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# Establishing the needs of Type 1 diabetes users for mobile application design

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**Establishing the needs of Type 1 diabetes users for mobile application design**

by

**Amanda J. Skinner**

A thesis submitted to the graduate faculty  
in partial fulfillment of the requirements for the degree of  
MASTER OF SCIENCE

Major: Human Computer Interaction

Program of Study Committee:  
Stephen Gilbert, Major Professor  
Michael Dorneich  
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Iowa State University

Ames, Iowa

2015

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## ABSTRACT

Living with Type 1 diabetes as a child presents a great deal of responsibilities at a young age. These responsibilities require knowledge of the disease, constant monitoring, awareness, and more. A variety of mobile applications have been created to aid children with these responsibilities, but a thorough investigation of these users' needs is a missing piece that is not often, if at all, conducted. This research aims to understand these users' needs in great depth in order to offer appropriate design guidelines for a mobile application to aid in the daily management and medical adherence of a child living with Type 1 diabetes. Six family cases (11 participants) provided qualitative support to these ideas through interview sessions. Thorough qualitative analysis following a critical ethnography epistemology approach was conducted from this data.

Interview transcripts about the daily life and experiences of the 6 families living with Type 1 were analyzed and coded for emergent categories. The categories included responsibilities, travel, school, exercise, impression, diagnosis, communication, and devices/technology. These coded categories were later turned into a set of four themes. The themes related to participants' need for support and assistance (e.g., by an app). These themes included daily responsibilities, emotional effects, support, and not feeling different from others. The conclusions drawn from this information provided the justification for the set of design guidelines for a mobile application aiding in Type 1 diabetes care.

## CHAPTER 1

## INTRODUCTION: PROBLEM STATEMENT

## 1. Type 1 diabetes

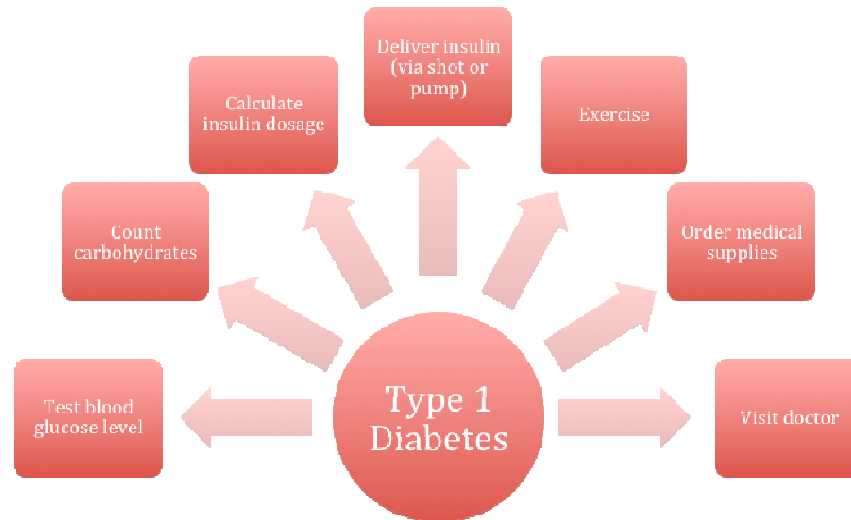
There are many components of living with Type 1 diabetes that affect not only the health of the person who suffers in the present and future, but also her quality of life. According to the National Diabetes Statistics Report 2014, 29.1 million people in the U.S. suffer from Type 1 or Type 2 diabetes. Of this group, 208,000 of those diagnosed with Type 1 are under the age of 20. These numbers are only growing, which is why it is important for this research to address the current problem. This research aims to discover ways to help children with Type 1 diabetes monitor themselves, as well as take control of this new lifestyle through a mobile application. One problem for newly diagnosed children is that parents and doctors manage the disease by adjusting insulin levels, remind children when to test their blood-glucose levels, and even take care of the insulin injections. This can result in the child developing learned helplessness, which can often be misdiagnosed as depression, or even turn into depression if not recognized (Dantzer & Swendsen, 2003).

In 2007 my brother Zachary was diagnosed with Type 1 diabetes. My family members' lives immediately changed. Being my only sibling, this news was devastating for me. My brother, who is 2 years younger than me, has always been my best friend. Knowing the struggles and changes his life would undergo was scary, and I vowed to always help him in any way possible. I made sure I was educated along with my parents to help him adjust and live a healthy lifestyle. I reminded him to test his blood-glucose

levels, injected his insulin multiple times a day, and was there to support him in the toughest of times. Back home in Buffalo, New York, my brother has been both a camper and counselor at the local diabetes Camp through the American Diabetes Association. My brother is the most selfless person I know, and has been a voice for the ADA (American Diabetes Association) on a few occasions. He wants to help others understand that despite the difficulties and hardships, he will not be defeated and will continue to find strength and hope. I have seen how much this illness can affect children who are diagnosed, as well as their families, which is why this research has been put in place and is taking action for others like Zachary.

Type 1 diabetes and Type 2 diabetes deal with different challenges because those who suffer from Type 2 are not insulin dependent, whereas those with Type 1 are insulin dependent (Preuveneers, 2008). Children who are diagnosed with Juvenile diabetes or Type 1 diabetes must adjust to a structured eating plan and lifestyle changes. One way to begin the breakdown of these responsibilities is through constant monitoring. Currently, it has been discovered that constant glucose monitoring can decrease the amount of time a sufferer of Type 1 diabetes stays in hypoglycemia (Battelino et al., 2011). This result prompted the idea of making monitoring daily routines and responsibilities easier, and more controlled. When constant monitoring does not occur in a daily routine, there are long-term complications a person with Type 1 diabetes must consider. These complications can affect the eyes, kidneys, and peripheral and autonomic nervous systems (Manuscript & Treatment, 2009). There are also associations with other autoimmune conditions, such as thyroid disease, and celiac disease (Silverstein &

Klingensmith, 2005). Figure 1 shows some of the responsibilities associated with living with Type 1 diabetes.



*Figure 1: A visualization of responsibilities of a person living with Type 1 diabetes.*

To gain a better understanding of what this complexity means for a child, let us take a look into a typical day in the life of Max, a character synthesized from multiple real-life scenarios for the purpose of illustration. Max is a 13-year-old boy who was diagnosed with diabetes two years ago. Since being diagnosed, he has taken insulin shot injections at least three to four times a day. Soon he hopes to “graduate” to being on a pump. The pump, which will inject insulin from an inset. An inset is a patch with a small plastic tube that is inserted with a needle device. The inset must be changed every couple days eliminating the constant daily shots, but for now he is no stranger to being pricked with a needle. Max wakes up for school at 6:30am and tests his blood sugar. Luckily today, his level is 110, which is in a good range. He continues to get himself ready for the day. Max has to pack his lunch for school, which means he needs to measure out the serving sizes of his snacks to make sure he takes the correct amount of insulin at



lunchtime. He also packs an extra juice box, just in case his blood sugars drop low during the day. Before he leaves, Max makes sure he has enough test strips for his blood-glucose meter. The school nurse has a supply of syringes, insulin, juice, and Max's Glucagon in case of an emergency. Around 11:00am, Max starts to feel different, which makes him check his blood sugar by pricking his finger. He usually tests while he is at his desk, although sometimes he will leave class and go to the restroom or the nurse's office to test. When he sees that his blood-glucose level is at 60, which is quite low, he asks his teacher if he can get a pass to the nurse's office and leaves class. He drinks a juice box, a fast-acting carbohydrate, with the supervision of the school nurse, and waits. After about 20 minutes, he rechecks his blood sugar, and when he sees that he has returned to a normal range, he goes back to class. At lunchtime, Max heads back to the nurse's office to check his blood sugar, and calculate how much insulin he will need to take based on what he eats. This is the second shot of insulin today for Max. The rest of the day at school goes smoothly. Before soccer practice, Max realizes his blood sugar levels are elevated at 210 by testing again, but since physical activity can help lower it, he drinks a large glass of water and goes to practice. In this case, Max was correct, and did not have to take an extra injection of insulin to correct his blood sugar levels, which is good news for him since he doesn't enjoy getting poked with needles all day. Once Max is home from practice, he tests his blood sugars again, prepares and measures his dinner, calculates the amount of insulin he will need to inject, and eats. Finally, before going to sleep Max takes an injection of Lantus, his slow-absorbing insulin that lasts for 24 hours. In the morning, his day will repeat similarly.

There are many mobile applications available that assist with enforcing a healthy lifestyle and routine, as well as applications focused specifically on diabetes care. Current applications include, but are not limited to, the following: *Fooducate*, *Glooko*, *Diabetic Connect*, *Glucose Buddy*, and *Diabetes App*. These applications have a number of capabilities, ranging from providing nutrition information, providing recipe libraries, keeping records and statistics, recording goals and reminders, logging personal information, and carbohydrate counting. The successes and failures of these applications are typically dependent upon how helpful they are in the spectrum of responsibilities these patients have each day. Each application typically focuses on one or two key components for adherence, instead of the entirety of what a person with diabetes is responsible for. These issues will be discussed further in Chapter 2.

This research aims to understand what it is that users who suffer from Type 1 diabetes and families see as the biggest challenges. The heavy burden of these responsibilities can be difficult to accept. Carrying out the necessary actions daily to maintain a child's health involves a large number of extra steps in many daily activities. These challenges will be explored to determine if a mobile application can help address the needs and daily maintenance. This will be accomplished through a needs assessment with children with Type 1 diabetes and their parents. During the needs assessment, participants will be asked to complete a self-efficacy survey to help the researcher understand how the participants view their ability to control the disease and affect their outcomes. Self-efficacy surveys are concerned with gathering information that determines how capable people believe they are in certain aspects of life. Bandura (2006) says, "The efficacy belief system is a differentiated set of self-beliefs linked to distinct

realms of functioning” (p. 307). This is not a measure of self-esteem, locus of control, or outcome expectancies, but rather a judgment of capability. Using self-efficacy as a tool in this research is beneficial because perceived efficacy plays an important role in human functioning through its impact on areas such as goals, outcome expectations, and opportunities in the social environment, to name a few. These beliefs influence the difference between thinking optimistically or pessimistically, or erratically or strategically (Bandura, 2006).

In order to understand the need for this type of application, it is important to understand the mechanics of the responsibilities of a person with Type 1 diabetes. One aspect of management involves maintaining a low HbA1c level. This is a measure of glycated hemoglobin, and reflects the consistency of the patient’s blood-glucose level over a period of time. The more consistently their blood-glucose levels have been in the desired range, the better and lower their HbA1c levels will be (Dusan, Jovan, & Nada, 2010). However, in order to achieve this, a person with diabetes must be testing their blood-glucose regularly, and use the correct units of insulin for their meals and blood-glucose levels. These two measures of insulin units are dependent on a calculation that is unique per the individual, and can be affected by the level of physical activity they perform as well. Children with diabetes typically require multiple injections of insulin each day. These injections are combinations of long-acting insulin or short-acting insulin before meals, at bedtime, and to maintain healthy levels throughout the day if necessary (Silverstein & Klingensmith, 2005).

This research will be exploring current methods of assistance (e.g. mobile apps, information logging, support, etc.) as well as conducting a needs assessment, to

determine design criteria for a mobile application that provides is assistive and supportive, answers to common concerns or questions, and helps educate about common misconceptions. (Preuveneers, 2008). While these features are currently available in mobile applications on the market, something the current applications lack is the capability to calculate the specific insulin dosage required for an individual's unique ratios (El-Gayar, Timsina, Nawar, & Eid, 2013). This specific insulin dosage is an individualized measure from one patient to the next and could be difficult to implement accurately. However, this is a feature that can help give patients the ability to calculate the amount of insulin they will need, and ideally give them a sense of control and maturity. Instead of feeling helpless, these children will feel helpful and gain an understanding for how to manage their diabetes with their families, instead of being managed by their families. Another problem in this area deals with how children are educated when they are diagnosed (Hopkins et al., 2012). Due to this disease being technical and insulin dependent, children have a hard time understanding what it is they are doing, and ways to help themselves. This research focuses on children typically old enough to use a mobile app, which is 8-18. Since this range include children, all patients in this age range will be referred to as children. This application could have a game-like aspect or game feature that can help teach children proper diet, how and when to test their blood sugars, what different numbers and terms mean, and that their diabetes does not make them different or not normal.

Ultimately, this research aims to answer the following questions in this qualitative research:

1. What are the biggest challenges families and children with Type 1 diabetes face?
2. Is a mobile application a supported solution to these challenges?
3. What motivations help children adhere to the medical responsibilities associated with Type 1 diabetes?
4. What capabilities would a mobile application need to have in order to assist children successfully?
5. What are the design criteria a new mobile application should follow in order to be successful and helpful?

The next chapter of this thesis will outline existing research to support the methods used and framework applied to the findings. Chapter 3 will then include a detailed description of the methods for data collection with participants. Chapter 4 will describe the results and findings extensively. To finish, Chapter 5 will provide discussion and conclusions from the research.

## CHAPTER 2

## BACKGROUND: LITERATURE REVIEW

To design an appropriate application for this target audience, it is important to develop a set of guidelines for design criteria. In order to do that, it is important to understand the mobile applications that have been developed and are available currently. In addition, it is crucial to acknowledge what we already know from previous research of others about children with Type 1 diabetes. The story of Max in Chapter 1 is a synthesis of previous research, upon which will now be elaborated below. The difficulties Max faces each day alongside his parents, friends, and other family members cannot be ignored. This research helps to build evidence for why these design criteria are relevant, and what information needs to be gathered to answer this research question.

There is a wide range of available materials than can help guide a further understanding into the difficulties of living with Type 1 diabetes, and the need for assistance. This review will cover a more in-depth overview of Type 1 diabetes from Chapter 1 ranging from diagnosis to care options to psychological effects. The review will then discuss the issue of medical adherence, especially with the children studied in this research. Support communities and the impact these have on patients with Type 1 will conclude the overview. After the gaps in previous literature are addressed, mobile applications in the health domain will be covered.

Type 1 diabetes onset peaks around the age of 10 typically. On top of that, in the U.S., Type 1 affects numerous ethnic groups such as Caucasian, non-Hispanic black, Hispanic, Asian and Pacific Islander, and American Indian/Alaska Native (Imperatore et

al., 2012). As mentioned in Chapter 1, Type 1 diabetes means that a person is dependent on insulin injections (Preuveneers, 2008). This is because Type 1 is a metabolic disorder characterized by chronic hyperglycemia (high blood-glucose levels), with a defect in insulin secretion resulting from metabolism disturbances (Alberti & Zimmet, 1998). It is an autoimmune disorder that is a result of different risk factors in people's genes and in a person's daily environment (Barrett et al., 2009; Belle, 2011).

There are a number of symptoms to recognize before making a diagnosis, such as extreme thirst, polyuria, blurred vision, and unexplained weight loss. In children, many times the diagnosis can be found by testing blood glucose levels. This can lead doctors to begin treatment immediately. While this can be life saving, it can only happen if symptoms are severe. Otherwise, further testing and blood work may be required before making the diagnosis (Alberti & Zimmet, 1998; Belle, 2011).

Continuous glucose monitoring is one of the most effective practices of a patient with Type 1 diabetes. Reducing the amount of time spent in hypoglycemia is possible through continuous monitoring, and can in turn lower HbA1c (Battelino et al., 2011). People who suffer from Type 1 diabetes have two options for receiving insulin. Patients can either take multiple daily injections through shots, or through continuous subcutaneous insulin infusion, more commonly known as an insulin pump. Both of these methods require the person to plan meal carbohydrate content, the current blood-glucose level, and knowledge of how the activity or food intake will affect future blood-glucose levels. Once these have been considered and calculating into an insulin dosage, the delivery of insulin can occur (Garg et al., 2011).

The JDRF (Juvenile Diabetes Research Foundation) has worked for over 40 years to find a cure. The reality is that this goal is far from near, which is why the JDRF remains equally determined to finding better treatments and prevention. JDRF focuses on funding and supporting the development of therapies and devices that aid in the daily care of a patient with Type 1. The goal is to ease the daily burden and undeniable challenges of this disease (Insel, Deecher, & Brewer, 2012).

In addition to the potential health risks that can follow a person with Type 1 diabetes later in life, there are psychological affects that are not as frequently discussed. Diabetes, compared to other chronic illnesses, is considered to be one of the most demanding psychologically and behaviorally. Although most patients suffer from psychological concerns, only a few actually receive treatment (Ciechanowski, Katon, Russo, Ph, & Walker, 2001; Kalyva & Malakonaki, 2011). Stress is just one psychological factor that can play a large role in the control of glucose levels. Children with chronic diseases can be at a higher risk for depression, anxiety, and low self-esteem. There is an underlying stress related to imperfections in managing diabetes, as well as with the fear of complications (Markowitz & Laffel, 2012). Poor metabolic control can be associated with different types of coping behaviors as well, such as avoidance. Often, a significant association can be found between learned helplessness and metabolic control. Depression may not link directly to metabolic control, but it is linked to both living with juvenile diabetes, and caring for a child with juvenile diabetes (Dantzer & Swendsen, 2003). Anxiety has been found to be linked to metabolic control. The more present anxiety is, the better metabolic control is due to protecting against the fear of complications (Dusan, Jovan, & Nada, 2010). Reynolds & Helgeson (2011) performed a



meta-analysis and found that children with diabetes did in fact report more symptoms of depression, were more likely to have clinical depression, had higher anxiety levels, and had more psychological distress than children who were unaffected by chronic illness.

Medical adherence is a factor in this research that cannot be ignored. Adherence can be defined as the extent to which the recommendations from a healthcare provider are adopted into a person's behavior (Davies et al., 2013). Chronic illnesses require a lifetime of care, which is why it is important to acknowledge adherence. As mentioned, continuous glucose monitoring is just one proven method in lessening the amount of time spent in hypoglycemia, or low blood-glucose levels (Battelino et al., 2011). Diabetes is the seventh leading cause of death in the United States, which can be often related to medical adherence and self-management. Due to individuals with Type 1 diabetes being at a greater risk of long-term complications, it is crucial to follow the medical regimen. The patient conducts 95% of this regimen. Patient-provider relationships contribute significantly to adherence to treatment (Ciechanowski et al., 2001). It is also crucial for professionals to understand the importance of involving adults (parents, teachers, school nurses, etc.) in a child's diabetes management. The goal is to gradually transition a child with Type 1 toward independence, but adult supervision remains highly important during this transition (Silverstein & Klingensmith, 2005).

Patients who are adherent typically perceive the consequences of diabetes to be less of a problem. Two common findings are that insulin injections are disliked, and patients can feel embarrassed about injecting in public situations. These areas contribute greatly to non-adherence. Unfortunately, there is a stigma of injections that causes problems from the beginning (Davies et al., 2013). Many times, children who have less

motivation and less support are more non-adherent. This concern can be perceived as an issue of personal freedom. There are ways to help improve adherence, which can include but is not limited to, reducing the financial burden, providing additional support to patients (both medically and otherwise), educational programs to increase awareness, peer support, and developing coping skills (Davies et al., 2013; Silverstein & Klingensmith, 2005). It has been proven numerous times that constant glucose monitoring can severely reduce hypoglycemia in both children and adults. This can then reduce the HbA1c as well (Battelino et al., 2011).

Self-management is crucial when living with a chronic disease. It involves maintaining, changing, and creating behaviors in life that are meaningful. Successful self-care can improve the quality of life (van Houtum et al., 2014). In addition, those suffering from a chronic illness can benefit greatly from the support of others. Attending to diabetes daily and incorporating these routines into the school or workplace, explaining the challenges of diabetes to those outside of the community, and handling unexpected curveballs related to management are popular areas of concern. Support groups have the ability to lessen the burden of diabetes, as well as increase self-care behaviors (Markowitz & Laffel, 2012). Self-care behaviors occur around peers, making peer relationship dynamics a crucial point of study. These relationships have the ability to provide social support necessary to increase self-esteem and social control, while at the same time introducing social conflict, failed support attempts, and social constraints (Palladino & Helgeson, 2012). Due to developmental changes from childhood to adolescence, these support benefits that cannot go unnoticed (Markowitz & Laffel, 2012). The natural transition into a more peer-focused lifestyle into adolescence can present

challenges to those suffering from Type 1 diabetes (van Houtum, Rijken, Heijmans & Groenewegen, 2014).

Related to this idea is the way family behaviors affect self-management. The changes in daily routines brought on by Type 1 diabetes diagnosis occurs in family settings. Family members often take an active role in these changes in helping loved ones with chronic illness needs. Family cohesion has the ability to improve self-management behavior in children (Rosland, Heisler, & Piette, 2012). Research has proven that daily text messages can assist in feeling the connectedness of peer support (Rotheram-Borus et al., 2012). Structured self-help groups are promising, allowing for ongoing patient education and tools for lifestyle change between peers (Rotheram-Borus et al., 2012).

To summarize, previous research relating to the needs of people with Type 1 diabetes shows that their needs include the following:

1. Constant monitoring
2. Support from family and peers
3. Education

However, these previous studies did not conduct full needs assessments, thus do not account for:

- A. Highlighted individual cases on experiences and daily life
- B. Individual opinions of current methods in place for care, support, and information logging
- C. Mobile applications to aid in care specifically linked to previous research in Type 1 diabetes
- D. Emotional effects linked to personal experiences of families and children

## 2.1 Mobile Applications for Health

One way to compile some of these gaps is through a mobile application that is regularly accessible. Video games that involve psychological therapy are frequently able to find success. Entertainment and educational power through gaming has centered on disease management, education, and promoting physical activity. High quality design features, including interaction design and aesthetics, tend to have the most positive results, though research in this specific area is limited (Primack et al., 2012).

Since it has been made clear that improved health is a result of adherence and involved health care consumers, it is important to understand how to maintain this relationship. Mobile technologies can assist in providing individual level support (Free et al., 2013). These interventions are designed to increase healthy behavior and improve disease management. Mobility and technological capabilities are two features that lend mobile technologies to be appropriate in this field (Free et al., 2013). It is important as well to ensure that healthcare is constant. Care that is both constant and reliable has the potential to aid in assisting a patient through transition periods in the medical aspect of his life (Dixon, Dehlinger, & Dixon, 2013). People carry their mobile devices with them daily, which can allow temporal synchronization of an intervention through this transition. This also means that information can be delivered to doctors or otherwise, including requesting support (Free et al., 2013).

In 2013, El-Gayar, Timsina, Nawar, & Eid conducted a meta-review of diabetes self-management applications available from 1995 to 2012. Their final analysis included 71 applications and 16 articles. 27 of the 71 applications supported self-management tasks for living with Type 1 diabetes. From the list of applications analyzed in this

review, many are still among the highest rated in the App Store today, in 2015. Mobile applications have the ability to upgrade patients from paper logbooks to an electronic system. Paper logbooks are commonly used between doctors and patients to deliver information back and forth. Patient-provider communication, as mentioned previously, is a crucial component. This means data needs to be synchronized with other devices, or be exportable. When it comes to usability, mobile applications in this field are preferred over web or computer-based systems. However, the findings of the meta-review suggest that applications need to emphasize more than data entry. There are concerns with the usability of adjusting personal settings, learnability, aesthetics, and error management. “There is a distinct need to employ a user-centered design that will take into account the needs and characteristics of the individual patient” (Elgayar et al., 2013, p. 260).

For example, Figures 2 - 10 show screenshots from the applications *Fooducate*, *Glooko*, *Diabetic Connect*, *Glucose Buddy*, and *Diabetes App*. *Fooducate* is an application that is often advertised for those with diabetes. However, Figure 2a shows the home screen of the mobile application, which is brightly colored and easy to read. Figure 2b shows a subpage with a list of options to choose as goals. It appears that the application, while easy to read and understand, is strictly for general health, leaving a large gap for Type 1 diabetes users. This lends the researcher to believe that the application would be beneficial for someone with Type 2 diabetes, but not as much with someone living with Type 1 because Type 1 care is more concerned with insulin and blood-glucose levels than monitoring eating and activity levels. *Glooko* required the researcher to sync a Glooko Meter (a type of blood-glucose meter) to the application. After then switching to the Internet to search what this meant, it was clear that in order to

use the application you would first need to set everything up on the computer. There is no trial or preview of the application until a user syncs his personal information. This is a problem because there is no way to test out the application to decide if it has what a user needs without giving the app personal data and records. In addition, this requires multiple steps to set up. *Diabetic Connect*, shown in Figure 3a and Figure 3b, is an application that is almost strictly used for connecting and communicating with other persons with diabetes. The gap here is that there is no way to tell if the users have Type 1 or Type 2, and from first glance most users seem older. *Glucose Buddy* (Figures 4a, 4b, 4c) has a clean, easy to understand interface at first glance. The icons represent the expected logs a person with Type 1 would need to make. The items that appear to be the gaps for this app are exercise, the option for food logging, and a calculator. However, the research will help to tell whether or not these items are important. *Glucose Buddy* also does not have a social aspect to it. Finally, *Diabetes App* is shown in Figures 5a and 5b. It is similar to *Glucose Buddy* with being straightforward and simple icons in one place. Different from *Glucose Buddy*, *Diabetes App* includes an activity section, medication section, water intake, and more customizable settings, which addresses some of the gaps in other apps.



Figure 2a: Fooducate home screen has bright colors, large icons and seems easy to understand.

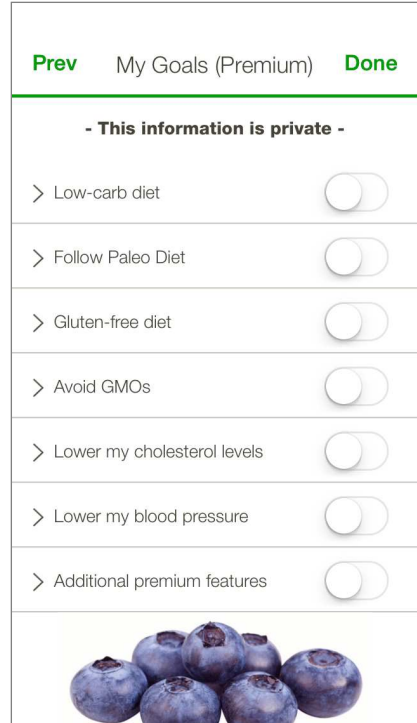


Figure 2b: Fooducate sub page displaying the list of goals a user can choose from, none of which list diabetes.

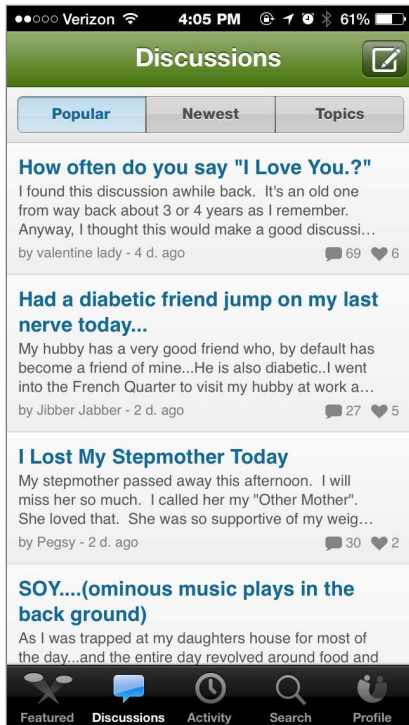


Figure 3a: Diabetic Connect app shows top discussion topics to view and reply to.

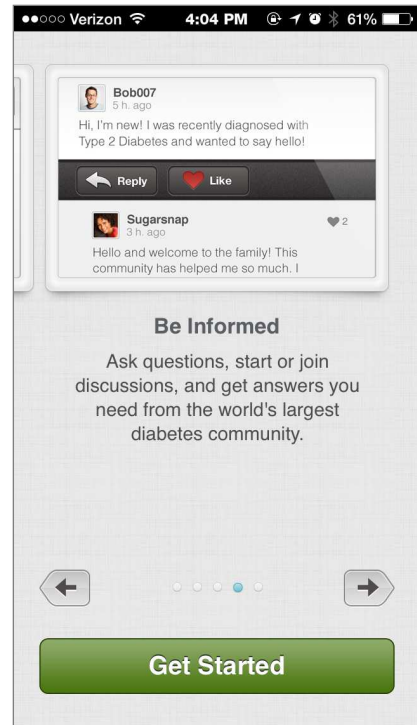


Figure 3b: Diabetic Connect tips for getting started with joining discussions.



Figure 4a: Glucose Buddy home screen showing large, basic icons

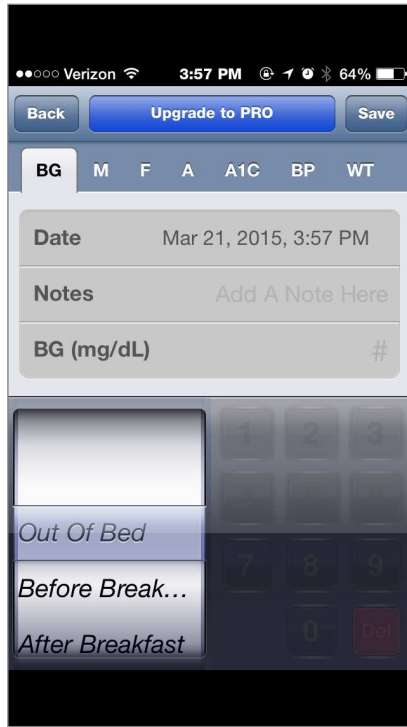


Figure 4b: Glucose Buddy log screen to enter blood-glucose at different times of day.

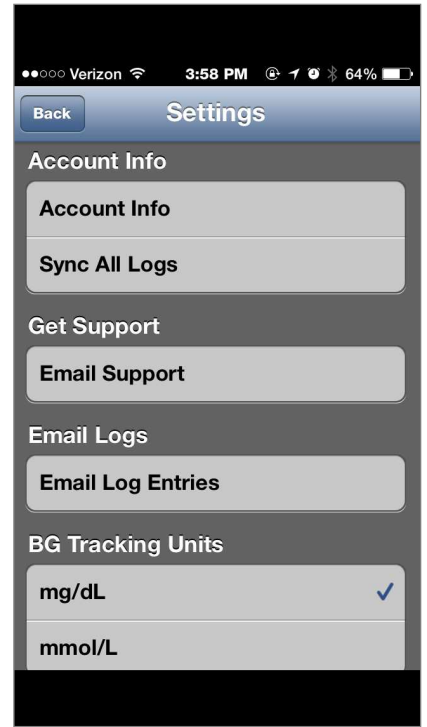


Figure 4c: Glucose Buddy settings allow users to adjust unit measurements.

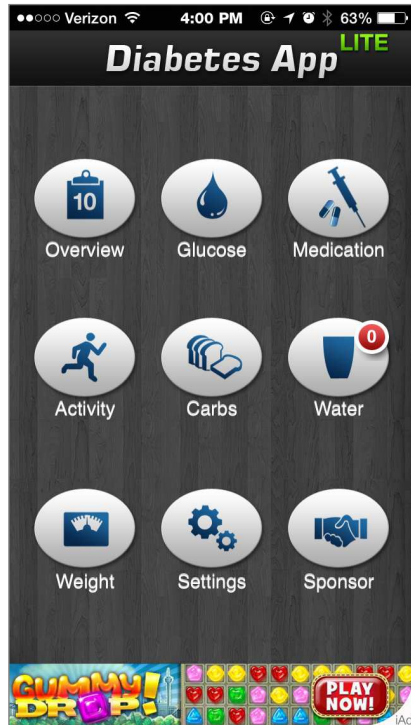


Figure 5a: Diabetes App home screen shows simplistic, readable icons.

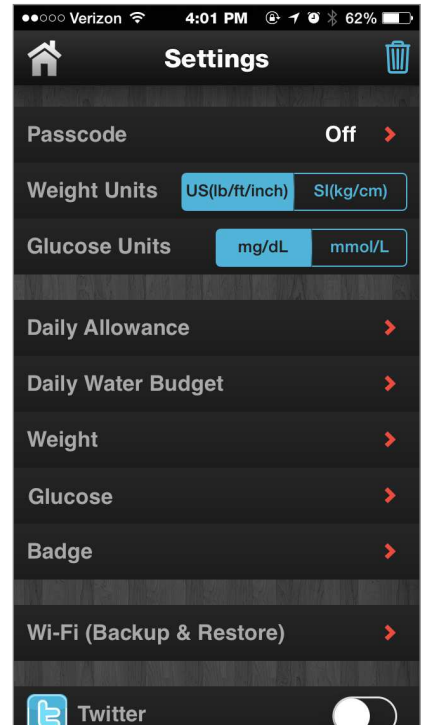


Figure 5b: Diabetes App settings are customizable for diabetes care.



## 2.2 Summary

To summarize, when dealing with Type 1 diabetes, there is a range of components to recognize. After diagnosis, sets of care options are put into place. Negative psychological effects can commonly follow diagnosis, ranging from anxiety to depression. Medical adherence is an issue that is crucial to acknowledge, considering people with Type 1 diabetes are insulin dependent. As a child matures into adolescence, there are new concerns presented with the type of lifestyles she desires. From diagnosis and beyond, support communities play a large role. These support communities have an affect on self-management habits, especially with adolescents who have a peer-focused lifestyle. Previous research leaves the following gaps: highlighting individual cases on home experiences and daily life, which can help understand what needs patients have at different age levels and from different experiences, individual opinions of current methods in place for specific homes, mobile applications related to health care, and the emotional effects of this disease. After using selected mobile applications advertised for Type 1 diabetes, a brief analysis of the gaps in these applications was addressed. The displayed applications were typically aesthetically pleasing, but were missing capabilities such as calculators, logs, features specific to diabetes, and differentiation between Type 1 and Type 2 diabetes care/needs. It can also be argued that the above applications were more data-centered instead of user-centered. That is, the apps have logging capabilities for numerous actions related to diabetes care, but lack some of the personalization and personal timeline features found in apps such as *Nike+* and *iPeriod*, which focus on the user's personal history and its patterns.

These gaps are what prompted the research method that will be discussed in Chapter 3. Based on the lack of information on individual needs from no existing needs assessment, and the importance of support for people living with Type 1, it was necessary to address the gaps by reaching out to the source: real families living with Type 1. The goal of this research is to find answers to these missing pieces to develop a complete, supported list of design guidelines.

## CHAPTER 3

### METHODOLOGY

#### 3.1 Participants

Participants for this research are parents and children in which a child of at least five years of age has Type 1 diabetes. The children must have been diagnosed for three months or more, to take into account the adjustment period and lifestyle changes immediately following diagnosis. These criteria allowed gathering information about users' needs directly from the source. These families experienced first hand the changes in their life and continue to carry out additional routines and responsibilities each day for Type 1 diabetes. Family members outside of the immediate family and families without a child with Type 1 cannot provide the same insight and knowledge. Figure 6 displays the experimental method that was followed from recruitment up until the interview session.



*Figure 6: Experimental procedure*

#### 3.2 Recruiting

It was important for the participants to understand the motivation behind this research, and thus recruiting included a personal contribution from the researcher explaining what it was like to grow up with a sibling with Type 1 diabetes. This process began with IRB approval from ISU. The recruitment process began with sending a personal letter to the director of a camp specifically aimed at children and their families

who are either newly diagnosed with Type 1 diabetes or who are continuing to live with Type 1 diabetes. The letter asked recruits to participate in an interview session to help the researcher learn about their experience with Type 1 diabetes. The director then forwarded this request and call for participants to the members of camp, who responded with interest. It is worth noting that the camp is open to all families who have a child with Type 1 who are interested, so there was no possible coercion in the director's recruiting, e.g., families feeling that they had to participate in order to gain the director's favor. There were also personal contacts made by the researcher at a diabetes Clinic. The researcher described the study to families briefly at their scheduled doctor appointments and provided a flyer with more information about why this research is being conducted, and how to contact the researcher if interested in participation.

### 3.3 Contact

After recruitment process was complete, the researcher used an algorithm to randomize the interested recruits to select the order in which participants would be contacted, since it was not feasible to interview all interested volunteers. As well as being randomized, there were also recruits who did not respond or could not schedule a time with the researcher. Those recruits were removed from the list of potential participants and the next randomly selected participant was contacted. The randomized recruits (assigned to a participant number) were contacted via e-mail. The researcher set up a time to meet either in person, on a video call, or phone call for the interview to be conducted. E-mail conversations were typically between the researcher and one or both parents of a child with Type 1 diabetes. For distant families, consent documents were e-mailed to parents prior to the scheduled interview to ensure signatures were received in time. Once

the consent documents were received (via fax or scan), parent participants were asked to complete a set of surveys via links through Qualtrics survey software either before the interview or at the start of the session.

### **3.4 Interview sessions**

Interview sessions were scheduled for 2 hours. First, parents were asked to fill out a three-part demographic survey and a self-efficacy survey. This survey was used to gather information about how parents view their child's Type 1 diabetes care, struggles, and lifestyle. As mentioned in Chapter 1, self-efficacy is a crucial component in this research for a number of reasons. Bandura (1997), states "Perceived self-efficacy is concerned with people's beliefs in their capabilities to produce given attainments." This set of self-beliefs helps researchers understand how a person differs from others through his judgments of his own abilities. Typically, the standard self-efficacy survey is customized for the topic of interest during the research. In this study, the self-efficacy survey was used at both an adult and adolescent level and customized for diabetes care. The self-efficacy survey for this research also included questions from a Diabetes Coherence Scale as well as the Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al., 2002) for diabetes. The questions used from the IPQ-R focused on the constructs of consequences, personal control, illness coherence items, and emotional representations. Participants were asked to rate the answers on a Likert scale. This scale ranged from 1-7 with 1 representing strongly disagree and 7 representing strongly agree. For the purposes of this research, timeline items, treatment control items, and timeline cyclical items were removed from the questionnaire. These items were removed because the researcher was more concerned with the personal conceptualization of diabetes, reflected in personal

control, illness coherence, and emotional representations. The questions reproduced from the Diabetes Coherence Scale pertained to which items were helpful or unhelpful in diabetes management. The list included activities such as exercising, diet, checking blood sugar, staying positive, and more. Participants were asked to rank these items from most helpful to least helpful on a scale from 1-9 respectively. Participants then chose the item that was most helpful, and the item that provides the most evidence that treatment for diabetes is working.

Due to comprehension levels differing between the different age groups, the self-efficacy survey was rewritten in two ways. First, it was rewritten in simpler terminology to be better understood by child participants. Secondly, the questions for adult participants were posed to gather the parent opinion of the child's illness. This, in turn, was not specifically asking parents how they monitor any illness they themselves may have, but rather their perception of how their children's illness affects the children and themselves. The Likert scales remained the same between the two versions.

At the time of the interview, whether in person or via video/phone call, the child participant was provided the assent document and gave the researcher verbal agreement to participate. Then, the child was asked to complete the self-efficacy survey about herself. Once the responses were collected, the interview session began. Each interview was divided into three sections. The interview included questions with just the parent responding and the child not present, questions with just the child responding with the parent present, and questions that the parent and child answered together. The interview protocol included a series of questions about the daily responsibilities and routines of living with diabetes. The researcher wanted to understand how parents view the

responsibilities they have, as well as how the child views the responsibilities she has. It was important to get a sense for the relationship between parent and child as well, which led to questions about activities each enjoys with the other, and ways they work together to take care of the child's diabetes.

### **3.5 Epistemology, data collection and analysis**

Interview design was an important area to understand in this research. There are various types of design for interviews that are widely used in order to obtain rich data through a qualitative perspective (Creswell, 2007). The type of format used in this research was general interview guide approach. General interview guide approach is more structured than informal interviews, but less structured than standardized open-ended interviews. The wording and delivery of the questions is dependent upon the interviewer or researcher (Turner, 2010). Although there are concerns with lack of accuracy, there are many benefits to this type of design. The informal environment in this type of interview session allows for the researcher to create a rapport with the participant. This then allowed the researcher to ask follow-up questions based on previous responses to planned questions. This provided the ability to make each session more personal, while maintaining a sense of structure and adaptation (Turner, 2010).

Analyzing the information required the use of a critical ethnography approach. This approach speaks on behalf of participants to not only describe, "what is," but also stating "why this is and what can be done about it" (Cook, 2005). This method tests the status quo, and can provide a path for meaningful health related practices and promotion. The analysis process is intricate, in that it involves creating meaning by naming possible implications. Critical epistemology is more concerned with the validity of the statements

and claims, and can be regarded as valid if they “make sense” within human communication (Carspecken, 1996). Since the purpose of health promotion is to influence people to take care of and take control over the situation specific to them, the goal of emancipation is shared with critical ethnography. Critical ethnography was the appropriate epistemology in this research because it aims to promote an understanding of the experiences of the research participants, as well as the social factors that influence these experiences. All of this, in turn, can have an impact on the participant’s health (Cook, 2005). This supports the goals of my research, because there is a gap of needs assessments in this field, leaving much of the experiences these families face out of the picture.

In order to analyze the qualitative data within the cognitive ethnography frame, the researcher used the approach by Tesch (1990). Tesch’s Eight Steps in the Coding Process were used to gather the richest information from the data set. Following these guidelines, he researcher read the transcripts carefully while taking notes on the content and asking the question, “What is this about?” After reading in full the first two interview transcriptions, the researcher made a short list of recurring ideas. From this, the researcher went through each interview in detail multiple times with these ideas in mind, and noting when new ideas were presented. Once each interview had been read enough times to ensure all ideas had been extracted and highlighted by color coding, this list became the set of coded categories used to separate the useful information from unrelated information. Then, the researcher took this list of the categories that emerged in the previous process, clustered them together to form a set of themes, and determined which information belonged under each theme. The themes were determined based on the



frequency of the topic within the interviews as whole, as well as the impact the topic had within the scope of the research. At the end, the researcher did recode some of the data with the categories and themes in mind, and reported on the findings below.

Once all families were interviewed, the recordings were transcribed and used for analysis. The surveys for demographics and self-efficacy were also analyzed. The scoring of the IPQ-R survey differed slightly based on the category of the questions. High scores on the consequences items represented a strongly held belief about the negative consequences of having diabetes. High scores on the personal control and coherence dimensions represented positive beliefs about how controllable diabetes is, and a positive personal understanding on the disease. The results of the ranked items in the Diabetes Coherence Scale questions in the self-efficacy survey helped to determine what the participants found to be the most helpful and least helpful items in caring for diabetes. This information guided in the decision-making process for the design guidelines and necessary capabilities of the mobile application.

### **3.6 Predictions**

Based on previous research, the researcher expects that the survey ratings for helpfulness will trend towards diet, exercise, taking medication, reducing stress and testing blood sugar levels as most helpful (low scores). The researcher predicts that parents will feel more strongly about the helpfulness of visiting doctors and knowing HbA1c levels than children, as well as with exercise. It is also expected that Self-efficacy scoring will differ between parents and children due to differing levels of understanding of the illness. More specifically, parents are expected to score Type 1 diabetes as a more serious condition, with a more negative association to the disease.

In addition, in the interviews the researcher expects parents and children to report differently on daily responsibilities. Parents are predicted to carry out more responsibilities than the child, although it is predicted that children will report higher responsibility than what is factual. The researcher also predicts that there will be a strong emotional connection to the illness. Finally, it is expected that the families will already have some type of mobile health application in place, although this might not be an app that is specific to Type 1 diabetes.

### **Positionality**

As mentioned in Chapter 1, I, the researcher, have a strong relationship to this topic. A positionality statement is common practice in qualitative research. The purpose of this statement is to provide information about the researcher. This information is provided because it is likely to have influence in the shaping and execution of the research that will be discussed (Atkinson & Sohn, 2013). After my younger brother was diagnosed with Type 1 diabetes, I was not only educated on his care and the illness, but also helped him to carry out his responsibilities. I helped remind him to test his blood glucose levels, gave him insulin injections, helped him count carbohydrates for his meals, and looked out for his general health and wellbeing. Due to living with this experience, I may be more sympathetic with families, and might be prone to overlaying my own experiences over the data. This could in turn result in ignoring some of the messages in my data because my personal experience is strong. In order to account for these biases, I asked participants to provide honest, detailed explanations. This helped to ensure that there were little to no assumptions about my prior knowledge and understanding. In

addition, to shield myself from overlaying my experiences, I tried to keep personal stories to a minimum until after the formal interview session was complete. Finally, I was sure to read and code interviews as individual words and sentences, as well as by the whole topic. This helped to guarantee that I was not forcing preconceived notions upon the data, but instead found keywords and phrases that were resonant, compelling, and frequently addressed throughout the interview sessions.

## CHAPTER 4

## RESULTS: DATA ANALYSIS

## 4.1 Survey Analysis

There were six total family interview sessions conducted. After six, I began hearing similar responses and had begun reaching saturation or redundancy in the data collected. Therefore, I felt that six sessions were sufficient for this study. Each session lasted between 40 - 90 minutes, yielding a total of 4 hours and 25 minutes minutes of audio recordings. For four of the interviews, there was only 1 parent and 1 child present. One interview had only 1 parent present. One interview had two parents present, however only 1 of them spoke. All families were dual-parent families, although mothers spoke on behalf of the parents in the sessions.













	Parent Participant	Child Participant	# Years with Type 1
Case Study 1	P1 	C1: 9 years old 	3-4 years
Case Study 2	P2 	C2: 14 years old 	3-4 years
Case Study 3	P3 	C3: 11 years old 	3-4 years
Case Study 4	P4 	Not interviewed (21 year old) 	8-9 years
Case Study 5	P5 	C5: 13 years old 	1-2 years
Case Study 6	P6 	C6: 16 years old 	>10 years

Figure 7: Participant demographics collected through pre-survey information.

Five of the participant families had not used a mobile application for long-term Type 1 diabetes management. The purpose of the self-efficacy and demographic surveys was to make comparisons between information scored in questionnaires and gained through interview conversation. Due to the small sample size it is not possible to draw statistically significant conclusions from a quantitative data analysis. Often times however, results were scored similarly high or similarly low on Likert scales between participants. These data provided evidence for further support of the qualitative analysis to follow.

Self-efficacy data presented some unexpected conclusions. The questions were scored on a 1-7 Likert scale, 1 corresponding with “strongly disagree”, and 7 corresponding with “strongly agree.” The data were run through the Wilcoxon Signed Rank Test to determine if there was any significance. All six parents scored 7 on "believe their child’s diabetes is a serious condition," whereas the 5 children scored this question an average of 3.4. There was moderate significance with this question, however not strong significance ( $Z = 2.0319, p = .0579$ ). The question pertaining to the major consequences diabetes has on their child’s life was also moderately significant ( $Z = 2.0702, p = .0533$ ) (parents mean =6.3; children mean = 3.8). This is shown in Figure 8. On the subject of whether diabetes strongly affects the way others see the child, responses had a mean score of 3, which was not mirrored during the interview sessions. This question was not significant, ( $Z = 1.633, p = .1344$ ). During interviews, the participants do believe diabetes changes how others view their child or themselves. This will be elaborated on later.

### Self-efficacy results on effect of diabetes

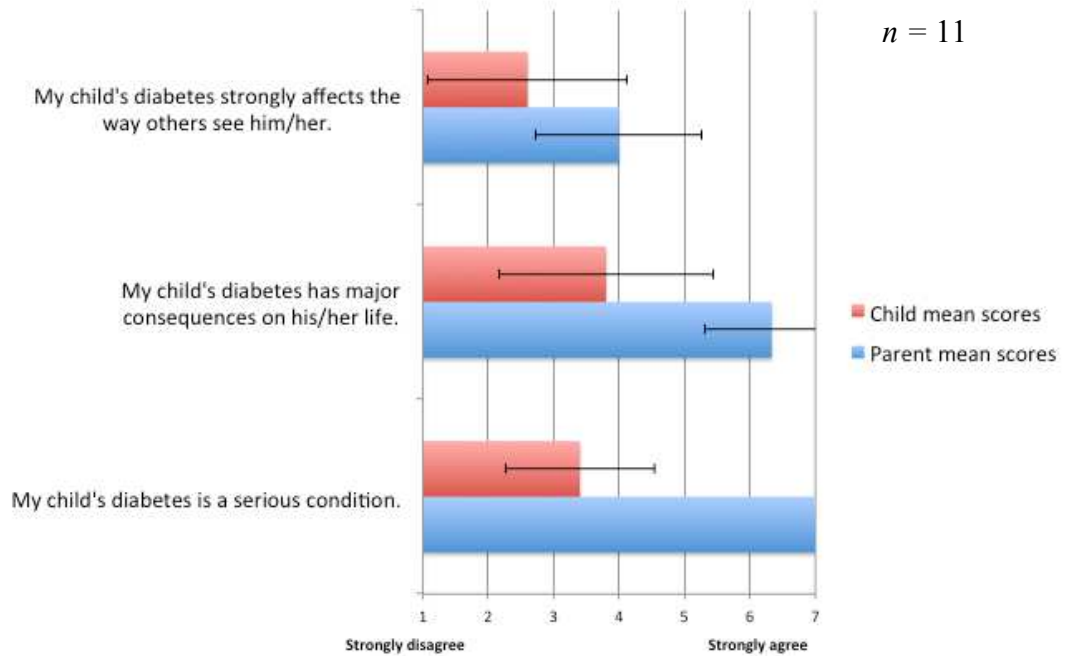


Figure 8 shows the mean scores of participants ranking the questions on a Likert scale from 1-7

Questions related to negative emotions associated with diabetes had mixed responses, represented in Figure 9. Parents scored these questions in the mid-range (depressed mean: 4.5, upset mean: 4.8, angry mean: 4.3, not worried mean: 3.3, anxious mean: 3.1, afraid mean: 2.6), where as children mostly scored these questions lower (depressed mean: 3, upset mean: 2.4, angry mean: 2.6, not worried mean: 3.6, anxious mean: 2, afraid mean: 1.6). This discrepancy was also reflected in the interviews and will be discussed below.

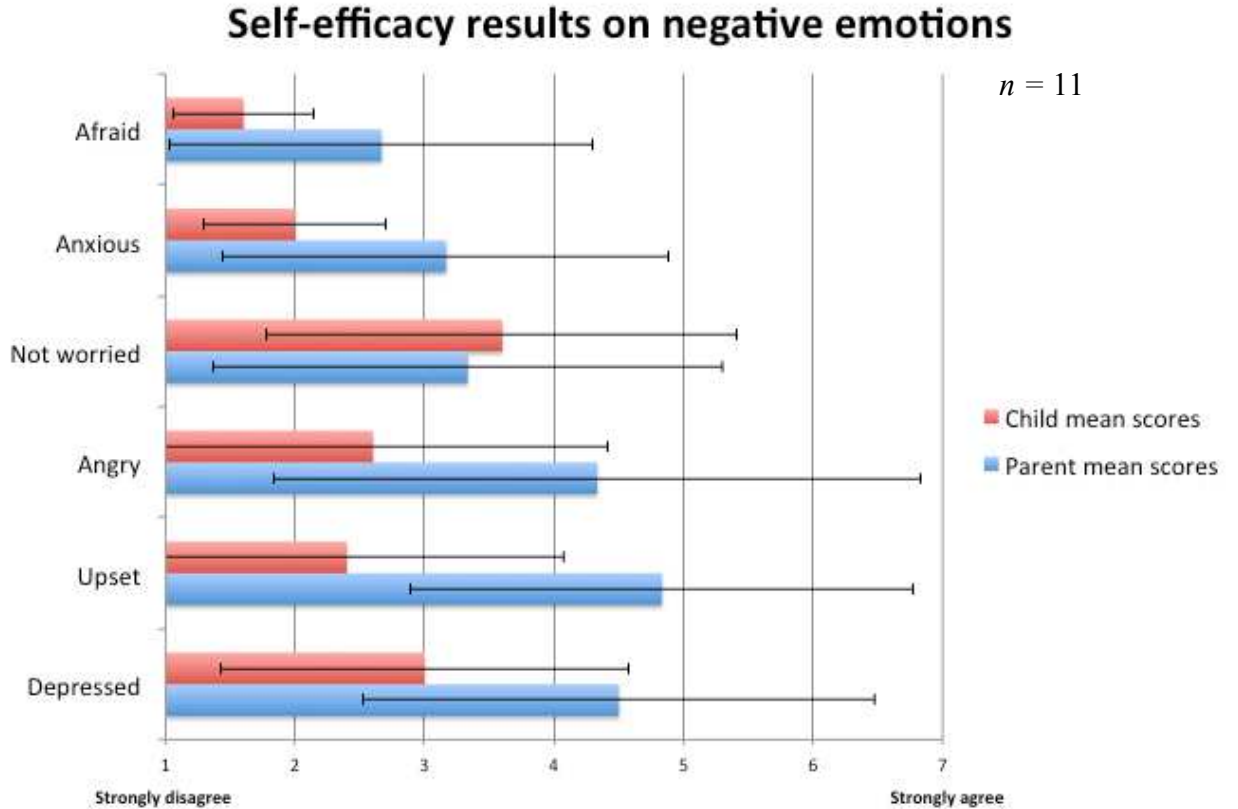
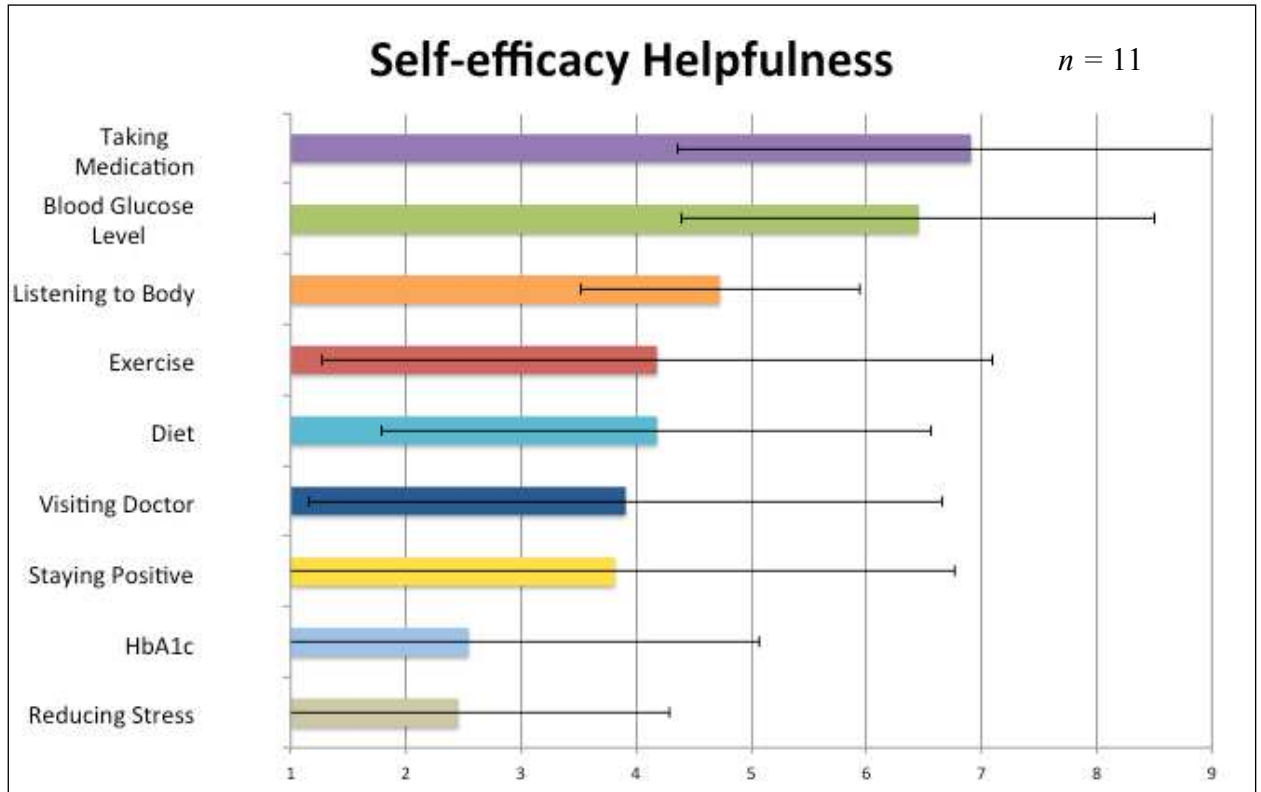


Figure 9 shows the mean scores of participants ranking the questions on a Likert scale from 1-7

Of these questions, none presented statistical significance. Depressed ( $Z = 1.6971$ ,  $p = .1814$ ), upset ( $Z = 1.914$ ,  $p = .0975$ ), angry ( $Z = .2828$ ,  $p = .9999$ ), not worried ( $Z = 1.1094$ ,  $p = .3447$ ), anxious ( $Z = 1.914$ ,  $p = .1975$ ), and afraid ( $Z = 1.3672$ ,  $p = .1975$ ). Due to the small size of the sample, this is not a surprise. The difference in the means suggest that with a larger sample size that reduces variation in a future study, this would ideally change and stronger statistical significance could be found.

From a list of nine items, participants were asked to rank each item on a scale from 1-9, with each item only corresponding to one number. 1 was the most helpful, 9 was the least helpful in managing diabetes. The items scored were exercising, diet, visiting the doctor, staying positive, taking medication, reducing stress, checking blood-

sugar, listening to the body, knowing HbA1c level. Figure 10 shows these items as most participants ranked them. The top represents the most helpful, and moves down to the bottom representing least helpful.



*Figure 10 shows the mean scores of participants ranking the items from 1-9 for how helpful – unhelpful the items are in diabetes care*

From these results, it was common across participants that taking medication (mean = 2.09) and testing blood sugars (mean = 2.54) were the most helpful items when it comes to managing Type 1 diabetes as a child and a parent. For participants, knowing the A1c level (mean = 6.45) and visiting the doctor (mean = 5.09) were scored quite high, meaning they are not as helpful in daily management.

The reports provided through the self-efficacy and demographic surveys provided a base for establishing a set of categories to code when considering the qualitative data.



These categories include communication, responsibilities, exercise, devices and technology, applications, support, school, camp, social life, feelings, diagnosis, and games. These categories were developed based on recurring information provided during the interviews.

#### 4.2 Qualitative Analysis

After coding and analyzing the interview transcripts, there were clear themes in the data that emerged. Common between both parents and children, the following themes could be identified.

1. **Daily Life:** The heavy burden of the daily responsibilities on parents, children, and siblings upon diagnosis and beyond. This information was present in 23% of the interview transcriptions (9,000/42,000 words).
2. **Emotional Effects:** The emotional effects resulting from living life with diabetes. This information was present in 8% of the interview transcriptions (3,300/42,000 words).
3. **Support:** The support from others, physically and emotionally being critical for management and acceptance. This information was present in 18% of the interview transcriptions (7,600/42,000 words).
4. **Normalcy:** Children with Type I diabetes should not feel different from other children. Children should not be defined by diabetes, which relates to how this disease makes them feel around others. This information was present in 4% of the interview transcriptions (1,300/42,000 words). This small percentage does not entirely account for the presence of this information in the above themes as well.

Finally, there was overwhelming support for an assistive application to manage Type 1 diabetes (25% of the interview transcriptions, 10,500/42,000 words). Generally, multiple interviewees agreed upon different ideas. Interviewees that are not mentioned below as supporting or disputing a specific claim did not speak to the particular idea.

### 4.3 Daily Life

In the theme of daily life, the follow categories were strongly represented: diagnosis, responsibilities, travel, exercise, and technology.

#### 4.3.1 Diagnosis

Before diagnosis, four of the six parents shared similar general symptoms experienced by their children: extreme thirst, polyuria, extreme hunger, and other unexplained sicknesses. Of the parents who discussed these symptoms, two mothers noted that they recognized the signs before fathers did. The initial diagnosis of Type 1 diabetes was unfamiliar to these families. Despite the education classes provided by the hospitals, there was a lot to be learned. P1 did not understand the seriousness, and even told her husband, “I think she has a touch of the diabetes.” Parents P1-P4 mentioned that once they figured out the routine, diabetes just became a part of life. Figuring out this routine was crucial. “I had to be on call at all times...It just kind of put everybody on high alert for a while.” (P4) The ways in which this diagnosis changed life for these families included changing food in the house, changing the daily schedule, being on call for child and school, and being in heavier communication with each other. Parent P5 already had a husband with Type 1 diabetes, so the changes to her family were less extreme in the home; the only change was having one more person to plan for. All families were required to keep paper logs that traveled back and forth between home,

school, and the doctor's office. Eventually, these logs became less crucial for families, due in part to children using a pump instead of insulin injections through syringes.

#### 4.3.2 Responsibilities

When it comes to the responsibilities that are carried out each day, age plays a large role in what the child does, and what the parents do. All six children participants test their blood sugar multiple times a day. C1, C2, C3, and C5 find it easy to remember testing before meals and when feeling low or high. C6, who is 16 years old, does not remember to test her blood-glucose nearly as much as her mother and doctors expect. Her mother, P6 said, "You know, they get more easily distracted, because they're getting more responsibilities." All children take their own insulin, assist in counting carbs, and communicate with their parents daily via text messages or phone calls. The younger child participants (C1 and C3) still check with parents before delivering units of insulin to be sure calculations are correct. As these children continue to grow, more responsibility is expected. Eventually, all children will reach the point of P4's child, who is now responsible for everything on his own. He orders his own medical supplies, checks his blood-glucose, calculates and delivers his own insulin, and makes his own meals.

Four of six parents expressed similar concerns with ordering medical supplies such as test strips for the blood-glucose meter, insulin, needles, and infusion sets for the pump. In all six sessions, parents and children expressed a different idea of what it means for the supply to run low, "He's not real great, he's not a planner, so I have to say go count... I'm always asking him or checking behind his back when he doesn't think I know." (P5) This results in parents having to place rush orders to keep their child healthy. P1, P2, P5, and P6 were complimentary of their children, explaining that despite the slip-

ups, they are mature, responsible, and articulate. Unfortunately, they noted, Type 1 diabetes forced these children to grow up at an early age, but each child has learned to adjust and take on the responsibilities. P1, P3, P4, and P5 made a point to mention the focus on health in their home, and how their meal preparation reflects this for their children. Children are included in making grocery lists to ensure not only that they are eating healthy, but also that they are eating foods that help them feel good.

### 4.3.3 Travel

When it comes to travelling, there is a long list of items that need to be packed. Children are responsible for packing strips for the blood-glucose meters, snacks in case the levels drop low, insulin, infusion sets for their pump (if they have one), glucagon for emergencies, ketone strips to measure sugar in their urine if blood-sugar levels are too high, glucose tablets, and more.

*P3: I mean, we have to make sure we have the prescriptions orders and make sure we have enough, like ten times more than you'd need or anything. Vacations are different from school. I mean, she has all her stuff at school...But if we're leaving the house for even, even a day trip, we have to make sure that you have insulin and extra set changes and stuff for the sensors for the CGM and juice and snacks.*

P1 and P2 said this process is not too stressful since they know what they need, but the preparation is time consuming. When supplies are not packed, it can be a stressful experience to purchase from a pharmacy in the area, but so far each of the two families faced with this has found success. The goal is to not forget any supplies, both current needs and backups.

#### 4.3.4 Exercise

Exercise was briefly touched upon in the interviews as well. C1, C3, and C5 noted that they regularly do some type of physical activity and find this to be helpful. C3 said, “It helps me feel better because it lowers my blood sugar.” Not only does the physical activity lower blood-glucose levels, but it helps them feel better overall. C6 works out on occasion, but has not seen a huge impact on her body from the physical activity. The motivation to exercise and feel good is mostly experienced by C1, C3, and C5.

#### 4.3.5 Technology

All child participants own multiple devices. C1, C2, C3, C5, and C6 all use their own phone, and all but C5's is a smartphone. In addition, C2, C3, and C5 use their own computer, C3 an iPod, and C5 a tablet. All of them play game applications on these devices. C5 is the only participant to use an application for diabetes management called Glucose Buddy. This application will be discussed shortly. Most parents have used some type of application for their own personal health and fitness. P4 uses three apps for her health relating to diet and exercise.

*P4: It's just easy to log in your information, and it keeps it all for you. You don't have to worry about paper or pencil. You just punch it in. It's as easy as sending a text or writing a text or email. It's just all very convenient and in one spot.*

However, only P5 finds Glucose Buddy to be helpful in monitoring her child and husband with Type 1. The other families did not mention this application, which is why P5 and C5 are the only participants who could speak to its assistance.

The other five families do not use a long-term tracking application for diabetes. P1 and P2 tried using the CarbCounter application, “which was useless” (P1's words).

The application did not include a wide enough range of foods. P2 and P3 choose to use Google for nutrition information, and P1 uses Siri on her iPhone. The nutrition information is easier to access through Google because there is no limited database. Google is also helpful because many restaurants do not have actual nutrition information available, so similar menu items can be searched for carb information. For example, Starbucks has a nutrition menu for baked goods, but not for the individual syrups and contents of the drink menu. This makes it extremely difficult to calculate how much insulin to take when ordering drinks.

All but C5 use a pump to deliver insulin and keep records. This means that the information needs to be downloaded to the computer to be printed for personal records or sent to an endocrinologist. P2 dislikes having to use the “big computer” for this task, and admits to being lazy. Many parents admitted to not downloading the information nearly as often as needed due to it seeming like a hassle. Although there is hope for new pump models to have Bluetooth and WiFi capabilities, it is not yet a reality for these families.

#### **4.4 Emotional Effects**

In the theme of emotional effects, the follow categories were strongly represented: diagnosis, and impression.

##### **4.4.1 Diagnosis**

Parent participants were eager to speak on the diagnosis of their child. P1-P6 all took a large sigh before responding to the question about diagnosis and how life changed after the news. Participants could have spoke for a long time on the subject. It was clear the experiences and memories flooded back to them.

*P1: You'll feel like your whole world collapses, and it feels that way, and it seems that way, and it does. One of these days, I'll accept it...*

For all parents but P5, this was a completely new experience, which left much to be learned and added to this feeling of holding onto the weight of the world. The unknowns of Type 1 diabetes seemed overwhelming and a large burden to take on at once. Doctors had families keeping daily paper log records that then had to be brought back to appointments. All parents agreed that eventually, it did become a part of life and a routine set in. There were changes, however, that shouldn't be ignored. P2 expressed the changes in the amount of communication between family members. Checking in, taking trips to the store, and contacting the doctor occurred far more than before diagnosis. P4 talked about how the food in the house needed to change, and how everyone's daily schedule was adjusted. P3 shared that life become more complicated between keeping track, taking extra bags everywhere, and having a young family. P3 felt more worried always wondering if her daughter was ok, "but you do what you've got to do."

#### **4.4.2 Impression**

One thing that was helpful to these parents, as noted by P1, P4, P6, was that they perceived their children as more resilient. The pain of the disease that parents feel is not the same pain the children feel emotionally, they explained, so it was important to keep life as normal as possible after diagnosis. P1 still feels out of control, which places a heavy burden on her. She is very emotionally tied, "every day I feel like I'm getting stronger." Despite P5 knowing what to expect from the disease, the emotional side of the diagnosis was not easy. C5 and P6 dealt with depression once the diagnosis and new lifestyle set in. Unfortunately, when they were depressed they didn't realize it was

happening, making the adjustment that much more difficult. P4 made a point to help understand the importance of alleviating the stress and anxiety of the disease.

*P4: You have to keep your fears about the disease to yourself, because especially with the younger children, they don't have the fear. It's not that they shouldn't be aware of the seriousness of it, but you don't need to make them so afraid of it that they have all this extra added anxiety and stress.*

P6 has had a more difficult time emotionally since her daughter is becoming resistant to self-care. She explains that teenagers don't want to be told they have to do anything, and watching her daughter care less about her disease than she did at age four is difficult. P6 became emotional when telling the researcher about an interaction she had with her daughter about testing her blood-glucose levels:

*P6: Why do you think I ask you all the time?*

*C6: Because you don't think I can do it.*

*P6: No, it's because I love you.*

This brought tears to her eyes when she shared this dialogue because no matter what, she wants to keep her daughter safe and healthy, and wants her daughter to know she nags because she loves her. Watching her daughter see only the negative side of diabetes and slack on her health regimen takes a toll on P6 as a parent. It is clear to the researcher that for P6 and the other five parents, this disease creates an emotional attachment and introduces a wide range of feelings.

The children also expressed a range of emotions associated with diagnosis. They were asked how they think a friend would be feeling if they were diagnosed tomorrow. The responses from all six children included scared, nervous, distressed, sad, upset,



depressed, and strange. They noted it would be hard, it wouldn't feel good, and with diabetes being unfamiliar there would be a lot to learn. C6 even said a person may ask, "Why me?"

It is important to note that not every reaction was negative, and there is a great deal of positivity for these families. P1, P2, P4, and P6 expressed that they try to remain positive and recognize that so much is taken for granted. P1 mentioned that the diagnosis could have been worse "in the whole spectrum of life." P1 and P2 even said they feel lucky because they are financially able to support this illness and have the support from family and friends. Parents feel as though they do not need to make a bigger deal out of the disease. One of the most resonating responses with the researcher was when P1 asked, "Why not us?" She is aware that many people ask why it had to be them, but the real question for her is "Why not?" Although the disease is difficult and "sucks" (P1), she knows her family has the support and stamina to make life for her daughter healthy and livable.

## 4.5 Support

In the theme of support, the follow categories were strongly represented: family and friends, advice, and normalcy.

### 4.5.1 Friends and Family

Due to the heavy emotional burden of Type 1 diabetes, support plays a large role in easing the transition and acceptance after diagnosis. Support from both family and friends have an immeasurable impact, which was noted time and time again in the interviews. 15 times, it was mentioned that parents of other Type 1 children helped these parents immensely. Parents were grateful for the support that reached out to them.

Siblings of the children can be helpful in certain aspects. For C1-6, all siblings know enough about Type 1 diabetes to be a general helper. When a child drops low or runs high with blood-glucose levels, siblings know what plan of action to take to help them return to a normal range. P1 is grateful for the support of her other children with her daughter, since they know enough about the disease to help her.

*P4: If she's low, she's gotten really good at taking care of it herself or having her brothers help her. They know. I mean, as much as they all harass each other, I mean, they know. And it is a relief, but it's a burden. I don't want them to feel that they are encumbered to or enslaved to it.*

C2 discussed how people just accept diabetes for what it is, and may not even realize he has diabetes. When it came to receiving support, C2 really benefitted from hearing that it would get easier to manage with time. An interesting discrepancy between P5 and C5 was that C5 claimed, "I'm not really the kind of person who looks for support on disabilities...I don't want like really major support." This was interesting, because, P5 disputed the claim made by C5 by explaining how C5 was depressed post-diagnosis and only started to return to normal after attending camp.

Diabetes Camp had the biggest praise for successful support from all six families. All parents agreed that camp was worth it, no questions asked. P4 and P5 said camp was the best support for their children. Seeing other kids with the same disease helps others learn new ways to take care of themselves such as where to give shots, different foods to try, and general positivity. It was and is a place for all of these children to connect with others who understand them. C1 and C6 talked about how much help older friends are who have been through the same experiences with diabetes already. C3 said that camp is

her favorite time. P6 discussed how camp gives these children the opportunity to connect, become educated, and learn responsibility. Much of the maturity and self-management is a result of the positive examples set at camp by directors and counselors. The children who are old enough are now becoming counselors for these camps, like P4's child, to help other children like them. The reports from participants on the benefits of camp support could not go unnoticed by the researcher in this analysis.

#### 4.5.2 Advice

Participants were asked what type of advice they would offer to a family finding out they had a child with Type 1 diabetes. Based on the positive experience from receiving their own support, these participants had a great deal of help to offer. P1 urges parents to understand that they did nothing wrong, their child will be ok, and it will get easier. As a parent, she learned and continues to learn how to carry the weight differently. All parents agree that you need to hang in there and find a routine that works for your family. P3 and P4 want parents to know that although the information is overwhelming, you learn it quickly. P5 added that staying educated is crucial to maintaining a healthy child.

*P5: Research everything you possible can for your child's disease. The more you know, the better off you are...Don't stress. Anxiety and stress affect you so much. It's not worth it. Just take it day by day and do your best.*

Some of the most important messages included realizing that you are not alone, keep life as normal as possible, and get your kids to camp. The positive peer pressure at camp and support from other families makes all the difference, parents P1, P2, P4, P5, and P6 mentioned.

Children focused more on the specifics on how to take care of yourself when you are first diagnosed. Check blood sugar, listen to your body, and be healthy were some more specific words of wisdom. C2, C3 and C6 want someone newly diagnosed to know that they can provide support, answer questions, and be of help since they know how it all works. C3 even said it will make you closer friends, and you can't give up.

*C5: "Don't stress out over everything, because stress leads to bad things with your blood levels. You want to stay as calm as possible. Just remember to take your insulin and test your blood sugar. Stay calm and everything will be okay."*

These participants were all eager to offer their advice based on what they have learned over the years. Whether the participant was 9 or 16, that maturity, care, and inclusion they all expressed seems unusual for their ages. Despite living with this chronic illness, they continue to stay optimistic and encourage others.

#### **4.6 Normalcy**

The final theme that this analysis presented was the concept of normalcy and not feeling different from other kids. P1 and P4 stressed the importance of trying to normalize Type 1 and not making their children feel different or special. According to them, Type 1 diabetes does not define the child, but rather is something about them just like anyone who has blonde hair or blue eyes. P2 tries not to make a big deal about it. When out in public places, P1 said it is hard for her child to admit she doesn't feel well. Having to step aside to test blood sugar or eat a snack makes her feel different and she puts up a fight to do it. P1 feels upset that other 9-year-olds don't have to deal with this, but she still tries to make her daughter feel like everyone else. Children noted that they like to feel normal. C1 said other kids would ask why she is testing if they don't know

anything about Type 1. This could contribute to her feeling embarrassed to test in public. C2, when asked how friends without diabetes know about his diabetes, said “People just accept it. It doesn’t really change anything.” In addition, C2 doesn’t want to feel like Type 1 is a big deal, and C5 said at school he is treated normally because no one else really knows much about diabetes. To him, it is great to feel like everyone else. Camp helps these children to not feel different because they fit in with each other. P6 described camp as “their vacation away from the world that doesn’t understand them.”

#### 4.7 Application

Participants were asked what their initial thoughts were of a mobile application to help aid in Type 1 care, including features that would be beneficial. Specifically, the questions were, "Do you think it would be fun to play a game that helped you take care of your diabetes?" (For child), “What do you think of an application on a phone, iPod, tablet, etc that you can use together to keep track of your diabetes information with?” “Would this be fun or no?” “Why?” (For both), “What are your thoughts on an application that you could use with your child to monitor their diabetes?” “Do you have any reservations about this type of application?” “What are they?” (For parent). There was an overwhelmingly positive response to this possibility, especially from participants who had tried using an existing application and were unhappy with the usability and functionality. Since all child participants enjoy playing games on different devices, and frequently text message, the application did not seem far-fetched for a child to use. Parents had more to say about this possibility than children, with some unanticipated reservations. This will be discussed in further detail in 4.6.3.

#### 4.6.1 Fun and friends

C1, C2, and C3 all used words like “fun” and “cool” to describe their initial reaction to an application for Type 1. C1 liked the idea of being able to use the application with her friends on the other end to compare progress and rankings, especially if it had a game she could play with them. She liked the idea of playing with others who have the same disease as her. Whether it was something that had a gaming aspect similar to what they are using now, or a completely new idea sparked excitement physically through smiles and widened eyes. C2 liked the idea of something similar to *TriviaCrack* because “I feel like it would be useful, and it would be fun to like communicate with others and learn more about it.” He finds this type of game enjoyable. C2 and C3 agree that it would be fun to communicate with others and not just play alone. P1 also sees the benefit of connecting with other kids to help her daughter not feel different. P4 expressed concern of the novelty of a new application wearing off. “I think it’s going to be like anything – in the beginning it’s going to be a novelty, and they’re doing to do it right away.” (P4 words) She also said that while connecting with others with Type 1 would be helpful, it would need to be monitored because “when your kids are younger, the fact that you want them talking to social media with people that you don’t know and they don’t know from all over is a scary thought.” C6 could see the benefit for younger children but both her and her mother agree that at her age of 16, an application may not make much difference. Since they currently struggle with getting her daughter to test her blood sugars at all, this might not be the best solution for them. An application would need to be engaging to keep children coming back to use it regularly.

#### 4.6.2 Information sharing

C2, C5, and C6 believe that an application would be good not only because of the ease of use and accessibility, but also because being able to share information with parents is invaluable. C2, C5, and C6 like the idea of being able to share the information with parents via phone apps, instead of constantly checking in or texting. “I think it would be cool, because then especially when he’s not around, I can know and then I can check in with him or not bug him if I don’t need to.” (P2 words) C5 would like his parents to be able to see what is going on so that as well as being informed, his parents can help to remind him to check his blood sugar or upload the data. P1 would feel comfortable and more secure knowing the information about her daughter’s wellbeing at all times. P2 and P6 could see a significant benefit when their children go to college and are no longer able to check in as frequently. They noted that there would also be the opportunity to know if they needed to contact a friend or roommate at college if they can see that her child’s blood sugar has been dropping low all day and has not been updated since.

*P6: That would be beneficial to me. I don’t want to do it because I’m checking up on her to be that nagging voice continually in her life, but I do think it would be great to have some sort of tool that could help us to protect her from being so far away.*

The accessibility between accounts where multiple family members and doctors can see the same information seemed to be one of the most popularly desired features.

### 4.6.3 Reservations

C3 raised concerns of being bugged constantly by her parents to make sure she uploaded her information. P1 raised concerns about an application being hacked or crashing: she would need to feel confident that information has a backup and is secure. P2 discussed the issue of honesty, and whether or not children would be honest with potentially more independence. This would more depend on how parents react to having the information, which leaves this concern out of control of the designers. P2 and P6 made a great point about customization: no two families are alike, and Type 1 is different for children at different ages. P3 shared that she does not have much time to learn something new. This means she would need the application to be straightforward and easy to learn. This was a common concern among families. P4 works in a school, and mentioned how typically students cannot have phones. Fortunately, according to Keima (2015), the largest school district in the country will be reversing the ban it currently has in place on cell phones in the schools. Teachers reported in the article that it is time to embrace the technology instead of punishing students for it. This is due to the importance of parents being able to contact kids. However, P4's concern is that being allowed to have a phone could make them feel different when no one else is logging and checking phones. Other than these reservations, the support for a successful, easy-to-use application was overwhelmingly positive.

### 4.6.4 Additional thoughts and suggestions

C3 already likes to be on her devices regularly, so this would not be a difficult addition into her routine. C6 feels that the app itself could provide positive reinforcement that would be helpful and beneficial to younger children. C5 sometimes forgets to log, so



there would need to be alarm and notification capabilities. C6 also mentioned this idea, since she does not like to test her blood sugar. If there was an alarm or notification that went off until she entered her numbers, this might force her to enter information. P5 feels that something like this would be less intrusive for the child, whereas P6 felt like she might know a little too much.

*P6: Part of me doesn't want to know. Part of me wants her to ... I want this to be her disease. I want to be there for her, but I don't really want to know. I don't want to have to know all those things.*

However, she can decide how much and how often to check up on the information. This concept goes back to the issue of how a parent reacts to the information they will be provided. One last suggestion worth mentioning was the idea from P6 of introducing an app at camp. This would provide children who are already friends with each other the opportunity to add each other as friends in this app to keep in touch, work together to stay healthy, share tips, and play together. Based on reports from participants, it seems as though camp instills a sense of responsibility and maturity.

## CHAPTER 5

### DISCUSSION: FINDINGS AND CONCLUSIONS

The goal of this research was to gather a rich collection of qualitative data to assess the needs of real families caring for an adolescent living with Type 1 diabetes. Previous research primarily used quantitative techniques to assess these needs, obstacles, and difficulties, which yield statistics and frequencies, but not explanations. The interpersonal aspect of previous research is notably lacking, which is why this study's qualitative approach was important in determining a list of user-centered design criteria for a new mobile application. Of the current diabetes applications described in Chapter 2, the majority of the required capabilities were present, but not as an all-inclusive application. Also, most apps were designed with more focus on the data than the user and personalization for users. Interviews helped dissect the current assistive needs for families living with Type 1, which could then be translated into the design of a mobile app. The design guidelines below are justified based on the needs described in each of the themes and their categories in Chapter 4.

#### 5.1 Findings

Based on the results in Chapter 4 under theme Daily Life, an application to aid in the self-management of Type 1 diabetes needs to do more than just collect information. The application needs to fit well within the existing daily routines and schedule of users. To relieve the burden of the numerous responsibilities, the app needs to be flexible

enough to enhance the regimen. Daily structure and routine should be complemented by an application. In addition, the application needs to be motivating.

As reported in Chapter 4 in the theme of Support, parents and children alike agreed that an application should be fun and rewarding. One way this user need can be met in terms of design is through gamification. Gamification is the act of implementing video game elements to non-gaming systems. An example of this is with fitness apps, such as *Nike+* and *FitBit*. These apps promote healthy lifestyle and achievements by rewarding users with badges and level advancements based on daily progress. There are goals users set out to achieve, and the application provides some type of reward for reaching these goals. The purpose of this approach is to drive user engagement through motivation and rewards (Deterding, Sicart, Nacke, O'Hara & Dixon, 2011). As noted in Chapter 4, participants supported this concept by expressing interest in playing a game with friends, feeling rewarded by having a ranking system or level achievements, but also being able to keep track of glucose levels, carb intake, etc. There was also a reference to an app similar to *TriviaCrack*, which follows a similar concept. The potential users want something fun, and something that will instill rewards and motivation. By implementing gamification, children can be ranked among their friends with diabetes, and rewarded for carrying out healthy behaviors. Intrinsic motivators could eventually replace these extrinsic motivators if self-management and medical adherence benefits from the application structure.

As noted in Chapter 4 in the themes Emotional Effects and Daily Life, after diagnosis, life becomes difficult and changes quickly for families. Not only do the foods in the house change, but also the way a family plans for meals and outings becomes

completely new. It is common to forget certain medical items when leaving the house for travel, which then presents an entirely new problem. Families work with pharmacies they don't normally use to try and buy the supplies they need when away from home. This is not an easy task, and would make traveling less stressful knowing nothing was forgotten. In addition, there are a large number of responsibilities that are introduced immediately that need to be remembered, sometime multiple times a day. Incorporating this routine all at once can be daunting. Having to remember exactly how to count carbs, calculate insulin, how to deliver the shots, how often to test blood sugar levels, and more is not easy to remember. Education classes can be helpful, and over time these will all become routine. However, in the beginning and as children grow older and take on more responsibilities, certain aspects of care can be easily forgotten. These findings are important to application design because an app could have the ability to set reminders, save checklists, and have calendar events. Events for upcoming travel could alert users when they need to order supplies, prompt the checklist in the days leading up, and remind users to pack items they have not checked off the list. In addition, these could be useful tools for day-to-day responsibilities.

Emotionally, living with Type 1 diabetes and caring for someone with Type 1 diabetes is not easy (as noted under Chapter 4, Emotional Effects). There are a number of feelings that can be associated with the disease, and unfortunately many are negative. Parents and children feel frustrated, angry, sad, and the participants frequently reported episodes of depression. One way to address the emotional toll this disease takes on families is through support. As noted under theme Support, support from families and friends provide an immeasurable sense of stability. In addition to this support, diabetes

camp programs were talked about at a very respected level. Diabetes camps for children with Type 1 diabetes provide a sense of community to these children. Camp allows these children to feel normal, and to realize they are no different than everyone else there. Understanding and learning about diabetes together helps instill responsibility. Campers learn new things together, such as new places to insert a pump infusion set, or new places to take insulin shots. They can help each other learn about foods to eat, ways to remember everything, and make lifelong friendships. This enforces the need for some type of support capability within an application. Being able to connect with friends at camp, or even others from around the world has the potential to enhance the emotional state of both newly diagnosed users and those diagnosed previously.

As also reported in Chapter 4 under theme Emotional Effects, children with Type 1 diabetes tend to be more resilient than parents and other family members. In four sessions, the parent praised her child's ability to be able to stay positive and continue living life as if nothing changed. This is something that can be difficult for parents because separating the pain a parent feels vs. the pain his child doesn't feel is challenging. Children are educated and are made aware of the seriousness of the disease. In addition, it is important for a child to understand that if she takes care of herself, she will be ok. A child needs to be in a position to take care of himself to the best of his ability at his age. A 13-year-old has different responsibilities than a 5-year-old, as proven by the interviews. This aspect is an important thing to remember when caring for a child with Type 1, and when providing assistance for a child with Type 1. These are considerations an app design would need to cover.

## 5.2 Application guidelines/requirements

With a positive support for a mobile application for children with Type 1 diabetes (per Chapter 4, section Application), it is important to discuss the proposed solution for an application. Mobile applications on the market advertised for Type 1 diabetes have three primary gaps.

1. They may combine Type 1 and Type 2 diabetes user.
2. They do not truly offer any diabetes components and instead focus on daily health (which is more applicable for Type 2 diabetes users).
3. They do not include a full spectrum of features for users.

Participants expressed a need for an application that is not only easy to use, but also easy to learn. If the application is too difficult, it will not be adopted. This is because there is already heavy cognitive load on new families learning about this disease. Adding another level of difficulty would not be helpful in lessening stress. Instead, the application would need to be straightforward, clean, and easy to pick up with a few tips or hints. In addition, information provided from El-Gayer et al., (2013) metaview, current self-management applications focus heavily on data entry and are data centered, instead of user center, focusing more on the other areas a user needs. After the detailed needs assessment presented above, the researcher has been able to integrate these results with previous research to create a list of feature requirements for a mobile application that could best benefit the target audience.

1. **Blood glucose level log:** As one of the most heavily discussed actions and responsibilities by both parents and children, this is a feature that an application would need to have. Keeping track of blood glucose levels with Type 1 diabetes is

one of the most important actions to carry out a minimum of three times a day. Having a place to log these blood sugars allows parents to keep track of the changes throughout the day. This log feature addresses the need described in Section 4.3.2 about responsibilities. While younger children check in with parents regularly, this is not the case with older children (teenagers). As the responsibility is handed off from parent to child, this feature allows parents to ensure the habits are being formed. This will also help users remember the trends of the day to adjust insulin dosages accordingly. The ability to view these logs in a chart would be beneficial to refer back to days when blood glucose levels were out of range, or to replicate dosages on similar meal days. The feature caters to the parents who spoke to keeping informed when their children go away to college, when information from their child may not otherwise be as accessible.

2. **Insulin dosage calculator:** As a newly diagnosed child, learning how to calculate the amount of insulin to inject is difficult. Each patient is different because the carbohydrate to insulin ratio is unique to each patient, determined by a doctor. The calculator would have information that corresponds to the individual child's needs, ratios, etc. A child could calculate the insulin amount with parents to develop an understanding of how to correctly perform calculations to potentially help take on this responsibility earlier on. In addition, a personal profile would need to be created for the unique carb to insulin ratio, since it does vary. Just as in the first feature, this also corresponds to the responsibilities reported in Chapter 4 between parent and child.

3. **Insulin dosage log:** Keeping track of how much insulin can help patients refer back to what may contribute to certain trends. This log ideally would be linked to the insulin calculator and have a button allowing users to save the information on the same page. This log would be helpful for parents and doctors to ensure a child is taking the correct dosage and calculating correctly. It was reported in Chapter 4 that different emotions, such as stress, and physical activities play a role on blood glucose levels. These can be adjusted at times with insulin injections. This is also a helpful feature for the parents who only check in with their children once or twice a day because now they can see information more regularly if they so choose.
4. **Social network/messaging:** Support from others with the same illness has been proven to be one of the best resources for children and parents. Allowing users to add friends from camp, school, and anywhere else they meet another person with diabetes allows the user to keep in touch. Messaging capabilities allow for the user to share stories and give advice to others. Posting on a child's success will also allow for others to see the progress of a friend, and can assist in pushing them to be successful as well. This relates to the information presented in Chapter 4 related to support from friends and family, as well as normalcy. The benefits of physical and emotional support were heavily supported, thus making this feature a crucial component.
5. **Sync between multiple accounts** (cloud-based): One capability that was requested was being able to view a child's information from a parent's personal device. The parent would have a different account than his child, because the



child's account would cater to her needs. The parent account may have different settings. This would also mean that if a parent entered his child's insulin dosage for dinnertime, it would show up on the child's end of the application as well. This related directly to the emotional effects reported in Chapter 4, specifically Section 4.4.2, Impression. It was found that parents need to help alleviate the stress and anxiety put on their children with this illness by keeping fears to themselves. By having this information at their fingertips, parents may be able to check up on their children in a less intrusive way.

6. **Sync between all devices** (smartphone, tablet, computer, laptop, medical records/charts): Participants complained about having to use the home computer to sync information from the glucose meter or pump. This is something that should happen either weekly or monthly. As reported in Chapter 4 under the theme Daily Life, parents shared that since this is outside of a their daily routine, they does not remember to download the information as often as they should. Syncing the information every week or month to a computer would allow for the information to be easily backed-up, and easy to send to doctors. Participants expressed hectic schedules and lifestyles. This feature can help remove one item off of the to do list.
7. **Syncing information to medical records**: One of the responsibilities of families is downloading the information from the pump or glucometer before going to the doctor's visits. The application would instead be able to send the information to the doctors ahead of time, or during a moment of crisis when something is wrong. This feature would eliminate an extra step for parents and doctors, a step that

parents reported they do not carry out nearly as often as they should. As mentioned previously in Chapter 4, this is a responsibility that can be easily forgotten and not carried out by participants. This capability would help to alleviate the stress of downloading information, or having to travel back and forth with paper logs.

8. **Notifications and reminders:** Remembering to test blood sugar as frequently as a patient can be hard when life is hectic. Setting reminders and notifications to test blood sugar levels, order more supplies, and even lists of what to pack when traveling can help eliminate some daily stressors. Notifications and reminders can also be set and sent by parents. This would also be useful if a parent notices her child has not uploaded recent blood glucose levels or has not eaten in a few hours and needs to. This addresses the issue that was presented in Chapter 4 about children feeling like parents are nagging them. If parents have the ability to see that a child has or has not added new information to the logs, they already know whether or not the child needs to be bothered about a certain action. For example, if a child tested his blood sugar level before dinner, a parent could get this notification to her phone and not ask the child again whether or not he tested. Notifications and reminders are also useful for travel plans, ordering supplies, etc. Setting reminders to calendar dates can help ensure supplies are ordered on time, and help children understand how far in advance supplies need to be ordered. This was a concern addressed in Chapter 4, with parents and children have different concepts of what running low in supplies means.

9. **Customizable settings:** As mentioned, children at different age levels have different amounts of responsibility. Being able to add and remove features will help the application's usability and understanding for younger users vs. older ones. In addition, parents and children will be requiring different capabilities of the application and would benefit from the ability to make these changes. This was an issue addressed by both P2 and P6. In Chapter 4, it was discussed how the responsibilities change as children mature, which is what P2 and P6 are dealing with currently. This may mean that as a child, there are fewer options available for logging to not overwhelm a young child, and as they get older more can be added in. This can also be related to the fact that no two families are exactly alike, and needs will differ between children and family units.

Components that are less crucial, based on lower prevalence of these needs mentioned in interviews, include:

10. **Exercise activity log:** While exercise is helpful in keeping blood glucose levels in a healthy range, not all participants found this to be one of the most important factors in personal health care. This log could be beneficial for users who regularly exercise and use this as a method of staying healthy.
11. **Food log:** Logging foods is not a top priority for any of the participants. There are already a number of items being logged daily, so this could be an added bonus for families in the beginning of diagnosis, but not necessarily long term.
12. **Recipe database:** Many restaurants do not offer full nutrition information, which is why many participants reported using Google instead of other applications with this information. However, some users may find this to be beneficial.

### 5.3 Conclusions

It has been made clear through both literature review and qualitative data analysis that a diabetes mobile app that adheres to these guidelines and requirements would appeal more strongly to people with Type 1 diabetes than previous apps, and that such an app has the potential to improve their self-management. This research is one of the only needs assessments of its kind. Through an extensive literature review, gaps in the research with both Type 1 diabetes information and Mobile Applications for Type 1 were uncovered. These gaps were then addressed through a qualitative approach to gathering information through interview sessions. Qualitative analysis showed the benefit of an application, and addressed the gaps in the previous research. This supported the claims made for an application and requirements to put in place. However, future work is needed to continue the assessment and further validate the findings.

### 5.4 Future Work

For future work, the answer to this problem may not be that an entirely new application be made, but rather that an existing application be adjusted by adding new features. It could potentially be beneficial to explore applications used by other support communities. Through this process, future work can gather information on successful support aspects for other illnesses, diseases, and communities where there is already success, and apply these concepts to Type 1 diabetes application requirements. Application designers could also team up with hospitals and camp programs to introduce the application with the patients present. By introducing the application while children are with other friends with diabetes, or at doctor's offices, the adoption could be

increased. The immediate connection between other parents, other children could have a positive impact on the success of the application. In addition, training families to use the application while being educated on the other responsibilities could be beneficial as well. A final suggestion would be to incorporate the work done in cooperative inquiry, which is a method of participatory design involving children. These children partner with designers and researchers to enhance an application for the target audience (Yip, Clegg, Bonsignore, Gelderblom, Rhodes, & Druin, 2013). Since this research is specific to children's needs, this would be an appropriate opportunity to test this concept further in the stages of designing an application including the feature requirements and guidelines.

### **5.5 Limitations**

There is a need for a more heterogeneous pool of participants. The benefit of speaking with families differing in race, SES, family structure, and age can help provide more information on experiences. Since all children interviewed attend camp, it would be beneficial to speak with children who do not have this support outlet and the impact it has emotionally. In addition, if this research was funded and had a longer time frame, it would be worthwhile to interview families across the country. This could influence the emotional aspect and support aspect of the disease, especially for a family without health insurance or in a less stable financial situation. Areas where the Type 1 community is not already established could have an impact as well.

This study provides a qualitative evaluation of the needs of families affected by Type 1 diabetes, with the aim of proposing a set of criteria to help alleviate the daily struggles of self-management, medical adherence, and other responsibilities.

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## APPENDIX A

## SURVEYS &amp; INTERVIEWS

T1Dapp\_I\_PreSurvey.docx

**Demographic Pre-Survey Part 1****Study Title:** Design of Mobile Application for Children with Type 1 Diabetes

1. What is your age?
2. What is your race?
  - a. American Indian or Alaska Native
  - b. Asian
  - c. Black or African American
  - d. Native Hawaiian or other Pacific Islander
  - e. White
  - f. Other: (please specify)
3. What is your ethnicity?
  - a. Hispanic or Latino
  - b. Not Hispanic or Latino
4. What is your highest level of education?
  - a. High School
  - b. Associates
  - c. Bachelors
  - d. Masters
  - e. Doctorate
5. What is your profession?
6. With which do you identify?
  - a. Male
  - b. Female
  - c. Other:
7. What devices do you own?
  - a. SmartPhone
  - b. Tablet
  - c. Laptop
  - d. Desktop computer
  - e. Other \_\_\_\_\_
8. If you own a smartphone, describe how you use it:
  - a. Just for phone calls
  - b. Phone calls and basic app use (email/messaging, weather, camera)
  - c. Phone calls and heavy app use (the above apps, plus Internet browser, music, GPS, games, social media, etc.)

T1Dapp\_J\_PreSurvey.docx

9. How often do you play video games?

- a. Never Play
- b. Rarely Play
- c. Play Monthly
- d. Play Weekly
- e. Play Daily

10. Have you used any mobile phone applications for health management?

Please list all that apply.

---

11. Do you have diabetes?

- a. Yes
- b. No

12. Do you have a child with diabetes?

- a. Yes
- b. No

T1Dapp\_J\_PreSurvey.docx

**Demographic Pre-Survey Part 2**  
**If you have diabetes:**

1. How long have you had Diabetes?
  - a. Less than 1 year \_\_\_\_\_
  - b. 1-2 years \_\_\_\_\_
  - c. 3-4 years \_\_\_\_\_
  - d. 4-5 years \_\_\_\_\_
  - e. 6-7 years \_\_\_\_\_
  - f. 8-9 years \_\_\_\_\_
  - g. More than 10 years \_\_\_\_\_
  
13. Have you used any mobile phone applications for diabetes management?  
Please list all that apply.  
  
\_\_\_\_\_

T1Dapp\_J\_PreSurvey.docx

**Demographic Pre-Survey Part 3**

**If you have one or more children with diabetes:**

2. How many children do you have?
  
3. What are your children's ages?
  
4. How many of your children have Diabetes?
  
5. How long have your children had diabetes? *(Select all that apply and label corresponding child's age)*
  - a. Less than 1 year \_\_\_\_\_
  - b. 1-2 years \_\_\_\_\_
  - c. 3-4 years \_\_\_\_\_
  - d. 4-5 years \_\_\_\_\_
  - e. 6-7 years \_\_\_\_\_
  - f. 8-9 years \_\_\_\_\_
  - g. More than 10 years \_\_\_\_\_

\_\_\_\_\_

6. Have you used any mobile phone applications for diabetes management?  
Please list all that apply.

\_\_\_\_\_

## Self-Efficacy Survey

Please indicate how much you agree or disagree with the following statements about your diabetes by selecting the appropriate box.

*(Note: all responses will be recorded on a 1-7 Likert scale)*

1. My diabetes is a serious condition.
2. My diabetes has major consequences on my life.
3. My diabetes does not have much effect on my life.
4. My diabetes strongly affects the way others see me.
5. My diabetes has serious financial consequences.
6. My diabetes causes difficulties for those who are close to me.
7. There is a lot which I can do to control my symptoms
8. What I do can determine whether my diabetes gets better or worse.
9. The course of my diabetes depends on me.
10. Nothing I do will affect my diabetes.
11. I have the power to influence my diabetes.
12. My actions will have no affect on the outcome of my diabetes.
13. The symptoms of my condition are puzzling to me.
14. My diabetes is a mystery to me.
15. I don't understand my diabetes.
16. My diabetes doesn't make any sense to me.
17. I have a clear picture or understanding of my condition.
18. I get depressed when I think about my diabetes.
19. When I think about my diabetes I get upset.
20. My diabetes makes me feel angry.
21. My diabetes does not worry me.
22. Having this diabetes makes me feel anxious.
23. My diabetes makes me feel afraid.

Please rate the following items based on how helpful or unhelpful they are in managing your diabetes:

- A. Exercising
- B. My diet
- C. Visiting my doctor
- D. Staying positive
- E. Taking my medication

- F. Reducing stress
- G. Checking my blood-sugar
- H. Listening to my body
- I. Knowing my A1c

From the list above, which letter corresponds to the item you feel the most helpful in managing your diabetes?

From the list above, which letter corresponds to the item you feel provides the most helpful evidence that your diabetes treatment is working?

### Self-Efficacy Survey (age 5-10)

Listen to the questions as I read them out loud to you. Please tell me how much you agree or disagree with the things I say by telling me your answer on this scale. (not at all --- very much)

*(Note: all responses will be recorded on a 1-7 Likert scale)*

1. Do you think your diabetes is a very big problem?
2. Does your diabetes make things in your life very difficult?
3. Does your diabetes not make things in your life very difficult?
4. Do you think kids see you differently because of your diabetes?
5. Does your diabetes cost a lot of money?
6. Does your diabetes make it hard for your parents to take care of you?
  
7. Do you think you know how to take care of your diabetes?
8. Do you think you get to decide what makes your diabetes good or bad?
9. Do you think you have power over your diabetes?
10. Do you believe nothing you do will make your diabetes better?
11. Do you think you can change your diabetes?
12. Do the things you do everyday change your diabetes?
  
13. Is the way your diabetes makes you feel confusing?
14. Do you think diabetes is a mystery to you?
15. Do you think you don't really understand what your diabetes is?
16. Does your diabetes not make sense to you?
17. Do you think you do understand what your diabetes is?
  
18. Does your diabetes make you feel bad?
19. Does thinking about your diabetes make you feel upset?
20. Does thinking about your diabetes make you angry?
21. Are you not worried about your diabetes?
22. Do you think your diabetes might get worse?
23. Are you afraid of having diabetes?

Please rate the following items based on how helpful or unhelpful they are in managing your diabetes:

- A. Exercising



- B. My diet
- C. Visiting my doctor
- D. Staying positive
- E. Taking my medication
- F. Doing relaxing things
- G. Checking my blood-sugar
- H. Listening to my body
- I. Knowing my A1c

From the list above, which letter corresponds to the item you feel the most helpful in managing your diabetes?

From the list above, which letter corresponds to the item you feel provides the most helpful evidence that your diabetes treatment is working?

### Self-Efficacy Survey (age 11-17)

*(Note: if child can read questions by themselves, they will be asked to do so. If not, questions will be read out loud by the PI and responses will be provided verbally).*

Please indicate how much you agree or disagree with the following statements about your diabetes by selecting the appropriate box.

*(Note: all responses will be recorded on a 1-7 Likert scale)*

1. My diabetes is a serious problem.
2. My diabetes has major effects on my life.
3. My diabetes does not have much effect on my life.
4. My diabetes strongly affects the way other people look at me.
5. My diabetes is very expensive for me/my parents.
6. My diabetes is hard for my family and friends.
  
7. There is a lot that I can do to control my diabetes.
8. What I do will make my diabetes better or worse.
9. Change in my diabetes depends on me.
10. Nothing I do will affect my diabetes.
11. I have the power to influence my diabetes.
12. My actions will not affect on the outcome of my diabetes.
  
13. The symptoms of my condition are confusing to me.
14. My diabetes is a mystery to me.
15. I don't understand my diabetes.
16. My diabetes doesn't make any sense to me.
17. I have a clear picture or understanding of my diabetes.
  
18. I get depressed when I think about my diabetes.
19. When I think about my diabetes I get upset.
20. My diabetes makes me feel angry.
21. My diabetes does not worry me.
22. Having this diabetes makes me feel anxious.
23. My diabetes makes me feel afraid.

Please rate the following items based on how helpful or unhelpful they are in managing your diabetes:

- A. Exercising
- B. My diet

- C. Visiting my doctor
- D. Staying positive
- E. Taking my medication
- F. Doing relaxing things
- G. Checking my blood-sugar
- H. Listening to my body
- I. Knowing my A1c

From the list above, which letter corresponds to the item you feel the most helpful in managing your diabetes?

From the list above, which letter corresponds to the item you feel provides the most helpful evidence that your diabetes treatment is working?

### Self-Efficacy Survey

Please indicate how much you agree or disagree with the following statements about your child's diabetes by selecting the appropriate box.

*(Note: all responses will be recorded on a 1-7 Likert scale)*

1. My child's diabetes is a serious condition.
2. My child's diabetes has major consequences on his/her life.
3. My child's diabetes does not have much effect on his/her life.
4. My child's diabetes strongly affects the way others see him/her.
5. My child's diabetes has serious financial consequences.
6. My child's diabetes causes difficulties for those who are close to him/her.
  
7. There is a lot which my child can do to control his/her symptoms
8. What my child does can determine whether his/her diabetes gets better or worse.
9. The course of my child's diabetes depends on him/her.
10. Nothing my child does will affect his/her diabetes.
11. My child has the power to influence his/her diabetes.
12. My child's actions will have no affect on the outcome of his/her diabetes.
  
13. The symptoms of my child's condition are puzzling to him/her.
14. My child's diabetes is a mystery to him/her.
15. My child doesn't understand his/her diabetes.
16. My child's diabetes doesn't make any sense to him/her.
17. My child has a clear picture or understanding of his/her condition.
  
18. My child gets depressed when he/she thinks about his/her diabetes.
19. When my child thinks about his/her diabetes he/she gets upset.
20. My child's diabetes makes him/her feel angry.
21. My child's diabetes does not worry him/her.
22. My child having this diabetes makes him/her feel anxious.
23. My child's diabetes makes him/her feel afraid.

Please rate the following items based on how helpful or unhelpful they are in managing your child's diabetes:

- A. Exercising
- B. My child's diet
- C. Visiting my child's doctor
- D. Staying positive
- E. My child taking his/her medication

- F. Reducing stress
- G. My child checking his/her blood-sugar
- H. My child listening to his/her body
- I. My child knowing his/her A1c

From the list above, which letter corresponds to the item you feel the most helpful in managing your child's diabetes?

From the list above, which letter corresponds to the item you feel provides the most helpful evidence that your child's diabetes treatment is working?

T1Dapp\_M\_InterviewQuestions.docx

### PARENT INTERVIEW QUESTIONS

**Study Title:** Design of Mobile Application for Children with Type 1 Diabetes

This list of questions includes the primary topics of interest for the interview. However, not all questions will be used, and some related questions not listed might be asked in natural follow-up conversation.

- When your child was diagnosed, in what ways did your lifestyle change?
- Please list your responsibilities for your child with diabetes?
- Please list your child's responsibilities for their diabetes?
- What is a typical day for you in regards to your child's diabetes?
- Do your other children help your child with their diabetes? How?
- What are some methods you use for scheduling, logging, and other tracking?
- (If they have used other applications for health) Can you explain how you used other applications for healthcare and/or diabetes?
- What are your thoughts on an application that you could use with you child to monitor their diabetes?
- Do you have any reservations about this type of application? What are they?
- What is your current method for monitoring your child when they are not with you?
- What would your advice be to another family who just found out their child had Type 1 Diabetes?

### PARENT-CHILD INTERVIEW QUESTIONS

- List and describe a few activities you enjoy doing together.
- How do you work together to take care of diabetes?
- List and describe any games you like to play together?
- What do you think of an application on a phone, iPod, tablet, etc that you can play together and keep track of your diabetes information together with? Would this be fun or no? Why?
- What are some things you have to get ready for going to/on school, trips, vacation, etc to make sure you have everything you need to take care of your Diabetes?

### CHILD INTERVIEW QUESTIONS

- Can you draw a picture of yourself on a typical day? Add as much detail as you can think of. (If needed: with what you would wear, what you would bring with you, where you would be going.)
- How old are you?

## T1Dapp\_M\_InterviewQuestions.docx

- How old were you when you were diagnosed with diabetes?
- What are your responsibilities for your Diabetes every day?
- Can you tell me about sports or activities you do for fun?
- Do you have any friends who have diabetes? Can you tell me about them?
- Do you think it would be fun to play a game that helped you take care of your diabetes? What if you could play the game with you friends?
- Do you have an iPod, phone, tablet, computer, etc?
- What kinds of things do you do on those devices?
- Does your sibling(s) help you take care of yourself or do you help your sibling(s) with diabetes?
- How do you remember to test your blood sugar?
- Can you tell me some things you are interested in?
- What do you want to be when you grow up?
- What is your favorite part of the day? What is your least favorite part of the day?
- What is your favorite color?
- What is your favorite food? Least favorite food?
- If you had a new friend who found out they had diabetes, what would you tell them to make sure they do? What do you think they would be feeling?
- Do you think a game would help my brother take care of his diabetes? How come?

## APPENDIX B

## INTERVIEW TRANSCRIPTIONS

**Design of Mobile Application for Type 1 Diabetes****Interview #1 – 1/26/15****Interviewer (“I”): Amanda Skinner****Parent (“P”)****Child (“C”)**

---

I Okay, ready? So can you tell me how old you are?

P Sorry. Okay, go ahead.

C I’m nine.

I You’re nine, okay. And how old were you when you were first diagnosed with diabetes?

C Six.

I Six years old. Okay, so can you tell me, since you were diagnosed, what your responsibilities are for your diabetes every day that you take care of?

C Checking my blood sugar, taking insulin, and counting my carbs.

I Okay. Can you tell me, during the day or during the week, any sports or activities that you like to do for fun?

C Well, I play soccer, and during the winter I ski, and I also do gymnastics.

I Ooh, that sounds like fun. So you like to stay really active?

C Yeah.

I Do you find that to be helpful?

C Yeah.

I Yeah? (Kind of lost my place.) Okay, so you said that one of your responsibilities is to test your blood sugar. How do you remember during the day that you have to test your blood sugar?

C It’s just like, as I grew, like every day I remember like to test it, like in the morning to test it and like before lunch to test it, and it’s really easy to remember that.



- I Okay, so you're good about testing your blood sugars then? Good. That's awesome. Do you have any friends who have diabetes?
- C A few.
- I Can you tell me a little bit about them?
- C Yeah. One of them is named --. She's trying to. She had diabetes when she was two years old.
- P You [inaudible] -- --.
- I Yeah.
- P Oh, you know, okay, you know.
- C Yeah.
- P Who else is your friend? She might know her.
- C [inaudible]
- P Yes, tell her. --.
- C She met --. She went to \_\_\_\_ School, and I know her sister and her brother.
- I Okay, thank you.
- C And I have a friend named --.
- P Do you know -- --?
- I Huh-uh.
- P He's younger than you, okay. He's just in [inaudible] --.
- I Okay, all right. So is it helpful to know other people that have diabetes?
- C Yeah.
- I Yeah? How come?
- C Because they're like older than me, so like they give me advice.
- I Yeah, absolutely. That's awesome. Okay, so, based on earlier, I'm interested in the answer to this question: Do your siblings help you take care of yourself with your diabetes? Do they help out?

- C Yeah, like my brother --, he, like in the morning I will sometimes drop on weekends, and my parents and my brother, my other brother's asleep. So like I say, [inaudible], so he runs up the stairs but really slightly, grabs my tester and grabs me to [inaudible].
- I That's awesome.
- P And they help out tonight.
- C Yeah.
- I Good. So is it helpful to have them around, knowing what to do and everything?
- C Yeah.
- I Okay, so do you have an iPod or a computer, anything like that that you use, or an iPad?
- C I have a phone, actually, that like I would use, so...
- P So what kind of phone do you have?
- C I have an iPhone 5C.
- P It was a Hanukkah present.
- C So like if I..., so I can contact my parents. If I'm like at a sleepover, I can text them my numbers and how many grams I should give, and like if I'm on the bus, I can like text them if like something happens to me.
- I Oh, that's awesome. Do you do anything else on your phone besides..., like do you play games or anything like that?
- C Yeah.
- I What kind of games do you play?
- C Minecraft, Geometry Test, and Fall(?) Free.
- I Oh, that's a good one.
- P [inaudible].
- I Do you use any applications that aren't games?
- C I don't think so.
- P Oh, she'll [inaudible] time and...

- C Yeah, like text, yeah.
- I Okay, so do you think—and be honest—do you think it'll be fun to play a game to help you take care of your diabetes?
- C Yeah.
- I Yeah. Why do you think that?
- C Because then like you would play a game and then it would like help you care for your diabetes.
- I Yeah. What if you were able to play the game with either friends or other kids who also had diabetes?
- C It would be cool, because like then they're all just like, hey, [inaudible] and we have like the same disease, and we're just playing like the same game.
- I Awesome. Okay, so if you met a new friend or if one of your friends now found out that they had diabetes, what would you tell them to make sure that they do when taking care of themselves. They're brand new to it—what would your lesson be?
- C Oh, at least remember to check your sugar and give them \_\_\_\_\_, and like to know what their body feels like when they're low or high.
- I Yeah, that's awesome. How do you think that they would be feeling if they just found out they were diagnosed with diabetes?
- C Probably scared and nervous.
- I Why do you think that?
- C Because when, like it seems to me that, when children find out they have diabetes, they're like, oh, my god, what is that like?
- I Yeah, and what kinds of things go into... When you first find out about it, what's, what happens in your life? What's everything you have to go through at first?
- C It's like hard because, if you're like the only kid in your class who has it and like you have to go like in a corner to test your blood sugar and all, and many people say, like, "Hey, why are you doing that?" So it's strange.
- I Yeah. No, absolutely. Okay, so a normal day in the life -- —what's your favorite part of the day?
- C I like, well, when I come home, because I know I have math homework. That's why I do it in school—it's really easy, and it's still really easy.
- I Oh, that's good. What would you say your least favorite part of the day is?

- C Oh, my brothers \_\_\_\_\_, because they're always so loud. That's what I mean—my nanny, we're like, here's the time we have.
- I That's really funny. Let me see. That might be all the questions I have for just you. What's your favorite color?
- C Blue or turquoise.
- I And what do you want to be when you grow up?
- C Oh, I want to be a writer, and my friend, she is like a really good drawing illustrator, so we're planning on working together.
- I That's cool! What kind of stuff would you make?
- C Like I write a lot, so I would make [inaudible] and maybe a series.
- I Ooh. Do you know what you'd want it to be about?
- C I don't know.
- I That's okay. I think you have a little time to figure it out.
- C Yeah.
- I All right. Well, thank you. You are extremely helpful.
- P Is that it for her?
- I I have a couple of questions for just the two of you.
- P Oh, all right, tag team.
- I These ones are hard—not really. Okay, so...
- P Okay, that's fine.
- I Can you guys tell me—List and describe a few activities that you enjoy doing together.
- P [inaudible – both talking]
- C Let's see. We like to get our nails done.
- P [inaudible]
- C Yeah, get our hair done, and...

- P Manicures, pedicures, out for lunch, shopping, \_\_\_\_\_ Musical Theater, everything, golf. [inaudible]
- C Yeah.
- I That's awesome.
- P She wants to talk... She went, yeah, we like napping, but not, I don't think...
- C Glamping.
- P What?
- C Glamping.
- P Glamping—no, I don't go glamping. I do [inaudible] glamping.
- C I do, I do.
- P No. She, we, -- likes to come to temple a lot.
- C Yeah.
- P So she'll come. She'll be like...
- C Or like I'll go like every week.
- P All the time, and she actually helps out and she greets people. She loves to hand out prayer books. She loves to come to temple. She loves to sing.
- C Yeah.
- P Right?
- C Yeah.
- P Yeah. [inaudible] I mean, she's got a beautiful voice, yeah. So does that give you an idea of what we like to do?
- I Yeah, it does. No—it's great, though. You have a lot of things you like to do together—that's awesome.
- P Yes.
- I Okay, so how do you work together to take care of --'s diabetes? And it doesn't all... It might not all be positive things necessarily.
- P It's not, because, because she is the youngest of three and she's the only girl, I think she pushes my buttons quite a bit. So, for example, well, she installed them, so, of

course. For example, when I have to give her her infusion or ask her to check her sugar, she gives me a harder time about it than my husband.

C He's a doctor.

P It doesn't matter that he's a doctor. So I think that some of, for her...

C [inaudible] sugar.

P You do, but like even changing the infusion, I don't do as good of a job.

C It's just because when you...

P [inaudible]

C I mean, you do, you don't [inaudible].

P You know, when we're out and stuff, I'm probably not as vigilant with counting carbs. I like to bake, I like to cook, as a typical Jewish mother. And so often -- will help me, and now as we're baking or cooking, and I don't give her insulin, and that causes her to be a little high. So -- is much more vigilant, and he's much more no-nonsense than I am, especially when it comes to this. That's how we \_\_\_\_, that's how we manage it. Does that answer your question?

I Yeah, yeah, yeah. And to further that, --, what kinds of things do you ask for help with? So things that you don't do on your own that Mom helps you with?

C My infusions.

P Have you ever done your own fusion?

C Once.

P She goes to an all-girls diabetes camp in Massachusetts called the Clara Barton Camp and Sleepaway Camp. You might want to know about this. It's a great camp. It's very expensive.

C But it's worth it.

P But it's so worth it. She goes for two weeks. I can't remember if I mentioned -- -- (?).

C Oops.

P Oh, my god. -- -- is also one of her friends, who sleeps over here, whose mom... Our face time is [inaudible]—whose mom basically peeled me off the ceiling when was -- was diagnosed, literally, and has helped me out with a ton of stuff. And her daughter is just two years older than --.

I Okay.

P And we drove together to this camp. They went to the one in Rochester, but they liked it, but they heard about this one out in Massachusetts, and it's a haul to get out there, but it's fun and she loves it, and she sees \_\_\_ girls with Type 1. It's all girls. I mean, there's a boys' camp, too, and they do dances and stuff like that.

I Ooh.

P Yeah, so, you know, she's... I feel lucky. And this is like the way I \_\_\_\_—I feel lucky that we are in a financial situation that we can afford to send her to that kind of camp, you know.

I Yeah, absolutely.

P Yeah, so what else? Anything you want to say?

C No.

P No.

I So what do you think about...—and be very honest, like I said—about having an application that you both had on your phones. Um, you know, you could, kind of you can monitor what's going on. They sync together, they work together, you can play it together, keep track of your information, your diabetes \_\_\_\_, your blood sugar levels. Would this be fun, and would it be helpful and why?

P For me, as... I know for her it would be fun \_\_\_\_.

C Yeah.

P But I think having...

C A game would...

P A game makes it a little more child friendly. I think also having her connect with other kids is, even throughout the country or the world, would be good to know that she's not alone, she's not different. I mean, even though she... We don't tell any of our kids that they're special, 'because they're not. You know, she's... You've got blonde hair, and, yes, you've done [inaudible], all right.

C [inaudible] I'm special.

P Oh, yeah, I tell each of my kids at night that they're my favorites. You know...

C [inaudible]

P No. [inaudible]

- C No [inaudible] have a favorite.
- P Okay. I want you to know that the reason why we got her a phone for Hanukkah is because socially... I mean, -- is very social; you can see that just in her interactions. She doesn't do much socially—playmates, sleepovers. She's had... In her almost ten years of her life she's had maybe three sleepovers in her life.
- I Okay.
- P I mean, I don't know about you, but like for me, I think I was at home less than I was at sleepovers when I was her age. And also she gets a little... You know, you're having fun with your friends or whatever, and you've got to stop and check your sugar. And, you know, and that's hard. And -- has a longer tether than I do with that. You know, I mean, as independent as this little person is next to me, I am still concerned, and I wanted to give her the opportunity with the cell phone to text blood sugars and text things to us.
- C And carbs.
- P And carbs. And maybe it's my own, I want to be in control of everything, and maybe, 'because I feel so out of control of it, and maybe it's also, you know, so it gives her a little more freedom. You know, she's now gone like around the neighborhood.
- C I bike around the whole neighborhood.
- P You know, I don't feel as frightened if the bus is running late. Or if I'm running late and, you know, I don't think there's ever been a time you've had to let yourself in the house by yourself for a few minutes.
- C No, I don't think so.
- P But, you know, there are times the bus is running late, and I'm panicking, like, oh, my god. You know, I know she checked her sugar at two o'clock. It's three o'clock, she's not home yet. What if she's dropping. So having that ability is amazing. So I know with having some kind of app, where, whatever, either it's entered into her phone, her numbers or maybe if there was a way that there's a glucometer attached to the phone, that we both have the apps, we both see the information, would make me feel just so much more...
- C Secure?
- P Yeah, that's a great word, exactly—secure. Yeah, thank you, yeah, for sure, you know?
- I Yeah, definitely.
- P How old was Zach when he was diagnosed?



- I Twelve or thirteen.
- P How old were you?
- I I'm two years older than him, so I think I was a sophomore in high school.
- P Do you remember the guy that Wegmans used to see and I talked about the pump, big tall guy?
- C Yeah.
- P Do you remember he worked in the food stuff, like I'm [inaudible] food. That's her brother.
- C Oh.
- I Okay, my last question.
- P Okay.
- I So when you have to get ready to go to school or your field trip or you're going on vacation, soccer practice, whatever, what are things that you could do to make sure that you have everything to take care of yourself?
- C What I would do is I would check so that I test my sugar and use something called strips where I can plug into my meter.
- P She knows [inaudible].
- C I would always check it by [inaudible] enough if I have like five or less, I would at least change it. And I would always make sure I have like Fruit Roll-ups or like...
- P Fruit Roll-ups, and she just loves...
- C Yeah.
- P They're so much more portable than Jewish juice boxes.
- C Yeah, because if I bring juice boxes, they would like spill all over. And I would make sure I have like a...
- P What else when we go on vacation?
- C Oh, infusion sets.
- P Oh, my god, yeah, and insulin in your pump and...
- C [inaudible]

- P I know you did. When Dad gets home, we'll do that. Yeah, it's a [inaudible]. You know, it takes time out of the routine, even though it's been, you know...
- C \_\_\_\_ years.
- P No, not yet. You were six and a half when you were diagnosed. Maybe it is three years.
- C It is three.
- P Yeah, it's been three years.
- C [inaudible]
- P Yeah, it's funny—it just flies, you know. Anyway, it's a lot of \_\_\_\_, a lot of... In fact today we, -- and I forgot to order insulin, like diabetes supplies from Animas Corporation, which is where she gets her pump. I think your brother has Medtronic.
- I Uh-huh.
- P And -- and I were like asking, like does she have any more insets, does she have any more infusions, does she have any more pump..., you know, whatever. So I called Animas today and got a rush order on it. We're going away in a few weeks, and going out of the country is stressful. Yeah, I know she's excited. Like, she's... We travel a lot. We're making our third trip out to the Caribbean in a couple weeks, and it's a bunch of \_\_\_\_\_. Yeah, I know. You know, and at first [inaudible] with family friends, and then last year I took -- and my mom—my other sympathy gift; she's had breast cancer twice.
- C And [inaudible] be coming here [inaudible].
- P Oh, yeah, the three of us went to Cancun.
- I That is awesome.
- P And then we're going to do a family trip to Jamaica, and just even the planning, making sure we're traveling with insulin, traveling through the security. You know, nothing can go... I mean, it's just a headache, you know, just having it. It's just exhausting, the details. In, particular, road trips, anything, you know. So, yeah, that's probably it. You want dessert.
- C Yeah.
- P [inaudible] for --?
- C I don't. you earned your dessert. Thank you so much.
- P Take your... [inaudible]. Okay, so Miss \_\_\_\_ is going to be, Miss \_\_\_\_ is going to hang out with me, right?

I Right?

P You have questions for me? Okay. I filled out all the surveys. --, have fun. Check your sugar. Go. Bye-bye. Oh, shoo—no, get out of here. You're not listening. Go.

C [inaudible]

P Go have your dessert.

C I'm [inaudible] as fast as I can, all right?

P I know. Welcome to my life. Okay. Well, Monday is my day off, so it's a little..., much more cash— here. I'm waiting for her to close the door. All right, close the door.

C Okay.

P Bye, love you.

I Okay, so my first question, which might be a little heavy—So when -- was diagnosed, in what ways did your lifestyle change?

P Greatly. God, you know, it just sucked. It still sucks. It still sucks. You know, I saw the symptoms before -- did. You know, she presented with all the classic symptoms—excessive thirst, weight loss; after high-carb meals like bagels and milk, she'd immediately puke. And I don't do puke—I have puke phobia; you know, it's true. She was lethargic, and it was... I said to --, "I think she has a touch of the diabetes." I didn't know how... You don't know how serious it is, you know? And I had dated a guy for three years who had..., when I was in high school and college, who has Type 1, and I mean that was the \_\_\_\_, and he didn't have a problem. He just did insulin twice a day out of a vial, and so I'm like, you know, we had to go to Children's Hospital and we were there for a few days.

And --, as a medical doctor, he's not as emotionally tied to this whole thing as I am. He is—I mean, it's not fair for me to say that he's not, but especially the numbers and the management. And it gets me down, and it's... Every day I feel like I'm getting stronger, but it sucked. I mean, really it sucked. Now it sucks to think that your kid is different. It just sucks. And she had... And I hate, hate it, and I still do. I hate every other like nine-year-old or eight-year-old or seven-year-old or six-year-old I see who doesn't have to worry about carbs, counting carbs, what you eat, what you're doing, checking before you [inaudible]. It's just, oh, you know? You know, pissy—I'm all pissy about it \_\_\_\_. And I will be totally upfront and frank and honest about it. So I'm sorry to do that to you, but it's true.

I No. I welcome complete honesty. And I saw the change in my family as well, so I do understand it.

P I know, and your mom has been a great help. I mean, I know on a personal note that your mom reached out to me, and I'm really grateful for your mom, your [inaudible]. You know, the \_\_\_\_\_, they check on me. Because as a clergy person I'm constantly involved in everyone else's lives, and I try not to think of mine. It's hard. It just sucks. It's just lousy, you know?

I Yeah.

P You know, you know, you know, so, yeah.

I Okay, so I think you guys were pretty honest with \_\_\_\_\_, but can you list your responsibilities for --, some of the things that you do specifically to help her?

P Oh, god. I mean, we, -- and I are pretty health conscious anyway, so I mean the food issue is a nonissue, because we don't... we follow modified Kosher—you know, chicken several times a week, fish several times a week, no seafood, no shellfish, no pork. -- is actually, she's calling you right now—nonsense. It's just an everyday, all-day, like weird thing that's around us. I mean, just thinking about strips and insulin and pens. And it's more of a pain in the --- when she's at school, because you're running out of supplies and alcohol swabs and strips and glucometers and it's just a lot. It's just a lot of details. Food—keeping stuff in the car, you know, stopping a road trip that would otherwise you'd make it to \_\_\_\_\_ in one trip, but you have to stop. She's got to check her sugar, she's got to eat a little something. And with living in buffalo, it's not like you can keep certain... You know, like juice boxes are awesome, and they're quick and they go in quickly. And she skis. You know, I don't ski. -- takes the kids on weekends and skis. So juice boxes would explode all over his legs, because he'd keep it in this... But those little Fruit Roll-ups are just amazing because..., yeah. So it's a little, like I say, grocery shopping, getting all that stuff, so... do you need to stand up? You can exercise?

I No.

P So yeah.

I And so I know -- had mentioned like she does a good job of checking her blood sugar and things like that. Is there anything else that she is like responsible for herself that she takes care of well during the days?

P Yeah, but she reminds us when she's low on stuff at school; she's good about that. She can guesstimate her carbs better, I think, than us. You know, she can guess how many she's having. She's good at—now that she has the cell phone, she actually has like Tim Horton's app, so she can look things up like... Or Starbucks if we go get hot chocolate, she's good at... It's a relief that I can say to her, "Look it up on your phone or look it up on my phone." And thank God for technology.

I Right.

P Right? You know, she'll always ask us, though, even if she's correct, even if she's figured everything out. This is one thing she's really good about—she'll say, "It says to give me 2.2 units." No, and I'm, like we're all like go, you know, go for launch. She always asks us, "No. I'm high." And she always asks us. She's not... When her sugar is really high and she's in the middle of a fun activity like shopping or \_\_\_ or anything, she doesn't want anyone to see her checking. She doesn't want to have to stop and check. She'll do it, but she doesn't like it, you know?

I Uh-huh, yeah.

P I mean, there'd be some... If you ever, if you interviewed a parent, and they were like, yeah, fine, no big deal. Like I would just be stunned. I mean, I would love to meet that person, because I wish I was that, I don't know, strong.

I Yeah. No. I mean, my brother's had it for almost nine, eight, nine years. My mom's just...

P [inaudible]

I My mom still has her...

P Moments.

I Oh, yeah, absolutely.

P Oh, I have, yeah.

I So, and -- kind of already answered this for me, but your sons help --. Is that like a relief for you at all that they're helpful to her or...?

P Yeah, of course. I mean, I think that they look out for her. I mean, if I'm in the middle of cooking dinner, like tonight or in the middle of like doing... I was actually doing work even though it's my day off, doing emails or something, because we've got some big services coming up. And -- is like, "I don't feel good. I feel wobbly. I feel dizzy." And I'm like, all right, she's like, "Can someone get my meter," and I'm like, "\_\_\_, will you go get it?" You know, he'll whine, but he does. He goes and gets it and they get her juice. I mean, yeah, it is nice on a weekend when I don't have to work, which is pretty rare, that I can sleep in. And if she's low, she's gotten really good at taking care of it herself or having her brothers help her. They know. I mean, as much as they all harass each other, I mean, they know. And it is a relief, but it's a burden. I don't want them to feel that they are encumbered to or enslaved to. Just every now and then—it's not every day, so...

I Okay, so a day in the life. Can you kind of go through morning while --'s getting ready for school until she goes to bed—a typical day?

P Never any day is typical. All right, so she... I don't even know. I mean, I'm usually, she gets up before I do. This is sad to say. I'm a late owl, I'm a night owl, so I'll

like be up late, reading in bed or whatever. I don't do music anymore at night, because I actually found I would never sleep for [inaudible] saying, you know, something would be in my head, and I just couldn't relax. So I'll be, like I go to bed later than everybody else. So she gets up. I think her alarm gets her up or she gets up on her own, or my husband wakes her up. And honestly I know she does her own sugar, she eats breakfast. She usually makes her own breakfast. Sometimes she'll even make eggs, you know, a little supervision. But she'll make cereal or bagel or whatever we have or fruit. She's really good about eating some yogurt. She's got a live palate for a kid. And, you know, check her sugar, normal morning routine—watch the Today Show, wait for the bus. She goes to school, checks her sugar when she gets to school. [inaudible] and the school nurse has been awesome. She's got a whole like kit in the nurse's office, has a whole kit in her classroom. What's really hard is that more and more kids are becoming nut-free. And for a diabetic kid, those are the best snacks to get—low in carbs, high in protein, sustains blood sugar. So she can't have like all these awesome bars that she would normally eat that would sustain her. I have to buy the --, I have to buy the junk. I'm sorry for swearing on your audio, but...

I That's okay.

P It's me. I have no [inaudible]. It's me. So I pack her ---, and like goldfish and it's junk. You know, a few times I've packed her a [inaudible], but that stuff's got to stay cold, and sometimes she doesn't have a long time. She does have a Medical 504, which is awesome for the school. Are you familiar with 504s?

I Oh, a bit, yeah, because of Zach and because my mom has run some workshops.

P That's right.

I Yeah.

P That's right, yeah. So she could check, she could have her sugar checked three to five times while she's at school. I mean, that just happens. She comes home, she'll check her sugar when she gets home. She'll have a snack. She's always ravenous. The girl's always hungry. Has a snack, does homework, watches a little TV, helps set the table, checks her sugar again. Sometimes she feels low, she'll check it. You know, a lot of checking. Homework, bedtime, maybe some TV time, and then check her before she goes to bed, and then before we go to bed we check her, which is usually a few hours after she goes to bed.

I Okay.

P When she has adjustments to her pump—because we download the pump information to a software company, and then they send that to the endocrinologist—it feels like there's always adjustments, like every few weeks there's adjustments. So we have to wake up at 3 in the morning and check her. -- does that, because he can fall asleep so much more easily. You know, he'd sleep on a dime when he was

in med school. For me, no; I mean, all my emotions are all out there and tied into her numbers.

So just socially she doesn't have... She's in sports, she's well liked, she's very popular, but she doesn't do much. She doesn't get invitations to friends' houses. I don't know if she gets invited and she doesn't bring that home to us. I don't know if other kids feel like it's... You know, 'cause she wears the pump—it's got the cord on it, you know.

I Right.

P And I feel like she's missing a big chunk of her childhood with that stuff. You know what I mean?

I Yeah.

P [inaudible], so yeah, that's, yeah.

I Okay. What are some methods that you have, if any, that you use for scheduling, logging, other tracking, whether it's with her diabetes or even just you, yourself or health or anything like that?

P Well, when she was first diagnosed, I was keeping very meticulous logs. I mean, that was done by the endocrinologist, and that was also done as my way as a Type A control freak wanting to feel like I had no control over her body or what was happening—even though I made her and she came from my [inaudible], it was just my way of controlling it. Now we are like so much on the technology of her pump, because we can actually access and see what's been given. I mean, how many times I could tell you that—couldn't remember if I gave her for something, like an hour ago, because... So you could look at her pump and you look at the meter, and it says INSULIN ON BOARD. It's just so amazing, so you know not to give her anymore.

The school keeps a log that goes back and forth to the home, and I don't even want to jinx it, but only once has she had the stomach flu since she's been diagnosed, which is three years. Like I said, I don't want to jinx it—it was last April, and we had passing ketones that she had to go to the hospital for. But I was not taking her—that was definite. But she's a real... I'm not just saying this because she's my kid—she's very articulate, and she's very conscientious, you know, in a very creepy way for a kid. Like she can always tell me like what her sugar was, what time of day—she's aware.

I No. That's really, I mean...

P It's awesome.

I Yeah.

- P It is. We really lucked out like that, I have to say, because lots of kids aren't like that. I know you know that.
- I Unfortunately, yeah.
- P Yeah.
- I Do you have any reservations about the application that I have described? So having the ability to sync between your phones and whether it's a game or being able to share your information, things like that, sending it to a doctor, anything? Is there anything that immediately strikes you as not a positive about it?
- P What happens if an app crashes? Sometimes that happens, you know, there's a bug—that would be my only concern. I mean, that's going to happen with anything. It's like if this is our sole method of tracking, like if she... I know that if this was the only, sole method, we didn't have the meter, what happens if the app crashes or it's down for a day or...
- I Right.
- P Or it gets hacked, you know what I mean? You know what I mean?
- I Uh-huh, absolutely.
- P And what happens if like, when she gets older and she really becomes a teenager, much more so than she is now, and suppose she... Suppose she develops body \_\_\_ issues—she wants to alter the numbers. So maybe she doesn't eat as much, or she gives herself too much insulin to burn off. Do you see what I'm saying?
- I Yup.
- P I'm hoping that that doesn't happen. I'm looking at my bedroom door, seeing what's [inaudible]. I'm really hoping to God that there's a very small correlation between Type 1 and eating disorders, because there's such a control on foods.
- I Right.
- P Not a controlled limit but a control of.
- I Yeah, and you're very conscious of it, so that's...
- P Yeah, we are all conscious. I mean, we don't do diets. We just, we're just healthy. - and I both run, we exercise, so yeah. That would be my only thing. I mean, I think it would be awesome. I knew that there was something already for the Apple phone, the iPhone, something that you could plug into here, and that would be like your glucometer. Or I don't know much about it. I never actually saw one. It was just like this urban legend.



- I Yeah, I don't know if it was ever like released. I don't know. I would need to look into that.
- P And that would be so awesome, because it would be so, like you can plug microphones and everything else, but like why couldn't they just create like some... I mean, the glucometer is so small anyway, why couldn't they just create one and put it in there. You test your sugar, and it like uploads it automatically to your phone and you don't have to bring an actual glucometer with you, you just bring strips. That to me would be just so awesome.
- I Yeah.
- P An app would be awesome.
- I Yes, sorry.
- P No, no. You're taking notes. Don't be sorry—it's all good.
- I Okay, so you already said... I just didn't know if there is any further extension, but your current method for monitoring right now is the text messaging. Is there anything else. Sorry, if -- is not with you.
- P Yeah, text messaging whoever she's with. Our nanny has Type 2 diabetes, which is not the same, but there's a weird cold comfort in that. I'm trying to think. Verbal texting. No email—we don't do email—books in between, notes going home, but that's it.
- I Okay. So, sorry, just to reiterate, so do you use like, I don't know if you like a Fitband or if you use any like My Fitness Pal, like apps like that, that are used for logging, whether it's like for your running, anything like that where you keep track of anything, whether it's your diet or exercise or whatever.
- P No, and if I was a little more, I don't know, sleep... I don't know. I've never really keep track of what I eat or what anyone eats. I mean, I did with -- initially because we were told to.
- I Right.
- P The only apps I use, but it's not for like long-term tracking, it's just for the in the moment. You know, I don't use a Fitband. I'm just trying to look at the apps on my phone that I use. I think I have like, was it MapMyWalk, MapMyRun?
- I Uh-huh.
- P Those fitness apps, like so I could see distance or where I've gone or how many steps if... You know, I just had my gall bladder out like a month ago, and so I really was trying to like gauge what I was doing or how I was doing. And I like to see where I'm going, what my timing is if I'm preparing for a run, like training for a

run. I did have, when she was first diagnosed, I did download the CarbCounter, which was useless. I did download like the Atkins thing, because it also had carbs listed on there, and that was useless; I mean, those are long, long gone. I did have, there was like, called MyDiabetes app or something; that was useless also. That was like for Type 2. You know, it was just, it was not helpful, so that's, you know, I don't use anything else really.

- I Okay, so I think that one of my final questions... Okay, so what would your advice be to another family who just found out that their child had Type 1?
- P On the record or off the record.
- I You can decide to have as much on the record. If you want, I can turn the recording off at any point.
- P No, no, no, no. It does get, it does get easier to have a well-stocked liquor cabinet for the child. I'm being totally, completely honest. You can keep that on. You can keep that on—I'm totally fine with that. To just trust that your child will be okay, and you're not alone, and you did nothing wrong. And I wouldn't say that it gets... All right, maybe "easier" is not the word. You just learn to carry the weight of it differently. You'll feel like your whole world collapses, and it feels that way, and it seems that way, and it does. And you... It just sucks, you know. One of these days, I'll accept it, and then you'll have to ask me this question again. You'll have to ask me, honestly. I mean, [inaudible], I mean, in my line of work I have been... You know, last week I was just with a man who was on his deathbed and doing all the perfunctory, spiritual Jewish things that are required when someone is imminent to death. And I have been with congregants whose father who was 42 dropped dead in the middle of work and passed, leaves behind three small children, being in the hospital with them as they're identifying their father's body. I mean, I've been through with other people's ---, so much worse than actually this, like in the whole spectrum of life. It's just when it happens to you—it's not that you don't think it does. You know, and -- and I would look at each other. We never asked the question, "Why us?"—which is incredible. We never... We said, "Why not us?" And we have so much. We have so much love in our family and with our kids, and we have, you know, we are lucky to be financially set that we are able to give Tzedakah. We believe in paying it forward; we give a lot of money out. Instead of living more flamboyantly, we'd rather give it to Tzedakah, you know, charity. It was more like—Why not us?

And it's like I said, the kids are much more resilient than the parents. They live in the moment, where parents live in the..., are constantly reflecting an reevaluating and assessing and planning. Children are incredibly brilliant that they just live in the moment. And for -- I don't know how much she remembers of her life without [inaudible] six and a half. They just, the kids just go with the flow. I mean, they really, really do.

And your pain is not going to be your kid's pain—that would be great advice to give to parents. What you're feeling, your kids aren't feeling. Yeah, they're going to feel sick and lousy, but you just learn to carry it all differently.

I All right. Do you have any final thoughts for me?

R No. Tell me... Well, yeah, I want to ask you. Can I ask you. If you want to keep it on the record [inaudible], I'm curious to know, so tell me, how many people have you interviewed?

[end of recording]

## Design of Mobile Application for Type 1 Diabetes

Interview #2 – 1/29/15

Interviewer (“I”): Amanda Skinner

Parent (“P”)

Child (“C”)

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I All right, so to start—When -- was diagnosed, in what ways did your lifestyle change?

P Immediately, or that are still current today?

I Starting with immediately and then can be continued on.

P Because that whole first couple of months is so completely different; but, once you get into the routine of it, then it’s just part of life, and it just doesn’t seem... It’s just your life.

I Right.

P The first couple months had changed because we were just like we were thinking about it all the time, so there were lots of trips to the drugstore and the school and a lot more checking in with him and a lot more communication. And now I have no idea what any of his blood sugars were all day, so it’s just kind of been losing... So what’s different as opposed... It’s our life, so it just is what it is. What’s different as opposed to life before with him? He was a little kid then, so as he’s grown and matured he’s so much more independent...

I Right.

P It’s different. Life is just different than it was then.

I Yeah. How old was he when he was diagnosed?

P He was 11. So any specific things that you’re thinking about? I mean, we...

I Just, it falls on pretty hard, so...

P Yeah, I mean, it’s part of our life now, so it’s different than... In that sense, it’s just part of our life, which wouldn’t be the case if he hadn’t been diagnosed. But as far as... Traveling, I guess is a big, huge one that’s obviously different—the thinking about things, thinking about getting ready for stuff; that’s a big one that’s different, because no matter where he goes, we have to make sure that he’s got all of his supplies, all his backup supplies, all of the food and snacks he wants. Traveling or sending him... So, yeah, that’s a big one—just the preparation for anything and making sure that he’ll always have what he needs. So we’re thinking about... Okay, and it’s pretty much routine, but we still have our 9:30 p.m. drugstore trips. And the traveling—but we, so we weren’t, it didn’t change for us; I mean, the traveling didn’t. We went to Switzerland, actually, maybe two months after he was

diagnosed, because we just, because we had a plan; and we determined that we were just going to do what we had done before. So he's been out of the country multiple times, and we just do it.

I Yeah.

P But it's a little bit... It makes us a little bit joggle things a little more. It has changed—gradually he didn't go to... We didn't go to Ireland last year, because sometimes it's too hard to figure out the medical system and figure out how they'll respond to it. So it's changed probably where we travel a little. And I think that when he gets older, if he makes that choice, that's okay. But not knowing some things about what's available, you know, the medical care that's available when you don't speak the language is different. It's different traveling to a developed country than a somewhat developed company.

I Right.

P So traveling is different. And I guess what's different than would have been for him are the... Well, he still goes to the... He was able to go camping, Iowa City. We just did do a lot of research and be in touch with a lot of people to make sure things are going to go smoothly. And the band trip that he'll go when he goes to Orlando in March--- and I are actually going to go along, just kind of... You don't... It's not that we're even worried about it, but if something did happen, we don't want to put that burden on someone else, because it affects everybody else on the trip. You know what I mean?

I Right.

P So I guess traveling \_\_\_\_\_. We travel, and the way we have to think about our days is a big one. I mean, mostly the changes are for him, because he's so independent now; it's his life that it usually affects. But I don't know if he thinks about it that way, because it's who he is, you know?

I Right, yeah, you get used to it, if you can.

P You kind of do, yeah. And the pump is so huge. And, oh, that's another thing. So there's the first three months, and there is the time for the shots and then the pump is just such... Zach doesn't have a pump, does he?

I [inaudible]

P He does?

I Yeah. He's been on and off, but he's on now, yeah.

P Oh, he is. Oh, my gosh, I mean, just [inaudible], 'cause -- eats, but it's just not as good.

I Yeah, absolutely. Okay, so, and this might be a little bit short, but—What are your specific responsibilities in helping --?

P Checking in with him; we do check in with him every day. And making doctor appointments. Making sure that he's uploading the diasend and getting the information received on track. Making sure that we have all the medica—, everything, you know.

I Right.

P Doing the pump supplies and all the insulin and all the backup supplies and everything, making sure we've got all that and making sure there's enough of it, especially if he needs it for traveling. Just checking in with him a midnight—still at night; you know, he checks in every night at least and tells me his blood sugar and that. It's funny how much I don't think about it [inaudible] to do that survey, wondering how he would answer and thinking about how some of it \_\_\_ maybe too much of a routine about, you know, what I mean? Like I probably should know his blood sugars at least once, other than once a day. But he knows—he's a pretty responsible kid.

I Yeah.

P And if he was much younger, though, it'd be so different. I remember when he went to middle school, the nurse will ask if you want to be testing their blood sugar every day at lunch.

I Oh.

P Or if you want that information from her. You know, they're much better, and they keep all the supplies in the nurse's office at the middle school. I don't know if you're interviewing a bunch of families of different ages, but you'll see that the nurse's care in schools really changes as they get older. This is --' first year at the high school, and the high school nurse said, "You know, we do everything differently here, because we want them to be independent and be able to do it on their own when they leave." So he hasn't been keeping his emergency backup \_\_\_ at the school with the nurse. He just keeps it all... I mean, I'm surprised at what they let kids carry around at the high school, just because I thought [inaudible] really, you know, you can carry [inaudible] around, you can carry, I don't know. As long as it's been okayed, you can carry medications and stuff around. But, so he just, you know, he doesn't have to go to the nurse and check his blood sugar. And so I don't know. Where was I going with that? I don't know. Just that now things at the high school, it's just becoming even more hands-off, because I know I used to be in touch with the nurse at the middle school. I used to get calls. So now nothing from high school.

I Yeah. Does that set okay with you, I mean?

P Absolutely, yeah, oh, yeah, absolutely. I love the way they handle it. I love that it makes him so independent, and he's real good about it.

I Well, that's good. That's really important.

P Absolutely.

I So then pretty much everything that you didn't mention, I'm sure, -- takes care of specifically for himself.

P He does. He's amazingly good at that. He, and the pump, again not necessarily a good thing, but I don't know, I'm not even [inaudible] know how to do some things on the pump, but he knows how to do it, you know—some things probably I should know how to do, but because he's just taken over, he knows how to, like adjustments, levels, he know how to. He's pretty mathematical, so he knows what are things he should do [inaudible], you know, the carbs for what he's eating, all day, based on... and usually that kind of stuff. If it's big, we check in, but little adjustments, he knows how to make; he knows how to do a pump [inaudible]. I figure I could figure it out, but [inaudible] his pump like his clock too. He just, he's very comfortable with it.

So, yeah, he does his blood sugar, obviously, by himself. Yeah, it's been a long time since I've done anything.

Only time... And that might go back to the first question. When --... This is when it is a big difference—when --' blood sugar is really low when he goes to sleep, when we still have, uh, every two hours [inaudible], and sometimes if it's still well and he feels fine... There have been times that I have just slept in his room [inaudible] second bed in his room, because I have this [inaudible] baby, you know. It is hard—those are the hard nights, and that's when it's definitely different, when his blood sugar is low at night. So that's really the only time that I am more con—, just maybe more on top of what he's doing.

I Yeah.

P [inaudible] Because he's asleep. [inaudible] he never wants to wake up and do it.

I Yeah, yeah, absolutely. So then he like counts all of his own carbs and all that for his meals, everything?

P Yeah, absolutely.

I That's great.

P [inaudible] I feel so lucky. Isn't that a funny thing to say? I think of all the ways that I'm just so fortunate, and it's a weird thing, isn't it? But it's just [inaudible] he could be..., yeah.

I Yeah, but it's great to have that.

P I know that.

I So a typical day for you, is it any different than...

P If he didn't have bad [inaudible]?

I Yeah, what does your typical day look like?

P As far as with --, some, no. There might be a question that I ask him. It's pretty much the same, unless I forget to get his insulin. You know, we are struggling with that a little bit, because his idea and my idea of he's running out of insulin is... You know, we can [inaudible] 24 hours.

I Right.

P So the only time it [inaudible]. I mean, more runs to the drugstore. Yeah, I mean, dealing with enemas, I'm not..., I don't like to deal with enemas, because we always have to wait forever. You know, that kind of [inaudible] stuff—again, minor, but in some ways it interferes with my life if I have to make phone calls or something like that or..., so it's very little.

I Okay. Do your other children help out, or did they help out at all with anything?

P At times. In the beginning I was... [inaudible] --. I don't think -- ever gave him a shot. I'm pretty sure. I'm trying to remember. In the beginning when I was more concerned, I'm trying to remember. -- tested her blood sugar. I don't know if -- ever did. He was little, so maybe he got away with it. But they know and understand what's going on. They know enough about carbs and counting carbs, but I don't think they really help him so much.

I Okay. As far as, if they know that he drops low or that, you know, in an emergency situation, are they aware? Like would they be able, like would you feel comfortable if it was just them together? Would they kind of know what to do and be helpful to him?

P Yes. I don't think I've ever left him alone at night with just them. It's funny. I mean, the day, absolutely, because at least from my understanding, if you go... Anytime it's low in the day, he knows it, and they know what to do. If he got to the point where they needed glucagon, no—they don't know what to do. But as I understand it, the only time you would really need glucagon is if you're really sick, which I don't... or if you go so low at night. And so that's what I'm trying to think. So that's another way that it would have changed.

His \_\_\_\_\_ might be different. He doesn't sleep over at other kids' houses. I don't know if teenage boys do normally or not act [inaudible]. But he doesn't because... Yeah, I'm trying to think. Surely, I mean, he stayed... Well, he has a friend that he



stayed with a couple times—his dad’s a physician. So for the most part he’s... I mean, surely... I’m trying to think if he was left alone with parents. Yeah, anyway.

I Yeah, but he’s never really been left without family, like completely on his own.

P I’m trying to think. I don’t think, not for a night. Yeah, he’s 14—probably I wouldn’t leave him alone for a night when he was 14 anyway.

I Yeah, makes sense.

P [inaudible] can’t remember. It’ll be interesting to see what he has to say about it, because I know... Yeah. We’ve left... [inaudible] --, when -- and I actually went to Iowa City with --. --, have we ever left you all alone for the night without Mom and Dad? Like I know we’ve left -- and -- a little bit. Have we ever left you alone for like the whole night? Isn’t that funny, that I don’t know.

I It’s not a huge deal, just curious.

P Well, it’s funny because I’m... I know it sounds weird, but we don’t... Well, because before -- was diagnosed with diabetes, [inaudible]... frightening, blah, blah, blah. I’ve always tried to make him just be moving. He’s got these other things going on, but he’s --, so it’s not that we don’t make a big deal about it, but we don’t... We’re not one of those families... Again, I don’t care what other people do, because I understand that you do what you need to do, but we’re not one of those families who goes and makes sure that the [inaudible] doesn’t have the peanuts in it before we go in. I just figure we just don’t want that focus on it, because it creates anxiety about it, so we kind of focus on diabetes the same way. Just us.

I So are there any current methods that you have for scheduling, logging, other tracking? So whether it’s something on the computer, on your phone, anything like that, anything that’s up at the school.

P We do a reminder for him to upload the diasend, and currently we’re not doing it weekly, even though [inaudible] reminder, because we are..., which isn’t good, but we know that; we’re aware of it. So other than to upload stuff, upload his numbers into the pump. So ask the question again.

I Yeah. Methods that you use for scheduling, logging and other tracking.

P Yeah, mostly just that, because it’s all in his pump, with the pump. And we’ll go to the doctor; they upload it all and tell us everything, so...

I Right. Was there any kind of, ever anything back and forth with the school or when he was first diagnosed, any kind of...

- P In the beginning, yes. See, so it's hard because that first three months especially was so intense, and there was so much. Oh, my gosh. At that point, you know, I had no books of stuff. Again, it's like a new baby...
- I I don't know, but yeah.
- P ...you're kind of freaking about it. You're like \_\_\_\_\_ what they eat and everything, and then you just relax and don't worry about it.
- I Yeah, okay, so then you had mentioned before the carb diet something.
- P Oh, yes.
- I So if you can speak to that and if there's any other applications that you use for healthcare, not necessarily diabetes, but it could be including diabetes. So if you use anything for, whether it's like a FitnessPal or Weight Watchers, MapMyRun, anything like that.
- P For him or for me?
- I For you.
- P I use like Nike-something or other. So I don't know what it's called. Running—Nike—it's just called running. Nike. And I use Lose It!, which I don't use, but I should use Lose It! Mostly I use my, yeah, it's just, I don't know even know if it has a name. It just says "Running" on it, just logs your miles. But then --... Well, for me that's what it is. He doesn't. And we only use Google if we're out and we need something. You know, a lot of restaurants have their carbs, and so we just Google the food. You know, how many carbs does a waffle have if we don't know, but he knows it all now for the most part.
- I And then the carb, the app, the Carb Diet.
- P Carb Diet.
- I Yeah. Can you talk about that?
- P Again, we just used it to look up carbs in the beginning. You know the little book they give you when the kid's diagnosed. We used to carry it around everywhere. If there was something... When we tried to leave at home and just do it on our phones, we went with the carb app. But Google is better than the carb app, I think. Well, it has been for us. It's so just so easy to just say, "How many carbs does..." something have, and it just tells you.
- I So what was it about Carb Diet app that you didn't like?
- P I don't remember. Sorry. I can't think of it. I mean, it was easier to find the carbs by looking for the specific thing we wanted, then it was just more general.

- I So would you recommend that app to anybody?
- P Carb Diet, probably not.
- I Okay.
- P We just simply don't use it.
- I Yeah, yeah. So what are your initial thoughts on an application that you could use alongside with -- to monitor their diabetes? So it could have a range of whatever you think would be helpful, capability-wise.
- P Do you want -- [inaudible] to wait until you're ready for him?
- I You could actually start filling out this... Oh, wait.
- P [inaudible].
- I Actually, can you first read this? This is just explaining what I'm doing, why I'm doing it. And then I'll need you to print or sign your name. Thank you.
- P Sorry.
- I No, you're okay.
- P Ask me the question again. Oh, I know.
- I Thoughts on an application.
- P Okay. It'd be cool if... Because I am not, again, even as I think about him going away to college, yeah, it'd be cool if I could see what his blood sugars are, that are in his pump. I mean, he's got them. He can look at them at any time. I think it would be cool, because then especially when he's not around, I can know [inaudible], and then I can check in with him or not bug him if I don't need to. So, yeah, that would be cool. Otherwise, I really hadn't thought of it, but mostly, I mean, that's the biggest thing, is just knowing, because then I kind of know how he's doing.
- I Right. What is your current method for monitoring when he's not with you?
- P Asking him every once in a while. Well, the diasend—have you seen the diasend printouts where they print it out. So when you put your pump... He can tell you better, but when you upload your pump into diasend and we print out the sheets, then you can see the number. I mean, you can just look at all the numbers. It has highlighted in one color when you're high, highlight in another color when you're low, which is a printout. The problem is that we don't do it. If I had an app that was in my phone... Because it means we have to go use the big computer. If I have that

on the phone, I mean, his phone is with him all the time, too. If he had on his phone or I had it on my phone, we would do it. If it was easier, we would do it more often.

I Right, yeah.

P [inaudible] convenient. Basically, we're lazy—that's what I'm saying.

I That's okay. It's all about trying to make it easier.

P I mean, that—just having the access to those numbers would allow us to... So right now we have them as printouts, but we don't do the diasend nearly as often as we should.

I Okay. Do you have any reservations for an app that would contain this type of information and be used potentially together or anything like that?

P Reservations about it?

I Yeah, is there anything that concerns you about having an app for it with medical...

P No.

I No? Okay. My final question for you—what would your advice be to another family who just found out their family had Type 1?

P Just hang in there. You know, wow, just hang in there, because I mean just tell them that I'm available for questions or any support that they need. Because that's all you can do, I think. I mean, everybody has to... You just have to get through it on your own. Each family has to get through it and work it into their own lives, figure out a routine and... Just do people want to hear that it will become routine when it's so awful? I mean, I can't... so many times people said to me, "It's just going to become part of your routine. It's just going to become part of your routine."

I Yeah.

P I don't remember if I took it well or not. It's kind of a bore.

I Yeah. Is the support helpful from other people to know what's going on?

P You know, it's funny. You know, I actually relied on your mom a lot in the beginning. I did because I didn't know anybody.

I Yeah.

P And so I think the support is helpful, but it's not necessarily... I mean, and then a week or so later we knew another family whose little girl was diagnosed. So we supported each other, but we didn't have someone that had already been through it.

I Right.

P And probably... I'm sure you can get online and find groups like that and find people.

I Yeah.

P So, yes, the support is helpful if, I guess, if it's the right person. I don't know. Maybe the fact that your mom was helpful because it almost, she wasn't here. It was almost..., I don't know. I know that sounds funny, but she was the first person [inaudible]. Because I remember seeing --, and he was just like, "What is going on with you?" And I told him, and he said, "Oh, you need to talk to my sister." And I did. I don't think... I know I didn't... We just were... Well, we talked to the nurse a lot, so the support of the nurses absolutely is [inaudible], but at some point you feel like you can't call them every day. You don't want to bother them, so...

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### **Interviewer with -- and his mom**

I Right, okay, all right. So can you list and describe a few activities that you guys do together?

P What do we do together? [inaudible]

C [inaudible]

P Do the puzzles.

I Or some other interests that you have, things that you share.

P Music.

I Music?

P Yes?

C Yes, absolutely.

I In what way?

C We just play a lot of music.

I Do you both play instruments?

P We do.

I What do you play? Does someone play the harp?

C Where would you start?

- P Let's see. -- plays the piano. The piano and the drums are his main instruments. He also plays the cello, the... I don't know. He's very musical. The dude can play whatever he picks up.
- I Boy, that's awesome!
- P Yeah, so he's pretty musical? What else? I don't know. We study a lot. We study a lot together.
- I Yeah.
- P I study a lot of... He's in [inaudible] this year. Yeah, fun, so we studied up.
- C That helped with my studies.
- P So we do that. We play games, though. We do that. We play games, we watch movies and we do puzzles.
- C Yeah.
- P Actually, we do a lot together. I bug you.
- I That's okay.
- P And we eat together. You know, we do a lot together when you're here. I mean, obviously, today he's been gone for... What, were you gone for 12½ hours today—right?
- C It's 12 hours.
- P 12 hours.
- C I think it was longer actually, but anyway.
- P You remember. When you were so busy in high school. You were in theater, so you were doing it... I mean, you don't get home from school until...
- I [inaudible]
- P And when I actually see him...
- I Okay. How do you work together to take care of --' diabetes? And it can be things that you do now and things that you did in the beginning as well.
- P Do you want to talk about now or the beginning?
- C I do a lot of it myself now. I'm not sure exactly... You track [inaudible] my blood sugar [inaudible] but like I tell you that every night before we go to bed, so it's not low.

P Right.

C [inaudible]

P And that's amazing now. We check him every night, and he tells... You tell me sometimes. Every once in a while, every once in a while I tell you to check your blood sugar—right?—if you're acting weird?

C Yeah.

P And also you tell me when you're running low on stuff. You tell me when I need to order stuff.

C Yes.

P And I order it. So that's another thing we do together—right?

C Yeah [inaudible].

I Are you picky about what groceries get bought? Are there certain things you like to have, or even things that you like to have when you're low or anything like that?

P Yeah.

C [inaudible].

P Yeah, he'll write it on the list. Yeah, and that is a good point, Amanda. You know, he's pretty..., just because it's easier, he eats the same thing a lot. Yeah, it's true—for breakfast and lunch you do eat the same, because he knows the carbs, and he has wants, so he does like me to have those foods. And we do write them on the list, and sometimes I get them for you. But that's, so that's now. I mean, in the beginning, oh, my gosh. In the beginning it's super different, because in the beginning when he was giving himself shots... Remember, before, you couldn't even give yourself a shot at night—remember?

C Right.

P I mean, which was fine, but I'm just saying, I was, -- and I were much more involved.

I Yeah.

P I don't even. Did we give... Gosh, it seems so long ago and it's not, but did we give you the shots in the beginning or did we help you? Did we do...

C [inaudible] gave them to myself, other than the NovoLog.

P Other than the NovoLog.

- C No, not NovoLog but the Lantus.
- P The Lantus, right, at night.
- C Yes.
- P So we did a lot of that. But we did put it... So I feel like we were there a lot...
- C Yeah.
- P ...when we did your shots and everything. But even the pump [inaudible]..., I've done none of that. I don't even think I could fill a canister from you, too, which is not good. I've never put his..., you know, put your [inaudible], have I? And I have yet to [inaudible] myself. I know a lot of moms who did it to themselves. Have you ever done that? I know. I've never done it either.
- I No.
- P I mean...
- I I pricked my finger.
- P Yeah, well, yes, I've done that, sure.
- I That was..., yeah.
- P I figure if he can stand it...
- C Yeah.
- P Anyway, yeah, I do know moms who have done that to show their kids they could do it, put in that inset in the pump.
- I Right. When you were diagnosed, did it have any strain on your relationship together?
- C I don't think so.
- P Strained?
- I I mean, because it was stressful or anything like that, because everything was just changing really fast. Was the adjustment hard, and was there any...
- P Well, I think the adjustment was hard, because it's a huge life change, but it wasn't strained. I mean, if anything, I mean, you're, we're very close. I mean, I would pull us closer together during that time. That was pretty intense. So I wouldn't say strained, but a strain on -- and I. I think more strain on -- and I than you, because when he was diagnosed, I mean, -- is living in the present. -- and I, when he was diagnosed, were thinking of long term.



- I Right.
- P He's just thinking about that he wants to eat and he can't eat [inaudible].
- C No. [inaudible].
- I Yeah, okay. So if there was application in which you could both have... You know, it syncs together, so you can send alerts, and you can upload your blood sugars or whatever, and all of that works together. In your mind, what are the good and bad things about being able to work together in that type of medium?
- C I think it's good to be able to record my blood sugar, just to have it for easy use. It's good to be able to like share it with my mom, so she knows whether I'm low or high and whether I should do something. I feel like this is more situational, but a bad use would be that you would constantly be picking on me about it. You probably said that was a good thing.
- P No. I agree with all of that.
- C I think it would be helpful [inaudible].
- I So would the negative aspect, would that hinder your use? Would that make you not want to be as honest on it, or you know what I mean? Would you want to try and hide things.
- C [inaudible] honest on it, but, huh.
- P I think that would almost depend on how I responded when, if he started it—right? You know, if I handled it well...
- C If I'm like at 250 and you called me, you know, like, "You're high! You need to like correct [inaudible]," then I might [inaudible] recording as my [inaudible].
- I No. That's, it's important for me to know. So anything like that.
- C [inaudible].
- P Right. It would also be good... So in the pump it says it adjusts within the +30 or the -30. It would almost be good for a app to say... So you need to with each parent know what the kid's tolerance for being bugged. Like if the... So if I want my part of the act to have a little ding, like I get a little ding if his blood sugar goes over a certain level, that would be negotiable between parent and child—you know, if he doesn't want to be bothered at 250 but I want to bother him if it's 300.
- I Right.
- P Like if you could in the app choose that.
- I Yeah, just being able to customize it to your family.

- P Yes, right.
- I Because you said before, every family is different.
- P Absolutely.
- I Yeah.
- P And also different kids. He [inaudible] so well. When I talk to friends, like the little girl I was telling you, and I mean her blood sugar routinely gets much higher than -- ' does. I would probably freak out, but they're so used to it, and maybe that's just because she's little or, [inaudible] understand a little kid with fluctuations or something. Anyway...
- I Okay, so you sort of already spoke to this, but just to get this feedback too. As far as getting ready to go on vacations or to school or any kind of trip, what are things that you need to do to make sure you are ready to go, for your diabetes?
- C It takes quite a bit of time. Like I have to guess how many canisters I'll need for how much I'll be eating and how fast [inaudible], how much insulin I'll need, like backup supplies or [inaudible]. But it's not like terribly stressful for anything. It goes pretty smoothly.
- I That's good.
- P He's done it a lot. We travel a lot.
- I And that's helpful.
- P Both in the states and out. It is, so it's just like everything else once you've done it. But I'm jumping around, Amanda, but...
- I It's absolutely fine.
- P The pump—oh, my gosh. Our experiences with airport security are just all over the place, talking about different things—things that have been different. It doesn't apply to the app, but yeah.
- I That's okay. You can still speak to it. That's about absolutely fine.
- P They're just... depending on where you are in the country, depending on the size of the airport, depending on where you are in the world, the size of the airport, they just don't know what to do with that pump. And so then we've learned a lot. We've learned that if mom...

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[Interruption:]

- P Are you going to bed?
- ? Uh-huh.
- P Okay. Will you check in with --? What time is it, sweetie?
- ? Like 8:30
- P Okay. Just check in with -- and maybe read a little bit.
- ? [inaudible]
- P Fantastic, okay. Sleep well. So do I need to pick you up after school?
- ? Uh-huh.
- P Okay, see you then.
- ? Will you... [inaudible].
- P Of course I will.
- P Like --, she gets up at 6, you know.
- ? [inaudible] let -- talk.
- P I will let -- talk. I'm going to actually leave, so -- can talk.

- P What was I going to say? Oh, yeah, so now we know. But they won't ask you to take off the pump, because it's a..., but yet you can't go through certain things with the pump. And so how many times have they had to like...
- C There have been a lot of times where they've had me pat down, and then they like...
- P Then they pat down you and...
- C [inaudible] something on my \_\_\_ hands to see if it's like [inaudible] harmful drug or something.
- P Right. They do all kinds of..., and I just, and I'm like he... And so who gets [inaudible] a lot but during most of this he's been little. He's been shorter than me, and I just want to say—"He's a little kid. Leave him alone. It's traumatic." I would. We're almost used to it now. We were so used to them doing... Because I think, there's a ton of diabetic kids in this world. I am just shocked at the number of people who just don't know how to handle it, don't know how to handle the problem when you're going through it. People are really cool about insulin supplies

if you have a letter from the doctor. They just let you go through, and they let it all go through security. And when you [inaudible], you could almost stick anything in that backpack with insulin supplies. They don't... You could probably put a whole bottle of shampoo in there or something and they'd just let it go. But the pump and -, yeah. So I hate even thinking about having to deal with that when you're not with Mommy... out there and more people it seems like [inaudible]. But when he's traveling by himself, and he's your brother's age and they're... And he doesn't have... And he's a kid. I'm sure everyone thinks a 25-year-old kid is trouble, you know, boy, so, anyway. Sorry.

- I No. It doesn't matter. It's okay. And so are there any experiences you guys had together you want to share with me through anything you've learned, any...?
- C I can't think of anything.
- P Yeah, I can't think of anything off the top of my head either. We've really just done it all together, and then they're so independent, but we've learned how, again, just let them out [inaudible] every morning.
- I Okay.
- P Are you done with me?
- I I am.
- P I'll go make lunches.
- I Okay. So, first, how old are you now?
- C 14.
- I And how old were you when you were diagnosed?
- C I think 11.
- I Okay, so currently, we've already talked about this a little, but what are your responsibilities every day that you take care of every day for your diabetes?
- C I check my blood sugar a lot, like every time I eat. I change my canisters. I have to change my site. And sometimes I have to like check for ketones or whatever, rarely.
- I [inaudible].
- C Not too much.
- I Keep on. You're good.
- C [inaudible].

- I Can you tell me some things that you do for fun, whether it's sports or activities, anything at school?
- C I am part of Team --, which is \_\_\_\_\_, so that's a robotics organization. We build robots.
- I That's awesome.
- C It's fun.
- I Okay. Tell me about that. That's cool!
- C So the goal is to build robots for certain tasks that the first organization provides for you. So this year the task is like to stack plastic boxes and garbage bins on top of each other, and you get different amounts of points depending on how they're stacked and how they're arranged. So we're just trying to build a robot for that. So we're divided into four or five groups. It's like machining, which is building the robotic and computer-aided design programming, which I am in, and then like wiring. And I think there's something else, but I don't know [inaudible].
- I Oh, that's awesome. So what programming languages do you...
- C Last year we used Java. We're using C++ \_\_\_\_ this year.
- I That's awesome. So you like doing that?
- C Yeah. And I'm also, I also play the piano. I'm in band and chorus—those are fun. And then I play tennis.
- I So I assume you enjoy doing all these things—it's all a choice for you. Do you ever have a problem with any of them because of your diabetes?
- C No.
- I No? Good. Doesn't stop you from doing anything? ... That's awesome. Do you have any friends or know of anybody that has diabetes?
- C I know like one person who is in my grade, and I'm not really friends with him.
- I Okay, so you ever talked about it or just have that mutual understanding?
- C Mutual understanding. We don't really talk.
- I So your friends who don't have diabetes, how are they with you? What do they know?
- C They know I have diabetes. I think they know generally what it is, like it doesn't really apply to them. They just kind of... So a lot of people actually don't know in

my grade. Like just express it openly, but people just find out [inaudible] diabetes. Yeah, people just accept it [inaudible].

I Good.

C It doesn't really change anything.

I No, it doesn't. Okay, so in your opinion, do you think it'll be fun to have this application on your phone? And if it had a gamelike aspect to it that you could play with other people and it could be something that's just with your friends or with other kids with diabetes or what-have-you, that helped keep you educated—I know that you know a lot about it, but even starting out you didn't—so that it could help educate you, it could be fun and get you connected with other kids. What are your thoughts on something like that, either for yourself or thinking about if somebody you knew would be diagnosed?

C Like that would be cool. Like do you know Trivia Crack?

I I do.

C Something like that, that would be kind of fun just to be on something [inaudible] up with work. I just feel like [inaudible]. It just popped into my head when you said “game.” I feel like it would be useful, and it would be fun to like communicate with others and learn more about it. [inaudible]

I Okay, so you know the one kid in your grade. Other than that, do you, really like it's just your family who deals with the diabetes, like there aren't any other families or kids who you have for support or who you connect with on that level? Anything?

C I know a couple other people, but I don't... [inaudible].

I Okay. If you had the opportunity to, through this application, if it connected you with somebody in Washington State or something like that?

C I probably would more than [inaudible].

I But so you're not opposed to the idea... Okay, so as far as devices, do you have a smartphone, a computer, a tablet? What do you have?

C I have a smartphone, and then our school issues computers to each of the students, so I have that.

I And what kinds of stuff do you use them for, applications and things?

C The computer I mostly use for schoolwork. Sometimes I play games on it, but the phone I mostly use for games and then sometimes for like actual usage.

I For making a phone call. What kind of games do you play?

- C Everything, pretty much. Trivia Crack; I actually play [inaudible] a lot, but I'm into really \_\_\_ games that no one knows.
- I That's okay. Do you prefer stuff that's more strategy or like word games or interactive games? What kind of stuff kind of speaks to you the most?
- C Strategy games, like I'm really into Pokemon, like RPT is kind of like that. But then I'm also, I can also easily become addicted to stuff where it's just like running and jumping, like \_\_\_\_\_ Ride or [inaudible].
- I I know all [inaudible]..., so it's okay. So a little different direction. Do your siblings help you take care of your diabetes, and what kind of knowledge do they have to be able to help you if you need it?
- C I think they know a little bit more than my friends, like they check their blood sugar about once, but they don't really like do anything with it. They just acknowledge it and realize that I have it. I'm not sure how helpful they would be in an emergency—should probably work on that, but...
- I Did they ever give you shots or anything like that or help you count your carbs?
- C No.
- I No.
- C I'm good at math, so I can count the carbs very easily.
- I That's good. Are they a good support for you, though?
- C Yes.
- I They help you and support you?
- C Yes.
- I That's good. Are you close with your siblings?
- C Yeah.
- I What's the age of you guys?
- C I am two years younger than --, but she's 17 right now because her birthday is [inaudible], and then -- is 10, so he's 4 years younger than me.
- I Got'cha, all right. So this one will kind of like be a no-brainer, but how do you remember to test your blood sugar usually times a day? Is it just routine for you, or do you have to really think about it?

- C It's kind of routine. Whenever I eat, I always have my blood sugar checker with me, just in case. I keep glucose [inaudible] just in case I get low and I can [inaudible], so it is basically just a little packet that helps me regulate my blood sugar.
- I What is your favorite part of a typical day for you?
- C The Neutrino meetings are fun. Robotics is fun, and I like [inaudible] a lot—that's fun too.
- I What would you say your least part of the day is?
- C Social studies.
- I Why is that?
- C Not because I have a bad teacher, but I just don't like the subject and [inaudible].
- I All right, that's okay. What's your favorite subject?
- C Probably chorus...
- I Really?
- C ...if that counts.
- I Yeah, it absolutely counts. I'm a music person. That counts.
- C [inaudible] English.
- I Awesome. If one of your friends were to find out that they have diabetes, what would be your advice to them from the get-go?
- C I'm just ready to help [inaudible], like I can provide support. I know how it works now.
- I Is there anything that you wish someone had told you when you first got diagnosed?
- C Not really. People told me a lot of good advice, like—"It'll get easier as you come. You just need to get things right." [inaudible]
- I How do you think that, if one of your friends is diagnosed, how do you think that they will be feeling to get that news?
- C Probably a little distressed, like that's about it. [inaudible]
- I Yeah, okay, and last thing—I could probably piece some of it together, but walk me through a day in the life of you from morning when you wake up 'til when you go to bed.



- C Okay, so I wake up about 6:30. I usually lay in bed and play games in my phone for about 20 minutes, and then I actually get up and come downstairs. Then I eat breakfast and leave, and I don't really like communicate with anyone or anything very bad—I'm not a morning person. And then I go to school, so my first period is band, so we [inaudible] 'til that starts, and then I play percussion, so that's fun. Then second period is chorus; singing is fun, too. Then I go to third period AP Bio, so Bio is really fun. It's hard, but we have a lot of homework, but it's really fun to be in. I really understand it. And then fourth period is either basically a study hall or a chorus lesson, band lesson, or more Bio. Then I have fifth period, which is English. Then we like [inaudible] stories, which isn't fun, but the stories are fun.
- I Well, that's good.
- C And then I have lunch, so I'm part of the Outdoor Eating Club, so we eat outside every day. We have a [inaudible], so even when it gets like below zero, we eat outside, and it is fun.
- I Oh, really? How many of you do that? That's cool.
- C There's like ten.
- I Oh, that's so funny.
- C Most of them are juniors. So then I go to pre... No, pre-calculus, that's right. We don't really do... pre-calculus, so I just kind of, study hall again. I'm really [inaudible]. Then world studies, which isn't a terrible class, because I have good people in my class and I have a good teacher, but it's just not my favorite, because I don't like the subject. Then I have Spanish. So Spanish comes pretty easily to me [inaudible]. And then I generally go straight to Neutrino after school. We're into six-week doe season, so I've noticed we go to Neutrino for a while, and then I learned programming for about three and half hours, two and a half hours straight, and sometimes I leave early because of [inaudible]. Then I come home, do homework, shower and go to bed.
- I Okay. Doesn't sound like a bad day to me. Okay. Is there anything else you feel you want to share with me? That's about it? That's you? Okay.

## Design of Mobile Application for Type 1 Diabetes

Interview #3 – 1/31/15

Interviewer (“I”): Amanda Skinner

Parent (“P”)

Child (“C”)

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I So can you tell me how old you are?

C I’m 11.

I Eleven, and how old were you when you were diagnosed with diabetes?

C 7.

I You were 7, okay. Can you tell me what your responsibilities are every day for your diabetes that you take care of?

C I have to check my blood sugar. I have to check my blood sugar and take insulin, and, yeah, make sure I eat right.

I Okay. What kinds of things do you like to do for fun? So it could be some kind of sports or after-school activities. What kind of stuff do you like to do?

C I’m on the junior high school volleyball team, like, yeah, and I do gymnastics, which I’m going to in like an hour.

I Fine. What do you like about both of us.

C I am flexible, and I like to bounce around, so I like gymnastics. And then I just like volleyball because it’s fun, and like it’s fun to win the games and stuff.

I I hear ya. Do you think that being active helps with your diabetes? Does it help make you feel good or bad? How does that affect it?

C It helps me feel better, because it lowers my blood sugar, and, yeah, if I’m high.

I Okay. Do you have any friends who have diabetes?

C I have a couple.

I Can you tell me a little bit about them?

C Yeah. One, her name’s --, too, and she is the same age of me, but she got diagnosed just like either a year or two ago. And I have another. There’s this little girl in my school whose name is --, and she’s in second grade, and she’s really cute. Well, I have a friend from camp, from Camp \_\_\_\_, and her name’s \_\_\_\_, and she is a year older than me, and, yeah, and I’ve been going to Camp \_\_\_\_ for two years.

- I Okay. Could you tell me a little about camp? I don't really know much about it.
- C Yeah, so there's like each... There's girls and boy cabins; they're not together. And there's like five counselors in each, and then they have different activities you can do every day. Like some of them are volleyball, soccer, basketball, and they have a tower [inaudible]. And they have the meals laid out; the carbs are listed on like a dry erase board, so you can do what you want to eat and like add it up and give insulin. And we do site changes every two days, so that's...
- I That sounds like fun.
- C Huh?
- I I said that sounds like fun.
- C Yeah, it is. It's like my favorite time. That's what I look forward to every summer.
- I Yeah. What's the best part about it?
- C Seeing all my friends and like playing in the sun, and we go to the pool together. And I have one more diabetic friend—her name is --. I met her at the family weekend at camp, but she hasn't been going to camp lately, so, yeah.
- I Okay. Well, it sounds like you have a nice little group of people who can relate to you.
- C Uh-huh, and my friend's dad has Type 1, so, yeah, she knows a little bit about it too.
- I That's good, so do any of your other friends know anything about your diabetes?
- C Only my super-close friends, like one of my friends I've known since I was born, and like her mama has Type 2 diabetes and [inaudible], so she knows a lot about it. And then my other friend I've known since kindergarten knows a lot about it because we've been friends since then.
- I Yeah, well, that's good, must be kind of helpful.
- C Yeah.
- I Okay, so in your honest operation, do you think it would be fun to play a game on your phone or iPod that would help you take care of your diabetes, and you could play it alongside your friends who have diabetes as well and other kids that you maybe have never met who also have diabetes? What are your thoughts on that kind of a game?
- C Sure, I'd like that.
- I What would you like about it?

- C Because I like playing on my devices, and it sounds fun because you'd get to play with other kids with diabetes, yeah.
- I What other devices do you have besides your iPod?
- C I have, well, my iPod, and I have a Samsung Galaxy Tab that I got for Christmas. And for Christmas me and my brother got a laptop to share.
- I Fun, so what kind of stuff do you like to do on those?
- C My laptop, I like to go on YouTube or shop or stuff like that. On my tablet, I usually play Minecraft, and on my iPod I like to either play apps on it or watch YouTube.
- I What other kind of games do you like to play besides Minecraft?
- C I like Don't Touch the Spike, where this little birdie has to fly around, and I have to keep it from touching these spike things. And then, huh, I like to play Jetpack Joyride. Those are the only, and Flappy Bird.
- I That's a fun one.
- C Yeah.
- I Okay, so you have siblings, right?
- C Yeah, I have a younger brother who's nine and a younger sister who's four.
- I Does your brother help you at all with your diabetes? Does he know a lot about it or...?
- C I'd say he knows some about it, but he's not like the most educated. I mean, he knows about it and stuff, and he's good at helping me with it.
- I What kinds of things can he help you with?
- C If I'm going low, he could like get me a juice or get my blood checker or stuff [inaudible].
- I Well, that's good. How do you remember to test your blood sugar throughout the day?
- C If I feel low, I test it, or if like my monitor says I'm going up, and then when my monitor says I'm falling, or before any meal or snack.
- I Okay, and it's just easy to remember that you have to do it?
- C Uh-huh.

- I Well, that's good, good to be in a routine. Can you tell me a day in the life of --, from morning to night, what you do?
- C Wake up, check my blood sugar. And if I'm high, I would pre-bolus before I eat. I would go downstairs. I usually have like either, on the weekends I usually have like [inaudible] or something, but on weekdays I'd have like French toast. And then, so I'd [inaudible] for that, and then on the weekdays I get ready for school, and I just go to school. I have morning check at 10 o'clock, a check before lunch, and then a check at the end of the day. And then go home, pre-bolus for dinner and eat dinner and then like watch TV or something and then go to bed.
- I Doesn't sound like too bad of a day to me.
- C Huh-uh.
- I What is your absolute favorite part of your day?
- C On Tuesdays it's my volleyball games, Saturdays it's gymnastics. Yeah, so that's like a weekday and a week.
- I Okay, and what's your least favorite part of any day?
- C On the weekdays, I don't like going to school. I'd rather sleep in. On the weekends, we usually have a lot of stuff to run around to, and we don't just get to stay at home and like play and stuff.
- I Okay, and what do you want to be when you grow up?
- C I want to be an orthodontist.
- I Really?
- C Yeah.
- I Why do you want to be an orthodontist?
- C Because I like playing with... I think like people's teeth, putting on braces, I guess, or rubber band looms with the rubber bands.
- I So do you used rubber band looms?
- C Yeah, I have one that I got for Christmas a couple years ago.
- I That's fun.
- C A lot of my friends have gotten braces recently, and I really [inaudible] braces, so, yeah.

- I All right, sounds good to me. Okay, so if you found out that one of your close friends who does not currently have diabetes had diabetes tomorrow, what would your advice to them be?
- C Like, come over to my house whenever you want, and we can play. And then like—don't give up and just try to be healthy and stuff. And my friend that I said her dad has diabetes, we're still kind of waiting to see if she gets it. And my friend who's like the same age as me whose name is --, her close friend just got diagnosed with diabetes like last year. And I'm like, why don't I get a friend with diabetes, but...
- I Yeah. Do you think it'll be easier if one of your friends also had diabetes?
- C Yeah, because we could help like take care of each other, especially if we went to the same school. We could go down for checks together to the nurse.
- I Absolutely. If one of your friends was diagnosed, how do you think they would be feeling when they found out?
- C They'd probably feel kind of like, I don't know, sad, sort of, because it's a big change. But then like I would be there and tell them that it's okay and that we could be friends over that, and it'll just be something to help us get even closer as friends, I guess.
- I They would be lucky to have you to help them, I think. Okay, those are all my questions for just you. Is your mom back?
- C No, but I can go get her.
- P She waked me up, so I figured...
- I Okay, so I just have a few questions to ask the two of you to answer together. Okay, so can you first list and describe a few activities that you enjoy doing together?
- C Shopping.
- P Shopping.
- I What do you like to go shopping for?
- P Clothes.
- C Clothes, and we like to go shopping for the American Girl Doll store.
- P Some of us like that more than others. My wallet does not like the American Girl Doll store, but it's fun.
- C [inaudible].
- P What else? We like...

- C Volleyball.
- P Well, yeah, I go to most of her volleyball. I guess we do that together. You get to have fun, I get to watch. We like to clean the house and organize together.
- C No, we don't.
- P We... You're a good organizer.
- C Yeah, but I don't like...
- P Or sometimes we do crafts together, and sometimes we watch TV.
- C Like [inaudible].
- P Is that good?
- I Yeah, very good. How do you work together to take care of --'s diabetes?
- P That's a good question. Well, we, I think we're a pretty good team, because she's pretty responsible, but I am there to remind her about things if she forgets—would you say?
- C Uh-huh.
- P Yup, and I look out for her, so if she's not feeling good, I'll help her out and take over.
- I When it comes to counting carbs and preparing for meals and things like that, is that solely... --, do you do that on your own, or do you guys kind of work together to figure out how much insulin to take?
- C We work together.
- P She usually kind of adds it up, and then I kind of add it up and see if we get to the same thing.
- I Yeah, makes sense. All right, so what do you think of an application you guys could use together and anything that -- were to update on it, Rachel, you would get some kind of notification, so the app would work between, you know, on both of your devices, and you can share information and you can keep checking her blood sugar, and you can nudge her—"Hey, I haven't seen you update in a while"—that kind of thing. How would you feel if you had that kind of communication together at all times with something like that?
- P Sorry. No. I think that would be a good thing, because she's on her device all the time. But if the question is how would it interface with some of the other technology that we're using, now that we're on the CGM, so there's probably a place to connect the two or something, I don't know.

- I Yeah.
- P We check the CGM all the time, and then we have her pump that we check all the time, and so it'd be just how it would interact with all of those devices.
- I Yeah, absolutely. --, how would you feel about that if you had an app you could put all your stuff in and your mom can see it and you guys can use it together?
- C That would be cool.
- I Yeah, would that make it easier or harder for you?
- C Easier, except for she'd be bugging me all the time.
- I There it is.
- P Uh-huh, like I don't already bug you all the time.
- I Well, you can just get a bunch of notifications from your mom instead of her, "--!" Okay. When you are going to school or going on vacation or some kind of trip or camp or whatever, what are some things that you guys need to do to make sure that you have everything for --'s diabetes?
- P Oh, well, that's pretty much my job. You mean just in terms of packing supplies? I mean, we have to make sure we have the prescriptions ordered and make sure we have enough, like ten times more than you'd need of anything. Vacations are different than school. I mean, she has all her stuff at school, and she's in charge of talking to the nurse about that, and I get a notification from her if they're low on something. But if we're leaving the house for even, even a day trip, we have to make sure that we have insulin and extra set changes and stuff for the sensors for the CGM and juice and snacks. Right?
- C Uh-huh.
- P Did I forget anything?
- C Huh-uh.
- P [inaudible] strips, all that good stuff.
- C It's so cool.
- I All right. Is there anything else about you two and taking care of -- and your relationship? Anything like that that is important to share with me?
- C You have to wake up to feed me.
- P Oh, yeah, she was reminding me about the night checks, but my husband and I share waking up at night to check on her a couple times a night, because she tends



to go low overnight. That's a big part of it. We let her sleep and just makes sure that she's in a safe range overnight. And then most of the time she takes all her blood sugars; she enters all that in her pump. She pretty much runs her pump all day, and then I take over at night.

I All right.

P Anything else I'm forgetting?

I Nope.

P Okay. She said no.

I Okay, all right. Then, --, I'm all done with you. Thank you so much for all of your help. I appreciate it.

C Thank you.

P Wait, wait. Come here and say goodbye. Turn and look at people.

C Goodbye.

I Goodbye, thank you.

P She's going to go get ready for gymnastics.

I And I'm jealous.

P Sounds like more fun, huh?

I Yeah, it sounds like a lot. I know I have to clean today. I don't want to clean. I'd rather go to gymnastics.

P Me, too.

I Okay, so to start—When -- was diagnosed, in what ways did your lifestyle change?

P Can you say that once again. Her monitor just went off and alarmed me. I've got to tell her one thing quick.

I Oh, yeah, go ahead.

P Hey, --.

C What?

P Your monitor just went off. [inaudible] can you give another five carbs? Did I hear a yes?

- C [inaudible].
- P Okay, sorry. Dealing with after-breakfast blood sugars.
- I That's okay.
- P Okay, how did life change when she was diagnosed?
- I Uh-huh.
- P It got very much more complicated. I mean, just the stuff to keep track of and stuff to take everywhere, and, yeah, much more complicated. And I had a six-month-old at the time, so it was already a little complicated. But you do what you've got to do. And a lot more worry, too—I'd say that's a big part of it is the always wondering, worrying if she's okay and trying to give her independence and all that.
- I How, what way do you use to communicate if she's ever not with you, to make sure that she's doing okay?
- P Well, we're starting... We have a phone that's not really her phone, but she'll take it with when she's gone for extended periods of time. And we'll text back and forth, or typically she's still, I mean, she's with good friends of mine, usually, so I call the moms typically and communicate through the moms, kind of at that in-between.
- I Okay. Can you list your—and you've kind of already done this—but your specific responsibilities for -- that she doesn't take care of on her own yet?
- P Well, there's on her own, and there's on her own. I mean, if I'm not with her, she'll forget to check her blood sugar, she'll forget to give insulin sometimes. So I mean I guess that's still my responsibility, all, pretty much everything. But she's getting better, and every month she takes on more responsibility. But I would say the things I do completely are: I change her pump sites, I change her sensor sites, I do her night checks, I take care of ordering all her prescriptions, I'm making sure we have what we need for supplies and equipment, schedule all her appointments, make sure that menu planning..., making sure that she has decent choices, healthy choices for meals, make sure that she knows the carbs. I'm the one that changes all her settings, so we change basal and bolus settings on her pump almost daily sometimes. So I deal with that, all the analysis, downloading her pump, making sure that she's not going too high or too low theoretically, ideally.
- I Right, so a further extension of that, a typical day for you in regards to what you do and what you have to do to take care of -- kind of lines up with that. What does that look like in a day?
- R Well, everything, you mean? How much time do you have? No. We make sure, I mean, in the morning I make sure that she's on a safe level, so when she's showering, getting ready and everything, she's not going to experience low blood sugar, because we try and keep her somewhat low in the morning but not too low.

And then I make breakfast for her, make sure she knows the..., make sure she's pre-bolusing, because we try and bolus like a half an hour or 15 minutes ahead, so make sure that happens. Make sure that she's eating everything that she gave insulin for. So if she gives 30 parts of insulin, I have to make sure that she didn't forget to drink the milk and leave it sitting on the counter, make sure that the carbs and insulin match, and then kind of check her one more time before she heads off to school and see if I need to adjust any basal settings on her pump, make sure her monitor is working, and I may send her off. And we have a great school nurse, so usually I'll hear from the nurse at least once. Well, the nurse uses Blue Loop. I don't know if you know what Blue Loop is.

I No.

R Blue Loop's really cool. It allows a nurse to enter her blood sugar at school, and then I get notifications on all my different emails, so I get real-time notification of what her blood sugar check is. That's handy. So then if there are discussions that need to happen, like I'll call her up—"Hey, I notice she's going low. Did you do this?" or she'll kind of tell me on there, like, oh, I'm having her sit out for PE or whatever, so I know what's going on when I pick her up from school. And then after school we do snack, and that's kind of the same routine, and then we do dinner, and that's kind of the same routine, you know, pre-bolusing, making sure the carbs and the insulin match. And then every other day, we change her site after dinner or we change a sensor site, so there's usually something to change after dinner. And then her really difficult time is snack time at night, so I make sure that she has a snack, make sure that it's got protein in it. Sometimes we have a big snack, sometimes we have a little snack, depending on where her numbers are going into that. That seems to be her really volatile time, so we try and even things out if we can. And then she goes to bed and I stay up for about three more hours usually, making sure she's kind of in a good range, since she's still got insulin on board. And then I go to bed at midnight. Then I get up at 3 and then I get up at 5, so...

I Do you guys monitor like every night, not all night every night, but you know what I mean. Every night do you check her in the middle of the night?

P Yeah. And then we also have the CGM Share system so we can get notifications from anywhere in the house if her blood sugar goes low at night, if it's working, everything's going well, if the technology is.

I Yeah, absolutely.

P And then now the new Share, I don't know if you follow diabetes technology, but Dexcom just came out with an announcement that their next receiver is going to have Bluetooth capability so that I'll be able to get her data everywhere, like, when I get an iPhone. So that'll be really awesome, so then I can see when she's at school or at a friend's, I can just see what her numbers are.

- I Right, and then you can keep her away from having a real phone for a little bit longer.
- P Well, she has to carry something with her for the technology to work, so she'll be carrying her own with her.
- I Got'cha.
- P She's pretty excited about that, but she wishes it was an iPhone, and I said, "Yeah, so do I."
- I Right. Okay, so you have, your son is nine—right? Is that what...?
- P Yeah.
- I Okay. What's his range of knowledge, and is he of any help really to -- at all?
- P He's somewhat of a help. I mean, he's a little brother, so, but he thinks the technology is cool, so like he has an iPod, so now we've set up the Share so he can get the numbers on his iPod, like in the evenings or whatever. And he has fun, like, "Hey, --, okay, you're going low," "You're going high." So I mean he kind of nudges her sometimes, but for the most part he just ignores her diabetes. I mean, he's not... Well, he kind of ignores her too. We try to... I mean, once in a while I'll say, "You know, you can't have that because -- can't have that right now, and we're not going to pull out the ice cream because the numbers are high." And he's like, "Ah, man!" But he's pretty understanding and pretty good about it.
- I Well, that's good.
- P And we try not to do that a whole not, you know, penalize him for things that she can't have but once in a while he understands it.
- I Yeah, well, that's good. What is your current method, if any, for scheduling, logging and any other tracking?
- P Well, I mean, I used to do all paper logs. I haven't done that in probably a year and a half, since we got the CGM. So I don't log very much at all. I download from the CGM, probably not as often as I should, but probably once a month or once every other month I'll download—really when we're having issues with needing to change a lot of stuff, I'll download from the CGM. So other than that, I don't log food right now, I don't log carbs. We could do that, I think, on the pump, but we've just never taken the time to do that.
- I Yeah. Do you use any applications for any kind of healthcare monitoring? It doesn't have to be diabetes. It can be, but even if it's like a running thing or a carb counter, anything like that?
- P We do not, no. Mostly, I've just never researched the [inaudible] or whatever.

- I Yeah, I know in the beginning some people like to use some sort of carb counter. What was your method when she was first diagnosed?
- P You mean in terms of like logging stuff or in terms of finding stuff?
- I In terms, you know, just for meals and things like that, finding out how much insulin she needed to take.
- P Yeah, yeah, I mean, I would look it all up on my phone, so I can't remember. I didn't really have an app, but I would just go out, and it was like, I can't even remember. Certain websites would keep coming up, and I could just put it in. And now -- has figured out if she just asks Siri, like, "How many carbs are in a piece of bread?," Siri will look it up and tell her.
- I Oh, that's nice.
- P She does that a lot now on her phone.
- I Yeah, okay, so what...
- P We have a book we use too, like old-fashioned, whatever that red book was that we looked everything up in.
- I Yeah, I know I remember that from my brother. It was a little book for a counter book.
- P Yeah.
- I What are your thoughts on an application that you and -- could use to help monitor?
- P Yeah, I think it would be helpful, but I mean it would take a little bit of... I just don't have time to learn that new stuff, so I don't always take the time to do it. But if someone kind of gave me a kick in the pants or a friend showed me how to do it or somebody introduced me to it, I'd be all for it.
- I Yeah. Do you have any reservations about an application that deals with her diabetes?
- P Just if it would make things more complicated, like one more thing to track, one more thing to... If it was really easy reads, like one screen, one place I could put stuff. It was like, go to these seven screens and enter these seven things, I'd be like, ah! I already got to enter it in the CGM, I've got to enter it in... But if it was easy, I'd be all for it.
- I Okay, yeah, no. I mean, and that's completely fair. It makes sense. There's enough going on, I think.

- P You can tell I'm already kind of frazzled. I've got enough on my plate. Can't even talk properly.
- I What would your advice be to another family who just found out that their child had Type 1?
- P Just that you learn a lot quickly, and you get where it's second nature for the most part. I hated it when people said that to me, so that's not very good advice, but it really is true. You figure it out, it becomes part of your daily life, and it doesn't have to change what your kid does, it doesn't have to change what your family does for the most part. You can still do anything you want to do, but it just takes a little more planning and a little more time and a little more maintenance.
- I When she was diagnosed, was there anyone else in your life who also had a child who was able to identify with the situation?
- P We actually had a family in our church, which is really small, whose daughter was Type 1, so it was interesting. But they weren't really open about. They didn't really talk about it, so we didn't know that much about it at first.
- I But was it... I don't know at what point in the year she was diagnosed, but did you go to like the family weekend at camp [inaudible]? Was that of any help at all either?
- P It was super helpful, but she was diagnosed in August, and then I think, I can't remember. It was like clear the next like April, or maybe it was [inaudible]... It was a while, so I remember thinking like, wouldn't it be cool if we had done that sooner. We had, like JDRF was really helpful, so we met a couple families pretty quickly through JDRF, so that was good too.
- I Okay, so they are really all my questions. Is there anything else you want to share with me?
- P Gosh, oh, I could [inaudible] on and on about diabetes. So how old is your brother?
- I He's 21 now.
- P Okay, so was he a younger brother?
- I Yup, yeah. He's two years younger than me. He was diagnosed when he was 12 or 13.
- P Okay, so did you get to know a lot about his routine and help out as the older sister?
- I Yeah.

## Design of Mobile Application for Type 1 Diabetes

Interview #4 – 2/18/15

Interviewer (“I”): Amanda Skinner

Parent (“P”)

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- I When your child was diagnosed with diabetes, in what ways has your lifestyle changed immediately?
- P We had to change all the foods in the house. We had to change our daily schedule because he had a test at certain times for his insulin. We had to start packing a bag full of medical supplies and other things that had to be with us at all times.
- I Okay. Was there anything that changed in the dynamic between your family? Or with school and things like that, what kind of changes came about?
- P For him? Oh, I had to have meetings with his teachers to explain to them what could, will change with him, what to look for, bus drivers. I had to be on call at all times because the nurse wasn't really aware of all the new changes in the diabetes, so they constantly called me to help with treatment or his numbers or his blood sugars. So it just kind of put everybody on high alert for a while.
- I Okay. Could you list your current responsibilities, if any, for your child?
- P I don't have that many anymore, because he's an adult, but I still check to make sure he's eating healthy and make sure that his A1Cs are within normal range.
- I And who takes care of ordering all those supplies and things like that?
- P He does.
- I Okay, so just further than that, can you list the other responsibilities that he takes care of on his own?
- P He orders his supplies, he tests his own blood sugar, he takes care of his own pump, he takes care of his own bolusing, his own diet, and that's it.
- I Okay. Would you say that a typical day for you currently is affected at all by your child's diabetes?
- P Not anymore.
- I Would you be able to go through kind of a day in the life when he was a little bit more dependent on you?
- P Yes. Those days were... I always had my phone with me, because I never knew when he was going to need some assistance. I was just always on call, like I never knew when something was going to happen that was going to need my..., either to

take him to the doctor or me to help him figure out something. So you were just kind of always aware that at any moment something could happen.

I Does your other child currently or previously help with your child's diabetes? And in what way?

P Yes, she was always very helpful. She would help give him his shots, and she would always make sure that he was testing. And it was a part of our whole family.

I So did you make sure that everyone was educated and...?

P Yes. Everybody knew how to give shots, everyone knew how to test, everyone knew how to count carbs. Everyone was educated in our family so everyone could help at any time.

I Okay, great. What are some methods that you currently use for scheduling, logging, other tracking? And this might be a little bit more of things that you used to use in order to help him monitor what he was eating, when he was eating, when he took insulin, that kind of stuff?

P What do you mean—what did I used to use?

I Was there an application that you used? Did you have a notebook, did you have an Excel document? Was there anywhere that you kept all of these records?

P Oh, just in notebooks, or we had log sheets from the hospital that we had to fill out daily, depending on when his appointments were. Usually within a couple week sort of an appointment, we'd fill them out, or a couple weeks after, because they would change his medication, so he had to log all of his numbers.

I Okay, so it was mostly pen and paper, not a lot of technology involved in that.

P Yes.

I Okay. Did you like that? Did you feel... Was it difficult because you had this one thing going back and forth, in case you left it anywhere or anything like that, or did it just seem to work the way you needed it to?

P It's all I knew. This is how I knew how to do it. I didn't know any other way.

I Okay. Do you use any applications, whether it's on iPad or your phone, for either your personal healthcare or that you used for diabetes, whether it was carb counting, calculating?

P I use things, like I use applications like MyFitnessPal or Weight Watchers or those kind of apps. MapMyRun—like I use things like that. As far as for the diabetes, I don't use anything.



- I Do you find those apps to be helpful for your purposes?
- P Yes.
- I Can you explain why?
- P It's just an easy to log in your information, and it keeps it all for you. You don't have to worry about paper or pencil. You just punch it in. It's as easy as sending a text or writing a text or email. It's just all very convenient and all in one spot.
- I Okay. What are your thoughts on an application—and I guess this would be kind of making more of an assumption, since your child is older—but if you had an application that you could use with your child to help monitor their diabetes. So instead of having a single notebook, you have an application, you both have an account, the information can be transferred back and forth. What are some thoughts on that?
- P I think that's a great idea, as long as the child is old enough to be able to do that. If they're a younger child, they probably are not able to keep track like that, or is not going to be as responsible about it. And also a lot of younger children in schools are not allowed to have any of their technology out during the day, which would cause another issue, because I don't know that they're. If they have school plans in place, I don't know that they could actually put in there that they have to have their phone with them to use an application for diabetes.
- I Right, and as someone who works in a school, how would you feel if there was a child who presented this as a need of theirs? How would you feel handling that type of situation? Would you be comfortable or uncomfortable?
- P Oh, I mean, I would be okay with it. I think I would be okay with it, as long as the child is responsible enough. But the problem is, I think some kids also don't want to be different, and they're not going to want to do it, because they don't want to stand out.
- I Okay, so aside from the issues with school and being responsible, are there any other reservations you have about this type of application. If so, could you explain?
- P No. I think it would be very helpful, because I know we use it for a lot of things. Everybody these days uses it for, like MyFitnessPal, people are logging their foods and their carbs and all those things. So I think it would be helpful for kids to be able to have an app, or parents to use.
- I And would you like to know that as a parent, you can also monitor without nagging, essentially.
- P I think you're still going to nag, because I think the kids aren't going to put it in. I think it's going to be like anything—in the beginning it's going to be a novelty, and they're going to do it right away; but as it goes on, I don't know that an app is going

to make any difference. It's still the annoyance of having to keep track of things that nobody else has to keep track of, from their eyes.

I Yeah, that's a completely fair point. So before your child took care of himself more, what was your method for monitoring when you weren't together? Did he have a cell phone, or how did you go about making sure that they were okay?

P He had a cell phone.

I And how old was he when he got a cell phone compared to when he was diagnosed?

P I think he already had the phone, or we got it right after. Actually, I don't remember, because it's been a while.

I Okay, and so it was just text messages and phone calls and that?

P Right, yes.

I Okay, and what would your advice be to another family who just found out that their child had Type 1?

P My advice would be: Keep your life as normal as possible. It's very easy to keep it normal. And you have to keep your fears about the disease to yourself, because especially with the younger children, they don't have the fear. It's not that they shouldn't be aware of the seriousness of it, but you don't need to make them so afraid of it that they have all this extra added anxiety and stress, which does add to their low blood sugars and high blood sugars. And just stay educated, as educated as possible. And just to know that it is manageable as long as you're willing to really work with your child and keep them healthy.

I What would you say one of the best choices you made was, as far as helping you child?

P Making him go to diabetes camp, because he did not want to go. That was the best thing we did.

I Why didn't he want to go to camp?

P Because he didn't know anybody else going, and he was afraid.

I And what was the outcome of him going?

P It was great. Before he went, he wasn't really doing well with giving himself shots or... I really don't remember all the little things, but he learned so much at camp, and he was with a whole bunch of kids that did the same. Everyone was the same, so everyone had to do the same thing.

- I So that sense of community was helpful as far as adjusting for him?
- P Yes, and now he's a counselor there.
- I Okay, so if the application were to have some sort of community support—whether it's reaching out to kids in the area, there's other kids available that you can message; they're all going through the same thing, they could be across the country, they could be wherever—is that something that's helpful for a child who is going through this and learning how to grow up with it?
- P As long as it's monitored. Like anything else, when your kids are younger, the fact that you want them talking to social media with people that you don't know and they don't know from all over is a scary thought. But if it could somehow be monitored and you know that they're talking to people that are safe, I think it would be a nice way for them to connect with kids who are like them.
- I Okay. Well, those are all my questions for you. Is there anything additional that you feel you want to add ?
- P Nope.
- I Okay.

## Design of Mobile Application for Type 1 Diabetes

Interview #5 – 2/19/15

Interviewer (“I”): Amanda Skinner

Mother (“M”)

Father (“F”)

Child (“C”)

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I So how old are you?

C 13.

I Okay, and how old were you when you were diagnosed with diabetes?

C 12.

I Okay, so you’ve had diabetes for about a year?

C Yeah.

I Okay, can you tell me what your responsibilities are every day for your diabetes that you take care of?

M Actually, he’s been... On February 12<sup>th</sup> it was two years.

I Okay.

C Yeah, so I would actually have been 11. Sorry.

I That’s okay. Okay, so your responsibilities every day to take care of your diabetes?

C Yeah.

I What kinds of things do you do?

C I test my blood sugar, and I take my shots, and I make sure that I get it at all the correct times, yeah, and it’s just whether or not I get it good enough. Like, my phone here tells me what time everything is, so it just gives me a sudden buzz whenever it’s time. I programmed it to do everything, or to tell me when things are, so I think it’s pretty good on what times. It’s just a matter of actually testing or not and actually logging it on my tablet. I have a tablet that has an app, and I can log all my blood sugars right there.

I Okay. Do you use anything to help count your carbs, or how do you take care of that?

C I have a white board. It’s hanging up by the fridge on the wall, and I just like look at things on the box, and I add it all together and use a calculator to divide, and yeah.

- I Okay.
- M [inaudible].
- I Yeah. Could you tell me about the app that you use on your tablet?
- C Yeah. Can I go get my tablet real quick?
- M Yeah, you can go get your tablet, buddy. Hold on.
- I Okay.
- M Him and his dad both use the same tablet or same app.
- I Okay. What's it called?
- M Glucose Buddy.
- I Okay. I've heard that one a few times.
- C It's yesterday morning, but it should be good. Okay, so this is the app. It's just these simple little icons, and you can click on this center one, LOG, and it's supposed to pull up a page. I don't know if you can see that clearly. It has like a list, and you can click on MONTH instead of LIST and it gives you like a calendar. You can go back, click on this little icon here that says ADD TO LOGS, and you can select, time, date and then you can select about what meal it is, before breakfast, after breakfast, etc. You can click on MEDS and you can tell it what kind of insulin you're taking, and you can click on FOOD, what you're eating, what activity you're currently doing and what your current A1C is. But I only just normally log my blood sugars. Those are the two biggest things. There's also blood pressure, weight, Facebook, Twitter, graphs and reminders. But I only use LOGS and ADD TO LOGS.
- I Does that sync up to your phone then, so can you also use it on your phone and it sends between them.
- C I can't get apps on this.
- I Okay, so you just use it on the tablet.
- M -- uses it on his cell phone.
- I Okay.
- M But a 13-year-old boy, smartphone—no.
- C Those are good; they're cheap.

I Okay, great. So do you like the way that the app, that Glucose Buddy works for you?

C Yeah.

I What are some things that you like about it.

C I used to have on the whiteboard, like it'd be sheets that you print off every couple months, and I'd have to write them down. At one point my mom tried setting up her own thing. She set up this thing on Google Docs with a graph. I could not do that. Is skipped out on like months worth because it was just so hard. And on my brother's Kindle it's just so hard to do every little thing when everything's all microscopic. So my mom showed me this app, and I'm like, "That is way so cool. I'm gonna use that 'cause it's easier than I'm doing on Google Docs, and it's easier than writing it on paper."

I It is?

C Yeah.

I How long have you been using the app to help you out?

C I don't know. Ever since camp this summer.

M Oh, about six months.

C Yeah, about six months.

I Okay, great. So a little different topic—can you tell me any sports or activities, clubs, anything like that that you do for fun?

C Martial arts.

I Ooh, what kind of martial arts do you do?

C Taekwondo.

M No, it is not Taekwondo. It's not [inaudible].

C [inaudible]. I'm sorry. I forgot.

I How long have you been doing that for?

C Since first grade.

I Oh, cool, so that's a big part of your life?

C Yeah.

- I What do you like about it?
- C It's fun, yeah. Some people find it hard and like really difficult, but whenever I actually do it, I find it is fun, yeah. Our instructor like says the weirdest things, like really mean things to most normal people, but I just laugh. Like a lot of people at high ranks just laugh, 'cause they're used to it.
- I So what rank are you at?
- C Well, I'm gonna be a black belt this month, so...
- I That is awesome. Congratulations!
- C Thank you.
- I Does the physical aspect of it help you at all with your diabetes?
- C Yeah.
- I And how does it help?
- C I get my exercise.
- I Why is that good?
- C It helps me stay fit, in better shape so that it's easier to do things.
- I Is it good for your numbers?
- C Yeah. When I first got diabetes and I was still in martial arts, I had a hard time, 'cause sometimes it'd be high. But then like after the first couple months, every time I went to martial arts, I dropped to like 40s and 30s, like 34 is like the lowest I've ever been, but that hasn't happened in like a half a year, so I've been doing good.
- I Good. Do you have any friends at school or from camp, anywhere, well, obviously from camp, but who have diabetes?
- C Have one from my old school, Aldo. He's been diabetic since he was three, so he's the only I've ever known that's been diabetic in Burlington.
- I Was he helpful at all when you found out that you were diagnosed?
- C Sort of.
- I He'd just like give me little tips about things here and there and like what to do, and that was basically it. We joked around and stuff. We'd sit in the clinic right before lunch. Just as [inaudible], while I'd get to my shot, he'd just press this little thing on his pump.

- C Okay, so he had a pump.
- I Oh, okay, so he had a pump.
- C Yeah, I'm just like, that's so cool, I want one.
- I Yeah, my brother has the pump—pretty nifty.
- C Dad used to have the OmniPod. He didn't like it.
- I Yeah, there's all different kinds, and I know my brother has tried out quite a few before he found one he really liked, so it's all personal preference. You've got to make sure you like what you have. Okay, so Glucose Buddy is just you put your own stuff in. What would you think about an app that allowed you to connect with other kids your age who also had diabetes, whether they're in the area or across the country, things like that, to give you some sort of like support system? How would you feel if it had that kind of capability?
- C Well, I'm not really the kind of person who looks for support on disabilities and stuff. I really look for things on how I can really use it to... I don't want like really major support. I just look for [inaudible] who finds it interesting, who is okay with it but doesn't like show too much sympathy for it. I make sure that, like if I'm gonna have a friend, I pick out a friend who really like just understands but like doesn't really necessarily know.
- I Yeah, no. That makes sense. So your friends, when you're together, if you were to drop low or anything like that, do they kind of know how to help you in those situations?
- C Well, one of my friends, his dad is a pediatrician, so...
- M No. He's a physical therapist.
- C Oh. I don't...
- M That's okay.
- I It's okay.
- C It's a media place.
- M No. He works in --.
- C That wasn't... Yeah, but at my new school, no one knows what diabetes is, so they don't know really how to treat like kids with diabetes or what to do about it because there is no one else. So they kind of treat me more like a normal kid and one of them and not someone who has a giant obstacle in front of him.
- I And do you like that?



- C Yeah, because a lot of kids there do have certain obstacles, not as bad but they still have to put up with it. Like a lot of them have ADHD. My two greatest friends there both have high things of ADHD—you can tell.
- I But it's nice not to feel different?
- C Yeah.
- I That's great. That's really good. So you have a phone, a tablet, computer?
- C Yeah.
- I That kind of stuff. Okay, so what kind of things do you do on your devices? What kinds of apps, games, anything that you do?
- C I have sounds on this. I just randomly play music, and I take pictures just for quickness. Like computers...
- M And it's your phone.
- C And it's my phone. My tablet, I play games on it, I watch a lot of YouTube. Oh, I love YouTube. I also put Dr. Who on it because my neighbor has it. And my computer, I just use it for like Internet stuff. I just had it like rest, so I really only use it for like looking up stuff and playing Minecraft and stuff like that.
- M He also has an Xbox and a Wii.
- C Yeah.
- I But you like to game?
- C Yeah. I don't really play too long. We don't like play the Wii that much now that we have the Xbox. We still play both.
- I You seem happy about the Xbox.
- C Yeah.
- I What are some of your favorite games to play on the tablet?
- C I can open it. I've got a whole file for games. I have Marble Champions, which is like Street Fighters except for with like XMan and the Avengers. Clash of Clans—I just started that. Crossing Road is like Frogger except for chicken crossing the road. The Angry Birds games—I have Angry Birds Transformers and Angry Birds Star Wars. Stair Dismount and Turbo Dismount—those are [inaudible] where you just mess around [inaudible] like throwing them off of things.
- I Fun.

- M His school also provides him with Kunos .
- C Yeah, I use that, though, for like homework and stuff.
- I What was it called, I'm sorry?
- M A Kunos.
- C Kuno.
- I What is that?
- M It's another tablet.
- C It's a table that the school provides. I just use it like people suggest me games, and I download them on my Kuno, and I play them on there, and I try them out. And if I like them, I get them on here. So it's kind of like my trial thing, because, yeah.
- I Okay, so do you have a sibling?
- C Yes.
- I Older or younger?
- C Younger.
- I Is it a boy or a girl?
- C Boy.
- I Does he help at all with your diabetes? How educated?
- C He knows pretty well what goes on. He knows if I am low that he has to go and get stuff for me. He knows if I'm high, he has to stay out of my way. Like he knows when to bring me my tester and my insulin. The only thing I don't let him do is give me my shots.
- I Yeah. You don't want him to stick you with a needle?
- M [inaudible].
- I See, my brother was younger than me, so I used to help give him shots, because I wasn't the little one. He trusted me a little bit more, I think.
- C Yeah, I used to have my dad and my mom do it. Now I can do it myself.
- I That's good.
- C Yeah.

- I So you said you remember to test your blood sugar because you have a reminder set on your phone. Right?
- C Yup.
- I And if you had a new friend who found out they had diabetes, what would you tell them to make sure they do. What would your best advice be to them?
- C Don't stress out over everything, because stress leads to bad things with your blood levels. You want to stay as calm as possible. Just remember to take your insulin and test your blood sugar. Stay calm and everything will be okay.
- I How do you think that they would be feeling if they were just diagnosed?
- C Pretty upset. I remember I was super-duper depressed, and yet it wasn't, it didn't feel good at all.
- I Yeah, it's tough. So can you describe a few activities you like to do together?
- C What do we like to do together. Oh.
- M Watch TV.
- C We watch TV and movies. We love movies. We have a ton of them.
- I Any specific \_\_\_ or just everything?
- C Mainly action. She likes rom coms. I like Star Wars.
- M He likes anything that has to do with guns and racecars.
- C A lot of bust 'em up, shoot 'em stuff.
- M [inaudible] comedies movies that no one [inaudible].
- I Okay, so you like to watch movies. Anything else you guys like to do together?
- C We go out occasionally to—I don't know if you ever heard of it—Fun City.
- I Huh-uh.
- M It's a giant arcade/pool/hotel/casino. It's a whole thing that we have down here where it's like they have a velocity, which is a ball area for kids where they can climb and do... They've got indoor swimming, outdoor swimming, bowling alley and arcade and restaurants and bar, laser tag, racing cars.
- I Wow.
- M Yeah, it's cool. We do that. What else?

- C Me and Dad love to mess with our guitars.
- I That's cool.
- M Yeah, they do guitar. The boys and I...
- F We grapple.
- M We grapple, we wrestle. Dad normally wins. The boys and I kind of like, if we know a movie is coming out that's based off of a book, we like to try and read the book. And then when we see the movie, then we like compare it to the book. Mays Letter, Higher Games, Percy Jackson, all of them.
- I Yeah, I'm the same way.
- C [inaudible] the biggest ones, I'll read comic books and base superhero movies off of comic books. But Mom and -- won't know anything that I talk about.
- M We do lots of arts and crafts, the boys and I do, though [inaudible] is a bit more independent now or whatever.
- C I love art.
- M I just started to teach them how to cook.
- I Ooh.
- C Dad will occasionally play video games with us, mainly Rocksmith, which is like a videogame that teaches you how to play guitar, and Super Street Riders.
- M I think it's important for the kids to know how to cook and cook healthy meals. So like --, that's what I focus on more with him. And then my youngest one likes to bake, so he's been learning more of the cakes and the cookies and the brownies and stuff like that.
- C We love Legos. We could recreate LEGOLAND with all that we have.
- I Really?
- C Yeah. We got... I wish we had a whole 'nother room we could just put everything out and be like—look at what all we have—spectacular, you know. Instead, we have cluttered bookshelves and desks and stuff, dressers.
- F The boys help me do construction from time to time.
- C Yeah, me... I have an idea. Dad's gonna help me. It's I want to build a TARDIS from Dr. Who. I don't know if you've heard of it. And when you open it, it's a bookshelf on the inside; it's like a shelving in it.

- I Oh, cool.
- C It's going to have a feature where you can flick a switch and it lights up, and it's got... It's just gonna be cool. [inaudible] got lots of plans.
- I Yeah, that's okay.
- C I know where it's gonna go, too. We're a pretty typical American family. We dabble in this, dabble in that.
- I Yeah, well, it sounds like you're nice and well rounded to me.
- M Oh, with the turtles.
- C Yeah, we have turtles and a dog.
- M Well, it's a baby that's the size of a turtle.
- I The turtle, I assume.
- C Yeah. I can't think of anything else.
- I Okay. That's a pretty good list. Can you describe some ways that you all work together to take care of --'s diabetes?
- M Well, Dad and I, -- and I have been trying to step back a bit and give him more control and more power over it, instead of just saying, okay, well... Instead of scooping up his plates and saying, "Take this much amount of insulin," we've really like, "Okay, you need to look at the package. You need to figure out what your serving is, and then you need to figure out your insulin." I'll still... I mean, I guess I'm just Mom—I still put it on the plate for him, but I mean we're just trying to get him to be more independent, because he is going to be 14 in a couple months, and he really needs to learn how to take care of it himself. I ask him daily, "How is your blood sugars?" You know, if he's been high, "How many times have you been high in a row?"
- C We kind of as a family make a decision. Like he has recently made a decision to try and get on the insulin pump, and so we're signed up for classes for that in April. I don't know. At first they were kind of like over everything, and they make sure that everything I do was like, oh, okay. And now it seems, now it's just more like, okay, I can do this and this and this, and then I'll take so much of this, and they just kind of like, if I'm not doing something right, they just say, "Okay, you need to fix this and this, and you need to take more of this or do more of that." They only tell me a couple of times whether or not I'm doing something wrong, so I think I'm getting the hang of it.
- M We're letting him make the mistakes, but we're not letting the mistakes be consequential. We try and catch it. Like if he forgets to actually take his shots, and

he starts eating, I'll sometimes just not say anything to see how long it takes him to catch it. And then I think it makes more sense to him in training his brain to be more independent later on.

C I do forget sometimes.

M He does. Everybody forgets, but I mean if you don't make mistakes, you don't learn.

C But if you make too many mistakes...

M You don't. yeah, if he makes too many mistakes, he's gonna have a sore behind.

C And probably be the smartest person.

I Okay, so as a whole what do you guys think of an application that you would be able to use together? So there would be—I guess you kind of have this Glucose Buddy—but being able to keep track between all of your phones, and -- would have his own accounts. You guys would have accounts as well, and you can watch everything that he's logging in, and you can keep track together. How would that work in your lifestyle? How helpful do you think that would be?

M I think it would be extremely helpful. I mean, I don't know if he's logged anything in until I actually open up his tablets and get on the program myself, and the same thing for his dad. I don't know, and I like to know these things. I like to be prepared. I like to know what's going on, and that's just the mother in me, I guess. But it would be nice if they were all interconnected and I could—click okay on my phone—like --'s name. Okay, he was high today, he's gonna be grumpy. Okay, I'm gonna send him to bed early. Just, I mean, it would be nice to have an application where, not that I want control, but I want to know what's going on, because I want to know how family is feeling. I need to know how many carbs I need to plan for, for a meal. If we're having a high day, maybe head more towards the protein area. If we're having a low day, let's load on the potatoes.

I Right.

M I just think it would be easier for me and less intrusive on them, so I don't have to get into their phone or their tablet and snoop through their stuff—not that I would but not that I wouldn't either. You only get so much [inaudible].

I What are your thoughts, --?

C Sometimes I honestly forget to log. I forgot to log like say yesterday morning, but I said I was gonna take care of that. But there was a time for like a whole week I actually forgot, and so I am like sudden... I'm like one morning waking up. I get my hot chocolate ready and I'm drinking when Mom's getting into the bathroom, getting in the shower ready to come down and have breakfast and go to work. I'm thinking—huh, I wonder what my blood sugar is [inaudible]. Like blood sugar?

And I'm looking at my tablet, I said, oh, no—I'm like, it hasn't been a week. So I'm quickly..., and just like she's coming down the steps going towards the kitchen, like... and I turn it off, put it down, just like nothing to see.

M You did realize you just [inaudible] yourself out—right?

C Well, it's not like you didn't find out later that day.

M He gets in trouble when he doesn't log, just because for the doctors when we go to Iowa City and stuff like that, they need to know it. And I want to know. I've got to keep track of how many times in a row his blood sugar is too high or too low so that we can make adjustments to his... And we just started the ratio for insulin. We are on a set carbs, set insulin, and we just started ratioing. Especially now, I mean, we really need to know this information.

I Right, --, how would you feel—so your parents are able to see you're logging all this in the way that you're supposed to be. Or they notice that you're not logging and they could send you a little notification or a little nag on the app. How would you feel, knowing that they can kind of see all that you're doing?

C I'd like to be able for them to see what's going on with my Glucose Buddy and help remind me sometimes, yeah.

I Okay, so you don't have a lot of negative feelings, not a lot of reservations toward anything like that?

C Huh-uh.

I Okay. So my last question for you guys together—can you go through some of the things you have to make sure you remember when you're getting ready, whether it's going to school, going on trips, like a field trip or a vacation? What do you have to do as that extra step to make sure that you're prepared for your diabetes?

C Are we talking a long like road trip, or are we just talking, like, we know we're going to grandma and grandpa's for the day.

I I guess really either one, when you know that where you're going your stuff isn't going to be there. So if you could go through both, that would be helpful.

M Which one do you want to start with?

C Well, I'll start with Grandma and Grandpa's. Normally, when we're going there, it's just like Super Bowl or something, or I'm staying the night, it's like a weekend. I'll pack my nighttime insulin and all my stuff. Normally, because they raised a diabetic, they have snacks there in preparation, because they know what's going on. They know better than us what... They know well, like... [inaudible] they know better than us.

- M They know what it's like, is what you meant.
- C And they know what I can and can't have. They even like give me tips, like, yeah, they'll tell me that I shouldn't have this and this, or this has too much sugar, stuff like that. So I don't really have to worry too much when we're there.
- M What do you pack? What do you take with you?
- C My tester, nighttime insulin, and my regular insulin. I normally don't have to package the test strips unless I'm running super-duper low. They only live across town, so it's not like supplies aren't close by.
- I Right, yeah.
- C Yeah, it just takes like ten minutes to drive home, get something, drive right back.
- M So you get your nighttime insulin, your regular insulin, your test strips. What else is in your diabetic... He has a bag that we keep that we keep all his supplies in.
- C It's technically a lunchbox, but we repurposed it as a diabetic bag.
- M And then what about when we go on road trips?
- C I normally pack all my insulins and my tester. I make sure to grab like stuff.
- I What kind of stuff?
- C Like my insulin and stuff [inaudible] the night. Look through the cover and say, okay, what do I have? It's all [inaudible], and I grab snacks, and I just stuff it full. And if not, then we have like 20 Casey's we can stop by, buy stuff for like \$1.50.
- M We also, depending upon how your blood sugars are running, will sometimes take extra insulin.
- C Yeah.
- M Or if it's a car ride, because car rides always seem to make them run high. Did that answer your question?
- I Yeah, no, absolutely.
- C We've never got anywhere outside of Minnesota, Iowa, Missouri and Illinois.
- M Well, not since you've been born.
- C That's why I said "We," not you guys—we.
- M We haven't traveled too far since he's been diabetic either.



- C Since I've been born.
- M Just because it's just life. Life has happened, so we're very busy doing things. Dad's getting a call. Okay, next question.
- I That's actually all my questions for you guys together, so, --, you can stay or you can go. I don't have any more questions for you.
- M Up to you, \_\_\_\_.
- C I really don't care.
- I Just the rest of the questions, I'm not going to have you answer at all. If you're going to stay here, that's my only...
- M You need to get your insulin out of the fridge, and you need to test.
- C Oh, yeah, I've got another minute. Yeah, here I go.
- I Thank you so much. I appreciate it.
- C Yup.
- I So my next set of questions: When -- was diagnosed, can you kind of go through how your lifestyle changed pretty immediately?
- M Not a whole lot, with -- already being a diabetic.
- I That's true.
- M Just...
- F One more person to plan for.
- M Yeah, just one more person to plan for and got a little more strict on our times and stuff like that. Because we like to make sure that we're eating right around the same time.
- F Keeping a fairly rigid schedule actually helps you maintain health better. I know that's not something they preach too much at hospitals or anything anymore, but I'm living proof of that.
- M The doctors are amazed at how healthy and how few side effects -- has had since he's been diagnosed. I mean, he's been diabetic for 45 years, and we're just amazed at how well he is doing.
- I Yeah, that's great. I mean, did that make it easier—not that it's an easy thing. But when you found out that -- was diagnosed, was that situation a little bit more comfortable? Did you feel more confident, knowing you're in such great health?

F Yes.

M Yeah, yeah, I think it helped a lot. We knew what we needed to do. And then I know things have changed over the years as far as what they do or recommend. And we did learn new things, having to go through the boring training all over again, but...

I I sat through them.

M We're like—seriously, we know this, that item. But things do change, not a lot, not really a lot. It really encouraged -- to try a pump, an insulin pump. I mean, we started talking about it for --, and we're like, well, he said he wanted to try it first to make sure how it worked with him and that we knew what we were doing and stuff like that. And unfortunately, it didn't work out with that type of insulin pump, but I think we're confident enough to go forward with --.

I Yeah, it's definitely not a one size fits all thing.

M And especially diabetics have a tendency to have sensitive skin, and my husband, --, his skin is super sensitive. And he ended up having an allergic reaction to the adhesive. And it just was not a pretty sight. And we decided when we talked to the doctors and we didn't want to risk infection from the allergic reaction we were getting.

I Right, absolutely.

F As it was, I ended up [inaudible] now.

I Oh, I'm sorry.

M That's life.

I It is, unfortunately. Okay, can you list the responsibilities—you've kind of already gone into this, but you can just gloss over—the things that you take care of every day for --. So he tests his blood sugar and he remembers. What are the responsibilities that you really still do for him?

M Sometimes he has a tendency to turn off his alarm and go back to playing his game, so we have to kind of keep on him to make sure that he does actually test, he does actually eat. And he's a teenager—I mean it is what it is. It's just how it's going to be until he accepts it, being an adult. And, unfortunately, having diabetes is going to make him grow up early. It's just how it is.

I Yeah. Do you take care of ordering all of his supplies, counting his carbs? Do you still give him any shots, that kind of stuff?

- M Only when he asks us to give him shots. I'm more than willing at any time. I don't force him to have him make me do it, but if he feels like he wants me to do it, or either one of us, we will. We make him count his carbs.
- F But I have a tendency to always count his carbs, along with, just to make sure he's figuring them correctly.
- I Right.
- M And then [inaudible]. Counting carbs...
- I Ordering supplies.
- M Oh, ordering supplies. He's not real great. He's not a planner, so I have to say and count. I about know when, whatever, or the school secretary emails me—"-- is low on this." Okay. And they understand, and I talk... I have great communication with the school staff, and they realize he's a teenage boy, hormonal teenage boy, and the light's not always on. So they are right there with me, making sure he has the supplies, because they don't want to be out. They would be responsible at that point in time if he ran out and didn't have the supplies he needed and I wasn't informed. So they tell me when he's getting low, and I'm always asking him or checking behind his back when he doesn't think I know.
- I Can you go through a typical day in your life in regards to -- having diabetes?
- M Well, right now -- goes to work at... He has to be there at six in the morning, so he's gone and out of the house in the mornings. I get the boys up. They come downstairs. They pack a lunch. -- has found that it's... Well, not only does school food suck but... Sorry, it just does. But it's easier for him to, when he needs to take his shot, he packs his lunch and he knows his carbs ahead of time. So he knows how much insulin he's going to have packed when he gets his insulin before lunch. So both the boys pack their lunches, and, depending upon our time, I try to have stuff we can grab here for breakfast, or it could go on-the-go with them, or they can have school breakfast. And they wanted school breakfast for a while, and then they stopped, so I mean it's really up to them. But I get the kids up and going out of the house. I get them to school. Then I go to work, and the school nurse will call me if there's any problems or if they have any questions. And to be quite honest, it's been, I don't think I've gotten a phone call since October, so it's been really, really steady. His blood sugars have been very, very steady lately. Other than that, there were some days I was getting two, three calls a day because he was high. They just couldn't get them to come down for whatever the reason was. Sometimes it just happens. And then we go home. Of course he has his snacks and lunch at school, two snacks and a lunch. We come home, cook supper, he takes his insulin, and then do homework or whatever. Homework is supposed to be done like as soon as they get home. And then like you just seen, like when I reminded him just now that he needed to get his insulin, his nighttime insulin out of the fridge.

To --: He's supposed to be testing, instead of playing with your Legos. He's sitting in the dining room just being goofy now.

So they'll do that, and baths and bedtime, and we do it all over again. Days that we don't have school or work, I have an alarm on my phone that gets me up about 7:30 in the morning so I can get him up and try and keep him on a schedule.

I Okay. So can you just talk about your other son. What kind of... I know -- touched on this a little bit, but what kind of knowledge does he have, and what does he actually help with, if anything?

M He's a very good helper. He's very concerned. You can very much tell he loves his brother and his dad. He's very nurturing; he's a lot like in that way. He's a very nurturing person and very concerned. If any of us are sick, he's right there. He's our little snuggle buddy, and "Do you need anything? Do you need a glass of water?" I mean, he's very nurturing and very helpful. And I think he has a pretty good grasp of diabetes. I mean, he's lived with it his whole life. He witnessed... At one point in time we almost lost -- to his diabetes, and --ua was a witness to that. -- slept through the whole thing—it was in the middle of the night. But -- got to see the paramedics come in and give -- a Glucagon shot and help us get his blood sugar back up to where he should be. And I think that he remembers that, and it's really made an impression on him, and he was only like three years old when that happened, so it was very traumatic for him.

I Right, yeah, I can't imagine. So what are methods that you use for scheduling, logging, other tracking? I know that Glucose Buddy plays a pretty big role, but what do you use for your own record? Is it pen and paper? Is it something like Google Docs or what-have-you?

M Well, the Glucose Buddy will email me. I can go into his app, and then they'll email me the information, so I have it that way. Other than that, we have the paper logs on the refrigerator, killing trees. And I just thought, this is ridiculous—it's just so old school. There's got to be more to this, the way technology is. So I did the research, and we tried one app. And, oh, I tried doing an Excel spreadsheet, and you heard -- didn't like it. And then we tried one app, and I didn't really care for the format of that either. So then we found this Glucose Buddy, and -- liked it right away; -- liked it right away. So we just... If they liked it, we just kept it and kept it going.

I Right. What was the other app that you tried but you didn't like it? Do you remember what it was called?

M I do not. I mean, we didn't even... I mean, we just downloaded it and took kind of a look at it, and it did not seem easier. And that's one thing I know. If it's too complex, --'s not going to do it. He just doesn't want to take the time to do it.

I Right. It makes sense.

M Yeah.

- I Have you used any applications for personal health, whether it's like your own food logging or fitness, against, any apps for those?
- M I like FitnessPal. Actually, I lost about 40 pounds on that, and it was a great app. Yeah, that was a couple years ago, and I've gained it all back, but that's a whole 'nother story. But I started using... When -- got diagnosed, at first I was using MyFitnessPal to look at carb information, especially when we were out at a restaurant. Because, I mean, restaurants don't post this information. And if you go to the website, it takes forever to find it. And I found that MyFitnessPal was for me the quickest and easiest way to get to it. And we backed away from that. We don't need it nearly as much. Even that book that they give you when you're first diagnosed, that *Calorie King* or whatever it is, it's not complete, and it's confusing, and it doesn't have everything. It's just, I think MyFitnessPal was just a better option, and I wish restaurants were better at having that information available or readily available, even if it is on an app or in a menu or something. Like, my husband and I went to Starbucks, and we're not big coffee drinkers, but we went there just to get whatever and check them out. And I asked them, "Do you have a carb count thing?" "Oh, yeah, it's over there." Well, it was on their food; it wasn't on the syrups that they use and their drinks or anything like that. So I'm like, well, this is useless.
- I Right.
- M And people don't think about that. We've got to count carbs in everything. It's not just food, it's not just potatoes.
- I Right. Were there other aspects of MyFitnessPal besides the access to the nutrition information, other aspects of the app that you really liked?
- M Well, it would tell me way to go when I would exercise, although the exercise area, I thought, kind of lacked. Because we do martial arts, and I couldn't put in there, ten minutes of sparring—it doesn't know what sparring is. [inaudible] the exercise [inaudible] we were doing, so for me that area was a bit harder to put in the exercise. I don't know, I just liked the nutrition information and being able to put in there what I ate, and it would tell me—this is how many calorie and carbs you ate for the date. I really liked that. I stopped, not because it was bad but I had injured my foot doing martial arts, and I just kind of stopped everything and focused on getting my foot better. And you know how hard it is to get back into something once you kind of stop it?
- I Yup, going through that right now, so, yes. Okay, so you mentioned a lot of stuff, a lot of thoughts you have on the application you could use to monitor, and it would be helpful to see what's going on, and all that kind of stuff. Were there any other thoughts you have, or maybe positive or negative reservations you might have to an application of this sort, where -- will be logging everything? You can look over it and keep track of everything in one place, you know, the potential of there being

other kids his age who he can connect with and that kind of stuff. Just some other thoughts you might have on those types of capabilities.

- M I think it would be extremely positive. -- was so depressed when he first was diagnosed. I didn't realize how depressed he was. We just knew he was moody and being difficult. And then he was at that 12-year-old, 13-year-old age, and so we're like, okay, is this hormones? We really didn't know. And once we got him to camp, diabetic camp and everything like that, he was different; and he was able to connect with people and talk with people. And I think it made a really... around his own age, and it just made a big difference. He was a lot more positive.
- F At first he was reluctant about going.
- M Yeah, he was reluctant about going to camp at first, and now he looks forward to it every year.
- I Yeah, my brother had the same reservations, and my mom said, "Nope. You're going," and now he's a counselor at the camp he goes to.
- M Is it the one in --?
- I No. I'm actually from New York, so it's not even..., different state.
- M His camp is up in --,--, and actually last year we stayed the night in -- and then took him to camp the next day.
- I Yeah, I know, because he didn't express a lot of like interest in the big support, but you think that that was really beneficial for him.
- M Yeah, it was extremely beneficial. I mean, you could tell the difference in him.
- I Yeah. Are there immediate reservations you could think of for an application that has medical information and things like that?
- M No, because I think if he... -- is the type of kid that, when he has a question or if he wants to know something, he researches, whether it's about a character or a movie, he is into... He's very artistic, and he's thinking about a filming-type career, so especially stuff like that. But if there's other things he wants to know about or is inquisitive about, he has no problems going to YouTube or the Internet and finding that information out. I think if he needed to know something, like that this app could offer, I think it would be extremely beneficial. I would like to see something that would maybe combine, an app that combines the carbs and his logs a little better, a little more easier accessible for both of them. So like if you were at a restaurant, and this is me thinking of him as a teenager—he's at a restaurant, and he could just go to his app and sustainable agricultural—I'm at McDonald's getting a Big Mac and fries, and it counts his carbs for him, quick and easy for him, and especially if he's on a band trip, because he's in band. We did wrestling one year. It

would just be easier for him, I think, the less he actually has to think and have more time to interact with others.

- I Yeah, absolutely. Okay, so when -- is not with you, he has the phone. Is your current method of monitoring just through phone calls, text messages? How do you make sure everything's going well with him when he's not with you?
- M Phone calls, text messages. His best friend that he's known since kindergarten, his dad is a physical therapist. And they just live like a block and a half away from us, and they're really good. His mom will give me a call and, "Well, can -- have this?" or whatever. And -- actually does really good. He'll make sure and test his blood sugar and help guide. And then if they have questions, they'll call us. I mean, he has taken that responsibility—you know, I'll test first and see, blah, blah, blah. Other than that, grandparents, they do really good with it. Both my husband's and my mom's, because my mom is Type 2, and of course my husband's parents raised him.
- I Right.
- M You know, other than that, he really hasn't... He hasn't really spent the night at anybody else's house, has he? Most of the friends come here, but we have the playroom. We have a room in our basement with air hockey and the Wiis, and they have their own TV, so the kids have an area. They've got a Boy Cave. So the friends have always come here, even before he was diabetic. This is the house. That's just how it's always been.
- I Can you talk a little bit how it was finding out that -- had diabetes, knowing you already knew the ins and out and you knew the impact that it has? How were you feeling? What were your initial thoughts, and how did that..., for the two of you?
- F Like a [inaudible] We are the ones, of course, [inaudible].
- M Yeah, well, okay. So here's the back story. -- had been sick, and we knew something was wrong, but we didn't know that it was diabetes. I did not recognize the signs that -- had as being diabetes, and so I had to fight the doctor to have him tested for it. We went through, before he did the blood glucose, we had an EEG done, we had MRIs done and went to the doctor. We did this, we did that, and it wasn't until -- finally told me, "Mom, I'm thirsty. I'm thirsty, and I am peeing all the time." And as soon as he told me that, I knew exactly what was going on. And I take him to the doctor. Well, actually I brought him home, and it tested him with my husband's test kit, and he was over 300. And so I took him to the doctor, and I fought him on getting him tested. And long story short, I was right. And then they rushed us kind of up to Iowa City. Luckily, because of my husband and our knowledge, we did not have extended hospital stay. We were able to come home. We had to go back. They knew we knew what we were doing and that we had a good handle on it. Emotionally, it's... Even though we knew it, it was still hard to think why. I mean, we didn't want that for him. [Go away. He's standing behind the

computer staring at me.] I don't know. Do you have anything to add? I mean, you go through any emotion that a parent normally goes through when they find out there's something wrong with their child, an autoimmune... you know, it's genetic.

I Right.

M I guess it's better to have that than cancer.

I So, though, you were prepared at home, and with your knowledge the emotional aspect is still all there. It's still, you know...

M Definitely.

I Okay.

M Definitely.

I The last thing I need to ask you really is: What would your advice be to another family who found out their child had Type 1 and under the assumption this is completely brand new to them and their lifestyle? What advice would you have for them right from the beginning?

M What do you think, dear? You want to start this one?

I [inaudible] on how well balanced... balance your exercise or sleep, your diet. Research everything you possibly can for childhood disease. The more you know, the better off you are.

M Did you hear him?

I Yup.

M So this actually happened to a lady that I used to work with. Her son just got diagnosed at the beginning of this school year, and I just provided the emotional support for her. I mean, they've already been through Iowa City and been through the training and stuff like that. And then I'd say, "If you need to talk, contact me. We're here." It's good to have the emotional support. I felt like, yes, we knew what we were doing. Yes, we were kind of old school with diabetes, but it would have been nice to have had emotional support. And I felt like we didn't have that here, even with having... I know he's not the only diabetic here. In fact, there was another kid a couple grades younger than him that I knew is diabetic. And his dad is a principal at one of the schools here, and his mother at the time—I don't know if she still is—was head of the Juvenile Diabetes Association in this area. And she was supposed to contact us and talk to us, and I never heard a word from her. So it just, it would have been nice to have somebody emotionally there.

I Absolutely.



- M You know, let them know they're not alone. I think one of the hardest things is when we tell people -- has diabetes or that -- has diabetes, one of the first things that comes out of their mouths is, "Well, they're not fat." And I'm like, "No. You don't have to be fat to be diabetic." It's just they are so... People just don't understand the disease, and the media and everybody so focuses on diet and exercise and Type 2 diabetes, and we're all obese—and that's not the problem. It's genetics.
- F Everyone is concentrating on Type 2 diabetes.
- M Yeah.
- F They don't recognize Type 1.
- M Type 1 has been pushed off on the side, they so focus on Type 2, and everything is Type 2. Even though they don't say Type 2, they just say diabetes. And they lump all of it into one, and it's like, no. It's like all of these diets you see on TV of these no-carb diets—they don't help these guys. They have to have the carbs.
- I Right.
- M I'm sorry. I'm going off on a tangent on this, because it's one of our pet peeves is to be...
- F People are not informed. It's actually two completely different entities.
- M They shouldn't even have the same name. It should not be Type 1, Type 2.
- I Yeah, they are very different.
- M It's frustrating and irritating and all the above.
- I Yeah. No, absolutely.
- M There just needs to be more education in it, and that's one of the... On my Facebook, I'm always putting down things like—This is what Type 1 diabetes is. This is what ketoacidosis is. This is what happens when this is... I see all these articles, and I'm always liking and sharing and linking in, sharing, because I'm trying to educate people.
- I Right.
- M And my husband and I have offered to go to the schools and educate the teachers. Like when -- did football one year, the assistant football coach goes, "Oh, yeah, I'm Type 2. I know what's going on. I've got a Snickers in my pocket." No! No! And they fought us on him getting his shots and having his meals. It went to the point where I had to go to the athletic director and doctor's notes wrote and stuff like that, saying, "This is his care. You have to have his medical kit on field, point blank." People are stupid. I mean, we had issues with teachers. He had no excuse being late

testing, being late to class only because you're testing. That testing is not important. Are you kidding me? Do you want me to use you?

I Yeah. I remember my brother had a problem with teachers letting him go to the bathroom.

M Yeah.

I And he's like, "I have to." Yeah.

M There used to be more education.

F There's a woman that I work with that's recently diagnosed with Type 2 diabetes, and she's getting no support whatsoever through her physician or whatever. And so I've been trying to help her a little bit with what she should be doing to try and maintain and what she can do to try and prevent actually becoming insulin dependent and stuff of that nature. There's not enough endocrinologists around.

M There isn't an endocrinologist in Burlington.

I Okay, so how far do you have to travel?

M Iowa City, and that's about an hour...

F It's 146 miles.

M It's 146 miles one way. Yeah, there is nobody here.

I Yeah, that's not very convenient.

M I mean, that's where our traveling has been, going up to Iowa City every three months. So we go up there, and we might go to the mall, go to Costco, go to Best Buy. But I mean that's what our "vacations" are, because we have to take time off from work and take care of that. And I'm not only doing it just for one person. I'm doing it for two people. And we had braces on top of that, and they're in Iowa City, too.

I Time to move.

M Well, it's a great little town, not that it's little, but Burlington is what, 25,000? We've got about 25,000 people here, and we've got a good-size hospital. No endocrinologists. And when your family doctor... Like we had to fight the family doctor. Well, the doctor that I thought was to get -- tested was my husband's doctor at the same time, how knew my husband and who knew the family history.

F And also was one of the instructors for endocrinology in Iowa City. [laughter]

M So, yeah, we lack in medical professions around here or medical doctors.

I Yeah, especially the specialties.

M Yeah, but I kind of went off on a tangent on you there.

I No. That's perfectly fine. Anything you want to tell me, I am happy to hear. As far as my questions, I don't have any more to ask you. Is there any other information you want to share with me, anything else you can think of that's important in your life and things like that?

M Don't stress. Anxiety and stress affect you so much. It's not worth it. Just take it day by day and do your best. Don't you agree, dear? I mean, we don't take our days for granted, I don't feel, not that we have every moment packed full of everything. But family is important.

I Yeah.

M And don't be so serious. We like to joke around and have fun.

I It's healthy.

M Especially me. I'm extremely ornery. I've got to be to put up with you.

I All right. Well, I'm going to stop the recording.

## Design of Mobile Application for Type 1 Diabetes

Interview #6 – 3/04/15

Interviewer (“I”): Amanda Skinner

Mother (“M”)

Child (“C”)

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I Can you guys describe a few activities that you like to do together?

M Shopping.

C Yeah.

M What else?

C Just going out in public, I guess.

M Let’s see. We watch movies and go out shopping. He likes to go shop.

I What does she like to shop for?

M Clothes, of course. She’s 16, so makeup, hair stuff.

I All good things, in my opinion. Can you explain some ways that you work together to help take care of --’s diabetes?

C She reminds me to check my blood and bolus, a lot.

M Yes. Let’s see. We try to get her to manage on her own, to have more independence. So I think our biggest thing is just making sure that she is checking her blood and making sure she’s covering her [inaudible] and then eating healthy and such. But I will say that probably one of the difficult things is just the dynamics that happens between parent and child when you think you’re helping them but they don’t see it that way. So it’s kind of, the question to me feels weird, because I don’t feel like... We really feel like we work together on taking care of her diabetes, other than getting her to the doctors and doing those kinds of things and ordering her supplies and things—but I don’t think she sees that necessarily as working together. Does that make sense?

I Yeah, I know, absolutely. Do you agree?

C [inaudible] yeah.

I Okay, so what are some ways then, --, that you think it might be easier to not feel... I don’t know if nagging is the right word, but I know it comes across that way sometimes, you know, ways that you think it might be easier to not feel like..., to feel like you’re more in couldn’t.

- C I don't know. Maybe if there was like just a note left on the fridge every day or something like that, because I go to the fridge usually to get breakfast, so if I see it, I'll be like, oh, yeah, I need to check my blood or something like that. I don't really know. We've [inaudible] a lot of things, and none of them really worked.
- I A lot of trial and error. So then what are your thoughts on an application that would have the ability to..., you would share the information between two accounts? The accounts would be linked from each of your phones or tablets or whatever you use mostly, and that is how you were tracking your diabetes or blood sugar, how much insulin you're taking while you're eating throughout the day. And your mom can check up on it, and she can nag you through that, but it's less of that face to face. What are your initial thoughts on that, and positive or negative—you don't need to say what you think I want to hear.
- C It sounds like a good idea. I would use it probably.
- I What sounds good about it?
- C Just the fact that I can share it and it's always, it's like right there so I have access to it 24/7.
- I Yeah. Any thoughts that you have initially, --?
- M I feel that I'm not sure if it would make that much of a difference at times, just because you have to check your blood to have the information in there—and that's a struggle that I know she's had. She's gotten... She goes through days where she'll do really well, and then she'll just like go a whole day without checking blood sugars. And so to me it's... I mean, we've tried texting her to remind her. We've tried not doing anything, and it's so hard. I don't probably do as well with that, because I really want her to get insulin in if she's eating. So I don't know if it would be something that she would... I think it would have to take somebody who's really using it to help them get better with diabetes. I think with any tool that's out there, you have to want to do really well and see the results and know that you're the one doing that. I think when you have young kids, mid-teens and teenagers, it's really hard for them to see anything as a positive sometimes when it comes to having to do something. So to me I'm not sure. I think it's a great idea, and I love the whole concept. It's just I still feel we would have that same relationship of, well, I didn't see you check your blood today kind of thing and her responding with, "Oh, I forgot." And then nothing's changed. So I don't know how it would... Maybe you could have like a little reminder like every four to six hours or something, like—Hey, you have [inaudible]. Maybe it should like check your blood or something [inaudible], like a little reminder like—Oh, it's been four hours. Check your blood—kind of thing.
- I For you personally, if you saw that, would you want it to have the ability to snooze it and turn it off or not stop until you test. So what would work best for you, based on...?

- C Probably not stop and like put something in, because otherwise I'll just ignore it.
- I Yeah, that's what I would think. I mean, I know how I am in the morning with my alarms to wake up.
- M Oh, my! [inaudible]
- I Yeah, the snooze button and I are quite close. Can you just talk about some things you have to take care of when you're going on trips or vacation, things that you have to make sure that you have with you, that process that's extra, besides packing your clothes and your makeup and all that kind of stuff?
- C Insulin, exercise, extra reservoirs, IV and strip things to like hold on tight if they're falling off, batteries, shots in case the sites run out.
- M Like syringes.
- C Syringes.
- M Glucagon.
- C Glucagon, ketone strips, extra strips, extra lancets, extra batteries for the meter. I don't know, snacks sometimes.
- M Yeah, you've got to have juice and lots of food.
- C [inaudible] glucose tablets.
- M And she's also celiac, so we have to always make sure we have food with us that...
- C I can eat.
- M Yeah, that she can eat, because if we have an incident and we have to get her food and there's not the right stuff there for her, we're in trouble.
- I Is getting all that together really easy to remember, or do you find yourself forgetting things, or how does that process work for you?
- C I don't know. If we usually forget something, it'd be like batteries, ketone strips, just because, I don't know, they don't run out as often as the other supplies. So it's not a big deal if you forget it, but sometimes we'll run out, we'll forget strips, and then, ah, crap. So then you have to call a local pharmacy or something [inaudible].
- M And syringes one time, because she had ketones and we didn't... We bought extra... This is in the beginning where we were still kind of learning how to do it. She had ketones and was on the pump, but we didn't bring syringes, so we had to buy syringes from a pharmacy. It was quite interesting. It can be difficult to buy things [inaudible] when you're out of town.

- I Do you travel out of the country or anything since...?
- M No.
- I Okay, just wondering.
- C I'm told that that's a hassle.
- I Yeah, that's what I've heard. Have you flown anywhere, any kind of airport travel that you've had to deal with?
- C Yeah, we flew to Florida last year, and with that like you have to tell airport security that you have a pump, so like if it sets it off, they're not like, "What the heck is this?" and you have to tell them. And I don't think you can take insulin [inaudible] you can, but it's difficult for it not to explode on like pressure changes with insulin in like the cartridge or whatever or the vial, because those can explode, and it can make your insulin go bac sometimes.
- M Yeah, one thing we have found with travel, not necessarily at airports, but we went to South Dakota one time, and it got so hot when we were there that her insulin went bad. And it can get too cold. One time we actually bought this cooler pack—my mother-in-law gave it to us—and then we froze it and ruined it. So we learned a lot of lessons [inaudible]. You're supposed to let the freezer piece sit out for just a little bit and then... We know how to do it now.
- I So I'm going to go through some questions that are just for --, if that's okay.
- M Sure.
- I So can you tell me how old you are?
- C I'm 16. I'll be 17 next month.
- I Exciting. How old were you when you were diagnosed with diabetes?
- C Four.
- I Okay, so can you go through for me your responsibilities every day that you take care of for your diabetes?
- C Check my blood, give insulin, and if I'm high, correct for it; if I'm low, eat sugar. That's really about it. Make sure I don't run out of insulin.
- I That'd be good. And how long have you been on the pump?
- C 12 years.
- I Oh, nice, okay, so...

- C Well, maybe...
- M [inaudible] like 11. Well, you've only had it 12 years.
- C 12, okay.
- M So she was on it when she was five, and then she'd go off of it for like 2 months and then realize she [inaudible]. So I'd say about 11. I'm sorry. I just want for you to make sure it was right.
- I So what are some things that you like to do for fun—sports, activities, anything?
- C I'm in \_\_\_\_ speech. I usually do like fall plays. I'm in jazz choir—anything like music or [inaudible] related, basically. I don't do sports. I'm not athletic. Actually about it. Hang out at homes, hang out with friends.
- I Do you do any kind of physical activity to help with your numbers and with your help or...?
- C Yeah, lately I've been working out, but I need to get back on that.
- I Do you find that it has a huge impact or not so much for you? Are there other things you focus on?
- C Like working out?
- I Uh-huh.
- C Sometimes. It depends on what time I work out or what I do. If I work out later at kind of like 8 o'clock, I'll usually wake up in the middle of the night low or in the mornings low. If it's more towards the afternoon, it won't be as bad, because I'll eat something most likely afterwards. But usually it doesn't affect me too much, I think.
- I Do you have any friends with diabetes?
- C Yes, a lot.
- I Okay. Can you tell me about a couple of them?
- C Yeah, so I have a friend of mine—her name's --. We met at camp, and we're both diabetic and celiac, and so we'll talk occasionally about anything. I've got another friend whose name -- \_\_\_\_\_. He's older than me. He was a counselor for me last year, but we're good friends, and we'll talk about diabetes and stuff. There's a few kids at my school, but they're younger than me; I don't really talk with them, but like I'll babysit for them, so we'll talk like over the summer about it. The majority of them are camp friends, though, that I've met.
- I How old were you when you first went to camp?



- C Six, seven, six.
- M She's holding fingers [inaudible].
- I So would you say that you've had a pretty good support system friends-wise since you can remember?
- C Uh-huh.
- I Can you speak to how that has helped you or not helped you?
- C They give you like tips and stuff. Like if I don't know how to do something or like what to do for a certain problem, they usually have like their experiences with it and they'll be like, "Well, this is what I did." And I'll try it out and think, oh, this works for me or this doesn't work for me. So they just kind of help me and give me like different ideas to try and stuff. So like either if it's with like site location or what I should do for high blood sugar or pump problems or anything like that.
- I So I mentioned this application—obviously, talked about it a couple times. I don't know if this is something that would be of interest as your age now, but when you think about yourself a little bit younger, if you had an application that helped you take care of your diabetes with a gamelike aspect and you could play it with your friends, and it could be kids you've never met before but who are your age, and you'd have that level of support—you're all going through the same thing—do you have any thoughts on that?
- C What kind of gamelike aspect, I guess, [inaudible] have to be a deal breaker kind of.
- I It would definitely be something that has rewards. The whole concept of gamification of different nongame things, whether it's in business or medical, is that there's a reward system, and that's what helps with motivation. And then the other thought is that if there is this support community of other kids who are in the same lifestyle, they're experiencing the same things, and there is that connection as well.
- C Our connection is kind of getting bad. Did you notice that?
- I I'm still hearing you clear.
- M Okay.
- C Okay. Yeah, I mean, that'd be good. Like if there's like rewards, like a positive reinforcement kind of thing, I think it'd go over pretty well. So what would... Like an example, if you had like four blood sugars entered in a day, like you'd get like so many points or something like that kind of thing?
- I Yeah, yeah.

- C Okay, yeah, I think that'd be a good idea.
- I So what type of devices do you have—phone, computer, iPod, that kind of stuff?
- C An iPhone. That's really about it.
- I And what kind of stuff do you use it for?
- C Usually just social media. I don't have many games on it.
- I And I assume that you text.
- C Yes.
- M All the time.
- C Not all the time anymore. I'm so busy with sports.
- I Things we don't like. So I mean like general, so like Facebook and Twitter and that kind of stuff. Okay. Do you have any siblings?
- C Yeah, I have two younger ones.
- I How much younger are they?
- C Two and four years.
- I Younger.
- C So two [inaudible] four years [inaudible].
- I Okay. Are they helpful at all, or have they been helpful with you with your diabetes?
- C Only time Mom tells them to remind me—that's really about it. Like, "Did you check your blood?" "No." "Well, Mom told me to tell you." [inaudible]
- I What about if you drop low? Do they know how to help get you what you need and take care of you?
- C Yes, they do. Like I'll be like, "Go get me orange juice or food," and he'll be like, "Oh, are you low?" I'm like, "Yeah. Just go get me food." They usually know to get me like a glass of milk or something to eat.
- I Okay, so they have a pretty decent understanding of what you're living with.
- C Yeah.
- I Okay, well, that's good. So how do you remember to test your blood sugar?

C I'm not really good at it. Sometimes I'll remember. Sometimes I just get distracted by other things.

M So she's asking you how—how do you when you do?

C I'll see it sometimes, or they'll remind me. Sometimes I'll just remember, be like—oh, I didn't check my blood.

I So that habit hasn't totally formed.

C [inaudible] It's kind of bad.

M It's interesting. Can I interject here?

I Yeah.

M When she was young, like at age four and five, she was giving her own shots. I mean, she'd check her blood all the time; she'd share it with people, she'd show people. She was very open about it. She cared about her diabetes at that age. It seemed like it was important to her, and we didn't really have to talk to her too much about it in the same way we do now. It was really once she turned 12. It was almost like the alien starts to invade your child. And then on top of diabetes, I think the other side to it, it's like they don't want to be different at all anymore.

I Right.

M I just feel like they don't want to deal with it, and so they find ways to... You know, they get more easily distracted, because they're getting more responsibilities, too. But I think they just kind of want to be done at that age. And so for me, 12 and 13 was really hard, and 15 and 16 was, it's still kind of... It's getting better, but it's still not consistency, or an independence responsibility for her. It's more of a... I mean, she still really relies on us. Maybe that's the problem. And I don't mean as a parent, it's hard—you don't want them to experience something really bad.

I Right.

M So you do kind of ask questions. You want to find out, and we know if it has... But I would say, I guess what I was trying to get at is sometimes I think it's an age thing. I know when kids get diabetes when they're 12 or 13, they go through the same things that she is. They don't like it, they're angry, it's hard. But to see it from when she was so young doing so well and really caring, and then seeing it to a point now where there's so many excuses, so many distractions and things like that, it's just, I don't know what would help sometimes.

I Right. My brother was, I think he was 12 when he was diagnosed, so he was right in that...

M Yeah, it's a tough age, yeah.

- I If someone you knew—and maybe you’ve been through this before, so feel free to share—but found out that they had diabetes, what is the first thing that you would make sure you tell them, and how do you think they would be feeling?
- C Usually, like what we do when we find out people that’s been diagnosed, you kind of like give them a CARE package, like we’ll send them a bunch of like, here’s some low sugar stuff, and like we give them kind of like a gui--ook-ish thing. We’ve done that I think once or twice. I don’t know. You should tell them like, “I’m here if you have questions. Like, feel free to ask me like anything that you have a problem with. Like I know everything, because I’ve had it for so long.” And, I mean, I’ll get a lot of questions like, “I don’t want to put a shot here. Where else can I do it?” or something like that. Like I have..., like you can do it anywhere. And I just help them out the best I can with any questions that they’ve got.
- I Yeah. How do you think that they will be feeling, finding out that they were diagnosed?
- C Probably pretty crappy. I think they’d be like—why me?—kind of thing. I don’t know. I don’t really remember what it was like when I was [inaudible], but I know it would probably be pretty upsetting.
- I Yeah, definitely. It’s not something that’s easy. Okay. Those are all my questions for you, --.
- C All right, cool. Thank you.
- I Thank you. Okay, so if you remember, when -- was diagnosed, in what ways did your lifestyle change?
- M Oh, everything kind of changed really, because now you have to start thinking about everything differently. Food now affected her whole lifestyle. Time affected your lifestyle, because you had to make sure they ate, because she’d have a [inaudible] you had to eat by six o’clock. If we went out to eat, you had to think about how long it’s going to take to get a seat and if they had crackers available—this is before she had celiac—crackers available on hand to help her get through until we got a chance to eat. So a lot of that. I always try to see things in a positive light, so I always looked at it as how much people really take for granted, their life, and how easy it is to just throw food in your mouth or just go wherever you want. And now it’s not like that anymore. You really have to think, and you have to plan, and you have to be prepared. And so those things were really difficult, I think—but also not all bad. I think -- and I, he was familiar with Type 1, because his mother was Type 1, and that’s kind of how we found out about --. He recognized some of the signs. I didn’t. I thought she... You know, she was four, she was really thirsty. She wanted water [inaudible], she was really hungry, she’s growing, she’s my first child. I never knew different. But the only thing that did concern me was her urinating every five minutes, and so I thought she had a urinary tract infection. So I said something, and -- had been with her all day, and he then took me to the

computer and showed me all the symptoms. And I was like, yeah, she's doing this, this, this and this. And so I think he was prepared more so, but I think we both took it in stride as to she's still going to have a great life—we're going to do everything we can to help her, and we love her, and we'll just not create this as being a negative thing, because it's just something we have to do. So even though it's hard, and it was a little shocking when you kind of figure out what it's all about. I didn't know as much as my husband, so I was just, you know, God will take care of everything, and we'll be fine. I had those... You know, I have a very strong faith, but it was quickly challenged when every time she ate something we were having to do all this stuff and then realizing it wasn't going away. Then we kind of go, oh, I don't know if this is really all that great. So there's a lot of different emotions that happened. I think the biggest change is just seeing your very small kid have to take shots and have to be so mature about, and responsible about things. I remember when she was first diagnosed it was, oh, what was it, around Valentine's Day and her getting candy and saying, "Well, I can't have that right away. I have to..." You know, see her friends look at her like... You know, those little kids are like, what? So having to be so responsible and then seeing her explain it to her little kids, her little friends, it was just different. But I feel like as a family we did really well and dealt with it the way..., in a positive way, I guess.

- I When did you get involved with the camp? So she went after being diagnosed for two years—correct?
- M Yeah, it was two years after she was diagnosed. See, we went to a family camp. It was the very first family camp they ever did. They'd been around for 30-some years, and they decided to do family camp weekends for newly diagnosed families. And so Dr. -- in town with the -- Children's Hospital would tell families about it. And so we went there and realized that this is where she needed to be, because it was so catered to her lifestyle and our lifestyle. It was a wonderful weekend. It was very impactful for me in particular. I was very depressed, and I didn't know it. We had it for a year, and it wasn't going away. And so being with other families really helped.

So then after that, I just realized I wanted to help the camp to raise money to get more kids to be able to go and not have to worry about finances. I know her grandparents helped us right away to help her go the next year. And the thing that impacted me was, right after the family camp we had raised money for her to go to the mini camp, and then she got diagnosed with celiac. And I thought, well, there's no way she can go now, because there's so many more restrictions with food, and there's no way. And when I talked to, at that time, the camp director, --, she said, "Bring her. There's seven others just like her." And now they have about 24 celiacs between kids and staff. It's getting more common or more diagnosed maybe. So that's how I got involved. I just started doing fundraisers, creating events, like community events and trying to raise as much money as possible, and then I just never went away; and I guess they decided they better hire me or something. So I just started out doing part-time stuff for them, and it just seemed like, I don't know, just everything kept evolving and getting bigger and more responsibility. And I

love, love camp. I love what they do. I love the people involved. Our staff are so tenderhearted and loving towards our kids, and they are what brings them back. It's not me. It's these counselors are so important to these kids and the experience they get there with other kids like them. So, yeah, that's how I got involved.

I Was it helpful being involved in different fundraising in the camp and things like that as a support for you?

M I don't know. I think honestly it was a lot of work. I thought, what am I doing? I don't know if it was... I think part of it, part of my motivation really was probably - . I think that was... You want to do everything you can for your kids. So, knowing how important camp was to her and what a great experience she had, even the first time I wasn't out at camp. I tried to stay away from camp as long as I could, because I wanted her to have her own thing. I didn't want to be that helicopter mom and I'm gone. [inaudible] She won't probably believe that. But I wanted her to have her thing, but then it ended up having [inaudible]. So, but no. I just, I don't know if it was even as a support for me. It was more or less trying to help other kids. But of course it's my motivation, but the more I got involved with camp, I saw just what a reality it was for some of these families. They aren't as, I don't want to say blessed or lucky, to have the finances, the same situations we have; but those kids need to come, just even one time, so they can get that as a reality that they're not alone. So really it was just, I don't know, I'm just really inspired to help other families and be a part of that.

I My mom does some volunteering for the American Diabetes Association, and she does a lot within schools and that kind of stuff, so...

M Yeah.

I So I got to see her helping a lot with that, and from an outsider perspective, it's really great.

M Huh. Is she local, or is she...

I She's back at home, so I'm from Buffalo, New York.

M Oh, I didn't know that, okay.

I Yeah, so she is out there, and my brother goes to a camp out there. He's a counselor, actually, now. He's 21, but the kids adore him, and he just has such a blast. So it made a huge difference for him.

M Yeah, I think even as counselors, I know several of our campers who became counselors, and I think they need it, too. It's like their vacation away from the world that doesn't understand them.

I Yeah.

- M And that they don't have to answer to you all the time. So it's just like, it's such a special place.
- I Yeah, I think that's what... My brother had a tough time. His teen years were really hard for him, and he didn't want to test, he didn't want to do anything. He wasn't in a great place. And I think him becoming a counselor made a big difference, because he had to be a positive role model for kids. So you have to practice what you preach. And so I think that helped him kind of turn over a new leaf with it.
- M Well, and I notice, though, in a lot of... I interview. Right now I'm interviewing a lot of new staff that have been campers. And one of the things that they say—and I know this is true for ---is after camp they really get that motivation to, let's do this. We can do this. And then it eventually goes away. You don't keep that motivation for them. So even as campers, I think it helps for a while, and then once you do get older, you get a little more mature. At that age when you are counselors, it is easier. It helps, I guess.
- I Yeah, and I think it's easier to see the direct benefits with how you're feeling. You don't understand that 'til you're older. And even as someone without diabetes, I mean, it's only been the past few years... I'm like ---always musical theater, never sports. But you have to take care of yourself, and so even just for me without having that extra layer, it just comes with age.
- M Well, and I have a lot help for --, and that's one of the things I love that I guess I have gotten from camp, is, we have so many counselors I can talk to and say, "You know, I don't know what to do." And I've called a couple of them and say, "I know you struggle, because you shared with me. You helped me." A lot of them are like, "She is going to be just fine." Like I see where they are now, and I've seen some of them a lot worse than [inaudible]. And they are... Gosh, their A1Cs are 7.1. Some of them are 6.8. It's like they're really rocking it. They're really doing extremely well. And I have hope that that's what she'll do, too. I don't think this will be forever. But it's hard to watch.
- I Yeah, my brother and I are very close, so it was hard. And I'm obviously not a parent, but at least for me seeing him go through that and not taking care of himself—I mean, he means the world to me, so it's scary.
- M Yeah, and what's hard is I don't think they get it. I remember asking her one time. Sorry. I'm a little emotional. I asked her one time, I'm like, "Why do you think I ask you all the time?" And she goes, "Because you don't think I can do it." "No, it's I love you."
- I Right.
- M "And I really want you not to have the complications that we all know and have heard of." I don't want it to be a reality for her. And so she sees it as nagging, and I try to tell her, like every time I ask [inaudible], it's like put something behind it so that you can see it as what it is. And it's not that you can't do this—I know you can.

That's why we want you to take that responsibility. Because she can do it. She's capable. She's extremely..., she's amazing. She really is. She's a great kid and takes a lot on herself, I think, and doesn't see that we understand that. I think she just sees the negative of the diabetes and it's hard.

I Yeah, it's a hard age.

M Yeah, yup.

I So you've mentioned you remind her to test her blood sugar and ordering supplies. Are there any other responsibilities that you really help her take care of every day?

M With her diabetes or just in general?

I With her diabetes.

M Not, not really. I mean, I make sure that she eats, and then I want to... I usually ask if she's bolused, or I always ask if she's checked her blood, which she... And then I really don't... There's nothing else specific that I do other than asking and talking to her. I do try to keep up on her supplies, but we've also told her she needs to let her know. This really is her time to be the responsible person in letting us know if we need to order when it's time. And she does pretty good with most of that. But, yeah, I don't know what else I could do, really. And I've asked the doctors, too—you know, what else can I do? Because I used to text her and ask her or remind her to check her blood or ask her what her numbers were if she checked for the day. But I really don't know if that's really... I don't think that's what's going to help her. It's going to be her needing to really own it.

I Yeah. Can you go through a typical day for you in regards to --'s diabetes? I know you don't have that many responsibilities but anything when you go through your day, from waking up to going to bed that you..., just your routine and anything that is diabetes related as well.

M Well, she gets herself up in the morning, so she has her own routine, really. She's very routine oriented, other than checking. So, yeah, I just make sure that I go get the other kids up in the morning, and I make sure her light's on. She gets herself ready and does everything on her own, and then she comes down and gets her breakfast, and that's usually when I'll say, "Don't forget to check your blood," because I can tell, if she's starting to eat, I usually wait, and she'll go, "Ahhh," and then go grab it. And then when she's done, she should be... Most of the doctors will tell you to give insulin before you eat. So when she was little and she was four, they always had us do it after, and she is one who absolutely hates change. I mean, it could be such a simple change, and it's really hard for her. Like, for instance, we had a pump and after five years you get to do an upgrade. She did not want to upgrade. It was the same color, same size, the same pump; it just had more bells and whistles on the inside that she didn't even have to use if she didn't want. You would have thought we took her arm off. I mean, she literally hated the fact that we had



her change to a better pump, a big, newer pump. So where I was going with that... I just think that... where was I going with that?

I You were talking about insulin before versus after meals.

M Oh, yeah, so changing to then giving insulin before. She fights it. She never does it. She fights it, fights it. And so usually then after she eats, I'll say, "Make sure you [inaudible] need to do bolus." And I think it's sad—as I'm talking to you right now, I'm realizing just what a habit it is. And I don't think I realize how much I ask or talk, or ask her those questions. So it probably would annoy her. You know, I mean it's a fact you do. And then she goes off to school. And the other concern I have sometimes is driving, and it's not just her. I try to tell her that... That's when her brother or sister will say... If I know she hasn't checked her blood or something, she'll say, "Oh, I'll check it in the car." Well, I want them to make sure she checks it, because she's driving them as well. And to me, I try to tell her, "It's not just about you. You're caring for them as well, and you can't have an accident without really affecting you if you knew something happened to them. I don't want that for you." So maybe we'll ask her to check it before she leaves if I don't feel like I caught her in time before she ate. And then she goes off to school, and then I obviously go to work. And occasionally maybe I'll ask her when we text throughout the day. If she asks me a question, I'll say, "Have you checked your blood today?" or "Are you at lunch? Did you check your blood?" But it's not very often. I really try not to ask, because I just feel like it's not going to help anything really, other than... That is not what's going to get her to do that. It's going to be her. So I do try really hard. And then sometimes she works after school, and then so she's pretty much on her own. And then I'll have her check her blood before she goes to bed, but she gets annoyed... if I do that. And before, when she was younger, we always checked her blood at night before she went to bed, or sometimes we'd get up. We would let her go to bed, and then before we went to bed, we'd check it.

I Has she tried at all... I don't know what the real name for them is, but the constant glucose monitor?

M Oh, it's CGM.

I Yeah, with the dual inside, or is that not something that she's willing to try?

M I pray that she will change her mind—again, change. One time, when we got the new Medtronic, they did have a censor with it at the time. It was not a good censor. And I love Medtronic, but they don't [inaudible]. And Dexcom, no sensors. I wish we would have done that with hers. Because what happened was it was like a drain tube, very, very painful. It was really long, and it would work, and we had it for a week; and she was just so stressed out. And I'm like, "This isn't going to change your life, so I don't care if you decide not to [inaudible] this part of your diabetes. Other stuff, you don't have a choice, but this you do." And so she was like, "Yeah, I don't want to do it." And so because of that bad experience, again, you [inaudible] now doing something, she'll never do that sport again. So I don't know if I'll get

her do a CGM pump. She'll talk to her friends about, "Well, you should do a CGM," but she won't do it. And I would love to have her consider doing that, because I think it would really make a difference in things, but...

I Yeah, I wonder if my brother tried the same one, because I remember him saying it was really painful, and so he stopped using it very shortly, like I don't even know if he made it a full week. He was like, no way.

M Yeah, does he have Medtronic?

I He does, yeah.

M I bet'cha that's the one. It was horrible, and everyone who tried it said it was horrible. And now they've got a new one, but I don't know.

I Yeah, he [inaudible] yet. What are some methods that you use for scheduling, logging, other tracking, whether it's pen and paper or something on the computer? What are methods that you use?

M We don't anymore, because we've left it up to her. And before, we had like little booklets that we have, and then I know that I think it was Medtronic had a quick link that you could do, and we tried to do that a few times, but we didn't stick with it. So that was with the computer you could see the tracking and everything, and we thought that would be really cool, but you'd have to do it once a week, and it seemed like we just were not doing it, working well. So really we just kind of hope that she's doing her blood sugars. And I don't check it and I don't ask her a lot of questions. Like I don't make sure that she's doing it; I don't do any of that. But when we do go to the doctors, that's when they come to her and say, "Wow, you're not checking your blood at all when you go to school! The only times we see you're checking your blood is when you're with your family," which would be in the morning or night. And then if they say, "Well, it looks like you have trends of not checking your blood at dinner this week," well, she was working, so she wasn't [inaudible]. So I mean we really don't do a lot of logging.

I Okay. Do you use any applications for health, whether it's like a fitness app or like food logging, Weight Watchers, MapMyRun? Do you use any applications for your personal health?

M I have in the past. I can't remember the name of it. I have a Fitbit I need to get back into using, but there was another one. It was just logging your calories and things like that. I don't know the name of it now. But I don't currently, though.

I What kind of steered you away from using, or continuing using them?

M Time. I mean, it's just time. I mean, yeah, yeah, I would just have to say that my husband's in the military, and he was gone for eight months, and I have the three kids, I work full time, my boss had been fired; I was acting director. So it was just I had no... I was nutrients.

- I Spread pretty thin?
- M So I just didn't stick with it, and so it's been really hard to kind of get back into that caring for yourself type thing. I've been struggling with that.
- I Yeah, okay, so you've already expressed some of your opinions on this, but from a parent perspective, what are your thoughts on an application that you could use with -- and you could receive constant updates and you could have the ability to send her an alert or something like that? What are your initial thoughts on having that ability on your phone?
- M You know, I do have a couple thoughts. One is, part of me doesn't want to know. Part of me wants her to... I want this to be her disease. I want to be there for her, but I don't really want to know. I don't want to have to know all those things. So part of me feels that way. The other part of me says—Oh, great. When she goes to college, there is absolutely no way I'm going to know anything. So it would be nice to know at two o'clock in the morning if I need to contact her roommate and say, "You've got to get her some sugar, because I'm seeing that she's [inaudible]." That would be beneficial to me. I don't want to do it because I'm checking up on her to be that nagging voice continually in her life, but I do think it would be great to have some sort of tool that could help us to protect her from being so far away.
- I Yeah. Do you think it would have been an easier addition when she was..., not easier but more helpful when she was younger?
- M Yes, yeah, oh, yeah. I definitely think when they're younger, it's almost not an issue. That's just, that's your role when they're younger, to take care of it and to be more on top of things and to be a little more helpful and controlling the things that are going around with your child as far as the food and how much insulin. You're in control of that time in their life, so having something like that and there at school would be absolutely comforting, great. I would love it. I think it would have been super. And then you could use it to help with the nurses and stuff. Because honestly if they need help, they're... Sending your child to school—oh, my gosh. We've been lucky, having fairly good support and results with her going to school. But I homeschooled her for three years prior to her actually getting, during the three years she got both diseases. So I felt like when we sent her to school, she had a really good handle on how to do things. And I think that was helpful to the nurse, because she even would say, "Wow! She is very good." And she rode circles around a lot of these diabetics, because she, I think we took a lot of time and had that time to teach her, to help her, to be there, and all that. Yeah, I think sending your kid to school and having something like that would really put the parents at ease and have that extra set of eyes, just in case.
- I Yeah. Have you used any application strictly for diabetes whether it's logging, finding the carbs of a meal, or just any of the diabetes applications that are available? Have you tried any?

- M No, I haven't. I know that there was... Is there something called CareLink out there? MyCareLink [inaudible]?
- I Possibly. There's a lot.
- M I think there are things out there, but I have never tried one.
- I Any particular reason, or you were just more comfortable with what you were doing?
- M I don't think it was really available when she was younger. So, once we got to that age where it was supposed to be more her responsibility, it just didn't seem like we really needed it or it was even going to work for us at that time; because, well, she wasn't checking her blood, that kind of thing. So I think the teen years is when things started to get more available. That's probably why. Because I would have been so on it if it was.
- I Yeah, absolutely. Besides not necessarily wanting to know when she's checking, that kind of thing, do you have any other reservations about the application that I was talking about?
- M No. I think when you were talking with -- about maybe playing games, is that... Can you explain that just a little bit to me, because that... Is it something kind of like Xbox, like all are on it together and doing something, or is it just kind of like you can see if somebody checked their blood and got a reward and you're all kind of in the same group—if you could explain that a little bit to me.
- I Yeah, so part of that is also what I'm trying to figure out what will be best. The research that I've done on gamification is that it is more of a, oh, you know, Joey checked his blood sugar, and he was 110 or whatever—he was in a good range for two days. You know, he ranks number one or something. There's different rewards that help motivate kids, and they can send thumbs up or smiley faces or what-have-you, things like that. But there then is the idea where you use a real game behind the scenes, teaching these skills of scheduling and responsibility and all of that. So there's different sides to it, and I'm trying to figure out which, if either, is an appropriate route to take. So, yeah, that's part of what I'm hoping to gather from all of this.
- M Yeah, so I think that that would be... I would totally be supportive of that a hundred percent, because I think especially, I guess, I'm thinking of—if you got in with like say the diabetes camps where these camps become friends and they want to stay in touch, then I could see this being a really great way to stay connected and kind of keep... You could even have the game be like a camping theme. You know what I mean? Like we went to the dining hall and we had this today, or however it would be, but it would be kind of that reminder of their time together, and it would be something that would keep them coming back. I think that would be a challenge, to find a game that would keep them coming back and wanting to continue to do those routines...

I Right.

M ...for the fact that they're with their friends. They're not going to do it because they want to check their blood. They're going to want to do it... You're going to want to find a way that really engages them and find... There's so many things. Gosh, I'm just going crazy thinking. I would love for you to come out, if you're not going back home this summer, to our camp and see some of the... We have an education program. We don't call it "education" anymore. We call it DIG, which is Diabetes Information Guidance. And so we got together with the Buena Vista University, and they have their physical education professor and one of their students help us design and create games and activities for each age group. So not everyone's doing the same thing like we used to. Education was horrible at our place. Kids hated it. Counselors hated it. And I hated that they hated it, because that's our biggest mission is to get them to be educated and do it in a way that's going to help them. So doing this was a huge success.

And what I'm thinking of is like some of the games that we did were with [inaudible], certain, like the eight, nine-year-olds. We had these huge [inaudible] stacks and little \_\_\_ stacks, tiny, and we would have them do like relays. And you'd try to... When you first start out, everything's balanced, some are low and some are high, so that's kind of a balance. And then you try to race to... Like one person is always trying to get them down, and another person is trying to build them up, and then when you're done, you see—are you balanced? And what does that mean with your blood sugar if you have too many highs? What can be done differently in your routine. So things like those little games that you can have options for them to play. They're different—they're not all the same game, maybe something like that. But teaching them the value of keeping their blood sugars... You know, you're not just teaching them to check their blood—you're teaching them why and things like that. I could see that being really beneficial. So if you'd ever want to come out and see what we do and how we kind of work all the way from six, seven, all the way up to 17-year-olds and how we use those activities to teach them about A1C and all that kind of stuff, I'd love for you to do that.

So I would say it would be amazing to have some sort of connection, I guess, with kids that do know each other. And then you can introduce them to like say someone at school now has diabetes—they can join your group of boys or girls or whatever. But I think it would be harder if you didn't know them already, type thing. So I could see how camps... I mean, there's them all over the world, how that would be a great opportunity for you to get into them and get that product introduced in a way that is really sustained. It's almost like when they're at camp they learn so much—how can we get them to continue that when they're not at camp anymore.

I Right.

M And that's I think where something like this could help doing that. And then the only reservation I would have, I guess—and it's not really a reservation but more or less, not sure how you would get the age group, how far the age group you're trying

to reach. Like if you do do the teens, which I really wish that that could... I mean, knowing and seeing it myself, what can we do to help them? This is such a crucial time, and what happens now affects them later, and they don't see that. And how do we engage them in something like this that's cool—it's not like videogames all the time. Boys now, our sons, would play a videogame [inaudible] I'm sure, that kind of thing. But how do you get them to engage in an app like what you're looking to do, to get them to really have that support, I guess, would be challenging to figure out.

I Oh, absolutely, yeah. It's not small task. So your current method for monitoring -- when she's not with you, is that mostly just text messaging, or is there anything else that you use to keep in touch?

M Well, I'll just call her or, but yeah, mostly text message, and that's all you do. They date by texting now—don't you know?

I Yeah. I have a 14-year-old cousin who, she thinks that I'm like 50. She thinks I'm ancient. And it's, oh, my gosh, yeah.

M Yeah, so it's usually through text because of it's all they, it's the only way. Yeah, it's hilarious. So, yeah, and that's about it. And then when she's with us, and she's with us a lot. I mean, she doesn't go out too much. When she's home, she's kind of a home body, so just kind of asking her and talking to her about doing it.

I Do her friends know a decent amount about everything so when she's with them that you feel comfortable with them helping her out if something were to happen or just in general reminding her... I don't know if her friends remind her to check her blood sugar, but...

M Oh, I've tried that one too. "Encourage her to check her blood at lunch, please." And that didn't work [inaudible]. They were happy to do it, but, yeah, it doesn't work. And she even had a boyfriend for a short amount of time. And we sat him down and talked to him about the importance of... We try to... So, yeah, I guess to answer your question, I'm going off here. To answer your question, yes, I feel like they do know how to help her, and they are very, very caring and want... If they were to know she was low, they would take really good care of her. I don't know if they know everything as to how to do things or if they would even contact me, but I think we all... Every year when she was in grade school, we would go to the school within the first week, and we would read a book and talk to them about things to notice and things to look for and just to be her friend and to be encouraging if she's having to have a snack or some things like that—if she's low, don't let her go low, and to the nurse's office. So I think we in some ways kind of helped them to understand some of that, and then she continued to do that. And so, yes, she's got a great support, as far as I know. Just they're not going to tell her to check her blood.

I Right.

M [inaudible] really think too much of it anymore [inaudible].

- I So my final question for you... And then afterwards if there's any other information you want to share, feel free. But your advice—and I think you do this frequently, but to another family who just found out their child had Type 1 diabetes.
- M Get them to camp. I mean, that would be my biggest... It is something for these kids that they don't get anywhere else, and that is that support and that opportunity to ask questions, and it's positive peer pressure. If they see other kids not telling them to give them their shot in the belly but they're seeing them do that and they know they've been told to do it—it's a good place to change your site—so they'll ask them, "Does that hurt?" "No, no." Then they'll end up doing it. So to me, even if I wasn't the camp director, I would say, "Get your kids to a camp." You know, DRF(?) here in -- had a support group, and we did start with that, but it didn't last a long time, and it kind of fizzled out, I think. But just finding support if they don't have a camp, or just finding other families. And I know our hospital did really good at trying to connect families together. So just finding somebody else you can talk to and get the kids introduced.
- I Yeah, all right. Those are all my formal questions for you. I don't know if there's anything else you think to add.
- M No. I think this is great. Thank you for being so patient with me. My goodness gracious.