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***Danny the Diabetic Dinosaur: A Resource for Families Impacted by Type 1 Diabetes***

**Mellitus**

Honors Thesis

Submitted

in Partial Fulfillment

of the

Requirements of HON 420

Fall 2023

By

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Mentor

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*Danny the Diabetic Dinosaur: A Resource for Families Impacted by Type 1 Diabetes Mellitus*

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### **Abstract**

Type 1 diabetes mellitus (T1DM) is a chronic condition that impacts approximately a quarter of a million children in the United States alone. T1DM is a complicated diagnosis that requires specialized treatment and education. Research has shown that families of children with T1DM experience a burden related to a lack of education in the healthcare system. Educational resources such as children's books can act as a bridge between the healthcare system and families as they allow parents and children to increase their knowledge about T1DM and open the doors for communication. Education is shown to decrease further complications related to T1DM such as diabetic ketoacidosis, which in return reduces healthcare costs to the client and the healthcare system as well as increasing the overall quality of life. In response to the need for an educational resource on T1DM, *Danny the Diabetic Dinosaur* was written and illustrated to target children ages 7-11, with potentially younger audiences if assisted by an adult. *Danny the Diabetic Dinosaur* demonstrates to children that having diabetes does not mean they cannot have a productive and happy life. The evidence-based research on T1DM along with the creative, age-appropriate writing and illustrations of the book create an invaluable resource for families impacted by T1DM.

*Keywords:* Type 1 diabetes mellitus (T1DM), juvenile diabetes, health literacy, diabetes education, *Danny the Diabetic Dinosaur*, healthcare education resource, children's book, honors thesis.

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## Table of Contents

Abstract.....	ii
Acknowledgments.....	iii
Table of Contents.....	iv
Introduction .....	1
Background .....	2
Prevalence and Cost .....	2
Manifestations .....	4
Significance .....	5
Development and Cognition.....	6
Reading Level.....	7
Materials and Methods.....	7
Illustrator Software.....	9
Publication.....	9
Implications for Families.....	10
Implications for Nurses.....	11
A Guide for Parents.....	12
Conclusion.....	13
References .....	14

## T1DM EDUCATION RESOURCE

*Danny the Diabetic Dinosaur: A Resource for Families Impacted by Type 1 Diabetes Mellitus*

### **Introduction**

Juvenile diabetes mellitus (JDM), type I diabetes mellitus (T1DM), or insulin-dependent diabetes mellitus (IDDM), is a chronic disorder that manifests in children ages 0-19 with peak prevalence occurring at 4-6 years of age and 10-14 years of age (Sinha et al., 2020). T1DM is characterized by hyperglycemia, and abnormally high blood glucose levels, caused by insufficient insulin production due to the destruction of the beta cells in the pancreas (Mobasseri et al., 2020). Insulin is the hormone responsible for the transportation of glucose into the cells resulting in the energy for organs to function and individuals to accomplish daily activities. Children diagnosed with T1DM must undergo a lifetime of insulin therapy to facilitate their growth and development and improve their glycemic control (La Banca et al., 2021). Over the last two decades, T1DM has been increasing annually in prevalence by 1.9% according to SEARCH, a multi-center study aimed at understanding more about diabetes among children and young adults in the United States. SEARCH was initiated in 2000 and funded by the Centers for Disease Control and Prevention (CDC), the National Institute of Health (NIH), and the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) (Dabelea et al., 2021). The growing prevalence of juvenile diabetes contributes to the increased healthcare burden, costs to families, and emotional toll on children and families, as well as a decrease in the quality of care in the United States and internationally.

Children diagnosed with T1DM experience a great emotional burden associated with the complex management of juvenile diabetes throughout their lives. Management includes altering diet and exercise along with receiving daily finger pricks for blood glucose checks and injections of insulin for glycemic control. Young children often lack an understanding of their diagnosis

and the importance of T1DM management which can lead to feeling overwhelmed, angry, frustrated, guilty, afraid, and lonely (Toh et al., 2021).

Not only are the children themselves affected, but over one-third of caregivers experience a burden related to the diagnosis of a child with T1DM which has been connected to increased rates of depression and family dysfunction (Balcázar-Hernández et al., 2022). Caregiver burden is defined as “the physical, psychological or emotional, social, and financial problems that can be experienced by the members of the family caring for an impaired person” (Moghadam et al., 2022, p.1). Caregivers experiencing burden express that a major form of distress includes being unable to explain T1DM and its treatments to their young child in a way that they can understand (Commissariat et al., 2020). With a growing number of patients to see, healthcare professionals lack the time and resources to thoroughly educate and support families with children newly diagnosed with T1DM increasing the need for alternative forms of healthcare literature. Research indicates that families and children can benefit from developing and implementing a children’s picture book that explains T1DM from diagnosis to management. The children’s book, *Danny the Diabetic Dinosaur*, will create a new resource for families and providers to use with young children to help relieve some of the burdens associated with a new diagnosis of T1DM. Furthermore, this resource will reduce readmission rates associated with DKA decreasing healthcare costs and improving the overall quality of life for all individuals with T1DM, especially racial minorities, and children with low childhood opportunities index (COI) scores.

## **Background**

### **Prevalence and Cost**

Juvenile diabetes has been increasing at an alarming rate over the past several decades raising concern for the future quality of care. From 2001 to 2009 SEARCH noted that T1DM

increased in prevalence by 21% (Sinha et al., 2020). SEARCH has since reported an additional 1.9% increase in the prevalence of T1DM each year (Dabelea et al., 2021). As of 2019, there were 244,000 children and adolescents less than the age of 20 living with T1DM in the United States (Centers for Disease Control and Prevention [CDC], 2022). The United States national incidence rate of T1DM in 2019 was estimated at 35 per 10,000 children (CDC, 2022). The growing prevalence of T1DM is of major concern to healthcare professionals nationwide.

Furthermore, attention is being given to the disparity between racial and ethnic groups including non-Hispanic Blacks, Hispanics, and Asian/Pacific Islanders who are experiencing an increased prevalence of T1DM at rates two, three, and even four times greater than non-Hispanic Whites respectively (Dabelea et al., 2021). These disparities raise significant concern considering many of these children are the most vulnerable coming from low-income families and communities with lower child opportunities index scores (COI). The COI is a comprehensive assessment tool that measures a child's opportunity for healthy development by considering educational, health, environmental, and socioeconomic resources and conditions available in the child's neighborhood based on zip code (Bergmann et al., 2022). Children with lower COI scores are more likely to experience diabetic-related exacerbations and increased healthcare costs.

While T1DM is not preventable or curable in the current healthcare system, education measures could be largely beneficial in decreasing the financial and emotional burdens through the prevention of diabetic-related exacerbations. Diabetic ketoacidosis (DKA) is a common complication associated with T1DM that results in the readmission and hospitalization of children. It is estimated that 30-day readmissions for DKA after an initial T1DM diagnosis account for 678 million dollars of all annual healthcare costs and on average cost the child's family \$12,000 (Bergmann et al., 2022). These children and their families also experience greater

emotional burdens due to the stress of hospitalization. Additionally, African American children had a 365-day readmission rate of 59% for DKA whereas White children were readmitted at a rate of 28% (Bergmann et al., 2022). Racial minorities are more likely to have lower COI scores resulting in increased readmissions from DKA and overall healthcare costs and emotional burden. Severe DKA can also lead to extended hospitalizations, acute kidney damage, or admission to an intensive care unit all of which increase the cost of care.

### **Manifestations**

Juvenile diabetes manifests in various intensities, typically before the age of 19, and is most commonly diagnosed between the ages of 4-6 years or 10-14 years (Sinha et al., 2020). Symptoms of T1DM are related to hyperglycemia and include increased frequency of urination, nocturia in previously toilet-trained children, excessive thirst, weight loss over weeks, feeling excessively tired, increased hunger, itching in the genital area caused by a yeast infection, slow healing cuts and sores, and blurred vision. The more severe presentation may not occur until a child is experiencing DKA characterized by severe illness including nausea and vomiting, abdominal pain, altered mental status, Kussmaul respirations, ketotic breath, and coma (Mobasserri et al., 2020; Sinha et al., 2020). Diagnostics for T1DM include obtaining blood samples to check for hyperglycemia and urine specimens to check for an acidic pH and the presence of glucose and ketones. The American Diabetes Association outlines diagnostic criteria for diabetes as a fasting plasma glucose greater than or equal to 126 mg/dL (7.0 mmol/L), or a post-prandial plasma glucose greater than or equal to 200 mg/dL (11.1 mmol/L), or a glycated hemoglobin (HgbA1c) greater than or equal to 6.5% (48 mmol/mol), or a random plasma glucose greater than or equal to 200mg/dL (11.1 mmol/L) in a client with symptoms of hyperglycemia as previously discussed (American Diabetes Association Professional Practice Committee, 2021;

Sinha et al., 2020). Regardless of the severity of the child's presentation, when diagnosed with T1DM most primary care providers hospitalize the client until education and family/self-management can be established. If the child is in DKA they require an extended hospitalization for stabilization through intravenous fluids and insulin therapy.

Juvenile diabetes is a chronic disease that affects the client for the duration of their lifespan. Long-term management depends on insulin therapy, but diet and exercise are critical components of improved glycemic control. Many modalities exist in insulin therapy including insulin pens, insulin pumps, and long-acting, intermittent-acting, short-acting, and rapid-acting insulin preparations. Individuals must learn how to manage their T1DM as children because research shows that proper adherence to management as a child leads to better transitions into adult management and lifelong outcomes (Dabelea et al., 2021). Improper management of T1DM can lead to DKA, organ damage, heart disease, acute kidney injury, blindness, loss of limbs, stroke, and potentially death. These long-term effects are the result of chronic hyperglycemia.

### **Significance**

Diabetic ketoacidosis is a preventable exacerbation in children with T1DM with proper education and management. Decreasing the readmission rate from DKA would substantially reduce healthcare costs and improve the quality of life for families and children with T1DM. Low levels of health literacy are disadvantageous for child health outcomes in chronic conditions (Riemann et al., 2021). By producing a children's picture book using simple language and child-friendly explanations of T1DM, health literacy can be improved and DKA readmissions could be decreased leading to lower child and caregiver burden. Furthermore, the benefits of parent and child interaction in reading and discussing difficult topics surrounding a T1DM

diagnosis would greatly reduce parental and child emotional burdens and result in better health outcomes for the child with T1DM. Virginia M. Axline notes the benefits of parental involvement in the course of the therapeutic process in her book *Play Therapy* (Axline, 1969).

### **Development and Cognition**

When creating a children's book and healthcare literacy it is important to consider the developmental stage of the target audience. *Danny the Diabetic Dinosaur* was designed to target ages 7-11 years old, and potentially some younger audiences with assistance from parents in reading and comprehension. The developmental stage of 7-11-year-olds falls in Piaget's concrete operational stage of development. Thus, these children begin exhibiting logical thinking patterns. They can focus less on themselves and more on the environment and cause-and-effect relationships (Piaget, 1962). This is important in the reading comprehension of *Danny the Diabetic Dinosaur* because children must recognize that their behaviors affect the outcomes of their health, just as Danny's actions in the book affect his T1DM. It is important to recognize that these children are developing their cause-and-effect recognition and that they still need assistance in understanding when reading. They are not at a mastery level.

Another developmental theory applicable to the target audience of 7-11-year-olds is Erikson's school-age psychological stage. According to Erikson, school-age children face the psychosocial crises of industry versus inferiority (McLeod, 2023). At this age, children need to begin trying to accomplish things on their own. In other words, parents and providers should begin to include children in the care for their T1DM. When children enter the concrete operational stage and face the industry vs. inferiority crisis, they must transition from having their caregivers provide all their care to including them in the decision-making process. Research shows that children benefit most at this age from encouragement and recognition of their

achievements (McLeod, 2023). If caregivers do not allow children to participate in the care for their T1DM, the child may develop inferiority complexes and feel unable to manage their disease process. Erikson's theory recognizes that school age is when children build life skills.

Recognizing that T1DM is a lifelong disease process, it is critical to help these children begin building the necessary skills and behaviors needed to have successful lifelong management.

*Danny the Diabetic Dinosaur* demonstrates to children and parents ways that the child can begin to assist in the management of their diabetes through making educated food decisions, exercising, and alerting adults when the child feels "low or funny". Another aspect critical to this stage of development is making sure the child feels included in the social setting. If a child feels different from their peers they may also develop feelings of inferiority, which is why it was important to include the aspect that the child can do anything their peers can do in the children's book.

### **Reading Level**

*Danny the Diabetic Dinosaur* was created to target children ages 7-11, with that in mind the reading level was assessed through an online program using mathematical formulas that consider the total number of words, length of sentences, and syllables in words to assess the Flesch-Kincaid score associated with grade-level reading. The manuscript for *Danny the Diabetic Dinosaur* came out as a 5, meaning it is written on approximately a fifth-grade reading level and is appropriate for the age range of 7-11. The Flesch reading ease score was also calculated and the result was an 80 which is associated with easy school-level reading (Readable, n.d.). In totality, *Danny the Diabetic Dinosaur* is appropriate for the reading level and developmental stage of school-age children ages 7-11.

### **Materials and Methods**

The process of creating a children's book requires much preparation and planning. The initial challenge was developing a character and plot for the story. Considering the aforementioned information regarding T1DM and the disproportionate impact on minority populations, it was desired to develop a character that would appeal to all races and ethnicities. The thought was to incorporate children's love of animals, mythical creatures, and cartoon characters to create a character all children would enjoy reading about and could relate to. Thus, it seemed appropriate to create a cartoon purple dinosaur as the main character. "Danny" the main character in the book has humanistic qualities that every child should relate with.

The key consideration in writing the manuscript for the book was how to convey the intricacies of a diabetes diagnosis and its management in a way a child ages 7-11 would understand while keeping the content interesting and not scary. The use of analogies and creative terminology to reference injections, blood sugar checks, and dietary limitations helped to create a story that would educate the child in Piaget's concrete operational thinking while preventing fear in the school-age child with an already stressful diagnosis. The adventurous storyline that Danny follows in the book should maintain the child's attention. Most importantly, the information in the book is founded on scholarly research and was reviewed by nursing professionals. Before publication, the product will be vetted by a panel of experts on T1DM and endorsed by experts in the field.

Once the manuscript was created, the process of creating the illustrations and end product had to be considered. Options for creation range from physical paper creation to online programs and illustrator software. When designing a children's book it is critical to consider the end goal for publication and distribution. Creating a physical book with pencil and paper may give the artist more control over their designs, but it limits the opportunities for mass production.

Therefore, the decision was made to do only the rough sketches on physical paper before transferring the work into software designed for professional illustration.

### **Illustrator Software**

After much research on software designs and the most user-friendly technology to use when illustrating a children's book with minimal experience, the decision was made to purchase and use Procreate on iPad. Procreate allowed for physical sketches to be scanned and digitalized for further editing and coloring. The Procreate app allows the artist to build work in layers and use duplicating functions to quickly add completed characters to other pages in the book. The Procreate app is widely used by professional illustrators and fits the needs of the desired end product. Adobe Illustrator was considered for use, but came with a much higher cost and less user-friendly technology for the inexperienced.

When illustrating the book, artistic considerations must be taken into account. The goal of the creative design was to create a colorful cartoon world that children would find exciting. Decisions to use rich colors, as opposed to pastels, were made. Furthermore, the use of white space was desired by the artist to be at a minimum. Decisions to use complimentary and vibrant colors throughout can be noted by the viewers. Research shows young children prefer the use of cool colors and that purple is the most common favorite color of girls and boys being chosen as the first or second favorite color in over fifty percent of kids (Read & Upington, 2009). Based on this evidence, Danny was designed to be a purple dinosaur. Additionally, the book has a cool colored palette throughout the book as the main color scheme. The artistic style is similar to a cartoon to appeal to young readers.

### **Publication**

The process of publication is an ongoing project. Considerations must be made on whether to self-publish or go through a corporate publishing company. Self-publishing will likely be the best route as it allows for the author to maintain rights to their work and potentially a future series. Additionally, the profit margin for self-publication is far greater for the individual than it is for corporate publication. The next steps include obtaining a copyright for *Danny the Diabetic Dinosaur* and purchasing an ISBN number for the book. If self-publishing is done, the book will be made available to the public on Amazon and Kindle, and physical copies may be printed and taken to local bookstores and hospitals for distribution. The author would develop an LLC for the book and future works to reside in. There remains a potential need for a grant if the self-publishing route is pursued. Corporate publication would result in widespread distribution of the book and would be cheaper, but there would be a loss of personal rights to the product.

### **Implications for Families**

*Danny the Diabetic Dinosaur* serves as a resource to families impacted by a T1DM diagnosis. Children are often overlooked in the healthcare setting when it comes to education, and parents often don't know how to explain medical conditions to their children in a way that they can understand and relate to the topic. *Danny the Diabetic Dinosaur* acts as the bridge for parents trying to cross the rough waters of helping their child understand diabetes and its management. Families can sit down together, read, learn, and have conversations with their children who may have questions or worries. This book helps create a stress-free environment for learning and promotes family interaction to reduce child and caregiver burden. If parents feel empowered to help their children, and their children feel included, the emotional burden can be greatly reduced and health outcomes will benefit as a result. Furthermore, child participation in their healthcare plan can reduce rates of readmission and complications from diabetes such as

DKA. Children have the natural desire to learn and take control of their situation as a part of the industry vs. inferiority psychosocial development stage. This resource opens the door for communication and can promote increased involvement from the child in their treatment.

Additionally, *Danny the Diabetic Dinosaur* can serve as a great educational tool in the classroom setting where a child may benefit from peer education on T1DM. School is known as a time when children do not wish to be different. Education on what T1DM is and how it affects a student may promote inclusion and understanding among peers when they realize that T1DM does not limit their classmates from normal activities. Children are typically inclusive when they are educated and recognize what makes their friends different. It is the unknowing and lack of normalizing differences that results in bullying and exclusion. *Danny the Diabetic Dinosaur* helps children realize that Danny is just like everyone else and so is their classmate who may be impacted by diabetes. The potential beneficial uses for this resource are numerous and range from home, clinical, hospital, and school use.

### **Implications for Nurses**

The heart of nursing is founded on providing therapeutic care and support to clients and their families. Nurses aim to meet the needs of clients where they are at. When a nurse witnesses a gap in care whether it be in physical treatment, policy, emotional burden, or educational needs, it is the nurse's duty to bridge the gap in the healthcare system to promote the overall wellbeing of the family unit.

*Danny the Diabetic Dinosaur* serves as a bridge to the gap in educational needs for children and families impacted by T1DM. Nurses as well as all healthcare professionals can use this resource to help educate children and their families. This resource can decrease the emotional burden on children and their parents, and the nurse can be guided by the book in

explaining T1DM to children and families. *Danny the Diabetic Dinosaur* was written based on evidence-based research and targeted to be appropriate for child development. The possibilities of using the book are endless between home, clinic, or school use.

### **A Guide for Parents**

Whether a child is newly diagnosed or has had T1DM for quite some time, they likely still have questions about their condition and management. As you read *Danny the Diabetic Dinosaur* help your child to make comparisons to their diabetes management. How did they feel when they got diagnosed? Do they see similarities in their own life to Danny's? Help them grasp the concepts of insulin and glucose. Do they know that glucose comes from food and insulin comes from their medication? Do they understand that they need glucose for energy? Discuss the appropriate sugar levels for them based on their doctor's recommendations. Your child may also want you to journal their foods as Danny does in the story. Make a list with your child of the best foods they could eat throughout the day. Take your child grocery shopping the next time you go and pick out foods together to satisfy all the food groups in the book. The most important part of reading together is just being present and having fun. Ask them what questions they have about Danny or themselves and do your best to answer them. Maybe you don't know the answers to all their questions. That is okay. Children don't expect lengthy medical explanations, they just want to be included in the process and feel heard. Next time you check their blood sugars let your child wipe their finger off with the alcohol wipe, or let them hold the glucose monitor. Make connections to the story when you can throughout the next few days or weeks. Write down your and your child's questions for the next time you see their provider, or call the diabetes educator on staff at your local clinic or hospital. Most importantly, relax and know that you all are going to develop a smooth routine that works for you and your child.

### **Conclusion**

Ultimately, T1DM has a major impact on numerous children and their families in the United States and globally. The prevalence of T1DM is growing, and the burden associated with the diagnosis of a child not only negatively impacts the child, but also the family. Implementing a resource to assist parents, teachers, nurses, and other healthcare providers in explaining diabetes to a child in a manner that they can understand can reduce the emotional burdens associated with the diagnosis and management of T1DM in the family unit. Furthermore, education can improve the quality of life of a child and prevent complications such as diabetic ketoacidosis from improper management. In totality, the need for a resource to bridge the gap in education between healthcare providers, parents, and children was recognized. *Danny the Diabetic Dinosaur* serves as the bridge to improving the communication and education pathways for families impacted by type 1 diabetes mellitus.

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