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# Navigating Insulin Access for Pediatric Type 1 Diabetes: Caregivers' Experiences and Challenges

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# Navigating Insulin Access for Pediatric Type 1 Diabetes: Caregivers' Experiences and Challenges

A Clinical Dissertation Presented to

The University of San Francisco
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In Partial Fulfillment of the Requirements for the Degree of Doctor of Psychology

By
Ella G. Anderson

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## PsyD Clinical Dissertation Signature Page

This Clinical Dissertation, written under the direction of the student's Clinical Dissertation Chair and Committee and approved by Members of the Committee, has been presented to and accepted by the faculty of the Clinical Psychology PsyD Program in partial fulfillment of the requirements for the degree of Doctor of Psychology. The content and research methodologies presented in this work represent the work of the student alone.

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# Dedication

To my brother – being your big sister has been the greatest and most proud role I have ever had the privilege of holding.

To my parents – saying "thank you" will never be enough to show how much I truly love and appreciate you both. It is an honor to be your daughter.

# ABSTRACT

Between 2012 and 2018, the annual 14% increase in insulin prices made Type 1 Diabetes (T1D) the most expensive chronic health condition, significantly raising out-of-pocket costs for uninsured or underinsured individuals in the United States (Hayes & Farmer, 2020; Willner et al., 2020). This study utilized a qualitative content analysis methodology to explore the challenges and experiences of parents with children diagnosed with T1D with accessing insulin for their child. Five participants from various areas of the United States responded to open-ended questions both in person and via Zoom. The analysis revealed three main themes: pragmatics of managing diabetic care, the emotional impact and caregiver concerns, and the art of coordination and support networks. Three subthemes emerged: financial constraints, insulin injections/pump, and navigating insurance. The study emphasizes the importance of access to healthcare services in order to address the multifaceted needs of children with T1D and their families, and also raises clinical implications related to T1D management. Practical recommendations for clinicians, educators, and policymakers to enhance support and improve outcomes for pediatric patients with T1D are provided and discussed. Future research should prioritize inclusive recruitment strategies and address barriers to participation among minority populations to ensure interventions are tailored to the diverse needs of all individuals and families affected by T1D, particularly given the widespread mistrust within the healthcare system among marginalized communities. Additionally, exploring systemic barriers, including social determinants of health (SDOH), and advocating for policy reforms aimed at expanding healthcare coverage and promoting health equity are essential steps in addressing healthcare disparities and improving access to care for vulnerable populations affected by T1D.

# CHAPTER I

## Introduction and Critical Literature Review

### Identification of the Problem

In 2020, the Centers for Disease Control and Prevention (CDC) declared that there was a 30% increase in Type 1 Diabetes (T1D) diagnoses in children and adolescents in the United States, particularly among racial and ethnic minority populations (CDC, 2021). T1D is an autoimmune disease in which pancreatic Beta cells (ß-cells) are attacked and destroyed leading to insulin deficiency as well as hyperglycemia (Kahanovitz et al., 2018). Hyperglycemia can lead to cognitive deficits in memory functioning, learning, and problem solving (Kodl & Seaquist, 2008). Individuals diagnosed with T1D may experience hyperglycemic episodes every day depending on glycemic control, which is largely dependent on proper insulin adherence (Juvenile Diabetes Research Foundation (JDRF) Hyperglycemia: Symptoms, Causes, and Treatment, n.d.). There are no statistics on the prevalence of hyperglycemic episodes in children diagnosed with T1D since it is implied that every individual (adult or pediatric) diagnosed with T1D experiences repeated hyperglycemic episodes nearly daily. T1D is unique compared to other forms of diabetes mellitus because it requires patients to adhere to daily self-administered insulin therapy to avoid serious, long-term health consequences. In the most severe cases, a lack of adherence to insulin can lead to death (Beran et al., 2018).

In 2020, 28 million people did not have health insurance coverage at any point during the year (Keisler-Starkey & Bunch, 2021). As of 2020, the CDC announced that 3.7 million children were uninsured in the United States and 27.5 million working age adults (18-64) were uninsured (Cha & Cohen, 2022). Between the years of 2012 and 2018, the accessibility of insulin decreased dramatically due to a 14% price increase annually, making T1D the most expensive chronic health disease (Hayes & Farmer, 2020). Thus, for uninsured or underinsured individuals in the United States, the dramatic rise in price generated higher out-of-pocket costs (Willner et al., 2020).

The increase in cost to insulin has made it incredibly difficult for families to routinely adhere to insulin administration for their T1D-diagnosed children, not because they do not want to provide the proper treatment to their child, but because the healthcare and insurance system has created financially impossible barriers to overcome. Many barriers and limitations exist in terms of access to insulin treatment for those with and without insurance due to out-of-pocket costs and complex insulin supply chain dynamics (Willner et al., 2020).

The systemic healthcare and insurance barriers experienced by individuals with T1D have exacerbated the physical, cognitive, and financial consequences of poor healthcare (Willner et al., 2020). Negative cognitive consequences associated in those diagnosed with T1D can be further exacerbated without proper insulin adherence. When compared to non-diabetic controls, individuals with T1D generally perform worse on tasks of intelligence, psychomotor functioning, information processing speed, visual attention, and cognitive flexibility (Shalimova et al., 2019). Additional research examining neurological profiles in children with T1D have found that poorer working memory is associated with those who experience hyperglycemia (Lin et al., 2010). The current research on children diagnosed with T1D who experience hyperglycemic episodes and their working memory functioning disproportionately underrepresents those who are insulin non-adherent due to being uninsured or underinsured, and are therefore unable to participate in these studies. With the continuous rise in cost of insulin and the healthcare inequities growing in the United States, there is a need to research how these factors impact parents’ experiences in accessing insulin and the developmental consequences of their children diagnosed with T1D, who relatedly, are less likely to be adherent to insulin.

# Critical Literature Review

## Overview of Critical Literature Review

The literature review starts with a description of diabetes, first providing a definition, specific diagnostic criteria for T1D, and then a discussion of the intersection of socioeconomic status and T1D. Next, attention is placed on the specific complexities of hyperglycemia, including the causes, symptoms, treatments, and impacts on children's development. Finally, the literature review will conclude with the economic history of insulin, and the complexities of access to insulin and insurance in the United States. The literature review aims to provide the reader with the foundational understanding of T1D, followed by the importance of access to insulin and insurance to the cognitive development of children.

## Diagnostic Criteria for Diabetes Mellitus

There are three different ways in which an individual can be diagnosed with diabetes mellitus (DM), all requiring access to a healthcare provider. The three methods are imperfect in the sense that they each identify a different subset of diabetes (Menke et al., 2013). These three approaches are: fasting plasma glucose level (FPG), 2-h plasma glucose (2-h PG) value after a 75-g oral glucose tolerance test (OGTT), or the A1C criterion (American Diabetes Association, 2022). An individual's glucose level for the FPG must be greater than or equal to 126mg/dL after fasting for a minimum of eight hours. An individual's glucose level must be greater than or equal to 200mg/dL for the 2-h PG method during the oral glucose tolerance test. Finally, an A1C greater than or equal to 6.5% must be attained in order for a DM diagnosis to be made (American Diabetes Association, 2022).

## Type 1 Diabetes

Type 1 Diabetes (T1D) is an autoimmune disease in which pancreatic Beta cells (B-cells) are attacked and destroyed, which in turn leads to insulin deficiency as well as hyperglycemia and diabetic ketoacidosis (DKA) (Kahanovitz et al., 2018). Patients must learn to manage their blood glucose levels to appropriately treat their diabetes. Individuals with T1D constitute 5-10% of patients with diabetes, and the remainder have Type 2 Diabetes, monogenic forms of diabetes, or diabetes associated with other sources of islet cell injury (Kahanovitz et al., 2018).

The typical period of onset of T1D is in childhood or adolescence; however, T1D can be diagnosed at any age (Kahanovitz et al., 2018). There is currently no known cause for T1D, but genetic markers and the presence of certain autoantibodies have been shown to increase the risk of developing T1D. Before being diagnosed with T1D, there are common signs and symptoms of severe insulin deficiency and hyperglycemia, which include: polydipsia (increased thirst), polyphagia (increased appetite), polyuria (increased urination), weight loss, and fatigue. The above symptoms are due to a faulty transportation of glucose from the bloodstream into the tissues, which results in increased glucose in the blood and urine as well as caloric loss. While these are seemingly inconsequential symptoms, they are incredibly vital to identify due to the neurological consequences. When insulin levels fall so low that lipolysis (the metabolic process of breaking down glycerol and free fatty acids (Edwards & Mohiuddin, 2022) is unable to occur, products of fat metabolism called “ketones” gather in the bloodstream. This process leads to metabolic acidosis as well as respiratory alkalosis (Kahanovitz et al., 2018). Metabolic acidosis is the increase of acid in the plasma (Burger & Schaller, 2023), and respiratory alkalosis is an increase of the body’s pH level (Brinkman & Sharma, 2023). If these conditions are left untreated, the body’s natural response system eventually fails and ketoacidosis results in cerebral edema, mental confusion, unconsciousness, coma, and sometimes death (Kahanovitz et al., 2018). Hyperglycemia and the health crises that it can cause are detailed in the headers below.

## Hyperglycemia: Causes, Symptoms, and Treatment

Hyperglycemia is a blood glucose reading greater than 125 mg/dL during fasting and greater than 180 mg/dL two hours after a meal (Mouri & Badireddy, 2022). In order to regulate blood glucose, the hormone insulin is secreted into the blood via the pancreas. An individual with T1D has a malfunctioning pancreas and insulin is not secreted automatically. Insufficient insulin availability causes the aforementioned processes of metabolic acidosis and respiratory alkalosis as well as spiking blood glucose levels if not managed with daily insulin therapies. Severe hyperglycemia can also result in neurological signs such as labored breathing, nausea, vomiting, severe abdominal pain, and comas (Mouri & Badireddy, 2022). Untreated hyperglycemia complications include neuropathy (damage to nerves), nephropathy (failure of kidneys), retinopathy (damage to the blood vessels in the retina), coronary artery disease (narrowing or blockage of main artery to the heart), cerebrovascular disease (conditions that affect blood flow and the blood vessels in the brain and spinal cord), and peripheral vascular disease (progressive circulation disorder) , making it vital to manage appropriately (Mouri & Badireddy, 2022).

To treat hyperglycemia, one must utilize insulin therapy as well as a balanced nutritional diet. The most common insulin administrations include syringe injections, insulin pens, and insulin pumps (Shah et el., 2016). The categories of insulin range from, “short-acting, rapid-acting, or long-acting” insulin (Cefalu et al, 2018). The type and task of insulin one must receive is dependent upon the type of diabetes—T1D or T2D (American Diabetes Association, “Insulin Basics”, n.d.). In order for medical doctors to determine the type and amount of insulin an individual needs, they examine levels of C-peptide, a hormone secreted in the pancreas along with insulin that indicates how much insulin is made (Insulin Basics, n.d.). The insulin receptor (IR) in the brain (found across many brain regions) plays a critical role in functional behaviors such as food intake, reproduction, and cognitive functioning (Zhao & Alkon, 2001). The IR is a protein on the cell surface that binds to the hormone "insulin" and triggers intracellular signaling pathways to induce various physiological responses (Lui & He, 2017).

Syringe injections deliver insulin through a needle with individual dosages recommended by a doctor. Insulin pens use pre-filled insulin cartridges that are inserted into the pen. The insulin dose is dialed on the pen, and the insulin is injected through a needle. An insulin pump is a small, wearable device that is either placed directly onto the skin, or under the skin via a needle and small tube, that delivers short-acting insulin every few minutes in small amounts for 24 hours a day, mimicking a pancreas.

A limited amount of literature acknowledges that patients must have access to healthcare, insurance, and in turn, insulin, to treat hyperglycemia. The amount of insulin needed per individual varies; however, the American Diabetes Association (ADA) recommends the use of insulin for T1D patients be a minimum of three to four times a day, which is approximately one vial per week (Westen et al., 2019). The price of one vial of insulin (10 mL) rose 164% within six years, from $9.61 in 2013 to $25.38 in 2018 (Brown-Georgi et al., 2021), making adherence to insulin therapy nearly impossible for uninsured and underinsured families.

## Impact of Hyperglycemia on Children's Development

In children diagnosed with T1D, chronic hyperglycemia commonly overlaps with the developmental period that involves the most active neurological and cognitive growth (Cato & Hershey, 2016). Cognitive differences between children with and without T1D may be observed as early as two and a half years post diagnosis (Cato & Hershey, 2016). Thus, identification of age of onset is critical for properly treating hyperglycemic episodes with insulin therapy to avoid the detrimental cognitive consequences. Recent research by Mouri and Badireddy (2022) determined that young children with T1D are actively experiencing hyperglycemia for long portions of the day, which may play an integral role in negative cognitive outcomes.

The sections that follow describe structural and cognitive impacts to children with T1D due to hyperglycemia and/or because of challenges accessing insulin, which assists with regulation of blood sugar and reduction of hyperglycemia.

### ***Brain Regions Impacted During Hyperglycemic Episodes/Insulin Deprivation***

Perantie et al. (2007) conducted the first quantitative study observing regional brain volume differences in a sample of 108 children and adolescents diagnosed with T1D with severe hyperglycemia and hypoglycemia. Authors used the T1D participants' nondiabetic siblings as a healthy control group (ages seven to 17). Hyperglycemia was associated with differences in both grey and white matter volumes, particularly a decrease in grey matter volume in the posterior cortical areas in the diabetic group. These brain areas are associated with visuospatial skills and episodic memory. Grey matter decreased over time across the age range in the T1D participants, which the authors indicated may be suggestive of an abnormal brain volume development projection (Perantie et al., 2007).

Children with chronic hyperglycemia have been shown to have differences in grey matter and white matter volume when compared to peers without chronic hyperglycemia (Nevo-Shenker & Shalitin, 2021). A recent MRI study found children diagnosed with T1D who demonstrate poor glycemic control had an overall decrease in grey and white matter volume in brain regions associated with verbal cognitive abilities compared to healthy controls (Nevo-

Shenker & Shalitin, 2021). Additionally, the relationship between cognitive functioning and hyperglycemia was further pronounced in children who were diagnosed with T1D at an earlier age and had a longer duration of the disease, highlighting the brain's susceptibility to hyperglycemic episodes.

Chronic hyperglycemia has been linked to neurodegeneration, which is the damage of developing neurons and myelin (Nevo-Shenker & Shalitin, 2021). Longitudinal research consistently demonstrates cognitive deficits in children diagnosed with T1D when compared to healthy counterparts who maintain glycemic control. These deficits particularly involve the areas of memory, processing speed, and visuospatial tasks. As children's brains are developing, it is vital for their general well-being as well as their potential for academic success to have glycemic control. The cognitive deficits and related is evidence for the importance of maintaining glycemic control via insulin therapies in children and adolescents diagnosed with T1D.

### ***Cognitive Abilities in Hyperglycemic Episodes and Insulin Deprivation***

Literature first documented differences in cognitive functioning of patients with T1D compared to non-T1D counterparts in 1922 (Kodl & Seaquist, 2008). The main differences were in memory and attention. Since then, literature continues to show the most common cognitive deficits in T1D patients to be in information processing speed and psychomotor efficiency. However, psychomotor efficiency, motor speed, attention, verbal IQ scores, memory, and academic achievement do improve with better glycemic control (Kodl & Seaquist, 2008). Studies have further examined cognitive abilities in children diagnosed with T1D who have experienced multiple prolonged, severe hyperglycemic episodes (i.e., DKA) and found differences in overall cognitive functioning compared to the respective norms for each cognitive subdomain (Lehmkuhl et al., 2008). A study of 64 children and adolescents between the ages of eight and 16 who experienced at least two episodes of DKA over their lifetime were given the Wechsler Intelligence Scale for Children, Revised and Wechsler Intelligence Scale for Children 3rd Edition (WISC-R, WIS-III) to assess verbal, performance, and overall intelligence. The participants' performances fell significantly below those of the normative samples on measures of verbal intelligence and performance intelligence, particularly in subtests of auditory attention, abstract verbal reasoning, and non-verbal reasoning (Lehmkuhl et al., 2008). These findings suggest children and adolescents who experience multiple severe hyperglycemic episodes may also demonstrate poorer cognitive abilities associated with executive functions (EFs) (i.e., mental manipulation of information, complex attention, verbal abstract reasoning) compared to normed data counterparts.

Research is very limited on the impact of hyperglycemic episodes on working memory (WM) among children with diagnosed T1D. WM is defined as, "the brain system that provides temporary storage and manipulation of the information necessary for such complex cognitive tasks as language comprehension, learning, and reasoning" (Baddeley, 1992, pp. 556-559). Further, it is the workspace to allow and encourage for goal-direction actions (Martinez-Briones, 2021). Practical impairments in WM impact activities of daily living such as planning, organizing, and goal setting, which may cumulatively present as a "dysexecutive syndrome," and may reflect dysfunction of children's growing prefrontal cortex (PFC). A recent study performed on children diagnosed with T1D who experience hyperglycemic episodes found spatial working memory capacity to be significantly decreased compared to a healthy control group (Foland-Ross et al., 2020).

Creo and colleagues (2021) performed a study in which they specifically examined the cognitive results of insulin deprivation in individuals diagnosed with T1D between the ages of

14-28. They performed two trials; trial one where insulin was administered, and trial two where insulin was withheld. In the first trial, they found no differences in cognitive functioning between the T1D participants and the healthy control group. However, in the second trials, they found worsening significant changes in fine motor speed, attention, and short-term memory, specifically in the adolescent population.

In sum, the literature indicates that there remain gaps in understanding about the intersection between insulin deprivation and brain development. However, the limited data on this relationship provides key findings pertinent to the T1D community. Research shows a lack of insulin production and poor IR numbers are correlated to deficits in learning and memory formation (Zhao & Alkon, 2001). Importantly, the hippocampus contains a high number of IR, which further suggests insulin may have a role in memory formation (De Felice & Benedict, 2015).

## Intersection Between Socioeconomic Status and T1D

According to the CDC National Diabetes Statistics Report (2022), there are 1.7 million Americans living with T1D, including 304,000 individuals under the age of 20. Little is known regarding the prevalence of T1D specifically in the pediatric population in California and in the San Francisco Bay Area. Nationally, however, the overall incidence of T1D has increased largely in the populations of Non-Hispanic Asian or Pacific Islander youth, followed by Hispanic and non-Hispanic Black children and adolescents (CDC National Diabetes Statistics Report, 2022). The literature suggests that adult ethnic minorities are inordinately affected by common co-occurring diabetic issues such as retinopathy, amputations, and end-stage renal disease (Haw et al., 2021). Furthermore, Haw and colleagues (2021) state that complications in diabetic care within minority populations are likely higher due to lack of healthcare access when compared to their White counterparts. Additionally, low socioeconomic status has been correlated with higher rates of mortality in adults with T1D, even those with access to healthcare (Scott et al., 2019). These disparities in healthcare access and outcomes between ethnic and socioeconomic groups indicate that healthcare access varies based upon demographic factors, which in turn suggest that there is a connection between further T1D complications and social and systemic failure.

## Economic History of Insulin

The rising cost of insulin over the past two years in America has led to thousands of articles being written about the limited access to affordable insulin. Organizations such as the American Diabetes Association (ADA) (“American Diabetes Association Statement in Response to the President’s Call for a National Insulin Co-Pay Cap, 2022), the Endocrine Society (“Increasing Insulin Affordability, 2021), the Juvenile Diabetes Research Foundation (JDRF) (“JDRF Urges Senate to Support Insulin Affordability Provisions as Part of Inflation Reduction Act of 2022, 2022), and Beyond Type 1 (“The United States’ Insulin Crisis, 2020) have published articles addressing the “why” behind the increase in price, as well as a call to action to legislation to make insulin affordable for those whose life it depends on.

To further understand the accessibility options of insulin, it is important to gain information on the history and complexities of insulin. The introduction of human insulin in 1982 was priced at $14 per vile and increased to $24 per vile in 1996 (Hirsch, 2016). Though some authors (Hirsch, 2016) claim this to be “affordable” for most individuals and families, the literature continues to neglect the populations who do not have healthcare or have high insurance deductibles wherein insulin is not covered. The increase in cost is due to the loss of the 340B drug pricing program implemented from the federal government (Hirsch, 2016). This program made it possible for individuals to pay less co-pays for a three-month supply of insulin.

However, since many major pharmaceutical companies decided to no longer implement the 340B drug pricing program, individuals must now pay full retail price, which ranges from $181.67 to $367.69 per vial, depending on the type of insulin bought (Cefalu et al., 2018). The type of insulin is often characterized by company brand as well as the specific category of the insulin. There are three main insulin manufacturers providing insulin: Eli Lilly, Novo Nodisk, and Sanofi (Cefalu et al., 2018). After medical providers determine what type of insulin the individual needs, the individual then begins to navigate the complex intricacies within the American healthcare system.

## Complexities of Access to Insulin and Insurance in the United States

The type of insurance an individual has greatly affects how accessible insulin will be. Approximately half of Americans have health insurance through an employer or a family member (Kaiser Family Foundation, 2016). Depending on the employer, the company has control over which benefits are covered and their costs (Cefalu et al., 2018). A common health insurance program which covers over 68 million Americans (20% of population), Medicaid, is for low-income individuals (Cefalu et al., 2018). Medicaid is a federal program; however, each state can set guidelines and limits for the out-of-pocket costs (Cefalu et al., 2018). Medicare is another federal health insurance program covering approximately 14% of Americans aged 65 and older, as well as people with disabilities under age 65, and people with end-stage renal disease (Kaiser Family Foundation, 2016). Individual market insurance covers 7% of Americans who choose to purchase insurance individually directly from an insurer or state health insurance (Kaiser Family Foundation, 2016). Programs such as the Veterans Administration cover 2% of Americans, and approximately 9% of Americans do not have any type of health insurance program (Kaiser Family Foundation, 2016).

Table 1 details the costs of insulin based upon healthcare insurance status, and it illuminates the financial consequences and limited access to insulin for those with poor health insurance coverage. If an individual does not have the funds to pay for insulin, one can apply for a grant for free insulin through the Novo Care Patient Assistance Program (PAP). However, this option is only applicable to individuals with Medicare (Patient Assistance Program, n.d.).

**Table 1. Insurance Coverage and Cost of Insulin**

| **Insurance Status /Coverage** | **Cost of Insulin per Vial** | **Notes** |
|---|---|---|
| No healthcare insurance: Self-Pay | \$181.67 - \$367.69 | Full retail price and no government assistance |
| Insured: Medicare | \$92.21 - \$128.69 | Cost reflects amount an individual may pay; full retail price to 25% - 35% depending on deductible and coverage phase (Cefalu et al., 2018). However, 25% of \$367.69 is \$92.21, and individuals covered under Medicare must pay minimum \$120 per vial (Cefalu et al., 2018). |
| Insured: Medicaid | \$1 - \$5 | Co-pay amount varies by state and only covers insulin on the "preferred drug list." If the brand or type of insulin that is needed and not on the list, one may submit a request to the state to add it to the list (Cefalu et al., 2018). |
| Insured: Private | Varies | Cost per vial depends on deductible and contract with the insurance company. For example, if an individual is required to pay an annual deductible and the amount has not yet been reached, the individual will pay full retail price for the vial of insulin until they have spent enough to reach the deductible amount (Cefalu et al., 2018). |

The price of insulin tripled from the years 2002 to 2013 with little to no explanation (Cefalu et al., 2018). Furthermore, the inflation adjusted cost of insulin increased 24% between 2017 and 2022 (American Diabetes Association, 2023), with Black American adults diagnosed with diabetes paying the most in direct healthcare costs (American Diabetes Association, 2023). The lack of transparency from sellers to buyers is concerning because individuals with this chronic illness are fiscally damaged by the system. The literature still notes that consumers experience an immense amount of confusion in regard to the American healthcare system and have limited understanding of the "how" or "why" insurance covers what it does for individuals with T1D (Cefalu et al., 2018). Not only is this currently problematic, but this also raises legitimate distress for individuals and families who live paycheck to paycheck because of the ambiguous number to allot for vials of insulin with the everchanging price.

## Factors Impacting Caregiving for a Child with T1D

The mental health of parents caring for their child with T1D is profoundly impacted by the chronic and demanding nature of the disease (Azimi et al., 2024). Parents must adapt their behaviors and parenting styles to the changing social, emotional, and physical needs of their child with T1D, which is crucial for managing T1D while fostering self-efficacy in their child (Cunningham et al., 2010). Challenges experienced by parents of children with T1D have an impact on their parenting and children's mental health. For example, parental diabetes-specific stress about their child's T1D diagnosis predicted an increase in depression symptoms in their child with T1D (Butler et al., 2020). Helgeson and colleagues (2012) indicate that parents with a child diagnosed with T1D experience two types of stress: 1) general stress, which include financial, marital, and typical parenting difficulties, and 2) diabetes-specific related stress which comes directly from managing their child’s T1D. Diabetes-specific related stress is directly linked to decreased hope and reduced feelings of self-efficacy (Khemakhem et al., 2020). Mothers reported that food management, diabetes-related family conflict, insulin administration, blood glucose monitoring, and thinking about long-term complications were the most common stressors for them (Khemakhem et al., 2020). These stressors can negatively impact glycemic control and are often compounded by the need to navigate complex healthcare systems, financial responsibilities, work environments, and psychological and interpersonal factors involved in T1D related tasks (Butler et al., 2020). In turn, the experience of financial and marital difficulties in the parental relationship negatively impacts parents’ ability to manage their child’s T1D (Helgeson et al., 2012). Specifically, a low socioeconomic status (SES) was reflective of poorer clinical recommendation adherence and higher parental distress, particularly for parents of younger children and those who did not identify as White (Robinson et al., 2016). Furthermore, a higher SES was correlated to better glycemic control (Robinson et al., 2016), and lower SES was a predictor of higher maternal anxiety symptoms (Bassi et al., 2021).

Parents of children with T1D tend to experience higher levels of stress, depression, and anxiety directly related with the challenges of coping with their child’s diagnosis of T1D (Bassi et al., 2021). Coping is defined as “cognitive and behavioral efforts to master, reduce, or tolerate the internal and or external demands that are created by the stressful transaction” (Lazarus & Folkman, 1984, p. 141). In a recent study with 41 parents of children diagnosed with T1D (for at least six months), parents who endorsed symptoms of depression often blamed themselves and were less accepting of their child’s diagnosis (Khemakhem et al., 2020). Parents who endorsed both anxiety and depression were also found to utilize more maladaptive coping strategies, such as avoidance and distraction (Khemakhem et al., 2020).

## Purpose and Rationale of the Study

The cost of insulin has surged over the past decades, creating significant financial barriers for individuals and families across the United States to provide the necessary insulin therapies to their child(ren) diagnosed with T1D. Despite efforts by advocacy organizations and calls for legislative action to address affordability issues, many families still struggle to afford insulin due to various factors, including changes in drug pricing programs and lack of transparency within the healthcare system. This research aims to highlight the everyday barriers faced by families who have children diagnosed with T1D. The impact of chronic hyperglycemia on cognitive development in children diagnosed with T1D, as highlighted in the preceding sections, further emphasizes the urgent need for accessible insulin therapy. Ensuring equitable access to insulin is not just a matter of affordability; it is a fundamental necessity for the health and well-being of individuals diagnosed with T1D and mitigating the long-term cognitive consequences of inadequate glycemic control. Thus, addressing the economic barriers to insulin access and the findings of this dissertation will provide data to inform future legislation changes that will benefit the T1D community.

## Research Questions

Based on identified gaps in the literature as indicated above, I undertook the current study guided by the following questions:

1). How have parents with children diagnosed with T1D navigated the healthcare system?

2). What are the barriers parents with children diagnosed with T1D experienced with accessing insulin?

## Project Specific Definitions

Researchers in public health and public policy have struggled with how to accurately define “underinsured” for over 25 years (Lavarreda et al., 2011). The broad and widely accepted definition of “underinsured” is as follows: “the state in which persons who have medical coverage are still exposed because of medical care expenses to financial risk that causes them some form of harm” (Lavarreda et al., 2011). Examples of the financial risks include: premiums are high relative to income, deductibles are high and individuals must pay out-of-pocket before insurance coverage begins, copayments required are high relative to income, and insurance coverage stops after annual or lifetime limits are reached (Lavarreda et al., 2011). For the purpose of this study, the researcher followed the widely accepted definition of “underinsured” as stated above. Participants were asked to disclose their insurance status (if comfortable) and expand upon their coverage.

## Clinical and Theoretical Relevance

The proposed impact of the study is to responsibly contribute to the conversations being held in our nation surrounding accessibility to insulin, and to expand upon the reasons why families may be non-adherent to insulin. This investigation includes exploring the relationship between the United States healthcare system, which has failed to meet the immediate insulin needs of families with children diagnosed with T1D, and the lived challenges and experiences of these families. This study was developed in line with the Jesuit values espoused by the University of San Francisco, which include promoting “the common good by addressing inequities to create a more humane and just world.” As such, this study was designed and implemented with the intent to explore inequities of the United States healthcare system specifically with regards to the T1D population. Additionally, the study is meant to serve as a measure towards advocacy for legislative change, to support clinicians who work with families and children diagnosed with T1D, and to inform school systems with practical tools to better support children diagnosed with T1D.

# CHAPTER II

## Methods

### Original Research Design

The present study was approved by the dissertation committee on September 28, 2022 and the modified IRB protocol #1867 was approved on February 22, 2023. This study protocol was renewed on January 16, 2024, and will be active until February 6, 2025 (see Appendix A for the initial and subsequent IRB approval letters). The study was originally approved as a cross-sectional quantitative design that involved recruiting children with T1D and administering select working memory measures[1] in order to conduct an analysis of the impact of hyperglycemic episodes on working memory. A parent questionnaire was created to collect information about family demographics, children's health, and insulin access. Feasibility at the time of the proposal to recruit a target sample size of $n = 119$ participants was based on interest signaled by a major T1D organization that had indicated their willingness to support recruitment, which was believed to be sufficient for the analyses that were originally proposed.

Despite these early attempts at securing partnerships with organizations and other networks that would support robust recruitment efforts and allow the originally planned study to meet its target enrollment, this plan did not come to fruition. The researcher continued to work towards engaging a number of other organizations and social media channels that would be likely to serve a demographic that would meet eligibility criteria for her study until

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[1] Wechsler Intelligence Scale for Children – Fifth Edition (WISC-V) selected subtests: Digit Span, Picture Span, and Letter-Number Sequence from the working memory (WMI) index.

approximately March 2023, or about six months following the initial IRB approval. Please see Table 2, titled, “Recruitment Efforts,” in Appendix B for a list of the organizations she contacted with a good faith effort to request support with recruitment.

### *Modifications to the Research Design*

In March 2023, the researcher and then dissertation chair discussed options related to moving forward with the project within a reasonable timeline based on the lack of response from potential participants. In consultation with the dissertation committee members, they made the decision to add four open-ended questions to the end of the demographic questionnaire that would ask parents to share their experiences with access to insulin and concerns or challenges they had related to insulin adherence for their child. The committee agreed that the researcher would still attempt to recruit data on working memory measures from children, and simultaneously, prepared for the possibility that the researcher would be limited to using exclusively parent data and may need to shift to a qualitative research design. Ultimately, this is the direction that the study took after the researcher encountered ongoing challenges with recruiting a large sample size for a quantitative study involving child and parent data. The components discussed below are reflective of the final sample, measures, and protocol utilized for reporting results of the current study, which employed a conceptual content analysis (Wilson, 2011).

## Participants

Participants were recruited through convenience sampling. The final sample consisted of five parents. Two participants were recruited from a social media platform and the other three were recruited from a summer camp. Working memory data from the child(ren) of participants was also collected but will not be reported in this manuscript due to insufficient sample size for a meaningful aggregate quantitative analysis.

### *Eligibility Criteria*

Parents were eligible for the study if they had a child who met all of the following criteria: a) is between the ages of 6-16 years old; b) has been diagnosed with T1D by a medical provider; c) has experienced a hyperglycemic episode (blood glucose greater than 180) in the last year; d) is fluent in spoken English; and e) has access to the Zoom application (if recruited online). Parent participants were additionally screened for eligibility using the following inclusion criteria: a) they are at least 18 years of age, b) are a primary caregiver for a child with T1D, and c) are fluent in reading and compositional English. Potential participants were excluded if they did not meet the above inclusion criteria at the time of enrollment.

## Procedures

### *Recruitment*

Recruitment occurred via social media, word of mouth, and summer camps specifically for families with a child or children diagnosed with T1D. Initially, the recruitment flyer, which included eligibility criteria (see Appendix C) was shared electronically via social media platforms. Social media platforms that were targeted included individual Facebook pages and Facebook closed groups, Instagram, and Reddit. When a social media platform was restricted to members of a specific group (such as parents of children/adolescents with T1D), the researcher contacted a member of a group or channel on these platforms to request that they circulate the flyer on their respective websites/media platforms.

The researcher continued and broadened her recruitment efforts by communicating with colleagues and professionals in the field since considerable time was spent in enrolling the first two participants of the study. She presented the original dissertation project to Kaiser Permanente endocrinologists in June 2023 and engaged in dialogue regarding the challenges in recruitment within the T1D population. Additionally, the researcher contacted multiple summer camps in June and July 2023 that served families and children with T1D. One camp was holding their annual camping trip for families and children diagnosed with T1D, and the researcher was invited to attend and attempt to recruit families from this camp. The researcher drove to this camp for the weekend of July 29th-30th 2023 and invited families to consider participating if they believed they met the eligibility criteria.

### ***Screening and Consent***

Eligibility for the study was determined through an electronic screener on Qualtrics software (Appendix D). The link to this screener was available on the recruitment flyer via a QR code. When participants were deemed eligible, they were invited to enroll in the study and provided with a consent form[2] via e-mail or in person (Appendix E). Informed consent was obtained via e-mail for families that enrolled online, and in person for families that enrolled at the camp.

### ***Data Collection and Security***

Once families enrolled in the study, they scheduled a time to meet online with the researcher if they were recruited through a social media platform. Families recruited at the summer camp completed their participation in person. Following completion of study measures, participants were provided an option to participate in a $40 Visa gift card raffle to thank them for their time and contribution to this research study.

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[2] Because the original study design included children and parents, children were also encouraged to complete an assent form (see Appendix F).

Participants completed a demographic questionnaire (Appendix G) that asked about their family demographics, healthcare access, insurance access, cost of insulin, ability to provide insulin to their child during hyperglycemic episodes, their child's A1c at time of diagnosis, and their child's most recent A1c. Participants were provided with three options to choose from when describing their annual income status (e.g., "Comfortable", "Living Paycheck to Paycheck", "Not Making Ends Meet") and invited to provide their actual annual income if comfortable. The researcher determined to utilize categories when asking about income level in order to gain rapport with the participants, as well as gain an understanding of the participant's perspectives of how they feel about their income level in relation to their family's needs. Thus, asking for qualitative descriptors rather than absolute amounts was deemed more valuable for the purpose of this research. Qualitative questions asked participants to describe their most significant barriers when accessing insulin for their child, strategies they have developed for accessing insulin for their child, barriers for maintaining timely insulin administration during hyperglycemic episodes, the impact of accessing insulin and treating hyperglycemic episodes on the family system, and information they feel is important for health service providers to know connected to the experience of accessing insulin for their child.

The researcher stored all electronic and written record forms collected in a locked box which was kept in a home office. To ensure proper deidentification of the children and their families, the researcher followed the methods of deidentification according to the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule (U.S. Department of Health & Human Services, 2022). Specifically, the researcher followed Section 164.51(b)(2) of the Safe Harbor Privacy Rule which removes 18 types of identifiers (e.g., name, address, zip code, etc.) (U.S. Department of Health & Human Services, 2022).

## Data Analysis

### *Content Analysis*

This study utilized a qualitative content analysis approach. Content analysis is a method that can be used both qualitatively or quantitatively to analyze written, verbal, or visual documentation (Wilson, 2011). Content analysis is used in a variety of fields, including sociology, ethnography and cultural studies, political science, psychology, and cognitive science (Busch et al., 2005). The content itself can be extracted from diverse sources, including books, manuscripts, photographs, online forums, blog posts, etc., and is analyzed by breaking it up into conceptual "chunks" that are then coded (Wilson, 2011). Content analyses are used to identify trends of communication of individuals or groups, describe attitudes and behaviors, determine the psychological or emotional state of individuals or groups, reveal patterns in communication content, or analyze focus group interviews and open-ended questions that accompany quantitative data (Content Analysis by Columbia University, n.d.). Qualitative analyses develop categories or themes, and the results are used to make inferences about the data (Wilson, 2011). There are two types of content analysis: conceptual analysis and relational analysis (Wilson, 2011). For the purposes of this study, a conceptual analysis approach was utilized.

Conceptual analysis codes content for particular words, themes, or concepts, and the researcher makes inferences based on the themes that appear (Wilson, 2011). Prior to beginning a conceptual analysis, however, the research question(s) and the sample must be identified (Content Analysis by Columbia University, n.d.). There are eight steps of content analysis (Content Analysis by Columbia University, n.d.), described below.

#### *Step 1. Decide Level of Analysis*

The researcher for this study analyzed the written content on a thematic level. Phrases in the dataset were also coded to assist in identifying the themes.

### *Step 2. Decide Concepts to Code*

There are two options when deciding how many concepts to code for: either a pre-defined set of categories and/or concepts, or an interactive set of categories and/or concepts (Content Analysis by Columbia University, n.d.). The researcher for this study utilized an interactive approach, which allowed for flexibility to add categories throughout the coding process (Content Analysis by Columbia University, n.d.). An interactive approach is used for the introduction and analysis of new material that can impact research questions (Content Analysis by Columbia University, n.d.).

### *Step 3. Existence or Frequency*

The researcher then decides whether to code for the existence or frequency of a concept in the data set (Content Analysis by Columbia University, n.d.). The researcher for this study coded the existence of a concept within the data set. A concept is only counted if it appears more than once in the data set (Content Analysis by Columbia University, n.d.).

### *Step 4. Distinguish Among Concepts*

Text can either be coded implicitly or explicitly (Content Analysis by Columbia University, n.d.). The researcher for this study coded explicitly, meaning text was coded exactly as they appeared. Nevertheless, a level of implicit coding was employed, meaning words that had the same meaning but stated differently were still coded under one category (e.g., “anxious” vs. “worry”).

### *Step 5. Develop Rules for Coding*

To ensure validity of the coding process, translation rules were created (Busch et al., 2005). Translation rules are used for understanding when and how each identified theme should be applied to the content and later coded. For the current study, there were five key themes that emerged from the participants' responses and translation rules were created based off the themes. Table 2 details the complete translation rules applied. Implicit codes were utilized in the larger themes of anxiety and insulin (e.g., method of insulin administration). This allowed for consistency throughout the text and valid interpretations of the data (Busch et al., 2005).

**Table 2. Translation Rules**

| Theme | Definition | Include | Exclude |
|---|---|---|---|
| Insurance Issues | Statements that mention problems related to insurance coverage, losing insurance, or lack of insurance. | Words or phrases that include "insurance" and/or "loss," "problems," "not having." | General statements about cost not specifically tied to insurance. |
| Financial Barriers | Statements regarding the cost of insulin or other financial burdens related to managing diabetes. | Words or phrases indicating financial strain specifically related to diabetes management. | Costs related to general healthcare that is not specifically tied to diabetes management. |
| School-Related Barriers | Statements that describe difficulties in managing diabetes within the school environment. | Words, phrases, and/or references to school staff, coordinating with the school, issues during school hours, training staff. | Statements about managing diabetes outside of school contexts. |
| Technical Issues with Insulin Delivery | Statements that mention problems with insulin pumps, delivery methods (i.e., injections), or other technical issues related to insulin. | Phrases or words like "Omnipod," "pump settings," "shots," and/or "injections. | General statements about insulin not linked to administration or access difficulties. |
| Emotional and Psychological Impact | Statements that describe the emotional or | Words, phrases, or references indicating emotional strain, fear, | Statements that focus solely on physical health without mentioning emotional |

| | | | |
|---|---|---|---|
| | psychological effects of managing diabetes. | anxiety, or frustration. | aspects, and statements about emotions that are not specifically related to diabetes. |

### *Step 6. Irrelevant Information*

Irrelevant information was defined as filler words for the purpose of this research (e.g., “and,” “the,” “like”).

### *Step 7. Code the Text*

Coding can either be done by hand or software (Content Analysis by Columbia University, n.d.). The researcher for this study coded first by hand, and then by software (Atlas.ti) to support accuracy and consistency in the initial coding process. Furthermore, given the use of both implicit and explicit coding, coding by hand was essential to ensure for accurate coding that software may not recognize.

### *Step 8. Results*

Results from the qualitative content analysis were interpreted carefully as conceptual content and are presented in the following chapter.

## Reflexivity Statement

Unlike quantitative research which oftentimes aims to minimize researcher biases, qualitative research embraces subjectivity and relies on reflexivity (Olmos-Vega et al., 2022). Reflexivity involves continuous and critical examination of the researcher’s own beliefs, experiences, and environments, and how those experiences influence interpretation of data Olmos-Vega et al., 2022). By engaging in reflexivity, researchers can better understand how their perspectives shape their opinions, which improves the quality and ethical standards of their research (Olmos-Vega et al., 2022).

I am a white, cisgender, heterosexual female with higher education and was raised in a middle-class family. My younger brother was diagnosed with T1D when he was six years old, and I was nine. We were on a family vacation in Oregon, which is already a statement of immense privilege, and he had been sick for many months at this point. He had lost a lot of weight, to the point where you could see through his spine, and his lips were constantly blue. From my memory, he only drank milk and ate Slim Jims during the months leading up to his diagnosis. It all came to a head while we were in Oregon. My brother had become so weak that he was unable to close the car door. I remember looking at my parents and saying, “We need to go to the hospital.” The first hospital we went to was unable to handle the severity of his case, but I remember my mom telling me the first doctor noted the fruity smell of his breath – a common sign of DKA. He was airlifted to a children’s hospital that was able to safely stabilize him, and slowly but surely, we all learned this new way of life. His diagnosis story was not uncommon, and the medical trauma that my family experienced was also, unfortunately, not uncommon in the T1D community.

As such, my personal connection to this research has likely greatly impacted my lens into interpretation. Growing up in a middle-class family with stable access to healthcare, I witnessed firsthand the many challenges my brother faced with managing his T1D, however, we were privileged to have the financial resources and insurance coverage that allowed us to manage his T1D effectively.

My position of privilege, including racial and socioeconomic factors, has sheltered me from the systemic racism that affects many marginalized communities in the United States, particularly in accessing and receiving equitable healthcare. While my family experienced the stress of managing a chronic illness and navigating the healthcare system, we did not have to contend with the compounded difficulties of racial discrimination or financial barriers. For instance, my family never had to choose between purchasing insulin or other basic necessities, a decision that many underinsured or uninsured families face regularly. Additionally, my racial privilege means that my interactions with healthcare providers were typically positive and free from the bias and discrimination that many marginalized individuals and communities encounter. My experience in the healthcare system has largely been positive, and the hospital was a place someone can go to when they need help. However, my socioeconomic status and racial identities certainly contribute to that bias, as I recognize the healthcare system as a whole and hospitals across the country are not a safe place for many individuals in the United States.

As a student now in a clinical psychology program who has had clinical practicums in hospitals and the larger healthcare system, I recognize that I am now part of this healthcare system – a system that is often broken and fails to meet the needs of all individuals equitably. My privilege to access to training and higher education has made me acutely aware of the systemic issues and barriers within the healthcare system, including the basic need of safe access to healthcare.

My goal is to contribute meaningfully and responsibly to the understanding and improvement of the healthcare system, particularly for marginalized individuals and communities. I recognize that nobody has explicitly asked me to do this, which highlights an important lesson I have learned throughout this process: the importance of self-initiated advocacy and the responsibility of active listening. I have learned that active listening means going into the populations and communities that may appear to need help, and **asking** them for what **their** needs are, not what I may think their needs are or what my training has told me, and then adjusting my plans/expectations. I hope to contribute to practical solutions in the healthcare system that can be adopted by clinicians, educators, and policymakers, by collaborating with communities, listening to their needs and experiences, and incorporating their voices into the development and healthcare strategies.

# Chapter III

## Results

### Participants

Four individuals directly contacted the researcher via Facebook to inquire about the study. After learning more about the study procedure, these individuals did not complete an eligibility questionnaire and reported that they were no longer interested in participating since the study protocol included involving their children in the study, although they commented on the importance of the need for research to be done in the T1D community regarding the healthcare system and access to insulin for their children. The researcher is aware that the four individuals who declined to participate were mothers to children diagnosed with T1D (unknown if they all identified as female), and had access to technology (i.e., Facebook), but additional demographic information about the participants was not obtained.

Five individuals completed the eligibility questionnaire via Qualtrics software between April 2023 and July 2023. These five individuals who completed the eligibility questionnaire were recruited via Facebook groups where the researcher had advertised the study (it is not known from which specific group each participant learned about the study). All five individuals met eligibility, and the researcher contacted them via e-mail. Two participants responded to the researcher and were part of the final participant group. Additionally, three families from the summer camp expressed interest, met eligibility criteria, and enrolled in the study. There were no other families from the camp who expressed interest and/or actively declined to participate.

Thus, the final participant group for this study consisted of five parents from across the United States who had at least one child diagnosed with T1D at the time of this study. Ages of the children ranged between six and 15. Two of the families were recruited through Facebook support groups, and three families were recruited through a summer camp. All participants identified as female. Three participants identified as Caucasian, one identified as European, and one identified as mixed Mexican, Croatian, Haitian, and white. Please see Appendix H for all reportable demographic data based on Health Insurance, Portability, and Accountability Act (HIPAA) guidance.

- Participant 1 (White female) lives in the Eastern United States. She has a six-year-old son diagnosed with T1D and is part of a two-parent household. She reports a “comfortable” income status, has active public insurance, and an annual deductible between $1,000 - $2,500. She reports not paying out of pocket for insulin (insurance coverage). She also reports her son receives disability services at school (unspecified).
- Participant 2 (White female) lives in in the Mid-Western United States. She has a nine-year-old daughter diagnosed with T1D and reports a two-parent household, a “comfortable” income status, has active private insurance, and an annual deductible greater than $2,500. She reports paying $75 out of pocket for insulin, which is approximately $150 per month. She also reports her daughter receives disability services at school (unspecified).
- Participant 3 (multiethnic adult) lives in the Western United States. She has an 11-year-old son diagnosed with T1D and reports a one parent household, an income

status in which she is "not making ends meet", active private insurance, and an annual deductible between $1,000 - $2,500. She reports paying $25 out of pocket per vial of insulin (unknown how much per month). She also reports her son receives disability services at school (504 Plan).

- Participant 4 (White female) lives in the Western United States. She has a six-year-old daughter diagnosed with T1D and reports a two-parent household, a "comfortable" annual income status, active private insurance, and an annual deductible between $1,000 - $2,500. She reports not paying out of pocket for insulin (insurance coverage). She reports her daughter does not receive disability services at school.
- Participant 5 (White female) lives in the Western United States. She has two daughters diagnosed with T1D, a nine-year-old and a 15-year-old. She reports a two-parent household, a "comfortable" income status, active private insurance, and an annual deductible less than $1,000. She reports paying $25 out of pocket for a three-month supply of insulin per child. Both children receive disability services at school (504 Plan(s)).

## Emerging Themes

Individuals responded to five open ended prompts regarding accessing insulin and their child(ren)'s hyperglycemic episodes based on their personal experience of being a parent to a child with T1D. The prompts were: 1) Describe the most significant barriers when it comes to accessing insulin for your child; 2) Describe any strategies you have developed connected to accessing insulin for your child; 3) Describe the most significant barriers when it comes to maintaining timely insulin administration when your child is experiencing a hyperglycemic episode; 4) Describe how accessing insulin and treating hyperglycemic episodes has impacted you and your family; and 5) Please share any other information you feel is important for healthcare service providers to know connected to the experience of accessing insulin to treat hyperglycemic episodes.

The analysis yielded three themes and three subthemes. The themes are presented in Table 3.

**Table 3. Emerging Themes and Subthemes**

| **Theme(s) and Subtheme(s)** | **Number of Participants Endorsing Theme** |
|---|---|
| Pragmatics of Managing Diabetic Care | 5 |
| Financial Constraints | 2 |
| Insulin Injections/Pump | 3 |
| Navigating Insurance | 2 |
| The Emotional Impact and Caregiver Concerns | 4 |
| The Art of Coordination and Support Networks | 5 |

## Pragmatics of Managing Diabetic Care

All five participants discussed the practical challenges and considerations involved in ensuring effective diabetic care for their child(ren). Challenges that were identified ranged from logistical, to financial constraints, insulin administration methods, and navigating insurance systems. Participant 3 described the most significant barrier to accessing insulin for their child as being able to "pick up prescriptions." She highlighted the often overlooked, but crucial, logistical aspect of diabetic care, where even the simplest tasks can become formidable obstacles. Participant two described how learning the math [for the insulin pump] and teaching it to others has been difficult and impacted their family.

### *Financial Constraints*

A prominent subtheme within the theme of pragmatics of managing diabetic care was the financial barriers that parents face in accessing essential diabetic care supplies. Participant 2 expressed financial strain during a transition in insurance coverage, stating the most significant barrier when accessing insulin for their child was, “money when we weren’t on Medicare.” She went on to describe, “It [diabetic care] is so expensive, and the initial cost is shocking. We were not prepared for the cost at all.” Participant 3, who reported active private insurance, also identified “money for shot pens and pump vials” as the primary barrier for providing insulin for their child.

### ***Insulin Injections/Pump***

Three participants discussed the challenges associated with insulin injections and the insulin pump. Participant 4 discussed emotional and logistical difficulties of injections, expressing concerns about the risk of hypoglycemia from incorrect shots, stating, “[I] worry about her going low from incorrect shots.” Participant 2 identified Omnipod issues (a particular brand of insulin pump) as a significant barrier for maintaining timely insulin administration during hyperglycemic episodes. Furthermore, participant 2 discussed the challenges of learning the necessary math for insulin dosage, teaching others about proper insulin dosage as well as navigating familial attitudes towards injections. Participant 3 reported struggling to “keep up on pump settings,” citing this as a significant barrier for maintaining timely insulin administration during hyperglycemic episodes. Participant 5 further added that making sure families have extra insulin to have in case insulin is lost or gets too warm is something that health service providers need to be more aware about.

### ***Navigating Insurance***

Two participants also shared their experiences of navigating insurance, further expressing fears about coverage loss and uncertainties about future insurance accessibility. Participant 1 identified “fear of insurance issues” as a significant barrier when accessing insulin for their child. They elaborated on the underlying anxieties, expressing concerns about the sudden loss of insurance coverage, and fear that her daughter will not have insurance when she turns 26. Additionally, participant 2 shared the primary strategy they developed for accessing insulin for their child was joining Medicare in their state. They described their decision to join Medicare not only as a proactive measure, but as a necessity to ensure continued access to insulin for their child.

## The Emotional Impact and Caregiver Concerns

Four participants reflected on the profound emotional toll they experience in managing their children’s diabetes. A sense of anxiety, fear, and worry was apparent within each response, regardless of the content of the question. Participant 4 described the emotional impact on the family system, stating there is, “jealousy from siblings due to less attention on them.” She further reported there is “lots of need for empathy around frustration and moods related to blood sugar.” Participant 5 shared her desires for other families with children diagnosed with T1D stating, “Nobody should have to worry about running out [of insulin].”

Two participants expressed their everyday anxieties related to their children. Participant 4 expressed worry about her child during school hours when she is not directly with her, stating, “[I] worry about her having to leave class for the [insulin] shot, [I] worry about her going low from incorrect shots.” To mitigate this anxiety, participant 4 shared she goes to her daughter’s school to administer shots and do the carb count to ensure proper administration. Participant 1 discussed her fears of sudden insurance loss, reflecting how the anxiety has impacted her family.

Participant 1 also reported anxiety regarding her daughter's future, stating, "I fear of when she is an adult, she will not have insurance and go without insulin." She further stated, "It is very important that all people needing insulin have it. Omitting [insulin] can cause significant health consequences and death."

### The Art of Coordination and Support Networks

All five participants discussed their efforts to coordinate care and access support networks, including sharing responsibilities with family members, collaborating with healthcare professionals, and advocating for their child's needs within educational settings. Participant 4 described the most significant barrier for accessing and administrating insulin for her child was, "coordinating with nursing staff [at school], coordinating amongst multiple people, and finding her on campus." Participant 1 shared her experience within the school system, stating the most significant barrier for maintaining timely insulin administration during hyperglycemic episodes was, "school time." Participant one also described, "making sure she has access to insulin at all times" as a strategy for accessing insulin for her child. Participant 5 identified the most significant barrier for timely insulin administration as "school when no nurse is present. We have worked with school to get other staff trained." Participant 3 reported sharing responsibilities with her ex-husband as a strategy to access insulin for her child and stated that "school training for support" was important information for healthcare providers to know when accessing insulin to treat hyperglycemic episodes. Participant 2 reported that teaching the math of insulin administration to adults around her child has impacted her family system.

## Chapter IV: Discussion, Limitations, and Clinical Implications

The purpose of this study was to explore the lived experiences and challenges encountered within the healthcare system by parents of children diagnosed with T1D in their efforts to access insulin for their child. This study also aimed to identify barriers families experience when accessing and administering insulin during hyperglycemic episodes.

## Discussion

The study utilized a qualitative conceptual content analysis methodology (Content Analysis by Columbia University, n.d.; Wilson, 2011), in which the researcher examined written data (through participant-completed questionnaires) to code and identify specific themes, then make inferences based on the emerging themes. Five participants shared their experiences and challenges with accessing insulin and navigating insulin administration during hyperglycemic episodes, and they discussed the impact these experiences and challenges have had on their families. There were three themes and three subthemes that emerged across their narratives.

## Participant Demographics

Prior to discussing each of the study themes, it is important to note, both as an observation and as a limitation (which will be discussed in greater detail later), that all five participants in the current study reflected demographic characteristics that were not necessarily aligned with the original intent of the study. Five participants reported having active healthcare insurance and were female (mothers), and four participants identified as white. Although the study intent was to recruit an ethnically and socioeconomically diverse group of participants, there were several challenges with recruitment as earlier mentioned. As such, the potential impact on the generalizability of the findings is that they are not fully applicable to uninsured or underinsured families, or racial and ethnic minority communities, who may encounter other unique experiences that were not captured in this study. Two participants had access to social media (i.e., Facebook). Access to social media is often indicative of privilege, as it not only requires internet connectivity, but also the digital literacy to navigate these platforms effectively.

This access can provide additional supports and resources and can influence the participants' ability to participate in healthcare services (Campanozzi et al., 2023).

Additionally, three participants were recruited specifically at a summer camp for families with a child diagnosed with T1D. Participation in such camps requires financial resources and time availability, which may be indicative of families with greater socioeconomic means and support systems, including access to healthcare. There were four individuals who personally contacted the researcher, though declined to participate in the study. Those who did reach out, however, were female, and had access to social media accounts (i.e., Facebook).

The current research is limited in regard to understanding how to gain parental engagement in research studies involving their children (Engster et al., 2019). Nevertheless, prior research has noted factors that impact a parent's decision to provide consent in clinical research include the child's age, recruitment strategies (McCullough et al., 2017), race (Shaw et al., 2009), socioeconomic status, perceived risks (Hoberman et al., 2013), and child health status (Buscariollo et al., 2012). In T1D studies in particular, research has indicated parents' willingness to participate in research directly involving their child diagnosed with T1D include healthcare provider trust, comfort with consent, and minimal fear of their child being a "guinea pig" (Buscariollo et al., 2012).

## Theme 1: Pragmatics of Managing Diabetic Care

This theme focused on the practical challenges and considerations involved in ensuring effective diabetic care for their child(ren). All five participants identified challenges that ranged from logistical, to financial constraints, insulin administration methods, and navigating insurance systems. This first theme illustrates the ripple effect that such challenges can have on familial dynamics and highlights the need for comprehensive support systems to address the multifaceted needs of parents and caregivers to meet the basic needs of their children. Participant 3's emphasis on the seemingly simple, yet formidable task of, "picking up prescriptions" highlights the often-overlooked logistical barriers that can impede access to insulin. The numerous demands on parents' and caregivers' time, coupled with the challenge of navigating traffic, pick-up/drop-off from school or other activities with other siblings, and transportation issues to reach the pharmacy during its open hours while being a working parent, make this task particularly difficult, especially when this task is done at least a few times per month. Similarly, participant 2's account of the complexities involved in learning and teaching the math associated with the insulin pump is profound in the impact these practical challenges can have on familial dynamics and everyday life. For example, a study by Patton and colleagues (2018) found that parents of children with T1D often face challenges related to medication management, including obtaining prescriptions, refilling medications, and coordinating care between healthcare providers; all these themes were noted in the present study.

Financial barriers emerged as a prominent subtheme within the pragmatics of managing diabetic care, reflecting the significant economic barriers that families face in accessing essential diabetic care supplies such as glucose monitors and strips, insulin pens, injections, different types of insulin, and sugar tablets. Participants described the financial strain associated with the high costs of insulin, including diabetic supplies and insurance coverage. Participant 2 described experiencing financial difficulties during a period of changing insurance coverage, highlighting the high cost of diabetic care and the unexpected initial expenses. Similarly, participant 3 identified the cost of shot pens and pump vials as the primary barrier to providing insulin for their child. Such financial burdens are consistent with findings reported by Holtz and Mitchell (2023), who emphasized the substantial financial strain faced by families managing T1D, ranging from the cost of insulin to the unpredictability of insurance coverage. Lipman and colleagues (2020) highlighted the financial burden of managing T1D, particularly in the context of rising insulin prices and inadequate insurance coverage. They discussed the health consequences associated with the financial burden and racial disparities in treatment and outcomes of children diagnosed with T1D, stating that children less than 18 years of age who are diagnosed with T1D have an 8% risk of developing DKA annually, with increased risk during adolescent years (Lipman et al., 2020). Non-Hispanic Black children have higher rates of DKA than non-Hispanic white or Hispanic children and are more likely to be hospitalized because of DKA (Lipman et al., 2020).

The challenges associated with insulin administration methods, including injections and insulin pumps, were reported as additional hurdles for families, an additional subtheme in the study. These challenges resonate with similar findings from another qualitative study performed by Haegele and colleagues (2022), who documented difficulties with the Omnipod as well as the financial challenges associated with managing T1D. Sawtell and colleagues (2015) found that structured education programs for families of children with T1D significantly improved their knowledge and confidence in managing their child’s diabetes related care, including insulin administration. Furthermore, Hilliard and colleges (2016) emphasized the benefits of multidisciplinary education interventions in improving glycemic control and reducing treatment burden for families of children with T1D. The familial concerns and attitudes towards insulin injections shared by participant 2 are consistent with research by Whittemore and colleagues (2012), who described the importance of psychosocial support for families of children with T1D, particularly in addressing concerns about hyperglycemia, hypoglycemia, and navigating familial attitudes towards injections.

Two participants reflected on the difficulties with navigating insurance systems, further expressing fears about coverage loss and uncertainties about future insurance accessibility, leading to the final subtheme within the pragmatics of managing diabetic care. The anxiety surrounding transitions in insurance coverage, particularly for young adults with T1D, aligns with findings by Buschur and colleagues (2017), who highlighted the uncertainties and fears associated with changes in insurance eligibility. Nevertheless, Addala and colleagues (2021) described how navigating insurance companies is a significant cost, both financially and emotionally, and often dictates how individuals (adults in their study) with T1D will manage their disease, including access to newer technology.

## Theme 2: The Emotional Impact and Caregiver Concerns

The profound emotional toll experienced by parents managing their children's T1D was a critical theme that emerged in the present study. Across four participants, a consistent theme of anxiety, fear, and worry was evident, emphasizing the immense psychological burden associated with caring for a child with T1D. These concerns are consistent with previous research, which demonstrate the emotional strain experienced by caregivers of children with chronic illnesses has a profound impact on the parent/child relationship (Cousino and Hazen, 2013). Anxiety about children's safety during school hours from the participants reflects the constant vigilance of parents with children diagnosed with T1D, which is consistent with previous findings highlighting the stress experienced by parents with perceived greater parental involvement in their child's diabetes-management (Di Riso et al., 2020). In addition to the emotional strain reported by parents in the present study, previous research has highlighted the complex interplay between parenting stress and metabolic control (Helgeson et al., 2012). Interestingly, greater parental stress was correlated to poorer metabolic control in children aged 10-17; however, a reverse correlation was noted in children aged 0-9 (Stallwood, 2005).

Participants' fears regarding insurance loss, the potential of lack of access of insulin for their children, and its potential long-term health consequences, including death, resonate with broader global concerns in accessing insulin (Beran et al., 2018). Despite the discovery of insulin in 1921, its availability remains limited for many individuals in both high-income countries and low and middle-income countries, as well as among low-income populations within high-income countries (Beran et al., 2018). In the United States, ethnic minorities, specifically African Americans, are disproportionately affected by DKA with the cost of insulin being the primary factor (Randall et al., 2011). The lack of access to insulin continues to be a leading cause of mortality in children with T1D worldwide, as life expectancy can be as low as the one year observed in sub-Saharan Africa (Beran and Yudkin, 2006).

### Theme 3: The Art of Coordination and Support Networks

All five participants remarked on the coordination and support networks needed in order to manage their child's T1D, particularly within the school system. The American Diabetes Association (ADA) (Safe at School, n.d.) reported federal law gives students the right to receive proper diabetes care, and schools are required to provide trained staff to monitor blood glucose levels and administer insulin. Furthermore, the ADA recommends that schools should not require family members to go to school to manage their child's T1D (Safe at School, n.d.). Importantly, one of the current participant's reported going to their child's school to administer insulin and assist with carb counting. School nurses play a critical role in improving metabolic control, as well as educating those in the school system who are around the child with T1D (e.g., teachers, administrators, cafeteria workers, gym teachers, etc.) (Stefanowicz and Stefanowicz, 2018).

Barriers faced in the education system for effective T1D management include lack of informed or trained staff, poor and limited knowledge of T1D, lack of communication and equipment, lack of a nurse on campus, and lack of diabetes management policies (Pansier and Shulz, 2015).

Coordinating and support systems in the management of T1D can also have impacts on the family system. Participant 3 reported the importance of sharing responsibilities with her ex-husband as a primary strategy when accessing insulin for her child. This highlights the significance of family support and collaboration in managing T1D, especially in situations where parents may share custody or responsibility for diabetes care. Interventions that increase social support for parents can improve their child's T1D management, while mitigating symptoms of psychological stress on parents (Bassi et al., 2021).

## Limitations

The limitations encountered during this study were multifaceted and are described here transparently in an effort to provide caution regarding generalizability of the findings, as well as to support future efforts to conduct research in this area. This study is comprised of data collected from a small sample, largely consisting of White identifying individuals (5/6 individuals). With only one participant not identifying as White, the study's ability to capture the experiences and perspectives of individuals from different racial and ethnic backgrounds is restricted. Additionally, all participants identified as female, and all reported an active healthcare insurance status; originally, the study was meant to increase representation of underinsured or uninsured families with children diagnosed with T1D, and recruitment of this population was particularly challenging. The data reflect a sample who had more financial resources and thus, more access to the healthcare system and insulin supply. Moreover, the requirement for the children diagnosed with T1D to be aged between 6-16 years old may have impacted the data gathered, given there may be differing experiences reported from parents who have younger or older children not included in the age range. These limitations impact the applicability of the findings to a more diverse population, where cultural, socioeconomic, and healthcare access factors may vary significantly. Additionally, the researcher is English speaking and requested for participants to be English speaking. This limitation is particularly relevant given the multicultural impact of language barriers significantly impacting access to healthcare services and contributing to disparities in health outcomes. Of significance, three individuals in this study had financial access to a diabetic camp and reported access to healthcare services. Notably, all participants disclosed being able to administer insulin to their child daily.

Another significant challenge was the issue of funding. As an independent graduate student researcher, the lack of financial resources posed a considerable hurdle. For example, opportunities to travel to other states and collect data from other T1D camps were limited due to financial constraints. The camps are intended to be attended in person given each camp has a set itinerary and the researcher gathered data in between set activities, so virtual presentations from the researcher were not feasible. Attempts to secure funding through personal means, affiliation with a lab, or independent research with major T1D organizations were met with various obstacles. For instance, pursing independent research with organizations required a separate Institutional Review Board (IRB) process, and potentially compromising the autonomy of the research in order to align with organizational priorities. Some organizations declined to participate in the recruitment efforts altogether, citing policies that do not support external research initiatives. Additional efforts to obtain funding from the University of San Francisco (USF), where the researcher is enrolled as a graduate student, were unsuccessful. In attempt to broaden recruitment efforts, the researcher explored alternative avenues, such as Facebook ads.

However, changes in Facebook’s privacy policy included the need for the researcher to have an individual website with their own privacy policies. The lack of funding and access to legal consultation to navigate these requirements ultimately prevented the research from utilizing Facebook ads as a recruitment strategy.

Finally, the ways in which the data was collected (i.e., written, asynchronous data rather than a synchronous interview), did not allow for further dialogue or further questions from both the researcher and the parents. Thus, the researcher was limited to what parents reported, which may not reflect as comprehensive a story of their experiences and challenges as may have been obtained if data collection was synchronous and face-to-face. While this study provides valuable insights into the experiences of a specific demographic within the population, its limitations in terms of sample size and demographic representation (including language requirements), highlight the need for caution in generalizing the findings to a broader context.

## Clinical Implications

The findings from this study highlight the importance of a comprehensive, integrated approach in managing T1D in children. An important factor in mitigating consequences relates to proactively addressing the pragmatics of care, acknowledging and addressing the emotional impact on families, and supporting families to leverage support networks. Healthcare providers can enhance their clinical practices and improve outcomes for children with T1D by prioritizing innovative strategies for supporting children and families with T1D. This may include creating a “toolbox” for home and school with information regarding T1D, including symptoms to look for during hyper/hypoglycemic episodes, glucose tablets, insulin, and phone numbers for immediate nursing and mental health services. However, access to healthcare is integral to addressing these multifaceted challenges faced by families and children managing T1D. Without access to care, individuals with T1D are at increased risk of developing acute and chronic complications, including DKA, cardiovascular disease, kidney failure, and vision loss (Mouri & Badireddy, 2022). These complications not only impair quality of life, but also impose significant economic burdens on patients (American Diabetes Association, 2018). Healthcare providers should prioritize ongoing support and follow-up to ensure families feel confident in their ability to manage their child's diabetes. This can involve regular check-ins (via telehealth for accessibility), access to educational resources, and referrals for endocrinologists for further specialized education and support. Furthermore, providing transportation for families would increase access for in-person services, especially if access to technology in a private space is not feasible. By offering comprehensive support, healthcare providers can help families with the practical challenges of managing T1D.

The emotional toll of managing T1D on families is significant, and families from the current study reported feelings of anxiety, fear, and frustration. Recognizing and addressing the emotional needs is essential for providing care and improving glycemic control (Helgeson et al., 2012). Integrating mental health professionals into diabetic care teams can offer families with the support necessary to cope with the emotional challenges of managing T1D and help develop strategies for improving resilience and coping skills. Hood and colleagues (2006) found that children with T1D and their families are at higher risk for developing anxiety and depression compared to their non-T1D counterparts. Behavioral interventions, such as cognitive behavioral therapy (CBT) have been shown to improve glycemic control and further reduce symptoms of depression (Dong et al., 2023). Thus, by providing mental health services within an integrated team can improve both the physical and emotional well-being for the family system.

Furthermore, accessing support networks is vital for families navigating the complexities of T1D management. Peer support groups, online communities, and local resources can provide families with additional support, guidance, and practical skills necessary for managing T1D. Healthcare providers that promote and facilitate these support networks locally and encourage families to attend in order have the potential to significantly reduce feelings of isolation.

All five participants from the present study reflected on the challenges in timely insulin administration within the school setting, especially without a nurse present on campus. The ADA provides comprehensive support and training resources for schools to help educate staff on hand (Training Resources of Schools, n.d.), including virtual workshops and childcare modules. Each child should have "toolkit" in every classroom that outlines what T1D is, the common signs and symptoms to look for during hyper/hypoglycemic episodes, and the administration details (including who is allowed to administer insulin for the child). Federal laws such as Section 504 of the Rehabilitation Act of 1973 and the Individuals with Disabilities Education Act (IDEA) protect children with diabetes by ensuring schools provide reasonable accommodations (Jackson et al., 2015). Schools can support children with T1D and their families by also providing a school social worker for the family who can advocate for the appropriate accommodations within the educational system. Parents become the advocate for their child's health and education needs; however, oftentimes, parent's do not know where to start. Provide the Safe at School (ADA, n.d.) pamphlet to parents at the beginning of each academic year, which outlines the federal laws and rights parents do have when requesting services for their child. This is an area that has been researched over many years by the ADA and continues to be a barrier for parents in regard to providing insulin for their child.

## Future Research

In order to enhance understanding of inequities among families affected by T1D and to address the multifaceted challenges they experience in healthcare access and equity within the United States healthcare system, future research must focus on inclusive recruitment strategies that address systemic mistrust and explore the impact of social determinants of health (SDOH). The challenges encountered in participant recruitment were compounded by the widespread mistrust that caregivers hold regarding the healthcare system, particularly among the target demographic of children diagnosed with T1D, their parents, and their access to insulin. Conversations with representatives from major diabetic organizations shed light on the pervasive sense of skepticism and apprehension within the T1D community. This mistrust stems from various factors, including historical injustice and racism, disparities in access to quality care, and concerns about the integrity and intentions of medical research. Historically, marginalized communities, including those affected by chronic illnesses like T1D, have experienced systemic discrimination and exploitation within the healthcare system (Racism and Health, 2023). Socioeconomic status, including factors such as education, income, and occupation, play a significant role in determining access to quality healthcare services (Hill-Briggs et al., 2021). Additionally, concerns about the integrity and intentions of medical research, and moreover, **access** to medical research, further contribute to the mistrust of the healthcare system to the general population.

The systemic disparities in representation within research studies are evident, including this study. Black and Latino identifying individuals consist of 30% of the United States population, though only account for 6% of all participants in federally funded clinical trials (Konkel, 2015). Decades of advocating for the inclusion of race in psychological research have been overlooked (Roberts et al., 2020). Across 1,149 articles published between 2015-2016 in 11 psychological journals, 73% of those articles never mentioned the race of the participants (Roberts et al., 2020). Future research must prioritize inclusive recruitment strategies and address barriers to participation among minority populations to ensure interventions are tailored to the diverse needs of all individuals and families affected by T1D.

Limited healthcare access exacerbates existing healthcare disparities and widens the gap in health outcomes between privileged and marginalized groups (Riley, 2012). In order to address the healthcare disparities and improve access to care, future research must explore the systemic barriers in place, including environmental factors, such as social determinants of health (SDOH). Policy reforms aimed at expanding healthcare coverage, reducing out-of-pocket costs, and promoting health equity are essential for addressing the financial barriers to care (ElSayed et al., 2023). Additionally, interventions targeting environmental factors, such as neighborhoods and physical environments, food environments, and social contexts, can help mitigate the impact of SDOH on healthcare access and outcomes among vulnerable populations (Brown et al., 2019).

Future researchers are encouraged to continue to explore access to insulin in the pediatric population through different methodological approaches, as well as to include perspectives of multiple stakeholders. This includes "on the ground" research with the population of interest and spending considerable time building rapport with the potential participants. For example, researchers are encouraged to continue to gather data from summer camps specifically for families with children diagnosed with T1D. Furthermore, researchers are encouraged to examine the impact of T1D on siblings who are not diagnosed with T1D, and explore their experience in order to identify areas in which clinical psychologists can be proactive (i.e., individual therapy and/or family therapy). Additional qualitative inquiry through semi-structured interviews and analysis techniques such as thematic analysis or interpretative phenomenological analysis (IPA) would allow caregivers to further expand on challenges, barriers, and coping strategies related to insulin access. Researchers are encouraged to inquire about the length of time since their child's diagnosis as means to explore the relationship between initial T1D diagnosis and parent's ability/ willingness to participate in such research. Including healthcare providers, school staff, and children with T1D in these studies would provide valuable data regarding their experiences in navigating insulin adherence. It is critical to include diverse voices in learning about the ways that barriers to insulin access and adherence can be overcome.

The original study proposed for this dissertation involved collecting working memory data from children in order to examine the possible connection between hyperglycemia, insulin access/adherence, and cognitive performance. The challenges previously shared in this manuscript prevented this study from being undertaken; however, it is essential to continue this path of research in order to build upon existing data regarding the connection between children's development and T1D diagnosis. Further, the implementation of longitudinal studies can track changes in healthcare access and changes in cognitive development (e.g., WM), which can provide insight into the long-term impact of healthcare disparities. Future research may also analyze current healthcare policies and insurance coverage to assess their impact on access to insulin for children and families. This research could identify gaps in coverage, policy barriers, and opportunities for policy reform to enhance access to insulin and diabetes management.

## Conclusion

This study explored the challenges and experiences faced by parents of children diagnosed with T1D in accessing insulin, managing hyperglycemic episodes, and navigating the healthcare system. Key themes identified included the pragmatic difficulties of managing diabetic care, the emotional toll on caregivers, and the importance of coordination and support networks. The findings highlight the profound emotional impact of families, marked by anxiety and fear, and highlight the necessity of comprehensive support systems. Future research should focus on inclusive recruitment strategies to better understand and address the barriers faced by minority populations, ensuring interventions are tailored to diverse needs. It is essential to explore the impact of SDOH and advocate for policy reforms that expand healthcare coverage and reduce out-of-pocket costs. By addressing these multifaceted challenges, future research can contribute to more equitable and effective healthcare solutions for families affected by T1D.

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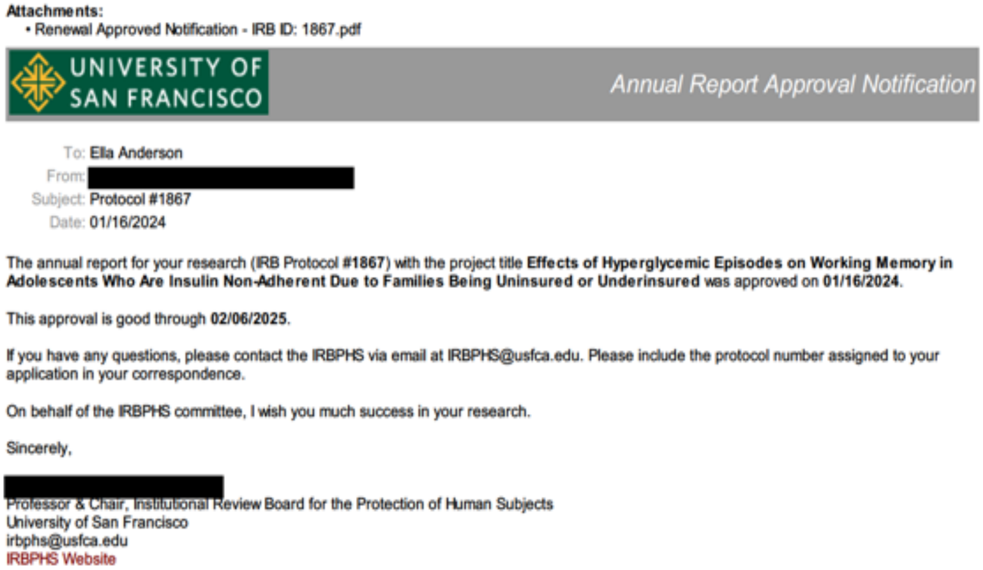
# Appendix A

## IRB Approval Letter



**Attachments:**
- Renewal Approved Notification - IRB ID: 1867.pdf

UNIVERSITY OF SAN FRANCISCO

*Annual Report Approval Notification*

To: Ella Anderson
From: [redacted]
Subject: Protocol #1867
Date: 01/16/2024

The annual report for your research (IRB Protocol **#1867**) with the project title **Effects of Hyperglycemic Episodes on Working Memory in Adolescents Who Are Insulin Non-Adherent Due to Families Being Uninsured or Underinsured** was approved on **01/16/2024**.

This approval is good through **02/06/2025**.

If you have any questions, please contact the IRBPHS via email at IRBPHS@usfca.edu. Please include the protocol number assigned to your application in your correspondence.

On behalf of the IRBPHS committee, I wish you much success in your research.

Sincerely,

[redacted]
Professor & Chair, Institutional Review Board for the Protection of Human Subjects
University of San Francisco
irbphs@usfca.edu
IRBPHS Website

## Appendix B

## Recruitment Efforts

| Date | Organization/Social Media/Activity |
|---|---|
| June 2022 | *Major Organizations/Research*<br>1. Southern California JDRF<br>2. JDRF Research Administration and Operations<br>3. American Diabetes Association, Northern California<br>4. Insulin or Life<br>5. Beyond Type 1<br>6. UCSF Madison Clinic<br>7. UCSF endocrinologists (Dr. XX) |
| June 2022 | Dr. XX[3] from USF for consultation |
| October 2022 | Dr. XX, UCSF |
| February 2023 | Beyond Type 1 |
| April 2023 | *Major Organizations/Research*<br>1. Media at JDRF<br>2. CureUp.Org<br>3. American Diabetes Association<br>4. Brave Buddies<br>5. Diabetes Research Institute Foundation<br>6. Diabetes Institute, Type 1 Diabetes Research at University of Florida |
| May 2023 | *Facebook Groups*<br>1. T1D Mom Squad<br>2. T1D<br>3. Moms of T1D<br>4. Metronic Diabetes<br>5. Living with Type 1 Diabetes<br>6. Type 1 Diabetes<br>7. Type 1 Diabetes Awareness<br>8. Parents of Teens Living with Type 1 Diabetes Support Group<br>9. The Parents' Corner San Francisco<br>10. Type 1 Diabetes Support and Information<br>11. Type 1 Diabetes Parents Group<br>12. Parents of Children with Type 1 Diabetes<br>13. Diabetes Support Group<br>14. The Research Exchange Group<br>15. Research/Theses/Assignment Writing and Publication<br>16. Dissertation Survey Exchange |

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[3] Researcher intentionally left the name(s) out from individuals consulted with for confidentiality reasons

| | |
|---|---|
| | *Reddit Pages (never posted since the pages disclosed they do not participate/promote research).* |
| | *Podcasts*<br>1. Taking Control of your Diabetes<br>2. Diabetics Doing Things<br>3. This is Type 1<br>4. Juicebox Podcast<br>5. Talking Type 1 Podcast |
| | *Consultation with Professionals in the Field*<br>1. Presented to Kaiser Permanente Endocrinology<br>2. Neuropsychologist Dr. XX<br>3. KP researcher, XX |
| June 2023 – July 2023 | *Summer Camps*<br>1. Camp Conrad Chinnock<br>2. Lions Diabetes Camp<br>3. Camp Possibilities<br>4. Kamp for Kida<br>5. Brainy Camps<br>6. Kamp Kudzu<br>7. The Barton Center for Diabetes Education, Inc<br>8. Diabetic Youth Foundation<br>9. Nevada Diabetes Association/California Diabetes Association<br>10. Camp Angels |

## Appendix C

## Social Media Recruitment Flyer

A dissertation research project by Ella Anderson, USF
PSYD Doctoral Student
IRB#1867

UNIVERSITY OF SAN FRANCISCO

**ARE YOU CONCERNED ABOUT HOW HIGH SUGAR LEVELS AND INSULIN CAN BE IMPACTING YOUR CHILD LONG-TERM?**

***LET'S HAVE A CONFIDENTIAL TALK ABOUT TYPE 1 DIABETES, THE COST OF INSULIN, AND ACCESS TO HEALTHCARE FOR YOUR CHILD***

**ELIGIBILITY CRITERIA:**

1. Child between the ages of 6-16 who is diagnosed with Type 1 Diabetes
2. Consenting adult (over 18 years old; fluent in English)
3. 15 minutes of your time and access to the virtual meeting platform, "Zoom"

**To participate and enter a raffle to win a $40 gift card, text Ella Anderson at [redacted] OR scan the QR code**

# Appendix D

## Eligibility Screener

1. Are you a parent 18 or over?
    a. Yes
    b. No
2. Do you have a child between the ages of 6-16 who is diagnosed with Type 1 Diabetes?
    a. Yes
    b. No
3. In the past month, has your child experienced a hyperglycemic episode? (Greater than 180 when checking sugar levels)
    a. Yes
    b. No
4. In the past month, have you skipped insulin administration for any reason?
    a. Yes
    b. No
5. Do you have access to the platform Zoom?
    a. Yes
    b. No
6. Is there a parent/guardian in the home who is English speaking and able to provide consent?
    a. Yes
    b. No
7. Contact information (name and email): ______________________________

# Appendix E

## Parent/Guardian Informed Consent

### CONSENT TO PARTICIPATE IN A RESEARCH STUDY:

You and your child are being asked to take part in a research study being conducted by Ella Anderson, a clinical psychology doctoral student in the Clinical Psychology PsyD program of the School of Nursing and Health Professions at the University of San Francisco. The faculty supervisor for this study is Alette Coble-Temple, Psy.D., a core faculty member in the Clinical Psychology PsyD program at the University of San Francisco. Below is a description of the research procedures and an explanation of your rights as a research participant and as a parent. Please read this information carefully. If you agree to participate, you will sign in the space provided to indicate that you have read and understand the information on this consent form. Should you decide to allow your child to participate in this research, you will be asked to sign this consent form once all your questions have been answered to your satisfaction. You are entitled to and will receive a copy of this form.

### WHAT THE STUDY IS ABOUT:

The purpose of this study is to examine the effects of hyperglycemic episodes on working memory in Type 1 Diabetic children who are insulin non-adherent due to families being uninsured or underinsured.

### WHAT I WILL ASK YOU TO DO:

Your child will partake in a brief neurological battery comprised of three subtests which will assess for working memory abilities. While your child is participating in the brief neurological battery, you (a parent or guardian) will complete a brief demographic survey. The survey will ask for basic demographic information such as ethnic/racial identity, gender identity, and zip code. Additionally, the demographic survey will request information about your child's Type 1 Diabetes, insulin adherence, and information on your current insurance coverage.

### DURATION AND LOCATION OF THE STUDY:

The brief neurological battery will be performed via the HIPPA compliant Zoom platform and take approximately 25 minutes. The neurological battery will be performed by myself, Ella Anderson, and two trained PsyD students. The demographic survey will take approximately 10 minutes completed online via Qualtrics link, an online questionnaire platform.

### COMPENTATION:

There is no compensation for participating in this study. However, your participation is greatly appreciated as the data collected may be helpful in forming future legislation around access to insulin in the United States.

### RISKS:

There are risks of engaging in telehealth research that differ from in person research regarding limits to confidentiality. Protocol will be taken to ensure breaches of confidentiality are minimized. Each Zoom meeting will be password protected. The audio recording will be placed directly onto the researcher's laptop, rather than to the cloud. The waiting room feature will also be utilized as a means to ensure no one else can join. There are no physical or financial risks involved in participating in this study. Your child completing the brief neurological battery is not expected to be distressing, however, it may be challenging. Completing the demographic questionnaire is also not expected to be distressing, however this cannot be ruled out given the sensitive nature of inquiring about insurance, and your child's health.

### BENEFITS:

As stated before, the data collected from this study may be helpful in forming future legislation regarding access to insulin. Additionally, it is hoped the results from this study can further contribute to the limited literature to Type 1 Diabetes, working memory, and access to insulin.

### CONFIDENTIALITY:

All participating parties will complete the study using a secure internet connection, rather than a public connection or free Wifi. Data collected from this study will be kept private. Any names will be changed prior to sorting through data to ensure confidentiality. Any reports that will be made available to the public will not include information that will make it possible to identify you or your child. Collected data will be stored on a password protected file on a password protected computer. The only time privacy may be breached if a disclosure is made regarding imminent danger to yourself, someone else, or there is ongoing abuse of minor, elder, or dependent adult as I am required to make mandated reports of such disclosures under California state law.

**TAKING PART IS VOLUNTARY:**

Participation in this study is completely voluntary. If you do not feel comfortable answering a question, it may be skipped. Furthermore, you may quit the study at any time. All data obtained from participants who did not complete the study will be omitted. If the participant is experiencing technical issues, or feels that the internet connect has been compromised, they may end the study. Your child's participation is entirely voluntary. They are free to choose to not participate. Should you allow your child to participate, they may quit the study at any time.

**RESULTS:**

Participants wishing to receive results can inform researcher of their interest. Results will be received via email, following completion of entire study.

**IF YOU HAVE ANY QUESTIONS:**

Please ask any questions you may have now. If you have questions at a later time, you may contact me at (415) 827-6911 or eganderson2@dons.usfca.edu as well as the chair of the study, Dr. Alette Coble-Temple, at acobletemple@usfca.edu or (925) 575-7381. If you have any questions or concerns regarding your rights as a participant in this study or your child's participation, you may contact the Institutional Review Board (IRB) at IRBPHS@usfca.edu.

**STATEMENT OF CONSENT:**

I have read the above information and have received answers to any questions I asked. I consent to my child taking part in the remotely conducted, brief neurological battery. I consent to taking part of the remote demographic survey.

______________________________
Name of Child (Printed)

______________________________
Name of Parent/Guardian (Printed)

______________________________ ______________
Name of Parent/Guardian (Signed) Date

______________________________ ______________
Name of Researcher (Signed) Date

## Appendix F

# Research Assent Form

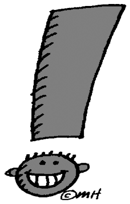
### What is a research study?

Research studies help us learn new things. We can test new ideas. First, we ask a question. Then we try to find the answer.

This paper talks about my research and the choice that you have to take part in it. I want you to ask me any questions that you have. You can ask questions any time.

**Important things to know…**

- You get to decide if you want to take part.
- You can say ‘No’ or you can say ‘Yes’.
- No one will be upset if you say ‘No’.
- If you say ‘Yes’, you can always say ‘No’ later.
- You can say ‘No’ at anytime.



### Who is the researcher?

My name is Ella Anderson, and I am currently in school to become a Doctor of Clinical Psychology at the University of San Francisco. A clinical psychologist studies the way people think, feel, and behave. I have a supervisor who oversees the research project and makes sure everyone is safe. Her name is Dr. Alette Coble-Temple. A main reason why I chose this research topic is because my younger brother was diagnosed with Type 1 Diabetes when he was 5 years old.

### Why am I doing this research?

I am doing this research to learn more about Type 1 Diabetes, and how insulin works with a part of your brain! Specifically, I am wondering what happens to your “working memory” when you have high sugar levels. Your working memory acts as a sticky note in your brain. It holds information in place so your brain can solve problems. For example, when you’re in math class, your working memory helps you “see” the numbers in your head when the teacher is talking.

### What would happen if you joined this research?

If you decide to be in the research, I will ask you to do the following:

- Talking: A person on the research team will ask you questions. Then you would say your answers out loud.

- Utilize your computer mouse: A person on the research team will ask you to use your computer mouse to click or “stamp” pictures on the screen.

### Could bad things happen if you join this research?

Some of the questions might feel harder than others, and that’s okay! I will do my best to make sure nothing bad happens during the questions.
You can say ‘no’ to what the researcher asks you to do for the research at any time, and we will stop.

### Could the research help me?

This research will not help you right away. I do hope to learn something from this research though, and someday I hope it will help other kids who have Type 1 Diabetes like you do.

### What else should I know about this research?

If you don’t want to be in the study, you don’t have to be.

It is also OK to say yes and change your mind later. You can stop being in the research at any time. If you want to stop, please tell your parent/guardian or the researcher.
You would not be paid to be in the study.
You can ask questions any time. You can talk to myself, Ella Anderson, or Dr. Alette Coble-Temple. Ask us any questions you have. Take the time you need to make your choice. Your parent/guardian has our phone numbers and emails.

### Is there anything else?

If you want to be in the research after we talk, please write your name below. We will write our name too. This shows we talked about the research and that you want to take part.

***Name of Participant*** ________________________________________
(To be written by child)

**Printed Name of Researcher** ________________________________________

**Signature of Researcher** ________________________________________

____________ ____________
***Date*** ***Time***

## Appendix G
## Demographic Questionnaire

1. Age of child: ____________
2. Gender identity of child:
    a. Male
    b. Female
    c. Non-binary/third gender
    d. Prefer not to say
3. Ethnicity of child: ________________
4. Zip Code: _______________
5. Is your child registered to receive any disability accommodations at school?
    a. Yes
    b. No
6. Current living situation:
    a. 2 parent household
    b. 1 parent household
    c. Other relative(s)
    d. Other: ____________
7. Approximately how many hyperglycemic episodes does your child experience per month?
8. Do you have insurance?
    a. Yes
    b. No
9. If “yes”, what insurance company? ___________________
10. Which describes your annual deductible the best?
    a. Less than $1,000

   b. Between $1,000-$2,500
   c. Greater than $2,500

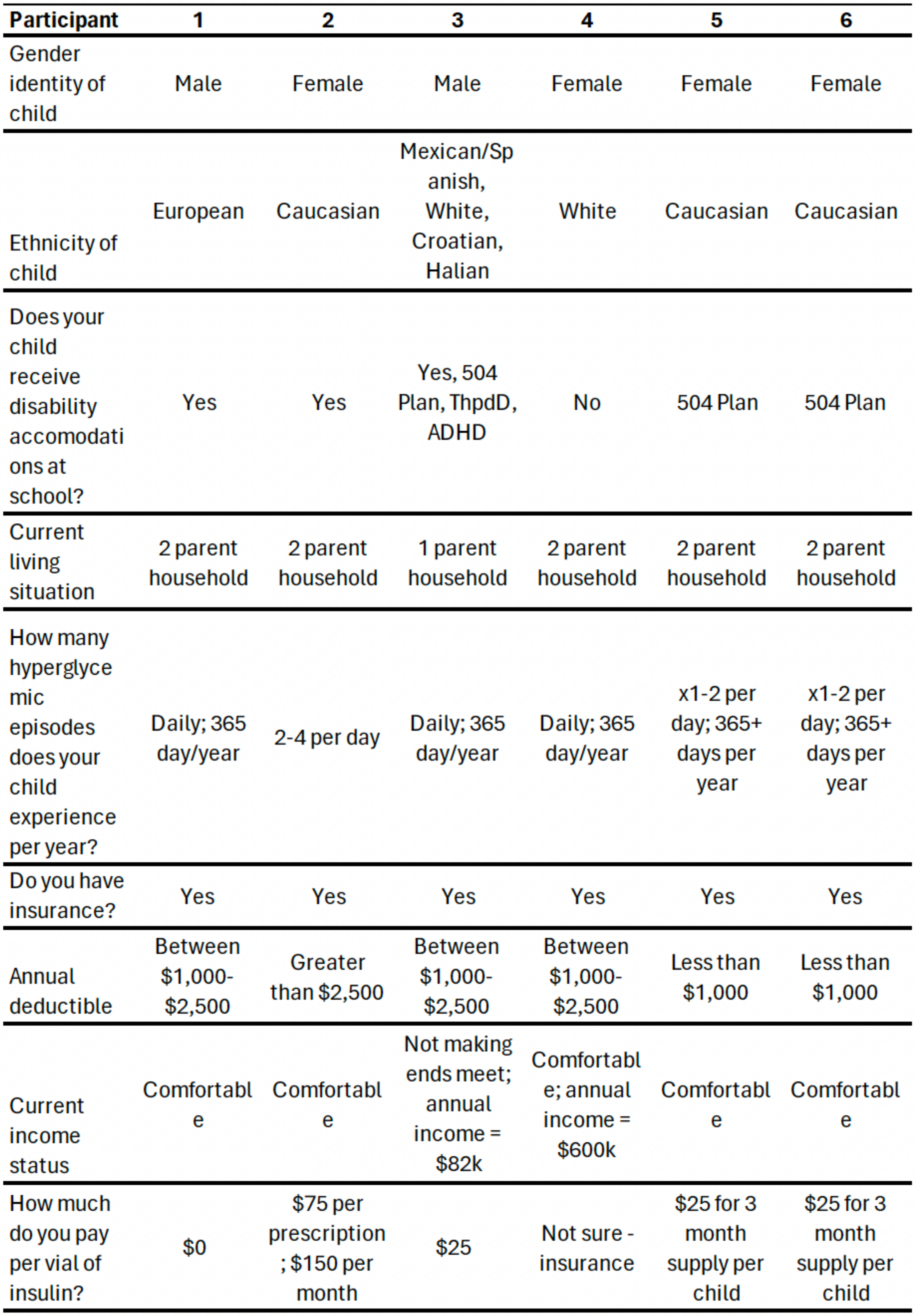
11. Which would you describe your current income status? If you are comfortable, please disclose your annual income.
    a. Comfortable
    b. Living Paycheck to Paycheck
    c. Not making ends meet
12. How much are you paying per vial for insulin?
13. How much of your monthly income goes to insulin?
14. What was your child's A1c at time of diagnosis?
15. If available, what was your child's most recent A1c level?
16. Which statement best describes your ability to provide insulin to your child in the past month when they have high levels (greater than 180 when checking their sugar levels)?
    a. Always (100% of the time)
    b. Most of the time (75% of the time)
    c. Sometimes (50% of the time)
    d. Rarely (25% of the time)
    e. Never (0%)
17. Which of the following best describes your situation during the times you are unable to give your child insulin?
    a. My insurance deductible for insulin was too high.
    b. I do not have insurance and must pay out of pocket for the insulin.
    c. I have health insurance, but I have to pay out of pocket for insulin with my current insurance plan.
18. Which best describes your insurance coverage?
    a. Private through employer?

   b. Public through state program (e.g., Covered California)
   c. Government subsidized healthcare (Medicare, Medicaid, Medical)

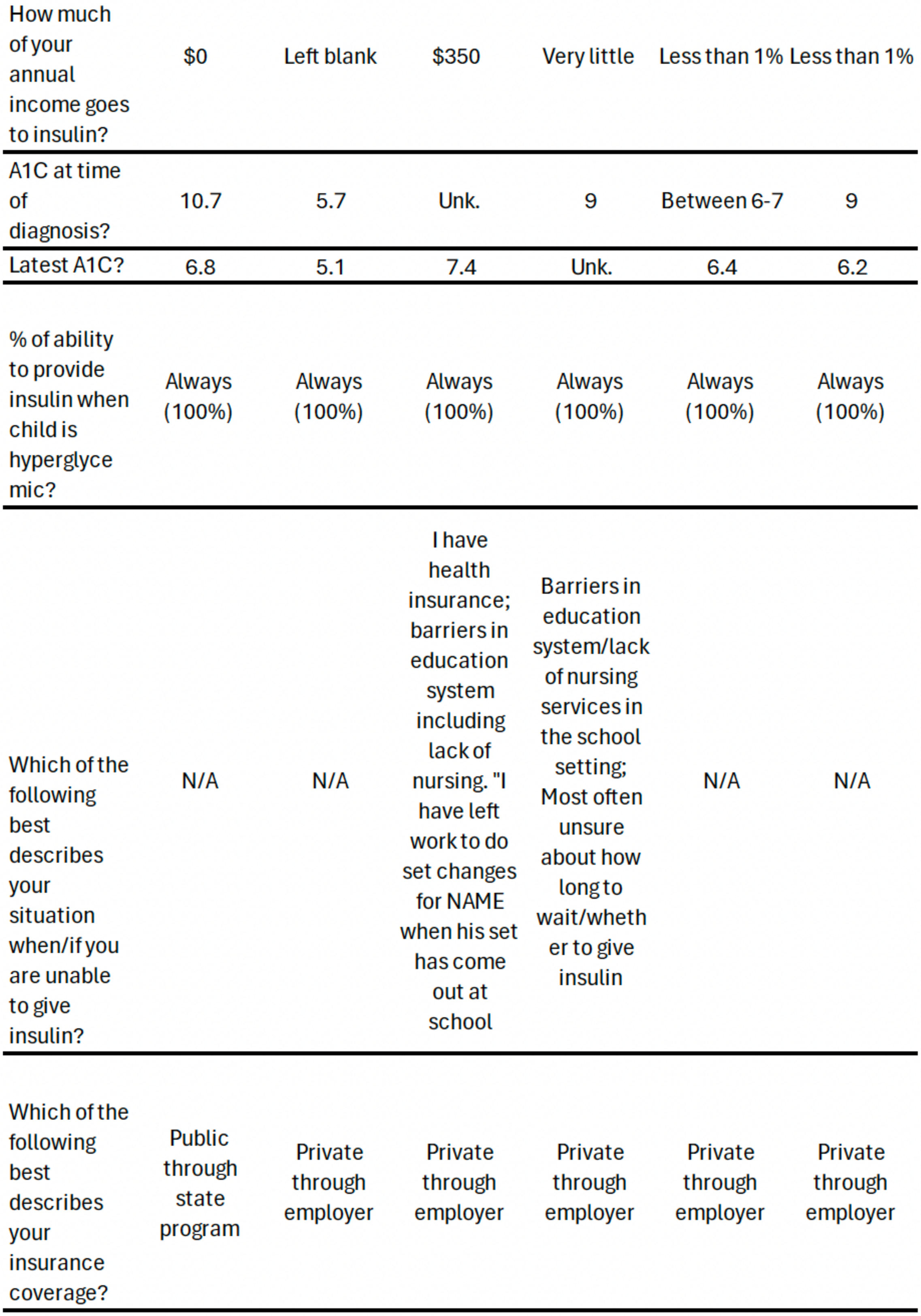
19. How much do you pay for your monthly health care? ________________
20. To what degree is insulin covered by your healthcare?
    a. Fully
    b. Partially
    c. Not at all
21. If "partially", what percentage does it cover?
    a. Scale provided in linked survey
22. How many insurance plans cover your child?
    a. 1
    b. 2
    c. More than 2
23. Describe the most significant barriers when it comes to accessing insulin for your child.
24. Describe any strategies you have developed connected to accessing insulin for your child.
25. Describe the most significant barriers when it comes to maintaining timely insulin administration when your child is experiencing a hyperglycemic episode.
26. Describe how accessing insulin and treating hyperglycemic episodes has impacted you and your family.
27. Please share any other information you feel is important for health service providers to know connected to the experience of accessing insulin to treat hyperglycemic episodes.

# Appendix H

## Demographic Information



| **Participant** | **1** | **2** | **3** | **4** | **5** | **6** |
|---|---|---|---|---|---|---|
| Gender identity of child | Male | Female | Male | Female | Female | Female |
| Ethnicity of child | European | Caucasian | Mexican/Spanish, White, Croatian, Halian | White | Caucasian | Caucasian |
| Does your child receive disability accomodations at school? | Yes | Yes | Yes, 504 Plan, ThpdD, ADHD | No | 504 Plan | 504 Plan |
| Current living situation | 2 parent household | 2 parent household | 1 parent household | 2 parent household | 2 parent household | 2 parent household |
| How many hyperglycemic episodes does your child experience per year? | Daily; 365 day/year | 2-4 per day | Daily; 365 day/year | Daily; 365 day/year | x1-2 per day; 365+ days per year | x1-2 per day; 365+ days per year |
| Do you have insurance? | Yes | Yes | Yes | Yes | Yes | Yes |
| Annual deductible | Between $1,000-$2,500 | Greater than $2,500 | Between $1,000-$2,500 | Between $1,000-$2,500 | Less than $1,000 | Less than $1,000 |
| Current income status | Comfortable | Comfortable | Not making ends meet; annual income = $82k | Comfortable; annual income = $600k | Comfortable | Comfortable |
| How much do you pay per vial of insulin? | $0 | $75 per prescription; $150 per month | $25 | Not sure - insurance | $25 for 3 month supply per child | $25 for 3 month supply per child |



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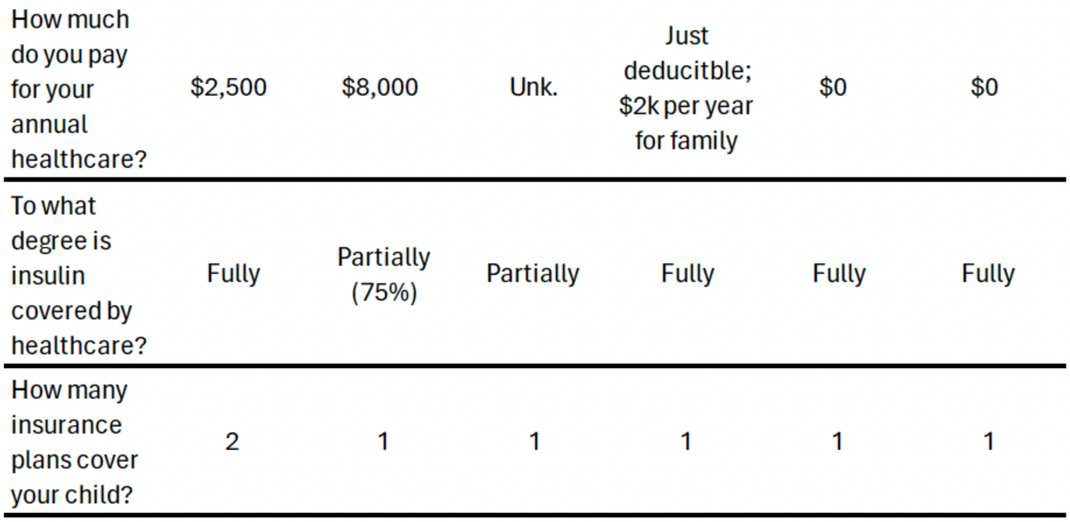
|---|---|---|---|---|---|---|
| How much of your annual income goes to insulin? | $0 | Left blank | $350 | Very little | Less than 1% | Less than 1% |
| A1C at time of diagnosis? | 10.7 | 5.7 | Unk. | 9 | Between 6-7 | 9 |
| Latest A1C? | 6.8 | 5.1 | 7.4 | Unk. | 6.4 | 6.2 |
| % of ability to provide insulin when child is hyperglycemic? | Always (100%) | Always (100%) | Always (100%) | Always (100%) | Always (100%) | Always (100%) |
| Which of the following best describes your situation when/if you are unable to give insulin? | N/A | N/A | I have health insurance; barriers in education system including lack of nursing. "I have left work to do set changes for NAME when his set has come out at school | Barriers in education system/lack of nursing services in the school setting; Most often unsure about how long to wait/whether to give insulin | N/A | N/A |
| Which of the following best describes your insurance coverage? | Public through state program | Private through employer | Private through employer | Private through employer | Private through employer | Private through employer |



| | | | | | | |
|---|---|---|---|---|---|---|
| How much do you pay for your annual healthcare? | $2,500 | $8,000 | Unk. | Just deducitble; $2k per year for family | $0 | $0 |
| To what degree is insulin covered by healthcare? | Fully | Partially (75%) | Partially | Fully | Fully | Fully |
| How many insurance plans cover your child? | 2 | 1 | 1 | 1 | 1 | 1 |