all aspects of a child's life (Burns et al., 2018). Diabetes

involves the hormone insulin that is created by the body. Insulin is the hormone that is responsible for clearing out glucose and ketones from the blood.

***Etiology.*** There are two types of diabetes. In T1DM, there is a failure to produce insulin by the pancreas. Given this, the body needs injections of insulin to make up for the body's failed production. This particular form of diabetes typically has an onset during childhood (Al-Haidar, 2006). It also does not necessarily manifest due to environmental factors.

The second form is known as Type 2 diabetes (T2DM). This form of diabetes is a metabolic syndrome that occurs when one's body creates insulin, but the body does not use it the way it should. This is considered a form of insulin resistance. Because of this, the body attempts to make more insulin, leading to the buildup of sugar in the blood and leading to hyperglycemia (Olokoba et al., 2012). This form of diabetes has a substantial environmental factor but can also have a genetic component (Dabelea et al., 2014; Mayer-Davis et al., 2017).

Oftentimes diabetes can go undiagnosed due to failure to recognize symptoms. Although the most common form of measuring glucose levels is through a blood test, this is not something readily available or commonly done by individuals. Individuals might first experience increased urination, excessive thirst, extreme tiredness, and weight change (Brown, 1997). These symptoms might be the first indication that something is wrong and therefore feel the need to seek medical attention. Since this study focuses on T1DM, the remaining sections will focus on

### ***T1DM***

**Incidence and Prevalence.** Most diabetes cases in children are that of T1DM. Juvenile diabetes makes up 80-85% of diabetes cases in children and cases continue to rise (Al-Haidar, 2006). Mayer-Davis and colleagues (2017) investigated the incidence trends of T1DM among youth from 2002-2012. The researchers found that the incidence of T1DM had an upward trend

in most age groups for children and adolescents, except for those aged 0-4 years of age for which the incidents of T1DM decreased. The age groups of children and adolescents found to have grown in the diagnosis of T1DM included those in ages 5-9 and 15-19 of age.

Mayer-Davis and her colleagues (2017) also examined the trends in the diagnosis of T1DM in racial and ethnic groups. Their study found that the incidence of T1DM rose for Hispanic youth, but there were no significant trends shown among other ethnic or racial groups. Dabelea and her colleagues (2014) found that while there were more cases of females diagnosed with diabetes when compared to males, the difference was not statistically significant. However, a study on mortality rates indicated that those who were female, older youth with type 2 diabetes, and non-Hispanic Black had a higher mortality rate (Reynolds et al., 2018).

**Management.** T1DM is an increasing concern for children. When considering management, it is imperative to incorporate racial and ethnic considerations in treatment and management. Willi and his colleagues (2015) investigated the disparities between treatment management and outcome among children with T1DM who identified as White, Black, or Hispanic. Their study included 10,704 children and adolescents diagnosed with T1DM. Within two years, Willi and colleagues (2015) were able to gather information on treatment (use of pump vs. insulin injections), HbA1c levels, self-monitoring of glucose levels (SM), and DKA events (a severe health crisis can occur with poor self-management; Kitabchi et al., 2001). The study found that SES and parent education levels accounted for some of the discrepancies seen in Hispanic youth relative to their white counterparts. Disparities in treatment and diabetes outcome continued to exist between Black youth when compared to white youth, despite controlling for SES and education level. Black youth were less likely than the other two ethnic groups to use insulin pumps and had more episodes of DKA. Additionally, Black participants had less frequent

blood glucose monitoring, and therefore an increase of HbA1c was also seen when compared to their counterparts. Overall, this study showed that while SES and education level can explain some of the disparities seen in children of different ethnicities with T1DM, there may be other factors that contribute to T1DM treatment and management.

Chowdhury (2015) sought to find information on T1DM during a critical period in a child's development, puberty (De Wit et al., 2008). On its own, puberty plays a significant role in youth. Therefore it is critical to know about youth with T1DM during this time. Physiological disruptions to youth are present during puberty, which can affect their growth. Insufficient levels of hormones can delay puberty, including menarche in female youth. Chowdhury (2015) also found that increased levels of HbA1C and poor glycemic control can also delay puberty. In females, an increased risk for vascular complications also exists. In all, adolescents' development also brings its own set of unique challenges to T1DM management.

Managing T1DM for youth can be challenging and may result in serious health emergencies. Kitabchi and his colleagues (2001) completed a review of two widespread medical crises for individuals with diabetes, diabetic ketoacidosis (DKA) and hyperosmolar hyperglycemic state (HHS). DKA is when one's body breaks down fat too quickly, which causes blood to become acidic, while HHS is when high blood sugar results in a cluster of symptoms such as dehydration, altered consciousness, hyperglycemia, with minimal ketoacidosis (Kitabchi et al., 2001). The researchers found that factors contributors to these complications included poor insulin treatment and infections. Communication with health care providers, education, and better self-management of T1DM can be preventative factors of severe complications such as DKA.

In addition to complications with medical problems, children and adolescents with diabetes may also experience psychiatric issues. Zenlea and his team (2014) sought to identify children with T1DM who may have psychosocial problems. Children and their parents completed screenings during a visit to a diabetes program. Even after controlling for the distress that may be caused by an initial diagnosis of diabetes, Zenlea and his colleagues (2014) found substantial emotional problems in young children with T1DM.

The American Diabetes Association (2020) recognizes the need for change in the treatment of diabetes. The standards of medical care recommend a multidisciplinary approach in treating patients with diabetes. The standards include, but are not limited to, the following providers, physicians, nurses, exercise specialists, dentists, and mental health professionals (ADA, 2020). A more comprehensive evaluation and assessment approach can help prevent or delay complications. This type of holistic approach can also help prevent other unhealthy self-management techniques. Mental health symptoms and their manifestations will be reviewed in more depth later in the chapter, following a general overview of mental health in youth.

### **Mental Health**

The concept of mental health encompasses an individual's overall psychological well-being (Manderscheid et al., 2010). When a person has poor mental health, a mental disorder or impairment is said to be present. Mental health symptoms are seen in one in every three or four children, while 10% of youth suffer from a debilitating mental or emotional disorder that causes impairment to their daily lives (Capp, 2015; Merikangas et al., 2010; NAMI, 2013). Mental illness affects individuals regardless of sex, race, SES, educational level, and age. However, patterns between mental health symptoms and demographic factors exist, predominantly when looking at sex and age among youth.

Merikangas and her research team (2009) sought to identify the patterns in mental health disorders among children and adolescents. Several studies were reviewed which included mood, anxiety, behavioral, and substance disorders in youth. The findings in this study suggest that certain patterns exist when it comes to the age of onset and gender differences. Anxiety disorders were found to be the most prevalent condition in children, followed by behavior disorders, then mood and substance use disorders. Female youth had greater rates of anxiety and mood disorders, whereas males had greater rates of behavioral disorders. No sex difference was found for substance use disorders. Anxiety disorders and ADHD had a younger age of onset, while conduct disorders tended to have an onset early in adolescents. For mood disorders, typical onset tended to show up in later adolescents. (Merikangas et al., 2009) The prevalence of mental health disorders in youth calls for the need to identify how these disorders and their symptoms affect children and adolescents.

Mental health symptoms cause children's impairment in multiple settings, including in schools. One study sought to examine the relationship between academic achievement and depressive symptoms in Latino youth (Zychinski & Polo, 2012). Adolescents' standardized test scores and report card grades were compared to the youth's self-reports of depression using the Children's Depression Inventory (CDI). Results from the study indicated that a significant and negative correlation between depression symptoms and adolescent achievement in school. This study included both teacher perspective, as measured by the grades they gave the child, and formal standardized testing. The study found a negative correlation between depression symptoms and both forms of assessment scores, indicating that a child's mental state can negatively affect overall achievement (Zychinski & Polo, 2012). It is necessary to have a better understanding of mental health to support children and their performance at school.

There is no one apparent cause of psychological and behavioral symptoms. However, to promote better mental health, youth need to have a better understanding of mental illness and symptoms within themselves and in general. Wright and his colleagues (2007) showed just how the misinterpretation of symptoms could interfere with youth seeking support. Adolescents in the study completed telephone interviews that consisted of answering questions about a vignette they heard. The youth in the study responded to questions about the best mode of treatment, who should deliver the treatment and the time frame for seeking help. The study showed that correctly identifying the disorder in the given vignette led to the proper identification of help-seeking and treatment (Wright et al., 2007).

Similarly, Olsson and Kennedy (2010) provided students with hypothetical scenarios about typical adolescent problems and diagnosable mental health symptoms. Only 27% of youth were able to identify anxiety symptoms as a mental health disorder correctly, and 42% identified depression as a mental health problem. Youth who correctly identify each disorder were also three to four times more likely than those who did not identify them, to report the appropriate help-seeking. These findings indicate the importance of knowledge about mental health to treat them appropriately.

### ***Mental Health and Chronic Illness***

**Endocrine and Mental Health.** Research on mental health symptoms in endocrine youth is scarce. Identifying the services needed for these is, therefore, more challenging to establish. Health problems can create additional problems, including emotional and psychological. In children and adolescents, this can have an even greater impact as they are still in a crucial developmental stage. Certain endocrine disorders have shown to have psychological symptoms

associated with them. However, it is difficult to understand whether the medical condition created the psychological symptoms or if the psychological symptoms were already present.

***Thyroid Dysfunction and Mental Health.*** Thyroid-related issues have links to mental health symptoms. Both an underactive and overactive thyroid can be related to psychological issues. The most common psychiatric symptom seen in individuals with thyroid issues is depression, with mania and being present as well (Conner & Solomon, 2017; Hong et al., 2018). Studies have indicated different conclusions as to whether subclinical hyperthyroidism and hypothyroidism both experience an increase in psychological symptoms or just when overproduction of the thyroid hormone is involved (Geffken et al., 1998; Hong et al., 2018). Anxiety disorders in patients with hyperthyroidism are also well documented (Conner & Solomon, 2017; Geffken et al., 1998). With proper treatment for thyroid disorders, psychiatric symptoms have resolved.

***Growth Disorders and Mental Health.***

Growth hormone issues in children and adults can appear differently. In children, the excess of the growth hormone leads to excessive growth and height that is well above average, known as gigantism. When the growth hormone is a deficit, it can result in short stature or dwarfism. Research is present about growth and its medical effects, but little research on the psychological impact on children and adolescents is present. Short stature has a negative effect on the development and emotional wellbeing of adolescents. Shorter adolescents are at a higher risk for anxiety, depression, and lack of self-confidence (Geffken et al., 1998; Dhamayanti et al., 2018).

***Tumors and Mental Health.*** Psychiatric symptoms are also associated with children with certain growths caused by the endocrine system. When there is an increase of epinephrine and

norepinephrine, a pheochromocytoma may occur. Anxiety symptoms can co-occur with these tumor growths (Conner & Solomon, 2017). Frequently, this type of tumor may go undiagnosed since the symptoms of hypertension, headaches, sweating, and heart palpitations frequently are misdiagnosed as a panic attack (Levenson, 2006). These findings show that not only do endocrine disorders co-occur with psychiatric symptoms, but they can also mimic particular characteristics that can make medical treatment more difficult.

**T1DM and Mental Health.** As noted above, a significant amount of responsibility for the youth to manage his or her illness is present, which can lead to distress and poor mental health (Stahl-Pehe et al., 2014). Existent literature suggests that youth with T1DM have a greater proportion of social-emotional difficulties, with higher prevalence rates documented in this population (Northam et al., 2005; Perfect et al., 2011). However, not all studies have found significant differences on measures assessing emotional or behavioral functioning. To detect behavioral and emotional problems in youth with chronic illness, Hysing et al. (2007) surveyed teachers and parents. Parents identified their child with at least one of the following chronic illnesses, asthma, epilepsy, diabetes, or another disease. Participants completed the Strengths and Difficulties Questionnaire, and those scoring in the 90<sup>th</sup> percentile completed the Development and Well-Being Assessment (DAWBA). The study found that the prevalence of mental health diagnoses was 10% higher for children with a chronic illness. Emotional, conduct, and peer problems were all found to be more significant in this population than in children without a chronic illness.

Children with diabetes tend to have higher rates of depression, anxiety, adjustment, and conduct disorders (Al-Haidar, 2006). Research completed by Northam et al. (2005) was aimed to describe the relationship between metabolic control in youth with T1DM and psychiatric

symptoms. Forty-one adolescents completed a self-report measure and metabolic control was measured from their diagnosis. The results of this study indicated that 37% of adolescents met the criteria for a DSM-IV disorder, which is higher than the general population (Hysing et al., 2007).

Blanz and his colleagues (1993) investigated the rates of psychiatric disorders in adolescents with diabetes. In interviewing adolescents and their parents, the study found three times higher rates of anxiety disorders, depression disorders, antisocial disorders, and hyperkinetic disorders, which included ADHD in youth with diabetes, when compared to their healthy counterparts. Youth with diabetes and elevated rates of mental disorders did not correlate with higher rates of stressful life events nor family adversity (Blanz et al., 1993). This last finding is contrary to the research completed by Blader (2006).

Blader (2006) set out to examine pre and post-discharge symptoms for any youth hospitalized at a psychiatric inpatient treatment center. The study examined several family factors to identify how they contributed to children's symptomatology. Parents of hospitalized children completed questionnaires about their child's symptoms, parenting practices, parenting, and parenting stress and distress. The findings showed that parents who reported more stress at times of admission and less stress at the time of discharge reported a decrease in their child's externalizing behaviors. Parents who reported less stress at admission and remained at a similar level of stress at admission did not see much change in their child's behaviors. Although this study found that life events can negatively impact parental perceptions of their child's mental health, it is difficult to understand the real impact of stress and other family factors because each family can perceive and react to things differently (Blackshaw et al., 2018).

Hagger and her colleagues (2017) set out to show how diabetes distress had a greater impact on glycated hemoglobin (HbA1c) than depression symptoms. The study hypothesized that more significant amounts of diabetes distress correlated with more poorly controlled glucose levels. The examination of 450 youth found that diabetes distress often came about due to the daily struggles of managing the illness, worrying about the disease, and not understanding the future course of the disease and its social implications (Hagger et al., 2017). Hagger and colleagues (2017) also found that diabetes distress was more prevalent in youth than depressive symptoms; however, neither one related to increased or decreased glycemic control. These findings are contrary to other research. Stahl-Pehe et al. (2014) found that adolescents reported a steady increase in HbA1c when experiencing emotional distress, self-care, and peer conflict.

### ***T1DM Management***

**Self-Management.** Diabetes in children involves a lifelong commitment, including medical care, insulin injections, blood testing, dieting, and exercise (Hilliard et al., 2017; Yang, Lou, Lien, & Gau, 2018). Regular self-management helps maintain and improve the quality of life. Auduly (2013) aimed his study to describe self-management techniques and their maintenance over time for individuals with chronic illnesses, including diabetes. Self-management encompasses a set of strategies undertaken to control disease, promote health, and live well with illness. These strategies also include help-seeking behaviors and the following of a treatment regimen (Auduly, 2013). Interviews occurred on several occasions. Findings indicated four forms of self-management patterns. The first two, consistent and episodic, showed a lifelong trajectory. Transitional patterns of self-management included changing behavior to adapt to a new environment or routine, and on-demand self-management occurred for acute problems or crisis episodes of the individual's illness. Overall, Auduly (2013) found that the most consistent

pattern in self-management was the use of medication every day, while preventative measures such as dieting and exercising were more episodic. Self-management takes time and commitment. For children, this can take a toll on their overall wellbeing and quality of life.

De Wit and her colleagues (2007) took a different approach to self-management of diabetes for adolescents. Their study aimed to monitor and discuss the health-related quality of life (HRQoL) to promote T1DM care. Parents and adolescents completed assessments that included measures of physical and psychosocial well-being, depression, diabetes-specific family conflict, satisfaction with care, glycemic control, the Pediatric Quality of Life Inventory (PedsQL), and a diabetes module. Her study found that evaluating and discussing the quality of life led to fewer behavioral problems, better self-esteem, increased mental health, and less withdrawal during family activities. These findings remained true even at a year follow-up. Glycemic control, on the other hand, was not affected by the discussion and assessment of the quality of life (De Wit, 2007).

The quality of care that youth receive also has a significant effect on their T1DM management. One study investigated whether youth-specific services helped decrease the length of hospitalization and decrease DKA severity (Burns et al., 2018). Youth-specific services included more frequent appointments, technology such as SMS text reminders, annual complication screening, young adult diabetes specialist educators, dieticians, and after-hours phone support. Participants split into two groups, those receiving youth-specific services and those receiving regular care. The study found that tailoring services for youth reduced hospitalization and length of hospital stay for T1DM complications. Youth receiving customized care had milder forms of DKA than those who did not receive youth-specific services. This study

suggests that youth's outcomes can be better supported by providing age-appropriate services (Burns et al., 2018).

Given that T1DM primarily begins in childhood, it is critical to include a care management routine that involves both the child and his or her parents. Research has demonstrated that child and parent investment in care management can be challenging to achieve. It is essential to have an understanding of the acceptability of screening and assessment to predict self-management and parent support.

One study by Perfect and her colleagues (2011) investigated the perception of youth with diabetes and their parents' understanding of mental health screening, assessments, and perceived barriers for care. Youth completed the Brief Symptoms Inventory (BSI) and Diabetes Quality of Life-Youth Version (DQOL-Y) questionnaires, while one of their parents completed a demographic survey and the Pediatric Symptoms Checklists (PSC). In the assessment phase, youth completed the Beck Youth Inventory-Second Edition (BYI-II), the Resiliency Scales for Children and Adolescents (RSCA), and the computerized version of the National Institute of Mental Health Diagnostic Interview Schedule for Children-Fourth Edition (NIMH-DISC-IV; C-DISC). Researchers obtained feedback from adolescents and parents, and referrals for coordination of care occurred. The study found that adolescents and parents perceived the screenings and assessment portions to be acceptable, although 15 and 16-year-olds reported mild discomfort with the questions asked. When looking at referrals for services, half of the refusals came from Hispanic families, even though they only made 20% of those participating (Perfect et al., 2011). It is important to mention that the data set used in this study is part of the current study.

### **Help-Seeking and Barriers**

Research has suggested that when it comes to seeking help for T1DM and mental illness, children and adolescents have a more difficult time. Several factors can impact help-seeking (Tomczyk et al., 2020). Individuals often indicate cultural differences as barriers to treatment. Rastogi and her colleagues (2012) explored Latino's utilization of mental health services and categorized the different barriers participants reported. Participants of her study listed the four categories as barriers: individual, familial, sociocultural, and legal obstacles. Personal barriers to seeking mental health services included ignorance about services and the notion that therapy was for those who were "mal de la mente," or sick of mind. Other barriers stated by participants included an invasion of privacy, embarrassment, denial, and being too prideful. On a family level, stigma was a concern given by individuals, as well as worrying about what others might think of their family if they found out they were seeking mental health services. Some sociocultural barriers identified included lack of awareness for community-based mental health services, discouragement from family and friends, and help-seeking through non-mental health professionals. One significant obstacle listed by Latino participants was the competency level of the therapist or mental health professionals, primarily when working with minorities. Lastly, participants in the study also stated legal barriers concerning deportation and unequal services. Cultural factors can create a perceived and actual barrier, which compounds with the inclusion of additional factors.

Venditti and colleagues (2018) examined the barriers to oral medication adherence in diabetic adolescents. Adolescents had several visits within the first two years scheduled, with each visit tracking glycemic control and barriers to treatment. The most common reason for failing to adhere to medication included forgetting to take medication, which was more significant for morning doses. The second most common reason reported for not taking

medication had a disruption in the schedule, which caused them to miss their dosage. Participants in this study were already receiving treatment for diabetes, possibly indicating less likelihood of seeking guidance for better treatment adherence. However, initial engagement in the treatment process may help with future treatment adherence to diabetes in children and adolescents.

One study examined initial client engagement as a predictor for compliance with mental health services (Roeg et al., 2015). Engagement described a patient's involvement in collaboration and participation in his or her care, measured by the Engagement Measure. The Health of the Nation Outcome (HoNOS) measured the participant's problem severity and the reason for their intake at the mental health center. The researchers found that higher levels of mental health severity lead to participants engaging more in their care, while longer wait time for the first contact for care resulted in less engagement in care. Demographic characteristics did not predict engagement in care. Overall, this study found that certain characteristics can predict engagement levels in services and therefore are a good area for interventions (Roeg et al., 2015).

Ofonendu and her colleagues (2017) also sought to understand the engagement of parents for their children's first mental health appointment. Parents completed the Child Behavior Checklist (CBCL), the Parenting Stress Index-Short Form (PSI-SF), and the Center for Epidemiologic Studies Depression Scale-Revised (CESDR). Their study revealed that parents who did not attend their child's first mental health appointment were more likely to live with more than four individuals in the household and had higher depressive symptoms. Unlike other findings, this study found that parenting stress and the severity of the child's psychological problems did not affect engagement in services (Blader, 2006; Roeg et al., 2015). Qualitative follow-up interviews of those who missed their child's first appointment reported long wait time

for an initial appointment as the number one barrier. Perceived barriers to treatment and mixed feelings about research participants were also reported (Ofonendu et al., 2017).

### *Help-Seeking Framework*

When considering help-seeking, the process typically tends to focus on formal aspects of seeking help from professions (Rickwood & Thomas, 2012). Additionally, help-seeking is typically viewed as a behavior, instead of a multi-facet concept that involves cognitive processes (Guo et al., 2015; Roeg et. al., 2015). An early model was developed by Rosenstock and colleagues (1966) that viewed the threat of an illness and the expectations of treatment as a predictor for help-seeking behavior. The Health Belief Model (HBM) viewed the threat as one's perceived vulnerability to an illness or disease, along with the potential benefits and possible barriers posed by seeking treatment. Together, this was viewed as aiding someone in the decision to seek help. An updated version of the HBM model was created to include self-efficacy when considering the expectations of treatment (Rosenstock et al., 1988).

One study used the HBM to predict help-seeking behavior in adolescents and young adults (O'Connor et al., 2014). The study used nine predictors from the HBM, including the five constructs of severity, susceptibility, benefits, barriers, and health motivation and psychosocial characteristics of self-efficacy, social support, extraversion, and health knowledge (Rosenstock et al., 1988). What this study found was that an individual's perceived benefits were a significant variable in seeking help and that perceived susceptibility of the mental health issue was less likely to influence help-seeking behavior (O'Connor et al., 2014).

The HBM model continues to emphasize help-seeking as a behavioral construct, although it also incorporated some cognitive traits. One study aimed to explore the individual, familial, economic, and cultural influences on women's decisions to seek help and support for domestic

violence (Liang et al., 2005). Instead of viewing help-seeking as a behavior, the model identified in the study used a complex process to understand help-seeking among women who experience partner violence. The study highlighted the importance of social support, particularly as a protective factor against mental health issues. Additionally, a three-stage approach was presented, with an emphasis on influences on an individual, interpersonal, and sociocultural level during each stage. Rather than viewing it as linear, Liang and colleagues (2005) presented the model as a changing feedback loop.

The process of help-seeking involves individual and cognitive processes. Liang et al. (2005) identified three stages: problem recognition and definition, decision to seek help, and selection of help provider. Each stage is marked by the person's individual, interpersonal, and sociocultural influences. The first stage is viewed as the individual's personal definition of the problem. Stage two is a changing process that is dependent of the individual's definition of the problem and their cognitive appraisal of their current situation. The third stage includes the support selection of the individual on both a formal and informal level. In all, this framework of help-seeking is multilayered and changes depending on an individual's personal, interpersonal, and sociocultural factors (Liang et al., 2005). Although this model was used to assess help-seeking for women who experienced intimate partner violence, this same model can be a framework to help predict help-seeking in youth with mental and mental health disorders.

## Chapter 3: Methods

### Participants and Sample

The current study used two different datasets developed as part of a more extensive study entitled *Integrating Medical and Psychological Services for Adolescents with Diabetes* (Institute for Mental Health Research [IMHR] #2008PM803). The first study (Study 1) examined the identification (screening and assessment) and the referral process for youth with diabetes. Following a feedback discussion, questions assessed caregivers' willingness to accept a recommendation for mental health services. The second study (Study 2) examined caregiver reports of their perceptions and experiences with mental health needs and services for their child.

#### *Study 1*

The current study included 50 adolescents diagnosed with diabetes and at least one of their parents. However, five families did not complete Phase II, the Assessment portion, so only 45 participant dyads (e.g., 90 participants) were included in the present study. The ages of the adolescent participants ranged from 13-17 years of age. All adolescents had a diagnosis of diabetes. There was only one participant diagnosed with type 2 diabetes. Criteria for participating in the study included being able to read the materials and consent to instructions in English. Parental consent and adolescent assent were both required (Perfect et al., 2011).

As shown in Table 1, the demographic characteristics among adolescents indicate that there were more male (62.2%) participants in Study 1, with a mean age of 15.39 years of age ( $SD = 1.40$ ). The estimated median income for youths' parents based on census tract data was \$45,252.36 ( $SD = 1691.79$ ). Also notable is that most participants reported themselves as White (71.1%) when asked for their ethnicity/race. These did not include participants who reported being Hispanic. Table 2 summarizes the medical characteristics of participants. Adolescents had

a T1DM diagnosis. One participant was included with T2DM because it was considered that the participant's inclusion would not obscure the data and that the participant contributed qualitative information. Participants had a mean HbA1C of 9.56% ( $SD = 1.91$ ), which is above the recommended guidelines for glycemic control (Gross et al., 2004). Additionally, the majority of participants had been dealing with T1DM for several years ( $M = 10.14$ ,  $SD = 4.09$ ). More than half of participants (57.8%) used a pump as their method of insulin delivery, with the average testing their sugar levels about four times a day.

**Table 1**

*Demographic Characteristics among Adolescent Participants*

Characteristic	<i>N (%)</i>	<i>M (SD)</i>
Age		15.39(1.40)
Sex		
Male	28 (62.2)	
Female	17 (37.8)	
Ethnicity		
White	32 (71.1)	
African American	1 (2.2)	
American Indian	1 (2.2)	
Other	2 (4.4)	
Hispanic	9 (20)	
SES Median		45252.36 (1691.78)

*Note:* SES ranges = Low <29,000; Medium-Low 9,000-39,999; Medium-High 40,000-49,999; High >60,000

**Table 2***Medical Characteristics among Adolescents Participants*

Characteristics	<i>N</i> (%)	<i>M</i> ( <i>SD</i> )
Diabetes	45	
Type 1	44 (97.8)	
Type 2	1 (2.2)	
Last HbA1C		9.56 (1.92)
Body Mass Index (z score)	45	.72 (1.10)
Insulin Delivery Method		
Injection	19 (42.2)	
Pump	26 (57.8)	
Diabetes Duration (Years)	45	10.14 (4.09)

*Note.* Only one participant had T2DM.

**Study 2**

The second study used the perspective of a caregiver for a child with an endocrine disorder. The study investigated caregiver experiences with community mental health services and their perceived barriers to services. Caregivers complete an anonymous survey while they waited at a clinic in southern Arizona during their child's already scheduled appointment. One hundred and two parents obtained a caregiver survey, but only 97 were fully completed. Qualifying criteria included caregivers being 18 years of age and older, being accessible for the study, and having at least one child diagnosed with an endocrine disorder as a patient at the clinic.

As shown in Table 3, the sex of the youth were evenly distributed between females (49.5%) and males (45.4%) participants. Caregivers reported the mean age of their child to be 11.72 years old ( $SD = 7.07$ ), with ages ranging from four to twenty. Slightly more than half of participants reported themselves as being Non-Minority (54.1%). Racial/ethnic minorities included White (56.1%), Hispanic (32.7%, of those 89.3% were Mexican), American Indian or Alaska Native (4.1%), Black or African American (3.1), Asian (1.0%), Native Hawaiian or other

Pacific Islander (1%), or other 2.0%). Caregivers also identified their highest level of education. The majority of caregivers indicated a bachelor's degree (30.9%), with the second-highest level of education was a high school degree or diploma (22.2%), and the third-highest being some college or a technical certificate (18.5%). Other levels of education included some elementary or high school (2.4%), associate degree (11.1%), master's degree (11.1%), and Ph.D. /MD (3.7%).

The majority of caregivers indicated that their child's medical diagnosis was Diabetes Mellitus or another carbohydrate metabolic disorder (68.4%). The second most common medical diagnosis reported by caregivers was thyroid hormone disorder (11.2%). Caregivers' report (26.27%) of a mental health disorder for their youth included: Attention Deficit/Hyperactivity Disorder (combined presentation, predominately hyperactive/impulsive presentation, or predominately inattention presentation not specified by caregivers), Tourettes Syndrome, Autism Spectrum Disorder, Major Depressive Disorder, Intellectual Disability, Obsessive Compulsive Disorder, Posttraumatic Stress Disorder, and Generalized Anxiety Disorder (American Psychiatric Association, 2013). It is important to note that some of these are no longer recognized by the DSM V (American Psychiatric Association, 2013).

**Table 3**

*Demographic Characteristics for Youth and Caregivers*

Characteristic	<i>N (%)</i>	<i>M (SD)</i>
Youth's Sex		1.44 (0.60)
Male	44 (45.4)	
Female	48 (49.5)	
Missing	5 (5.2)	
Youth's Age		11.72 (7.07)
Race/Ethnicity		
Not Minority	53 (54.1)	
Minority	45 (45.9)	
Caregiver Education		5.07 (1.82)
Some Elementary/High School	2 (2.4)	
High School/GED	18 (22.2)	
Some College/ Certificate	15 (18.5)	
Associate Degree	9 (11.1)	
Bachelor Degree	25 (30.9)	
Master Degree	9 (11.1)	
Ph.D. /MD	3(3.7)	

*Note.* Some of the caregiver's education were group due to the number of those who participated who identified under that category. Certificate = Technical Certificate.

**Table 4**

*Youth Endocrine Diagnosis*

Endocrine Diagnosis	<i>N (%)</i>
Short Stature	2 (2)
Anterior Pituitary Hormone	2 (2)
Posterior Pituitary Hormone	2 (2)
Hypothalamic Hormone Regulation	1 (1)
Thyroid Hormone	11 (11.2)
Thyroid Nodule and Neoplasms	2 (2)
Adrenal Gland	2 (2)
DM or other Carb Metabolism	67 (68.4)
Nutrition (e.g. Eating Disorder)	2 (2)
Obesity/ Metabolic Syndrome	3 (3.1)
Turner Syndrome	1 (1)
PP/ Adrenarche/ Thelarche	2 (2)
Other	12 (12.2)

*Note.* Participants may have chosen more than one. Sexual DD = Sexual Differential and Development; DM = Diabetes Mellitus; Carb = Carbohydrate PP = Precocious Puberty; Other = write in from caregivers, although they fell under mental health diagnosis, not endocrine diagnosis.

## Measures

### *Study 1*

**Background Questionnaire.** Parents completed a demographic questionnaire, which included questions such as “What type of Diabetes Mellitus does \_\_\_\_ have?, What race/ethnicity is child and parent?, and What types of grades does \_\_\_\_ generally get?”

**Beck Youth Inventories-Second Edition (BYI-II) Instrument (BYI-II).** The BYI-II developed by Beck and colleagues (2001), incorporates five self-report scales that measure depression, anxiety, anger, disruptive behaviors, and self-concept. The current study only assessed depression, anxiety, anger, and disruptive behaviors. The BYI-II is in line with the criteria outlined in the Diagnostic and Statistical Manual of Mental Health Disorders, Fourth Edition, Text Revision (DSM-IV-TR; American Psychiatric Association, 2000). The inventories, used together or in isolation, are standardized for children and adolescents between the ages of 7 and 18 (Beck et al., 2001).

Each scale on the BYI-II consists of 20 questions. Administration time may vary but can go anywhere between five to ten minutes. To ensure understanding, the reading level needed for each item is second-grade. T-scores presented on the BYI-II have a mean of 50 and a standard deviation of 10. A four-point Likert scale, 0 to 3, is present with 0 indicating the statement occurring “Never” and 3 meaning the statement being true “Always.” High T-scores indicate higher levels of distress. T-scores of 54 or less is within the Average range, 55-59 are in the Mildly Elevated range, 60-69 are within the Moderately Elevated range, and 70 and above are in the Extremely Elevated range.

The norming sample consisted of two general populations and a clinical population of older children with previously diagnosed clinical disorders. Each inventory includes statements

about thoughts, feelings, or behaviors that assess emotional and social distress. The internal consistencies for all of the inventories on the BYI-II were high,  $\alpha > .85$  (Beck et al., 2001).

***Beck Depression Inventory.*** The Beck Depression Inventory for Youth (BDI-Y) is a self-report measure for children and adolescents. This scale was created to capture depressive symptoms in youth. The 20-item scale measure is the newest edition that includes new items and rewording of some older items from previous scales, which had adequate internal consistency and solid retest reliability (ranging from  $r = .73$  to  $r = .96$ ; Wang & Gorestein, 2013). The Cronbach alpha ranged from  $\alpha = .91$  to  $.95$  depending on age and gender (Beck et al., 2001). The BDI-2 also assesses changes in behavior involving sleeping, eating, and weight loss or gain. It also includes items to measure feelings of agitation and worthlessness (VanVoorhis & Blumentritt (2007). Items include statements such as “I think that my life is bad,” “I wish that I were dead,” “I feel lonely,” and “I feel empty inside” (Beck et al., 2001). The Cronbach alpha for this sample was  $\alpha = .91$ .

***Beck Anxiety Inventory.*** The Beck Anxiety Inventory for Youth (BAI-Y) contains items that assess children’s fears, worries, and somatization (Beck et al., 2001). Items found in this inventory include “I worry someone might hurt me at school,” “I am afraid that I will make mistakes,” and “I worry people might get mad at me.” When compared to the Revised Children’s Manifest Anxiety Scale (RCMAS), the correlation coefficient for children was  $r = .70$  ( $n = 192$ ) and  $r = .67$  for adolescents ( $n = 35$ ; CUP, 2011). The internal consistency coefficient ranged from  $\alpha = .89$  to  $\alpha = .92$ . For this sample, the Cronbach alpha was  $\alpha = .95$ .

***Beck Anger Inventory.*** Another inventory includes the Beck Anger Inventory for Youth (BANI-Y), which includes items that touch upon mistreatment, negative thoughts towards others, anger, and physiological symptoms that occur with anger (Beck et al., 2005). Items within this

inventory include “I feel like screaming,” “People make me mad,” “I feel mean,” and “I hate people.” The coefficient alpha was  $\alpha = .89$  for males and females ages seven to 10,  $\alpha = .89$  for females and  $\alpha = .91$  for males in ages 11-14, and  $\alpha = .92$  for ages 15-18 (Beck et al., 2001). This sample had an alpha of  $\alpha = .95$ .

***Beck Disruptive Behavior Inventory.*** The Beck Disruptive Behavior Inventory for Youth (BDBI-Y) measures behaviors and attitudes consistent with Conduct Disorder and Oppositional-Defiant Disorder (Beck et al., 2001). The BDBI-Y indicates items such as “I seal”, “I fight with others,” “I break the rules,” and “I tell lies.” When compared to the Conners’ Rating Scales-Revised Adolescent Self-Report (Short; CASS-S), convergent validity was higher ( $r = .89$ ) for older adolescents (ages 15-8) than younger children ( $r = .60$ ), ages twelve to fourteen (CUP, 2011). The internal consistency coefficient ranged from  $\alpha = .86$  to  $\alpha = .91$  (Beck et al., 2001). The Cronbach alpha for this sample was found to be at  $\alpha = .92$ .

**C-DISC Instrument.** Youth also completed the computerized version of the National Institutes of Mental Health Diagnostic Interview Schedule for Children Version IV (NIMH-DISC-IV) known as the C-DISC (Shaffer et al., 2000). The C-DISC was designed to measure over 30 psychiatric disorders found in both children and youth, using criteria from the DSM-IV (American Psychiatric Association, 1994; Shaffer et al., 2000). This assessment has a total of six modules measuring anxiety disorders, mood disorders, schizophrenia, disruptive behavior disorders, alcohol and substance use disorders, and miscellaneous disorders. Each module has sub diagnostic sections (e.g., Mood Disorders-Major Depressive Episode/Dysthymic Disorder, Manic/Hypomanic Episode). If the entire assessment were to be given, it would include over 3,000 questions with 358 “stem questions” that are asked to all respondents (Columbia

University DISC Development Group, 2006; Shaffer et al., 2000). Answering questions in a particular manner within the module will automatically initiate additional questions.

There are two parallel versions of the DISC, one for youth (DISC-Y) and one for parents (DISC-P) but for this study, only youth completed the questions. Questions on the C-DISC are short and easy to answer. The structure of each question has a time component (e.g., within the past year and currently within the last four weeks). Most questions are yes or no answers, although some have additional responses (e.g., sometimes, somewhat, or close-ended frequency response). Affirmative answers to symptoms branched to questions further inquiring about timing, duration, severity and/or impact of those symptoms. Administration can take between 70 to 120 minutes, depending on the number of modules and items given (Columbia University DISC Development Group, 2006; Shaffer et al., 2000).

The C-DISC has been used along with other instruments to show face validity of what it is intended to measure. Bird and his colleagues (2005) used the DISC-IV, along with other measures, to measure antisocial behavior in children. They concluded that the DISC-IV identified DSM-IV for ODD and CD criteria and was a good measure as a classification system for antisocial behaviors. Another study also found that the computerized DISC-IV (C-DISC) was highly agreeable with clinical diagnosis by psychiatrists using the DSM-IV (Roberts et al., 2005). When analyzed to match diagnosis with complete accuracy, the agreement between the DISC-IV and the psychiatric diagnosis was 56%, yet when the criteria were lessened so that the criteria matched at least one diagnosis, the agreeableness of the measure raised to 60% accuracy. These studies indicate that the NIMH-DISC-IV is a valid and reliable measure when attempting to capture diagnostic criteria consistent with the DSM-IV. Psychometric properties could not be derived given that the output provided included whether the item was administered, the

symptoms met, and the level of impairment, not the individual responses for each participant.

Instead, concurrent validity was measured using the Spearman correlation between the BYI-II and the C-DISC, which indicated significant correlations between all the measures, see Table 5.

**Table 5**

*Validity between BYI-2 and C-DISC*

	BAI	BDI	BDBI	BANI	C-DISC Anxiety	C-DISC Depression	C-DISC Bipolar	C-DISC ODD
					<i>r<sub>s</sub></i>			
					<i>p</i>			
BAI		.84 <.001*	.74 .000	.84 <.001*	.62 .000*	.55 <.001*	.47 .001	.31 .044
BDI	.84 <.001*		.72 .000	.86 <.001*	.65 .000*	.65 <.001*	.34 .024	.45 .003
BDBI	.74 <.001*	.72 <.001*		.82 <.001*	.57 .000*	.44 .003	.49 .001	.42 .005
BANI	.84 <.001*	.86 <.001*	.82 .000		.61 .000*	.60 <.001*	.39 .009	.52 <.001*
C-DISC Anxiety	.62 <.001*	.65 <.001*	.57 .000	.61 <.001*		.66 <.001*	.48 .001	.40 .009
C-DISC Depression	.55 <.001*	.65 <.001*	.44 .003	.60 <.001*	.66 .000*		.36 .016	.55 <.001*
C-DISC Bipolar	.47 .001	.34 .024	.49 .001	.39 .009	.47 .001**	.36 .016**		.34 .029
C-DISC ODD	.31 .044	.45 .003	.42 .005	.52 <.001*	.40 .009**	.55 <.001*	.38 .029	

*Note: \* = p < .001*

All participants in the study received the same four diagnostic sections. These consisted of Generalized Anxiety, Mania, Major Depressive Episode, and Oppositional Defiant Disorder. Some of the participants were administered additional sections (e.g., Obsessive-Compulsive Disorder, Schizophrenia, and ADHD). This study used the number of symptoms met by each participant and the level of their impairment.

**Barriers Instrument.** Those who met criteria for follow up mental health services and parents agreed to continue, completed a questionnaire about anticipated barriers to receiving mental health treatment, developed by Perfect and her colleagues (2011). The items on the questionnaire come from work by Hines-Martin et al. (2003) who focused on understanding mental health barriers in African American adults and Kazdin et al. (1997) who investigated barriers to outpatient child treatment, with additional items added to address understanding of child's medical condition and doctor visits (Perfect et al., 2011). The barrier survey consisted of a five-point Likert scale that went from "will not prevent [service]" = 0 to "will prevent [service]" = 5. Questions included items such as "unaware of services available," "someone I know might see me," "thinking it would not be successful," and "long wait time for next available appointment" (Perfect et al., 2011).

The items in this instrument have not been examined together in any previous research. The internal consistency of this instrument was tested using a Cronbach alpha and an item-total correlation was derived. Internal consistency is when items that are together in a measure are reporting the same construct; a Cronbach alpha of  $\alpha = .70-.95$  is considered to reflect good internal consistency (Terwee et al, 2007). All items of the barrier instrument were significantly correlated with each other ( $\alpha = 0.93$ ). Given that only a small number of participants completed the barrier survey, a principal component analysis was not run to determine factor loadings, especially since there was strong reliability for the full instrument.

## *Study 2*

**Caregiver Survey.** The caregiver survey was developed for the purposes of this study. Caregivers answered a variety of questions. Demographic information about the caregiver included questions concerning living accommodations, occupation (e.g., full-time, part-time,

retired, homemaker, and unemployed), education level, place of origin, language spoken, and religious affiliation. The rest of the survey inquired about child-specific questions.

The survey included multiple-choice questions, yes or no questions, and other open-ended questions. The last portion of the survey included a Likert scale that inquired about the importance of services (1 = “Not at all important” to 5 = “Very important”) and satisfaction with the services (1 = “No at all satisfied” to 5 = “Very satisfied”).

On the Caregiver’s Survey, caregivers were asked demographic questions about the child receiving medical services at the clinic, such as medical condition, age, sex, household composition (e.g., mother, father, siblings, grandparents, or others), insurance, and race. The survey also inquired about medical and mental health diagnoses. Caregivers were asked, “When has your child received the following mental health services?” with the options of indicating the service or services were *within the past year, more than a year ago, or never*. Some of the services listed included, *child therapy, case management, psychological evaluation or testing, mental health medication, family therapy, crisis counseling, and residential treatment facility*.

The survey also inquired about the setting of the services that occurred, “When has your child received mental health services in the following settings” and the timeline, *more than past year; 1 year; never*. The specific settings that were included were *private practitioner’s office, school-based services, in-patient hospitalization, clinic, religious setting, out-patient hospital, and other*. Caregivers were also asked, given the same timelines, “When did your child receive mental health services from the following providers?” with the following options, *psychologist, psychiatrist, social worker, school counselor, licensed counselor, therapist, religious leader, primary care physician, nurse, and other*.

The remaining questions on the survey investigated potential future barriers and past barriers in receiving mental health services. Participants were asked to select the barriers that *has prevented* or *will prevent* services. If the box next to a listed barrier was not checked, it was assumed that it was neither a barrier in the past or future. A list of possible barriers was included with the options of marking it as *has prevented* or *would interfere*. Some of the barriers on the survey included *unaware of services available, transportation, financial reasons, the possibility of friends or family finding out, thinking the problem would go away, previous experiences, child refusal, and availability of types of services* the child needed. Parents were asked: “Has there ever been a time when you thought when your child should get emotional or psychological counseling but did not?” to obtain a parent's belief regarding past issues with accessing services. The primary outcome regarding openness to follow through with recommendation (e.g., engage in help-seeking) for research question #3 used the following “I would follow-up with a referral to a mental health provider that my child’s endocrinologist recommended” with the answer choices being, *yes, no, or depends*, with additional room to explain. One of the last questions asked guardians to rate certain services on a scale of 1 (no at all important) to 5 (very important). Some of the services included, *easy and quick access to mental health professionals, access to support groups, help with child care, and help with school based services*. The last question asked caregivers what type of service (e.g., helping out family get along better, dealing with medical problems, making friends, etc.) they would like support from the clinic. Overall, this survey was created to help determine utilization rates for services and obtain a caregiver's perspective of their needs.

## **Procedures**

### ***Study 1***

Approval by the Institutional Review Board (IRB) was originally obtained for the Integrating Medical and Psychological Services for Adolescents with Diabetes study. Participants were recruited over a 12-month period in a southwest clinic during their regularly scheduled medical appointment. Explanation of eligibility criteria occurred upon caregivers expressing interest in the study. Interested participants had a further explanation of the study in a private area, where consent was obtained for those who agreed to participate ( $n = 44$ ). Two participants responded to advertisements for the study, and four were recruited by word of mouth. Eligibility criteria were ensured for all participants before participating in the study.

The parent-child dyad completed screening questions and only the adolescents completed the assessment questionnaires, regardless of whether their screening measures indicated symptoms at-risk for or consistent with a mental health disorder or not, to ensure there were no false negatives. The screening portion was approximately 20-30 minutes while the assessment portion ranged anywhere from 1 to 2 hours. The length of the assessment depended on the results and the need for the adolescent to complete additional questions. Participants were provided telephonic feedback, and those who qualified were recommended for an additional phase of the study. Participants who agreed to continue ( $n = 20$ ) completed additional questionnaires, which included a barriers survey (pre and post) and a treatment satisfaction survey. Both the caregiver and adolescent completed each additional questionnaire.

### ***Study 2***

Recruitment of caregiver participants for Study 2 occurred during their child's regularly scheduled visit at a southwestern clinic, within a three-month period. During their child's regularly scheduled doctor's appointment, participants had access to an informational sheet attached to the Caregiver Survey, explaining the purpose of the survey, eligibility (at least 18

years of age with at least one child with an endocrine disorder), instructions, and contact information for further questions. Questionnaires were answered either at the clinic or at home and then brought back to the clinic. One hundred and two participants completed the Caregiver survey.

## **Data Analysis**

### ***Study 1***

The following analyses were used to characterize the sample and test the hypothesis presented in Chapter 1. It also describes the perceptions of caregivers regarding factors that influenced referrals to mental health services. Basic sample characteristics (e. g. sex, race/ethnicity, age, and SES) were examined in relation to each comparison group to determine if any variables needed to be controlled for in the models.

**Research Question 1.** What is the relative contribution of mental health symptoms and demographic characteristics in youth with T1DM that predict caregiver acceptability of recommendations regarding mental health services?

**Hypothesis 1.1.** Youth with T1DM with higher levels of mental health symptoms with an accompanying impairment will significantly predict a caregiver's intent to accept a mental health referral.

**Hypothesis 1.2.** Certain adolescent socio-demographic characteristics (e.g., lower SES, racial, and ethnic minorities) will predict a greater likelihood that caregivers accept referrals to mental health services regardless of mental health impairments in youth.

**Data analyses 1.** In this hypothesis, demographic variable that were categorical (e.g., sex and race/ethnicity) were analyzed using Chi-Square to test the relationship with the outcome of willingness to seek help. A chi-square test is one of independence. It is one of the most useful

tests when measuring nominal variables (McHugh, 2013). For ordinal variables (e.g. age and SES), a Spearman rho was used to measure the relationship with help-seeking. A Spearman rank-order correlation measures the direction and strength of the association between two variables (Salkind, 2010).

For mental health symptoms, the Mann Whitney U Test was used to determine whether there was an association between mental health symptoms, as measured by the T-scores obtained from the BYI-2 (BDI-Y, BAI-Y, BANI-Y, and BDBI-Y) and the symptoms and impairment scores on the C-DISC, with the caregivers' openness to help-seeking as reflected in their responses to the question that asked whether they were willing to follow recommendations for a referral versus not willing/unsure to follow recommendations with a referral. The rationale for combining the responses of not willing and unsure was due to the primary outcome reflecting readiness and/or willingness to seek or engage in mental health services. A response of unsure may indicate decisions depending on circumstances or certain conditions, which means a noncommittal response.

**Research Question 2.** Which mental health symptoms in children predict anticipated barriers to participation in mental health services by caregivers of children with diabetes?

**Hypothesis 2.1.** Caregivers of youth who have mental health symptoms associated with behavioral issues (e.g., ODD, disruptive behaviors, anger) will be more likely to perceive barriers to services.

**Data analysis 2.1.** Mental health symptoms were measured using the T-scores for the specific subtests on the BYI-2 and number of symptoms met and impairment scores on the C-DISC. A total barrier score was obtained. This analysis was completed through a Spearman Rank Order Correlation.

As a supplemental analysis, variables within Study 1 were identified to fit the Help-Seeking framework identified by Liang and colleagues (2005). The initial variable of help-seeking was used to fit this model. The first step of problem recognition and definition used the variable “You recognize yourself in what the research team member said,” essentially indicating that they were able to recognize the problem. The next step decision to seek help, the variable “Those who actually reported they would continue” was used to reflect their intention to pursue help. The last step identified in the model was the selection of a health provider. Although it did ask about specific providers, the question that best approximated this construct was, “You understand what services you need to help with your problem.” Additionally, caregivers’ reports of whether they were surprised by the results were also included to determine whether being completely surprised by the results interfered or promoted acceptance of recommendations, recognition of the problem, and knowledge of services needed.

## *Study 2*

**Research questions 3.** Which caregiver characteristics or demographic information predict help-seeking by caregivers of children with endocrine disorders?

**Hypothesis 3.1.** Past negative experiences in seeking treatment will negatively impact anticipated help-seeking by caregivers of children with endocrine disorders.

**Hypothesis 3.2.** When comparing White caregivers to caregivers who identify as a minority, minority caregivers will be more likely to note past negative experiences as a barrier to seeking treatment for their child.

**Data analysis 3.** Three questions from the Caregiver Survey were used to reflect negative past experiences: 1) a question about whether a caregiver perceived there was a time a child need emotional and psychological counselling and did not get it; 2) a specific item in the list of

barriers previously experienced; and 3) the total score of the summed list of past barriers.

Reliability analysis using Kuder-Richardson-20 indicated the 26-items on the list of future barriers had high internal consistency with a reliability coefficient of .85.

A Chi-Square was used to examine the association of the ethnicity of the child, whether a minority or non-minority, and whether a negative experience was noted as a barrier by the youth's caregiver. A Phi Coefficient was also used to measure effect size between associations.

**Research question 4.** Do anticipated barriers to seeking treatment reported by Non-White participant caregivers of children with endocrine disorders differ from their White caregiver counterparts?

**Hypothesis 4.1.** Barriers that are related to resource (e.g. financial situation, no transportation, not aware of available resources, and not finding adequate childcare) and stigma (e.g. possibility of family and friends finding out about treatment-seeking) are more likely to be stated as barriers by caregivers who identify themselves as minority when compared to their White caregiver counterparts.

**Data analysis 4.** Since response choices for the barriers were dichotomous (yes/no), Kuder-Richardson was used to determine internal consistency of the items. The Cronbach alpha value of  $\alpha = .85$  for future barrier indicated a good internal consistency. Since there was adequate internal consistency, each individual barrier was examined separately as well as summed to create a total score.

The caregiver's ethnicity (minority or non-minority) was compared to a group of barriers characterized by either resource or stigma. A Chi-Square was used given that each variable only had two possible responses. A Phi  $\phi$  was used to measure the effect size regarding the association between ethnicity and indicating a resource or stigma barrier. Exploratory analyses

also examined the other barriers that had not been classified as reflecting either resource or stigma.

## Chapter 4: Results

This study analyzed sociodemographic characteristics and mental health symptoms in an attempt to identify factors that influenced caregivers' acceptability of a referral to services. Additionally, perceived barriers to help-seeking were also investigated as a function of socio-demographics variables and mental health symptoms for Study 1 and previous experience and race/ethnicity for Study 2. The following are the research questions along with the findings.

### Research Questions

#### *Study 1*

**Research Question 1.** What is the relative contribution of mental health symptoms and demographic characteristics in youth with T1DM that predict caregiver acceptability of recommendations regarding mental health services?

The mean score of the four Beck Youth Inventories reflect that mental health symptoms of participants were comparable to children their same age, BAI ( $M = 49.3, SD = 9.55$ ), BDI ( $M = 49.8, SD = 10.63$ ), BDBI ( $M = 49.1, SD = 10.40$ ), and BANI ( $M = 47.0, SD = 10.43$ ). The percentages of youth with scores of 55 or above on the subscales measuring depression, anxiety, disruptive behaviors, and anger, were 31.11%, 28.89%, 22.22%, and 15.56% respectively, indicating mild to significant levels of psychological issues.

With regard to the C-DISC, the mean number of Generalized Anxiety symptoms met was four ( $SD = 2.7$ ), with a range of zero nine. Similarly, the range of scores on the C-DISC Generalized Anxiety-Impairment Index ( $M = 1.3, SD = 3.03$ ) was zero to 11, with the majority indicating no impairment. When it came to the number of symptoms met on the C-DISC Major Depressive Disorder, the mean was 8.70 ( $SD = 4.54$ ), with a range in scores that went from zero to 17. The C-DISC Major Depressive Disorder Impairment Index had a mean of 1.3 ( $SD = 3.31$ ).

More participants had an impairment of zero, although the maximum score was found to be 14. For the C-DISC Bipolar Disorder, the number of symptoms met ( $M = 5.1$ ,  $SD = 2.49$ ) ranged from one to nine, with the Impairment Index ( $M = 0.90$ ,  $SD = 2.85$ ) ranging from zero to eleven. However, only one adolescent (2.2%) had an impairment of eight and two (4.4%) had an impairment of ten. The final core test administered to all participants was the NIMH-DISC-IV-TR Oppositional Defiant Disorder yielded a mean number of symptoms met of 5.40, with a standard deviation of 2.79. Scores ranged from zero to 12 on this scale. When it came to the level of impairment ( $M = 2.60$ ,  $SD = 3.76$ ), scores similarly ranged from zero to 12, with more participants' reporting no impairment. Demographic characteristics were reported earlier (See Table 1). A correlation was found between SES and age ( $r_s = .42$ ,  $p = .004$ ) and a negative correlation was also present between SES and race ( $r_s = -.32$ ,  $p = .034$ ).

**Hypothesis 1.1.** Youth with T1DM with higher levels of mental health symptoms with accompanying impairment will significantly predict a caregiver's willingness to pursue or not pursue a mental health referral.

**Hypothesis 1.1 results.** Using the Mann Whitney U Test, Table 7 shows that neither mental health symptoms nor level of impairment yielded a statistically significant difference in acceptability of services amongst caregivers: BAI ( $U = 64.5$ ,  $p = .928$ ) with the mean rank 12.79 for those who accepted a referral and 13.08 for those who did not; BDI ( $U = 65.0$ ,  $p = .903$ ), with a mean rank of 12.71 for those who accepted a referral and 13.11 for those who did not; BANI ( $U = 55.5$ ,  $p = -.455$ ), mean of 14.07 for those who accepted a referral and 12.58 for those who did not; and BDBI ( $U = 50.5$ ,  $p = -.758$ ), with a mean rank of 14.79 (accepted referral) and 12.58 (rejected referral). No significant difference were found using the C-DISC and openness to help seeking: Anxiety Symptoms ( $U = 46.5$ ,  $p = .614$ ) accepted referral and 12.08 did not accept

referral), Anxiety Impairment ( $U = 49.5, p = .709$ ) ; mean rank of 13.25 for accepting a referral and 12.25 for rejecting a referral; Depression Symptoms ( $U = 46.0; p = .592$ ) and a mean rank for accepting referral 13.83 and 12.06 for rejecting a referral; Depression Impairment ( $U = 55.5; p = .125$ ), mean rank for accepting referral 12.25 and 12.58 for rejecting a referral; Bipolar Symptoms ( $U = 55.5, p = .919$ , mean rank 12.25 for accepted referral and 12.58 for not accepted referral); Bipolar Impairment ( $U = 52.0; p = .817$ ) mean rank 12.83 for accepted referral and 12.39 for rejected referral; ODD Symptoms ( $U = 40.0; p = .704$ ) 13.00 for mean rank of accepted referral and 11.72 for rejected referral; and ODD Impairment ( $U = 43.0, p = .876$ ) mean rank for accepted referral 12.40 and 11.89 for rejected referral.

**Table 6**

*Adolescent’s Beck Youth Inventory-2 Scores*

BYI-2	Mean	Standard Deviation	T-score N (%)
BAI	49.3	9.55	14 (31.11)
BDI	49.8	10.63	13 (28.89)
BANI	47.0	10.43	7 (15.56)
BDBI	49.1	10.40	10 (22.22)

*Note.* BYI-2 T-score  $\geq 55$ .

**Table 7**

*Adolescent’s DISC Scores*

C-DISC	Mean	SD	Mode	Range	%
C-DISC Anxiety S	4.0	2.7	3	0 – 9	9.1 – 6.8
C-DISC Anxiety I	1.3	3.03	0	0 - 11	79.5 – 4.4
C-DISC Depression S	8.7	4.54	10	0 – 17	2.3 – 2.3
C-DISC Depression I	1.3	3.32	0	0 – 14	84.1 – 2.3
C-DISC Bipolar S	5.1	2.49	4	1 - 9	9.1 – 6.1
C-DISC Bipolar I	0.9	2.85	0	0 - 11	90.9 – 2.2
C-DISC ODD S	5.4	2.79	6	0 – 12	4.8 – 4.8
C-DISC ODD I	2.6	3.76	0	0 – 12	58.1 – 12 2.3

*Note.* C-DISC refers to the computerized version of the NIMH DISC-IV TR

**Table 8**

*Help-Seeking with Mental Health Variables*

Mental Health Characteristic	Accepted Referral N (Mean Rank)	Rejected Referral N (Mean Rank)	Mann-Whitney U		p
			U	z	
BAI	7(12.79)	18(13.08)	64.5	.091	.928
BDI	7(12.71)	18(13.11)	65.0	.121	.903
BANI	7(14.07)	18(12.58)	55.5	-.455	.649
BDBI	7(14.79)	18(12.31)	50.5	-.758	.449
C-DISC Anxiety S	6(13.75)	18(12.08)	46.5	-.505	.614
C-DISC Anxiety I	6(13.25)	18(12.25)	49.5	-.374	.709
C-DISC Depression S	6(13.83)	18(12.06)	46.0	-.536	.592
C-DISC Depression I	6(12.25)	18(12.58)	55.5	.125	.901
C-DISC Bipolar S	6(12.25)	18(12.58)	55.5	.101	.919
C-DISC Bipolar I	6(12.83)	18(12.39)	52.0	-.232	.817
C-DISC ODD S	5(13.00)	18(11.72)	40.0	-.379	.704
C-DISC ODD I	(12.40)	18(11.89)	43.0	-.156	.876
SES	7(12.64)	18(13.14)	65.0	.152	.880
Age	7(14.29)	18(12.50)	54.0	-.545	.586

*Note.* z= standard error statistic; BAI=Beck Anxiety Index; BDI=Beck Depression Index; Beck; BANI=Beck Anger Inventory; BDBI=Beck Disruptive Behavior Index; C-DISC = computerized version of the NIMH-DISC-IV; S = Symptoms, I = Impairment

**Hypothesis 1.2.** Certain adolescent socio-demographic characteristics (e.g., SES, racial and ethnic minorities) will predict a greater likelihood that caregivers accept referrals to mental health services regardless of mental health impairments in youth.

**Hypothesis 1.2 results.** When examining sex, no significant differences between males and females existed in their help-seeking behavior. The percentage of male adolescents for whom the caregiver reported they would follow a referral was 78.6%, versus 21.4% who reported they would not follow a referral. For female caregivers, 63.6% indicated they would follow recommendations for a referral, while 36.4% reported they would not. Using a chi-square test of independence, the correlation between males and females was not significant,  $\chi^2(1) = .68$ ,  $p = .409$ . Negligible effect size was observed,  $\phi = -.17$ . For race/ethnicity, only 28.9% of

participants reported being Non-White, with 62.5% indicating they would follow a referral and 37.5% reporting they would not follow a referral for services. Of those who reported being White ( $n = 32$ ; 71.9%), 23.5% indicated they would not follow a referral, while 76.5% said they would. The chi-square  $\alpha$  test of independence yielded no statistical significance between race and following a referral,  $\chi^2(1) = .53, p = .468$ ; using the phi coefficient,  $\phi = .15$ , a weak effect size was obtained (Akoglu, 2018).

A Spearman rank was performed for demographic variables age and SES, given that they are continuous variables. No significant relationship was found between SES and caregivers accepting a referral ( $r_s = .03, p = .883$ ). Similarly, no correlation was observed between youth's age and accepting a referral ( $r_s = -.11, p = .597$ ).

**Table 9**

*Help-Seeking with Demographic Variables*

Demographics	<i>N</i> (%) Accept	<i>N</i> (%) Reject	$\chi^2(1)$	<i>p</i>	$\phi$
Sex			.68	.409	-.165
Males	11 (78.6)	3 (21.4)			
Females	7 (63.6)	4 (36.4)			
Race/Ethnicity			.53	.468	.145
White	13 (76.5)	4 (23.5)			
Non-White	5 (62.5)	3 (37.5)			

*Note.* Accept = Would accept a referral, Reject = Would not accept a referral.

**Table 10**

*Comparing Help-Seeking with Demographic Variables*

Demographics	Follow Referral		
	<i>N</i>	$r_s$	<i>p</i>
Age	25	-.11	.597
SES	25	.03	.883

*Note.* A Spearman rho was performed for ordinal demographic data.

**Research Question 2.** Which mental health symptoms in children and demographic characteristics predict anticipated perceived barriers to participation in mental health services by caregivers of children with diabetes?

**Hypothesis 2.1.** Caregivers of youth who have mental health symptoms associated with behavioral issues (e.g., ODD, disruptive behaviors, anger) will be more likely to perceive barriers to service.

**Hypothesis 2.1 results.** Contrary to the hypothesis that externalizing behaviors would lead to more endorsement of perceived barriers, internalizing behaviors lead to higher perceived barriers by parents. The Spearman rho was used to measure these relationships. The results were as follows: BANI ( $r_s = .22, p = .346$ ), BDBI ( $r_s = .14, p = .546$ ), DISC ODD S ( $r_s = .11, p = .631$ ), and DISC ODD I ( $r_s = .18, p = .453$ ). The following is the positive association between the sum of the total barriers and internalizing behaviors; BAI ( $r_s = .42, p = .068$ ); BDI ( $r_s = .57, p = .008$ ); DISC Anxiety S ( $r_s = .54, p = .013$ ), and DISC Depression S ( $r_s = .513, p = .021$ ). The rest of the mental health items had no significant relationship with the total barrier score (see Table 11.)

**Table 11**

*Barriers and Mental Health*

Demographic Variable	PreBarrierTotal ( <i>n</i> = 20)		PostBarrierTotal ( <i>n</i> = 11)	
	<i>r<sub>s</sub></i>	<i>p</i>	<i>r<sub>s</sub></i>	<i>p</i>
Age	.36	.116	-.08	.809
Sex	-.06	.795	-.16	.632
SES	.40	.081	-.19	.569
Race	.29	.214	.39	.232
BAI	.42	.068*	.21	.531
BDI	.57	.008*	.27	.426
BANI	.22	.346	.22	.512
BDBI	.14	.546	.25	.464
C-DISC Anxiety S	.54	.013*	-.32	.342
C-DISC Anxiety I	.11	.636	.26	.442
C-DISC Depression S	.51	.021*	.22	.516
C-DISC Depression I	.05	.840	.06	.873
C-DISC Bipolar S	-.00	.987	-.29	.388
C-DISC Bipolar I	.07	.765	-.41	.217
C-DISC ODD S	.11	.631	.24	.486
C-DISC ODD I	.18	.453	.314	.346

*Note.* BAI=Beck Anxiety Index; BDI=Beck Depression Index; Beck; BANI=Beck Anger Inventory; BDBI=Beck Disruptive Behavior Index; C-DISC = computerized version of the NIMH-DISC-IV; S = Symptoms, I = Impairment  
 \*Approaches significance

**Supplemental Analysis**

*Study 1*

In analyses applying the framework proposed by Liang and colleagues (2005), several relationships were found. Caregivers who reported that they would not continue with a referral were more likely to be surprised by the results presented to them ( $r_s = -.577; p = .008$ ).

However, being surprised by the results was correlated with understanding what services were needed to help with the problem ( $r_s = .384; p = .019$ ). Similarly, those who reported that they recognized their child in the feedback provided also reported greater understanding of what mental health services were available ( $r_s = .359, p = .032$ ).

**Research Questions**

## Study 2

**Research questions 3.** Which caregiver characteristics or demographic information predict help-seeking by caregivers of children with endocrine disorders?

The Spearman rho found no significant correlation between following a referral for services and the youth's age ( $r_s = .06$ ;  $p = .580$ .) or a caregiver's education ( $r_s = .06$ ;  $p = .637$ ). When looking at gender, 68.3% ( $n = 28$ ) of male adolescent's caregivers indicated they would follow a referral, while 73.2% ( $n = 30$ ) of females indicated that they would follow a referral. When using a Pearson correlation, the relationship between sex and following a referral was not significant,  $\chi^2(2, 87) = 2.26$ ,  $p = .322$ ,  $\phi = .161$ .

**Hypothesis 3.1.** Past negative experiences in seeking treatment will negatively impact anticipated help-seeking by caregivers of children with endocrine disorders.

**Hypothesis 3.1 results.** Regarding the independent variable of negative experiences, 30 caregivers (31.6%) believed there was a time their child should get emotional or psychological counseling but did not. Only three (2.3%) caregivers endorsed the barrier of a negative experience. The average number of past barriers recognized by caregivers was 1.4 ( $SD = 2.98$ ), with a range from 0-15 (maximum possible 26). The negative experience indicator of the total past barrier score had a moderate, significant relationship with the negative experience indicator of caregivers reporting they believed there was a time that their child needed mental health support but did not,  $r_s = .57$ ,  $p < .001$ . The hypothesis using all three negative experiences indicators was not supported. Indicating a previous negative experience did not relate to help-seeking  $\chi^2 = .561$ ,  $p = .454$ . The effect of past negative experience on following an endocrinologist referral for mental health services was low ( $\phi = -.038$ ). Spearman correlation indicated no significant correlation with previously needing help and not getting it  $r_s = -.07$ ,  $p =$

.497. Also not significant were the total number of past barriers,  $r_s = .02, p = .885$ , nor the sum of the anticipated barriers,  $r_s = -.05, p = .684$ , significantly related to whether a caregiver reported they would follow up with a referral if their child’s endocrinologist recommended it.

**Table 12**

*Negative Experiences and Help-Seeking*

Negative Experience	$\chi^2$	$r_s$	$p$
Previous experience was negative	.561		.454
Needed help but did not get		-.07	.497
Total past barrier		.02	.885
Total anticipated barriers		-.05	.684

*Note.* Needed help but did not get = Has there ever been a time when you thought your child should get emotional or psychological counseling but did not; Total past barrier = Sum of 26 past barriers; Total future barriers = Sum of 26 anticipated barriers

**Hypothesis 3.2.** When comparing White caregivers to caregivers who identify as a minority, minority caregivers will be more likely to note past negative experiences as a barrier to seeking treatment for their child.

**Hypothesis 3.2 results.** The association of race/ethnicity and belief that a child did not get counseling needed in the past was not significant,  $r_s = .05, p = .666$ . Similarly, reporting a negative past experience was also not significant for minorities,  $\chi^2(1, 88) = .017, p = .896, \phi = .014$ . Minority status did not significantly relate to the sum of past experienced barriers,  $r_s = .03, p = .778$ .

**Research question 4.** Do anticipated barriers to seeking treatment reported by Non-White participant caregivers of children with endocrine disorders differ from their White caregiver counterparts?

**Hypothesis 4.1.** Barriers that are related to resource (e.g. financial situation, no transportation, not aware of available resources, and not finding adequate childcare) and stigma (e.g. possibility of label and possibility of family and friends finding out about treatment-

seeking) are more likely to be stated as barriers by caregivers who identify themselves as a minority when compared to their White caregiver counterparts.

**Hypothesis 4.1 results.** The average number of anticipated barriers selected was 1.33 ( $SD = 2.59$ , range 0 - 22). The most frequently endorsed future barriers were: unaware of services  $N = 13$  (14.6%), financial reasons  $N = 11$  (12.4%), provider not understanding my child's medical condition  $N = 8$  (9.1%), and both long wait for next available appointment and lack of available providers who are qualified  $N = 7$ , (7.9).

The results of the Chi Square Test showed that there was no significant association between minority status and anticipated resource barriers: financial reasons  $\chi^2(1, 89) = .47$ ,  $p = .494$ ,  $\phi = .072$ ; unaware of available resources  $\chi^2(1, 89) = 1.69$ ,  $p = .193$ ,  $\phi = .138$ ; no transportation  $\chi^2(1, 89) = .49$ ,  $p = .486$ ,  $\phi = .074$ ; and lack of childcare  $\chi^2(1, 89) = .02$ ,  $p = .884$ ,  $\phi = .015$ . Barriers classified as reflecting stigma were also not significant when compared to minority status: possibility of family finding out  $\chi^2(1, 89) = 2.51$ ,  $p = .113$ ,  $\phi = .168$ , possibility of friends finding out  $\chi^2(1, 89) = 2.51$ ,  $p = .113$ ,  $\phi = .168$ ; and possibility of label given to child  $\chi^2(1, 89) = 1.53$ ,  $p = .216$ ,  $\phi = .131$ .

In the exploratory analyses, additional barriers that were found to be significant or trending towards significance, although the associations between these variables was weak: bad weather  $\chi^2(1, 89) = 3.80$ ,  $p = .05$ ,  $\phi = .207$ ; thinking it would not be successful  $\chi^2(1, 89) = 3.80$ ,  $p = .05$ ,  $\phi = .207$ ; and not understanding the child's condition  $\chi^2(1, 89) = 3.10$ ,  $p = .078$ ,  $\phi = .188$ . The remainder of the barriers included in the Caregiver questionnaire were not significant. Additionally, the sum of the past barriers significantly correlated with the sum of anticipated barriers,  $r_s = .22$ ,  $p = .036$ , indicating that past interference with help seeking was associated with endorsing more barriers in the future pursuit of mental health services.

**Table 13***Minorities and Barriers*

Barriers	Minority <i>n</i> (%)		Non-Minority <i>n</i> (%)		$\chi^2$	<i>p</i>	$\phi$
	Interfere	Not Interfere	Interfere	Not Interfere			
<b>Resource Barriers</b>							
Financial reasons	6 (15.0)	34 (85.0)	5 (10.2)	44 (89.4)	.47	.494	.072
Unaware of services	8 (20.0)	32 (80.0)	5 (10.2)	44 (89.8)	1.69	.193	.138
Transportation	3 (7.5)	37 (92.5)	2 (4.1)	47 (95.1)	.49	.486	.074
Lack of childcare	1 (2.5)	39 (97.5)	1 (2.0)	48 (98.0)	.02	.884	.015
<b>Stigma Barriers</b>							
Family finding out	2 (5.0)	38 (95.0)	0 (0.0)	49 (100)	2.51	.113	.168
Friends finding out	2 (5.0)	38 (95.0)	0 (0.0)	49(100)	2.51	.113	.168
Possibility of label	3 (7.5)	3 (92.5)	2 (2.0)	48(98.0)	1.53	.216	.131
<b>Significant Barriers</b>							
Bad weather	3 (7.5)	37(92.5)	0 (0.0)	49(100)	3.80	.051	.207
Not successful	3 (7.5)	37 (92.5)	0 (0.0)	49(100)	3.80	.051	.207
Child's condition	6 (15.0)	34 (85.0)	2(4.2)	46(95.8)	3.10	.078	.188

*Note.* Unaware of services = Unaware of services available; Family finding out = Possibility of family finding out; Friends finding out = Possibility of friend finding out; Possibility of label = Possibility of a label given to child; Not successful = Thinking it would not be successful; Not understanding child's condition = Providers not understanding of my child's medical condition.

## **Chapter 5: Discussion**

The present study utilized secondary data analysis from two prior studies (Study 1 and Study 2) to determine if characteristics predicted caregivers' willingness to accept a referral for mental health services for their child. In addition, this study attempted to identify what barriers would prevent caregivers from help-seeking. Help-seeking was defined as the behavior of being active in searching treatment, first by identifying the problem, then agreeing to obtain help, and finally by understanding what services to obtain (Liang et al., 2005). It was also important to understand how caregivers of youth with endocrine disorders, particularly T1DM and minorities, perceived barriers to mental health services. The data revealed a concerning prevalence of youth with higher than average medical and psychological problems, indicating the importance of continuing research in these areas.

### **Summary**

#### ***Study 1***

Mental health symptoms of youth did not predict intent to follow through with a mental health service referral. Youths' mental health symptoms were measured by the BYI-2 and C-DISC. Demographics of youth (i.e. sex, age, and race/ethnicity) and caregivers (SES) also did not predict intent to follow through with a mental health referral. Additionally, although the hypothesis predicted that externalizing symptoms would cause caregivers to endorse more barriers to seeking treatment, the results indicated the opposite whereby the internalizing problems of both anxiety and depression symptoms were significantly related to stronger ratings of perceived barriers.

#### ***Study 2***

The majority of respondents (62.7%) indicated that they would engage in help-seeking if recommended. In most cases, willingness to follow a recommendation and anticipated barriers did not differ based on race/ethnicity or previous negative experiences. Overall, the findings suggested that predicting the acceptability of services is more complex and neither study revealed specific factors or characteristics that predicted a caregiver's willingness to accept services.

## **Adolescent Mental Health**

### *Study 1*

Adolescents' mental health symptoms were measured using self-report ratings (BYI-2) and semi-structured interviews (C-DISC). Findings on the BYI-2 suggested that the number of participants' mental health symptoms and their level of impairment were comparable to their peers (see Table 5). This was determined by comparing the mean T-score from each BYI-2 composite with the BYI-2 cut-off score of 55 (Beck et. al., 2001). The frequency for which symptoms were endorsed by youth with T1DM on this same measure, anxiety (31.11%), depression (28.89%), disruptive behavior (22.22%), and anger (15.56%,) are similar to other studies but higher than the general population (Northam et al., 2005). Even youth with a diagnosed chronic illness, other than T1DM, have experienced lower symptoms of mental health disorders than those found in this study (Hysing, 2007). This is notable, indicating that this particular population is more susceptible to mental health issues.

Higher levels of mental health symptoms are not enough to predict help-seeking intent. When internalizing behaviors, such as anxiety and depression, are present, the intent to help-seek is lower. However, when caregiver's understand the youth's symptoms, it helps them in recognizing what is needed to help support their child. Yet, if parents are surprised by their

child's mental health symptoms, it is important to thoroughly explain the importance of services and what services are needed. This is due to the likelihood of caregivers being less inclined to pursue services if they do not agree or are surprised by realizing the extent of their child's symptoms.

An interesting observation in this study was how the number of symptoms on the C-DISC did not appear to match the impairment level. This; however, was not statistically analyzed (see Table 6). On the C-DISC Major Depression Disorder scale, the majority of participants noted no impairment (84.1%), yet one participant experienced an Impairment Index of 14 (2.3%), indicating significant distress in some areas that interfere with their ability to function. Similarly, on the C-DISC Bipolar Disorder scale, youth endorse an average of five symptoms, yet 90.9% of youth reported no impairment. However, some youth experienced symptoms that created significant functional impairment. This is important to report because youth may experience a significant amount of symptoms, but have higher levels of resiliency that buffers the impact of those symptoms. However, some adolescents may experience significant disturbances that merit immediate intervention. The symptoms and impairment of youth in this study give support to the ADA (2021) recommendations to routinely monitor mental health symptoms to track whether overtime new symptoms manifest, the existing symptoms worsen, or if symptoms remit. Additionally, even though youth with T1DM experienced low rates of the various mental health symptoms domains, as noted, they collectively had higher rates of mental health symptoms than typically reported in the general population. Therefore, screening protocols may wish to incorporate omnibus measures of mental health symptoms rather than narrowly focusing on one area (e.g., depression). Moreover, youth with T1DM are a unique subgroup that requires

additional emotional support and services (American Diabetes Association, 2021).

### ***Study 2***

Similar to Study 1, caregivers reported a variety of mental health diagnoses. While the diagnosis reported by caregivers were not the most current when considering the DSM V, the following were essentially the diagnosis reported by parents, although specifications were not noted in their write in answers; Attention Deficit/Hyperactivity Disorder (combined presentation, predominately hyperactive/impulsive presentation, or predominately inattention presentation not specified), Tourette's Syndrome, Autism Spectrum Disorder, Major Depressive Disorder, Intellectual Disability, Obsessive Compulsive Disorder, Posttraumatic Stress Disorder, and Generalized Anxiety Disorder ( American Psychiatric Association, 2013). Only 13 participants (12.75%) reported a mental health diagnosis, with four caregivers identifying more than one diagnosis. However, mental health symptoms in this study were harder to verify given that it was an anonymous survey. Further, the question asked about diagnoses rather than symptoms experienced by the youth.

### **Demographic Characteristics**

#### ***Study 1***

More than half of the adolescents who participated were males (62.2%), a similar presentation to other studies investigating chronic illnesses (Hysing et al., 2007; Villa et al., 1999). Trends from 2002-2012 also indicated an increase of T1DM cases among males, but not females (Mayer-Davis et al., 2015). When it came to SES, most caregivers fell within the medium-high range ( $M = \$45,252.36$ ; Perfect et al., 2011). A similar SES finding was discovered by Hagger and colleagues (2018) when investigating depression, diabetes distress,

and diabetes control. This may be a telling characteristic of caregivers who are willing to partake in a research study.

When looking at demographic characteristics as a predictor for help-seeking, this study did not find any evidence for SES or race/ethnicity as a source to predicting help-seeking. While demographic variables, such as gender, have previous shown to positively predict help-seeking intentions (Maiuolo et al., 2019), sex was part of a model and not measured individually. Looking at demographic variables in a model and a larger study may be beneficial for future studies looking at help-seeking for children with endocrine disorders.

### ***Study 2***

Despite there being evidence of minorities less likely to help-seek (cite), there was no evidence of this when looking specifically at previous negative experiences. A previous negative experience was also no more likely to be reported by White or Non-White participants. Previous negative experience was narrowly defined using three separate variables, so broadening the definition of negative experience may be one way to examine if there is truly no difference in minority groups. Additional demographic information was found to help predict acceptance of a referral. No significant relationships were found when comparing demographic variables. Studies should focus on other factors for aside from demographics when looking acceptance of treatment.

### **Help-Seeking**

#### ***Study 1***

The conceptualization of help-seeking focused on a caregiver's willingness to pursue a referral to mental health services. Based on previous research that caregivers were four times more likely to seek care if their child experienced psychological impairment (Alegria et al.,

2004), it was hypothesized that higher levels of mental health symptoms would predict willingness to accept a referral. However, levels of impairment were not a predictor for help-seeking. Research has also noted that several factors play into help seeking (Ajzen, 2002, Boulter & Rickwood, 2014, Guo et al., 2016). Noteworthy is the fact that the majority of referred caregivers (78.3%) indicated they would follow a referral. Caregivers may report their intention to follow through with a referral, the action of seeking treatment may not be taken. This is sometimes referred to as the intention-behavior gap (Tomczyk et al., 2020). Many have recognized that there are multiple aspects of help-seeking (Cauce et al., 2002; Guo et al., 2015; Rosenstock et al., 1966). Although parents have intentions to seek help, this does not necessarily relate to the behavior of help-seeking. Using the theory of planned behavior (TPB; Ajzen, 2002), Tomczyk and colleagues (2020) found that attitude towards help-seeking (perceiving that outside support would have positive results) and having a positive recommendation by a meaningful, or socially acceptable source, increased not only intention to seek help but also actual help-seeking behavior.

Demographic data did not correlate with help-seeking (Alegria et al., 2002). Neither higher SES status nor race/ethnicity were not found to increase help-seeking intentions. This shows that other factors unrelated to demographics play a bigger role at predicting help seeking.

Also hypothesized was that externalizing problems would lead to more endorsement of barriers. Previously it was found that only 19% of caregivers with behavioral disorders reported taking all the steps needed for help-seeking (Thurston et al., 2018). Parents reported not following through because they thought the problem would go away on its own. Additionally, evidence exists that seeking services for youth with behavior problems is often the last resort for minority groups (Cauce et al., 2002). Such a phenomenon may not be evident in children with

T1DM as they have to deal with additional complications that can impact several aspects of their life, which prompt caregivers for a quicker response (Cohen et al., 2004). Alternatively, as noted above expressing acceptability of the recommendation does not necessarily mean the family will seek help.

Supplemental analyses were conducted to examine some of the questions in the feedback evaluation that approximated the cognitive factors as part of the help-seeking process. The three-stage help-seeking model identified by Liang and colleagues (2005) included 1) problem recognition and problem definition, 2) decision to seek help, and 3) selection of help provider. A negative relationship was observed when looking at help-seeking and being surprised by results, supporting the supposition that caregivers are more likely to have intentions of helping seeking if they have recognized the problem. Recognizing themselves in the results explained to caregivers by a research member was also correlated to understanding what services they needed to solve the problem, which is similar to the selection of help providers found in this model. On the surface, it may seem that caregivers who were surprised by the findings rated high levels of understanding regarding what services they need. Although speculative, there may be four explanations for this association; 1) caregivers can be aware of a possible problem but dealing with some level of denial (Aldebot & Weisman, 2009), those who are surprised by the results may be more likely to tell someone else they are aware of services to minimize further discussion about treatment options, either due to mistrust of the profession or another reason (Taber et al., 2015); 2) the person giving feedback made sure that caregivers who were surprised by results understand services available; and 4) being surprised by results may have made them pay more close attention to the treatment options (Anderson & White, 2017).

## *Study 2*

A total of 72.7% of caregivers indicated that they would follow a referral by their endocrinologist. While past barriers correlated with future barriers, there was no relationships between negative past experience and help-seeking. Past negative experience was measured by a singular item on the Caregiver survey, the total sum of previous barriers, and the negative experience of needing services in the past but unable to get them, which may not have captured the totality of a negative experience. Additionally, negative experience may be better defined by more discriminatory experiences, particularly by minorities (Henderson et al., 2013).

## **Barriers**

### ***Study 1***

The barrier survey used in this study was developed and previously reported by Perfect and colleagues (2011). No significant correlations among externalizing symptoms, demographic characteristics, and barriers were found. It was hypothesized that youth with externalizing behaviors would have caregivers more likely to perceive barriers to services, because other research has shown that externalizing problems were more likely to receive a more informal approach to help seeking by caregivers (Thurston et al., 2018). However, it may be the case that just because caregivers may not seek professional services to address behavioral problems, they would anticipate barriers to do so. Additionally, a stigma surrounding externalizing problems sometimes impedes minorities from seeking help as well (Pavuluri et al., 1996). For barriers to seeking mental health services, caregivers of adolescents who endorsed internalizing symptoms were more likely to indicate perceived barriers to seeking services. This is similar to the findings of Ofonedu et al. (2017) who found that the severity of an adolescent's depression symptoms led to less engagement in treatment by caregivers. The opposite may have been found due to the nature of additional struggles that children with T1DM face.

## *Study 2*

Predicting the outcome for certain barriers was not found in this study. Negative experience, resource, and stigma barriers were not found to be endorsed by a particulate group of caregivers. A significant association between the following barriers and minority status was found, “thinking it would not be successful,” “bad weather,” and “not understanding child's condition.” However, the relationship of the association was weak. A deep understanding of all barriers to service seeking is important when working with youth with endocrine disorders, particularly those at a greater disadvantage for not following through with treatment.

## **Limitations**

### *Participants*

The sample size in both studies may have compromised power diminishing the ability to detect significant relationships. For Study 1, the number of participants was initially 50 but each phase dwindled down the number of participants. It is important to keep in mind that the primary purpose of this health service research project was to screen participants for a variety of mental health symptoms, conduct a more comprehensive assessment to verify screening results and treatment needs, and provide feedback to families and track their participation in and experience with mental health services. Therefore, the study enrollment was based on the feasibility to work with families rather than designed to be a large quantitative study. Small sample size can decrease statistical power and limit the generalizability of results (Forstmeier et al., 2016).

In Study 2, the Caregiver Survey was readily available to all parents during their regularly scheduled medical visit. The purpose of this study was to determine the use of different psychosocial services by caregivers and to obtain their perspective of needs; their perception of barriers to these services was also elicited. The survey was unmonitored and anonymous,

therefore, it is unknown the actual number of participants who were initially eligible or interested in participating but did not complete and submit the survey in the drop box provided at the clinic. Participant responses were not verified by other sources, including medical records.

### ***Measurements***

Another limitation came from the lack of adolescents' perspective of help-seeking. While the youth's medical and mental health information was obtained, the pursuit of help-seeking was measured using the caregiver's willingness to follow recommendations. This was true for both studies. A disconnect between youth and their caregivers can possibly create different findings. It is possible that caregivers have some understanding of a problem, but they may not know the extent of the youth's issues (Alegria et al., 2004). Conversely, indicators of a youths' mental health functioning were solely based on endorsements of symptoms on the evaluation tools administered to them. Including parental reports of their child's mental health symptoms would have been helpful as a way to collaborate symptoms perceived by youth through their completion of the BYI-2 and C-DISC.

Additionally for Study 1, as noted the dependent variable of help seeking was based on caregivers' responses to a question on a Feedback Survey that asked about their intention to follow through with the referral. Not all participants who were referred were given a Feedback Survey due to difficulty in scheduling and only those who were recommended for follow-up treatment (i.e., met criteria on one or more mental health assessment tools) were included. A re-code was made by viewing those who had been referred ( $n = 27$ ), those who had continued ( $n = 20$ ), and those who completed the Feedback Survey ( $n = 24$ ). The actual number of participants who reported they would follow a referral were eighteen (72%).

### **Implications/Future Research**

This study examined whether caregivers who identified as minority responded differently about help seeking intentions and if they identified certain anticipated barrier to help seeking when compared to their White counterparts. Although this study did not find differences, receiving services from clinicians trained on Multicultural Counseling Competencies (MCCs) has already shown to increase client satisfaction (Jones & Wells, 2007). When considering the age range of youth in Study 1, ages 13-17, it makes sense to look at culturally adapting programs and making them accessible within the school setting (Castro-Olivo, 2017). Making culturally adapted services available to youth also aligns with the American Diabetes Association (2021) Standards of Care, which recommends that youth with diabetes, and their caregiver, receive culturally sensitive and developmentally appropriate support during care and follow-up. Also recommended by the ADA(2021) is that screening for psychological symptoms begin in youth ages 7-8, and including eating disorders screenings starting at age twelve. This is yet another reason to also look at screening youth more consistently within the school setting.

In addition to screening youth within the school setting, the higher than typical frequency of mental health disorders in youth with T1DM, particularly internalizing disorders, makes it crucial for screening to also be routinely done at endocrine clinics. Looking closely at each individual is of great importance, given that lumping youth together may miss individuals who are experiencing significant distress, as seen in this study. Additionally, being able to clearly explain results of screening or assessments to caregivers is significantly important for caregivers to understand what mental health services their child needs. Although measuring the number of symptoms is vital, looking at the impairment level and the resiliency factors can also help provide support.

Early identification of emerging or existing mental health symptoms and the level of impairment is essential to holistic clinical care. Remembering that mental health can physiologically affect the body is also important, given that youth with endocrine disorders already experience many bodily ailments. Being able to distinguish if a symptoms is part of the prognosis of the medical disease (Hagger et al., 2017), a commonly seen form of distress due to the medical disease, or a mental health disorder that is developing is an important distinguishment to try and make. Finding ways to distinguish these may be an area for future research. Using the school settings, monitoring children with chronic illnesses, and educating parents on what to look out for are also areas for future research in distinguishing what a child is experiencing or may encounter in the future.

Maiuolo et al. (2019) also reported that parenting styles and social support predicted intent to help seek. In the current study, neither parenting style nor social support available to caregivers was investigated. Additionally, studies have echoed that social support or acceptability by social norms (reducing stigma) aid in reducing the intention-behavior gap (Cauce et al., 2002; Tomczyk et al., 2020). Understanding parenting styles and social support may also help explain why caregivers who are surprised about their child's mental health symptomology still refuse to seek help for their child. Future research needs to continue focusing on the various aspects that influence each step of the help-seeking process.

Attempting to solve the gap between help-seeking intention and help-seeking behavior is important especially with youth with endocrine disorders. One possible solution is to allow minors to seek out services themselves. Some states in the US have already outlined ages and what specific services are legally available to them (School House Connections, 2020). Following caregivers and youth through the process of seeking help is also important in helping

minimize barriers. This can be done through assigning a social worker to help facilitate the process and eliminate some of the perceived barriers, as well as using technology such as applications (apps) to set up appointments, provide reminders of appointments, assess symptoms, as well as obtaining feedback to improve care (Burns et al., 2018).

Additionally, continuous follow-through of families through the various stages of help-seeking is needed to help bridge the gap between help-seeking intentions and help seeking behavior. As this study showed, the majority of caregivers of youth with T1DM, or another form of endocrine disease, do intend to follow recommendations. However, other factors impede them taking the additional step of actually following through with services. Endocrine clinics should assign a support person, such as a social worker to help guide parents and remove some of the barriers that otherwise might hinder caregivers' help-seeking behavior (Saxe Zerden et al., 2019). The use of technology should also be further investigated as the world moves towards more technology-based services. These could include applications for medical and psychological check-ins, health monitoring by child-friendly wearable devices, appointment setting and reminders, as well as showing a directory of available resources and services (Burns et al., 2018; Sendra et al., 2018). Further, the integration of medical and mental health services needs to be extended to the school to ensure the continuity of care (Swartz et al., 2010). Mental health literacy also increases intentions to help-seek (Wright et al., 2007) but more needs to be done in terms of help-seeking behavior among youth with endocrine disorders.

## **Conclusion**

Caregivers are gatekeepers when it comes to their child receiving medical and mental health services (Reardon et al., 2017). Caregivers may also indicate their willingness to follow through with a recommendation from a professional, yet the actual act of seeking help and

treatment may not occur (Tomczyk et al., 2020). A disconnect between intention and action taking exists that warrants further exploration. The current study indicated that there are many more factors not yet identified that predict willingness to seek help and perceived barriers. Nonetheless, parents of youth with internalizing symptoms identified more barriers that might have prevented them from following through with recommendations. Even more importantly, the majority of participants experienced at least mild levels of various mental health symptoms that if left untreated could lead to a host of negative sequelae. These findings, along with the ADA Standards recommendations indicate the need for further research importance of incorporating cultural factors for this particular population so that clinics can implement evidence-based approaches for screening and referral services.

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