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## The Experiences of Families Raising Children with Type 1 Diabetes Mellitus: A Qualitative Investigation

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The Experiences of Parents Raising Children

with Type 1 Diabetes Mellitus:

A Qualitative Investigation

Carol A. Loucks

A thesis submitted to the faculty of  
Brigham Young University  
in partial fulfillment of the requirements for the degree of

Master of Science

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Barbara Mandelco  
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College of Nursing

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## Abstract

Title: The Experiences of Parents Raising Children  
with Type 1 Diabetes Mellitus:  
A Qualitative Investigation

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Type 1 diabetes mellitus (T1DM), a common, chronic disease, affects the patient as well as the family. It requires daily vigilance in blood sugar monitoring, dietary management and insulin administration. Research has examined the impact of T1DM on family adaptation and relationships. However, few current data describes parents' perceptions of challenges. The purpose of this study was to identify challenges and impact on the family perceived by parents raising children with T1DM. Using a qualitative descriptive design, 21 parents raising children with T1DM participated in audio-recorded focus groups. At the time of the interviews the children ranged in age from 2 to 17 years, with duration of diagnosis ranging from six months to 10 years. Seven major themes were identified, including issues regarding (a) children's behavior and development, (b) physical management of diabetes, (c) parenting challenges, (d) siblings and extended family, (e) friends and community, (f) school, and (g) health care system and diabetes organizations. Within each theme, numerous sub-themes were identified. The identification of challenges and unmet needs of families raising children with T1DM suggests health care and schools systems improve the services and support provided. Mental health issues should be managed. A follow-up plan should be in place at the time of hospital discharge, to include provider initiated contact as well as contact by another parent raising a child with T1DM.

Keywords: type 1 diabetes mellitus, children, parent, perceptions

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# **The Experiences of Parents Raising Children with Type 1 Diabetes Mellitus:**

## **A Qualitative Investigation**

The diagnosis of a chronic illness in a child affects not only the patient, but the child's family, as well (Knafl, Darney, Gallo, & Angst, 2010; Kratz, Uding, Trahms, Villareal, & Kiekhefer, 2009; Waite-Jones, & Madill, 2008). This situation has been researched extensively in families raising children with various chronic diseases. Findings indicate parents cope by changing their expectations, becoming knowledgeable about the disease, dealing with social isolation, handling discipline, working with professionals, connecting with peers, and caring for personal needs (Kratz et al. 2009). Parents also struggle with self-doubt, living a difficult life, parenting competence, self confidence and dealing with the disease over time (Knafl et al. 2010), in addition to decreased quality of life, increased worrying, decreased family activities, and employment difficulties (Goldbeck, 2006).

Type 1 diabetes mellitus (T1DM) is a chronic disease usually diagnosed in childhood with measurable impact on the family. Some reported responses of parents of children with T1DM include fear, grief, concern about complications, and the sense of experiencing a loss and of being different (Lowe, Gregory, & Lyne, 2005; Marshall, Carter, Rose, & Brotherton, 2009). Parents of adolescents have the additional challenge of relinquishing their responsibilities and encouraging their teenagers to assume more responsibility for managing their diabetes (Carroll & Marrero, 2006).

Although research has explored the experiences of children with diabetes and their families, there is little information asking about the challenges parents experience while raising a child with T1DM, the impact the diagnosis has on their family, situations they perceive as being difficult, and information needed to help them accomplish their roles as

parents and caregivers. The purpose of this study was to ascertain specific challenges, the impact T1DM has on the family, and difficult social situations perceived by parents of children with T1DM and then identify the support they need in raising a child with T1DM. Focus groups were chosen to allow parents to verbalize feelings and experiences, thereby avoiding limits created by surveys or questionnaires. Data collected from this study will be utilized to design interventions addressing challenges identified by the parents.

### **Background**

Diabetes mellitus is one of the most common childhood chronic diseases, affecting approximately 150,000 children under the age of 20 in the United States. The annual incidence of new diagnoses of T1DM is more than 13,000 (Centers for Disease Control and Prevention[CDC], 2010a).

Diabetes mellitus is characterized by hyperglycemia, stemming from defects in insulin production, insulin activity or both. It is a metabolic disorder with several subtypes. The two most prevalent are type 2, which includes 90-95% of patients, and type 1, which includes 5-10% of patients. (Maitra, 2010). In the United States type 1 is the most common form of diabetes in children, although data over the last two decades indicate an increase in the incidence of type 2 diabetes in those less than 20 years old [CDC, 2010b].

T1DM is an autoimmune disorder causing destruction of beta cells in the pancreas, resulting in an absolute insulin deficiency. Formerly referred to as juvenile onset or insulin dependent diabetes, those monikers have been abandoned for two primary reasons. First, although the onset of type 1 most commonly occurs in childhood or adolescence, it can develop at any age. Second, while all patients with T1DM are dependent on exogenous insulin, those with type 2 diabetes may also require insulin injections. Prior to the

development of insulin injections in the early 1920's, a 10-year-old child with a diagnosis of diabetes had an average survival time of 1.3 years (dLife.com).

Insulin is a hormone produced by beta cells of the pancreas. It facilitates glucose uptake by skeletal and cardiac muscle cells as well as the liver, allowing for glucose-mediated metabolism. In the absence of insulin, glucose remains in the blood, resulting in hyperglycemia. Hyperglycemia may exceed the kidney's reabsorption capacity, causing glucose to be excreted in the urine, which increases urine osmolality, resulting in polyuria. Dehydration caused by the polyuria, prompts polydipsia. These pathophysiologic changes explain the most common presenting symptoms seen in a child with T1DM. (Inzucchi & Sherwin, 2009). The reduced cellular availability of glucose leads to an outpouring of ketone bodies from the liver needed for metabolism. The acidic quality of ketone bodies can markedly reduce blood pH. If left unchecked, life-threatening ketoacidosis will ensue.

The diagnosis of diabetes is made by a fasting blood glucose level greater than 125 mg/dL or a random blood glucose level greater than 199 mg/dL, although children with T1DM often have a severely elevated blood sugar at diagnosis (Inzucchi & Sherwin, 2009). When a child is diagnosed with T1DM in the United States, he or she is immediately admitted to a hospital to lower blood sugar levels, manage complications, and educate the family about diabetes and its management.

Treatment of T1DM involves several lifestyle changes. It becomes necessary to check blood sugar levels multiple times a day and sometimes during the night. In addition, insulin is needed prior to eating any carbohydrates. An alternative to daily insulin injections is a continuous insulin infusion pump, which delivers a preset amount of insulin

as a steady infusion or as insulin boluses when carbohydrates are consumed (Strowig & Raskin, 2003).

Type 1 diabetes is associated with both short and long-term complications. The most serious and common short-term complication is hypoglycemia, which can result from too much insulin, inadequately compensated physical activity, insufficient carbohydrate intake, or a combination of these. It may be manifested by tremor, palpitations, agitation, weakness, confusion, and seizures and can cause irreversible brain damage and death. Another short-term complication is extreme hyperglycemia, which leads to diabetic ketoacidosis, diuresis, vomiting, hyperventilation, coma, or death (Inzucchi & Sherwin, 2009).

Long-term complications include microvascular and macrovascular disease, leading to retinopathy and blindness, renal disease, cardiovascular disease, immune suppression, neuropathy, autonomic nervous system dysfunction, and peripheral arterial disease. In fact, diabetes is the leading cause of adult onset blindness, end-stage renal failure, and non-traumatic lower extremity amputation. In males there is an increased risk for erectile dysfunction. In females there is an increased risk for spontaneous abortions, fetal congenital anomalies, large for gestational age babies, polyhydramnios, and cesarean section (Cunningham et al., 2010). There is a strong negative correlation between glycemic control and long-term complications. Therefore, to minimize the risks of these complications, blood sugar needs to be intensively controlled (The Diabetes Control and Complications Trial Research Group, 1993).

The potentially life-altering threat of diabetes and its attendant treatment demands lead to psychological and behavior adaptations of the family. Consequently parents have

described feelings of stress, fear, grief, and sorrow regarding their children's diagnosis with T1DM (Bowes, Lowes, Warner & Gregory, 2009; Lowes et al., 2005; Marshall et al. 2009). Mothers reported "constant vigilance" in managing their child's diabetes (Sullivan-Bolyai, Deatrack, Gruppuso, Tamborlane & Grey, 2003). Parental anxiety and depression which impaired disease management ability (Streisand et al., 2008) and frustration, insecurity and a sense of intrusion (Wennick & Hallström, 2007) have been identified in families raising children with T1DM.

The aim of this study was to identify challenges, difficult social situations, and family impact of raising a child with T1DM as well as support needed.

## **Method**

### **Sample**

After obtaining approval from the university's Institutional Review Board, recruiting flyers were placed locally in diabetes clinics, offices of pediatric endocrinologists and the annual American Diabetes Association Expo. Fourteen mothers and seven fathers participated, representing 16 children with diabetes; one couple was raising two children with diabetes. The children ranged in age from 20 months to 17 years (mean 9.08, *SD* 3.78). Time since diagnosis ranged from 6 months to 10 years (mean 4.23, *SD* 2.83). One child, a 16-year-old girl, had an additional diagnosis of Down syndrome. A 13-year-old boy had Asperger's syndrome and Attention Deficit Hyperactivity Disorder as comorbidities. Additional demographic data are provided in Table 1.

Table 1

Demographic data for parents and their children with T1DM

Variable	Number	
Parent gender		
Male	7	
Female	14	
Child gender		
Male	11	
Female	5	
Child ethnicity		
Caucasian	16	
Family household income		
<\$50,000	3 (20%)	
	M	SD
Children's age in years at diagnosis	4.8	2.8
Children's age in years at the interview	9.08	3.78
Duration of diagnosis	4.23	2.83
Number of children in the household	3.67	1.29
Years of education of parents in families		
Father	16.25	2.50
Mother	14.67	2.06
Ages of parents in families		
Father	39.67	8.85
Mother	37.33	9.35

## **Procedures and Measures**

Parents were invited to participate in focus groups held in the fall of 2009. The study participants received a \$10 gift certificate. Each study participant signed an informed consent.

The interviews were guided by seven questions, designed to ascertain characteristics of the child with diabetes, identify challenges parents faced related to the diagnosis and offer suggestions for ways of improving support for the child and the family (see Appendix). In addition, demographic information was collected from each participating family.

## **Data Analysis**

The interviews were voice recorded, and hand written fieldnotes were documented. The interviews were transcribed verbatim and recordings destroyed after transcriptions were completed.

In the tradition of phenomenology, or the attempt to define the meaning of lived experiences (Polit & Beck, 2008), as major themes emerged, they were identified and coded by the primary investigator and verified by other members of the research team. Multiple subthemes concurrently emerged, and were grouped under the appropriate major theme. Transcripts were read a second time to confirm initial findings. Themes and subthemes were discussed with members of the research team until consensus was reached.

## **Results**

Seven general themes emerged, and included issues related to (a) children's behavior and development, (b) physical management of diabetes, (c) parenting challenges,

(d) siblings and extended family, (e) friends and the community, (f) school and (g) health care system and diabetes organizations. Within each of these themes, sub-themes were identified. The themes and sub-themes will be discussed below.

### **Children's Behavior and Development**

The comments parents made about their children's behavior regarding diabetes touched upon developmental, physical, behavioral and emotional facets, including (a) the child's age, (b) the child's understanding of the disease, (c) resisting testing blood sugar or dosing insulin, (d) learning to assume responsibility for self-care, (e) emotional instability in relation to blood sugar levels, (f) emotional response to diabetes, (g) hoping others will be diagnosed with diabetes, and (h) the need for the child to meet other children with diabetes.

**Child's age.** The age of the child was identified as an issue by several parents for two reasons. First, parents of children diagnosed at a very young age (ages at diagnosis were 18 months, 28 months and four years) believed it was helpful for the child to be diagnosed when young; it was easier for the child to grow up with diabetes, rather than have to introduce blood sugar testing, insulin injections, and diet modifications on a child with more established eating habits. The parents of the child who was diagnosed at 28 months explained,

A lot of people say, "Oh, it's so hard that he got diabetes at such a young age," but we look at it the opposite way. He's grown up with it. I think that's been our biggest good thing, is that he was so young.

Second, the parents of school age children expressed concern about the potential conflict between the developmental changes associated with adolescence and managing the diabetes. The mother of a 12-year-old son lamented her position between her son and his doctor, who, in her words, said, “‘Well, if you want to kill him, keep doing what you’re doing.’ I’m like, ‘Why are you treating me like this when I am trying to do the best I can with a rebellious child?’”

**Child’s understanding.** Three mothers, of one three-year-old and two eight-year-olds at the time of diagnosis, said the children hadn’t gained an adequate understanding of their disease during initial hospital admission. While they spoke highly of the education provided, they suggested more education be directed toward the child during the hospital stay, including understanding the disease, counting carbohydrates, and the best places to receive shots. One mother of an eight-year-old reported, “When we came home from the hospital he said, ‘Mom, when are you going to stop giving me these shots?’ ... I don’t think the medical personnel let him know this was a life-long thing.”

**Resisting blood sugar testing or insulin dosing.** Parents often reported their children hid or resisted when it was time to test their blood sugar or administer their insulin. The youngest children, those diagnosed at 13, 18 and 28 months, would run and hide, or cry “No, Mommy, no!” The parents of a 27-month-old boy, diagnosed nine months ago, when talking about changing his pump injection site, stated, “He yells, ‘That hurts me, Mama, don’t do it!’”

**Assuming more self-care responsibility.** As the children got older they assumed more responsibility for self-care. However, this transition into becoming more responsible was not without mishaps; in fact, frequently children would forget to test their blood sugar,

make an error in calculating or administering insulin, not want to test their blood sugar in public, or would simply not want to be bothered with self-management activities. The mother of a 10-year-old girl trying to become more independent related an incident that happened while the daughter was at school. In her words,

She called me, "I was really high so I corrected like you told me." I said, "Would you mind going back to your complete history and reading me all the buttons you pushed?" She had added a unit of insulin to her correction. Her correction factor was like 350. So an extra unit and she's corrected to 100 would put her negative 250 [blood sugar level of negative 250 mg/dL].

An example of a 12-year-old boy who didn't want to be bothered is described by his mother, "I honestly think that he just doesn't care. I had to seriously get after him. I hound him, hound him, hound him." She further stated, "He doesn't want to get checked. He doesn't want to give himself a shot. He's so tired. He doesn't want to do his homework. Would you want to poke your finger every single time you had to eat?"

Although some children would forget or not want to be bothered, three parents said that as their children got older they were making an effort to be more responsible and autonomous in managing their diabetes. One father looked at the successes and didn't dwell on the mistakes. As he talked about his eight-year-old son he said,

He's got a pump; he puts in a number. I'd say 80% of the time he's on. The other 20% he knows it, but he doesn't care. Yah, I'm really proud of him for how well he's done and what he's had to deal with.

**Emotional instability in relation to blood sugar changes.** Four parents commented on their children's mood swings and the difficulty determining if the swings

were the result of an abnormal blood sugar or something else. Because of this, when the child has an emotional outburst, the parents' first response was to check the child's blood sugar. This was described by one mother, "When he throws a fit, you always have to test him. Is it because he's two, or is it because he has diabetes?" Another parent lamented:

It's hard for us because you want to get mad at him for doing things 'cause you're a parent, kind of teach him. But then you have to check his blood sugar. Well, if it's blood sugar related how do you correct the behavior?

**Emotional responses to having diabetes.** Parents described their children's emotional responses to having diabetes. Some parents conveyed their children's anger at having diabetes, while others described their children's acceptance and positive attitudes. Seven parents indicated their children often expressed anger or frustration with having diabetes. For example, according to his mother, one 12-year-old boy, diagnosed four years previously, "...goes through times when he's like, 'I hate diabetes! I wish I didn't have diabetes!'" A 10-year-old girl, who has had diabetes for seven years, complained to her mom, "I'm so sick of diabetes."

In contrast, four parents stated their children had maintained positive attitudes toward their disease. The mother of an eight-year-old son, diagnosed for three and a half years, said, "Never once has he ever said, 'I hate this'". Likewise, the mother of an 11-year-old boy, diagnosed at age eight, commented, "I just have to hand it to him. He's made it so easy 'cause he has had a great attitude". The mother of a 10-year-old girl with a seven year history of diabetes boasted of her daughter's good attitude with, " It happened to a good child. 'Cause any of the other children (referring to siblings) would have been a nightmare. She just doesn't mind, you know, just doesn't mind it."

Three parents indicated their children wished others in their social circle had diabetes. The father of an eight-year-old boy said his son was disappointed to learn that his newborn sibling did not have diabetes. According to the father, when the new baby was hypoglycemic shortly after birth, the older brother “was so excited, ‘He’s gonna be diabetic! He’s gonna be diabetic!’” The mother of a 10-year-old girl reported that her daughter “was like, ‘I wish all my friends had diabetes with me so I wasn’t by myself.’” The mother of a nine-year-old boy related, “Right after he started school he told me there was another kid in his class who was diabetic, and (child) was so excited to have a friend. Turns out it was an imaginary friend.”

**Need for the child to meet other children with T1DM.** Similarly, six parents felt strongly their children should meet other children with diabetes. In the words of three different mothers, talking about their child with diabetes attending activities with other children with diabetes, “That’s one thing that’s real nice about the (diabetes) camp because all of these little kids running around all have diabetes and they’re just at ease. They just love it.” “I think that’s a hard thing, ‘I’m the only person that has diabetes.’ You know, she doesn’t understand that there’s other people out there that do.” And, “It makes them not feel alone.” Mothers believed there was value for their children with diabetes to interact with children who also had diabetes. One mother’s assessment of this involvement was,

That’s one of the best things for our son, to be able to see that there are other kids just like him, and they can do normal stuff, just like everybody else can do. That’s been the biggest thing for him.

## **Physical Management of the Diabetes**

Dealing with the physical management of diabetes created challenges in various forms. Sub-themes identified by multiple parents were (a) the importance of maintaining a strict meal and snack schedule, (b) matching insulin dose to carbohydrate intake, (c) the child not recognizing symptoms of hypoglycemia, (d) the need for the child to have a cell phone, (e) controlling blood sugar during illnesses, (f) the cost of diabetes, and (g) issues regarding an insulin pump.

**Importance of maintaining a strict meal and snack schedule.** Those with type 1 diabetes must be vigilant about regular meal and snack times. Various types of insulin have differing times of onset and peak effects. Those who receive insulin injections need to consume carbohydrates in the right quantity and at the right time to prevent their blood sugar from dropping dangerously low. Because of this, meal and snack times are strictly adhered to. This issue was addressed by several parents. The mother of a seven-year-old boy stated, "(Son) eats breakfast, snack, lunch, snack, dinner, snack. You know, like rhythm." According to another mom, "Dinner's usually between five and six; it's not at eight at night. Dinner is the same time every night." One mom indicated the challenge on Thanksgiving, "Thanksgiving dinner is always a five hours wait because we were on NPH (insulin with a delayed onset of action) for a long time."

**Matching insulin dose to carbohydrate intake.** Blood sugar control is easier to achieve when the insulin dose is matched to the carbohydrate intake. Many parents commented on the challenges of aligning the insulin doses with the actual amount of carbohydrates consumed. These challenges stemmed from various factors – learning to estimate the amount of carbohydrates in the food consumed, anticipating the amount of

carbohydrates the child would consume, and the small volume of food consumed by very young children resulting in insulin doses being so small they were difficult to measure.

Determining the amount of carbohydrates in foods is commonly referred to as “carb counting.” This concept is introduced to parents in the hospital upon initial diagnosis. Carb counting can be accomplished by weighing food, reading nutrition labels on food packages or estimating. For these parents the challenge was not in determining the amount of carbohydrates the food contains, but rather in determining how many carbohydrates the child would consume. In addition, many children ate food without their parents’ knowledge. The father of a toddler stated he “tends to try to sneak stuff. If the other kids haven’t finished all theirs, he’s grabbing at their plate. We don’t know what he eats!” The older children sneak food as well. This father’s perception of his son, “He’ll go to sneak food cause he’s an eight-year-old kid and in my opinion that’s just what eight-year-old kids do. They eat when they’re hungry, and forget ...” A ten-year-old girl had been doing the same thing,

She used to steal food all the time. So she came to tell me about it and you feel bad, but I’m like, if you want some food, just come tell me. She’ll say, “You know those ice cream sandwiches you have hidden in the back of the freezer? Well, I took one, but I am going to get help to get help to bolus for it.”

Another mother acknowledged, “We’ve been through the whole sneaking food type thing, too.”

Another issue was some children ate less than parents anticipated, resulting in too much insulin for the amount of carbohydrates consumed. The father of a two-year-old said,

“We dose him for a certain amount, and then he eats half that much. And, so, it’s really hard to, you know, so it’s this up and down game.”

Parents with very young children faced the challenge of administering an appropriately small dose of insulin. According to one mother,

It was hard, really hard, when he was on injections, because he’d take such a small amount of insulin that we couldn’t measure it for snacks, so he either had to eat a full meal, or nothing. And try to tell a twenty-two month old, “Sorry, you either have to eat a whole sandwich or you can’t eat anything!”

Another mother reported, “At 18 months we were almost diluting insulin because his doses were so small we couldn’t even measure them on a needle.”

Administering insulin in restaurants was mentioned by three mothers. They found it difficult to find a place where they felt comfortable giving the child an insulin injection, since the dining area didn’t provide privacy, and restrooms were sometimes so dirty parents were concerned about maintaining sanitary conditions when preparing and administering the insulin.

**Child not recognizing symptoms of hypoglycemia.** Parents of four of the children said their children were not able to recognize symptoms of hypoglycemia. As one mother put it, “I would say the hardest thing when they are young is they don’t really pick up on their lows as much. You don’t send him anywhere, you don’t let him do anything.”

**Need for the child to have a cell phone.** Four children had cell phones because parents felt it was important to have immediate communication with their children regarding their blood sugar and insulin dosing if necessary. One mother described an incident while the child was at school,

He has a cell phone. So in elementary school he could carry it with him everywhere he would go. He would be out on the playground and call me, crying, "Mom! Someone's being mean to me!" I'm like, "Go to the office and get checked." And he would be low. So I was so thankful for that cell phone.

**Controlling blood sugar during illness.** Illness can also make it difficult to maintain an appropriate blood sugar. This was mentioned by several parents. One mother, whose child was hospitalized three times for illnesses making it difficult to control blood sugar, commented, "they are so much more fragile." Another mother noted, "stomach flu is a challenge." The mother of a child who is now on an insulin pump observed, "Sick days were hard that first year. Sick days are easier with the pump."

**Financial cost of diabetes.** The cost of managing diabetes, even with insurance, was an issue identified by four families. The mother of a recently diagnosed child commented, "Cost has been a huge issue, you know, having a hundred plus dollars of medical expenses every month, when we were kinda tight to begin with." Another mother, complaining about the cost of diabetes care, tried to find ways to get prescriptions filled less expensively. She stated, "It's crazy. I have to finagle, and say, 'Okay, I can get this prescription here, this one here, this one here', throughout the months. It's awful, awful." One family reported using needles twice to save money. Another said, "I worry about if something happens to my husband and I, who would inherit this child and her monumental monthly medical bills?"

**Insulin pumps.** The subject of insulin pumps was mentioned by several parents. Parents whose children had pumps said they made diabetes care much better. As indicated earlier, one mother said the pump made sick days much easier to manage. Another mother

observed, “The nice thing about the pump is that it normalizes your food again.” The mother of a ten-year-old girl loved the pump. She proclaimed, “It’s so great. It just gave us all kinds of freedom. It’s given her more freedom from us. Like she can go to parties on her own.” The parents of the youngest children found the pump an excellent solution for administering required small doses of insulin for these children.

There were also negative comments about a pump. Four parents said the pump was expensive. One mother related that her ten-year-old daughter “wants one for Christmas. She keeps saying, ‘I just want a pump’. Maybe I have to get the whole family to pitch in; I don’t know if we can do that alone because it’s a lot of money.” In addition to the expense of a pump, two parents reported having the pump malfunction, and one child developed a reaction to the adhesive securing the needle in place.

## **Parenting Issues**

Parenting issues addressed during the focus groups included (a) feeling overwhelmed with information and responsibility at the time of diagnosis and initial education, (b) feelings of self-doubt and guilt and the inevitability of making mistakes, (c) needing emotional support, (d) trying to strike a balance between glycemic control and allowing the child to be a child, (e) increasing self-confidence, (f) experiencing burnout, (g) fearing the child’s well-being, (h) changing the mother’s employment, and (i) maintaining a positive attitude.

**Feeling overwhelmed with information and responsibility.** A frequent observation was the overwhelming amount of information provided during the initial hospital admission. Descriptions included, “... in this kind of dazed world and you get all

this education”, “overwhelmed by all the information”, and “how am I going to learn all this?”

**Feelings of self-doubt and guilt and making mistakes.** Mistakes and abnormal blood sugars were reported by several parents. One mother confessed, shortly after bringing her child home from the hospital after the diagnosis, that she forgot to test his blood sugar and dose him with his insulin. Another mother talked about a family day trip when she forgot to bring the child’s diabetes supplies. Two parents dosed their children’s insulin incorrectly, one gave the wrong dose; the other gave the wrong type. These situations were often accompanied by feelings of failure and guilt. In fact, just after discharge from the hospital, one mother reported, “He was spiking. I’m going, ‘I don’t know what I did wrong.’” The mother of a two year old boy stated, “I feel like I’m the worst mom ever because I can’t, I can’t keep it under control.” One father observed, “I think that is the biggest underlying issue, is mothers feel guilty if their children spike up. You take it so hard.” Many parents learned to accept their mistakes, doing the best they could and not dwelling on shortfalls. In the words of one mother, “Treat the number and move on. You can’t dwell on it, because it’s going to make you crazy.” Other parents reached the same conclusion as the mother who stated, “It can never be managed perfectly.”

**Needing emotional support.** Grief, feelings of isolation, and the need for emotional support were recognized by eight parents. These feelings are demonstrated in the comments, “It just comes unexpectedly and it throws your life in a big upheaval”, and “With the initial diagnosis there is a grieving period...You kind of have an image of how life will be and it just died.” Two observations reflecting the isolation were “(You) feel like you’re an island sometimes” and “You kind of feel trapped in your little bubble”. The emotional stress

brought on by the diagnosis and the demands of caring for a child with diabetes were reflected in the comments this mother shared, “You see me now after I have been managing diabetes for five years. There were a lot of days where I sat in my living room and cried. I felt like I was not going to be able to do it.” One father pointed out the disparity between information regarding physical management and emotional management with his statement, “You’ve just been diagnosed with a chronic illness, with something that could cause your child to die at any moment. And there’s no social work or you know... support. There’s no emotional, mental health support for it.”

**Maintaining balance between glycemic control and allowing the child to be a child.** Many parents interviewed indicated the need to balance between managing the diabetes and managing the child. These concerns were voiced in two particular ways; two parents were concerned about proper disciplining of a child who required so much attention and whose moods could be affected by blood sugar changes. For example, the mother of an eight-year-old boy voiced the concern, “I don’t mind helping and taking care of him, but I want him to be a trooper. I don’t want him to be a little monster because he’s had everything just handed to him. And so it’s kind of a fine line.”

Another concern involved trying to maintain tight glycemic control while still allowing the child as normal a childhood as possible. Parents made conscious decisions to ignore diet guidelines so their child could be more like other children. One mother stated, “I tell mine they can have the snack at school. I’d rather them come home and be like a normal kid and be a little high than have all those kids get donuts and he didn’t get one.” Another mother echoed, “That’s what we do, too.” One mother admitted she will “feed him whatever he wants, because they’ve already got all this trauma going on with the shots.” One child

was diagnosed a few weeks before Halloween. The diabetes educator addressed dealing with Halloween, suggesting, “Just give him a shot. Let him eat. Let him be a kid. First and foremost, let him be a child.”

**Increasing self-confidence.** Parents indicated their confidence in their ability to manage their children’s diabetes increased over time. One mother referred to “getting in the habit.” The mother of a boy diagnosed for five years reported, “It was definitely a lot harder in the beginning. It’s so much easier now.” Another mother conveyed her increased self-confidence as she described, “We used to be really anal. We carried a backpack with us. We carried the little books that had all the calorie counts and the carbs. We’ve finally figured out pretty much how many carbs things are.” Another mother added, “Well, I think after you do it long enough you just start knowing.”

**Experiencing burnout.** When asked about challenges experienced, one mother responded, “I think burnout is the main thing.” Another mother described her feelings more explicitly when she said, “You know, I’m kind of at the point right now, I’m so glad when she’s gone, you know, to preschool for two hours because I can just sit and stare at her meter and hate her meter, and hate her insulin and hate the whole thing.” These feelings were shared by the father of a 13-year-old boy diagnosed for ten years, “Every so often, you have that day where you’re like I can’t do it anymore.” These feelings may arise, in part, from fatigue. Eight parents mentioned lack of sleep. When one mother spoke of “some sleepless nights”, the other mothers in the focus group agreed with, “yeah”, and “mm hmm, lots of those.”

Another potential source for burnout may be the difficulty these parents have in taking a break. One mother reported that, “the longest that I’ve left him is with my mom for

like an hour, hour and a half. Other than that, with my husband. So, not fun. I've never been away from my kids." According to another mother, "We have one person who will babysit for us. One. And so we go to one Christmas party for his work every year and that's it. You know, we don't date anymore."

One mother expressed a desire for respite. She described, "It would be nice to have some sort of respite care or something like that where you got someone that's trained to deal with this, and have them watch your kids for three or four hours." A mother of an eight-year-old, diagnosed for three and a half years commented, "I think my hardest thing has been up until he was diagnosed me and my husband went somewhere for about a week every single year, and so that's been a hard adjustment."

Not only did some parents find it difficult to get time away from their children, they also quit taking their families on extended outings or vacations, as this mother describes,

The first years we quit traveling. We would not leave more than an hour from (home). We wouldn't go anywhere, overnight, nothing. This summer we finally started going out because we started going to diabetes camp. And talking with one of the counselors up there, and she said the worst thing she remembers is her parents quit doing anything when she got diabetic. And I'm like, "We've done that."

**Fearing the child's well-being.** Although parents expressed feelings of fatigue and burnout, the day-to-day business of their lives is conducted over underlying fears for their children's long-term health and survival. These concerns are demonstrated in the dialogue between two mothers:

#1 My husband was kind of like that, you know, "Oh, he's going to die early", or "he's going to have these conditions."

#2 That's how he (husband) is, too. It's horrible.

#1 No, if you take care of it, you teach him, teach her how to do it well, they're going to live just as healthy of a life as you are.

#2 Well, it's still scary, though. Her first cousin has diabetes. And she has had it since she was four, so 11 years. Eleven years and she's starting to have kidney problems.

Another mother expressed a similar concern about long-term health consequences. As she did so, two other parents expressed the view that, "Well, I think if you keep your A1c down and under control, there shouldn't be any changes in life expectancy. You know the people who did have a different life expectancy weren't able to check their blood every second."

Not only were there concerns about the child developing complications, seven parents acknowledged the possibility their child could die suddenly of the diabetes. One set of parents remembered a time when their son went to a friend's house but hadn't returned when expected. The husband described his wife's response in these words, "She didn't know where he was. She just had panicked. It was this inward concern that is with her every second, just came out, and she said, 'He's probably dead...lying in a gutter somewhere.'" He then added, "With this disease you really wonder if that would happen."

**Changing mothers' employment.** In addition to guilt, fatigue, burnout and fears, several mothers experienced effects related to their employment, including quitting jobs outside the home, changing hours so they worked opposite hours from their husbands, or missing work frequently. As one father put it, "She really can't work outside the home because she is more or less a full-time pancreas." Two mothers took jobs at the children's

schools so they would be better able to monitor their children's blood sugar, insulin and diet.

**Maintaining a positive attitude.** In spite of the many problems faced by the parents, several maintain a positive attitude. They expressed the importance of being positive and of recognizing things could be worse. In the words of one mother, "I'm always trying to be really positive, because this is his life. This is what he's going to deal with forever. And so, you know, I just try to be positive." One mother's positive attitude came from her experience in the hospital when her daughter was diagnosed. As she put it,

We were in the nursery with her and there [were] kids with tubes coming out of their heads. And I just thought, 'Ok, this will be a walk in the park,' you know. So it was a good thing to go up there and see all of the other kids that have so much more to deal with. It makes you grateful that it's just diabetes.

Two mothers used the term "it has been manageable." However, the mother of a girl who has had diabetes for six years, and who also has Down Syndrome, declared, "I think diabetes is a nightmare!"

### **Siblings and Extended Family**

In response to the question about issues regarding siblings or other family members, parents discussed (a) the siblings' responses to the child with diabetes, (b) a healthier lifestyle for the entire family, (c) grandparents' willingness to learn and to help with the care of the child, and (d) understanding and support from other extended family members. Most subthemes included negative and positive comments.

**Siblings' responses to the child with diabetes.** Four parents said the sibling of the child with diabetes had negative experiences because of the diagnosis, yet two parents felt it had been a good experience for siblings. Mothers indicating a negative experience said, "Whenever they [the siblings] complain, I say, 'Do you want to test?'" and "Tell them (the siblings), 'So you want to do all that (diabetes care)?" One mother reiterated a conversation she had with her ten-year-old daughter with diabetes regarding her healthy sister,

I was like, "Do you think your diabetes doesn't affect her (sister)?" She's like, "Why would it? She doesn't have to do anything." She doesn't realize how diabetes makes her the center of the world sometimes, and how that's hard for her sister.

In discussing a positive sibling reaction, one mother, raising an eight-year-old son with diabetes and a 13-year-old without diabetes expressed, "I think it has made him [13-year-old] mature a little bit." Another positive experience was described by a mother who said, "A couple of my kids have done health fair (projects) like how much exercise it takes for (daughter's) blood sugar to come down. So that's been fun."

**Healthier lifestyle for the entire family.** Four parents felt their family is healthier because of the child with diabetes. One mother replied, when asked how diabetes had impacted her family, "We are so much healthier, I'm sure." Another mother added, "I think that's common." One mother attributed this to, "It's like, no more pop. No more, you know, Halloween. It's like, 'Oh yes, we only have to go to two houses.'"

**Grandparents' responses to help with the care of the child.** Grandparents' reactions ranged from rejection of the child, fear of learning diabetes care and of babysitting the child, to grandparents being willing to learn to test blood sugars, dose

insulin and participate in organized diabetes activities. There were several grandmas who wouldn't stop spoiling the grandchildren with treats.

Seven parents reported grandparents were unwilling to learn diabetes management. One mother described her mother-in-law's reaction in these words, "She just refused. She didn't want anything to do with it, just scared her to death." Another couple, in describing the husband's mother said, "My mom basically wants to pretend that he doesn't have diabetes. She essentially refuses, no matter how many times we've tried to get her to test his blood sugar or do anything, she doesn't want to." This same father also described his in-laws' attitudes. "My wife's parents are really, really, really helpful, and her family's really extremely helpful. We went to diabetes camp and they came with us. They know how to dose him. They know how to give him shots." Six other parents had similar reports. Another example is described by one mother who related, "My family has always been really gung-ho supportive. My mom got trained on it, she tested for it. My mom watches them a lot."

**Understanding and support from extended family.** Several parents commented on the lack of understanding other family members have regarding type 1 diabetes. One father stated, "I think the hardest part getting used to it for the family is that there is the misconception that it is all about the sugar. They'd be, 'Oh, it's sugar free so it's fine.'" One extended family has an annual Easter egg hunt. The mother described the event one year, "We go down as a family to this big Easter egg hunt. This one year they didn't use candy, or they didn't use much candy, and it was like, 'oh that's nice, but maybe too far.'"

Two grandmothers have difficulty not giving treats to the grandchild with diabetes. As one son tells it,

I have a mother that wants to, every time the grandkids come, wants to give a bowl of ice cream and cake and cookies without asking. We've tried to talk to her, but she does not realize how important it is. And it puts her in a jam, because she wants to serve the other grandchildren. She doesn't want to isolate our son. She doesn't know what to do.

### **Friends and Community Issues**

Community issues included (a) general misunderstanding of type 1 diabetes, (b) concern displayed by the children's friends, and (c) fears about sending sons on scouting activities.

**General misunderstanding of T1DM.** Thirteen parents observed a lack of understanding of the difference between type 1 and type 2 diabetes by members of the community. Such comments as, "I don't think people know there are two different types" and a neighbor saying, "Well, I have type 2 diabetes. Can't you give them a pill?" reflect this. One mother related an encounter, "She's (daughter) short and she's a little bit round and I had a woman come up to me and say, 'You know what? I could probably help you help her lose some weight and then she won't have diabetes anymore.'" Other parents reported receiving comments such as, "Oh, you fed her too much sugar, didn't you?" and "When's he gonna grow out of that? When he loses his chubbiness is it gonna go away?"

Speaking of type 1 and type 2 diabetes, one mother expressed the wish, "I wish they'd have different names!" Another mother suggested, "But I also think that the news, that there needs to be more commercials about children with diabetes. Type 1 diabetes versus type 2."

Another problem resulting from misunderstanding is that those with type 1 diabetes cannot eat sugar. Two mothers related similar experiences. One mother encountered this with her child's teacher and said,

One time a teacher gave treats to everybody and then gave him, I don't even remember, something, and I was fuming! I was so mad! I think that is probably my biggest thing that I get angry at is when they just assume you can't have sugar.

The other mother's story was,

I had that happen to me with one of (child's) substitute teachers in kindergarten. He got stickers and he came out to the car crying. He's like, "everybody got these treats." I could barely talk to the woman without crying. I was so mad!

**Support from the children's friends.** Many mothers talked about their children's friends. Children are naturally curious, and the mothers took opportunities to teach other children about diabetes. One mother invited the neighbor children and their mothers to her home for a class on diabetes. The mother also provided families with a flyer describing the snacks the child with diabetes could eat, and also signs and symptoms prompting a call to the child's mother. This paid off for her when later, "One time he was laying on our grass. He hadn't made it all the way home, and the little neighbor boy ran in. And (his blood sugar) was 21." Another mother, talking about her son's friends, related, "His friends, they're seven and eight year olds, look out for him. They go tell the teacher if they think he's kind of low. And they look out for him like no other. It's amazing."

**Fears about sending sons on scouting activities.** Parents with sons who have diabetes expressed worry about participating in scouting activities. In response to the

question, “what kinds of situations are difficult for your child?” one mother responded, “My concern is with cub scouts. And going on hikes.” The father of an 11-year-old admitted,

One thing I’m nervous about that’s coming down the road for us is scouting. I’ve been on an overnight. The scoutmaster has no clue. And there’s no timeliness when they eat. And then they’re serving high carb dinners. You know, starchy potatoes or candy everywhere.

One father simply declared, “The whole idea of scout camp absolutely terrifies me!” Some fathers try to go on overnight scout activities with their sons. They have asked scout leaders to notify them ahead of time so fathers can rearrange their work schedules if necessary.

### **School Issues**

School issues included (a) cooperation, or lack of cooperation, from school administrators or teachers, (b) dealing with the 504 medical directive form, (c) the value of going into the class at the beginning of each school year to educate classmates, (d) challenges associated with school lunch and (e) challenges associated with physical education classes.

**Cooperation from schools.** Parents reported both positive and negative experiences with their children’s schools. Some were satisfied with support received from their school, described as “I’ve had a great experience” and “I’ve never had a teacher that wouldn’t do what I asked”. Yet other parents had a difficult time contacting the principal, or getting needed cooperation. One mother described her problem in trying to meet with the principal,

When we transferred (daughter) to the school she goes to now it took me a week to get a hold of the principal. A week! I said, "My daughter needs to start school there on Monday. I really need to get with her. She's diabetic."

Another mother in the same focus group then asked, "Can I ask you what school? Just wondering, because we have the same problem at (our school)."

The mother of a 10-year-old girl wasn't satisfied with the school's response: "They told us basically she really couldn't come back to school until she was able to learn to do her own injection because there's a nurse per 4 or 5 schools and they cannot be there everyday." Another mother was given similar information. She recounted, "They will not let someone else administer her insulin. I'm like, by law you must provide her an atmosphere to get her medication at school. Their compromise was the adult could program the pump and she could hit deliver."

One father related that his child's kindergarten teacher did not want to deal with the mood swings associated with changes in blood sugar, so the child was placed in a class for behaviorally disturbed children. The parents ultimately withdrew their son from school and home schooled him. They have since moved to another school district, and are now happy with the school situation. As the father said, "It's like school's now great. We just got lucky. The teacher helped out a lot."

Two mothers pointed out many problems or lack of problems with the school will vary by teacher. As the mother of a boy who has had diabetes for ten years put it, "You'll find in grade school you'll have some teachers who are totally there, on top of things. And then you'll have a teacher the next year who could care less and doesn't give a crap." This experience was echoed by another mother, "Our last year's teacher was such a flake. She

was like, 'This seems really hard.'... And then this year's teacher has been really on top of it."

Some parents discussed the challenge of working through problems with the school. According to one mother, "We've had our little battles, but I feel like we've made progress." Another mother learned, "If they're not doing what I want, I have to tell them." The mother of an eight-year-old, diagnosed for over three years, said, "I don't want to push too hard unless it needs to be pushed." A mother with over five years' experience raising a child with T1DM had a similar approach. She stated,

I agree school was hard at first. (Son) was the first diabetic in their school and they were not too sure about the change at first. But I kept my cool and just went with the approach, "I really want my son to have a good experience at school. Can you please help me do this?" And after that, they bent over backwards.

**The 504 medical directive plan.** The 504 plan refers to a directive in section 504 of the Rehabilitation Act of 1973. The plan, prepared by the school, specifies a child's special needs, such as blood sugar testing, eating in class or dosing with insulin. Federal law mandates a school to complete a 504 plan for any child with special needs (U.S. Department of Education, 2011); however, it does not need to be completed if the parents don't feel it is necessary. Most parents participating in the focus groups had not asked their children's school to complete the plans. It is the perception of some mothers that schools object to completing a 504, as portrayed in this conversation:

- #1 When they found out, you know, what a 504 is, they get really irritated.
- #2 Because they don't want to deal with it. Our grade school would not even let us do a 504.

Parents felt the 504 was not necessary when the child was in elementary school and the schedule less complicated and more predictable. One father's perspective regarding the 504 plan was, "When there's only one teacher, that's fine. When you get into the junior high and you have eight, you have to have a 504 so they are all on the same page."

One mother was not getting cooperation for completing a federal 504 plan, until she challenged the school administrators by asking, "Who's going to be responsible if she falls over in a diabetic coma?"

**Going into the classroom to educate classmates.** Mothers talked about going into the child's class at the beginning of each school year to educate the class about diabetes. Some mothers do it every year, while one did it only once. One father reported the school nurse educated the child's class. The mother of an eight-year-old boy described the kind of information she shares by relating,

I go to the school at the start of every school year and talk to his class. I read one of those simple little books to explain why he's getting treats. And then I tell the kids, "If you ever see him laying down on the grass, you need to get somebody immediately, because he's not laying down because he's tired; there's something wrong".

Another mother felt it was important for classmates to see equipment. As she told it, "I go in the very first day and educate all the kids and tell them about it so that they're, especially when they see a catheter or poking...You just clarify the questions and let them see it."

**Challenges associated with school lunch.** Another common challenge with school regarded lunch. One mother described the arrangement she made with the school,

He leaves class 10 minutes early, goes to the office, gets checked, then he can go to lunch. Because I want him in there before lunch starts so that he's the first one in line and can take his time eating. So that he's not the last one in line, has two minutes to eat, and doesn't eat everything. Because once you give yourself insulin for what you're eating, you have to eat it, if it takes you half an hour.

Two mothers discussed the school lunch challenge in this dialogue:

#1 I cannot believe the amount of carbs in the food that they feed at school. I mean, we get maybe 60 carbs at home, and at school it's over 100, always, like 120.

#2 We print out the lunch menu every month so we can see what his options are for the day so that we know before he goes to school what he is going to have. And then he always has to check his sugar, and if he's running a little bit high we'll say go ahead and eat your fruit (or) you don't have to eat as much of your spaghetti.

One mother avoided this problem by sending her child to school with a lunch from home.

The mother of a 13-year-old boy was dealing with a challenge of different lunch times. As his mother told it, "Mondays they have lunch at 10:15, and then A days they have lunch at 11:25. And B days they don't have lunch till 12:35. So we've got three different lunch schedules we're dealing with."

**Challenges associated with physical education classes.** The mother of a 10-year-old girl commented she is worried about physical education (P.E.), "when they're running around ... they can go low so easily." Another mother in the same focus group offered this advice, "That's why you go to the P.E teacher before school starts and you give 'em a bucket of treats and drinks and you write your kid's name and you say this is only for my kid when they are in your class when their blood sugar goes low."

## **Health Care System and Diabetes Organizations**

Concerning the health care system and structured diabetes organizations, parents talked about (a) their hospital experiences at the time of diagnosis, (b) the importance of trust, encouragement, and a positive approach in a healthcare provider, (c) the importance of finding a healthcare provider with whom the parents are comfortable, (d) the need for support after discharge from the hospital, (e) the value of talking with other parents raising children with diabetes, (f) the benefit of participating in activities hosted by diabetes organizations, and (g) their preferred method of receiving information regarding diabetes.

**Hospital experiences at the time of diagnosis.** Most children were admitted to a children's hospital at the time of diagnosis. These parents had only good things to say about their experiences. One mother said her child thought it was better than Disneyland! The parents of children admitted to another local hospital had a more negative experience. Parents complained about the competency of the medical professionals. For example, the mother of a child who was 13 months at the time of diagnosis exclaimed,

We honestly had the most horrible experience ever in the hospital with them. It was horrible. It took them three times to poke him to get an IV running. But the IV that they put in wasn't a good IV. It was one that pulled apart. So as I am sitting there, holding him, he moved and it pulled apart and I had blood all over me. And then the nurses were not nice at all.

The parents of a child who was 18 months at the time of diagnosis, and at the same community hospital, were not happy with their experience either. As they retold it,

Mom: I felt we had a horrible experience. Apparently we were one of their first diabetics, and so they really had no experience.

Dad: Sat in the ER for what, five hours? Before one of the doctors would say, “Ok, I’ll admit him.”

Mom: And this guy, he was pretty old school knowledge of diabetes. We almost fired our doctor.

**Importance of trust, encouragement, and a positive approach in the healthcare providers.** The parents expressed feelings about the healthcare provider’s approach. Parents wanted healthcare providers to use positive reinforcement and encouragement. The mother of a boy diagnosed for six years talked about her physician, “I have loved my doctor. He is just very confident. He’s like, ‘You can do it.’ He points out the positive things that we do. It makes you feel like you’re ok.”

The parents also wanted understanding and trust as reflected in this statement by a parent of a child who had diabetes for several years, “Just be understanding and know that we’ve been doing this for 10 years. We ought to know something by now. I would hope we know something by now.” One father said, “One thing that would be nice for the healthcare professional is yeah, go ahead and give us advice, but understand that oftentimes we already know what’s working in our situation.” And one mother simply stated, “So we have to assume, unless you are going to report me for abuse, that I am a good parent trying to do what’s right. Teach me, but listen to me.”

Parents also want to hear positive things about diabetes, not negative. As one mother put it,

Another thing that I would suggest is having the health professionals tell you the good things. You know, the people who’ve lived with it for sixty years and they’re doing okay, rather than scaring you at the first and say if you don’t do this and this

then this is gonna happen. Say this might happen but this guy's had it for forty years and he's doing fine.

Another mother added, "Cause I don't want to hear about that one who died in his sleep."

Two parents reported their healthcare providers became defensive when questioned. One mother described this happening during their initial hospital admission, "Parents are on the defense already. We're scared, you know, it's our baby in the hospital. And nurses and doctors were getting mad at us for questioning." A father's advice for healthcare providers was, "Don't take it personally if we don't listen to you. Give us advice, and we can take it or leave it."

**Importance of finding a healthcare provider with whom the parents are comfortable.** Parents felt it was important to find a healthcare provider with whom they were comfortable. One mother reported going to one provider, switching to another, then going back to the first. After changing again, she reported, "We just switched doctors. And that's been a dream come true basically!" Another mother declared, "I think people ought to shop out there, I mean we all ought to be sharing names of our endocrinologists."

**Need for support after initial hospital discharge.** Several parents reported feeling "dazed" and that "it was just so overwhelming" during the education while initially hospitalized. Many parents received contact numbers of healthcare professionals and/or other parents raising children with diabetes if they had questions after being discharged. Some parents called the "nurse line", but one mother indicated she was told "they were not around right now." Another mother in the focus group responded, "They were just rude to me!"

One mother expressed her feelings about having someone follow-up with the parents in these words, “I think out of everything, ..., it would be great to have somebody follow up with you.” She further described how she felt,

Even if it’s just a call to see how you’re doing. That would have been so helpful to me, ..., I had no idea what I was doing. It was really hard, it was frustrating. Even to just have a support group call me and say, “Hey, how are things going?” You know, just keep in touch with me for that first month until I feel ok.

Another mother pointed out, “You know they have a local home baby program here? You have a premie baby? Somebody will come to your house every month and check on you. Why can’t they do that with diabetics?”

**Value of talking with other parents raising children with T1DM.** Many parents said one of the most helpful things was talking with other parents who were raising children with diabetes. In the words of one mother, “the most helpful thing I ever found was [www.childrenwithdiabetes.com](http://www.childrenwithdiabetes.com). Not because of the information on the website, but the parent support was more important than anything any doctor could ever give me.”

Another mother extolled the benefit of talking with other parents,

I think parents have been probably one of my best educators, too. Just like support groups. They would tell us what pump worked, what didn’t. What doctors were favorites. I learned probably more from other parents. They’re just fantastic. They know what they’re doing.

**Benefit of participating in activities hosted by diabetes organizations.** Parents stated participating in organized diabetes activities sponsored by local organizations was valuable for their child and for themselves. Benefits included being able to meet with other

parents, the opportunity for the children to see other children with diabetes, a chance to feel like they are making a difference, the opportunity for parents to have a break from caring for the child, and to have fun. One mother advised, "Try to be involved with any kind of groups, whether it's the Sweet Kids things. I really enjoy talking to other parents about things that you're going through, and issues that you've had. To me it's really helpful." Another mother stated, "The only camp that (daughter) will ever go to is diabetic camp. They were just so on top of it, and so I felt like I could leave her for four days and she would be perfectly fine." And the observation by the mother of an eight-year-old boy, "That's one thing that's really nice about the camp because all of these little kids running around all have diabetes and they're just at ease. They just love it!"

**Preferred method of receiving information about diabetes.** In response to the question about their preferred method of receiving information about diabetes, there was no consensus. One mother wanted discussion groups, while another described herself as a visual learner. Three parents indicated the internet, and two suggested "talking with people" would be their preferred method.

## **Discussion**

The purpose of this research was to identify perceptions of parents raising children with T1DM regarding challenges, the impact of the disease on the family, and difficult situations their children encounter. Also, parents were asked to identify their preferred means of support from the health care community. Participants addressed various issues, ranging from their children's behavior and development, to the physical management of diabetes, including cost, problems and worries of parenting, concerns with extended

family, friends, community and the school, and also the healthcare system and structured diabetes related activities.

### **Findings Supporting Previous Research**

Issues regarding the child's age and development were addressed by parents. A number of findings supported previous research. For example, parents whose children had been diagnosed at a younger age believed the younger diagnosis was advantageous for the child's adaptation to the illness, as also demonstrated by Jacobson et al. (1990). Another issue centered on the difficulty of motivating an adolescent to be compliant with the prescribed treatment regimen. This has been previously reported by Carroll and Marrero (2006) and Bowes et al. (2009). Other challenges associated with the child's age or behavior include the child not having an adequate understanding of diabetes, resistance to having blood sugars checked or receiving insulin injections. Roper et al. (2009) likewise found that children with T1DM expressed a wish for a better understanding of the disease. Amillategui, Calle, Alvarez, Cardiel and Barrio (2007) reported children feeling "annoyed" or "saddened" about blood sugar testing and insulin injections, while Antal, Wysocki, Canas, Taylor and Edney-White (2011) described "insulin injection distress". Negative emotional responses to having diabetes have also been previously reported (Northam, Anderson, Adler, Werther, & Warne, 1996). As in the current findings, Amer (2008) found children maintain a positive attitude toward their illness. In addition there was concern expressed about relinquishing control of the diabetes management as children matured. This confirms results reported by Carroll and Marrero (2006), Lowes et al. (2008) and Marshall et al. (2009). Several parents complained of difficulty distinguishing when bad behavior

needs to be disciplined or when it results from an abnormal blood sugar. Kratz et al. (2009) reported a similar predicament by parents raising children with other chronic illnesses.

Some findings concerning the physical management of diabetes also concur with other research. The child sneaking food appears to be an age-old problem, having been reported in 1947 by Bruch and Hewlett, and later by Wysocki, Huxtable, Linscheid, and Wayne (1989), who additionally discussed the need for a rigid meal and snack schedule. Concern that children were unable to recognize the symptoms of hypoglycemia confirms the Amillategui et al. (2007) study. Parents whose children were using insulin pumps felt they were advantageous for several reasons, supporting Müller-Godeffroy, Treichel and Wagner (2009), who discovered pumps decreased parenting stress and disease burden. The financial burden described by parents supports previous studies by Tao and Taylor (2010) and Ying et al. (2011). The affect of acute illness on blood sugar control is a commonly recognized phenomenon (Alemzadeh & Ali, 2011).

Regarding parental issues, findings corroborate those of other researchers reporting on parental feelings of loss and grief, which, over time evolved into a sense of normalcy (Marshall et al., 2009), the need for emotional support (Bowes et al., 2009), the inability to manage the disease perfectly (Smaldone & Ritholz, 2011) and the difficulty of striking a balance between glycemic control and allowing the child to “just be a kid” (Carroll and Marrero, 2006). Feeling “overwhelmed” and “in a daze” at the time of diagnosis (Jönsson, Hallström, & Lundqvist, 2010), fears for the child’s well-being (Haugstvedt, Wentzel-Larsen, Graue, Sjøvik, & Rokne, 2010, Wennick & Hallström, 2007, and Bowes et al., 2009) and the need for the mother to make changes to her employment (Amillategui et al., 2007)

were other issues previously identified by other investigators. Wysock et al. (1989) also reported difficulty finding a babysitter and feeling stressed.

The value of maintaining a positive attitude and of being grateful that it's "just diabetes" were feelings expressed by several parents. Similarly, maintaining a positive outlook was reported by Buckloh et al. (2008).

The response of siblings to living with someone with diabetes (Jackson, Richer, & Edge, 2008; Wennick & Hallström, 2007), support or lack of support from grandparents and other extended family members (Smaldone & Ritholz, 2011), and frustration stemming from others' misconceptions of type 1 diabetes mellitus (Carroll & Marrero, 2006) were subjects identified by parents, confirming earlier research findings. The level of cooperation from the child's school (Amillategui et al., 2007; Nabors, Lehmkuhl, Christos, & Andreone, 2003; Peters, Storch, Gefken, Heidgerken, & Silverstein, 2008) and the benefit of going into the classroom to educate classmates (Amer, 2008; Wagner, Heapy, James, & Abbott, 2005) were also discussed by parents. Wagner et al. (2005) also reported friends of the child with diabetes were helpful and supportive, as did parents in the focus groups.

Regarding the health care system, parents stressed the importance of trust and encouragement from health care professionals, as well as finding a healthcare provider with whom the parents and child are comfortable, as also reported by Jönsson et al. (2010) and Kratz et al. (2009). Parents expressed a need for support immediately following hospital discharge by way of phone calls or home visits, validating Smaldone & Ritholz' (2011) findings. As Buckloh et al. (2008) reported, parents preferred healthcare providers be positive in pointing out successes; negative motivators and scare tactics were not appreciated. Parents described the benefit of talking with other parents raising children

with T1DM, supporting the work of Smaldone and Ritholz (2011) through phone calls from an assigned mentor, support groups, participation at diabetes related activities, or on-line on the internet.

Parents indicated benefits of children participating in organized diabetes activities, such as diabetes camp, as did Bennett and Johannsen (1954) in their classic work, recently corroborated by Winsett, Stender, Gower and Burghen (2010).

### **Issues Not Addressed in Previous Research**

The parents also addressed issues not identified in prior research. These issues concerned the child's behavior, physical management of the disease, parenting challenges, community and school issues, and feelings about the healthcare system.

Regarding the child's behavior, three parents shared their children's hopes that siblings, friends or classmates would develop diabetes. The parents indicated their children felt alone because of their diabetes. Having a friend or family member with T1DM may mitigate the loneliness. Concerning the physical management of the diabetes, parents of very young children reported difficulty in measuring an appropriately small dose of insulin. The amount of insulin required is based, in part, on the number of carbohydrates consumed. Because young children generally eat small quantities, their insulin needs are small, resulting in doses that may be difficult for a novice caretaker to measure.

Parenting issues included feelings of burnout, lack of sleep, and the need for respite. Although previous researchers have measured parental stress or burden of disease (Müller-Godeffroy et al., 2009; Streisand, Mackey, & Herge, 2009), specific comments such as parental burnout or the need for respite were not found in the literature review.

Topics regarding family, community, and school included the belief diabetes created a healthier lifestyle for all family members, worries about sons participating in certain scouting activities, advantages and disadvantages of the 504 directive at school, multiple problems associated with school lunch, and problems associated with P.E. class.

Parents talked about hospital experiences at the time of diagnosis; those who were at a children's hospital unanimously had good experiences, while those at their local community hospital reported negative experiences. When asked to describe preferred methods of receiving information, several parents suggested the internet. Other suggestions included discussion groups, a visual presentation, and "talking with people".

### **Limitations**

This study was designed to identify perceptions of parents raising children with type 1 diabetes in a qualitative design. However, there are certain limitations to this study. All study participants were volunteers. There may be differences between parents who volunteer to participate in a research study and parents who do not. Also, most study participants were Caucasian from two-parent families living in a suburban community. This sample may not accurately represent parents from different backgrounds, cultures or ethnicities raising children with T1DM. Results were not examined according to age of the child at diagnosis, duration of the diagnosis, treatment with injections or insulin pump, or household income. Although this may lend strength because of the broader background of these families, it may also have affected results.

### **Recommendations**

Parents raising children with T1DM have elucidated many unmet needs, suggesting gaps in services provided. Several parents used expressions such as "the most frustrating

thing”, “the hardest thing” or “if you take anything home with you (from this interview)”, suggesting greater emphasis for certain issues, which included lack of community understanding of type 1 diabetes and how it differs from type 2 diabetes, and the need for follow-up care after hospital discharge. Another concern was the need for emotional support.

A public awareness campaign delivered by way of multi-media regarding type 1 diabetes and how it differs from type 2 diabetes may help dispel some misunderstandings among the public. Such a campaign may begin with coverage by news media. Further efforts would require funding by government agencies, professional societies or private contributions. Perhaps increased public awareness may result in multiple desirable endpoints. First, it may decrease seemingly insensitive remarks to parents about the children’s diabetes. Second, it may increase sympathy for T1DM which may result in increased national funding, grant awards and/or fund raising for diabetes care and research.

Parents reported feeling overwhelmed with information and responsibility at the time of initial diagnosis and teaching and needing follow-up after discharge. Although contact information had been provided for parents, they reported reluctance to call or difficulty reaching the contact person. A formal plan of follow-up after hospital discharge, including contact initiated by the health care system, may help parents with the support and confidence they lack initially. Also, a program that puts parents of newly diagnosed children with T1DM in contact with experienced parents may allay some apprehension as well as supply practical advice.

The emotional and mental health challenges besetting parents raising children with T1DM should prompt health care providers to assess mental health needs and make appropriate referrals. Emotional support should be provided during the initial hospital stay and as a regular part of follow-up visits to help parents address negative emotions, such as grief or guilt.

Likewise, help in procuring financial assistance, in communicating with third party payors, or obtaining financial counseling may reduce the financial burden of diabetes. The insulin pump was strongly preferred by parents whose children use them. Some families wished their children had insulin pumps, but found the cost prohibitive. An effort should be made to make an insulin pump available for every child who could benefit from one. Such an effort would likely require cooperation by insulin pump manufacturers, third party payors, and diabetes associations.

Problems involving the children's schools suggest changes need be made to provide more support for the child and the parents. Diabetes education for the child's teacher and at least one other school official should be provided. The availability of school nurses should be increased, serving not only children with T1DM, but also those with other health needs. Food services needs to be aware of the child's needs and must provide the child and family with timely and useful nutritional information. Learning materials need to be available for the child's family to take to school for educational purposes.

Organized opportunities for parents and children to meet together will give the children the socialization they desire and parents the contact they seek with other parents in a similar situation. An alternative to creating activities or events would be electronic access for such parents. In the current era of internet use and social media, referral to or

creation of an on-line resource for parents to communicate with other parents and for children as well may help fill the need. While this may supply the contact parents identified as important, some parents may desire face-to-face interactions.

The numerous needs elucidated by participants indicate the complexity of diabetes mellitus and imply much can be done to improve the situation for families raising children with T1DM. Parents often feel overwhelmed with their responsibilities. Therefore healthcare providers should be sensitive to the emotional, physical, mental, and financial challenges these families face. Being positive, trusting and encouraging may help these families cope, and ideally, thrive.

Suggestions for further research would include looking for evidence to support the findings not previously reported by other researchers, including children with T1DM wishing friends and family members would be diagnosed with T1DM, difficulty administering small doses of insulin, parental burnout, a healthier lifestyle for the family, challenges with scouting or similar activities, and problems at school including the 504 directive, school lunch and P.E. class. Further research could also aim to identify differences between parents maintaining positive attitudes and those with more negative responses. Is there a relationship between parents who have positive attitudes and children who are accepting of the disease? If so, are there differences between the physical characteristics of these children, such as age or difficulty in maintaining appropriate glycemic control? Additionally, research could compare differences between the initial T1DM education programs described by Jönsson et al. (2010), which includes a two-week hospital stay with multiple home leaves, and other programs. Also, research involving participants from

various ethnic groups and family structures may be useful in increasing our understanding of the impact of raising a child with T1DM on families.

Interventions designed to satisfy needs identified by parents should be implemented with appropriate evaluation of their effectiveness. One of the biggest needs in health care research is transformational research, or applied research. There are many ideas and recommendations, but implementing them in a cost effective way is essential to the well-being of society.

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## APPENDIX

## **Appendix A**

1. Tell me about our child with diabetes, such as age, gender how long he/she has had diabetes, how it is managed. Does the child have an insulin pump?
2. Talk about some challenges you have experienced while raising your child with diabetes, such as challenges with management, family, or school.
3. Talk about how diabetes has impacted your family, including extended family.
4. What type of situation is difficult for your child with diabetes to handle, school situations, church situations, situations with friends, etc.
5. What kind of information would be most helpful to you in raising your child with diabetes?
6. What would be your preferred method of receiving information that could be helpful to you?
7. Is there anything else you would like to share with us about raising your child with diabetes?