

Children's Literature and Diabetes

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Abstract:

My studies consider the genre of children's literature, specifically picture books, and their treatment of the topic of diabetes. I frame my argument with an examination of diabetes, the psychological effects of diabetes on the child, the need of thorough education about diabetes. I argue for the use of the picture book as an effective tool in educating and socializing the diabetic child. I first explore the implications of diabetes and the long term complications caused by one's poor control of the disease. I then explore the psychological ramifications of a chronic illness on the young child. Next I assert the need to combine the physiological and psychological factors of diabetes into a responsible text for children, one which both serves as an educating tool and a source of comfort in difficult times with the disease. I conclude my studies with critiques of existing materials in the limited genre of children's book written specifically for the child and compare them to the story I have written for children about diabetes.

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Chapter 1

Introduction

I have been a type 1 diabetic for a little over 21 years. I was diagnosed at the tender age of three and at the time type 1 diabetes was referred to as “juvenile onset diabetes.” I have spent most of my life hating my disease; wishing it was someone else’s problem, not mine. I have longed to taste a little of the normalcy other children enjoyed and sometimes flaunted in jest of me. I craved their seemingly delicious lifestyles full of candy bars at lunch and cookies after school. I have never known the childhood excitement and joy sparked by the sound of the ice cream truck coming around the corner. Birthday cakes without frosting held no appeal for me. The only treats I ever received were the ones labeled “sugar free.” Even three year olds know “sugar” and “free” do not go well together. Then there were the twice daily injections of insulin and the finger pricks multiple times a day to test my blood. My mother called me her “little pin cushion.” Meals were never spontaneous events, but had to be strictly regimented—six times a day at precise times. As I grew and changed over the years, so did the understanding and treatment of diabetes. Two shots a day turned into 6-8 shots a day, in an attempt to more accurately resemble a functioning pancreas. The dietary “exchange system” was replaced with “carbohydrate counting.” My insulin dose is dependent upon the number of carbohydrates I eat at a meal; dining out and Thanksgiving feasts are nearly impossible and cause more of a headache than enjoyment.

Until a few years ago, every aspect of my life was under the regulation of someone else. Growing up I was always told what to eat, when to eat, what I could do, and mostly, what I could not do. Normal human emotions, such as anger and sadness, and physiological sensations, like fatigue and headaches, can mimic the symptoms of a diabetic insulin reaction. Whenever I expressed a legitimate feeling, my family assumed it was a symptom of hypoglycemia and sped into action. If I became angry, my mother’s automatic response was, “Is your blood sugar low?” It was as if being diabetic meant I was not fully human. I could not take naps because my mother would think I was “low.” I could not go to slumber parties because “they would not

know what to do in an emergency.” As I entered and passed through the different phases of childhood and adolescence, I continually discovered new aspects of life that were hindered or made impossible because of my diabetes. Days at an amusement park or beach had the long, dark shadow of diabetes over them. Where normal children were deciding which rides to go on, I was asking myself the same annoying questions: Do I have enough snacks in case my blood sugar drops? Will this long line make me late for lunch? What if I start to feel a low blood sugar reaction while on the ride? Will I be able to bring my insulin into the park? What if I lose it or it breaks while I am here? Do I have backup insulin? And so on.

As a diabetic child, I had to grow up fast, mature at a faster rate than my peers, and take on responsibilities other children did not even have to contemplate. While I cherish all my childhood memories, I realize that many of them were blemished by the seriousness of my circumstance of being a chronically ill child. As I reminisce, however, the beautiful truth that emerges is how much I really gained from being a juvenile diabetic. I learned at an early age that I could view growing up with diabetes as a loss, but instead I chose to see my highly developed sense of responsibility and priorities as strengths. Being different has helped me appreciate my own and everyone else’s uniqueness. As a young child living with the diagnosis of diabetes, I could not understand that the apparent injustice I had been dealt was actually a blessing in disguise. In fact, over the years my disease has undergone a virtual metamorphosis, changing from a burden in my life to a constant lesson about life. It first happened at an idyllic, remote place known as Camp Glyndon, a summer camp for children and families with diabetes. I was fortunate enough to have had the opportunity to attend such a program, a program that offered me a chance to meet other children like me and form life long bonds.

At Camp Glyndon, I discovered that I was not alone in my struggles with this disease after all. Here was a place where hundreds of children gathered, all of whom were just like me. We all laughed the same, cried the same, and coped each day with the same illness. What set us apart from the norm in the outside world did not do so here. I was only 4 when I first started attending diabetes camp, but I grasped that important concept.

Life can pass out lemons, and each of us has to decide whether to wallow in the bitterness of a situation or discover the dissembled sweetness about it. That summer I met and began to fall in love with the greatest companions of my life. Our common diagnosis brought us together, but our friendships have kept us together. I have always found great consolation in the many friendships made at that beautiful place, which continue to sustain me during my bad “diabetes days” as we refer to them.

After thirteen years as a camper I began to work at Camp Glyndon as a counselor, and now after 21 years of attendance I am the current Program Director for Camp Glyndon. I continue the beneficial work of the camp, helping the confused young children learn and understand the same lesson I had learned so many years ago. I do this because I understand the importance of having a place like this, which offers comfort and a little sense of normalcy to children who are living anything but normal lives.

As a child I had a very fond, very deep love of books. My mother helped instill the value of books in me at a young age by reading to us every night. It never mattered what she was reading; I just loved to curl up in her bed and listen to her read, and when I was able, to read to her. My mother would take us on weekly trips to the library and would allow us to rent ten books each. I often found myself choosing the same books every time. I spent all my allowance on books, often purchasing the books I had repeatedly rented from the library. I would read all night under my covers, or hiding in a dark room. I packed books for every vacation. I would read entire series in a week’s time and I often reread the books I had purchased, until their covers were falling apart in my hands.

It is hard to name exactly what it was I loved about those books. I was not picky but I had my favorites. From picture books to novellas, from elementary favorites to giant literary classics, I loved them all. The heroes, the love stories, the adrenaline-inducing adventures, they all had an impact on me, one I still feel today when I flip through an old favorite. While my love of books is not directly related to my diagnosis with diabetes, there is a connection--or rather, a disconnection. As children we all had our favorite characters and stories. We went to them time and time again when we needed to escape the real world. We created scenes for them in our

imaginations. We related to them, understood them, and learned from them. Considering all of this, it pains me greatly that as a diabetic child I had no diabetic character in my early reading years of whom I could relate to and learn from.

The idea for this project first came to me last semester when I was enrolled in Nikki Giovanni's *Writing for Young Audiences* course. In that class we spent a great deal of time talking about what kind of writing for children is really the most beneficial to their emotional and mental development. We read many children's picture books in class dealing with difficult topics such as death, racism, and abuse. We also read stories about love and life, presented to the children in non-traditional ways. Our main assignment for the class was to write a story for children. Thus I decided I was going to write about what I knew best--living with diabetes. Before undertaking this assignment I thought it would be a good idea to go to the libraries and see what sorts of books were already out there for children living with diabetes (or a chronic disease). I was appalled to find there were literally no children's books about life with diabetes in the New River Valley and a rather poor selection concerning other chronic diseases. I realized at that time that this was an untapped realm in children's literature. As someone who has been diabetic for almost 21 years, and who knows first hand the difficult realities related to having such a disease, I can without doubt assert the need for these types of books for children. That is exactly what this project proposes to accomplish.

The powerful effect of a book on a child's socialization and mental development becomes particularly relevant when we consider all the harsh realities our children are faced with in the world today such as war, poverty, death, and disease. It is necessary to explain these difficult concepts to our children in a responsible manner that is respectful of their fragile and innocent nature. For the purposes of this project, I intend to explore children's literature and its treatment of the child living with a chronic illness, specifically diabetes. When we consider the learning potential provided by picture books it is hard to understand why there is such a gross lack of sufficient materials in this genre, focused directly on diabetes and targeted exclusively at the children living with this disease. The exploration, critique of, and hopeful expansion of this genre is important and necessary because diabetes affects the chronically ill child emotionally,

psychologically, and socially as much as it does physically. Picture books are an excellent educational tool for children, which offer a place of recognition and sense of “not being alone” in their plight. Furthermore, these books can be used to provide the chronically ill child with an education about and understanding of their disease, which can be seen as the only real way to overcome it and cope reasonably with the long term effects of the disease on the child’s body and mind.

In order to argue successfully for the expansion of this specialized genre of children’s literature it is important to address and answer several crucial questions. Throughout the beginning stages of the research for this project I discovered that there was very little offered in the area of children’s literature about diabetes and almost nothing offered or directed specifically to the child. Why isn’t it there already? How exactly do you talk to children about the difficult topic of diabetes? How do you explain to them the responsibility now required of them at such a young age? How do you explain to them, in a non-frightening or threatening manner, what will happen if they do not care for themselves the way they need to? Additionally it is necessary to examine closely the few children’s books about diabetes which are available, focusing on their strengths and weaknesses, how they do and do not work as educational and responsible materials. How can we improve this genre to meet the very special needs of these very special children? The psychology of children with diabetes and of the “sick child” is a reality we as a society cannot afford to ignore and this is an important, necessary, and untapped realm of children’s literature.

Chapter 2

Diabetes Overview

Diabetes:

In order to fully appreciate the need for books about diabetes directed specifically to children it is necessary to understand the implications of diabetes for our society as a whole and particularly for the children living with this disease. Diabetes is a group of diseases marked by high levels of blood glucose resulting from defects in insulin production (either the body stops producing insulin completely or it develops a resistance to the insulin it is producing). Diabetes is a chronic disease, meaning there is no cure; once diagnosed, you will have diabetes for the rest of your life. There are two main types of diabetes recognized by the American Diabetes Association, type 1 and type 2.

Type 1 diabetes was previously referred to as insulin-dependent diabetes mellitus (IDDM) or juvenile-onset diabetes. Type 1 diabetes develops when the body's immune system destroys its own pancreatic beta cells, the only cells in the body that produce the hormone insulin, which regulates blood glucose levels. In order to survive, individuals with type 1 diabetes must have insulin delivered either by injection or through a pump. This form of diabetes usually strikes children and young adults; however, recently it has been found that onset of the disease can occur at any age. Type 1 diabetes accounts for 5% to 10% of all diagnosed cases of diabetes. There are many risk factors for type 1 diabetes, including autoimmune, genetic, or environmental; yet, there is still no known way to prevent type 1 diabetes. The people who are most at risk of developing type 1 diabetes are the children and siblings of individuals with type 1 diabetes. (American Diabetes Association)

Type 2 diabetes was previously known as non-insulin-dependent diabetes mellitus (NIDDM) or adult-onset diabetes. Type 2 diabetes accounts for about 90% to 95% of all diagnosed cases of diabetes. It usually begins as insulin resistance, a disorder in which the cells do not use insulin properly. As the need for insulin rises, the pancreas gradually loses its ability to produce it. Type 2 diabetes is associated with older age, obesity, family history of diabetes,

impaired glucose metabolism, lack of physical activity, and with certain racial and ethnic groups. Recently, a new term has been coined to identify individuals at risk for developing type 2 diabetes, known as “pre-diabetes.” Pre-diabetes is a condition defined by a heightened risk of developing type 2 diabetes, heart disease, and stroke. People with pre-diabetes have blood glucose levels higher than normal but not high enough to be classified as diabetes. (American Diabetes association)

The International Diabetes Foundation proposes that more than 200 million people worldwide are living with diabetes; 440,000 of whom are children under the age of 16. In addition, the IDF estimates that over 70,000 children develop diabetes each year. (International Diabetes Foundation) According to the statistical data collected and provided by the American Diabetes Association (ADA), there are 20.8 million children and adults living with diabetes in the United States. It is estimated that one in every 400 to 600 American children and adolescents has type 1 diabetes. While it is rare, type 2 diabetes can occur in youth, and due to the trend of increasing obesity, the clinically-based reports and regional studies suggest that type 2 diabetes is being diagnosed more frequently in American children and adolescents. Currently there are 54 million Americans with pre-diabetes and 6.2 million people who are diabetic and have not been diagnosed.

According to the ADA someone is diagnosed with this chronic disease every 21 seconds. This is a particularly frightening reality of our society when one considers that diabetes is the fifth-deadliest disease in the United States, with a death rate that has increased by 45 percent since 1987, while death rates due to heart disease, stroke, and cancer have declined in the last two decades. (American Diabetes Association) Moreover, when one acknowledges just how many children nationally (and internationally) are living with this disease, it becomes even harder to understand why there are not more materials, specifically educational and informational picture books, directed to their special, physical, psychological, and emotional needs.

Diabetes Daily Rigors:

Upon diagnosis the immediate challenge the newly diabetic child faces is the realization that life as they once knew it will never be the same. There is no more sleeping late on the weekends; no more pigging out while watching a movie. They cannot make spontaneous excursions or take unplanned vacations. From the moment they are diagnosed with diabetes they must account for every aspect of their now highly regimented lives. The hardest reality is that they must now strictly adhere to daily routines.

A day in the life of a diabetic is almost entirely consumed with the management of their disease. Those on insulin injections must wake up at the same time every day, to test their glucose levels and calculate their first insulin dose according to what they are having for breakfast and based on their activity level throughout the day. They must again check their glucose levels before snacks and lunch, and take insulin injections as needed. They are required to eat three meals a day, and three snacks, according to a tightly locked schedule. In the evening they must check their glucose levels again before dinner, and calculate their evening insulin doses based on the activity of the day and any activity of the night. There is no room for spontaneity or lapses in time. If they forget a meal or snack, they run the risk of a low blood sugar reaction. If they overeat or neglect activity, they run the risk of a high blood sugar reaction. If their blood sugar levels are out of range, they must closely examine their blood glucose readings and daily events, to figure out and account for the fluctuation. If their blood sugar is high, they must urinate on an acetone strip to check for ketones. If ketones are present they must now take another injection, drink lots of water, and deal with the fact that they will be inconvenienced with frequent trips to the restroom all day long.

Every meal has to be carefully calculated. Insulin dosages are based on the number of carbohydrates the diabetic eats. This requires them to be consciously aware of what types of food they eat and how many carbohydrates are present. This can be particularly annoying when dining out or eating at a friend's house. Many diabetics own books that have the nutrition information for all the menu items at popular restaurants and fast food establishments. However,

this means the diabetic needs to have the nutrition books with them at all times, as well as always carrying their glucometers and insulin with them. For girls this is not so bad because they carry purses, but for boys this presents an entirely different, inconvenient situation.

The diabetic needs to make sure that their classmates, peers, and coworkers are aware of their diabetic status, in case of an emergency. The diabetic must carry or wear some sort of diabetic identification at all times. Actions that are normal to the diabetic are weird and uncomfortable for the non-diabetic. Testing one's sugar or taking an insulin injection in public attracts unwanted looks and questioning stares. Furthermore the diabetic is constantly and daily subjected to uninformed, often frustrating, questions and commentary from people who do not understand the disease. "Can you eat sugar?" "Why does she get to eat a snack in class?" "I thought diabetics can't eat salt?" "Why are you pricking your finger?" "Did you get diabetes because you ate too much candy?" On top of battling the normal anxieties of childhood about "fitting in," the diabetic child worries about blatantly standing out. Nothing could be more embarrassing than suffering a particularly bad low blood sugar reaction, complete with belligerence and seizures, in front of all your peers.

There is no escape from the rigors of the daily diabetic routine. Once the day is over, the diabetic will awake the next morning to the same mechanical regime. Not an hour passes when the diabetic is not thinking about his or her diabetes in one way or another. Even moments that are otherwise free of diabetes' overwhelming control can lend themselves to thoughts of the past before diagnosis or the future and fears of devastating complications. Even if one wanted to forgo the daily challenges, take a break from the diabetic routine, they know they run the risk of doing considerable harm to their bodies. It is a harsh reality. And it is a permanent reality.

Chapter 3

Diabetes and Complications Overview

The most obvious reason diabetes affects the child emotionally and psychologically is the fact that diabetes can lead to long-term complications and premature death. As stated earlier, diabetes is the fifth-deadliest disease in the United States. However, according to the ADA, studies indicate that diabetes is generally under-reported on death certificates, thus the toll of diabetes is believed to be much higher than is officially reported. As the ADA outlines, these serious and sometimes life-threatening complications include, and are not limited to, heart disease and stroke, blindness, kidney disease, nervous system disease, amputations, and sexual dysfunction.

Complications of diabetes can be categorized as short term (acute) and long-term. Acute complications include events such as **hypoglycemia**, **hyperglycemia**, and diabetic ketoacidosis (DKA). **Hypoglycemia** is a side effect of the treatment of diabetes and is noted as an abnormally low level of glucose in the blood. This can occur if the diabetic individual has taken too much insulin, has not eaten enough food, or has had an unusually high level of activity. Symptoms of hypoglycemia differ from person to person but normally include gross fatigue, dizziness, tremors, hunger, headache, irritability, sweating, confusion, and if left untreated for too long can result in seizures and/or loss of consciousness. Hypoglycemia can be treated immediately with a fast-acting sugar product, such as juice, candy, or glucose tablets. **Hyperglycemia** is also a side effect of the treatment of diabetes and is noted as an abnormally high level of glucose in the blood. This can result if the diabetic individual has not taken enough insulin, has eaten too much food, or has been inactive for too long. Symptoms of hyperglycemia similarly differ from person to person but normally include extreme thirst, frequent urination, extreme hunger, headaches, blurred vision, fatigue, nausea and if left untreated can lead to a presence of ketones in the urine. Hyperglycemia can only be treated with insulin. Ketones occur when there is not enough insulin in the body. Insulin helps the body use the sugar in the bloodstream for energy. Without enough insulin, the body cannot use the glucose, and the cells are literally starving. As a result, the body

begins to break down fat cells in search of alternate energy sources. When the fat cells are broken down they release a poison called ketones. Too many ketones can lead to ketoacidosis, which can then lead to considerable cell damage, comas, and long-term complications. Ketones can be flushed from the body by drinking lots of water but the only way to stop them is to administer insulin.

By comparison there are significantly more long-term complications than short-term (acute) problems. The list is expansive yet incomplete, as medical researchers are constantly attributing new problems to poor diabetes management over extended periods of time. Complications can begin to show themselves as soon as ten years after diagnosis in type 1 diabetics and sadly, most type 2 diabetics are not even aware they have diabetes until they begin to suffer from one of its devastating complications. The only way to prevent and lessen one's chances of developing a long term complication is the on-going proper management of glucose levels. Long-term complications include, but are not limited to, heart disease, kidney disease, complications of the eye, diabetic neuropathy and nerve damage, foot complications, skin complications, gastroparesis, and depression.

Heart disease in diabetics is especially frightening. Heart disease is a term that encompasses many evils including coronary heart disease, hypertension, cardiac autonomic neuropathy, cardiomyopathy, peripheral vascular disease, and cerebrovascular disease. High levels of glucose in the blood cause severe nerve damage and the only way to avoid these problems is to keep your diabetes under "tight" control, with regulated glucose levels and a healthy lifestyle. (Rubin, 61)

Not everyone with diabetes develops kidney disease. However, over time diabetes can damage the kidneys and cause them to fail. Failing kidneys eventually lose their ability to filter out waste products, resulting in kidney disease. High levels of blood sugar make the kidneys filter too much blood. All this extra work is hard on the filters and after many years, they start to leak, thus useful protein is lost in the urine. In time, the stress of overwork causes the kidneys to

lose their filtering ability. Subsequently, waste products start to build up in the blood. Finally, the kidneys fail. This failure is called End Stage Renal Disease (ESRD) and is very serious. A person with ESRD either needs to have a kidney transplant or go on dialysis. (American Diabetes Association)

It is a well-known fact that diabetes causes eye problems and may lead to blindness. But most people who have diabetes have nothing more than minor eye disorders. These disorders include glaucoma, cataracts, and retinopathy. Glaucoma occurs when pressure builds up in the eye. The pressure pinches the blood vessels that carry blood to the retina and optic nerve. Thus, vision is gradually lost because the retina and nerve are damaged. People with diabetes are 60% more likely to develop a cataract, which occurs when the eye's clear lens clouds over, blocking light. (American Diabetes Associations) Diabetic retinopathy is a general term for all disorders of the retina caused by diabetes. There are two major types of retinopathy: nonproliferative and proliferative. Nonproliferative retinopathy is the most common form of retinopathy. It moves through three stages (mild, moderate, and severe), as more and more blood vessels become blocked. In many people, retinopathy progresses after several years to a more serious form called proliferative retinopathy. In this form, the blood vessels are so damaged they begin to close off. The longer a person has had diabetes, the more likely they are to have retinopathy. It is a frightening fact that almost everyone with type 1 diabetes will eventually have some form of nonproliferative retinopathy. However, proliferative retinopathy, which destroys vision, is far less common. (American Diabetes Association)

One of the most common complications of diabetes is diabetic neuropathy. Neuropathy simply means damage to the nerves that run throughout the body, connecting the spinal cord to muscles, skin, blood vessels, and other organs. About half of all people with diabetes have some form of nerve damage. (Rubin, 71) There are two common types of nerve damage. The first is "sensorimotor" neuropathy which can cause tingling, pain, numbness, or weakness in your feet and hands. The second is called "autonomic." This type can lead to digestive problems such as feeling full, nausea, vomiting, diarrhea, or constipation, and problems with how well your

bladder works. It can also cause problems with having sex, loss of the warning signs of low blood glucose, increased or decreased sweating, and changes in how your eyes react to light and dark. Furthermore, people with diabetes are also at risk for compressed nerves which occurs when something in the body presses against a nerve, preventing it from sending a signal. (American Diabetes Association)

People with diabetes can develop many different foot problems. Foot problems most often happen when there is nerve damage also called “neuropathy,” which results in loss of feeling in the feet. Diabetic nerve damage can lessen your ability to feel pain, heat, and cold. This loss of feeling in the feet often means the diabetic will not be able to feel a foot injury. Diabetes can cause changes in the skin of the foot. At times the diabetic’s foot may become very dry and the skin may peel and crack. The problem is that the nerves that control the oil and moisture in the foot are damaged or no longer work. Poor circulation can also make the foot less able to fight infection and to heal. Furthermore, people with diabetes are far more likely to have a foot or leg amputated than other people. This is mainly because many people with diabetes have artery disease, which reduces blood flow to the feet and/or nerve disease, which reduces sensation in the feet. Combined, these serious problems make it easy to get ulcers and infections in the lower limbs that may eventually lead to amputation. (American Diabetes Association)

Many conditions involving the skin are unique to the individual with diabetes because of the treatment and inherent complications of the disease. These conditions include bruises (caused by the insulin needle), vitiligo (loss of skin pigmentation as a result of the autoimmune aspect of type 1 diabetes), insulin hypertrophy (the accumulation of fatty tissue at the sites of insulin injections), dry skin (a consequence of diabetic neuropathy) which can lead to cracks and breaks in the skin which can become infected and scar. (Rubin, 83) Furthermore, there is a higher occurrence of fungal infections under the nails or between the toes of diabetics because the fungus likes the elevated glucose levels. Due to the damages of the circulatory system because of neuropathy, many diabetics have a hard time healing small wounds. What began as a

tiny cut on the lower limb can become a gangrene infection in a short amount of time. Because the wounds take so long to heal, they often leave ugly, dark brown scars on the diabetic's skin.

Gastroparesis is a relatively new disorder attributed to people with both type 1 and type 2 diabetes as a long-term complication. It occurs when the stomach takes too long to empty its contents. It happens when nerves to the stomach are damaged or stop working. Gastroparesis can make diabetes worse by making it more difficult to manage blood glucose levels. When food that has been delayed in the stomach finally enters the small intestine and is absorbed, blood glucose levels rise. (American Diabetes Association)

Before attempting to assert the need for informative picture books about diabetes for children, it is necessary to examine the psychological and emotional implications of diabetes for the child. In order to provide our children with a responsible text that clearly outlines all of the harsh realities of this disease, it is essential to understand why this disease might have such a detrimental and lasting effect on the psyche of the child. A chronic condition like diabetes can have a profound effect on the mind of a child. Depression is three times more common among people with diabetes than in the general population, providing evidence for the assumption that there is a very emotional side to this physical condition. (American Diabetes Association) In fact during the seventeenth century a leading physician suggested that diabetes was the result of a "long sorrow." (Eiser, 98) At any given time, most people with diabetes do not have depression. But studies suggest that people with diabetes have a greater risk of depression than people without diabetes. This can be particularly troublesome for the diabetic child. Similar to denial, depression can become a vicious cycle, inhibiting good diabetes self-care. If the diabetic child is depressed and has no energy, he or she may find such tasks as regular blood sugar testing to be too much. If the diabetic child feels so anxious that he or she cannot think straight, it will be hard for him or her to maintain a good diet. For the child who has recently been diagnosed with diabetes, and even for the child who has had diabetes for many years, there are many new frustrations, strictures, and responsibilities they must deal with daily. For example, someone who has lived with diabetes for many years, and is now facing diabetes complications or

someone who is having trouble keeping their blood sugar levels where they would like, may feel like they are losing control of their diabetes.

The statistics surrounding the effects of the long-term complications of diabetes are alarming. Heart disease and stroke account for about 65% of deaths in people with diabetes while diabetes is the leading cause of kidney failure, accounting for 44% of new cases in 2002 alone. Diabetes causes 12,000 to 24,000 new cases of blindness each year, making it the leading cause of new cases of blindness in adults 20-74 years of age. More than 60% of non-traumatic lower limb amputations occur in people with diabetes because 60% to 70% of people with diabetes have mild to severe forms of nervous system damage, resulting in impaired sensation in hands and feet, as well as poor circulation to the extremities. (American Diabetes Association)

When a child and his or her family is faced with such frightening statistics and a daily regimen of blood testing, insulin injections, and often serious insulin reactions, it is easy to understand how he or she might become discouraged, frustrated, and depressed. I have watched the devastating effects of diabetes ravage my father's body and I know first hand just how terrifying that reality is. My father is 52 years old and has been a type 1 diabetic for 41 years. He grew up in an age when diabetes care was just not as effective or tightly controlled as it is today. Subsequently, his body suffered serious cell damage over the years. He has had two bypass surgeries to help improve his poor circulation caused by blot clots in his lower extremities. Due to his poor circulation, he has little sensation in his feet. A few summers ago he got a splinter in his foot, that he did not know about, and after several months the infection literally ate away his foot. Consequently, he had several of his toes removed from the foot with the splinter, and is forced to wear a special oxygen boot to help promote blood flow to the injured foot. He has also suffered from eye complications and sexual dysfunction because of poor diabetes management.

I have also seen diabetes complications develop in much shorter periods of time through my friends at camp. Many of them have had diabetes only half as long as I have and already

suffer from major kidney damage and eye complications. I know several friends, whose parents were also diabetic, and have passed away due to the complications of their diabetes. These sad events and occurrences of diabetes complications have very traumatic implications for the children living with diabetes. It is frightening to see first hand what can happen when diabetes is not properly managed; it is terrifying to think that one day, it could be me suffering with such physical ailments. I believe strongly that in order to write for children about diabetes and all of its accompanying complications we need to fully understand the psychological and emotional consequences of this disease for the child upon diagnosis and throughout their lives.

Chapter 4

Psychology, Diabetes, and Children

Insulin-dependent diabetes mellitus generates a formidable challenge not only to the children who are afflicted with this disease but also to those who are closest to them: their parents, siblings, teachers, and friends. In the book, *Diabetes Mellitus in Children and Adolescents*, co-authors Ben Brouhard, Travis Luther and Barbara-Jo Schreiner, along with other contributing scholars, provide us with a comprehensive outline of all the aspects surrounding diabetes. They describe the disease itself, along with several important topics such as how to develop a management plan, dietary management, psychological and family related issues, education, and consequences and complications of diabetes. In order to write to children about the disease, it is important to gather as much information as possible about the basic structure of the disease itself and living life with a chronic disorder. Children with diabetes must now tackle the disproportionate responsibility and burden of attempting to maintain a “delicate balance among daily insulin requirements, exercise, and diet just to survive and function normally.” (Brouhard, 101) In order to maintain this balance they are taught to test their blood sugar and urine glucose levels several times a day, administer several insulin injections daily, and adhere to what feels like a restrictive dietary requirement, as well as closely monitor physical activity. The concept of “functioning normally” is understandably ill-conceived when one considers the daily routines of the diabetic child. Diabetic children are often told that if they maintain tight control of their diabetes they can indeed preserve a reasonably normal life. But it does not take long for the diabetic child to realize that there is nothing normal about their daily routine of monitoring their body systems. According to Cindy Dell Clark, “situation normal, as perceived by a child with diabetes, is nevertheless a highly particular version of ‘normal’.” (Clark, 20) This notion that a child with diabetes can live a “fully normal” life in all social aspects is contradicted by the actual daily experience of diabetic children in everyday social affairs. They cannot eat as flexibly as other children; they have to eat snacks during school hours, when their peers are not eating, which contrasts greatly with this concept of “normality.” All of these efforts to maintain some

sort of metabolic balance are paralleled by a need for a psychological balance in relation to the chronic disease and its excessive demands. (Brouhard, 101)

On the most basic level, the diabetic regimen focuses attention on the child during his or her most intimate of functions, such as urine testing when their glucose levels are too high, as well as during public and social times, such as taking injections at meals or stopping play to treat a low blood sugar level. According to Barbara Anderson, “this complex daily regimen impacts on every aspect of the child’s development and family life.” (Snoek, 1) Children in the stage of early childhood (preoperational thought) and children in the stage of middle childhood (concrete operational thought) perceive and understand their worlds in different ways, thus it can be assumed that they understand and experience their diabetes in different ways as well. (Brouhard, 108)

According to Piaget, the major developmental shift from the preoperational stage of childhood to the concrete operational stage is the ability of the child “to differentiate between self and world, to distinguish between what are internal and external events, and to generalize from the specific case to the general situation.” (Brouhard, 108) Children shifting between these stages of development must be allowed to explore their environment in order to establish a sense of independence within the family setting. For the diabetic child, however, this is almost impossible as parents tend to assume the major responsibility of the child’s health behaviors, consequently making it impossible for the child to establish any independence. Furthermore, during these developmental years, it is important for the child to expand their sense of initiative, a sense of emotional self-control, and an ability to properly handle frustration. According to Brouhard, “This sense of ‘I can do’ must be fostered within the framework of successful control of diabetes as well. Because of the particular emphasis on learning and categorizing facts and figures, this is an optimal time to teach children factual data about diabetes.” (Brouhard, 108)

Additionally, diabetes not only affects the areas of exploration, independence, initiative, and learning but also has a strong impact on the child’s self-perception, in both a physical and psychological sense. Psychological development in school-aged children is assessed primarily with respect to the child’s sense of self-esteem and the development of strong peer relationships.

(Snoek, 10) Because of their not fully developed processes of logic and understanding, many diabetic children possess fearful misconceptions about their disease and what is happening to their bodies, combined with feelings of loss of control over their lives.

Children in both the early and middle childhood stages also have social developmental tasks that are affected by their diabetes. At these particular stages it is important for the child to participate in team endeavors as well as to possess a sense of peer support. Diabetes is a condition that engenders a sense of being “different” that can alienate the diabetic child and consequently interfere with the child’s ability to develop peer relationships. Experience proves for us that the years of childhood are a crucial time for the development of self-esteem. Children who are not allowed to exert their independence (such as the diabetic child), or are restricted from opportunities to interact with their peers, face the risk of developing a negative sense of self. (Brouhard, 109)

In her book, *In Sickness and in Play*, Cindy Dell Clark describes the plight of the chronically ill child and his or her daily toil with endless treatments, often painful symptoms, confusion, and even embarrassment. Her book does not focus specifically on children with diabetes, but on children with chronic conditions in general. In her book, she is suggesting that chronically ill children are at a greater risk of developing mental health or social adjustment issues. Again, Clark exemplifies why it is necessary to have books for children explaining their conditions to them in a way that they can understand because “medical treatments for diabetes present young patients and their families with unique trials at a tender age.” (Clark, 6) According to Clark, the procedures involved in treating diabetes permeate a child’s “life world.” Normal playtime is punctuated by bothersome interruptions to check blood glucose levels, eat a snack, and take a shot, leading the diabetic child to exclaim often, “I wish I didn’t have diabetes.” (Clark, 10)

Furthermore, diabetes treatment regularly invades a child’s emotional and social space. For the diabetic child playtime and typically relaxing amusements must constantly yield to “the business of diabetes care” which is a daily, never ending expenditure of time. (Clark, 10) The

children interviewed in this book expressed feelings of being “fenced in” by their disease, reflecting a dichotomy of “sad” and “happy” feelings when describing normal events such as vacations, trips to the park, and playtime. Overall, the children expressed mixed feelings about the necessity to “endure shots or other hardships of treatment” when describing life with diabetes. (Clark, 12) The explorations of the psychological implications caused by chronic diseases provide us with pertinent information and undeniable validation for the need to expand the genre of “children’s literature and difficult topics” in order to improve the lives of these children by understanding their perspectives, both imagined and real.

The Psychology of Childhood Illness, written by Christine Eiser, addresses the changes in how the psychology of chronic childhood illness is now studied. There is only one chapter focused solely on diabetes; however, the psychological implications of other chronic illnesses in children and the emotions attached to having a childhood disease can be easily translated, no matter which disease the child suffers. *The Psychology of Childhood Illness* proves to be a relevant resource because in order to confirm that there is a need for the expansion of books for children about diabetes (and chronic illness), it is important to understand the psychological effects of disease on a chronically ill child. In chapter 6, Christine Eiser discusses children’s knowledge about diabetes. She states that, “more than any other condition, diabetes demands that patients are as responsible for their own care as the physician.” (Eiser, 102) Consequently there have been many studies conducted to ascertain how much information children have about the disease (diabetes) and at what ages they are most capable of self-care. In order to assess this type of information, the children’s skills at urine testing, administering insulin injections, and establishing serving sizes of meals were observed on both the theoretical and practical level. On the whole, the children’s knowledge of their disease fluctuated greatly, and there was no correlation to how much the child understood about his or her disease with the age of the diabetic or the length of time they had been diabetic. The conclusion of the study found that children generally lacked a sufficient knowledge of their disease and ability to efficiently provide themselves with adequate self-care. (Eiser, 105)

There is clearly a need to create and expand upon the stories for children living with diabetes. The children need to be educated about the realities of their disease, while at the same time provided with tools to care for themselves as best as possible and ensure a long and healthy life, all while not terrifying them. The psychological explorations in these books help us to better understand this special need to carefully craft a children's book that accomplishes all those goals.

Chapter 5

Psychology, Diabetes, and the Family

It is my belief that diabetes is not a personal struggle, but rather a disease that encompasses the diagnosed child, each family member, and the community. Proper and successful diabetes management requires encouragement and support, and the family surrounding the diabetic child is the main source of both. According to The American Diabetes Association, “Diabetes control can be affected adversely by both physical and emotional stress and it is important that the family recognize, understand, and be ready to give loving support during stressful periods [in the diabetic child’s life].” (Brady, 144)

As humans we tend to think of grief primarily in connection with a death, but a diagnosis of diabetes can feel like a death to both parents and the children. After all it is the death of a care-free way of life, the death of spontaneity, the death of the idea that parents can protect their child from all harm. As with a death, all the members of the family can, and most likely will, go through all the stages of the grieving process: denial, anger, depression, fear and anxiety, and guilt. (American Diabetes Association) In the denial stage the child may pretend that he or she does not have diabetes or that it will go away soon. The parents may try not to think about diabetes for as long as possible. In the anger stage the child may ask, “Why am I the one with diabetes?” He or she might become angry with the parents, his or her friends, or siblings more often than he or she used to. The parent may also deal with varying degrees of anger at themselves, the diabetic child, their spouse, or even the doctor when really they are simply angry at the disease itself. In the depression stage the child may feel sad, tired, and/or hopeless. He or she may claim that diabetes has ruined his or her life. The parent will also experience depression symptoms such as crying more than usual or dwelling on the most negative possibilities for the child. Fear and anxiety are reflected in the child’s worries about diabetes. The parent will worry about trying to remain strong for the child or what might happen if they make a mistake in treating the child’s diabetes. In the guilt stage the child may express feelings that having

diabetes is her fault. He or she may feel like they are to blame for burdening the rest of the family with diabetes. The parents may blame themselves for the child's diagnosis with diabetes.

A diagnosis of diabetes in the child involves the whole family and often imposes a considerable strain on each member of the family unit, not just the diabetic child. According to The Joslin Manual, diabetes is not simply a matter of mechanical treatment. It involves a child's emotional and social development as well, which are often influenced by their parents' and siblings' responses to their diabetes. Diabetes challenges the young child and the family to understand and utilize complex knowledge about physiology and nutrition, as well as calling for technical skills such as measuring and administering insulin. (Joslin, 2009) The whole family is involved in the care of the newly diagnosed child's diabetes. Both parents should know how to give shots, check blood glucose, interpret blood glucose results, and treat hypo- and hyperglycemia. Depending on age, siblings can also keep a watch for hypoglycemic symptoms, help write blood glucose results in the logbook and even learn how to check blood glucose. Allowing the sibling to take an active part in the diabetes may help to quash feelings of resentment or jealousy, as well as provide useful and beneficial education about the disease. The more support the child has from the rest of the family, the easier it will be to maintain good control of his or her diabetes care. Participation in diabetes care by the entire family can also help prevent "diabetes burnout" in the child or in the parent most involved in the daily diabetes management. (American Diabetes Association)

Parents can often feel a strong sense of depression and guilt, as well as incurring the brunt of the responsibility of management of younger children with diabetes. For the married parents, diabetes can put a strain on the marriage relationship. For the single parent, diabetes is an extremely heavy burden to carry alone, especially without the support of a spouse. This added stress on each family member can disrupt a peaceful family dynamic and thus create a dangerously stressful home environment for the diabetic child. Robert Brady states that, "The diabetic child should not use diabetes to get attention or to disrupt the peace of the family, nor should he/she expect special consideration either in the family or outside because of diabetes."

(Brady, 145) Sadly though, this is often the case for most diabetic children. Upon diagnosis their entire world is flipped, and they are left with feelings of complete loss of control over their lives. They quickly learn and adopt often disturbing behaviors to compensate for the sense of a loss of control. Without proper guidance this can lead to years of resentment and stress between the parent and child, as well as between the child and siblings. Help and support are what the child needs most, and the family is the first place they will go for comfort and understanding. For the particularly young diabetic, the parents will assume most of their day-to-day control and management. However, it is important that the parent offer support without demanding perfect adherence to the strictures of the disease. As the child learns how to cope with the diagnosis and care for him or herself, it is important for the parent to allow the child to assume responsibility of the treatment of their disease. (Maclean, 105) The importance of a supportive family is obvious, and the tolerant actions of the parent on the part of the diabetic child will have lasting, beneficial consequences.

Diabetes affects each member of the family differently and the siblings of the diabetic child often reflect this disruption to the family unit more obviously than other members. Brothers and sisters of children with diabetes may have a variety of reactions to the diagnosis. Some may fear that they will “get” diabetes so it is important to reassure them that they cannot “catch” diabetes from their sibling. Many siblings become jealous or feel left out because the child with diabetes suddenly begins to get more attention. Siblings often perceive added attention to the diabetic child to mean that he/she is “more loved.” They should be allowed to express their feelings freely. However, it is important to explain why the diabetic child might be receiving more attention.

I know first-hand how important the role of the family is in the life of the diabetic child. I have been extraordinarily blessed in my experience with diabetes, in many ways. From the day of my diagnosis my mother has taken an active and supportive role in the care of my diabetes. She has always been a source of great comfort, never dismissing my negative feelings about my disease but rather giving me new perspectives on my situation. She had a way of giving a

purpose to my disease, thus making it easier for me to carry the burden. My mother took the time to educate herself thoroughly about my disease and was constantly researching new advancements and techniques. She would prepackage my snacks and meals for the week on Sundays; measuring, weighing, and counting out the exact amounts. She gave me all of my shots, and though I first injected myself when I was 4 years old, I continued to have her give me my shots because she made it less painful (physically and emotionally). She took me to events and fundraisers for diabetes yearly and she is the one who first enrolled me in the diabetes summer camping program, Camp Glyndon. At this camp I fell in love with and forged lifelong friendships with other diabetics like me; diabetics who are much like an extended family. To this day, 21 years later, my mother is who I turn to for continued support and praise with my diabetes. She has long since relinquished the reins of my diabetes management, but I still feel the need to call her when I get a good report from my physician.

Chapter 6 Diabetes and the Importance of Education

“The single most important factor in coping with both the physical and emotional impact of diabetes is *education*. Only when there is a clear understanding on the part of the diabetic [and the family] of what diabetes is, how it can be managed, how to prevent emergencies, and how to cope with complications should they arise, will these feelings begin to be resolved.” (Brady 144)

It is my belief that education about diabetes self-management is the most important aspect of successful diabetes treatment. The better we care for our diabetic selves today, the longer and healthier we will live. This is an especially crucial factor when dealing with newly diagnosed children. They need to be taught information about diet, blood glucose monitoring, exercise, acute complications, and insulin. Furthermore, as this entire project argues for, they need to be educated about the serious long-term complications of diabetes. This should be done with sensitivity and without alarming or frightening the child. Children should be taught that near normal blood sugar levels can help prevent complications. This is a particularly important concept when dealing with diabetic children because they are young and their behavior patterns are still forming.

According to the Diabetes Education Handbook, published by the United States Department of Health and Human Services, there are several differing phases of diabetes education. The *initial* phase of education takes place at the time of diagnosis. Because most newly diagnosed patients with diabetes are in a delicate psychological and physical state, they are not ready or prepared to learn large amounts of information. This phase of the education process is intended to provide patients with a *basic* level of knowledge and skills so as to help them *begin* to cope successfully with their diabetes. The next phase is referred to as the *in-depth continuing education* and begins after the patient has had time to live with their disease for awhile. The goal of this phase is to provide the patient with knowledge and skills required to actively participate in the daily self-management of diabetes. It is hoped that individuals who

have undergone in-depth continuing education are now qualified enough to assume complete responsibility for the daily management of their disease.

There are a wide variety of diabetes education programs available. Most of these programs utilize teams of health care professionals because there are so many aspects of life with diabetes, which constantly affect other aspects. These health care professionals include physicians, dietitians, nurses, certified diabetes educators, exercise physiologists, podiatrists, optometrists, and psychologists. Education does not have to merely take place in group settings or with professionals, but can be delivered daily in the home setting or through personal research and investment.

The Diabetes Sourcebook offers an interesting approach to diabetes education while arguing for its overwhelming importance and value. There are certain basic facts about diabetes that all diabetics must know to care for themselves. According to *The Diabetes Sourcebook* this information can be presented on three basic levels: the “survival” level, a “home-management” level, and a “self-management” level. (Guthrie, 33) The “survival” level provides just enough information to help the diabetic individual complete his or her daily tasks. This information would be given to the patients before they left the hospital after diagnosis or by the physician during the initial visits, and would include the basics such as nutrition, insulin dosages, blood glucose monitoring, and checking urine for ketones. The “home-management” level provides more extensive information on all topics related to diabetes, such as the need to maintain good hygiene, vacationing with diabetes, how to regulate blood glucose levels in conjunction with another illness, and how to adjust to a new way of living. The “self-management” level includes what a person needs to know to truly “self-manage” his or her diabetes. This level can be divided into two sublevels: the undergraduate self-management and graduate self-management. The first tier of self-management involves decision making based on patterns established after a week’s worth of recorded blood glucose levels. If you noticed a trend of higher sugar levels in the evening, you would be able to accurately adjust your morning insulin dose to correct or eliminate the evening highs. It’s a process of trial and error but at this level of education, the

diabetic patient should be able to make these types of decisions. On the graduate level of self-management the diabetic patient has become familiar with his or her responses to insulin in relation to food intake and exercise, and is able to correctly determine how much insulin is needed prior to meals or on days of elevated activity. (Guthrie, 36)

The Diabetes Sourcebook also provides a section on how to evaluate the quality of educational programs offered through local hospitals and support groups. Points of criteria include an education program led by Certified Diabetes Educators, approved by The American Diabetes Association, and one which covers the most essential aspects of daily diabetes care. An educational program could be evaluated as poor if it does not provide news about recent developments in diabetes care that could improve the patient's control of their diabetes. Furthermore, *The Diabetes Sourcebook* argues for the benefits of a proper and thorough education about diabetes. It reflects my personal feelings about the importance of a lifelong education about diabetes, because "a good education regarding your diabetes is vital to you." (Guthrie, 38)

According to The Joslin's Diabetes Manual, "education [about diabetes] is not part of treatment, it is treatment." Dr. Joslin himself has stated, "The diabetic who knows the most, lives the longest." (Joslin, 30) Furthermore, the World Health Organization recently stated, "Education is the cornerstone of diabetes therapy, and vital to the integrations of the diabetic into society." In the "Learning for Life" chapter of The Joslin Manual, there is included a list of the benefits of being a highly educated diabetic such as 1) to live longer and happier, 2) to have fewer days of illness and complications, 3) to be able to function and cope with the rigors of modern life, 4) to have more productive and useful lives, and 5) to be less costly to oneself, one's family and community, and the health care system under which one lives. True, education alone cannot possibly achieve all of these things. But the more people can understand their condition and *know* how to care for themselves, the more their doctors and families can help to "direct them along the path to continued health." (Joslin, 39)

Dr. Joslin's manual also speaks specifically about the education of the diabetic child. According to the manual, education must begin from the moment of diagnosis and continue throughout the patient's entire life, and the education for the child and his or her family consists of three stages. The first stage is a simplified introduction to diabetes and basics of daily management, which includes information about insulin injections, self-monitoring, and the recognition of symptoms of insulin reactions. The second stage takes place over the weeks that follow diagnosis as the family and the diabetic child begin to acquire the skills needed for successful long-term care, in order to enable the child to return to normal activities. The final stage of educating the diabetic child is providing him or her with more sophisticated details of management such as what to do when sick, when and how much to exercise, and how to deal with diabetes in combination with other variations in the child's daily routine. This final stage of education does not have an end date; it continues for the rest of the child's life and should include regular reviews and updates of new techniques and advancements in diabetes care. (Joslin, 201)

Additionally, The Joslin Manual outlines many aspects of life with diabetes that the child should know and understand, as early as diagnosis. Importantly, the children should be made aware, in a non-threatening manner, that their diabetes will not go away, it is a chronic disease without a known cure, and will be with them forever. It should be made clear for the child, however, that it is a disease that can be lived with and that with proper care and control, it does not have to ruin their lives. (Joslin, 208) The Joslin Manual also insists that the child should be made to understand the reasons and importance of self-monitoring (of blood glucose levels, insulin injections, and food intake). The child should learn to identify symptoms of hypoglycemia and hyperglycemia. Enabled with these skills, children will also learn that proper care will allow them to participate in the normal activities of childhood. Dr. Joslin warns us "not to underestimate the young and their ability to understand and treat their diabetes." (Joslin, 209) I could not agree more with this notion. It is the child who has the diabetes and will

subsequently have to live with it for the rest of his or her life. It is not simply important that children learn how to manage their diabetes at a young age, it is crucial to their very existence.

The importance of a comprehensive education about diabetes and its ultimately beneficial effects can be seen through the comparison of my personal experience with diabetes and that of my fathers'. When he was diagnosed with diabetes, 41 years ago, there just was not as much information available about diabetes. He grew up in a generation when having a sick child was viewed as shameful and thus he did not feel comfortable talking about his disease. The systems of monitoring blood glucose and administering insulin were poor and insufficient. Today I wear an insulin pump, which mimics the pancreas, administering insulin to my body every hour. I have a glucometer that gives me a glucose level reading within five seconds. Although taking care of my diabetes and practicing good habits of self-care is still a major inconvenience, it is significantly easier for me than it was for my father. When my father was growing up with diabetes, glucose levels were checked by urinating on a strip, which would turn a color indicating a range of glucose, not an exact number. That range represented what his glucose levels were two or three hours earlier in the day. It was basically a game of guess and check. Furthermore, taking an insulin injection was for my father a truly painful experience. When he was growing up with diabetes there were no "micro-fine," "lubricated," "one-time-use" syringes. Instead, he used a glass syringe, with a giant needle on the end, which had to be boiled before each use, and was reused over and over again. Even if he was actively and consciously involved in his diabetes management, the means of managing diabetes were just not as advanced as they are today.

Luckily, as a very young child I began attending a camp for diabetic children. This camp was a major proponent of education; almost everything I know about diabetes I learned at camp. Furthermore, it provided me with a firm support base and an outlet to express my feelings about my disease. Guest speakers would attend the camp and talk to us about new technologies and advancements in the area of diabetes research; I never would have known about insulin pumps if I had not attended the camp.

However, as a young diabetic child, I would really have loved and bonded with a book that spoke directly to me about my circumstances and experiences with the disease. True, I was lucky enough to attend diabetes camp, but camp was only one week out of the year. That is hardly enough time to learn and put into practice all the important aspects of proper diabetes care. The important need of these special types of books is even clearer when we consider that not all children are able to attend diabetes camp. There just are not enough camps to house all the children living with diabetes and camp is an expensive luxury.

For my father, times have changed greatly from the date of his diagnosis and he is still trying to adjust to this new approach to life with diabetes. I believe that if my father had known more about his disease, if he had had a stronger support group, and a means of appropriately expressing his frustrations with his disease that he would not now be suffering from the terrible complications associated with diabetes. Sadly, most of what he knows about his diabetes he has learned from watching me grow up with diabetes.

I believe that I am as healthy and comfortable with my disease as I am, because I have always been invested in knowing as much about my disease as possible. It is my goal with this project to assert the need for comprehensive and rational education about diabetes for young children. I believe strongly that diabetic children should be aware of what their future holds if they do not properly manage their disease, as well as be provided with the information and tools necessary to avoid that future. Some people think it is too harsh to talk to diabetic children about the reality of the disease; “complications” is considered a dirty word in the diabetic community. However, “complications” is no more a dirty word than “consequences,” and in this sense they are parallel terms. Just as children learn the concept that there are consequences to bad behavior, they should be taught that there are consequences to poor diabetes management, which are long-term complications. It is my belief that we have a responsibility to carefully interpret for them the realities of their disease, the good and the bad. We need to give them positive reinforcement while also reinforcing the important regimes they must now strictly follow.

Chapter 7

Talking to Children about Difficult Topics

In order to talk to children carefully and responsibly about the difficult topic of chronic illness one needs to be informed on the appropriate ways to handle the fragile and underdeveloped psyches of children. According to the Merck Medical Manuals, certain major events, such as illness and divorce, can challenge a child's abilities to cope and understand. These events may also eventually interfere with the child's emotional and social development. As would be expected, many children have a hard time talking about difficult and unpleasant topics; however, these discussions are necessary to "dispel irrational fears" as well as explain that "anxiety is normal." (Merck, 2006) The Merck manual suggests that these discussions should be held in a quiet, private place, and should present the child with factual information. The child's feelings, fears, and anxieties should be validated with phrases or sentiments that suggest, "I understand." Finally, Merck asserts that the discussion should always emphasize that the child is loved and will be supported.

The PBS "Talking with Kids" website outlines a simple process for addressing a difficult topic with young children. First and foremost one should establish what the child already knows, to clarify any misunderstandings that might be present. Second, they suggest keeping your answers short, while maintaining responses that are appropriate for the child's age. (PBS, 2005) In the case of the diabetic or chronically ill child, this step may not be as beneficial to the child as intended. Children's books dealing with diabetes require us to talk to them about the consequences of not properly managing their disease. We should explain to them at a young age what will happen if they don't take care of their disease. Good habits are hard to form and bad habits are harder to break. The younger they are when they start practicing good diabetic habits of control, the less likely they are to experience these frightening long-term complications. Finally, the PBS website suggests asking more questions of the child to establish their real fears and concerns, and then suggests talking about the topic again and again. If there were more useful children's picture books about diabetes, which addressed all of these steps and the special

needs of juvenile diabetics, the children could read them over and over again, whenever they needed reinforcement and support.

In their book, *Tough Questions*, Celia and Shelia Kitzinger offer advice on how to talk to children about difficult topics, such as sex, death, religion and politics. While they do not explicitly address the issue of disease and chronic illness, they give advice on how to carefully frame a conversation when speaking with a young child. They suggest that the adult can help the child through the difficult situations and conversations by “talking as simply and honestly as [they] can, and by being willing to discuss [their] own feelings and ideas... as well as listening to the child’s.” (Kitzinger, 203) According to the Kitzingers, if we try to protect the child from the truths or realities of his or her circumstance, in this case the diagnosis of a chronic disease, we ultimately exclude them from significant social experiences. However, if we give them a chance to actively participate in their time of crisis they will learn important values, such as how much people love each other and the skills needed to cope with suffering and pain.

In her book, *Talking with Children about Loss*, Maria Trozzi implements a system for helping the child deal with the feelings surrounding a traumatic or life changing event, which she calls the ‘Good Grief Program.’ She is of the opinion that helping children confront tragedy openly amounts to a therapeutic experience. By giving them an open forum in which to share the thoughts, feelings, and fears of the adults around them, it allows them to mimic the coping mechanisms that most adults use when faced with tragedy. If one ignores the inner turmoil a child faces when diagnosed with a chronic disease, or if we deny them an opportunity to speak about their feelings, their psychological development can be greatly and irreversibly hindered. Trozzi, like the other authors cited above, suggests that open honesty is the best way to communicate the harsh realities of a difficult topic to children.

The Kids Health website outlines how to talk to children explicitly about diabetes. They too assert the need to keep the conversation at a level that is appropriate for the child’s age. The site also emphasizes the fundamental importance of telling the child the truth about their disease, as well as answering all the questions the child might ask. As suggested throughout this project, and paralleled by this website, it is important to make sure the child understands the disease is

not going away but that the child is also not responsible for his/her diagnosis. The child needs to be reassured that his/her feelings are completely understandable. When talking to children with diabetes it is important to give them all of the difficult and harsh facts about their disease, while at the same time maintaining a positive attitude about treatment. Diabetic children need to understand that they are not alone, so a sense of “togetherness” is also important. Stronger materials about this difficult topic are more than desirable, they are vital to the proper psychological, emotional, mental, and social development of the child. The expansion and improvement of this lacking genre could provide these children with a constant source of recognition and comfort as well as with positive reinforcement and tools to help them better care for themselves all the days of their diabetic lives.

Chapter 8

Children's Literature and Diabetes

The genre of children's literature, and particularly picture books, is probably the most effective, necessary, and powerful tool for socializing and educating our children at a young age. Picture books targeted explicitly at children are unique and different from other forms of literature because of the illustrations they contain, illustrations which can "enrich, extend, and expand young readers' background of experiences, their literary and aesthetic interests, tastes, and preferences by providing a variety of sensory images and vicarious experiences, settings, and themes" (Cianciolo, 3). An association with and an understanding of literary characters is one of the first experiences children have with attempting to make sense of what it means to be human in our society. Considering this, picture books are most often a child's earliest and most influential introduction to popular culture, fine art, and the world around them.

According to Arizpe and Styles, a picture book is "a text, illustrations, total design; an item of manufacture and a commercial product; a social, cultural, historical document; and foremost an experience for a child." (Styles, 19) While the literary characters and their stories are important components of children's literature, and more explicitly picture books, the illustrations are equally influential and effective, because the major task of the combined text and visual images in picture books is to communicate information and meaning. (Nodelman, ix) In other words, picture books are the primary, influential literature of childhood, which convey cultural, social, and historical messages in a means that is easily accessible to young readers. Nodelman, however, extends the definition a little further by arguing that "picture books are a significant means by which we integrate young children into the ideology of our culture."

The history of children's literature, according to Sylvia and Kenneth Marantz, depicts an evolution from books which were designed "to train the moral faculties, to produce the proper behavior needed in adult society," to those toward the end of the nineteenth century, "that began to understand the value of esthetic joy for youngsters." (Marantz, xii) It is important to understand that in a time when young children were considered extra hands for chores within and

around the household, there was no need for books targeted at their special requirements and development. Overtime, as children were separated from the adult working world, that need began to change as well.

To conclude this study of children's literature and its treatment of diabetes it is necessary to offer a critique of the strengths and weaknesses of the few materials available to children living with diabetes. Children's books written specifically for children living with diabetes can be divided into two main categories: informational picture books and fictional picture books. For the purposes of my project I will be focusing solely on the fictional picture books about diabetes, but I will say a few words in regards to the informational picture books.

Informational picture books can in their own ways be very beneficial to the child. However, they function on an unbalanced scale of strengths and weaknesses. They serve as strong reference tools because they provide encyclopedic information in a language and manner children can understand. They offer pictures (photographic, not illustrated) to enhance the information they are providing in the text. Their main weakness lies simply in the fact that they communicate most of their pertinent information verbally; through the text. A particularly young child, who is unable to read, cannot peruse the photographic pictures and understand what the book is saying. Additionally, the young child is dependent on an adult to read the text to them; he or she cannot find private consolation or refuge in a book of this nature. Finally, considering the very nature of informational picture books, they do not offer emotional support or a place of recognition for the child. They are simply informational.

The fictional picture books about diabetes are inherently more beneficial to the diabetic child. They have their strengths and weaknesses as most living texts do, but compared to the informational picture books, they just do a better job of meeting all the needs of the chronically ill child. Before I begin my examinations of the texts, it should be said that there are several fictional novels for young adults covering the topic of diabetes. They do not fall into the category of picture books so I will not be evaluating their educational and emotional qualities. I

believe that we need to begin educating the diabetic child before he or she reaches adolescence, thus these novels fall outside the scope of this project.

As mentioned earlier, the concept for the project first stemmed from my discovery that there was very little offered in the way of books for children about diabetes. It is not simply books about diabetes that are missing, but books in general that deal with difficult topics for children. I searched the depths of many libraries and online bookstores, only to find a few titles that fell into this important genre and were pertinent to my evaluation.

In the book, *Bo, the Puppy with Diabetes*, the author Norma Flaherty tells the story of life with diabetes through the experiences of a puppy. The book is like a mini-novel, rather than a picture book, but there are illustrations on every other page. The book is supposedly written for children ages 2-5, however, the text is poorly written and is full of highly advanced and inappropriate words. For young audiences this book would not be practical. It has too many words for the young reader and the wrong kind of words for the child that is old enough to read. The young child would be confused by the wording and an older child would be put off by the condescending attitude of the narrator. It does not offer information in a responsible or effective manner, with regards to the age and mental capacities of its intended audience. The illustrations do not depict Bo, the diabetic puppy, engaging in the daily regimens of diabetic human children. The illustrations that are present are inexpressive and poorly done; they do not offer the diabetic reader a “place of recognition.” On the whole, the book would not serve as an effective educational tool because it does not offer any actual information about everyday life for diabetic children. Nor could it serve as a source of emotional support because it espouses an overwhelming sense of negativity about life with diabetes and the diabetic child simply cannot relate to the character of Bo.

In her book, *Even Little Kids Get Diabetes*, Nadine Bernard Westcott uses a young female character to describe life with diabetes. From the perspective of the diabetic child, Westcott is honest and definitely addresses most of the issues surrounding the psyche of the

diabetic child, such as the annoyance of the daily routine, the effect on her family, the “unfairness” when it comes to what she can and cannot eat. She describes the stay in the hospital and the inability of the little girl to eat cake at a birthday party, all factual realities of the diabetic child. However, she is vague and brief in her presentation of life with diabetes. There is no description of how diabetes works in the body or what may have caused the onset of the disease. There is an overall tone of negativity that contrasts greatly with the rather vivid and lively illustrations. The book is written in an age appropriate tone and does cover the symptoms of diabetes and its treatment. The main strength of the book is that it is one of the few books actually available for children with diabetes. However, it falls short of being an adequate resource for young diabetic children. In other words, something is better than nothing, but it does not mean that “something” is responsibly addressing the issues.

As stated previously, most books about diabetes for children are targeted at older audiences. For example there is the diabetic character, Stacy, in the famous *Baby Sitters Club* series. Stacy deals with many issues regarding diabetes but it is blended with other aspects of being a teenager, such as boys, babysitting, school, and friends. Furthermore, Stacy only appears in certain volumes, and infrequently do those issues address her diabetes. On the whole Stacy’s experiences with diabetes are simplified and inaccurate. She is not believable as a character; she is not someone with whom a diabetic adolescent could actually relate. Moreover she represents diabetes for the diabetic teenage girl, completely neglecting the needs of the diabetic male. In all the research for this project, I was not able to unearth a teenage male diabetic character.

However, the book *Sugar Was My Best Food*, tells the story of an 11 year boy. It chronicles his struggles with diabetes from before his diagnosis. It is a beautifully accurate description of life with diabetes, the hard regimes, the physical ailments, and the emotional ups and downs. Yet, it is a short novel for preteens and has only 10 illustrations. These particular books do not benefit the diabetic child (preschool or school-aged) because they are not written in an age-appropriate language for younger children nor do they provide the necessary visual components of picture books. The obvious purpose of the visual elements in picture books is to

convey meaning in a manner that is more accessible to children and a larger audience. The usefulness of picture books for children needs to be combined with the pertinent information for diabetic children in order to create, amplify, and establish the domain of children's books written explicitly for diabetic children.

Chapter 9

My Story: *I Have Diabetes...*

The story I have written for children living with diabetes is the heart and soul of this project. I believe that it responsibly and fairly presents the intended information about diabetes to the child, in a way the child can emotionally and mentally comprehend and process. I believe that it offers children living with diabetes a “formal place of recognition in their plight” as well as instilling a strong understanding of their new responsibilities and the effects of their disease on their future health.

When critiquing the other books for children about diabetes, I judged them based on the following criteria: is the story an accurate description of life with diabetes? Is the information offered within the story provided in a responsible and effective manner, with regards to the age and mental capacities of the intended reader? Does the story offer, through both language and overall presentation, a place of understanding and comfort that will benefit the child?

My story is an accurate description of life with diabetes because I have been diabetic for 21 years and I wrote the story based on my own experiences and understanding of my disease. My story is intended for the young diabetic child; the type of child that would engage in a picture book. Thus I feel the basic information, regarding the physiology, psychology, and social effects of the disease, is presented in a manner that a young child can comprehend and process. These explanations of the complicated faculties of diabetes can be seen in figures 4, 6, and 8. I alternate between informational panels and the “I have diabetes” panels with the intention of offering the child beneficial, educational information about their disease and then an opportunity to personalize that information.

Furthermore, I alternate between biological descriptions of the disease and emotional descriptions. Children with diabetes often deal with conflicting feelings about their disease including anger, frustration, fear, and depression. These emotional components of the disease are present in my story and can be seen in figures 12, 13, 14, 16, and 18. I want the audience to

grasp that the physical and psychological aspects of diabetes are not separate qualities of diabetes but are actually uniquely connected concepts. I believe that books of this nature, especially designed to meet the many varying needs of the diabetic child, and the chronically ill child, should convey the realities of the disease but should do so in a positive manner. These books should not frighten the child but rather should offer a sense of hope and comfort. I have tried to reflect positive, hopeful sentiments about life with diabetes in figures 18, 19, and 20.

Additionally it is important for diabetic children to understand that they are not alone in this struggle. The “I have diabetes” panels feature children from all races, living in different environments, participating in different activities. This was done with the hopes of creating a character each child can relate to as well as establishing a sense that diabetes can happen to anyone. This important concept of diversity and “not being alone” can be seen in figures 3, 5, 7, 8, 11, 15, 17, and 20. I feel that the diabetic child could find comfort in this story. It could serve both as a reference tool and a place of consolation, of which the child could come back to, again and again, whenever they needed.

The ultimate objective of this project and my story is to form a connection between the art of creating children’s books and the prospect of making life better for these special needs children. By advocating for the importance of educating diabetic children about their disease, through the use of children’s picture books, I hope to ultimately improve the process of education through communication. Creative writing is after all a subset of communication. The more we talk about this disease with children, the more we make that information accessible to their young and fragile minds, the better chance we stand in combating the long term complications of diabetes and improving the quality of life for the chronically ill child.

Figure 1

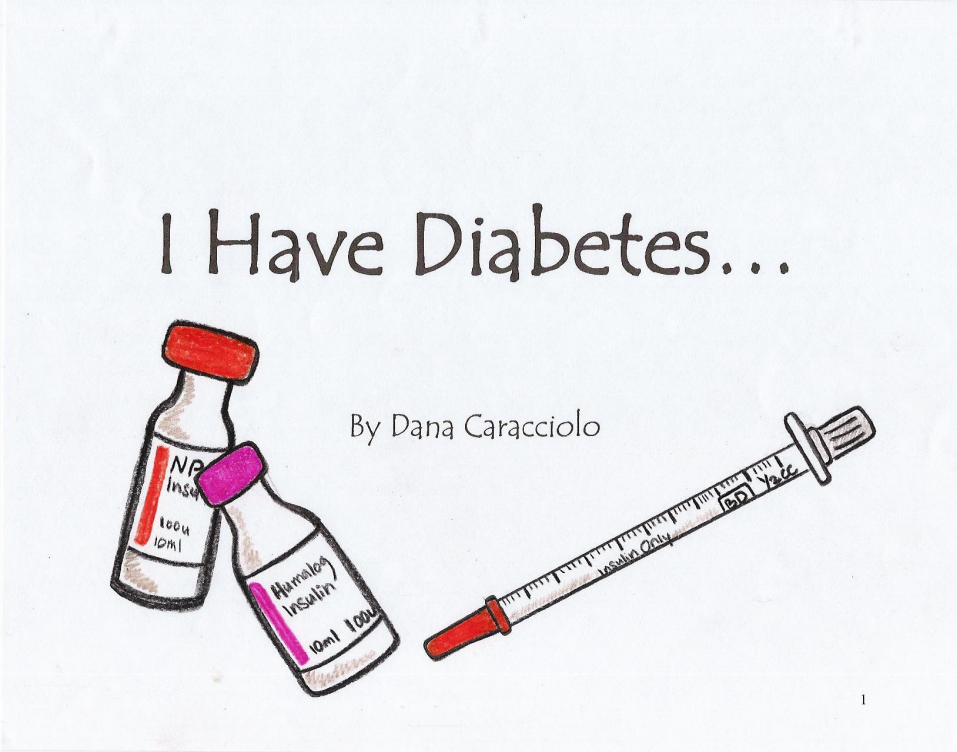


Figure 2

I dedicate this story to my beautifully supportive,
Diabetic family at Camp Glyndon.



Camp Glyndon @ Lions Camp Merrick Staff, 2006

Figure 3



Figure 4

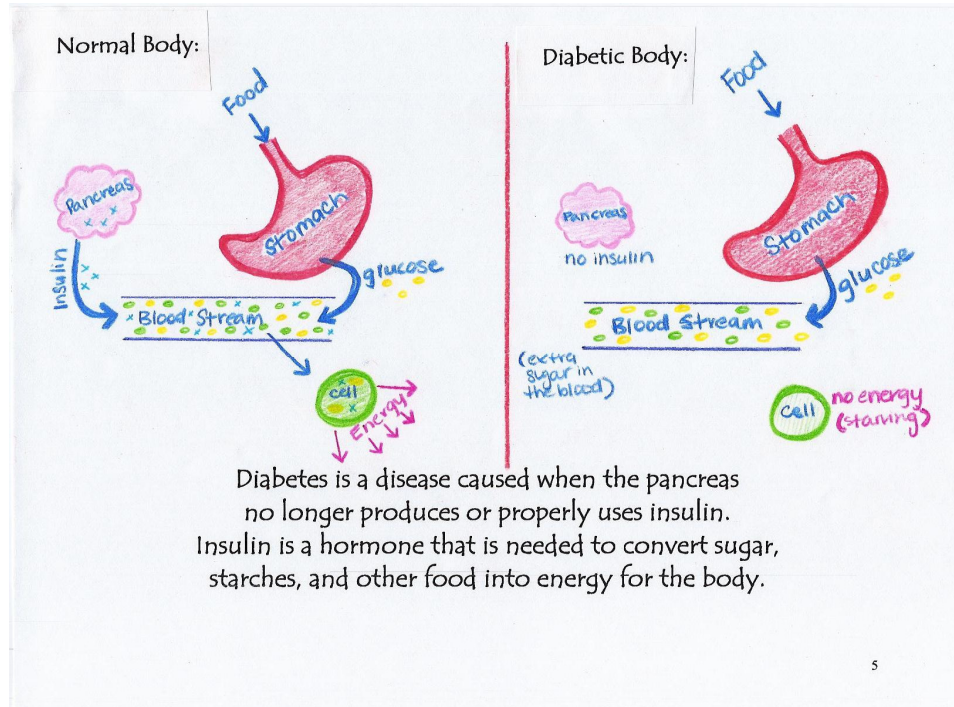


Figure 5



Figure 6

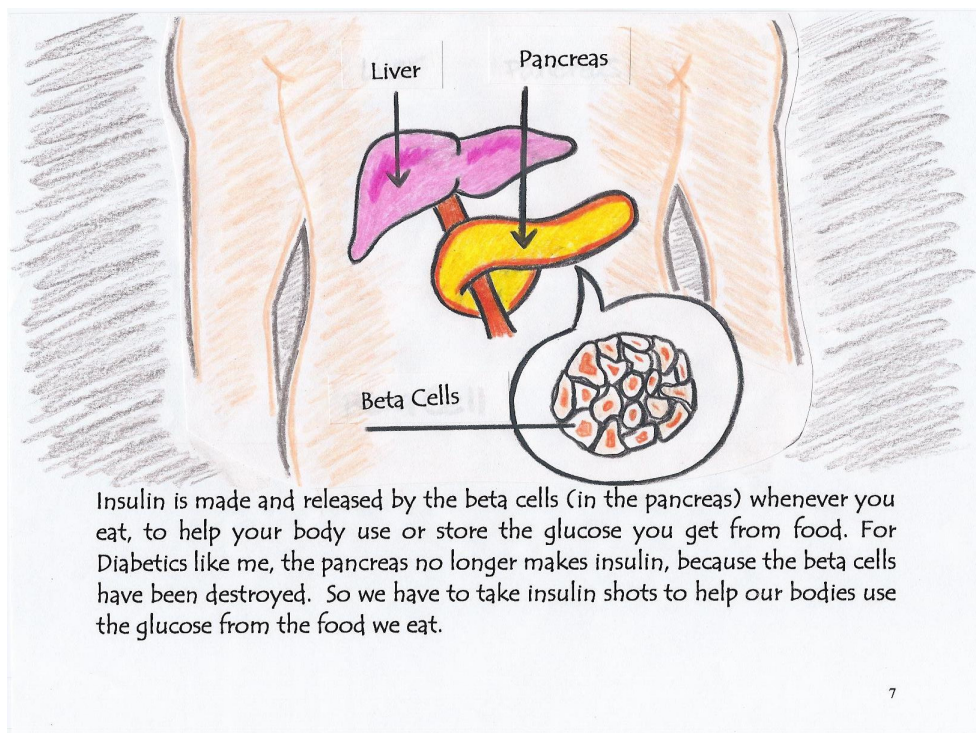


Figure 7



Figure 8

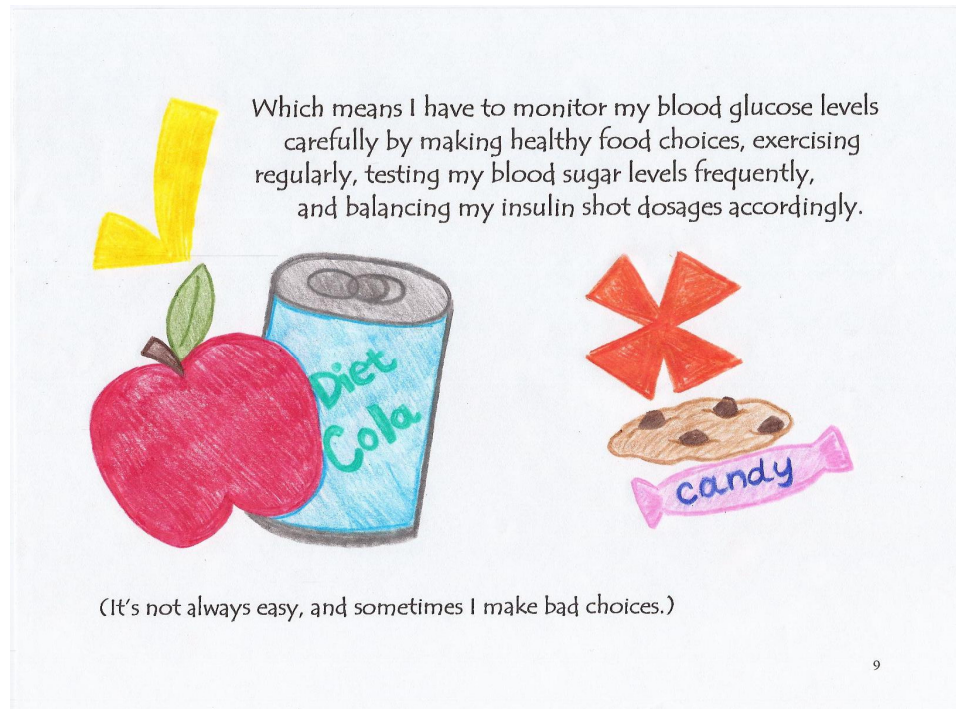


Figure 9



Figure 10



Figure 11



Figure 12

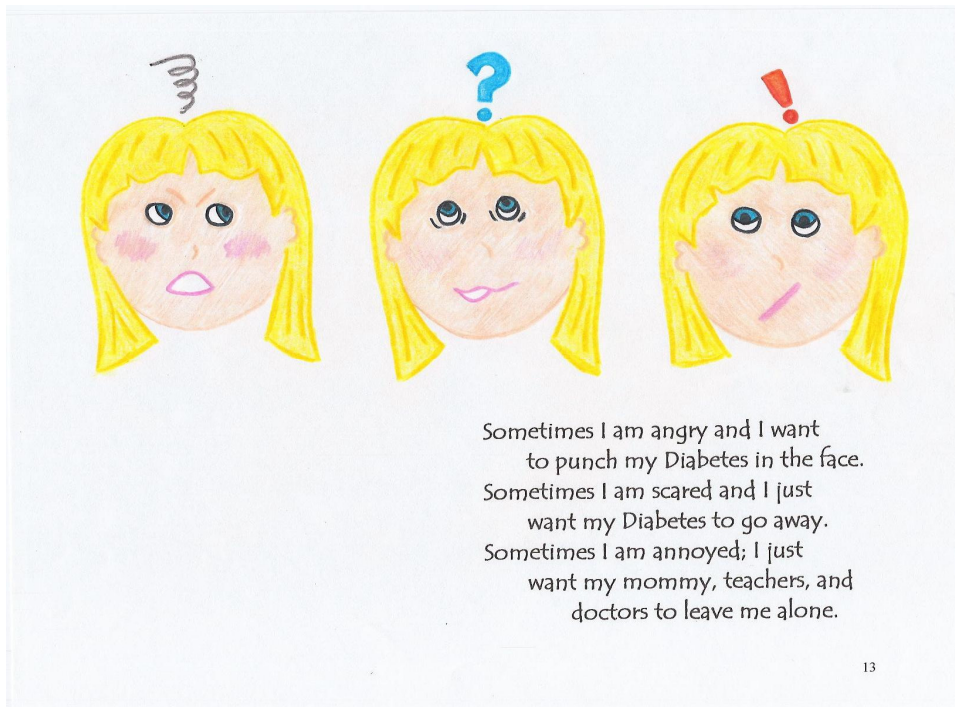


Figure 13

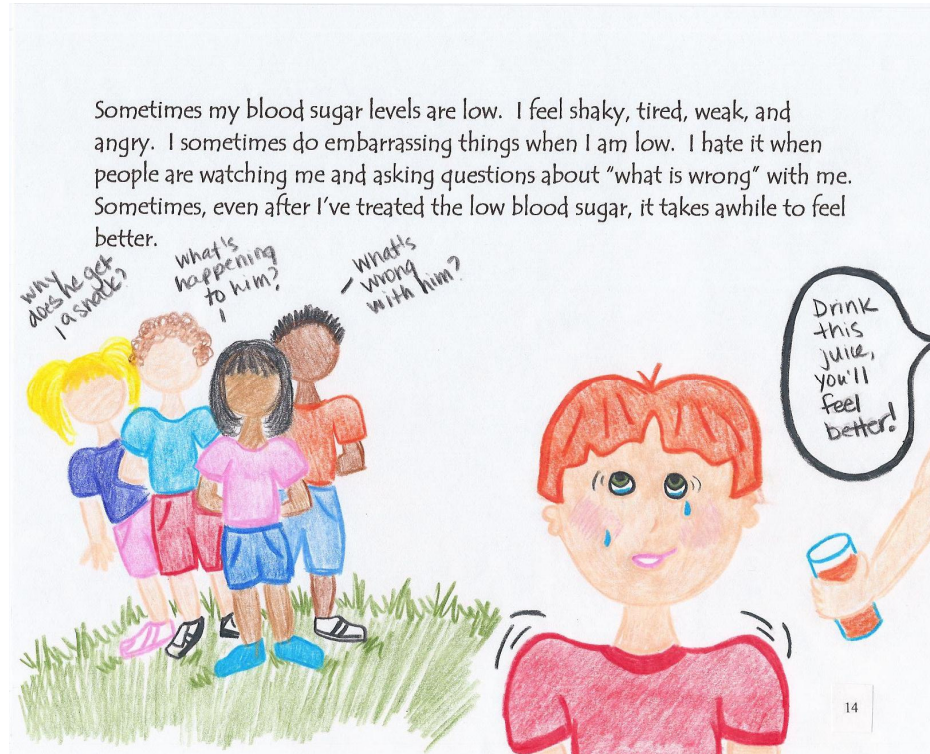


Figure 14

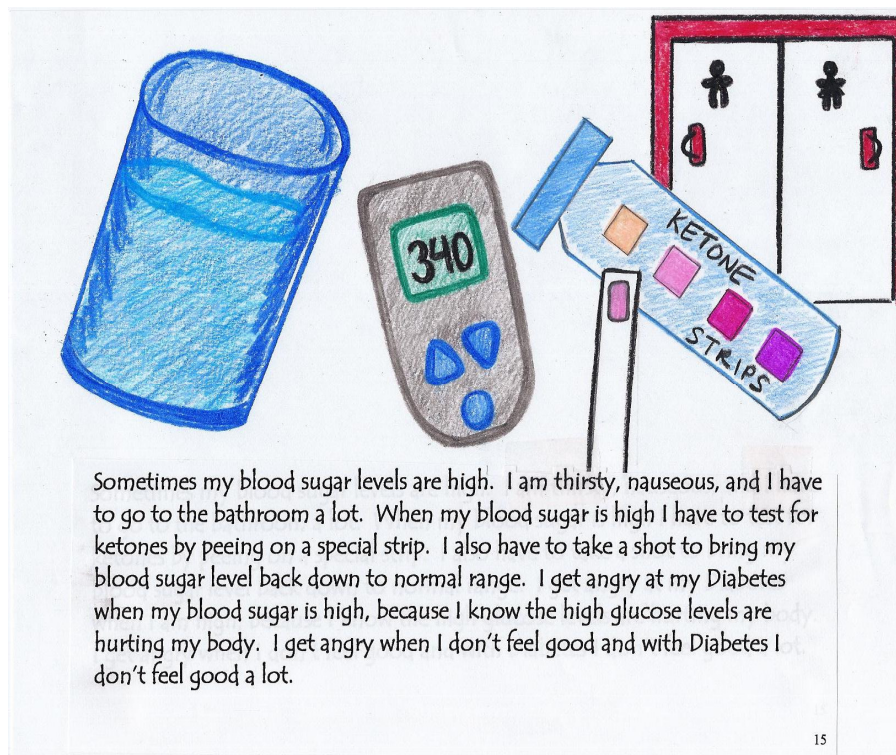


Figure 15



Figure 16

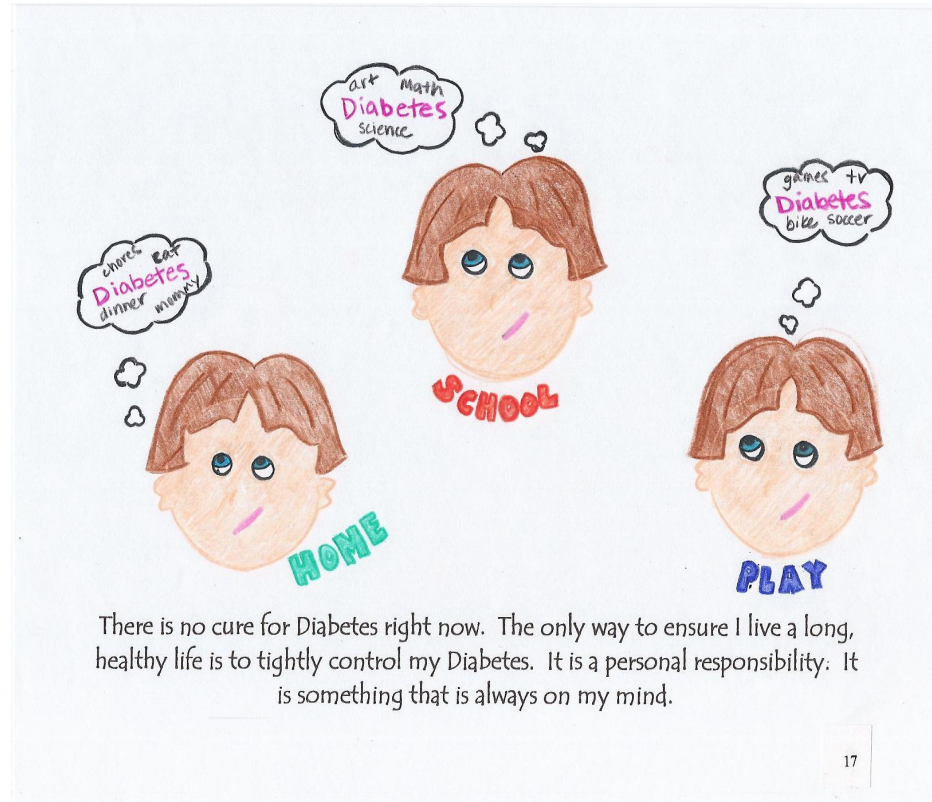


Figure 17



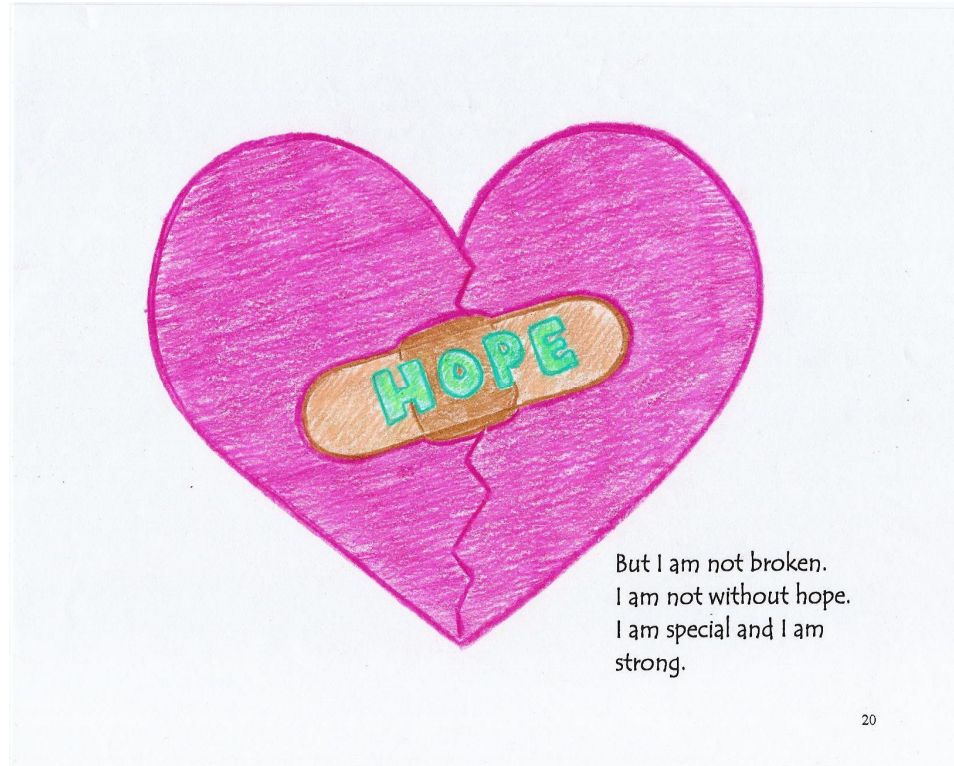
Figure 18

And sometimes I feel sad because I know I am different from most of my friends. It is hard to always say no to sweets and to take several shots a day, everyday. Sometimes I worry about the future and the long term complications inflicted on my body by the effects of Diabetes.



But sometimes, being Diabetic isn't so bad. I know a lot more about how my body works than most of my friends. I get to try out all kinds of new advances for Diabetics, like insulin pumps. I also get to go to great places like Diabetes camp and meet other awesome kids just like me.

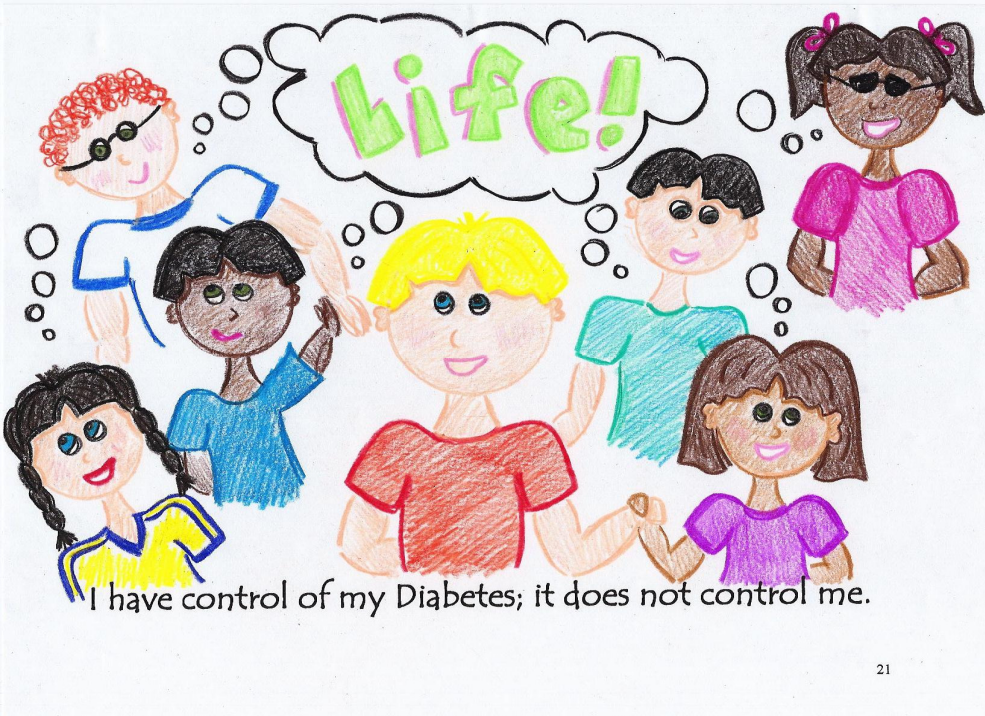
Figure 19



But I am not broken.
I am not without hope.
I am special and I am
strong.

20

Figure 20



Chapter 10

Conclusion

When we examine the demanding physical restrictions of diabetes on the daily life of the diagnosed individual, it is easy to understand both the emotional and psychological implications of this chronic disease for the young child. Early and middle childhood is when children naturally develop a sense of independence, initiative, and their sense of self. Diabetes is such a restricting disease that it threatens to disrupt the proper and positive development of these facets of the human psyche. Thus, early childhood is an optimal time to teach affected children about the realities, risks, and facts of diabetes. When we further explore and examine the importance of children's literature as a tool for educating and socializing our children in the early stages of their mental and emotional development, it is even easier to understand why books about this particular disease are so necessary for their benefit. As stated earlier, Perry Nodelman defines picture books directed at children as "the primary, influential literature of childhood, which conveys cultural, social, and historical messages in a means that is easily accessible to young readers." (Nodelman, ix) With this concept of children's literature, it can be concluded that picture books can also facilitate in explaining and outlining for children what is otherwise difficult to convey about the harsh realities of the world around them, that our children are coping with every day. If we find a way to develop a genre of children's literature that responsibly articulates and communicates information about the difficult topic of diabetes to children, while also tapping into their imaginative and innocent avenues of thought, then we can hopefully teach them the tools necessary to live long and healthy lives as diabetics. Diabetes is the fifth deadliest disease in American and it is attacking our children at a very young age. The statistics available about both type 1 and type 2 diabetes are staggering and we as a society need to accept the realities of this chronic and often deadly disease. We need to find a way to talk to our children about what can happen in their future if they do not take control of their disease, and we need to do it now while they are still young enough to formulate healthy habits for life.

I would like to conclude this analysis of children's literature and diabetes with a few words about my motivations for this project. Until the time I first left for college I was a pretty miserable diabetic adolescent. I hated the rigors and responsibilities this disease required of me; I hated being different from my friends. I hated never feeling good, either from a high or low blood sugar level, or the way my body was scarred because of the high rate of skin infection common to diabetics. I hated every day and often found myself battling depression.

Midway through college I stumbled upon Victor Frankl's, *Man's Search for Meaning* and was deeply moved by his concept of finding meaning through suffering. According to Frankl, when we give our suffering a meaning, a purpose, it ceases to be suffering. I began to think about my life with diabetes in a completely new way. I thought about how my experience with diabetes had helped motivate my father to take better care of his diabetes, perhaps extending the length and quality of his life. I thought about all the work I had done for the diabetes summer camp and my aspirations to do more. As Frankl would say, I began to "change my attitude towards my unalterable fate." I will never know why I was diagnosed with diabetes, and not my siblings. I will never fully understand or comprehend God's plans for my life. But I believe strongly that I am supposed to do great things with my experience with diabetes. I have served as a counselor at the diabetes camp for 6 years. I have been program director for the last two years. It is a very profound and deep satisfaction to hear a young camper excitedly talking about what they learned at camp, all the new friends they have made, and how camp has changed their lives. Even if I did not continue to learn or grow from my experiences at the camp, I would continue to devote my entire self to the program, just to ensure those other diabetic children could have the same life-changing experiences I had. I want to give back to the diabetic community that has sustained me for my entire memorable life. I want to do more with this disease than wallow in the memory of things lost or things never known. According to Victor Frankl "unique opportunity lies in the ways which one bears his burden." I see my work through the camp, and my goals for the expansion of this special genre of children's literature, as my opportunity to overcome my personal suffering and improve the lives and futures of diabetic

children. God has blessed me with many talents and skills, and perhaps I was meant to get diabetes, to be shaped and molded the way I was, so that I could change the face of diabetes.

As diabetics we live everyday of our lives in hope that someday there will be a cure. We think about it, pray for it, demand it. But until that day comes, responsible education and the formulation of good self-care habits at a young age is the only way we are going to successfully combat this terrible disease. Children's literature is an underdeveloped component of the education process. It has the vast potential to provide empowering information and comfort to young diabetic children; to enable them to take control of an uncontrollable situation.

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