

Normalizing: Adolescent Experiences in Living with Type 1 Diabetes

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Abstract

Normalizing: Adolescent Experiences in Living with Type 1 Diabetes

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The purpose of this research effort among adolescents ages 11 to 15 years was to gain a greater understanding, from the adolescent's perspective, of their experiences in living with diabetes and associated challenges and management issues they faced. The aim was to build a theoretical paradigm that captured the main categories and moving processes in the experiences of adolescents and provided much needed information and hypotheses to support interventional design. Classical grounded theory with constant comparative analysis using gerund coding was utilized. Fifteen individual interviews were conducted.

The substantive theory that was developed was “**normalizing**”. Normalizing is defined as the ability of the adolescents to integrate diabetes into the background of their daily life by creating routines to make diabetes ‘part of me’. The conceptual codes developed that describe normalizing for adolescents with diabetes included: a) ‘recognizing life is changing’, b) ‘taking action to prevent a crisis’, c) ‘disclosing to engage support’, d) ‘taking on the burden of care’, e) ‘accepting the ‘new normal’’, and f) ‘hoping for a normal future’. For adolescents with diabetes, the normal developmental tasks of adolescence are closely related to each step of this normalizing process and help to explain why adolescents struggle with diabetes during this phase of adolescence.

Needle fear, moving through transition to self-care, conflict with parents, and the interactions, reactions and emotions of others were key processes that affect the ability to

normalize. Strategies used by adolescents in managing their diabetes include maintaining motivation, building trust, and learning to cope. The supportive behaviors of parents, peers, teachers, and others were helpful. When researchers and clinicians view this difficult stage of adolescent diabetes care as an attempt to normalize their life, it places a very different and positive perspective on this process with a focus on wellness and maintaining a normal life rather than a focus on illness. This creates many new opportunities to provide education and interventions to not only help the adolescents normalize but also assist their parents, peers, schools, and communities to help them normalize their life as well.

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DEDICATION

To my mother, Katherine Hartman, who lost her fight to cancer
just days before I started my program.

&

To my Aunt Jean and Uncle Chuck who inspired me
to go into nursing and have cheered me on.

&

To the adolescents with diabetes, my patients, who inspired me to go back to
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Chapter 1 - Problem Statement

Introduction

Type 1 diabetes mellitus (T1DM) is the most common chronic illness in children and adolescents (Center for Disease Control [CDC], 2010). Complications from having diabetes are life threatening and costly (American Diabetes Association [ADA], 2010; Moore, Gregory, Kumah-Crystal, & Simmons, 2009). Diabetes is a complex, multifaceted disease that affects the health and emotional well-being of adolescents who have to cope with multiple daily insulin administration, blood glucose monitoring, dietary changes, and exercise (Silverstein et al., 2005). Adolescents struggle in balancing diabetes management tasks with developmental challenges as they move towards independence and autonomy (B. Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; Buchbinder et al., 2005; Grey, Cameron, & Thurber, 1991; Iannotti et al., 2006). While many studies have been conducted to examine issues in diabetes management with youth (B. Anderson et al., 1997; B. J. Anderson et al., 2002; Evans et al., 1999; Kyngas & Hentinen, 1995; Levine et al., 2001), little is ultimately understood about the total experience for adolescents and the challenges they face. Limited progress has been made in helping the adolescent effectively manage their illness. There is a gap in knowledge in understanding why adolescents with diabetes decrease testing their blood glucose (BG), giving insulin, and managing their diet and exercise. Needed is a greater understanding of the experience of having T1DM from the perspective of the adolescent, to build a theoretical model and generate hypotheses to inform intervention design and nursing practice. Knowledge that will be gained from the adolescent's perspective is unique in this current body of research. The purpose of this research effort in adolescents ages 11 to 15 years is to gain a greater understanding from the adolescent's perspective of their experiences in living with diabetes, and associated challenges and management issues they may face. Developing an understanding of

the adolescent's perspective of how they live with and manage their diabetes will create an understanding of what conditions are present when adolescents are successful with diabetes management. The adolescent's perspective of the barriers they encounter on their journey with diabetes management is also a key component of building a theory that covers the spectrum of diabetes management in the adolescent including the influence of diabetes on relationships with peers, school, and parents. In building a theoretical paradigm we will capture the main categories and moving processes or conditions when adolescents are successful in diabetes management from their own experience and perspective. The creation of this theory will generate hypotheses which can be tested in interventional research aimed to improve adolescent diabetes management. Findings are expected to advance nursing science and provide much needed support for adolescents and their families in successfully managing diabetes.

Background and Significance

There are many descriptive studies describing psychological and emotional challenges and diabetes management issues that have been identified in adolescents with T1DM. Many of these management issues and psychological challenges are associated with poor glycemic control. Some of these problems noted in the adolescent with diabetes include decreased blood glucose monitoring (BGM) (B. Anderson et al., 1997), decreased insulin administration (B. Anderson et al., 1997), higher hemoglobin A₁C (HbA₁C) levels from poor BG control (B. Anderson et al., 1997; Evans et al., 1999; Iannotti et al., 2006; Ingerski, Anderson, Dolan, & Hood, 2010; Ziegler et al., 2010), leading to an increased risk for life threatening diabetic ketoacidosis (Levine et al., 2001; Ziegler et al., 2010). Adolescents also show poor adherence to dietary changes (Hains, Berlin, Davies, Parton, & Alemzadeh, 2006; Mayer-Davis et al., 2006; Thomas, Peterson, & Goldstein, 1997; Vanderwel et al., 2010) and a decrease in regular exercise to maintain normal BG levels (Michaliszyn & Faulkner, 2010; Schweiger, Klingensmith,

& Snell-Bergeon, 2010). Some of the psychological issues seen are anxiety, depression, and poor self-esteem (Grey et al., 1991; Grey, Whittemore, & Tamborlane, 2002; Hood et al., 2006; Kovacs, Goldston, Obrosky, & Bonar, 1997; Kovacs, Obrosky, Goldston, & Drash, 1997), problems with coping (Grey, Boland, Davidson, Li, & Tamborlane, 2000; Grey et al., 1991), peer (Buchbinder et al., 2005; Grey et al., 1991) and parental relationships (B. J. Anderson et al., 2002; C. Dashiff, Vance, Abdullatif, & Wallander, 2009; Davidson, Penney, Muller, & Grey, 2004; Ingerski et al., 2010).

It is estimated that 1 in every 400-600 children and adolescents (approx. 186,300) in the United States (US) under the age of 20 have T1DM (ADA, 2010). Complications from diabetes are the 7th leading cause of death in the US (ADA, 2010). High glucose affects the nerves and blood vessels of many body systems leading to heart attacks, strokes, kidney failure, amputations, blindness, and early death (Moore et al., 2009). Total US costs associated with diabetes were \$174 billion dollars in 2007 (ADA, 2010).

Poor control of glucose in T1DM leads to costly acute complications. Diabetic ketoacidosis (DKA) is a common acute complication of T1DM prior to adulthood. DKA that occurs after initial diagnosis is usually caused by missed insulin doses (Morris et al., 1997; Palta et al., 1997). Most DKA episodes result in the need for specialized intensive care services and can cause cerebral edema and death (Finberg, 1996; Silverstein et al., 2005). Some adolescents have repeated hospitalizations for DKA (Angus & Waugh, 2007; D. Ellis et al., 2008). Adolescents with poor glucose control have higher rates of hospitalization for DKA (Levine et al., 2001; Palta et al., 1997) and are three times more likely to be hospitalized than their peers without diabetes (Angus & Waugh, 2007). Hospital admissions are approximately 40% of the total overall cost of diabetes care (Holmes-Walker, Llewellyn, & Farrell, 2007).

A great deal of adolescent diabetes research has been done to describe and identify the issues, risks and complications associated with poor glycemic control; however, only a few

interventional studies have been done to address these identified problems. For the most part current interventional work has not been successful in improving glucose control in adolescents. The decrease seen in performing diabetes management tasks and the associated psychological and emotional issues have not been studied from the adolescent's perspective. To create behavior change in diabetes management during adolescence, it is imperative to understand their perspective of not only having diabetes but also how they are managing their blood sugars. Understanding the perspective of adolescents will enhance the current knowledge of pediatric diabetes management and thus why this study is so important.

Definitions

The following definitions will be used in this paper. Common phrases, standards of care, and target goals for the adolescent with diabetes are included to help clarify these terms for the reader. These terms help to define the complexity of care and the challenges faced by the adolescent with diabetes.

- **Diabetes management tasks** include monitoring the diet, exercise, checking BG levels, managing low and high blood glucose, and taking insulin. These are necessary daily tasks required to manage the blood glucose level. The ability to manage these tasks will be referred to as diabetes management issues.
- **Associated challenges** include both emotional and relational issues that have been noted in the literature in adolescents with diabetes. These challenges include relationships with parents, peers and other contacts such as the school. Anxiety, depression, self-esteem, coping, adjustment, and quality of life are emotional challenges that sometimes overpower the ability to successfully manage diabetes.

- **Hemoglobin A₁C** (HbA₁C) is a measurement in percent of the average blood glucose level over the past three month period that is measured during a clinic visit to give an overall picture of glucose control. A normal Hemoglobin A₁C level is 4.3 – 6.2%.
- **Good glucose control** in adolescents is defined as a target blood sugar ranging from 70 mg/dl – 150 mg/dl or a Hemoglobin A₁C level of less than 7.5%
- **Poor glucose control** in adolescents is then defined as blood sugars that are less than 70 mg/dl or over 150 mg/dl and Hemoglobin A₁C levels of greater than 7.5%
- **Diabetic ketoacidosis** (DKA) is a life threatening metabolic acidosis that happens in the body from a lack of insulin resulting in increased blood glucose levels. When the glucose is not moved to the cells for energy, the cells then burn fat for energy; the byproduct of this fat burning results in massive ketone production and electrolyte imbalance. This acidosis can lead to brain swelling, hyperventilation, severe electrolyte imbalances, dehydration, vomiting and death.
- **Adolescent's perspective** is gaining an understanding of the viewpoints that adolescents hold - their beliefs and ideas about what diabetes is like for them. This will be accomplished through the use of a one on one interview with the adolescent using open-ended questions to allow them to express their views about their experiences.

Maintaining glycemic control

Many steps are involved in maintaining good glucose control. The steps needed to manage diabetes include monitoring the diet and exercise, checking the blood glucose levels and taking insulin as well as managing low and high blood glucose. These diabetes management tasks and the psychological issues create many of the known challenges that adolescents face when trying to manage their diabetes. Maintaining good glucose control is

important in maintaining health and preventing complications from poor glucose control. This section will discuss these diabetes management tasks and psychological issues in further detail.

Importance of good glucose control

In the Diabetes Complications and Control Trial (DCCT, 1993) researchers found that near normal glucose levels decreased the risk for complications from diabetes (i.e. kidney, eye, nerve, and cardiovascular damage) and improved long term survival. Adolescents now give five to eight injections per day and test their BG six to ten times a day to balance their blood glucose (Barbara Davis Center for Childhood & Children's Diabetes Foundation, Chase, 2000). Blood sugar control is one of the most complicated and challenging areas of Type 1 diabetes management for adolescents and in this section one will see that adolescents struggle to meet diabetes management goals to maintain good blood sugar control. Good blood sugar control for adolescents is a target blood glucose from 70 to 150 with HbA₁C <7.5% (Silverstein et al., 2005).

Diabetes management tasks

Diabetes management tasks needed to normalize glucose levels include monitoring the diet, exercise, checking BG levels, managing low and high blood glucose, and taking insulin. The complexity of these diabetes management tasks often becomes overwhelming to the adolescents as they transition to more self-care. In this descriptive study there is a significant reduction in glucose monitoring during late childhood, with only 39% still testing 4 times a day, and during early adolescence, where only 10% are testing 4 times a day. (B. Anderson et al., 1997). Less frequent glucose monitoring is associated with poor glucose control seen by higher HbA₁C levels as also seen in multiple other studies (B. Anderson et al., 1997; Evans et al., 1999; Iannotti et al., 2006; Ingerski et al., 2010; Ziegler et al., 2010). Adolescents with poor glucose control are more likely to be hospitalized for life threatening DKA than adolescents with good glucose control (Levine et al., 2001; Ziegler et al., 2010).

Diet Management

Diet management is an essential component of helping to balance the blood glucose levels. The type and amount of food influences the ability of the adolescent to maintain normal glucose levels (ADA, 2007). Adequate nutrition is important for normal growth and development (Rovner & Nansel, 2009). With the newer insulin regimens, there has been a movement away from set diet plans to carbohydrate counting which allows more flexibility in the daily food intake (Rovner & Nansel, 2009). This flexibility has allowed children and adolescents to eat what they want when they want, but it has decreased the number of children and adolescents who are now reaching the American Diabetes Association (ADA) nutritional goals and guidelines for healthy nutrition.

Daily dietary recommendations for adolescents with T1DM are 30% of calories from fat with less than 10% saturated fats, at least 2 servings per day of fruit, 3 servings per day of vegetables and 6 servings per day of grains where at least 3 are whole grain servings (Mayer-Davis et al., 2006). The SEARCH for diabetes in youth study (Mayer-Davis et al., 2006) looked at nutritional intake of adolescents with T1DM and found that they had high saturated fat (13.5%), high total fat intake (36.9%), and low intake of the recommended amounts of fruits (1.3 servings/day), vegetables (1.5 servings/day), and whole grains (0.1 servings/day). Less than 20% of adolescents with T1DM were meeting the daily fruit and vegetable recommendations in this observational study.

Adolescent's report that monitoring food intake is difficult, and often when they are with friends, they do not pay as close attention to their food intake (Hains et al., 2006; Thomas et al., 1997). However, most adolescents with diabetes were able to correctly calculate the correct carbohydrate content for meals and snacks in a recent study by Smart and colleagues (Smart et al., 2010). In clinical practice, many adolescents do not count carbohydrates carefully and guess at the proper insulin dose.

Exercise Management

Daily exercise helps to improve glucose control by improving insulin sensitivity, is good for cardiovascular health, and assists in maintaining a healthy body weight (Tsalikian et al., 2005). The recommended activity level for adolescents is a minimum of 60 minutes of moderate activity daily (United States Department of Health and Human Services, 2008). Only 8% of adolescents meet this goal (Michaliszyn & Faulkner, 2010), and only 4.7% of adolescent girls with T1DM (Schweiger et al., 2010) meet this goal. Adolescents with T1DM who have low levels of physical activity had higher total cholesterol, higher LDL-c, and higher triglycerides than those with higher levels of moderate physical activity (Michaliszyn & Faulkner, 2010). Adolescent girls with T1DM who had moderate physical activity at least 5 days per week had better HbA_{1c} levels, lower body mass index (BMI), lower systolic blood pressure, and lower diastolic blood pressure than those with less physical activity (Schweiger et al., 2010).

Low blood sugar

Hypoglycemia, or blood sugar less than 70, results from too much insulin, not enough food, or from an increase in physical activity (Clarke, Jones, Rewers, Dunger, & Klingensmith, 2009; Silverstein et al., 2005). The risk of severe hypoglycemia increases with more intensive insulin regimens (Clarke et al., 2009). The symptoms of low blood sugar include sweating, shaking, rapid heart rate, hunger, and confusion. These symptoms can lead to seizures, loss of consciousness, or death if not treated with rapid acting sugar (Clarke et al., 2009). Adolescents with T1DM should always carry glucose tablets or juice for immediate treatment of low blood sugar. Some adolescents are afraid of low blood sugar, and they let their glucose levels run high so they are less likely to experience these symptoms (Clarke et al., 2009; Di Battista, Hart, Greco, & Gloizer, 2009). A recent study showed that low blood sugar occurs during the night 8.5% of the time, and over 25% of those nights the blood sugar was less than 60 for over 2 hours (Juvenile Diabetes Research Foundation Continuous Glucose Monitoring Study, 2010).

Low blood sugar is difficult for the adolescent to manage as they need to make complex decisions on how to manage their blood sugar during a variety of events from exercise to driving and even prior to meals or bed to avoid a dangerous hypoglycemic event, and many adolescents under dose their insulin to avoid going low during the day.

These diabetes management tasks necessary to maintain normal glucose levels take skill, knowledge, and decision making that is often difficult for the adolescent. Several descriptive studies have supported how difficult it is for adolescents to navigate their day, to monitor their glucose levels, give insulin, and manage their diet and exercise in order to keep glucose levels near normal (B. Anderson et al., 1997; Ingerski et al., 2010; Mayer-Davis et al., 2006; Schweiger et al., 2010). Other studies have shown that less than 1/3 of adolescents are managing diabetes well enough to maintain HbA_{1c} levels in the target range for their age (Hoey, 2009). Persistent high blood sugar (BS) and poor adherence to diet, exercise and BGM and giving insulin lasts into adulthood for many with T1DM showing that this is not just a problem for those who are transitioning to self-care but more about being able to consistently perform these diabetes tasks daily, with a chronic illness like diabetes, in order to prevent long term complications (Lancaster et al., 2010; Moreland et al., 2006; Patton, 2011; Peyrot, Rubin, Kruger, & Travis, 2010; Snell-Bergeon et al., 2009). In adulthood still only 1/3 of adults with T1DM are able to maintain HbA_{1c} levels <7.5% with over 10% having very poor control of HbA_{1c} >12% (Toljamo & Hentinen, 2001).

There are set goals for good glucose control in adolescence. Studies above show that few adolescents are able to maintain good glycemic control by managing their diet and exercise as recommended, or by completing their diabetes management tasks in a way that keeps blood sugars normal. Again these studies have done a thorough job of describing the problem and the expectations but do not provide any solutions that can help adolescent's to be successful with their diabetes management. There have not been the studies done from the adolescent

perspective to help researcher's really understand the decisions that adolescents make about diabetes management and what other influences are part of these decisions.

A recent grounded theory study assessed the adolescent perspective on missed insulin bolusing for meals for adolescents on an insulin pump (Lindholm Olinder, Ternulf Nyhlin, & Smide, 2011). These authors found that the main theme that arose out of interviews with the adolescents was 'lost focus'. The discussions with the adolescents about what happened in their lives and minds when it was time to bolus their insulin, as well as strategies they used to remember their boluses were very rich. The authors believe they can then use the information that was obtained from the adolescent's perspective to better help other adolescents in clinic to avoid missing boluses of insulin.

Psychological Issues

There are a multitude of psychological factors that affect adolescent adjustment to having a complex chronic illness that affects not only their relationships with their parents but also their peers. These psychological factors include emotional, social, and cognitive changes that affect their ability to cope with diabetes and maintain their quality of life. Behaviors are also affected due to actual physical cognitive changes in the brain from either high or low blood sugars. In this section one will see that not only the concrete diabetes management tasks defined above but also many psychological factors affect the progression to independent care as well as the physical effects from high and low blood sugars also influence how the adolescent is able to manage their blood glucose to maintain good diabetes control.

Many adolescents with diabetes have poor self-esteem (Grey et al., 1991; Jacobson et al., 1987; Leonard, Garwick, & Adwan, 2005), more conflict with their parents (B. J. Anderson et al., 2002; C. Dashiff et al., 2009; Davidson et al., 2004; Ingerski et al., 2010), struggle with peer relationships (Buchbinder et al., 2005; Grey et al., 1991), and do poorly in school (Martinez & Ercikan, 2009; Northam, Lin, Finch, Werther, & Cameron, 2010). Adolescent males who

showed aggression, had attention problems, or exhibited delinquent behaviors were more likely to have high HbA_{1c} levels (Leonard, Jang, Savik, & Plumbo, 2005). Anxiety, depression, and poor coping behaviors are more common in adolescents with diabetes than their peers (Grey et al., 1991).

Psychological effects of low blood sugar

Hypoglycemia has been related to a decline in mental functioning particularly for those diagnosed prior to age 5 (Rovet, Ehrlich, & Hoppe, 1988). Newer research is showing brain effects from both high and low blood sugars that may affect cognitive abilities (Kodl & Seaquist, 2008; Musen et al., 2008; Perantie et al., 2007). The short and long term effects of high or low blood glucose may affect the ability of the adolescent with T1DM to think in school, to be successful in his or her job, and even to make successful decisions about his or her care. Maintaining these daily management tasks to control BG levels is frustrating for the adolescents who are trying to fit in with their peers and not be different (Davidson et al., 2004).

The psychological and emotional effects of having diabetes and changes in the brain affect how the adolescent is able to perform diabetes management tasks and maintain glucose control. The studies that have been done to date describe the problems that are often associated with adolescents who have diabetes, in particular, how their behaviors are affecting their relationships with others, but they do not provide information from the adolescent's perspective. Understanding more about the adolescent's perspective on the emotional pieces of diabetes management is critical to not only developing the whole theory around this phenomenon but also in learning ways that are deemed helpful by the adolescent. Learning the strengths that some adolescents use to cope with the psychological aspects of diabetes will provide important information for interventional work.

Another example of a recent qualitative study was done in adolescent girls to assess their quality of life and perceptions around diabetes (Maslakkpak, Anosheh, Fazlollah, &

Ebrahim, 2010). These authors used content analysis but were able to come up with two main themes of external and internal barriers to diabetes care. The perspectives these adolescents were able to provide about what it was like for them to take care of their diabetes and specific examples of things that got in the way are very important to researchers. Concerns about future jobs, issues with classmates in school and not wanting to self-inject insulin were some of the rich comments that were obtained from the perspective of these adolescents about caring for their diabetes and their quality of life. Developing an understanding of the perspectives of these adolescents is very different than external observations by adults who work in the field. Information from these types of interviews will allow the researcher to target interventions specific to issues or solutions that adolescents found helpful in their experiences with diabetes.

Developmental process

Adolescents with diabetes not only have to adjust to the physical and emotional tasks of managing a chronic illness but also must deal with the normal developmental processes in the transition from childhood through adolescence to adulthood (Schilling, 2006). The challenge of having a chronic illness during the already difficult adolescent years increases the burden of dealing with their diabetes (Davidson et al., 2004). During this transition to adulthood, the adolescent begins to do more self-care and become independent from his parents (Davidson et al., 2004; Grey et al., 1991; Ingerski et al., 2010; Kyngas & Barlow, 1995; Kyngas & Hentinen, 1995). Body image (Kyngas & Barlow, 1995), problem solving skills (McCaul K. D., 1987), independence (T. Wysocki, Hough, Ward, & Green, 1992), and autonomy (Schilling L. S., 2002) are important features of the developmental period of adolescence and pose challenges for the adolescent incorporating diabetes management tasks during this developmental stage.

As the adolescent becomes more independent, there is an increase in parental-child conflict that is detrimental to care (B. Anderson, 2009; B. J. Anderson et al., 2002; Kyngas & Barlow, 1995; Schilling, 2006). Parental-child conflict is associated with lower frequency of

BGM as well as higher HbA₁C levels (B. J. Anderson et al., 2009; B. J. Anderson et al., 2002; Kyngas & Rissanen, 2001; Leonard, Garwick, et al., 2005). In contrast parental support (Hanna & Guthrie, 2001; Kyngas & Hentinen, 1995; Kyngas, Hentinen, & Barlow, 1998; Kyngas & Rissanen, 2001; Leonard, Garwick, et al., 2005) as well as peer support (Kyngas et al., 1998; Kyngas & Rissanen, 2001) are helpful in consistently performing diabetes management tasks such as BGM and maintaining lower HbA₁C levels (B. Anderson et al., 1997; B. J. Anderson et al., 2002). While it is not clear if conflict is the cause of decreased parental monitoring during adolescence, increased parental support and involvement improves short term glucose control and quality of life (Weissberg-Benchell et al., 1995; Wysocki, Hough, Linscheid, Yeates, & Naglieri, 1996), yet it is not viewed as helpful by many adolescents (Hanna, Juarez, Lenss, & Guthrie, 2003; Hoey, 2009; Leonard, Garwick, et al., 2005).

Some adolescents report that they feel that their parents are too controlling and do not want the supervision for their care (Hoey, 2009; Leonard, Garwick, et al., 2005). Risk factors have been identified that increase the risk of poor adherence to care, and those include increasing age, single-family homes, lower socio-economic status, high family conflict, poor family communication and problem solving skills, and poor social skills and coping methods (T. Wysocki, 2006).

This project focuses on adolescents during these important transitional years. Ages 11 to 15 years was chosen for this study as during this time the adolescent's diabetes management begins to fall off with decreased BGM and decreased insulin administration, leading to higher HbA₁C levels and increased hospitalizations from DKA. This critical time when adolescents are transitioning to more self-care and adjusting to the developmental changes that are also occurring is an important time to focus on understanding how adolescents are able to manage their diabetes. Understanding the adolescents perspective of the challenges during transition is important for their future success as they learn to manage their diabetes on their own.

Justification for current study

There have been abundant studies that show that good glucose control leads to decreased complications and a decreased risk for costly DKA admissions in adolescents (DCCT, 1993; Levine et al., 2001; Morris et al., 1997; Palta et al., 1997). There have been multiple studies that show that there is a decrease in blood glucose monitoring and missing insulin injections resulting in higher HbA_{1c} levels in late childhood and into adolescence (B. Anderson et al., 1997; Evans et al., 1999; Iannotti et al., 2006) even in studies where subjects had more protective factors (Caucasian, private insurance, parents married, and 2/3 on insulin pump) (Ingerski et al., 2010). Increased parental monitoring or assistance with care usually leads to an increase in conflict between the parent and the child (Holmbeck, 2002) and does not always improve care. However, these factors alone do not predict which adolescents are going to be successful in performing diabetes management tasks and which ones are not going to be successful. Taking the prevalent attitude that 'they are just adolescents and will grow out of it', during this time of high risk behaviors and poor glucose control is not acceptable, and further research must be done to understand these risk taking behaviors.

There are also multiple studies that show that significant psychological issues arise from having a chronic illness with an increase in problems such as depression and anxiety during adolescence (Berg et al., 2010; Hoey, 2009; Insabella, Grey, Knafl, & Tamborlane, 2007). Other groups have studied factors that seem to be associated with improved glucose control such as parent involvement (B. J. Anderson et al., 2009), support from parents and peers (Carroll & Marrero, 2006; Kyngas & Rissanen, 2001; Leonard, Garwick, et al., 2005), authoritarian parents (Greene, Mandelco, Roper, Marshall, & Dyches, 2010), and support from the medical team (Carroll & Marrero, 2006; Kyngas & Rissanen, 2001). A few interventional studies have been done to assess programs to increase parental involvement and support without much success in improving HbA_{1c} levels and maintaining good glucose control.

Parents transition the majority of diabetes management to their children between the ages of 11 to 13 (C. J. Dashiff, McCaleb, & Cull, 2006; Ingerski et al., 2010; Schilling, 2006). It is developmentally appropriate to begin transition care for diabetes to the early adolescent as well as other home responsibilities (Kieckhefer & Trahms, 2000; Silverstein et al., 2005). Blood glucose monitoring and insulin injections are key tasks in good diabetes control. To maintain blood glucose levels near normal the adolescent must check the blood glucose level, count the carbohydrates in the foods to be eaten, and use problem solving skills to decide how exercise is going to affect the blood glucose level in order to calculate the correct dose of insulin. The adolescent needs to understand the importance of a heart healthy diet and maintaining a proper exercise regimen in overall glucose control. These tasks for maintaining the blood glucose levels near normal must be performed prior to each meal and snack and before going to bed at night – usually at least 6 to 8 times per day. There is a risk of hyperglycemia leading to DKA and hospitalization with poor insulin administration, and there is a risk of hypoglycemia possibly leading to seizures or coma with too much insulin or exercise. These daily management tasks, along with the emotional aspects of having a chronic illness, are daunting to many adolescents leading to a decrease in glucose control during these years. Good diabetes management during the adolescent years leads to better care during the young adult period and into adulthood with improved quality of life and a decrease in complications (B. J. Anderson & Wolpert, 2004; Insabella et al., 2007). It is important to understand the experiences of these adolescents age 11 to 15 years as they struggle to maintain glucose control during this time of transition to increasing self-care.

Multiple studies of young adults and older adults with Type 1 diabetes show that many continue to have problems with good diabetes control. There is ongoing poor adherence to a heart healthy diet with over 50% not meeting dietary recommendations to control blood sugars, maintain lower salt diet, and decrease the risk for heart disease (Gunther et al., 2009; Patton,

2011; Snell-Bergeon et al., 2009). Over 50% of adults with T1DM admit to intentionally missing insulin doses and 20% state they regularly miss insulin doses and the average for BGM is 1-2 times daily with only 33% maintaining a HbA_{1c} less than 7.5% (Moreland et al., 2006; Peyrot et al., 2010; Toljamo & Hentinen, 2001). Many young adults with T1DM ages 20-25 report ongoing conflict with family, problems with carbohydrate counting and psychological issues that are obstacles in maintaining good glycemic control (Lancaster et al., 2010). Barriers to exercise in adults with T1DM include fear of hypoglycemia, work schedule interfering, loss of control and low fitness level (Brazeau, Rabasa-Lhoret, Strychar, & Mircescu, 2008).

In summary, Type 1 diabetes is prevalent, costly, impacts quality of life, school, and relationships and ultimately long term survival, is difficult to manage, and these persist into adulthood. The adolescent struggles to manage diabetes and maintain blood sugar control as he or she takes on more self-care. While a great deal of research has been done to define the nature of the problems, little is understood about how to intervene, the relationship of the illness to the broader issues, and tasks the adolescent faces as a part of normal growth and development. There has been minimal research from the perspective of the adolescent and none in the area of understanding how the adolescent handles these diabetes management tasks needed for good BS control.

As the adolescents take on greater responsibility for self-care of their diabetes, they must use newly acquired skills of abstract thinking, problem solving, and reasoning to make appropriate healthy choices to control their diabetes. Gaining a greater understanding of the adolescent's experiences with diabetes and specifically diabetes management may be expected to provide important information for both researchers in the design of interventions to influence management behaviors and health care providers in being able to provide appropriate care.

Conclusion

The purpose of this research effort is to gain a greater understanding from the adolescent's (ages 11 to 15 years) perspective of their experiences in living with diabetes, associated challenges, and management issues they may face. The conditions related to management behaviors are of primary importance along with providing a greater understanding of the influence of diabetes on relationships with peers, school, and parents. We expect to build a theoretical paradigm that will capture the main categories and moving processes in the experiences of adolescents and provide much needed information and hypotheses to support interventional design. The moving processes and conditions related to diabetes management are how the adolescent accomplishes the tasks needed for diabetes management and what conditions or things are present for these management tasks to occur. Part of the identification of the conditions present will also be learning about when the adolescent is not able to accomplish their diabetes management, and what gets in the way to understand this process in the adolescent.

Understanding the challenges that adolescents face as they care for their diabetes will provide a foundation for more targeted interventional research. There is a gap in knowledge, particularly in understanding the adolescent's perspectives on their experiences with diabetes, such as how they make sense of and integrate daily life with diabetes management tasks such as performing blood glucose monitoring, giving insulin injections, managing low blood glucose, monitoring the diet, and exercise. These processes are an integral part of good diabetes management and decreased short and long term complications as well as ongoing success with diabetes care as an adult. If the adolescent is able to be successful in his or her transition to self-care, it may be expected that there will be decreased costs associated with DKA hospitalizations, fewer long term complications (to the eye, kidney, heart, and extremities), and improved quality of life.

Gaining an understanding of the conditions under which some adolescents are successful in managing their insulin and glucose monitoring provides information that is critical to developing programs to improve success in diabetes management. Understanding diabetes management in the broader context of adolescent life further contributes to understanding the influence of diabetes on the adolescent and contributes to the design of interventions and programs that may be expected to contribute to better quality of life as well as an improvement in diabetes management.

This research is expected to contribute to the advancement of nursing science, nursing practice and to the adolescents and their families struggling with Type 1 diabetes. For nursing research, this study will provide greater understanding of moving processes, conditions under which behaviors occur, and provide a theoretical model and hypotheses to inform interventional designs. For nursing practice, this study will provide much needed information that will inform understanding of the world of the adolescent and how to support them and their families in better diabetes management. For adolescents and families, this effort is expected to provide a greater understanding of the influence of diabetes and provide insights into balancing diabetes management with the normal growth and developmental process.

Chapter 2 – Literature Review

Overview

Adolescents have a difficult time maintaining adherence to their diabetes regimen; they often neglect blood glucose testing and do not give their insulin as often as needed to maintain good blood glucose control. Monitoring and adjusting their diet and exercise with their insulin to balance their blood sugar levels also becomes more problematic. Some of the factors that have been associated with this decrease in blood glucose testing include family conflict, problem solving issues, and coping with chronic illness while maintaining an acceptable quality of life. The purpose of this literature review is to discuss the research that has been done in these areas to improve adherence to care, blood glucose levels, and hemoglobin A₁C (HbA₁C), as well as the psychosocial aspects that are part of this difficult chronic illness. There have been no studies from the adolescent's perspective on performing these diabetes management tasks of blood glucose monitoring, insulin injections, and monitoring the diet and exercise to maintain normal blood glucose levels. Understanding more about the adolescent's views of performing these tasks is important to help the adolescent be successful with their diabetes care.

Introduction

The Diabetes Complications and Control Trial (DCCT, 1993) found that near normal glucose levels decreased the risk for complications from diabetes (i.e. kidney, eye, nerve, and cardiovascular damage) and improved long term survival. Intensive treatment regimens and new insulin therapies have improved blood glucose (BG) control but also significantly increased the complexity of daily care to achieve recommended glucose targets (Adhikari, Adams-Huet, Wang, Marks, & White, 2009; Frohlich-Reiterer et al., 2007). Adolescents now give five to eight injections per day and test their BG six to ten times a day to balance their blood glucose.

Diabetes management tasks needed to normalize glucose levels include monitoring the diet, exercise, checking BG levels, managing high or low blood glucose, and taking insulin injections. The complexity of these diabetes management tasks often becomes overwhelming to the adolescent as they transition to more self-care. There is a significant reduction in glucose monitoring during late childhood with only 39% still testing 4 times a day and during early adolescence where only 10% are testing 4 times a day (B. Anderson et al., 1997). Less frequent blood glucose monitoring (BGM) is associated with poor glucose control seen by higher hemoglobin A₁C (HbA₁C) levels (B. Anderson et al., 1997; B. J. Anderson et al., 2002; Evans et al., 1999; Levine et al., 2001; Morris et al., 1997) and increases with age (Ingerski et al., 2010; Leonard, Jang, et al., 2005). Adolescents with poor glucose control are more likely to be hospitalized for life threatening diabetic ketoacidosis (DKA) than adolescents with good glucose control (Angus & Waugh, 2007; Levine et al., 2001; Palta et al., 1997).

Understanding of the adolescent's behaviors related to this decrease in BGM or giving insulin is limited. Control varies between adolescents for reasons that are also not well understood. Behavioral and psychological factors have been assessed but don't fully explain poor adherence. Increased anxiety (Di Battista et al., 2009; Edgar & Skinner, 2003; Grey et al., 1991), depression (Edgar & Skinner, 2003; Grey et al., 1991), low self-esteem (Grey et al., 1991; Jacobson et al., 1987), fear of needles (Simmons et al., 2007), decreased parental monitoring (B. J. Anderson et al., 2002; Moreland et al., 2004), poor social and coping skills (Jacobson et al., 1987; Leonard, Jang, Savik, Plumbo, & Christensen, 2002; Northam et al., 2010), and increased family conflict (B. J. Anderson et al., 2009; B. J. Anderson et al., 2002; Ingerski et al., 2010; Laursen, Coy, & Collins, 1998; Weissberg-Benchell et al., 2009) have been identified as contributing factors.

Developmental Issues

The key developmental tasks during adolescence include the development of autonomy in particular independence from parents, self-image, and peer and romantic relationships. Those with chronic illnesses often have more challenges in completing these developmental tasks due to many factors (Fritz & McQuaid, 2000). There has been a significant amount of research on adherence and self-efficacy in adolescents with diabetes, and how these are affected by developmental issues (Chih, Jan, Shu, & Lue, 2010; Greene et al., 2010; Iannotti et al., 2006; Lewin et al., 2010; T. Wysocki, 2006). As children grow into adolescence, there are physical and mental changes that occur. Age 11 is described as the beginning of adolescence as there are significant new patterns and behaviors that occur during this time (Gesell, Ilg, & Bates Ames, 1956). During this time there is a migration to more self-care and autonomy. This development occurs due to the interactions with the environment in which one lives (Bronfenbrenner, 1979). Conflict that arises between the parent and the adolescent with diabetes during this time of transition is frequent and detrimental to care (B. J. Anderson et al., 2002; Hoey, 2009; Leonard, Garwick, et al., 2005; Viklund & Wikblad, 2009). Support from the health care team, parents and peers has been found to be helpful to the adolescent (Hanna & Guthrie, 2001; Kyngas & Rissanen, 2001). As we seek to understand how health behaviors and adaptation to chronic illness are influenced by friends and relatives, the adolescent's response to their illness, as well as how their culture, ethnicity, and socioeconomic status influences their beliefs and values, one must remember the developmental process. Integrating these important topics will help further understanding of adaptation to chronic illness and realize the multiple layers that are involved in daily diabetes management.

Transition to Self-Care

Many parents transition care to the adolescent too soon (B. Anderson et al., 1997; Ingerski et al., 2010; Schilling, 2006), while other parents are not ready or able to separate

(Marshall, Carter, Rose, & Brotherton, 2009). The adolescent may have the technical skills to do diabetes care but may not have developed the ability to do complex problem solving or maintain their motivation to provide self-care. The adolescent is not able to understand the consequences of their behaviors leading to poor blood glucose control (Schilling, 2006). Blood glucose control is improved if parents are able to maintain supervision (B. J. Anderson, Auslander, Jung, Miller, & Santiago, 1990; D. A. Ellis et al., 2007; Wiebe et al., 2005) of their child as well as provide support for their child (Kyngas et al., 1998; Kyngas & Rissanen, 2001). As children move to adolescence, there is less parental involvement in care with a decline in blood glucose monitoring and higher HbA_{1c} levels (B. Anderson et al., 1997; Ziegler et al., 2010). A loss of freedom and spontaneity has been reported due to having to care for diabetes as well as disruption and intrusion into family life (Marshall et al., 2009). Some adolescents like their parents to remind them to take shots, or test their BG, or even take over care at times during the transition process (Viklund & Wikblad, 2009). Adolescents reported that parental behaviors of lacking understanding, lack of engagement, being authoritarian or not agreeing with the adolescent's opinion were not helpful (Viklund & Wikblad, 2009). Humiliation, blame, shame, feelings of fear, nagging, or demanding behaviors by the parent were also seen as negative by the adolescent (Viklund & Wikblad, 2009).

A phenomenological study of 10 families where the children were ages 7-17 was done to explore the experiences of the children and their parents about T1DM (Marshall et al., 2009). They found that children talked about moving on and becoming independent and how this challenged the relationship with their parents. Attachment was also a recurrent theme, and they talked about how that was changed due to the diabetes resulting in the parent believing the child was more dependent on them and not ready or able to separate. There were also discussions on the loss of freedom and spontaneity they were able to maintain with doing diabetes care as well as disruption and intrusion into the family life. Some children talked about

teasing they encountered from friends and feeling different, but they worked on trying to be normal (Marshall et al., 2009). While this study is important to the overall knowledge of experiences with diabetes, it focused more on the parent child relationship and the parents' understanding of diabetes in their lives than the children's experiences. This study did not delve into the experiences of how diabetes is incorporated into the family's life and what parents and children did to care for their diabetes.

A large descriptive exploratory study was done at several clinics in the West and Midwest and enrolled 16 adolescents ages 11-18 in the sub study (Hanna & Guthrie, 2000). Semi-structure interviews were conducted to explore the adolescents' perspective on transferring care from their parent to themselves. Benefits described by the adolescents included feeling good about being able to care for self, being able to separate from parent and go away on own, and gaining approval of others for doing a good job. The primary barriers to doing care on their own were described by the adolescents as having all the responsibility for self-care on their own shoulders, and not seeing any disadvantages as they believe they are doing a good job of self-care. The adolescents also described the benefits they saw for their parents and believed the parent had relief from not taking on as much responsibility, had less worry, and had less stress. The adolescents described barriers for the parent as worry, guilt, and not having control over them anymore.

While the study by Hanna & Guthrie (2000) provides important information about the adolescent's perceptions around transition of care from their parent to self, it does not provide detailed information about these findings. This study was exploratory in nature to try and develop an understanding of the adolescent's perceived benefits to self-care and also what barriers they saw for themselves and for their parents. The study was done in only 16 Caucasian adolescents who were primarily living with both parents and they had a reasonable HbA₁C level (8.6%). This does provide a starting point for further exploration around transition

and how that affects relationships but does not explore the issues around how self-management occurred in these adolescents as they took on more care.

Despite all that is known about the multiple factors that are associated with poor adherence to diabetes management tasks, interventions have been of minimal use in increasing adherence to care. Interventions that specifically targeted behaviors in trying to increase BG monitoring and decrease HbA_{1c} levels have not been successful (Hood, Rohan, Peterson, & Drotar, 2010; Mulvaney, Rothman, Wallston, Lybarger, & Dietrich, 2010; Nansel et al., 2009; Nunn, King, Smart, & Anderson, 2006). Those interventions that incorporate psychosocial processes that engage parental help and aim to improve psychological outcomes have had some success in improving self-esteem and quality of life but have shown no significant lasting changes in glycemic control (Channon et al., 2007; de Wit et al., 2008; Delamater et al., 2001; Grey et al., 2000; Grey et al., 2009). If one hopes to use behavior changes to increase adherence, the more researchers can learn about the perspectives of adolescents around actually doing these diabetes management tasks should add valuable information to what is known today about improving adherence to care. Understanding the perspectives of how these adolescents view diabetes will allow the researchers to develop a new dimension to what is known about how diabetes affects their life, what barriers they have to managing their care and what things they have learned about successfully controlling their diabetes.

Diabetes Management Interventions

Adherence to Care

A meta-analysis of studies was completed reviewing interventions that attempted to improve adherence to the diabetes regimen (Hood et al., 2010). There were 15 studies from 1994 to 2009 that met the criteria of a randomized clinical trial (RCT), adolescents under age 19 with T1DM, that reported glucose control and used some type of adherence or self-management component. The interventions were categorized into two groups: either those with

a direct behavioral component – such as increasing blood glucose monitoring frequency - compared to those with a combined intervention that used behavioral tasks with an intervention that promoted coping, problem-solving or some family process to improve diabetes management. The authors also calculated the percentage of time the intervention worked on adherence to diabetes tasks. These studies had a combined total of 997 participants with a mean effect size of 0.11 for pre to post treatment change when comparing the intervention group with the control group, which shows only a very small improvement in the glucose control. They also found that interventions which also focused on other components such as emotional, social or family issues that help with diabetes control were better than those that only focused on changing behavior like increasing the frequency of blood glucose testing. In the experimental group there was a decrease in mean HbA_{1c} from $9.61 \pm 1.83\%$ at baseline to $9.17 \pm 1.53\%$ at follow-up. In reviewing specific interventions it appears that using added components like coping skills or problem solving was most beneficial and contributed to this decrease in HbA_{1c}. These studies also rarely included those determined to be at higher risk – with high HbA_{1c} values or with fewer resources or family support to see if these same interventions would be more valuable in this population.

Only four of the fifteen studies in this meta-analysis (Hood, Peterson, Rohan, & Drotar, 2009) were done with direct intervention in which the aim was to address influencing the behavioral process. Of these four only one had a positive effect size and that was only 0.09 which showed only a very modest improvement in glycemic control. The rest of the studies all combined some other components such as coping skills or problem solving. Even in the combined group there were only four studies that showed a pooled positive effect size of 0.39 or better so minimal improvement in glycemic control. Researchers early on concluded that focusing only on improving adherence with diabetes management tasks alone was not as beneficial as combining other types of therapies to try and improve glycemic control.

The authors of this meta-analysis (Hood et al., 2010) discuss some of the issues in adolescent research on adherence to diabetes care. Adolescents do not like to be told what to do so interventions aimed at just 'making' them adhere to care do not work at all. Interventions that included the psychological component most likely were more effective as there is not going to be just one component that needs to be addressed to address adherence. However, even in these multi-component interventions there was minimal change in glucose control. The authors decided to pool their results and look at an improvement in glycemic control – by doing this they may have missed if certain types of interventions were more successful for certain ages or in adolescents with certain HbA_{1c} levels. Including the behavioral studies was important to show that behavioral change alone most likely is not beneficial but building on some components of current research that has been done and addressing the multidimensional components of diabetes is more likely to be helpful in improving glycemic control. The other areas that were not addressed were length of time since diagnosis and length of the interventions as these components are most likely also influential in the outcomes. As one can see, there have been minimal advantages and improvements in glycemic control through the addition of a variety of methods to try and improve diabetes outcomes.

Coping Skills Training

One psychological factor that has been associated with decreased testing is poor coping with diabetes. Several studies have attempted to increase these coping skills in the adolescents in an attempt to increase adherence to blood glucose monitoring and giving insulin injections. A study of seventy-seven adolescents ages 12 to 20 with type 1 diabetes (Grey et al., 2000) examined the effects of coping skills training. The purpose of this study was to see if the effects on metabolic control and quality of life were able to be sustained over a 1 year period in those adolescents who received a behavioral intervention (coping skills training) and intensive diabetes management. Coping skills training included role playing a variety of life situations

such as managing food choices, decision making about drugs or alcohol, and conflict with others. The groups were randomly assigned to either receive the coping skills training (6 small group sessions and monthly follow-up) or not receive the extra training. Data were collected at the start of the study, then again at 3, 6, and 12 months using tools to measure self-efficacy, depression, coping, quality of life, HbA_{1c}, and adverse effects. In this study, researchers found that those who received the coping skills training had lower HbA_{1c}, better diabetes and medical self-efficacy and less influence on their quality of life than those only getting intensive therapy. There were significant levels of severe hypoglycemia in both groups that could have affected the HbA_{1c} levels and overall HbA_{1c} levels were still much higher than the normal range. The researchers noted that the effects of frequent patient contacts also could have influenced the outcomes of this study.

The focus of the above study (Grey et al., 2000) was to test coping skills training against control in adolescents ages 12 to 20 with a goal of increasing their competence in good use of coping skills. While there was a significant drop in HbA_{1c} levels in both groups, there was more improvement in the intervention group. Both groups received lots of attention and frequent monitoring which was more than what would be done in usual care. Despite the intervention and frequent monitoring, actually both groups had a very high rate of severe hypoglycemia which skews the results of the HbA_{1c} lower. Of interest was that the adolescents who received the coping skills training reported feeling better about dealing with certain diabetes situations. This shows that the intervention may have some use for long term changes in adjustment to diabetes.

Coping skills training has more recently been studied by Grey, Whittemore et al. (2009). The purpose of this study was to see if coping skills training worked with school age children (ages 8-12) and their parents. The goal of this study was to monitor metabolic control and psychosocial outcomes and see if there were specific mediators and moderators that influenced

the outcomes. This was a randomized controlled trial that compared a group of children who received coping skills training with a group that received attention and general education. Coping skills training was defined as retraining coping styles for communication, social problem solving, recognizing the interaction between behaviors and feelings, and stress and conflict management. Attention was defined as a control group that received general education in a group setting to all study subjects. Outcomes were assessed based on metabolic control, quality of life, depressive symptoms, coping, self-efficacy, and family functioning after 12 months. Mediators such as coping, self-efficacy, family functioning, and moderators such as age, sex, socioeconomic status and treatment modality were also assessed for influence on the outcomes of the study. This study only ended up with 58% of participants needed for power analysis and more were in the intervention group than in the control group. Also, the population was very low risk (white, high income, on pump therapy, with excellent metabolic control). The primary hypothesis of the study that the coping skills training would show improved metabolic control, quality of life, depression symptoms, coping, self-efficacy and family functioning was not supported in the data. It was concluded that since these children were in good control with good psychosocial adjustment, it is difficult to have further improvement.

This study done by Grey et.al. (2009) focused on a brief intervention lasting for 6 months. The study group was children ages 8-12 with T1DM and those in the intervention group were more likely to be Caucasian, their parents were highly educated, and most children in the study came from high income families. The subjects chosen for this study typically had minimal issues with coping and the support they had available was a protective factor. This same intervention may be useful if studied in higher risk children where the effect of the intervention during adolescence, when more problems typically develop in coping with diabetes, can be studied. This may be an ideal time to do an intervention, but the monitoring for true

effectiveness will most likely take many years and probably ongoing intervention would also be more useful.

Experiences of living with Type 1 Diabetes

A study conducted in Brazil (Damiao & Pinto, 2007) attempted to understand the meaning that seven adolescents (age 12-18) give to their daily experiences of living with Type 1 diabetes. The questions for this study focused on what it was like to have a chronic illness. The authors stated that grounded theory was used as the methodology for the study data collection and analysis but it was not used in traditional fashion. The authors found three themes in reviewing the data: a) what it was like to be diagnosed with diabetes, b) how they were transformed by diabetes, and c) having a prickly life. The adolescents talked about their experiences with being diagnosed with diabetes and that the awareness of all the things they would have to do to care for diabetes took a while after discharge. They also discussed how the whole family was affected by diabetes. The adolescents talked about how they are different from their peers even though they feel normal, and how there is a feeling of awkwardness because they are different now. Some adolescents discussed how they became aware that the disease was forever and how they need to make care part of their lives, and some even noted benefits to their health from having diabetes. Other discussions were on the changes in family dynamics and relationships, and this group of adolescents did not feel they were treated differently by their siblings or parents. Adolescents also discussed having to poke themselves so often and learn to do that to be independent; they talked about their feelings about being hospitalized or being sick and always having to think about diabetes as well as how their emotions affect their diabetes. The study authors believed that these participants had an inner personal strength that helped them live well with diabetes as it transformed their life with added meaning.

The biggest critique of this study (Damiao & Pinto, 2007) is that the authors stated they used grounded theory as their methodology but only partially used pieces of grounded theory. They did not describe the method of grounded theory and which methods they were using for the analysis (Glaser vs. Strauss) and used semi-structured interviews which are not appropriate to grounded theory. The authors also did not take their data to the conceptual level as is done in grounded theory. This study does describe some very interesting things that the adolescents reported about what it was like to live with diabetes and the authors clumped those thoughts into themes. The next important step that is missing is understanding more about the phenomena based on what the adolescents were saying - data collection may not have been in-depth enough to allow this level of understanding around the conditions when these themes were occurring, or the authors just missed that next step in creating a theory about what was occurring for these adolescents.

Another study (Carroll & Marrero, 2006) was done to explore the perceptions of the adolescents (ages 13-18) about how diabetes affects their quality of life and their relationships with their parents, peers, school, and health care workers. Focus groups were conducted with the 31 adolescents who participated in this qualitative study. The primary themes that were discussed were daily living with diabetes including BG testing, injections and dealing with BG variability, the influence of the adolescent's relationships with others and the influence on their school life. Related to daily living with diabetes, the primary focus of participants was on the daily hassles of having to do diabetes care and how it took control of their lives and made them more responsible for themselves. The participants also discussed that diabetes was stressful (primarily found in younger adolescents <15 years), time-consuming, made them more aware of their bodies, difficult to accept as there was no cure, and difficult with sports, career choices and driving. The adolescents discussed their relationships with their parents, their peers, and their health care providers. Primary issues in the parental relationship included the concern their

parents showed yet how overbearing their parents were and not allowing them to do activities that other teenagers were allowed to do. They also talked about the conflict with their parents, parents understanding of adolescent knowledge and ability to control their diabetes, and the lack of trust shown by the parents. There was also discussion on support that parents provide in obtaining medical supplies, making appointments and contacting the medical provider if needed. Discussions around peer relationships focused on supportive behaviors from their friends, intrusive behaviors that were deemed annoying, a lack of understanding from others about diabetes and being able to help the adolescent if something went wrong. The two main topics that arose when discussing the relationship with the health care provider (HCP) were the demeanor of the physician as well as access and communication patterns. Adolescents wanted their HCP to see them as an individual and not as a disease, not threatening them but helping them to get diabetes more in control by letting them figure out some things on their own without talking down to them. The adolescents also valued the time they were able to spend with their HCP and the relationship they developed, and they found they were more motivated to be successful after visits with the HCP in order to please them. The influence that diabetes has on the school was minimal for most participants in this study unless they were having unstable BG levels and had to miss class. Many did not appreciate the school nurse interference in their care, and the poor knowledge about diabetes that teachers had about diabetes.

The researchers in the above study on perceptions of adolescents (Carroll & Marrero, 2006) only briefly discussed blood glucose monitoring and insulin injections but focused more on the hassles of doing care and relationships with others. While this study did provide some important information from the perspective of adolescents on the perceptions of having diabetes and how it interfered with their life, it did not provide much information on the diabetes management tasks. The methodology was not well defined by the authors, they only did focus groups and seemed to only focus on certain areas of the topics that came up. Grounded theory

would go deeper with the questions, and the final analysis really tries to capture more about the conditions that are present for the adolescent. The small amount of information shared on insulin injections, BGM, exercise and diet management was valuable but did not provide any depth about how the adolescent was able to accomplish these tasks or many reasons about what barriers were present other than the emotional aspect of diabetes being frustrating and annoying. This study leaves a big gap in knowledge around the adolescent's perceptions of diabetes management tasks and how they accomplish them which needs further exploration.

A systematic review of qualitative studies done on adolescents (ages 13 – 16) with T1DM since 1988 was done and 20 studies were reviewed (Spencer, Cooper, & Milton, 2010). The purpose of this literature review was to explore the experiences of adolescents who were living with T1DM. Some of the studies pursued information on independence and autonomy of care for self-management and reviewed psychological and emotional maturity, the parent as a barrier or facilitator of autonomy, peer support, the role of health professionals and technology and the implications of adolescent autonomy. The second set of studies primarily assessed what it is like to live with T1DM and how the adolescent manages conflict, things that help or are barriers to care, and identified some of the restrictions, stress and coping problems that result from managing a chronic illness. Other studies focused more on the family relationship and how adaptation occurs, as well as the parent-child relationship, and the effects of parental anxiety. The last set of articles in the review were grouped under diabetes care and discussion about diabetes in school, learning about caring for diabetes, as well as information about perceptions of care by the health care team.

This study by Spencer et.al. (2009) was an excellent overview of the qualitative studies that have been done about the adolescent experience of living with T1DM. The authors critiqued each article for how well they followed procedures based on the type of epistemology or framework that was chosen to assure that the study seemed valid. The findings of the

studies chosen were then divided into the groups listed above. This overview of content that was studied by the various authors in this review concentrated more on independence and autonomy as well as relationships of the person with T1DM and others in their family. There were a few comments included from adolescents on their perceived barriers to care as well as things that helped them perform their care. This information is valuable in beginning the exploration with adolescents on what is going on with them but doesn't provide needed depth to fully understand this process. Most of the given comments were on the emotional pieces of living with diabetes and how the adolescents believed diabetes was affecting them. The biggest weakness in this study was the ability of the authors to draw conclusions as the research that was available didn't always talk about their philosophical grounding in how the studies were conducted and the validity of some of the studies was questioned. It is important for authors of qualitative work to provide good quality research and be able to fully disclose the methods they used for others to evaluate the traditions and acceptability of how the data was collected and analyzed.

Problem Solving

Poor problem solving skills is another psychosocial process that has been associated with decreased blood glucose monitoring and poor glucose control. Several studies have sought to increase problem solving skills and therefore to increase adherence to diabetes management tasks. A multisite feasibility study was done (Nansel et al., 2009) to test an intention for family problem solving for behavior changes. There were 30-32 families at each of 4 sites for a total of 122 participating families, the adolescents with Type 1 diabetes were ages 9-14.5 years. The goal of this study was to develop an intervention that could be done during regular clinic visit that would help families promote responsibility sharing, reduce conflict and improve problem solving in the areas of blood sugar monitoring, insulin administration, diet, physical activity and managing changes in blood sugars. The objectives for this study were to

improve disease management problem solving, to improve cooperation and communication between parent and child, and to facilitate sharing of diabetes management. Data was collected on metabolic control, adherence, quality of life, mental health and any medical events that occurred during the pilot study of 3 interventions during a 12 month period with follow-up phone calls at 2 and 6 weeks after clinic visit and longer pre and post assessment visits in the home. Data analysis was done on the feasibility of conducting the study which will now be conducted for a 2 year period with more intensive intervention provided. The results showed good retention of subjects though it was a fairly low risk group of Caucasian, 2 parent families with higher income and college degrees. The researchers noted that the measures were too long and will be shortened and those children who did not provide their glucose meters had a significantly higher HbA₁C level and overall the group had a higher HbA₁C level in both groups at the end of the study with only minor declines in conflict and sharing of responsibility. There was also less frequent blood glucose testing at the end of the study. There were few ER visits or hospitalizations for hypo or hyperglycemia. There were 20 mental health referrals for depression (16.5%) at the start of the study with 6 additional referrals at follow-up (21.3% of total participants). Most participants chose to focus on blood glucose monitoring, healthy eating or remembering to carry fast acting glucose for low blood sugars. The participants and families were satisfied with the intervention.

The strength of this study by Nansel et.al. (2009) is that it was a rigorous multicenter randomized trial of adolescents ages 9 to 14.5 years with T1DM. The intervention is a highly structured process to improved diabetes management and problem solving and seemed to be delivered appropriately for the interventional phase. This trial was just to test the feasibility and design of the study, so findings were really preliminary and showed the authors where there were weaknesses and what changes were needed in intervention, administration and evaluation of this intervention. The families were satisfied but the HbA₁C was increased at the end. The

primary weakness of the study was that the study population was primarily Caucasian; the exclusion criteria may be too rigid to allow for those who are having problems with diabetes management. There was also a fairly large burden for the family to complete the study in time and travel.

A recent study looked at improving problem solving skills via an internet based program (Mulvaney et al., 2010). This was a group of 72 adolescents (age 13-17) and was a randomized trial to usual care plus internet support or usual care and the purpose was to problem solve barriers to diabetes self-management care. With this internet intervention there were no interactions with the diabetes clinicians or parents but there were 6 stories used that showed psychological barriers to care over an 11 week period. There were also a personalized homepage, multimedia presentations on education of the steps of problem solving, a social networking peer site, and comparison of the adolescent's responses with other adolescents, help from a problem solving expert and weekly emails to encourage participation. Assessment was done with measuring the HbA_{1c} level as well as completing adherence and problem solving scales. The results showed that those in the intervention group had no significant difference in problem solving ($p=0.23$), but some improvement in self-management adherence by self-report ($p=0.02$) and there was no change in HbA_{1c} ($p=0.27$). The primary weakness of this study is that the self-management adherence was measured by self-report and that is typically inaccurate in this age group a poor way to measure success. Another weakness is which subjects were able to have computer access and if that limited participation and the study sample. This is a novel approach in using social media and current technology to try and engage adolescents that would take minimal staff time and could be a very effective tool for interventions in the future.

Decision making competence of adolescents was measured in a descriptive exploratory study of 31 adolescents (ages 12-17) (Viklund & Wikblad, 2009). The adolescents reported that

they needed to be able to think in abstract ways to see the consequences of their actions, and that takes time; they also needed to be able to rely on their own abilities for learning problem-solving, and that developing insight and awareness were useful tasks as they learned more about their diabetes. Personal qualities that they believed were important are intuition, flexibility, self-reliance, and self-strength (ability to make decisions and feel in control). The adolescents believed that they learned from their own experiences as well as from other people, and that they felt inspired by other people. They also believed their social network of parents, friends, health care team, and their environment influenced them in feeling supported and when making decisions on taking a shot. They appreciated when parents worked with them as a team sharing knowledge and responsibility only when they lacked knowledge or could not care for themselves. Some adolescents felt it was helpful for the parent to remind them to test their blood glucose and give their injections as well as take on more responsibility at times when the adolescent does not feel they are able to manage diabetes on their own. Things that adolescents felt were not helpful from their parents were a lack of understanding, lack of engagement with them, being very authoritarian, or disagreeing with the adolescent's opinion. If the parents made them feel humiliated, blamed them, or made them feel shame or fear, the adolescent found this to be negative. The adolescents also did not like when parents were nagging or demanding and felt this led to more conflict.

This important work by Vikland and Wikblad (2009) was done using open ended questions during qualitative interviews and analyzed with content analysis. The questions that were used by the authors were not really open ended and put some specific ideas in the adolescent's heads about perceptions of responsibility and how stress affects their ability to manage diabetes. This type of question implies that they should feel that way. Nevertheless the information obtained from these interviews did provide some important insights about how the adolescent is able to make decisions about their care and what types of help from their parents

was useful and what behaviors they did not like. This study was based in Sweden with adolescents who had just completed an empowerment program which probably skewed the answers they gave. It would have been interesting to have interviewed them before the program to see what perceptions they had at the beginning. This was most likely a highly motivated group of adolescents as well and may not be generalizable to those who would not attend this type of program.

Quality of Life

A randomized controlled trial was undertaken at four centers to test the effects of monitoring and discussing health related quality of life (QOL) (de Wit et al., 2008). The adolescents were ages 13-17 and were from the Netherlands. There were 46 participants in the intervention group, 45 in the control group, and they each had 3 regularly scheduled visits within 12 months. They were randomized by clinic, and each pediatrician was trained to discuss the health related QOL questionnaire results with the adolescent after completion. The control group completed a lifestyle questionnaire on the computer and was told not to discuss it with anyone. Baseline and follow-up assessments measured physical and psychosocial wellbeing, depression, diabetes related conflict, satisfaction with personal care in past 12 months and HbA_{1c} levels. There were 91 total participants (53%), but 10 were lost to follow-up during the study and overall those who dropped out had a higher HbA_{1c} level than the remaining participants. There was a significant effect found in the intervention group with improvement on psychosocial health primarily in behavior ($p=0.007$) and self-esteem ($p=0.016$). There was a significant interaction effect for those with lower HbA_{1c} levels who did better with the intervention but no effect found in those with highest HbA_{1c}'s >9.5%. There were no differences on health, family conflicts or depression over time. The intervention of discussing QOL was beneficial to those with lower HbA_{1c} levels in improving their behavior and self-esteem, and it most likely benefited because the researchers addressed that emotions are part

of diabetes; however, the intervention was not effective in those who had higher HbA₁C levels. The strength of this study is that it was a randomized controlled trial using four different centers and included a control group. One of the barriers to assessing outcome in this study is that they had a high number of eligible participants drop out including those with higher HbA₁C levels compared to the others. Self-care behaviors were not assessed during this trial and the HbA₁C levels did not show improvement with the intervention.

Telephone Interventions

A randomized controlled trial using telephone calls was conducted in Australia of children and adolescents ages 3-16 whose HbA₁C level was >8% (Nunn et al., 2006). The purpose of this study was to see if bimonthly telephone calls by a pediatric certified diabetes educator (CDE) to children with high HbA₁C levels would improve glucose control, hospital admissions, diabetes knowledge, compliance and psychological well-being. Both groups attended regular clinic visits as usual. The intervention group then received follow-up phone calls lasting 15-30 minutes by the CDE where they discussed insulin, food, and blood glucose values, and insulin doses were changed as needed. They also discussed current events such as a sporting event and how to manage diabetes for that, and an educational program was done to cover most diabetes educational topics for review. Parents of children younger than 11 years were also spoken to by the CDE. Some of the subjects received extra phone calls (>13) and all subjects were followed until they had returned to clinic two times after the initial visit. Outcomes were measured with an HbA₁C level and questionnaires to measure diabetes knowledge, strengths and difficulties, social and family functioning, a family assessment and parenting scale. The mean HbA₁C level in all patients increased significantly from 8.24% to 8.84% ($p<0.001$). These telephone interviews by the CDE were not found to be effective in improving glucose control. In fact, it got worse during the intervention. There was no improvement in diabetes knowledge or decrease in hospitalizations and also no change in adherence to

management or behavior scores. The benefit of this study was that it was a randomized controlled trial. One of the challenges was that it was time consuming for staff and did not have any beneficial effects. The intervention primarily focused on BG values, insulin changes and food eaten, and it did a set topical discussion on education, but it did not address psychological or adjustment to diabetes or methods to promote adherence.

Motivational Interviewing

A multisite randomized controlled trial was conducted on adolescents (ages 14-17) with T1DM from five clinics in South Wales over a one year period (Channon et al., 2007). The purpose was to assess the effects of motivational interviewing on HbA₁C and psychosocial functioning compared to participants in a control group just receiving support visits. The motivational interviewing technique was done using the strategies approach where the researcher asked about the participant's views and then discussed the differences between the beliefs and the behaviors. The goal was for the participants to change behavior by discussing the costs and benefits of the new behavior and problem solving and setting goals to accomplish the behavior change. Outcomes were measured by HbA₁C values and psychosocial questionnaires about quality of life, locus of control, knowledge, self-efficacy, wellbeing, support and personal beliefs about illness. The results showed that there was a significant improvement in the overall HbA₁C level of 0.5% from the intervention group to the control group ($p= 0.04$) and improvement in QOL, depression, anxiety, wellbeing, and rated diabetes as more serious with a greater importance on controlling blood sugars. The main difficulty with this study was that they did not measure if there was a change in insulin therapy, and so that may have contributed to improvement in HbA₁C levels. There was also quite a bit of attrition during the study with only 47 of the original 66 participants completing the questionnaires and HbA₁C levels. This study does show some promise for the intervention of using motivational interviewing to improve glucose control, behaviors and emotions, but further studies should be

done controlling for changes in insulin therapy and assessing if attrition of subjects influenced the positive outcome.

Family Behavioral Therapy

Previous studies have assessed behavioral family therapy to improve the relationship between the parent and the adolescent (T. Wysocki, Greco, Harris, Bubb, & White, 2001; T. Wysocki et al., 2000). This trial was to test a modified version of the behavioral family systems therapy (BFST) for diabetes program to see if it was better able to change family conflict, treatment adherence and metabolic control (T. Wysocki et al., 2007). Revisions for this trial included targeting diabetes' specific behavior problems, providing the intervention for 6 months, teaching the parent how to use a behavioral contract, and having parents live like they personally have diabetes for a one week period. The results of this study were from the 18 month follow-up and focused on HbA_{1c} levels, adherence to the treatment protocol, and conflict around diabetes care. Families were randomized to one of three groups – standard care, educational support, and the intervention group receiving the family therapy sessions. HbA_{1c} values at 6 months had decreased for all groups but between 6 and 18 months the two control groups went back to baseline HbA_{1c} values where the intervention group remained low 8.8% vs. 9.5 and 9.6% ($p < 0.001$). Treatment adherence and family conflict measures were not different between groups at 18 months as had been seen in the report after 6 months (T. Wysocki et al., 2008). The benefits of family systems therapy may be most beneficial in improving and sustaining BG control but with treatment adherence and family conflict no longer showing improvement over the control groups it will be interesting to see if the effects on BG can be maintained over time. The strength of this study was it was a randomized trial that builds on previous studies of BFST by now trying to improve adherence to care. One of the biggest weaknesses of this study is that those with lower socio-economic status and those from

single parent homes were most likely to drop out of the study leaving those at lower risk in the study.

A randomized waitlist controlled trial was done using behavioral therapy via the telephone (Lehmkuhl et al., 2010). There were 32 adolescents ages 9-17 and one parent who participated in 3 – 15 minute phone calls per week for 12 weeks. The adolescents who were assigned to the waitlist had baseline assessments, and 1 month after being on waitlist assessments, they were then provided with tele-health. The purpose of this study was to use tele-health behavior therapy for adolescents with T1DM who were in poor control to increase adherence with their diabetes care, decrease the amount of conflict within the family and lower the HbA_{1c}. The measurements that were chosen for the study were to assess diabetes management behaviors, family support, diabetes responsibility, HbA_{1c} levels, severity of illness and response to treatment. Set information was provided during each therapy session to be consistent with all participants and each participant had the same therapist for the entire intervention. The effect of time on HbA_{1c} had no effect ($p=0.03$) as was time by group interaction. When the means of participants who had completed treatment HbA_{1c} was inspected it had decreased by 0.74% compared to the reduction in the waitlist group of 0.09% but this was not statistically significant. Of interest was that the group that received the intervention actually reported an increase in unsupportive care from their parent and a decrease in caring parental behaviors. These two recent studies highlight that even with multiple trials and revisions to change the protocol to improve adherence to care there is still no short term benefit even with intensive family therapy and as seen in Lehmkuhl (2010) the more parents were involved the more the adolescent felt unsupported.

Care ambassadors

A two year prospective, randomized controlled trial was conducted that divided adolescents with T1DM ages 7 to 16 into three treatment groups (Svoren, Butler, Levine,

Anderson, & Laffel, 2003). These groups were a care ambassador (or care coordinator) plus a psychoeducational component (CA+), care ambassador only (CA), or standard multidisciplinary care (SC). The goal of this program was to decrease the acute adverse effects of diabetes including hypoglycemia, severe hypoglycemia, emergency department (ED) visits, and hospitalizations for hypoglycemia or DKA. They also measured HbA_{1c} levels and number of office visits. The results showed that those in the CA+ group had significantly fewer hypoglycemic events (25%), fewer severe hypoglycemia events (60%) and fewer hospital and ED visits (40%), and those in the CA and CA+ groups both had significant increases in office visits when compared to those in the SC group. While those in the CA+ group were 3.4 fold more likely to improve the HbA_{1c} level than those in the other two groups all groups had an increase in HbA_{1c} during the study period. Therefore, providing close contact through a care ambassador along with a psycho-educational component decreased the risk for acute complications from diabetes but did not improve overall glucose control though it did not worsen as much as in the control groups. The design of this study using randomization and a 2 year study period with almost 300 participants was exceptional. Those in the 2 treatment groups were more likely to come to clinic which then raises the question if the intervention was actually effective or just more contact with the clinical team. Those in the intervention may have felt more supported in their care from the design of the study thus leading to improved outcomes. Very few high risk patients were included in this study which also may have affected the outcome.

Conclusion

Despite all that is known about the many issues involved in good diabetes control, adolescents are at a difficult time of their lives and most interventions are not effective in improving glucose control or lowering HbA_{1c} levels. There have been no studies that have assessed what it is actually like for the adolescent to test their blood glucose, give their insulin

injections, follow a diet regimen, and exercise in order to control their diabetes. If the primary focus of research is to improve glucose control, then researchers need a better understanding of what it is like for adolescents to do these tasks necessary for improving glucose control and develop a comprehensive understanding of what this process is really like for the adolescent. Researchers do not have the knowledge about conditions that are present for adolescents who are successful with their diabetes care and conditions that are present for the adolescents who are not successful in performing these diabetes management tasks.

Many studies have been done in which family support, family behavioral therapy, coping skills, problem solving, and quality of life have been examined, along with a number of approaches for education such as care ambassadors, motivational interviewing, and counseling to help influence diabetes management. In addition, family dynamics and conflict have been examined as well. It has been determined that despite frequent, varied and prolonged intervention, improvement is usually only made in the psychological aspects of dealing with chronic illness but not in adherence to the care regimen to improve glycemic control. While this research has been helpful in laying groundwork for understanding diabetes management with adolescents, none have been able to show changes in diabetes control or improved HbA_{1c}'s; none have addressed the relationship of diet, physical activity, medication adherence, and monitoring.

The purpose of this research effort in adolescents ages 11 to 15 years is to gain a greater understanding from the adolescent's perspective of their experiences in living with diabetes and associated challenges and management issues they may face. The conditions related to management behaviors are of primary importance along with providing a greater understanding of the influence of diabetes on relationships with peers, school, and parents. We expect to build a theoretical paradigm that will capture the main categories and moving processes in the experiences of adolescents and provide much needed information and

hypotheses to support interventional design. Greater understanding of conditions related to adolescent management of diabetes (diet, exercise, insulin, and glucose monitoring) and the dynamic moving processes and interface with parents, school, and health care providers will contribute to the design of interventions grounded in the reality of the adolescents experience and may be expected to contribute to more effective intervention design based on grounded hypotheses. The contribution to adolescents with diabetes is helping them to successfully manage their diabetes to prevent short and long term complications and improve their daily health. The contribution to families of adolescents with diabetes is to help decrease the conflict and concern that arises when adolescents are not caring for themselves in a healthy way by engaging their adolescents in performing these diabetes management tasks to maintain good glycemic control. This study is expected to advance nursing science by providing greater understanding of diabetes management for adolescents and by providing hypotheses that may be helpful in the design of research interventions; it may also be expected to contribute to the body of nursing research in chronic illness management.

Chapter 3 – Methods

Research question:

What is the experience of adolescents living with diabetes, issues they face in diabetes management and the relation of diabetes to their developmental life tasks?

Study purpose:

The purpose of this research effort among adolescents ages 11 to 15 years was to gain a greater understanding, from the adolescent's perspective, of their experiences in living with diabetes and associated challenges and management issues they face. The conditions related to management behaviors were of primary importance along with providing a greater understanding of the influence of diabetes on relationships with peers, school, and parents. The researcher expected to build a theoretical paradigm that would capture the main categories and moving processes in the experiences of adolescents and provide much needed information and hypotheses to support interventional design.

Research Method:

Grounded theory (Creswell, 2007; Glaser, 1978, 1992; Glaser & Strauss, 1967), a qualitative method was selected to address this research topic. Grounded theory is the approach most appropriate for this study because: a) it meets the aims of this study, b) the researcher is looking for the conditions under which behaviors occur, and c) the researcher is trying to generate a hypothesis (Annells, 1997a, 1997b; Bowers, 1988; Creswell, 2007; Glaser, 1978, 1992; Glaser & Strauss, 1967; Guba, 2005; McCann & Clark, 2003a, 2003b, 2003c; Richards & Morse, 2007). Symbolic interactionism, the theoretical framework for grounded theory will be discussed in further detail below (Blumer, 1969). The primary purpose of grounded theory is to develop a theory around the social processes that are occurring in a given phenomenon to help explain, predict, and describe those behaviors (Glaser, 1978; Glaser &

Strauss, 1967). This theory is derived directly from the participants' words or 'grounded in data' (Glaser & Strauss, 1967). In creating theory, one is aiming to gain an understanding of the conditions under which behaviors occur; this then allows the researcher to generate hypotheses that may contribute to further interventional research (Annells, 1997a, 1997b; Bowers, 1988; Glaser, 1978, 1992; Glaser & Strauss, 1967; Guba, 2005; McCann & Clark, 2003a, 2003b, 2003c; Richards & Morse, 2007). Most theories developed are substantive theories, or those that discuss or explain just one area of inquiry, rather than a formal theory with broad descriptions that fit multiple group settings (Glaser, 1978, 1992; Glaser & Strauss, 1967).

The researcher was trying to understand more about a phenomenon and what the process was that the participants were experiencing. Understanding more about the steps of the process, when it is most likely to occur, and what happens when it does not occur are key features in developing a theory around this phenomenon under study. Not only focusing on the process but also on the structure and the interactions that are occurring in the social setting are important considerations in a grounded theory study

The grounded theory methodology includes purposeful sampling initially, followed by theoretical sampling to saturate codes that are identified (Glaser, 1978). The researcher poses a set of general questions, or a general question related to the research aim, and then introduces probes more specific to the research question if items of interest are not addressed. Throughout the study, the researcher asks the general questions, introduces the specific probe questions, and adds other questions as codes are identified to gain further information about the emerging codes. Interviews are coded line by line using the gerund (-ing) codes to capture the moving processes (Bowers, 1988; Glaser, 1978). Code cards are created in which the code is listed, defined, and examples from the data and hunches about relationships among codes are recorded. Memos are also written about these hunches and codes in a journal. Codes are sorted into related clusters and conceptual categories and are labeled theoretically (Glaser,

1978). This is called second line coding when clusters are identified. Conceptual codes that use the exact words of the study participant may be used in second line coding. Patterns and relationships are noted, and much like working a puzzle, a theoretical paradigm is built. Finally, codes that do not appear to be part of the central paradigm are set aside for further study. This is referred to as delimiting the codes.

The philosophical perspective of the researcher is basically described as ontology, or what the researcher believes about the reality of what can be known. The second piece of this perspective is the epistemology, or what is the relationship between what is known and the researcher. The post positivist view that reality can be known even if it is not a perfect reality, and that when one asks more questions reality will come out as the study progresses, most closely matches the views of this researcher (Guba, 2005). This post positivist view fits most closely with classical grounded theory.

Using in- depth interview techniques with open ended questions is important from the perspective of classical grounded theory. This approach will allow the information to emerge from the participants' views. The core theme, the basic processes, as well as the hypothesis that will form the theory, will be derived directly from the information obtained from the study participants' interviews.

Symbolic Interactionism

The classical form of grounded theory described by Glaser and Strauss (1967) has its theoretical roots in symbolic interactionism. Blumer (1969) is the primary author who has contributed to the development of symbolic interactionism in the post war Chicago style (Bowers, 1988; Musolf, 2003). There are three primary concepts about social interaction: a) self, b) world, and c) social action (Blumer, 1969; Bowers, 1988). The self is how one perceives self based on information from the environment. This is about how one acts based on the meaning they derive from objects or people that are around them (Blumer, 1969). The world is

the social world or how the world is interpreted or experienced by those around it. The meaning of the object comes from how others act towards that object or the people around them (Blumer, 1969). The importance of this concept is that “what is reality for one person is different from the reality of another person” (Bowers, 1988, p. 39). Social actions are formed by the interaction of the person in the social world, what one learns from observing others, how one is able to understand those actions, and the meaning that is derived from them (Blumer, 1969; Bowers, 1988; Musolf, 2003).

Symbolic interactionism views meaning in different ways than other traditional views. Symbolic interactionism “sees meaning as arising in the process of interaction between people. The meaning of a thing for a person grows out of the ways in which other persons act toward the person with regard to the thing.” (Blumer, 1969, p. 4). These meanings help the person to guide his or her actions and conduct, how one interprets, communicates and handles a variety of situations in which he or she finds him or herself (Blumer, 1969). Understanding these concepts is important in the process of grounded theory as one seeks to discover the reality that exists for study participants. It is imperative to understand that by looking at the world in which people live one can begin to examine this reality and it is not the method of grounded theory that defines reality. Grounded theory becomes a tool in order to study and examine this world to begin to understand the reality or meaning of others (Blumer, 1969).

Study questions:

The initial study questions for the interview guide are based on the study aims and in this study included the following:

1. Let’s discuss your experiences of living with diabetes.
2. Now let’s talk more specifically about taking care of or managing your diabetes. Can you tell me about that? Probes that may be used include: a) What is it like for you to take care of your diabetes? b) Tell me more about taking your insulin and testing your blood

sugar. c) What do you have to do to keep your blood sugar balanced? d) How do you manage your diet? e) How do you manage exercise? f) What, if any, challenges have you experienced? g) What strengths do you have for this situation?

3. Subsequent interviews will start with these initial questions and as codes are identified, additional questions will be included at the end of the interview to further saturate emerging codes. In some cases, an interview might be about only one code as appropriate.
4. Additional probes and questions were created after the first set of three interviews. These questions were submitted and approved to the University of Washington IRB and MultiCare IRB prior to additional interviews. (See Appendix H). These were created to obtain additional information on topics brought up by the adolescent's during those first interviews. These additional probes and questions included: a) When you heard you had the diagnosis of diabetes, tell me about that time. Tell me about learning about your diabetes. b) Talk about transitioning to self-care (or taking care of diabetes more by yourself). What pieces are you doing, what pieces are your parents doing (re: blood sugar, insulin, carbs, exercise, other). c) People talk about goals they have (how to be healthy or in control) with the blood sugar, insulin, carbs, exercise and other, tell me about that. d) Tell me about your experiences in balancing your blood sugar, your insulin, carbs, exercise and anything else about balancing or staying in control. e) Some people talk about coming to a place that says "I can take care of my diabetes", tell me if you have come to that place and what that is like. f) Tell me about any special routines or schedules that you have for your diabetes. g) People talk about their emotional experiences with having diabetes (such as being overwhelmed, being scared, being worried, etc.), talk about your experiences with any of these feelings or others about having diabetes and please give me an example. h) Tell me about your relationship with

others. i) People talk about the support of friends and how they help to remind them, stand up for them or help them to not feel different, tell me about that. j) Talk to me about your parents and your diabetes. k) Talk to me about other people you are in contact with (such as teachers, coaches, and other classmates) and your diabetes.

Study Sample:

The sample consisted of early adolescents ages 11 to 15, who identified as Caucasian and had Type 1 diabetes mellitus (T1DM). The researcher aimed to achieve a balance in representation in age and gender when selecting the study sample. This age group of adolescents was selected for the following reasons: a) it is expected that by this age the adolescent is cognitively able to express his or her thoughts in words and to respond to questions; b) this is an age group that is experiencing developmental transition from parental care to more self-care, and c) because this is the age group in which the decline in blood glucose testing and insulin administration is at its peak with resulting poor glucose control and increased hospitalizations for diabetic ketoacidosis (DKA).

The potential population of study participants with T1DM at the chosen institution was over 1000 that are under age 18, and it was expected that there might be at least 250 adolescents from which to select this sample. The ethnic mix of this clinic was primarily Caucasian. It was also recognized that diverse populations might present issues specific to their culture and therefore they might require more in-depth consideration and research focused on each specific culture. Thus, at this time the researcher elected to conduct this study with Caucasian adolescents only. Fifteen participants were needed to achieve code saturation.

Inclusion criteria:

1. Participants had a diagnosis of Type 1 diabetes and were on insulin therapy.
2. The study participants were diagnosed with diabetes for at least six months by parent report prior to study participation.

3. Participants and their parents were both able to read and speak English.
4. Adolescent identified as Caucasian by parental report.

Exclusion criteria:

1. Parental report of other diagnosed medical or psychological conditions except controlled hypothyroidism.
2. Parental report of a clinic visit with this researcher as the medical provider during the past year.
3. Emotional or mental disabilities that would prevent them from understanding or being able to provide an interview by parental report. Specific questions that were asked of the parent included the following: a) Has your adolescent been diagnosed with a mental health condition or been under treatment for a mental health condition in the past year such as depression, attention deficit disorder (ADD), schizophrenia, bipolar, anxiety or any other mental health conditions? If the answer to this question was yes, then the adolescent was excluded from the study; b) Does your adolescent have any mental health or emotional concerns that have not been diagnosed but that you feel would prevent him or her from being able to provide an interview for this study? If the answer was yes to this question, then the adolescent was excluded from the study; c) Is your adolescent currently in a special education program (for children with learning disabilities or extra help at school) or has your child ever been placed in special education due to learning challenges? If the answer was yes, the adolescent was excluded from the study (see Appendix A).

Research Protocol:

In discussing the research process, the researcher will begin with a discussion of the sampling approach and will provide an outline of the total research protocol. This will be followed by an in-depth discussion of each step in the protocol.

Sampling/Coding and Analysis Overview

Sampling, coding and analysis were done simultaneously. The study began with a purposeful sample. Three study participants were selected for this first sample. The parents and the adolescents were contacted to obtain the consent/assent to be included in the study. A balance of gender and age was sought. One anchor interview was done with each of these first study participants. Interviews of about one hour were digitally audio recorded, and the interview guide questions were asked.

Study participants were told that they might be contacted again for additional interview as data was analyzed. They also were told that they could have 48 hours to reflect on what had been said, and they could contact the researcher to delete any portion of the interview they may wish they had not said. The researcher's phone number was provided for this call. These three interviews were coded (first line) using a gerund coding process (-ing words). Gerund codes were used to look for the social processes or the behaviors that were occurring. The chair of the dissertation committee, who has extensive experience in grounded theory, also coded these interviews independently. The researcher then completed code cards which contained the following information for each code: a) the gerund code taken from the study participant words, b) quotes in which the code appeared in the data with subject number and page numbers, c) a definition of the code, d) notations about the conditions under which the code occurred or not, and e) hunches about relationships among codes. The researcher met every two weeks and had additional communication by email and telephone with the dissertation chair in this early stage of the research to review the codes, compare the coding process and together identified

additional probes to saturate codes and considered the next interviews (theoretical sample) that were needed for code saturation. The researcher kept a detailed audit journal from the initial recruitment work and throughout the study. Three more interviews were conducted and analyzed using both first line and second line (theoretical) coding. Additional interviews were conducted using the full interview guide and the last four interviews only used specific probes for one or two categories that needed additional data saturation. Sampling continued until all the categories were saturated, that is that there was no new information arising, there was a clear understanding of the relationships between the categories, and the social process was fully defined (Glaser, 1978; McCann & Clark, 2003a). Clusters of codes were sorted and the paradigm was constructed using this second set and ongoing interviews.

As the study progressed with the coding, sorting and determining the next samples, and probe questions, the dissertation committee was engaged at the end of the first three interviews to review findings to date and the initial study model as well as to review the additional probes and questions that were going to be asked. They reviewed cluster codes and the initial study mode, and provided feedback and suggestions about the direction of the study, and offered suggestions and feedback about the new probes and questions. In this way the full expertise of the dissertation committee was utilized in this research. Throughout the process, the researcher was asking, "What is the major task the study participants are trying to address?" Finally as the paradigm was constructed, data that was not a part of the central theme was set aside for a future study. The constructed paradigm, along with the integrated codes and the audit journal were presented to the dissertation committee for further feedback. To address rigor through credibility, fittingness, and auditability, codes were discussed with some adolescents to obtain feedback about the extent to which the information reflected their experiences. One adolescent focus group was also conducted to further gain adolescent feedback on the paradigm and codes. The focus group was also digitally audio recorded.

Finally the results of the research were integrated into the findings section of the dissertation and related to the original literature review as well as to additional literature on normalizing to show the extent to which this research has contributed to the advancement of the science.

Recruitment and Sampling

Recruitment for the study was done with flyers posted at the *Mary Bridge* pediatric endocrinology clinic which is part of *MultiCare*. From work with this clinic, it was known that it was possible to conduct this study at this institution. A Memorandum of Understanding (MOU) was negotiated with the clinic, which outlined the expectations of the clinic and the researcher in this study, as well as the use of findings in presentations and publications. The flyers briefly described the study and provided contact information. A letter was also mailed by *Mary Bridge* to all eligible families of patients with Type 1 diabetes seen in the pediatric endocrinology clinic in the target age range apprising them of this study and informing them of the steps they should take if they were interested in participating. The institution generated a computer generated mailing list of labels for all eligible subjects. Clinic staff affixed these mailing labels to stamped, stuffed envelopes, provided by the researcher for this mailing. Parents of appropriate aged patients were also given a handout by the clinic nurse or the medical assistant at their clinic visit to see if they were interested in talking to the researcher about having their adolescent participate in this research study. This was done by the clinic nurse and the medical assistant to avoid the possibility of coercion since the researcher was a nurse practitioner in the clinic. If the parents were interested in having their adolescent participate they were asked to contact the researcher directly. When the parent called with interest about the study, the researcher discussed with them the purpose for doing this study (the researcher used an outlined script for this discussion to be sure that the researcher was consistent in the information that was provided to each parent – see Appendix F) and obtained verbal consent to answering questions if their adolescent met eligibility criteria. The researcher then obtained verbal (by phone)

parental consent and obtained their contact information for further communications about the study.

Parents who expressed interest in having their adolescent participate in the study were given a brief questionnaire on the telephone to make sure that their adolescent met eligibility criteria for being in the study (see Appendix A). For those adolescents who met eligibility criteria by the parent answering yes to questions 1-9 (and only have hypothyroidism or no other conditions) and no to remaining exclusion questions, the researcher then told these parents that while their adolescent did qualify for the study, not all eligible adolescents would be needed. Parents were then contacted later to obtain their consent and the adolescent's assent when they were chosen to participate in the interview. Participants were given a \$25 gift card for their time after the interview.

Interviewing process

Once study participants were identified, the researcher described the study and obtained parent (or legal guardian) informed consent. The adolescent assented to participating in the study. The parent was asked to complete basic demographic information (see Appendix B). The researcher personally performed all data collection and interviews and conducted the focus group related to assuring confirmability, trustworthiness, and dependability. Data collection was done by digitally audio recording each interview session for clarity and transcription purposes. Two recording devices were used at each interview to make sure there was not battery failure or machine malfunction during the interview or transcribing process to prevent loss of data. Interviews were held in the study participant's home in a quiet private place where there were not disruptions. The interviews typically lasted between 50 to 70 minutes.

Interview recordings were then transcribed verbatim onto a typed word document by the researcher soon after the interview took place and then reviewed for accuracy. The data was then read and reread to identify codes. Data was hand analyzed by the researcher without the

use of computer software programs. After three initial interviews the major codes and categories become apparent. Interviews were done until the researcher felt there had been a saturation of codes and no new topics were being addressed and no further information was being obtained. Decisions on how to proceed were made as data was examined and interpreted after each interview.

Data Analysis

The goal of the analysis in grounded theory is to fracture the stories of each individual study participant and integrate into a conceptualized paradigm story representing the major story for all. The first step was to engage in “first line,” or “open ended” coding, which was to fracture the story of each adolescent to gain insights into the behaviors and moving processes that were occurring. The second step was “second line,” or theoretical coding, where one clustered the code groupings; the language for these grouping did not always actually appear in the interview. In the third step the emerging codes and categories were constantly compared to codes and categories that had already been identified. This is called constant comparative analysis and is sometimes referred to as axial coding. This process of constantly comparing new data with previous data contributes to the understanding of how the categories relate, as well as the determination of the core phenomenon. In the fourth step these codes were linked to create the paradigm. Throughout this process, the interviews were used to further provide detail about saturation of the codes. During the fifth step the theory was delimited by setting aside the codes that were not part of the major story. The ultimate product is a well-integrated paradigm that fully describes the codes, their relationships, the moving processes, and defines the major task the participants are aiming to achieve and the related hypotheses about conditions that may support movement in the processes.

Process of data analysis

STEP 1 -First line coding/open coding

Open coding is considered to be the first stage in the constant comparative method. Open coding is done looking for categories and their characteristics (when they occur and when they do not occur). It is done by carefully examining the data for gerunds (-ing words such as doing, eating, and playing) that describe actions being taken. The researcher's aim was to define the code, extract rich examples from the data, and identify conditions under which the actions occur or did not occur and consider the relation to other identified codes. Coding stimulates ideas, and coding was interrupted to write a memo as these ideas occurred. The codes that were derived were sorted into categories of similar codes and an understanding of the conditions under which behaviors occurred were noted.

Each interview may provide ten or twenty new characteristics about the categories. There were different ideas and perceptions by different study participants about how the behavioral processes occurred. These characteristics lead to new theoretical ideas, generated more interview questions, and defined the selection of new study participants to fully understand these moving processes. Most substantive theories only have 10 to 15 codes that are most relevant to the theory even though more are generated during the coding process. This is because the initial first line open coding is grouped into second line codes and clusters of related codes.

Coding was done right on the margins of the transcript and was then transferred to index cards with each code being separated. An additional sheet of paper was created with the details of each code card and the index cards only contained the code heading for sorting purposes. This process allowed for sorting and flexibility when comparing the codes with data as well as later with the memos. Code cards contained the gerund code, examples from the

data, conditions under which the behaviors occurred and did not occur, relations to other codes and hunches about the overall process.

During step 1 (first line coding) the researcher looked at the transcribed data line by line to identify codes and those were noted in the margins of each transcription. The codes were then listed on code cards with examples from the participants listed and identified by study participant number and page number to track them. On these code cards the researcher also described the conditions under which this behavior happened and when the behavior did not happen.

Memo writing

Memo writing, not to be confused with journaling, was done to track the research process and provide an audit trail to capture general thoughts and relationships among codes. Memo writing was done throughout the interview process, during coding, and during data analysis. Memos were used to track thought patterns, emerging ideas about the categories and codes, and thoughts about the emerging theory. The researcher used memos to document information about study participants that were chosen, how the interview questions were changing and why, and beginning hypothesis that arose, as well as hunches about code relationships. Initial memos were about the dimensions of the categories that were being discovered, while later memos consisted of comparing the categories and the relationships of categories to each other (Glaser, 1978). This memo writing helped the researcher identify preconceptions but yet enabled the researcher to use that knowledge in the end during the data analysis phase of theory building. This knowledge, referred to by Glaser and Strauss (1967) as theoretical sensitivity, is the ability of the researcher to have “insight, understand, and give meaning to the data, and to detach the relevant from the irrelevant” (McCann & Clark, 2003a, p. 10). The memos written provide a clear record of what the researcher was thinking during the process of interviews and coding. Memos helped to clarify how patterns emerged as the theory

evolved from the data, and showed the directions taken by the researcher during questioning. During constant comparative analysis, a new idea may conflict with previous ideas. Creating memos helped in identifying any conflict and sorting them out.

Memos were dated, and some were very brief or longer depending on how much the researcher is exploring theoretical ideas. This memo record can be used to help reconstruct the thinking process that occurred during the development of the theory. When writing memos they were given a title which can be either the category it falls under or the property of the item. This allowed the memos to be sorted later by category or topic.

The researcher wrote memos throughout this coding as ideas came to the researcher about the identified code or how it relates to other codes. These memos were kept in a journal. At the end of Step 1 and weekly or after new interviews were completed. The researcher provided the dissertation committee chair with a copy of each de-identified transcript. The dissertation chair did independent coding of some of the transcripts. The researcher and the dissertation chair met to discuss the codes derived, and the committee chair assisted the researcher in filling out the code cards and discussed differences in how the transcriptions were interpreted. Together the dissertation chair and the researcher moved through the data analysis section to complete the theory development.

In addition the researcher kept an audit journal in which the researcher recorded each step of this journey including dates of interviews, transcribing, as well as the coding and analysis processes. This journal provides a clear description of each action that has been taken in this study. Recording helps provide the detail that would allow another researcher to replicate the process (Chiovitti & Piran, 2003; Lincoln & Guba, 1985).

STEP 2 -Second line coding/theoretical coding

Theoretical coding was done once the researcher moved to the conceptual level of thinking and was trying to weave the codes derived from the participants into cluster categories

of codes that may not be in the actual wording of the data. Gerund code wording was still used. During this process, the researcher took the data that was analyzed step by step during the open coding and began sorting the codes into groups. These groups had specific properties or dimensions that helped to differentiate them from other groups and sometimes were placed under more conceptual or abstract terms.

During Step 2, (second line coding), the researcher sorted the codes identified in the “first line” coding by sorting them into groups that seemed to have similar properties or characteristics. This second line coding provided further fracturing of the data, integration and restructuring of the data into a conceptual story. The information written in the memos was included in analyzing and comparing the categories during this stage of data analysis.

Constructing the theoretical paradigm and delimiting the theory

Step 3 - Constant comparative analysis (Axial coding)

Constant comparative analysis is the foundation of how the researcher analyzes the data that is obtained (Glaser & Strauss, 1967). This form of analysis is integral to the researcher in using ones knowledge to form an understanding of what is going on in the situation and seeking the “characteristics, conditions, causes, antecedents, and consequences of events or responses as ways of drawing them together in an integrated theory” (Richards & Morse, 2007, p. 61). By constantly comparing the data to new data that arises, one will be able to see the categories of the social process that is occurring as well as the properties that are part of that category (Glaser, 1978; Walker & Myrick, 2006).

During Step 3, (constant comparative analysis), the researcher began working with the codes and categories that had been derived during open coding and second line coding. The first three interviews were coded; code cards created, and further code questions identified. Engaging in this level of analysis enabled the researcher to delineate categories and gain

greater insight into the major task the adolescents were addressing. The researcher then began to identify where there were gaps in the theory and code categories. At this point, additional interviews were conducted to gain further information about codes, emerging categories and to identify gaps in the paradigm and the need for additional information to saturate codes and complete the paradigm. Questions were created to obtain information specific to the categories in which there were gaps in understanding. After the first three interviews had been coded and code cards created, the process of interviewing, probing and analyzing, as in the analysis of the first three interviews, continued. The researcher continued with more interviews until each category was fully explained or saturated, and the researcher understood how each were fitting together, how the process was occurring, and no additional information was needed. Throughout data analysis the researcher was asking: a) How does this fit?, b) What processes allow this to occur?, c) When is this event likely to not occur?, d) What is happening in the data?, e) Is this conceptual label or code, part of the participant's vocabulary?, e) What is the context where this code or action is used?, f) Is this code related to another code? and g) Are there other codes that reflect similar patterns? These questions helped the researcher to understand the properties and dimensions of the emerging theory and to form more complete and precise explanations about the phenomena under study. During this process the researcher was looking at how the categories linked together. As the linkages were determined categories were collapsed/integrated to form more abstract or general categories.

Step 4 - Building the paradigm

The researcher then built the paradigm by linking the codes and clusters of codes to find the relationships among and between these categories by defining the conditions, context, intervening conditions, the action or interactional strategies, and the consequences that were occurring. As data was integrated the main goal was to identify the major task for the study participants and to determine the relationships among the codes. The researcher then began to

use selective coding to integrate and refine the theory. During the integration process the core category was identified and the subcategories were then linked with the core to outline and explain the theoretical paradigm. The theoretical paradigm was constructed throughout the study in that codes were identified, clustered, and linked to each other to provide a conceptual fractured and integrated story about the major task the adolescents were experiencing, and conditions under which behaviors occurred and the moving processes that were present. The final paradigm is the end product of this work, in which the major task the adolescents are addressing is discussed, the flow of the process described, the hypotheses shown, as well as the relationships among codes.

During Step 4, (building the paradigm), the researcher began further integrating information and noting their relationships. The researcher utilized the information obtained, along with memos that had been written throughout this process, to finish building the paradigm and delineating the hypotheses generated. As the relationships among the categories became more clear the categories became more compact, and the major task was identified, and then subcategories under that task as well as the relationships between each of these categories was completed in order to explain what was happening during this process.

Step 5 - Delimiting the theory

Delimiting the theory occurred over time as little new information arose and current information was consolidated. Some of the categories or properties that were not relevant to the overall theory were eliminated.

During step 5 (delimiting the theory) the researcher found that some of the categories that were first thought relevant to the major task and the paradigm about this task no longer fit or seemed to be a part of the overall paradigm being formed. As codes were linked, clusters of conceptual codes created, and the conditions under which behaviors occur determined, hypotheses become clear and were articulated about the conditions under which behaviors

occurred. In this stage of delimiting the theory, determining the relationships among the codes contributed to a greater understanding of the processes that were occurring and the major task the adolescent was addressing. The codes that were not needed were set aside but may be used in a future study.

Assuring rigor through credibility, auditability, and fittingness

Glaser (1992) discussed the key points of addressing theory validity and noted that judgments about fit, relevance and how it works are important. In this respect he noted that the theory must fit the data. By this he meant that the categories must be directly relatable to the data. The categories work because they are able to explain the process as it happened. Relevance happens by allowing the core categories and processes to emerge from the data. Glaser and Strauss (1967) stated that the best way to judge if the theory is credible should be based on the process of how the theory was generated by explicitly stating how the data was collected, coded, and analyzed to generate the theory as well as how others understand the theory presented. Providing a journal assures an audit trail to assure credibility. An audit journal was used in this study.

The terms validity and reliability are most appropriate for quantitative research where the aim is to test theory and generalize to populations. In qualitative research, the aim is to describe, build theory, generate hypotheses and gain understanding of meaning, thus the terms confirmability, trustworthiness, credibility, and dependability are most appropriate (Guba, 2005; Lincoln & Guba, 1985). Since the researcher is seeking to know the truth about the research findings and feel confident that these findings are trustworthy, one must look at the method of inquiry that one has used as well as how one has interpreted the results (Guba, 2005). Beck (1993) expanded on information first presented by Lincoln and Guba (1981) defining three criteria for evaluating qualitative research. These criteria are credibility, fittingness and auditability. Credibility “measures how vivid and faithful the description of the phenomenon is”

(Beck, 1993, p.264). Fittingness assesses how the hypothesis that is developed work in other situations (Beck, 1993). Auditability is defined as the ability of other researchers to follow the decisions made by the researcher in various stages of data analysis (Beck, 1993). Chiovitti and Piran (2003) believed that while these criteria may be helpful to qualitative research in general they wanted to make it more specific. They noted that it is best to have clearly defined standards for each type of qualitative inquiry and developed 8 standards to measure the credibility, fittingness, and auditability of a grounded theory study.

The standards defined for credibility include letting participants guide the inquiry process, checking the theory that was generated against the meanings the participants used, use of the actual words of the participants, and a clear explanation of the researcher's personal views and insights that can be explained through the use of a journal and use of the literature review. The standards recommended for assessing auditability include specifying the criteria that was built into the researchers' thinking and defining how and why the study participants were selected. The standards suggested for assessing fittingness include clearly defining the sample, the setting and the level of theory that is generated as well as fully describing how the literature relates to each category in the final theory (Chiovitti & Piran, 2003).

The researcher used the standards suggested by Chiovitti and Piran (2003) to evaluate the rigor of this study. The researcher included information on credibility, auditability and fittingness to show that each step was followed to enhance the rigor of the methods that the researcher used in this study through journaling, documentation of the final product findings and in the final discussion in which the researcher related the initial literature review and additional new literature review to the paradigm developed in this study.

Credibility

Credibility in this research study was maintained by the use of memos in a journal, as well as through an audit journal as described above, to make sure that one is able to validate

how the researcher proceeded through the study not only in his or her thoughts but in maintaining the voice of the research participant throughout the research process. The researcher also re-interviewed some of the participants, discussed codes and the study paradigm and gained their feedback on the extent to which the paradigm fit with their experiences. The researcher also conducted a focus group of participants for feedback at the end of the data analysis to review the paradigm and codes. The researcher discussed how the literature was used at the beginning as well as incorporating a second literature review at the end of the study to show where these findings fit with current knowledge in the literature.

Auditability

Auditability was shown by the ability of another researcher to follow the audit or decision trail that the researcher used during data collection and data analysis. The researcher did this through the use of the journal and detailed memo writing as described earlier in this section. The journal described the thinking that flowed through the process and how the categories were developed based on the words of the participant. By using set questions for each interview and showing how those questions changed during theoretical sampling as well as questions the researcher asked during data analysis is defined. The selection of study participants and why they were chosen was clearly defined as well as when data saturation occurred.

Fittingness

Fittingness is sometimes referred to as transferability, and this shows how well the research findings will be able to apply to others who may be in a similar situation. The researcher showed fittingness in this study by clearly describing the sample and their characteristics (see Appendix B) as well as the setting from which these participants were chosen. The researcher then defined the level of the theory that was generated from this study so that readers were clearly informed about the scope of this theory. In the second literature review the researcher linked any existing research to the categories in the final theory. The

researcher then showed the similarities in previous research findings with the findings from this study.

Human subjects

The study protocol was approved by the graduate school at the University of Washington and submitted to the Internal Review Board for study approval. Approval was obtained from the administrators at Mary Bridge/MultiCare to conduct the study in that facility and the approved University of Washington IRB protocol was submitted to MultiCare IRB for their approval. A MOU was negotiated to delineate the approach to approvals of study related presentations and publications. Consents were signed by the parent. Assents were signed by the adolescent's for participation in the study.

Each study participant was assigned a numerical ID number. That ID was linked to their identifying information and kept in a separate locked file from any other study information. Only the researcher had access to this identifying information. The study recordings and the transcripts only had the numerical ID on them. The audio recordings were only accessed by the primary investigator in order to do the transcription. When the transcriptions were completed and reviewed the digital audio recordings were deleted. Printed data was kept in a locked storage container and transcribed data was password protected on the computer. Study participant names and contact phone numbers were retained until study data collection was completed in case the study subject needed to be re-interviewed or were part of the focus group. The study participant names and phone numbers were destroyed by placing them in the locked *MultiCare* secure shredding bins once all study data was completed. The transcriptions will be kept for no longer than 5 years and then destroyed by placing them in the locked secure shredding containers at *MultiCare*. No one other than the dissertation chair will have access to these transcriptions. The dissertation chair has completed IRB training and HIPPA protocols

through the University of Washington and will not have any access to identifying patient information only the de-identified transcribed interviews.

CHAPTER 4 – FINDINGS

The purpose of this chapter is to present the research findings from the study “Adolescents’ Experiences with Type 1 diabetes ages 11-15”. The purpose of this research with adolescents ages 11 to 15 years was to gain a greater understanding from the adolescents’ perspectives of their experiences in living with diabetes, and associated challenges and management issues they face. The research questions were: 1) Let’s discuss your experiences of living with diabetes. Probes used include: a) when you first heard the diagnosis of diabetes, tell me about that time, and b) tell me about learning about your diabetes. 2) Now let’s talk more specifically about taking care of or managing your diabetes. Can you tell me about that? Probes that were used include: a) What is it like for you to take care of your diabetes? b) Tell me more about taking your insulin and testing your blood sugar. c) What do you have to do to keep your blood sugar balanced? d) How do you manage your diet? e) How do you manage exercise? f) What, if any, challenges have you experienced? g) What strengths do you have for this situation? h) Talk about transitioning to self-care (or taking care of diabetes more by yourself). What pieces are you doing, what pieces are your parents doing (re BS, insulin, carbs, exercise, other), i) Some people talk about things being hard. How do you define hard, what makes it hard (covering BS, insulin, carbs, exercise, other), j) People talk about goals they have (how to be healthy or in control) with their BS, insulin, carbs, exercise and other, tell me about that, k) Tell me about your experiences in balancing your BS, your insulin, carbs, exercise and anything else about balancing or staying in control, l) Some people talk about coming to a place that says “I can take care of my diabetes”, tell me if you have come to that place and what that is like. 3) Tell me about any special routines or schedules that you have for your diabetes. 4) People talk about their emotional experiences with having diabetes (such as being overwhelmed, being scared, being worried, etc.), talk about your experiences with any of these feelings or others about having diabetes and please give me an example. 5) Tell me about your

relationship with others. A probe that was used was: People talk about the support of friends and how they help to remind them, stand up for them or help them to not feel different, tell me about that. 6) Talk to me about your parents and your diabetes. 7) Talk to me about other people you are in contact with (such as teachers, coaches, and other classmates) and your diabetes. This chapter starts first with the characteristics of the participants, then the presentation of the data analysis, followed by the summary of findings.

The substantive theory developed was about how the adolescents with Type 1 diabetes normalized their life during the pubertal years while they were transitioning to independence. Included in the analysis are the relationships between codes, the axial codes, the categories and subcategories derived from the data, and the major task for each axial code. The conceptual codes and the paradigm and hypotheses that emerged during the evaluation of these data are also discussed. This discussion of the data focused on understanding the major task of the adolescents during each phase of their journey, the codes and conditions that occurred under each phase, as well as the behaviors or actions the adolescents took throughout their journey. Quotes from the participants are included to explain each concept and help the reader understand how the paradigm was created from the data.

Characteristics of the Population

The study initially began with a purposeful sample of three adolescents. Initial coding and data analysis was completed, and then theoretical sampling was done to secure the rest of the sample. Theoretical sampling was done to saturate codes. A total of 15 interviews were done for this study from 11 participants. Initial interviews of the 11 participants were done in their homes, and follow-up interviews of 4 of the subjects were completed on the phone. Adolescents ranged in age from 11 to 15 (mean = 13.9). All the adolescents had Type 1 diabetes and had been diagnosed longer than 6 months. Adolescents who participated did not

have any other conditions besides Type 1 diabetes, except one who had controlled hypothyroidism, and all were on insulin therapy using sub-cutaneous injections or the insulin pump. The sample included three boys (27.3%) and eight girls (72.7%). All subjects were identified by their parents as Caucasian, and both the parents and the adolescents read and spoke English fluently. Participants had not been seen by the researcher for their diabetes care for the past year. No adolescents were in a special education program at school nor had they been diagnosed with a mental health condition, or were they under treatment for a mental health condition during the past year. The adolescents had an average parent reported HbA₁C of 8.2% (range 7.2% – 9.2%, median 8.4%). All study participants attended school. The participants were from Western Washington in the United States of America. See Appendix J for table of characteristics of population including family income and educational status.

Grounded Theory Analysis

In this study a major task the adolescents addressed was '**normalizing my life with diabetes during adolescence**'. During this journey one will see the actions that adolescents take as they attempt to normalize their life and attain independence in their care. One will also be able to see the conditions that allow this process to occur, barriers for when it does not occur, and some of the emotions that are part of this journey during adolescence. The theoretical findings from this grounded theory study are found in the theoretical model of '**normalizing my life with diabetes during adolescence**' (see Figure 1). The major axial codes are the actions the adolescents take to manage their diabetes. The theoretical model of normalizing tasks will be discussed during each phase. The normalizing codes are the major tasks that adolescents are achieving in the process of managing their diabetes. This model includes six major axial codes and many sub-codes which will now be discussed. The axial codes will be described as phases and include the following: a) remembering the beginning of the journey, b) balancing blood sugars/preventing a crisis, c) integrating diabetes into the world outside the home, d) moving the

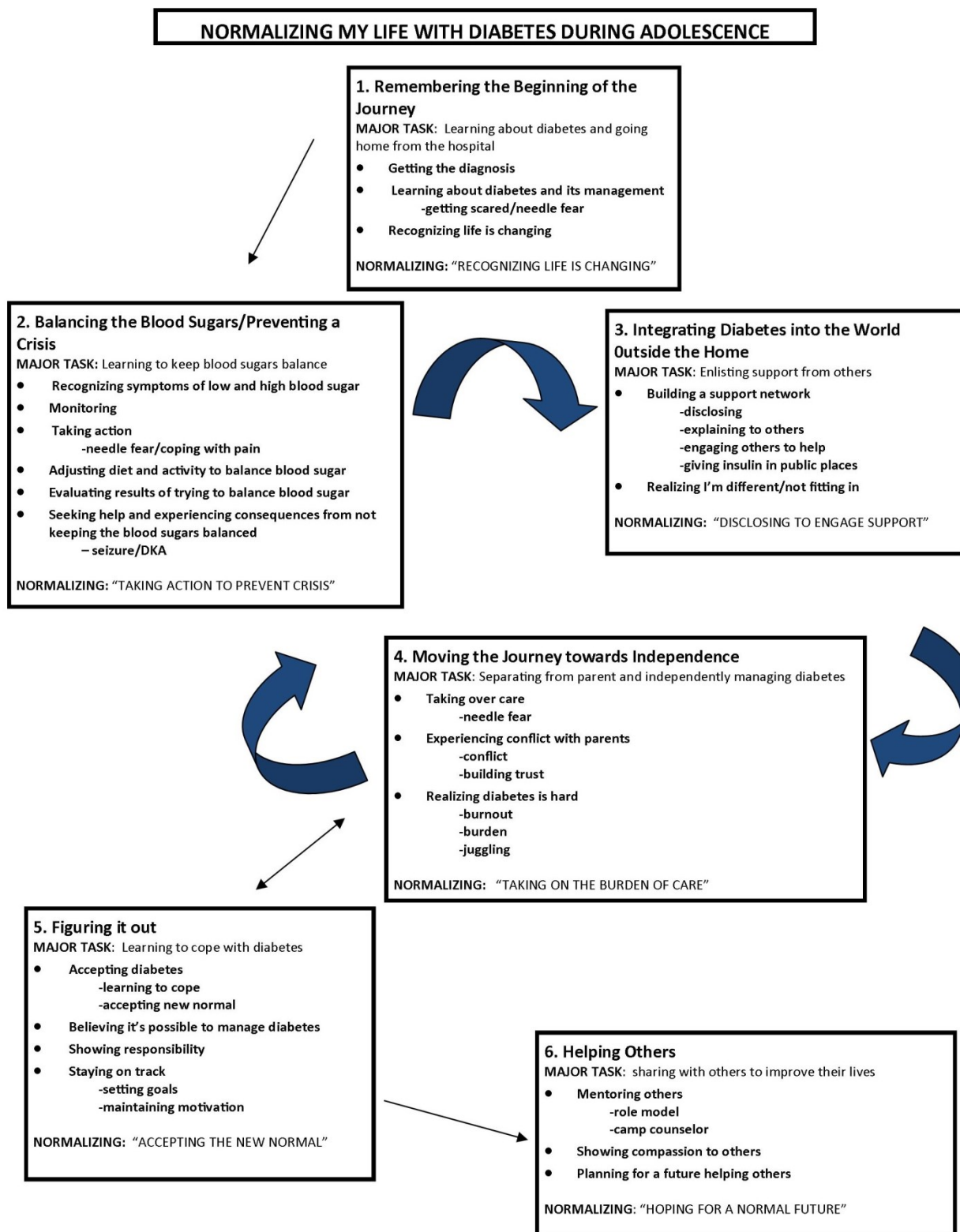


Figure 1. "Normalizing my life with diabetes during adolescence": A summary of operational codes, and conceptual codes of the model

Phase 1. Remembering the Beginning of the Journey

- 1.0 Getting the Diagnosis**
 - 1.1 Realizing you are sick
 - 1.2 Going to the doctor or emergency department
- 2.0 Learning about Diabetes and its Management**
 - 2.1 Reading.
 - 2.2 Learning from others.
 - 2.3 Practicing skills.
 - 2.4 Demonstrating how to care for self.
 - 2.5 Asking the doctors.
 - 2.6 Learning quickly.
 - 2.7 Getting scared.
 - 2.8 Experiencing feeling alone.
 - 2.9 Experiencing denial.

3.0 Recognizing My Life Is Changing

Phase 2. Balancing Blood Sugars/ Preventing a Crisis

- 1.0 Recognizing Symptoms of Low and High Blood Sugar**
 - 1.1 Recognizing symptoms of low blood sugars
 - 1.2 Recognizing symptoms of high blood sugars.
- 2.0 Monitoring**
 - 2.1 Testing Blood Sugars.
 - 2.2 Testing ketones.
- 3.0 Taking Action**
 - 3.1 Treating low blood sugar
 - 3.2 Treating high blood
- 4.0 Adjusting Diet and Activity to Balance Blood Sugars**
 - 4.1 Adjusting Activity
 - 4.2 Adjusting diet
- 5.0 Evaluating Results from Trying to Balance Blood Sugars**
 - 5.1 Assessing effects of low blood sugar treatment
 - 5.2 Addressing effects of high blood sugar treatment
- 6.0 Seeking Help and Experiencing Consequences**
 - 6.1 Experiencing a seizure/severe low BS
 - 6.2 Experiencing ketones/Going to the hospital in DKA
 - 6.3 Seeking assistance from others

Phase 3. Integrating Diabetes into the World Outside the Home

- 1.0 Building Support**
 - 1.1 Disclosing/Not Disclosing.
 - 1.2 Teaching and Explaining
 - 1.3 Answering questions
 - 1.4 Engaging Others to Help
- 2.0 Realizing I'm Different**
 - 2.1 Feeling like you don't fit in/have friends

Table 1—Phases with codes and subcodes

Phase 4. Moving the Journey Towards Independence

- 1.0 Taking over care**
- 1.1 Transitioning from parental care
 - 1.2 Independently monitoring the blood sugar
 - 1.3 Taking over administration of insulin
 - 1.4 Managing diet independently
 - 1.5 Managing activity independently

2.0 Experiencing Conflict with Parents

- 2.1 Struggling for independence
- 2.2 Experiencing nagging from parent
- 2.3 Building trust.

3.0 Realizing diabetes is hard

- 3.1 Experiencing Burnout
- 3.2 Juggling diabetes with other responsibilities
- 3.3 Getting frustrated
- 3.4 Getting annoyed
- 3.5 Getting stressed.

Phase 5. Figuring It Out

1.0 Accepting Diabetes

- 1.1 Realizing diabetes is forever.
- 1.2 Believing you are trapped.
- 1.3 Understanding things need to change
- 1.4 Learning to cope
- 1.5 Accepting the new normal

2.0 Believing it's possible to manage diabetes

- 2.1 Changing the attitude
- 2.2 Knowing how to do everything.
- 2.3 Realizing diabetes is manageable
- 2.4 Making diabetes a priority
- 2.5 Gaining confidence that you can do what you want

3.0 Showing responsibility

- 3.1 Putting in an effort

4.0 Staying on track

- 4.1 Maintaining health
- 4.2 Setting Goals
- 4.3 Maintaining motivation

Phase 6. Helping Others

1.0 Mentoring others

- 1.1 Teaching others about diabetes.
- 1.2 Motivating others to take care of their diabetes
- 1.3 Sharing with others ways to accept diabetes
- 1.4 Acting as a role model
- 1.5 Participating in advocacy boards
- 1.6 Participating as camp counselor

2.0 Showing Compassion To Others

- 2.1 Knowing how others feel
- 2.2 Helping others feel special
- 2.3 Trying to connect with others

3.0 Planning For a Future Helping Others

Table 1 (continued) —Phases with codes and subcodes

journey towards independence, e) figuring it out, and f) helping others. See Table 1 for an overview of the axial codes and sub-codes and Appendix I for a more detailed diagram to better understand their position and relationship to each other.

Phase 1. Remembering the Beginning of the Journey

A definition of **remembering the beginning of the journey** is the memories of the events that occurred when adolescents were first diagnosed with diabetes. The major codes that will be discussed in this phase of the journey include: **a) getting the diagnosis, b) learning about diabetes and its management, and c) recognizing my life is changing**. The **major task** in this part of the journey is **learning about diabetes and going home from the hospital**. In this first phase the adolescents realize they have a serious disease that is going to change their life, thus the normalizing task is **'recognizing my life is changing'**.

1.0 Getting the Diagnosis

Getting the diagnosis is defined as the point in time when the person with diabetes recognized that something was wrong, sought medical care, and were first told about their condition. Included in the process of getting the diagnosis are **a) realizing you are sick** and **b) going to the emergency room or hospital**. Either in their provider's office, an urgent care, or in the emergency room, the family and adolescent usually first hear the word diabetes. When they are given the diagnosis of diabetes, many things go through their heads based on prior knowledge of this disease in family members or friends, yet some families know very little about what this means and what is necessary for treatment of this disease.

1.1 Realizing you are sick is defined as when the adolescents or their parents notice that something may be wrong with the adolescents' health. Many family members are not sure what is happening, but some know their child is at risk for diabetes.

"I was sick and um like I had my mouth was dry all the time, mom thought it was mono so she brought me to the doctor and they said I had diabetes so they took me to (the

hospital). . .I had a stomach ache and my throat was dry and I didn't want to eat anything" Interview #3 p.1

"I had lost a lot of weight and I was always really tired and hungry and um I just like I was feeling really sick and my mom knew that I had the marker so we just knew it could have been (diabetes)" Interview #8 p.1

1.2 Going to the doctor or emergency department is defined as symptoms that are present that are severe enough to cause one to seek additional help from medical personnel by going to their doctor, and urgent care, or the emergency department (ED). Below is an example that describes this time for the adolescents and how they remember being told about their diabetes diagnosis. When adolescents are younger, they may not tell their parent about their symptoms.

"and then my doctor called me and told me that I needed to go to the hospital right away because my blood sugar was over 900 and I almost could have gotten into a coma because I was so high, I do remember that . . . it was really scary to me and I know that my parents were scared too and their kid was diagnosed with diabetes and they didn't even know" Interview #2 p. 7-8.

Conditions when the adolescents will seek medical intervention early include: a) being aware they are at risk for diabetes and b) knowing the symptoms they are experiencing may be related to diabetes. Conditions when the adolescents may not seek early medical intervention include: a) not alerting their parents to their symptoms, b) being young, and c) when the symptoms appear to be common (like the flu), and it is presumed they will go away. A hypothesis is that increasing knowledge of the symptoms of diabetes may lead to earlier diagnosis and treatment.

2.0 Learning about Diabetes and its Management

Learning about diabetes and its management is defined as the process that is necessary to understand the medical condition of diabetes and how you need to manage it. It is important to understand how the adolescents learn about their diabetes - what is helpful to them. Codes that describe the process of learning and the adolescent's experiences include the following: **a)**

reading, b) learning from others, c) practicing skills, d) demonstrating how to care for self, e) asking the doctors, f) learning quickly, g) getting scared, h) experiencing feeling alone, and i) experiencing denial.

“you kind of have to learn to work with what you eat how much carbs are in it, watching how much you take, watching your blood sugar making sure you’re not going too high or too low” Interview #4 p.2

2.1 Reading. Reading is one of the ways the adolescents described learning about their diabetes. They found this to be a helpful way to learn and understand what is happening to their body by reading materials provided to them by the hospital staff.

“when I was in the ICU um they that’s like my favorite learning process I think because they gave you a book to understand it but they read through the book to help you understand and it was really helpful getting to see what they really mean” Interview #8 p. 2

2.2 Learning from others. The adolescents also described that they learned about diabetes by watching what others were doing or by having things about diabetes explained to them through charts and pictures but did at times feel bored during the sessions. They felt it was helpful to them when the staff was friendly.

“we had like 1 or 2 classes every day scheduled for the learning and at some points it seemed like it would never end like one of the days it was like a 5 hour learning session because like one person after another just came in and um I got so bored” Interview #8 p. 2

2.3 Practicing skills. The adolescents discussed learning the skills necessary to provide diabetes self-care and how this was helpful to them. These included testing the blood sugar, giving insulin, and counting carbs.

“when I got diagnosed they got me through the process with a little doll and it would have this kind of flesh feeling little circle on it and then I would practice getting out the insulin into my needle and then I would practice putting it into the doll and then I would start to feel better because of practicing it on the doll” Interview #2 p.8

“in the beginning you are really good at carb counting because that is the main thing they really focused on at the hospital they give you papers with your meals and you have to count all of the carbs and then add it up and then you have to pull your own shot and you have to do it yourself and your parents are taught to do it” Interview #8 p. 7

2.4 Demonstrating how to care for self. Adolescents described that they had to show the hospital staff that they understood the skills needed to leave the hospital setting and take care of themselves.

“the second to the last day of being in the hospital they checked to see if I could actually do it on my own, add up the carbs, take my insulin, take my BS” Interview #5 p.2

2.5 Asking the doctors. Adolescents also described asking their doctor questions to verify or learn information about their diabetes.

“we would ask the doctors some stuff and they would say – well you know let me get back to you on that” Interview #6 p. 6

2.6 Learning quickly. Adolescents described learning about their diabetes quickly which made them feel better about taking care of themselves and gave them confidence to be able to manage their diabetes.

“we learned about diabetes very quickly I am a fast learner as long as it is present thru the right means... can you just tell me now and then I can do a few practice problems?” Interview #6 p. 5-6

2.7 Getting scared. The adolescents describe being scared about the diagnosis of diabetes partly from not knowing what this really means in their lives and partly from being young. They also described their fear of needles and the fear they were going to die.

“I was so scared because I was so young and didn’t know what to think of it” Interview #2 p.8

“when I was diagnosed I had somewhat of an idea about diabetes and got really freaked out because it had like ‘die’ in the ... I thought I was going to die” Interview #8 p. 7

"I was scared because it was something new and I knew I was going to have to take shots and I was horrified of shots and when I found out that you have to take them every time" Interview # 8 p. 11

2.8 Experiencing feeling alone. Feeling alone was also a common theme described by the adolescents. They did not believe that other people understood what they were going through and that they were the only ones who had diabetes and had to deal with not only the physical but emotional aspects of managing this disease.

"I think most of all I felt alone, I felt like I was the only one who understood what it felt like to have diabetes" Interview # 6 p. 3

2.9 Experiencing denial. Denial was another response discussed by adolescents.

"I just think probably the first few things I did was I try to, I don't want to say I resisted it but I was just like in denial for a day or two" Interview #6 p. 11

Conditions for learning include: a) really nice staff who are easy to work with and b) having someone explain things to you. Conditions for not learning include: a) being younger, b) being afraid of needles, c) being afraid of dying, d) being bored, and e) being scared. A hypothesis is that addressing the children's and adolescent's emotional state at diagnosis will facilitate learning about diabetes.

3.0 Recognizing My Life Is Changing

One of the challenges in this first stage of the journey was 'recognizing my life is changing', learning about their disease, the care needed, and how their relationships changed. Recognizing my life is changing is defined as realizing that diabetes is a life changing event that is permanent with no possibility of a cure. When adolescents are young at diagnosis, they do not have this same knowledge until they get older.

"everyone just had to change their lives and adapt to it (diabetes) even though there is more drastic things out there- diseases that people had to adapt to but to me this is drastic because it is never going to go away I mean I am going to have it I mean they

might find a cure after I die and I pray that they do but for my time being there probably won't be anything found" Interview #7 p.7

A condition when adolescents are able to recognize their life is changing is being able to understand the scope of having diabetes. A condition when the adolescents are not able to recognize their life is changing is being diagnosed very young. Recognizing my life is changing is part of the key process for the adolescent to begin the process of normalization. This recognition comes early in the journey soon after diagnosis and the recognition of the steps needed to control diabetes, and the loss of their previous normal life, thus the process of normalizing begins. This normalizing is an attempt to return one's life back to some state of normality. A hypothesis is helping the adolescents to cope with their feelings of loss of their 'normal life' they had previous to the diagnosis will help them to adapt to having a chronic life changing illness that is permanent.

The emotional burden of not only learning about diabetes but a) remembering parent freaking out, b) remembering parent being shocked, c) remembering parent being there for me, and d) feeling mad are common responses described about learning about diabetes and trying to integrate it into life. The adolescents also described how their parents' emotional responses affected them. The adolescents remembered how their parents responded to the diagnosis of diabetes even though it was many years prior to this interview and when the adolescent was very young.

"I know my parents were really upset...it was hard for me to see my parents so shaken...my dad...took it to heart, really, really hard and he was really upset for a long time, just his daily attitude was so, so different...that is the first time I like saw my parents cry really hard when I was first diagnosed and so it's just it's really hard to just see them that way" Interview #10 p. 2

A response the adolescents discussed was their parents being shocked about them having diabetes. This was not what they expected to be told, and it was shocking to them when they started learning about what diabetes was and what their life was now going to be like in

managing diabetes. The adolescents also discussed how important it was for them to have their parents with them through this ordeal and feel that they were being supported emotionally by their parents during their diagnosis and hospitalization. Another common emotional response during the early period of learning about diabetes was being mad. They were mad about having diabetes and about how little focus or emphasis is put on diabetes from the world in general.

Summary

Getting the diagnosis, learning about diabetes and its management, and recognizing my life is changing are the major codes under the axial code **remembering the beginning of the journey** with diabetes. Some of the key conditions that occur during this phase include: recognizing the symptoms of diabetes, the adolescents' emotional response to getting a diabetes diagnosis, and the ability of the adolescents to recognize the scope and permanence of this diagnosis. Key hypotheses include: a) increasing knowledge of symptoms of diabetes may lead to earlier diagnosis and treatment, b) addressing the children's and adolescents' emotional state at diagnosis will facilitate learning, and c) helping the adolescents to cope with their feelings of loss of their 'normal life' they had previous to the diagnosis will help them to adapt to having a chronic life changing illness that is permanent. The major task for adolescents in managing their diabetes is **learning about diabetes and going home from the hospital** with the normalizing task of '**recognizing my life is changing**'.

Phase 2. Balancing Blood Sugars/Preventing a Crisis

Balancing blood sugars is defined as keeping the blood sugar in a target range that does not cause problems from either high or low blood sugars and helps to prevent going into a crisis that can lead to hospitalization or a seizure. The adolescents must learn and be able to take appropriate actions to balance their diet, activity, and insulin to keep their blood sugar balanced.

Typically during this phase the parent is quite involved in monitoring care of the children or adolescents to assist in keeping the blood sugars balanced. The major codes in this phase of the journey include: **a) recognizing symptoms of low and high blood sugar, b) monitoring, c) taking action, d) adjusting diet and activity to balance blood sugars, e) evaluating results from trying to balance blood sugars, and f) seeking help and experiencing consequences from not keeping the blood sugars balanced.** The major task in this stage is **learning to keep blood sugars balanced.** The normalizing task during this phase is **'taking action to prevent a crisis'**.

"my range is from 75 to 150 that's where my range needs to be" Interview #2 p. 4

1.0 Recognizing Symptoms of Low and High Blood Sugar

Recognizing symptoms is defined as the ability of the adolescents to pay attention to their body and be able to assess what is happening and to take action. There are two parts including: **a) recognizing symptoms of low blood sugars and b) recognizing symptoms of high blood sugars.**

1.1 Recognizing symptoms of low blood sugars occurs when the blood sugar is below the target range of 70 or 80. The adolescents became aware of these symptoms during their education about diabetes, and once they experience the symptoms, they have to recognize what they are feeling is a low blood sugar. The symptoms of low blood sugar described by the adolescents include feeling shaky, walking weird, feeling weird, not being able to pay attention to your surroundings or to what people are saying to you, trembling, legs shaking, feeling pressure in your head, feeling dizzy, feeling the need to sit down, stomach hurting, feeling numb, feeling really hungry, feeling weak, feeling light headed, having a hard time standing up, feeling more spaced out, and not always being able to do things for themselves. Not recognizing symptoms of low blood

sugar and treating appropriately leads to a severe low blood sugar that could result in a seizure. Some of the conditions the adolescents report for not recognizing symptoms of low blood sugar are when they occur during the night, when they are sitting or during activity.

“sometimes when I’m really low I start trembling, like my legs start shaking a little bit and umm, my I don’t know kind of like it feels like pressure a little bit in your head, and it feels like I feel dizzy” Interview #1 p. 8-9

“a couple of times my BS has gone low and I find that quite scary since you are not really paying attention to your surroundings or what people are saying to you” Interview #5 p. 9

“(when) my BS is low I need to go and sit down now, my stomach kind of hurts, it’s just kind of a numb feeling it’s like you’re just really hungry there’s like nothing in your stomach and um I get kind of light headed and I don’t really get wobbly or anything, sometimes I’m not really quite balanced I guess would be the word and usually I’ll have a hard time standing up and staying erect and stuff” Interview #4 p.3

1.2 Recognizing symptoms of high blood sugars. Adolescents reported becoming

aware of the symptoms of high blood sugar from being diagnosed with diabetes.

Symptoms include headache, irritability, having a stomachache, feeling sick, and vomiting. Sometimes when adolescents are very high and having mood swings they do not recognize their symptoms of high blood sugar. Not recognizing symptoms and treating appropriately may result in ketones, flu like symptoms, or needing to go to the hospital for diabetic ketoacidosis (DKA). When they feel sick, they recognize they may have a high blood sugar.

“sometimes I will get really grumpy and snappish and then sometimes I used to feel almost like I was low when I was high, like when I was really high” Interview #1 p.5

“if my BS has been high for more than like 15 (minutes) to an hour I’ll start to feel really sick, I sometimes get headaches but not a lot but mostly my stomach starts getting sick and I feel like I am going to have to go throw up when my BS is high” Interview #4 p.4

Conditions when the adolescents are more likely to recognize a low or high blood sugar include: a) when they are aware of the symptoms and b) when they feel sick. Conditions when

the adolescents are less likely to recognize a low or high blood sugar includes: a) when they are sitting still or sleeping and b) when they are having mood swings/irritability from having a high blood sugar. A hypothesis is being able to recognize high or low blood sugar allows the adolescent to act on those feelings. An emotion that is connected with having high blood sugars is feeling frustrated.

2.0 Monitoring

Once the adolescents recognize symptoms that their blood sugar is too high or too low then blood sugar monitoring is done to validate the symptoms. Monitoring that is necessary for keeping the bloods sugars balanced and avoiding crisis includes: **a) testing blood sugars and b) testing ketones.**

2.1 Testing Blood Sugars. Testing blood sugars includes the action codes of using their poker, pricking the finger, getting blood, getting the meter ready, getting out the test strip, putting the blood on the test strip, and testing multiple times a day prior to eating or just checking to see how their blood sugar level is. The blood sugar is monitored to assess symptoms from above as well as to make appropriate decisions on amount of insulin to be taken with each meal and snack. The adolescents also discussed how at times they do forget to test their blood sugar or they really do not want to test it because it either takes a long time or they are too busy. The code **experiencing difficulty with testing blood sugar** will be discussed. The purpose of testing blood sugars is to make sure that the blood sugar is in the target range, to calculate the correct insulin dose, and to validate symptoms of too high or too low blood sugars. An example of testing blood sugars follows.

“Well I have this poker and you just have to hold it to your finger and then push it in by pushing this button and then put my blood into the test strip and it will tell me what my blood sugar is” Interview #3 p.2

“you need to check your blood sugar like at least 5 times a day just to make sure that your blood sugar is ok, umm, that it’s in the right range that you want it to be” Interview #2 p. 4

2.11 Experiencing difficulty with testing blood sugar is defined as having problems with being able to test the blood sugar because of symptoms of hypoglycemia or fear. It is helpful for their parents to assist them during this time and reassure them that they are going to be alright.

“(when I) feel low BS ... I get up to check my blood sugar ... but I’m shaking so it’s not working as well” #1 p. 8-9

Testing the blood sugar is associated with negative feelings such as fear, and it is also described as being annoying.

“It has been annoying, um, ‘cuz like anytime I have to eat I have to check my blood sugar and then do this whole process ...and that is kind of a pain” Interview #1 p. 1

“I was just always like uncomfortable with poking myself...it’s kind of an uncomfortable thing for a while when I was doing it myself ‘cuz it was kind of ah, is this going to hurt, I still do that a bit now, like is this going to hurt, am I going to have this sudden onset of pain from doing it” Interview #4 p. 11

Conditions related to testing blood sugar include: a) having mom remind them, and b) having mom reassure them. Those who report not testing the blood sugar suggest barriers such as: a) testing taking a long time, b) being too busy, and c) experiencing pain. A hypothesis is that the pain and annoyance of testing blood sugars hinders adolescents from consistently performing this task.

2.2 Testing ketones is defined as checking the urine with a testing strip to ascertain if you have ketones present that would need to be addressed by giving extra insulin. Sometimes the adolescents reported not testing their ketones so their mom would not question them about their blood sugar.

“Ketones are like sugar in your pee and you have to use this little test strip thingy to see if you have any and if it’s like dark, dark then you have a lot of them, if it’s lighter that means you don’t have any of them, when I got sick I think it was last year and I had like moderate, which is like the middle” Interview #2 p. 2-3

3.0 Taking Action

Taking action is defined as the adolescents responding to the blood glucose or ketone value. The steps included in taking action include: **a) treating low blood sugar and b) treating high blood sugar.**

3.1 Treating low blood sugar is defined as the steps needed to return the blood sugar to normal. Adolescents share that treating a low blood sugar is accomplished by eating a little snack, or drinking juice, but may require glucagon or calling 911.

“if I go into a coma of course, they (my parent) try to get the glucagon and if something happens they would call 911” Interview #5 p 1

“Sometimes I will have like a cup of juice or something, if we don’t have juice or milk or something I will have like a granola bar, something that doesn’t have too much carbs, will get my BS up quickly so it doesn’t keep dropping” Interview #4 p.3

If the expected result of treating the low blood sugar does not occur, then others may need to help. An example of this is:

“I had a really low blood sugar...my blood sugar would be in the range from 24 to 66 and no matter what I did it didn’t seem to go up... and my mom finally had to call the ambulance and they came over” Interview #2 p. 7

3.2 Treating high blood sugar is defined by adolescents as giving insulin by syringe, pen, or insulin pump to correct a blood sugar that is higher than the target. Taking insulin is recognized as an important aspect of balancing blood sugar levels and can contribute to blood sugars running too high or too low. Adolescents discuss how taking the insulin dose is important in keeping their blood sugar in their target range of 70 to 150. The following codes will be discussed: **a) taking insulin/responding to the blood**

sugar and b) responding to ketones in urine. Adolescents described their mixed emotions about having to take the insulin as well as their fear of needles and discussed ways of coping with getting an injection.

“we didn’t go from shots to pump, it was shots, insulin pen, pump and even in the pen period... it was great because we would go out and then put the cap on, dial it up, ckkk, and you were like good” Interview #6 p. 12

3.21 Taking insulin/Responding to the blood sugar is defined as the steps needed to bring the blood sugar back under control when it is high. Sometimes adolescents state they do not take their dose of insulin which makes them have high blood sugar. They also state at times they do not know why their blood sugar is high. Codes that will be discussed include the following: **a) using the insulin pump and b) experiencing needle pain.**

“well if my BS goes above 200... I need to take more insulin ... some extra every 50 above 150 I need to take an extra unit, so sometimes ... my BS goes below 70 which is not really very good” Interview #5 p. 1

3.211 Using the insulin pump is defined as a way to give insulin to control blood sugars. Adolescents preferred the insulin pump over the injections for a variety of reasons. At times they have a bad insulin pump site which causes high blood sugars and is frustrating. Codes that will be discussed include: **a) going on the insulin pump and b) evaluating the pump as easy.**

3.2111 Going on the insulin pump is defined as when the adolescent first starts pump therapy to give their insulin. Adolescents state they are not sure they want to take on something new, but once they do they realize how much better the pump is for them. They also find that the pump helps them to keep

their blood sugars more stable and is a benefit to them since they really hate to give injections.

“I can remember as a kid not wanting to go on the insulin pump, no I can do shots forever...now I like wearing the pump” Interview #11 p. 1

“I found it was easier for me to control my numbers with it (insulin pump)” Interview #10 p. 9

“the pump kind of was a lifesaver for me ‘cuz I hated shots, I really hated them” Interview #10 p. 9

3.2112 Evaluating the pump as easy is defined as the pump being a much easier method to administer insulin than giving injections. Adolescents state they like not having to take shots all day, having their insulin readily available, and not having to carry all their other supplies with them.

“with my pump it’s just easy ‘cuz I just have to just push the buttons and it’s really quick and easy” Interview #1 p. 2

“it makes my life easier because I don’t have to carry my insulin around with me...I don’t have to constantly take shots” Interview #11 p.1

3.212 Experiencing needle pain from shots/pump set is defined as having pain from putting in pump sites or giving the insulin shots. A few adolescents describe that the needles do not bother them at all, but most others are very afraid of the needles or pump sites and do not want to go near them, are worried about messing up or that it is going to hurt. A code that will be discussed is **coping with needle pain**. An example of experiencing pain is found below.

"I hated levemir because it hurt so much...was just like the worst because with 24 units I took 12 in each arm and um it was just sooo painful because even with like 12 units it is just so much and it is so painful"
Interview #8 p. 5

3.2121 Coping with needle pain is defined as finding strategies to deal with pain from insulin injections. The adolescents describe some of their reactions: from hiding in the bathroom, to avoiding shots, and begin to describe some of the strategies used to cope with needle pain. Coping strategies include: **a) using different spots on the body, b) using self-talk, c) engaging parent to help, and d) using new size needles.** An example of not coping with needle pain follows.

"I hate. . . even the needles for insulin, actually when I first got home I locked myself into the bathroom because I didn't want a shot. . . it took some coaxing to get me to get out of the bathroom"
Interview #6 p. 10-11

3.21211 Using different spots on the body.

"I usually try and find a different spot on my leg, I don't use my arms but I just try and find a spot that would work without having it hurt ... usually I put the needle in about I don't know about a mm or so and then if it starts hurting I pull it out and try and find a different spot" Interview #5 p. 2

3.21212 Using self-talk.

"it was kind of like ok a longer needle, this might hurt thing and then the shorter needles this isn't going to hurt as much it doesn't go as far ... I would just sit there and look at them in the case" Interview #4 p. 11

3.21213 Engaging parent to help.

"it helped when mom and dad used to give me my shot but I eventually grew accustomed to it" Interview #1 p. 6

3.21214 Using new size needles/comparing needles.

“when you use something for a while you just kind of know the look of it and then when you use something that is different ... you just see the difference in it ... the first time I started using the pump it was like- well this is a way bigger needle it’s going to hurt worse... let’s compare this needle to this needle, a little big, which one is going to hurt more” Interview #4 p. 12

3.22 Responding to ketones in urine is defined as drinking water and taking extra insulin to get rid of ketones which make you feel sick. Adolescents discuss feeling very ill and just wanting to sleep which makes it difficult for them to respond to the ketones.

“when I got sick I think it was last year and I had like moderate (ketones), which is like the middle and then I just stayed home and I had to drink a lot of water and they went away” Interview #2 p. 2-3

“when I (have ketones) it is hard to get all that stuff down, ...you take a shot, sleep, wake up, take a shot, sleep, until you finally feel better” Interview #7 p. 2

Some of the emotions that go along with having to give insulin include hating it, loving/hating it, emotionally not being able to poke oneself.

Conditions that may contribute to high blood sugars include: a) not understanding why you are high, b) experiencing a bad insulin pump infusion site, and c) missing insulin doses. Conditions the adolescents described as helping to avoid high blood sugars are: a) using other types of devices to give insulin such as the insulin pen or insulin pump and b) reminding themselves to take their blood sugar and insulin doses. Two hypotheses for this code are: a) needle pain from the insulin shots or pump sites is a barrier to the adolescents consistently giving their insulin to keep blood sugars balanced and b) use of the insulin pump as an insulin delivery method is preferred by adolescents and will improve adherence to care and decrease needle fear.

4.0 Adjusting Diet and Activity to Balance Blood Sugars

Adolescents discussed how they learned about the importance of other aspects of their life in balancing blood sugars. Two codes that will be examined in this section include: **a) adjusting activity, and b) adjusting diet.**

4.1 Adjusting Activity is the process of staying active to help lower blood sugar values and making adjustments to food and insulin to prevent low blood sugars during activity. Adolescents discuss the benefits of being in sports or working out on their own to help them stay healthy. They also discuss the issues they have with high or low blood sugars during some of their activities and the need to monitor their blood sugar extra, give insulin, or eat food prior to or after exercise to help in keeping their blood sugar balanced from the effects of the exercise on their body. Adjusting activity to keep the blood sugars balanced includes the following: **a) staying active, b) monitoring for effects of activity on blood sugar, and c) stopping activity.** An example of keeping blood sugars lower from staying active is:

"I try to (stay active) ... and that can help with your BS 'cuz it can actually help to keep it down and I hope it doesn't go up when you exercise 'cuz that would be bad" Interview #4 p. 19

4.11 Staying active is defined as keeping busy with exercise or other activity to help balance the blood sugars and stay healthy. Some adolescents talk about knowing they should exercise for their health but just do not like to.

"I do a lot of fast pitch especially lately and I try to go to the gym and I do PE at school and I do the "Wii" and all that...when I exercise ... tend not to get hungry as much and that helps a lot but it's that being fit is better, it's good for you and it is being healthy, it is good for your diabetes" Interview #2 p. 5

“I really don’t exercise all that much... my doctor says I need to start exercising more...but I’m not really an exercising person, I just like to lay down and watch TV and eat and take my shot” Interview #9 p.7

4.12 Monitoring for effects of activity on blood sugar is defined as learning that activity sometimes makes blood sugar go high and sometimes the blood sugar goes low. Codes that will be discussed include: **a) testing extra during activity and b) changing insulin dose.**

“I have found that I go high right after I exercise...and then the first reaction is oh my BS is high and I need to give myself insulin, but if you give yourself insulin then you are going to hit the low from the exercise and then you going to go really low so exercise is like really hard from me, any kind of strenuous exercise” Interview #11 p. 11

4.121 Testing extra during activity is defined as testing the blood sugar more often during activity to be able to address their blood sugar by taking extra insulin if high, or juice if their blood sugar is going low.

“when you are in sports you have to make sure to check your blood sugar throughout the whole thing...so I can take care of it before it goes too low” Interview #2 p.9

“I check before (exercise)...now I am high...I take a shot and it makes me go lower” Interview #2 p. 9

4.122 Changing insulin dose is defined as adjusting the insulin dose to try and prevent the low blood glucose that may occur from exercising. Some adolescents do not change their food or insulin doses when they exercise.

“sometimes I will take my basal rates down about an hours or so after I exercise because that’s when the lows will start so then I’m not taking way less insulin when I am running high” Interview #11 p. 11

4.13 Stopping activity is defined as having to stop an activity due to low or high blood sugar. Adolescents state that this is very hard for them to have to sit out of

their sporting event while they wait for their blood sugar to return to normal and are not able to participate.

“if I’m really high I’m supposed to wait until my numbers come down...it’s more anytime I can’t participate in activities just because I’m low...I had to sit down and I just feel really drained of energy...I remember I was like 54 and I couldn’t play the next game and it was really annoying and frustrating because I wanted to” Interview #10 p. 13

Conditions when the adolescents may not adjust activity to balance blood sugars include: a) not wanting to stop activity, b) not wanting to exercise, and c) not understanding the need to adjust insulin for activity to prevent a high or low blood sugar. Conditions when the adolescents may adjust activity to balance blood sugars include: a) realizing that activity helps to keep blood sugars more even and b) learning to adjust food and insulin to keep blood sugars steady during activity. A hypothesis is helping the adolescents learn to adjust their insulin during activity will increase their ability to stay active and keep their blood sugars balanced.

4.2 Adjusting diet is defined as steps adolescents take to manage their food intake to keep blood sugars balanced. The following codes will be discussed: **a) counting carbohydrates, b) recognizing foods that elevate the blood sugar, c) establishing routines/schedules, d) snacking, and e) eating healthier food.**

4.21 Counting carbohydrates is calculating the type and amount of carbohydrate in the food eaten and is used to then give the right amount of insulin. There are several codes included: **a) identifying foods that are carbohydrates, b) learning how to decide how many carbohydrates are in the food choice, c) knowing the correct carb ratio to be used for giving insulin, and d) avoiding carbs to not take a shot.**

4.211 Identifying foods that are carbohydrates is defined as learning what foods have carbohydrates in them.

“I had to learn what are carbs, what food has carbs, ‘cuz I never really thought about that before...why would I need to” Interview #10 p.3

4.212 Learning how to decide how many carbohydrates are in the food choice is defined as understanding how to calculate the carbohydrates in each food item. Some adolescents say they learn to eyeball or guess the amount of carbohydrates based on size or previous experiences with certain foods. They state if they do not have their book with them it is hard for them to carb count some foods.

“I know a ladle is this much carbs because you can generally get about the same amount of noodles in each ... it’s generally just a lot of reading labels” Interview #11 p. 11

“you have to count all the carbs and add it up ...it is kind of weird counting every single chip and everything you eat, but a lot of times you just guess this looks like a half a cup of ice cream” Interview #8 p.7

4.213 Knowing the correct carb ratio to be used for giving insulin is defined as knowing how to calculate insulin doses based on the carbohydrate count by understanding the carb ratio they use. Some adolescents just guess on dose based on what looks right. Others share that they have difficulty with math and figuring out the correct dose of insulin to give for their food.

“I have to check my blood sugar ...and I have to see how much carbs are in the food and then I have my carb ratio is 1:10 and I have to divide by 10 to see how many units I have to give...like if there is 30 carbs depending on my blood sugar I would do 3” Interview #3 p. 2

“before the bolus wizard...it was a guess where we did the sliding scale and then um mom was like well generally you are like 1:15, when In fact I’m like 1:8 ...but it was just you know this looks right” Interview #11 p.6

4.214 Avoiding carbs to not take a shot is defined as being able to know which foods will make the blood sugar level rise. Adolescents recount experiences where they have avoided carbohydrates for meals or snacks just so they do not have to take extra doses of insulin.

“I actually would snack on lunch meats that have no carbs... I remember actually skipping breakfast more, I would skip lunch more, I would eat bigger dinners, basically I would try and consolidate the number of shots I would have to get for a meal” Interview #6 p. 12

“I knew if I wanted a snack I would have to give myself a shot and it was just too much for me, it was just too much work and I was just like well I’m not going to eat, I’m not going to give myself another shot even if I was like really hungry” Interview #10 p. 11

4.22 Recognizing foods that elevate the blood sugar is defined as being able to know which foods will make the blood sugar level rise. Adolescents talk about avoiding some of these foods in order for them to keep their blood sugars balanced.

“things that affect my blood sugar but we just, like we used to not have pizza very often because it would always send me low or very high... and pancakes did that too and other fatty foods... donuts- we don’t have donuts anymore ...they really are bad for my blood sugars, they are like the pizza instead they are like stronger I guess so they are just kind of like crazy to carb count and to get my blood sugars on track after I eat them” Interview #1 p. 4

4.23 Establishing routines/schedules is defined as when adolescents define set times in their day to manage their diabetes or certain foods to eat. Adolescents stated that if they eat all day long they have more problems balancing their blood sugars.

“I ate the same thing for breakfast, lunch, and dinner every single day for a long time just because I was like a streak eater...I did that so like it was really easy to calculate” Interview #11 p. 6

“my day is structured I mean I am going to check 30 minutes before lunch... and get that out of the way...I get picked up around 5 and mom likes a blood sugar before I get in the car so I check at 4:45” Interview #11 p.5

4.24 Snacking is defined as eating between meals. Adolescents talk about snacking more on the pump than when they were on shots when they would avoid a snack.

“(on the pump) I found I was snacking more ‘cuz it was so much easier for me to just dial up like 30 carbs of food and like when I did shots I would never do that ‘cuz I would never want to take a shot” Interview #10 p. 9

4.25 Eating healthier foods is defined as picking foods to eat that are known to be better for your body and help to keep your blood sugar balanced. Some adolescents feel they can eat whatever foods they want as long as they take insulin for it but do say it may not be healthy for them or others who eat that way.

“I eat anything and everything you put in front of me...you can really eat whatever you want...I eat pasta and I eat like food and I mean that is probably not the best thing in the world...I don’t feel like guilty for eating and being diabetic” Interview #11 p. 9

“I didn’t really eat unhealthy... we have always been kind of healthy growing up but this was just the icing on the cake...we are just going to have less carbs, more protein, more fiber stuff like that” Interview #10 p. 8

Conditions when adolescents adjust their diet to balance blood sugars include: a) recognizing how different foods affect blood sugar, b) staying on a schedule with eating, c) not eating between scheduled times, and d) not eating all day long. Conditions when adolescents do not adjust their diet to balance blood sugars include: a) not wanting to give an injection, b) wanting to eat all through the day, c) not understanding how to carb count correctly, and d) eyeballing/guesstimating insulin dose incorrectly. A hypothesis is that by utilizing insulin pump

therapy you decrease the need for most math calculations and extra injections for snacks and meals and help the adolescent to eat more normally.

5.0 Evaluating Results from Trying to Balance Blood Sugars

Evaluating results are those activities taken in determining if the actions taken to balance the blood sugar have been achieved. Steps in evaluating their success include: **a) assessing effects of low blood sugar treatment and b) addressing effects of high blood sugar treatment.**

5.1 Assessing effects of low blood sugar treatment is defined as retesting the blood sugar after treating to make sure that the blood sugar is in the correct range. The adolescents describe the process of eating their carbohydrate to treat the low blood sugar and then having to wait 15 minutes and testing their blood sugar again by making sure that it is now in the correct range.

“(when I’m low I have to eat) anything to make my blood sugar go up I have to eat 15 carbs then I wait 15 minutes to see if it is up and if it’s not then I eat something else ...Like going from 63 to 75 that means it’s like going up but then I would eat like something else but if it’s like 75 to 100 then I’m good” Interview #3 p. 5

5.2 Addressing effects of high blood sugar treatment is defined as giving insulin and monitoring the blood sugar extra when the blood sugar is high. Adolescents share that if they are busy sometimes they are not willing to deal with their blood sugar at that time. The code **leaving school early** shows how adolescents address ongoing high blood sugars when they are not feeling well.

“I have to take the shots for my blood sugar and drink water . . . will check (my blood sugar) like every hour” Interview #9 p.6

“my blood sugar would go from like 200 240 to like 300 and then back to 100, it was really hard to bring it from high like that to back down...I was constantly giving myself shots but it seemed not to work” Interview #2 p. 1

5.21 Leaving school early is defined as the need to leave school to be able to address high blood sugars and ketones when you feel sick. Adolescents shared they will usually tell their parents when they have ketones or are vomiting to have them help them to manage their blood sugars and insulin.

“I had to leave school early a few times this year because my BS was really high and I had ketones and I was getting sick so my sister picked me up” Interview #9 p. 6

“you have to check your blood every hour or two hours and you have to give injections or change your sites or fill your reservoirs, if you get sick you have to go to the hospital” Interview #7 p. 2

Conditions when the adolescents are less likely to address the effects of high or low blood sugar include: a) when they are busy and b) when they are too sick. Conditions when the adolescents are more likely to address the effects of high or low blood sugar include: a) telling the parent, b) when they have assistance, and c) when they are feeling sick. A hypothesis is by following recommendations for assessing high and low blood sugars a crisis can usually be prevented.

6.0 Seeking Help and Experiencing Consequences

Seeking help and experiencing consequences is defined as when the adolescent needs help to manage their blood sugar usually if they have severe symptoms causing a seizure or large ketones. Codes that will be discussed include the following: **a) experiencing a seizure/severe low blood sugar (BS), b) experiencing ketones/going to the hospital in diabetic ketoacidosis (DKA), and c) seeking assistance.**

6.1 Experiencing a seizure/severe low BS is defined as when the blood sugar is too low to treat by yourself or causes a seizure to occur. Adolescents describe this process of feeling low and needing to call the ambulance to help you/your parent manage a low blood sugar and the frustration of not feeling in control.

“I had a really low blood sugar in the range from 24 to 66 and no matter what I did or how much juice I drank how much glucose tabs I had it didn’t seem to go up, and so my mom finally had to call the ambulance and they had to come over... I had the juice and the glucose tabs and like but I was scared because after all that stuff my blood sugar still wasn’t going up and I didn’t understand it and um it was scary to think that it seemed like I didn’t have any control over it” Interview #2 p. 7

6.2 Experiencing ketones/Going to the hospital in DKA is defined as having ketones from high blood sugar that result in DKA and may require hospitalization.

“if I eat a lot and my BS would go higher and then if it keeps going like that and if I didn’t do insulin for all the stuff I ate I would get sick again and I would get ketones and I would have to go to the hospital to get and IV and to get all that stuff flushed out” Interview #3 p. 2

6.3 Seeking assistance from others is defined as getting help from others to treat low or high blood sugars. Codes that will be discussed include: **a) seeking assistance with low blood sugars and b) seeking assistance with high blood sugars.**

6.31 Seeking assistance with low blood sugars is an action the adolescents take when the desired result of keeping the blood sugar balanced is not achieved. Seeking assistance includes alerting parents, friends, or adults such as teachers. Conditions when the adolescents are most likely to seek assistance include needing further assistance in treating the low blood sugar, or in case the adolescent would start going into a seizure or coma from the low blood sugar.

“if I can’t really do things myself they (parent) go get something easy like juice and help me open the packages of fruit snacks as usually when I have a harder time opening things, um and if I go into a coma of course they try to get the glucagon and if something happens they would call 911” Interview #5 p. 1

“if I’m at recess or something and if I tell the recess teacher that I feel like my blood sugar is getting low and he finds somebody that he know is a friend of mine and then asks them if they could take me to the office just in case I pass out in the hallway” Interview #4 p. 8-9.

6.32 Seeking assistance from others with high blood sugars is defined as getting help from the parent or doctor to assist with correcting high blood sugars. Sometimes the adolescents will need to seek assistance at the emergency room or be admitted to the hospital if they are in DKA.

“we didn’t know what was going on...we called the doctor, we had already called them before but we called them because my BS weren’t going down and then we had to go to a doctor’s appointment” Interview #9 p.6

“I will tell my parents that my blood sugars are high and they will check on me and make sure they are coming down” Interview #9 p. 6

Conditions for seeking assistance from others includes: a) when experiencing a severe low blood sugar, and b) when experiencing a high blood sugar with ketones. The following are actions taken in seeking help when the blood sugars are too high: a) alerting parent, b) calling the doctor, and c) going to the emergency department or hospital. A hypothesis is seeking assistance from others helps the adolescents appropriately deal with their high or low blood sugar to prevent a crisis.

Some of the emotions that appear to occur in keeping the blood sugars balanced include feeling scared and finding that diabetes is very annoying. Emotionally, the adolescents appear to be struggling, feeling annoyed, and scared. Fear of pain and the consequences of failure in keeping the blood sugars balanced are dominant in this process.

A major condition that contributes to the adolescents in balancing their blood sugars is feeling their parent is there for them. They discuss how that helped them with their emotional breakdowns and also just learning about how to take care of their diabetes, having mom help them with their carb counting, or remembering to take their insulin and also just reassuring them that everything is going to be ok.

“Others being there, just knowing that them telling me I’m going to be ok, it makes me stronger because it makes me think that I am going to be ok and um, every single time that someone told me that I was ok and it was nice to know that everyone is there for me

everyone is comforting me and they have faith in me that I am going to be ok after all and all that stuff, it was really scary, I didn't like it" Interview #2 p. 7

"if I start having problems I usually go and tell my parents about it and they talk about it with me, they ask a couple of questions like how is it bothering me and I've just I don't know just if I have a problem or start having emotional breakdowns I just tell my parents and they help me with anything I am having problems with and we just go a few days and then if I start having an emotional breakdown again they try and help me again" Interview #5 p. 2

A key contribution during this phase for adolescents is their willingness to address their high or low blood sugars appropriately. As the adolescents try to normalize their life during this stage they find that the work of managing diabetes day in and day out is tedious and time consuming. Sometimes it is just as easy to ignore testing their blood, taking their insulin, or managing their diet when it is interfering in their daily lives. If the adolescent is able to manage the steps in this process of balancing their blood sugars and still feel normal then they are able to **'take action to prevent a crisis'** and those who are not able to feel normal when they are managing their diabetes are more likely to experience consequences from high or low blood sugars.

Summary

During this second phase the axial code **balancing the blood sugars/preventing a crisis**, the major codes include recognizing symptoms of low and high blood sugar, monitoring, taking action, adjusting diet and activity to balance blood sugars, evaluating results of trying to balance blood sugars and seeking help and experiencing consequences from not keeping blood sugars balanced. Some of the key conditions that occur during this phase include: the adolescents ability to recognize and manage symptoms of high or low blood sugar, experiencing needle fear, not wanting life disrupted from having to take their insulin, test their blood sugar, or having low or high blood sugar, keeping blood sugars balanced is difficult for the adolescent in particular around food choices and calculating appropriate insulin dosing, and when the adolescents are high or low they don't always make appropriate treatment decisions.

Key hypotheses include: a) the pain and annoyance of testing blood sugars hinders adolescents from consistently performing this task, b) needle pain from the insulin shots or pump sites is a barrier to the adolescent consistently giving their insulin to keep blood sugars balanced, c) using the insulin pump as an insulin delivery method is viewed as easier for the adolescents to manage their diabetes and balance their blood sugars, d) finding ways to improve the ability of the adolescents to carb count or assist them with easy solutions will improve blood sugar control, and e) seeking assistance from others helps the adolescents appropriately deal with their high or low blood sugar to prevent a crisis. The major task for adolescents in managing their diabetes is **learning to keep blood sugars balanced** with the normalizing task of **'taking action to prevent crisis'**.

Phase 3. Integrating Diabetes into the World Outside the Home

Integrating diabetes into the world outside the home is defined as those actions that are taken to address diabetes management outside the home such as managing the diet, giving insulin, and engaging in physical activity. These steps require the adolescents to interface with systems or people outside the home such as: a) public places, b) school, c) friends' houses, and at times involve others in helping with care. Major codes that will be discussed during this process include: **a) building support and b) realizing I'm different**. During this phase adolescents discuss the annoyance they feel when asked so many questions about their diabetes. The adolescents discuss not feeling respected, and of feeling embarrassed about having diabetes. The **major task** to be accomplished by the adolescents during this phase is **enlisting support from others and learning when and how to disclose and who to disclose with**. The normalizing task during this phase is **'disclosing to engage support'**.

1.0 Building Support

Building a support network is undertaken for the purpose of gaining greater independence from parents and integrating diabetes into normal activities outside the home. Integral in

building the support network includes disclosing/letting others know and teaching others about diabetes by explaining what diabetes is, about complications that may occur, and about how diabetes is managed. Codes that will be discussed include the following: **a) disclosing/not disclosing, b) teaching and explaining, c) answering questions, and d) engaging others to help.**

1.1 Disclosing/Not Disclosing. Disclosing is seen as letting others know you have diabetes. Adolescents share that especially during junior high school they become more concerned with their privacy and do not want others to know they have diabetes. The following codes will be discussed: **a) telling friends, b) telling teachers, and c) telling others.** An example of this is:

“some days it feels like I have to explain it (diabetes) to everybody. . . I will explain that I have type 1 diabetes...I actually have friends or relatives ... or I have a friend who I know they will be like sure, what is diabetes- I say there are two types, there is genetic and there is lifestyle” Interview #6 p. 13

1.11 Telling friends is defined as disclosing you have diabetes to those you are close to. Adolescents share that they do not care if their friends know they have diabetes, but some prefer not to tell others unless they ask.

“everyone in my class knows now and everyone gets used to it really fast because um a lot of the kids in my classes are my friends so it doesn't really matter to me that they know and I know that they are my friends and will support me” Interview #8 p. 4

“kids never really notice that I go to the office my teacher made a specific time that I go to the office... so really nobody knows that I have diabetes unless they ask” Interview #5 p. 1

1.12 Telling teachers is defined as letting teachers know you have diabetes.

The adolescents relay information about how hard it is to tell the teachers about diabetes and to make sure they understand what it means, but they feel it is necessary to let them know what diabetes is and how they have to take care of it.

“it was kind of hard at first because I would have to explain it to everybody and all of my teachers and have them understand what it means and what I had to do and all of that” Interview #2 p. 2

1.13 Telling others is defined as telling other people you come into contact with that you have diabetes including those at work, school nurses, and coaches.

Adolescents state that not everyone needs to know they have diabetes, especially if they are not going to be seeing them often.

“I was at work and my numbers were high...I was on break and I was eating my food and I pulled out my needle and gave myself a shot and everyone was like what are you doing, there is just some girl just shooting up in the crew room and I’m just like no, no, no and I explained to them that I have diabetes” Interview #7 p.3

“the nice lady in the grocery store, and the waitress don’t need to know, like people that you are never going to see again don’t need to know” Interview #11 p. 17

Conditions when adolescents are more likely to tell others include: a) when it is their best friend, b) if they are classmates, and c) if they are having problems in school. Conditions when the adolescents do not want to tell others include: a) people who they may never see again and b) when they are in early adolescence and just want their privacy. A hypothesis is helping the adolescents feel comfortable disclosing their diabetes to close friends will allow them to seek assistance when needed.

1.2 Teaching and Explaining is defined as explaining diabetes to others to help teach them about what diabetes is. Codes that are included are: **a) teaching and explaining to friends, b) teaching and explaining to teachers, and c) teaching and explaining to others.** Adolescents share they it is important to answer others questions to help them better understand about diabetes even if it is difficult for them and that by clearing up misperceptions about diabetes, about their insulin pump, and about food are important in helping others better understand diabetes.

“as a kid I had a lot more challenges because now I’m more smart about it I guess – I have the ability to explain that I can do or I can eat what I want I mean I have diabetes and they like understand me I guess” Interview #7 p. 12

1.21 Teaching and Explaining to friends is defined as telling friends about what diabetes is, how they got diabetes, the difference between Type 1 and Type 2 diabetes, and what the consequences of having diabetes are. Adolescents share how they get tired of telling people over and over again about diabetes and are not really sure what to say. As the adolescents get older, they find that using a short consistent message helps them to explain diabetes easier.

“learn how to explain it in a nice little scripted thing so you are not trying to figure out what you have to say” Interview #7 p 13

“I guess when I was little I just didn’t care . . . but as I got older and...when I was at school and I had to go to the nurse’s office and people would see me giving a shot and they would be just like what are you doing? It’s hard to explain you know but you try your best” Interview #7 p. 3

“explaining to all my friends over and over again” Interview #2 p. 6

1.22 Teaching and Explaining to teachers is defined as explaining diabetes and care needs with teachers to help them understand what is needed for care, as well as to engage their help if needed. Adolescents state that not all teachers are willing to help, take time to understand, or want to be involved with the adolescents requiring them to explain diabetes over and over to them.

“we had to explain to them (teachers) that we have a 504 plan and that I have to do this and it’s hard sometimes because I have to explain it over and over and over again” Interview #2 p. 2

“I know that I have explained it so many times but like they (teachers) don’t and then they don’t mean to ask but they just don’t know about it and they just wonder about it” Interview #2 p. 6

1.23 Teaching and Explaining to others is defined as telling others about diabetes and how to care for it but being annoyed with having to explain about

diabetes over and over. Adolescents share that they get frustrated that people do not understand that they need to take insulin, the difference between Type 1 and, Type 2 diabetes, and that they can eat all foods. They again feel they have to explain about their diabetes over and over again which is annoying to them.

“I’ve explained a thousand times to other people but I can’t really be rude about it because they don’t know and it’s a different person so yeah it can be hard sometimes but then I think that well they don’t know so I’m just going to have to explain it one more time” Interview #2 p. 3

“really being annoyed, everyone just asking you and asking you the same questions over and over again” Interview #8 p.3

1.3 Answering questions is defined as responding to others questions about diabetes so they understand what diabetes is.

“a lot of people still do ask me when I first meet them because they see my pump and they think it is a video game...like every day I got like 5 questions on it and I got like annoyed being asked” Interview #8 p. 3

1.4 Engaging others to help is defined as getting others to help remind adolescents to check their blood sugar or assist them with low blood sugars. One time when the adolescents did not engage the help of others was at slumber parties, as they thought monitoring diabetes was too much to ask of a friend’s parent. They also shared that they are worried about others seeing them test their blood sugar or take their shots. Codes that will be discussed include: **a) keeping blood sugars balanced, b) dealing with a crisis, and c) counting carbohydrates.**

1.41 Keeping blood sugars balanced is defined as getting others to help manage diabetes when in public places. The adolescents discuss how challenging it is for them when they are out in public as they often forget when they are busy with other things, it takes time out from their other obligations, and they are more likely to not want to check their blood sugar when they are away

from home. The codes discussed include the following: **a) testing blood sugars and b) taking insulin.**

1.411 Testing blood sugars is defined as monitoring blood sugars no matter where they are or what they are doing. Testing blood sugars during this phase is different than in phase two, as here the emphasis is on dealing with the process in public places outside the home.

“I will just be walking the halls and checking (BG)... I have done it while bike riding” Interview #6 p. 13

“in the homeschool co-op I’m in a cooking class and so sometimes I forget to check my blood sugar” Interview #1 p. 8

“at school I get out a little early to go eat lunch and then in 7th period I have to go to the nurses office ... check my blood sugar, see what I’m eating that day, and then I do my insulin and then I leave” Interview #3 p. 6

Conditions for not checking the blood sugar in public include: a) when you are gone somewhere, b) that it takes a long time, and c) that you forget. A hypothesis for this code is that adolescents with poor self-esteem are less likely to want to test in front of others.

1.412 Taking insulin is defined as taking insulin in public places. Codes that will be discussed include: **a) taking insulin in restaurants, b) taking insulin at school, c) taking insulin in front of others, and d) taking insulin at parties.** The adolescents shared that they found it helpful to give insulin in the nurse’s office or in the bathroom and that using the insulin pump is more private as well. Some of the challenges they discuss are not wanting to have to do more than one shot a day in school, having other kids make fun of them or be afraid of the needles, having to let the school nurse watch them to make sure they are

calculating their doses correctly, when they forget their insulin, having to carry their bag and supplies with them, not wanting others to see them giving insulin, having other kids try to take their needles away from them, and having others think they are doing drugs when they take a shot.

1.4121 Taking insulin in restaurants.

“It has been annoying, um, ‘cuz like anytime I have to eat I have to check my blood sugar and then do this whole process and then like when we go somewhere there out to eat unless it’s like a restaurant or something then I have to do that like standing up... and that is kind of a pain” Interview #1 p. 1

1.4122 Taking insulin at school.

“I was the only one like carrying the bag around with me and like staying in with my teacher at lunch because she knew about diabetes and um when the nurse wasn’t there she couldn’t help me and the teacher could help me so I just ate lunch in with her because I had to come back down because I don’t, I didn’t want to take shots in public” Interview #8 p 3

1.4123 Taking insulin in front of others.

“when friends...come over it is a really special time and then we have to stop and wait for this to be whatever I’m doing (with my diabetes) to be finished and then we do continue but that takes time out of it” Interview #8 p. 9

1.4124 Taking insulin at parties.

“parents think you can’t have sugar so they won’t let you eat or if you go to a friend’s birthday party and you forget insulin so you have to leave the birthday party” Interview #7 p. 12

Conditions that are present when giving shots in public include: a) going to the nurse’s office for assistance, b) going to the bathroom, and c) having more privacy with the insulin pump. Conditions that are present when the adolescents are less likely to take a shot/insulin or

be frustrated by having to do insulin in public include: a) not wanting to take more than one shot a day at school, b) other kids not liking needles, c) someone having to check in to make sure it is done correctly, d) forgetting to bring your insulin along, e) having to carry your supplies, f) not wanting to take a shot where others can see, g) having others trying to take your needle, and h) believing others think you are doing drugs. A hypothesis is that by giving adolescents privacy when taking their insulin they will then feel better about themselves and decreases the questions they get about their diabetes. Some of the emotions that go along with having to give insulin include feeling self-conscious and feeling frustrated from having to interrupt what they are doing to take care of their diabetes.

“I felt really self-conscious getting injections in like restaurants and stuff because it probably looked really weird like I was taking drugs or something” Interview #1 p. 7

“at school when I’m doing work or reading a book I like I’m almost done with a chapter or I’m almost done finishing an answer and I have to go take my insulin usually I get frustrated” Interview #5 p. 7

“when I was feeling really self-conscious then I would like go into the bathroom but that didn’t happen often, we don’t go out to eat very often” Interview #1 p. 6

1.42 Dealing with crisis is defined as engaging teachers, friends, and coaches to help them with diabetes usually with a low blood sugar. Adolescents share they often experience challenges with teachers that are not helpful or understanding. Several codes that will be discussed include: **a) explaining to others need to go to office, b) explaining that diabetes needs to come first, and c) engaging friends to help.** The adolescents do not want special treatment, and will go and manage their blood sugars only when needed, and are not using their diabetes to get out of class. They state they get frustrated when others do not know what diabetes is.

“I don’t want to receive any special treatment at all, like I want to challenge myself and I know I can eat or drink at any time that I want, anywhere in the

school building, but I don't – I don't want to use that for any reason other than a low, technically I don't have to go to the nurses office for a low but I do" Interview #6 p. 16

1.421 Explaining to others need to go to office is defined as telling

others they need to go to the school office to manage their diabetes.

Adolescents state they need to remind teachers about the plan they have in place to be allowed to manage their diabetes, as they sometimes do not allow them to leave the classroom. They state they appreciate when the teachers are respectful of them and allow them to care for themselves as needed in or out of the classroom.

"I don't know why but lately there has been a lot of teachers at my school now who have been saying that I can't go to the health room or something when they know that I have diabetes and that we had to explain to them that we have a 504 plan and that I have to do this" Interview #2 p. 2

1.422 Explaining to others that diabetes needs to come first is

defined as telling others that managing their diabetes is the most important thing to them. Adolescents describe how teachers feel they are using their diabetes for getting out of class or not wanting to take a test or do an assignment when they have a low blood sugar.

"teachers they think that I am getting out of tests or assignments but that's not the case I need to take care of what I need to do and diabetes comes first and It's my health and I mean I need to take care of that and I also need to know that I need to take care of my school work but the teachers just think that I am using it as an excuse but my coach knows...but the other teachers don't" Interview #2 p. 10

1.423 Engaging friends to help with low blood sugars is defined as

getting friends to help when you have a low blood sugar.

“I have two backup friends in my classroom that would go with me places... like outside two people stay with me so like one can stay next to me and one can go get help and they just learn, most of them learned over a week like what it really was” Interview # 8 p.5

An example of when friends are not helping follows:

“when I was younger I actually had people say that it was contagious and that they wouldn’t be my friend because they heard or someone told them it was contagious and they didn’t want to get it and it was kind of hard for that” Interview #2 p. 2

1.43 Counting carbohydrates is defined as counting the foods you are eating that contain carbohydrates and how friends can assist. Adolescents share that by taking their own lunch to school is one way to help diabetes from taking less of their time. Having their friends help them with carbohydrate counting is described as helpful.

“when it comes to the lunches at school, I need to wait for the carbs to come back from the lunch ladies at the school or stuff people who are providing the food so it takes a long time, too much time out of my lunch since we only have 24 minutes to eat lunch and so I can’t wait for them to tell me the carbs, taking my own lunch is easier and doesn’t take as much time when I go to the office” Interview #5 p. 5-6

“they (friends) always look out for me and they always make sure that I’m, they double check my math, they really just help... I know that I have had my carb counts off before and double and triple check... it is nice to have my friends double and triple check me” Interview #8 p. 4

A challenge in eating in public with those who know you is when they make comments about your food selections. Having other people comment on your food choices, or those who tell you that you shouldn’t be eating that, or going to their parent to tell them what they are eating is difficult. The adolescents share that they know what they are supposed to be doing to manage their diet, and don’t appreciate input from others. Adolescents indicate they want to teach others what they are allowed to eat so those around them have a better understanding about diet management in Type 1 diabetes.

“I just think sometimes people just don’t know anything, one of my biggest pet peeves is like people will just say- you can’t eat that or you can’t eat sugar, I just want to shake them and say no – that is so wrong and I can eat whatever I want” Interview #7 p. 4

Conditions when the adolescents are able to deal with a crisis include: a) when others are aware of what diabetes is, b) when others are able to assist the person with low blood sugar, and c) when others are respectful of the adolescents need to take time to manage their diabetes. A hypothesis is that by increasing others knowledge of diabetes management and how to recognize and treat low blood sugars, the adolescents will feel more supported in managing their diabetes and being able to deal with a crisis.

2.0 Realizing I’m Different

Realizing I’m different is defined as feeling “different” or “not normal” or like you do not “fit in” or have friends. Realizing I’m different is described as not being like everyone else, not being good enough, not like other teenagers; it can also make the adolescent feel like a loner. They state they do not feel they fit in with the group, and they just do not feel normal since they have to do so many things to take care of their diabetes and often have to stop to care for themselves when they are out with their friends. Some adolescents with diabetes feel they are not very sociable with others. A code that will be discussed is **feeling like you don’t fit in/have friends**. An example of realizing I’m different is below.

“at the beginning it’s kind of like you know you are different you know, you are not going to be like everyone else so it’s not one of those things I didn’t really like about myself, it’s not like I’m not perfect I guess is how you want to put it and it was kind of hard to get used to when I started trying to figure out what type 1 diabetes was” Interview #4 p.2

“Sometimes I feel like it makes me not normal, ‘cuz I’m not like everybody else, ‘cuz I have to do that (my diabetes care) every day” Interview #2 p. 11

2.1 Feeling like you don’t fit in/have friends is defined as feeling you do not fit in with your peer group and feeling more mature than others.

"I wasn't like a very sociable person I was kind of a keep to myself I mean I have like close friends I will talk to them but I don't want to talk to those people I don't know"
Interview #4 p.15

"there's something wrong with me I guess you'd say... you are just kind of this loner maybe and you are never going to fit in with the group because you have diabetes"
Interview #4 p.15

Emotional feelings noted in trying to integrate diabetes into the world outside the home include: a) feeling they are not being treated fairly, b) feeling unsupported, c) feeling not connected to those around them, d) feeling alone, and e) feeling that diabetes is hard to manage when they are in the school setting. Adolescents also note feeling embarrassed about having diabetes and having to do care in public places.

"I felt very alone...I had no real male connection and no real external family connections and I still don't" Interview #6 p. 3

"it was mostly just an embarrassment of my friends and people seeing me carrying around a meter and stuff it was just kind of just do I really want people to see that do I really want people to think that I'm kind of messed up in a way" Interview #4 p.9

When the child first goes into the world, they develop an awareness of those around them, believe they are the only one with diabetes and having to do all these tasks every day, and often experience social isolation. As they reach adolescence, they become more aware of their body image and the feelings of being different and feeling alone becomes more intense and very challenging. The adolescents experience feelings of not being connected, being embarrassed, and feeling alone. Those diagnosed very young share experiences when they first realized that other kids in school did not need to take insulin and that was shocking to them.

Conditions present when the adolescents feel different include: a) when they realize that others do not have to take insulin, b) when they have poor self-esteem, c) when they feel more mature than their peers, d) when they have to stop to care for themselves when with others, and e) when they feel unsupported. Conditions present when the adolescents do not feel different include: a) when others are accepting of them and b) when they feel supported. Two

hypotheses are a) by improving the self-esteem of adolescents they will not feel different than others and b) the reactions and interactions of their friends, teachers, and others around them enhance feelings of embarrassment or self-consciousness and how they are able to view themselves as normal.

The key issues around 'disclosing to engage support' or not disclosing to their friends, teachers, coaches and others they come into contact with are an important step in how the adolescent is able to normalize their life with diabetes during this phase. When they have issues with their body image, fears about being normal or different, and during this phase of wanting privacy, they have more difficulty in disclosing to others that they have diabetes as they just do not want anyone to know. This creates challenges for the adolescents as they share that they often do not want to give injections or test their blood around others so they are not different than their peers. As adolescents get older they share that they do not care who knows about their diabetes.

Summary

The major codes of building support (disclosing to others) and realizing I'm different are seen in this third phase with the axial code '**integrating diabetes into the world outside the home**'. Some of the key conditions that occur during this phase include: when the adolescents are not comfortable disclosing their condition, not wanting to care for self in front of others, worry about how others are viewing you, when others respect the needs of the person with diabetes, and when the adolescents do not feel like they fit in with their peers. Key hypotheses include: a) helping the adolescents feel comfortable disclosing their diabetes to close friends will allow them to seek assistance when needed, b) adolescents who are having poor self-esteem are more likely to not want to test in front of others and feel different, c) giving adolescents privacy in giving their insulin allows them to feel better about themselves and decreases the questions they get about their diabetes, d) by increasing others knowledge of diabetes

management and how to recognize and treat low blood sugars, the adolescents will feel more supported in managing their diabetes and being able to deal with a crisis, and e) the reactions and interactions of their friends, teachers, and others around them enhance feelings of embarrassment or self-consciousness and how they are able to view themselves as normal. The major task for adolescents in managing their diabetes is **enlisting support from others** with the normalizing task of '**disclosing to engage support**'.

Phase 4. Moving the Journey Towards Independence

Moving the journey towards independence is defined as the ability of the adolescents to successfully transition to independence from their parent by taking on primary responsibility for their diabetes management tasks. Regardless of the age of the child at diagnosis, at some point they reach the age of adolescence. During this phase of their life they begin the normal developmental tasks of early and middle adolescence that greatly influences their diabetes management. The adolescents begin to deal with some of the emotional challenges of the adolescent years by becoming more aware of others around them and wanting to spend more time with their peers than with their parents.

In the last phase we saw how the adolescents valued their privacy and realized they were different. In this phase the adolescents begin the process of seeking independence from their parents in their daily life as well as with their diabetes care. The primary task of normalization during this phase is '**taking on the burden of disease**'. As the adolescents take on more of the diabetes management, they also begin to realize that managing diabetes independently is a challenge and sometimes frustrating. Adolescents' interactions with their parents are difficult as they strive to become more independent and do not want their parent's involvement in their diabetes care. During this stage three codes that will be discussed include: **a) taking over care, b) experiencing conflict with parents, and c) realizing diabetes is**

hard. The **major task** in this stage is **separating from parent and independently managing diabetes.**

1.0 Taking over care

Taking over care is defined as the adolescents wanting to independently manage their diabetes. Transitioning to self-care of diabetes is a slow process that usually occurs over time. One of the challenges in taking over care from the parent is the willingness of the parent to let go of the care and for the parent to not transition before the adolescent is ready. Codes that will be discussed in this section of taking over care include the following: **1) transitioning from parental care, 2) independently monitoring the blood sugar, 3) taking over administration of insulin, 4) managing diet independently, and 5) managing activity independently.**

1.1 Transitioning from parental care is defined as the steps adolescents take as they strive to become independent in their life. Included in this transition are the following: **a) depending on your parent, b) taking over some responsibility gradually, c) needing to separate from parent, and d) assuming full responsibility.**

1.11 Depending on your parent is the first step when the adolescents describe they rely on their parents for assistance and seek help in taking care of their diabetes. During this step the adolescents always review their care with their parents.

“for a while I was really dependent on my parents a lot to help me with everything and they were really, really good, ...they went to some parent groups to kind of talk about it and figure out and learn more about how to help me” Interview #10 p. 3

“at the beginning I would tell my parents like everything, I would tell them my BS I would tell them everything, everything I did” Interview #10 p. 4

1.12 Taking over some responsibility gradually is the second step adolescents describe when they begin to take on more responsibility for their

care. This usually begins with some independent responsibility for the adolescents, and as time goes on the adolescents take over more of the care without assistance from their parents. During this step the parents often check in with the adolescents to make sure they are remembering to do their blood sugar and their insulin. Adolescents share that they need to have the knowledge first about how to manage their diabetes. Around age 10-12 is when the adolescents begin to want more responsibility for their own care but they share that if they are given too much responsibility too fast it is hard for them to know what to do.

“I think just gradually, I just started doing a little bit more and a little bit more...I think that I might take a little more responsibility but I don't think that I am going to completely do it by myself and, like I might do it if I'm somewhere else but like if I'm home, mom helps” Interview #1 p. 11

“when I was a child my mom mostly took care of it, so she was always watching my blood sugars, I think it was about when I was about 10- 12 maybe between that time frame that I started doing it on my own” Interview #4 p. 1

1.13 Needing to separate from parent is the next step of this process when adolescents describe their parents as too overbearing, and they would like to have more independence in their own care. The adolescents struggle with how to take care of themselves when their parents want to be so involved. They also share that their emotional turmoil during this time of conflict with their parents makes it difficult for them to want their parent involved in their care and they often do not want to do the care just because of their parents' constant reminders.

“she doesn't want to give up and let go but I'm not just going to let her do it either, I'm not going to let her take care of me because I need to be able to function as a normal person” Interview #11 p. 15

“my first sleep over my mother came with me ... she's always been going it and trying to grab that control from her literally is probably going to be like highway robbery where I just grab it and run because she won't let go because she is so used to doing it herself” Interview #11 p.4

1.14 Assuming full responsibility is the final step where adolescents describe they finally believe they will have complete control of their own care. Some adolescents state they do not believe this will happen until they are able to move out of the house. They say they are worried their parent will be calling to check in on them once they are on their own.

“I think the only way I’m actually going to be able to do it (diabetes) full on my own is by leaving so I mean like when I start my freshman year at college and they drop me off, then I can assume full and all responsibility, but I’ll probably still get the phone calls at like 2:00 in the morning” Interview #11 p. 13

“as you are older you are more independent, you know you move out, you do your own thing, so I guess that’s different, it’s going to be different when I have to start taking care of all my medical stuff, I mean I don’t call in my prescriptions, or I don’t order more sets or anything I just expect them to come” Interview #7 p. 10

Conditions when the adolescents are able to transition from their parent include: a) when the parents are willing to let go, b) when the adolescents have the skills to take over care, c) when the adolescents are older, and d) when the adolescents are emotionally ready to take on diabetes management. Conditions when the adolescents are not able to transition from their parent include: a) when they are too young, b) when the parents are not able to let go of care, c) when the transition happens too rapidly, and d) when the adolescents do not have the knowledge to manage their own diabetes and make appropriate care decisions. A hypothesis is helping the adolescent and parent work through the transition process together will decrease conflict and improve care.

1.2 Independently monitoring the blood sugar is defined as being able to do a blood sugar reading on one’s own and knowing what that number means, and what to do with that blood sugar number. There are several important steps the adolescents must be able to accomplish in order to be successful in their transition from other’s assisting them with their diabetes care. The steps in this phase differ from phase 2 where the

adolescents first learn about blood sugar monitoring. During this phase the adolescents have some skills for caring for their diabetes but are taking on the additional step of learning to do the care independently from their parents. The following codes will be discussed in monitoring blood sugars: **a) reaching independence in blood sugar monitoring, b) remembering/forgetting, and c) creating strategies for remembering.**

1.21 Reaching independence in blood sugar monitoring is defined as being able to monitor the blood sugar on your own. Several steps are part of reaching independence in monitoring the blood sugar and those include the following: **a) knowing how to use the equipment, b) keeping up with the equipment, c) doing the blood test, d) interpreting the result, and e) understanding when blood sugar testing needs to be done.**

1.211 Knowing how to use the equipment is defined as when the adolescents understand the steps in the process for doing a blood glucose test. The adolescents state they feel confident in their ability to do a glucose test early in their diabetes management.

*“pricking my finger that was fairly easy, I never really had much help with that, they would just like to watch to make sure I was doing it correctly”
Interview #10 p. 9*

1.212 Keeping up with the equipment is defined as when the adolescents are able to locate where the meter and testing supplies are when it is time to do their blood glucose test. When they were younger they found it easier to keep track of their kit or want to carry it with them. When they were older the adolescents didn't always want to carry their kit

around as it made them feel embarrassed and uncool. Examples of this are below.

“I have two meters the one for my kit which ...I wear when I go places, and then I have my home meter which I have a little crate on the counter” Interview #1 p. 8

“it was hard mostly, I’m not the kind of person who likes to carry stuff around with me for one so carrying a meter around was never a thing I liked to do” Interview #4 p.9

“it was embarrassing if my friends and people seeing me carrying around a meter and stuff...teenagers don’t want other people that see them with things that make them look uncool” Interview #4 p. 10

1.213 Doing the blood test is when the adolescents are successfully able to obtain a blood glucose reading on their meter by poking their finger and placing a drop of blood on the test strip. When adolescents were younger, their parents or school nurse checked on them often, and as they got older, they started doing it more on their own.

“I have to check my blood sugar with my poker...you have to hold it to your finger and then push it in by pushing this button and then put my blood into the test strip and it will tell me what my blood sugar is” Interview #3 p. 2

“when I got to junior high and I got a little more independent I would go to the nurse an she would still make sure I was doing everything right and then I got to test on my own, it was taking things slowly, it was a slower transition rather than being right on your own” Interview #10 p. 4

1.214 Interpreting the result is when the adolescents are able to look at the blood glucose value and make a determination of what that number means and the action they need to take based on that value.

“the higher you blood sugar gets the more insulin you have to take to get your BS or get everything down, but if it’s normal you’re fine” Interview #5 p. 4

1.215 Understanding when blood sugar testing needs to be done is defined as the adolescents knowing when they should test their blood sugar based on the time of day, prior to eating, if they are not feeling well, or if their blood sugar has been running high. Sometimes the adolescents believe they know they are feeling fine so they do not want to test their blood sugar. Examples of this include:

“I know my body so if I’m thirsty it’s probably high, if I’m shaky ...it’s because I’m low...I just kind of know where my body is at and when I need to check and so I think that is why I just don’t say I need to check my blood right now even though I might be like 250 I won’t feel anything and I’ll feel fine” Interview #7 p. 6

“when I eat I connect that to checking my blood so like I do that first...I have some days where I just don’t want to eat so I just don’t check my blood...you need to check your blood every 2 hours regardless of eating or not” Interview #7 p. 6

1.22 Remembering/forgetting is defined as remembering to test the blood sugar and give the insulin independently without forgetting. Adolescents share that they could do a better job of testing their blood sugars. They feel there are days that taking care of their diabetes is just nonstop and gets away from them. They also find they are less likely to remember to test their blood sugar when they are busy, when they are stressed out, if they just do not want to or if no one is reminding them to do it. There are times they just do not want to test their blood sugar. One thing that helps to remind them to do their blood sugar checks is reminding themselves to do it.

“mostly on like really stressful days when I really have a lot to do sometimes it will like just totally skip my mind and it’s just that like a few hours and I’m like, oh no I didn’t do my BS, and then it’s like that time that I will usually go high or low ‘cuz I’m not like paying attention to like what I’m eating, when I’m eating and when I’m doing my BS” Interview #4 p.4-5

“other times you generally do forget ‘cuz its bedtime check, you don’t know exactly when you are going to bed until you actually climb into bed” Interview #6 p. 8

1.23 Creating strategies for remembering is defined as the adolescents being able to problem solve things that will help them do their blood sugar in a timely manner. Strategies that help the adolescents remember include the following: **a) keeping a log, b) setting an alarm, c) using app on iPod touch or phone, d) keeping a schedule, and e) using a planner.**

1.231 Keeping a log is defined as a way to write down their blood sugars, food, and insulin doses. Adolescents state that the use of electronic devices to keep this log makes it more exciting. The adolescents find that the insulin pump is very useful for them since they are able to easily have all the information available and no longer need to keep a written log.

“I thought it was the end of the world if I wasn’t putting something in my log honestly when I was that age I thought it was like the biggest thing that you had to worry about...I guess I had it drilled into my head that that is what I had to do and I can’t remember back to why I wasn’t doing it but I don’t know I guess...when I got to be like on my own in a way... I didn’t have to like keep a log... but my doctor is still on my butt about it... with the pump it got easier because there was a lot less on you and more on the technology part the pump logs your numbers and your insulin and your food, I love that” Interview #7 p. 6

1.232 Setting an alarm is defined as using an i-touch or pump to set an alarm that goes off to remind the adolescents to check their bloods sugars. Adolescents state that sometimes they do not pay attention to the alarm.

“there are various ways my mom has tried to get me to remember to check like say set alarms on her i-touch she has so whenever I hear the

alarms...I would know to check my BG if I haven't done it recently"
Interview #6 p. 6

"my pump alarms, however you end up getting used to that alarm and unless it is really quiet I am not paying attention to it...I actually don't hear my pump anymore" Interview #6 p. 6

1.233 Using mobile device application (app) on iPod touch or phone

is defined as putting blood sugar and insulin information directly on an app using technologic devices. Adolescents share using apps help since they are already carrying their device and is exciting at the beginning, but then they forget to use that as well.

"like she (mom) got an app on her touch that allows you to log in your BG, it helps you to log your BG's and that helped me, I don't want to say the excitement of using a touch in school helped me out but it was like I basically always have stuff in my pocket of a different shape and I would be like what's that for again, and I would say oh yeah, touch, oh yeah, BG" Interview #6 p. 8

1.234 Keeping a schedule is defined as having a routine of doing things at a certain time of day. Adolescents share that keeping a schedule helps them to remember to do the test. Some adolescents state that they do not keep a schedule and can do well without one because they test when eating. Other adolescents state that it is more difficult on weekends or during the summer when they are not on a schedule.

"I'm very fly by my seat of my pants when it comes to checking my BS, I mean if I get up at 10 in the morning I'll check then, if I get up at 6 I'll check then, It's not like I get up specifically in the night to check my BS...I don't follow like a set schedule I think that if you follow a really set schedule all the time it makes it really hard for you to adapt to change"
Interview #11 p.13

"I have a schedule so like I get up at the same time every day, test at the same times every day, come home test, go to practice, test, eat dinner, test, so the school year it's fairly easy, in the summer it's a challenge because I just want to go off and do things" Interview #10 p. 8

1.235 Using a planner is defined as placing information in a written planner for monitoring blood sugars and insulin doses. Adolescents state that using a planner is not helpful if they are not going to write in it, not use the information, and not have the time to keep it up.

“mom’s like use your planner and I’m like mom I can’t use my planner and she is like why not? And it’s like I can write them in there but I will never look at the planner and she’s like make a habit of it and it’s like I don’t have the time mom, I probably could have the time if I didn’t stress relief as much but that would not be very wise” Interview #6 p. 7

Conditions when the adolescents are able to independently manage their blood sugars include: a) when they feel they know what they are doing, b) when they have an insulin pump, and c) when they have someone reminding them. Conditions when adolescents are not likely to independently manage their blood sugars include: a) when they forget to test and b) when they do not want to. A hypothesis is by creating strategies the adolescents like to help them remember their blood sugar tests will improve adherence to care.

1.3 Taking over administration of insulin is defined as adolescents being able to independently give their own insulin. Steps in this process include: **a) determining amount of insulin needed, b) giving the insulin, c) remembering to give the insulin, d) experiencing high blood sugars, e) developing strategies to address issues, and f) seeing assistance from others.**

1.31 Determining amount of insulin needed is defined as the adolescents knowing how much insulin to administer. Part of the process in learning how to do this is for the parent to check in and help the adolescents as they are beginning to do more on their own. In the beginning the adolescents are unsure of how much insulin to give. The adolescents begin to see diabetes as hard

when they have trouble getting the blood sugar to go down. The insulin pump is easier for the adolescents as they feel it is less work and more exact.

“they (parents) would check to make sure I was doing it right, I mean like injections, drawing up insulin...my carb ratio has been like 1:90 and then it was 1:40 and now I’m like 1:30 ...I would just have my parents check to make sure I was drawing up the right amount of insulin” Interview #10 p. 9

“I had problems taking insulin...adding up the carbs which my mom helped with...I wasn’t sure what I should do when it came to either low BS or high BS” Interview #5 p. 2

1.32 Giving the insulin is defined as the adolescents knowing how to give their medication correctly and being able to physically self-inject. Steps in this process include: **a) knowing how to use the equipment, b) keeping equipment available, and c) giving insulin independently.**

1.321 Knowing how to use the equipment is defined as when the adolescents are able to understand how to give their insulin with their insulin pump or syringe. When the adolescents do not understand how to use their equipment, they are more likely to have complications including high blood sugars.

“(you) just enter your blood sugar ‘cuz my meter already sends the BS to my pump and so I just have to enter my carbs and press act and then it’s done” Interview #8 p. 5

“I have a needle thing that you put into the insulin pen thing and you turn it and it clicks on and you take off the cap and then the other cap to the needle and I stick it in my stomach and then give my insulin” Interview #3 p. 6

1.322 Keeping equipment available is defined as making sure that testing and insulin supplies are available when needed. The adolescents discussed liking the insulin pump better because it is always with them.

One of the problems they discussed was when they go somewhere and forget to take their insulin; they then have to leave to get their insulin.

“you go to a friend’s birthday party and you forget insulin so you have to leave the birthday party” Interview #7 p. 12

“the pump has made it easier because you are carrying insulin with you wherever you go without carrying all the syringes and the vial” Interview #11 p.3

1.323 Giving insulin independently is defined as the adolescents being able to give their insulin by themselves. This starts off with the parent or others giving shots, then at some point the adolescent decides it is time to give their own insulin but usually will still have someone double check the dose with them to make sure they are doing it correctly, but at times they state they do not like others checking on them. The insulin pump is easier for adolescents to feel they are able to give their insulin independently.

“at the beginning I would like have my parents help me with shots and stuff and then I kind of like I think maybe the first year, almost was I think I was 11 going on 12 and so I was still young and so they wanted to like go over it with me” Interview #10 p. 4

1.33 Remembering to give the insulin is defined as when the adolescents are able to independently remember to take their insulin dose when needed. Some adolescents relay information on how they sometimes just forget to take insulin, and sometimes they just do not want to as they feel that it is just a small amount of food. Other adolescents state they do not forget insulin very often.

“I think probably I was going high because I wasn’t taking insulin back when I was on the Novolog pen... I didn’t really forget it many times unless I was going somewhere where I wasn’t eating anything but I would have it but I wouldn’t

remember that it was there and that I needed to take insulin 'cuz I was just like, oh well does it matter, it's just a little bit of food" Interview #4 p. 5-6

1.34 Experiencing high blood sugars is defined as having higher blood sugars than your target range. Sometimes adolescents relate that their blood sugar is high because they did not take the correct dose of insulin, sometimes because they forgot their dose of insulin, and sometimes from having a bad insulin pump site. At times they just do not take their insulin because they get to a point of not caring about their diabetes which leads to high blood sugars and DKA. A code that will be discussed is **addressing high blood sugars**.

"the going high...might be that I'm not quite getting the carb ratio right, that maybe I'm not taking enough and I do admit sometimes I do forget to like take my BS or to take insulin for something little I eat, It's one of those things like when I have sleepovers or times out with friends" Interview #4 p.4

1.341 Addressing high blood sugars is defined as the ability of the adolescents to know how to manage a high blood sugar once they have identified they are running high. Adolescents share how they try to catch the blood sugar before it is too high by giving a bolus or changing their basal rate.

"if I see that I'm going up ...then I can give myself a unit or two of insulin and then I can stop the high when I'm at 203 instead of past 300" Interview #11 p. 9

"if you are running high in the morning maybe you should turn the basal rates up a little bit" Interview #11 p. 9

1.35 Developing strategies to address issues is defined as the adolescents recognizing that they need to find ways to help them independently remember to take their insulin. The adolescents share strategies they use for helping them to remember to take their insulin and to have their insulin supplies available to

them. Strategies to be discussed include: **a) creating a schedule and b) carrying a bag.**

1.351 Creating a schedule is defined as doing things at the same time each day and is one way the adolescents find it is easier for them to remember to take their insulin.

“I’m like really careful with on school days I have a schedule, so like I get up at the same time every day, test and take insulin at the same times every day come home test, go to practice, test, eat dinner, test, so the school year it’s fairly easy” Interview #10 p. 8

1.352 Carrying a bag is defined as keeping your supplies in one set place and is another strategy the adolescents use to make sure they have their supplies with them to be able to independently manage their insulin.

“it(bag) carries my phone, I prefer not to juice anymore I do powder sticks like pixie sticks but they are for diabetics and then...I have my poker and the checker in there and I have my glucagon” Interview #8 p. 3

1.36 Seeking assistance from others is defined as getting help from school nurses, diabetes educators, parents, coaches, or doctors. Sometimes the adolescents choose not to seek help from their parents so they do not have to experience conflict.

“if I am having problems I go talk to them but if everything seems to be going fine I will just take care of it myself and like the only time I still talk to them I still discuss with them how are your numbers, how have they really been” Interview #10 p. 4

“I’ve talked to the dietician and one of my really good friend’s mom is a nurse so whenever I go over we are talking about stuff” Interview #10 p. 13

Conditions present when the adolescents independently give insulin include: a) knowing how to use their supplies, and b) when they have their equipment available. Conditions present

when the adolescents are less likely to independently take insulin include: a) not caring if you give the insulin, b) forgetting to give the insulin, and c) having others check to make sure insulin is given correctly. A condition that is a barrier to independent care is when the adolescents are afraid of giving their own injection or placing their own pump site.

“she would put the orange next to my stomach and then here’s some saline try it with some saline and I would stand there with my little uniform and I would have it all bunched up and I’d be like whew, hew and I’d count to 3 and I couldn’t do it and then I’d count to 3 again and then I’d count to 5 and I couldn’t do it and then I’d count to 10 and I’d just prolong it and I would stand there for like a good 20 minutes okay you can do this, okay you can do this...it was a very long drawn out process” Interview #11 p. 5-6

“it is time to change your site and I’m like I’m not doing it, I’m not doing that nope, like I just started crying and everything and I don’t know why...I was like 12 or 13 and I was old enough that I didn’t need to be crying over that but it still wasn’t fun” Interview #7 p. 14

A hypothesis is that insulin pump use increases independence and improves care for adolescents and that use of the alarm feature can help adolescents remember to do their own blood sugars and insulin.

1.4 Managing diet independently is defined as being able to independently count the carbohydrates and make appropriate food choices and calculate insulin dosing.

Adolescents describe multiple strategies used to manage their diet including: **a)**

learning to identify foods with carbohydrates, b) learning to identify amount of

carbohydrate in products, c) learning to add the total carbohydrates, d)

calculating the correct dose of insulin for carbohydrates, e) learning from blood

sugar results how food affects the body, f) learning how to create a balanced diet,

g) remembering to take insulin for food, and h) developing strategies for carb

counting.

1.41 Learning to identify foods with carbohydrates is defined as learning about food choices and which foods contain carbohydrates.

“the diabetes educator came in...first of all I had to learn about what all this stuff was...like what are carbs, what food has carbs, ‘cuz I never really thought about that before” Interview #10 p. 3

1.42 Learning to identify amount of carbohydrate in products is a step the adolescents take to be able to correctly count the food they are eating. Parents help the adolescents when they are first learning this by putting notes in the adolescents’ lunch. Adolescents share steps in identifying the amount of carbohydrates that include: **a) using a scale, b) using a measuring cup, c) looking up information in the book, d) eyeballing the food, e) using hand values to estimate amount of carbs, f) memorizing certain foods, and g) eating prepackaged foods.**

“other than that it is just a lot of reading labels” Interview #11 p. 11

“if it’s something with the carb count on the back that’s like that makes it real easy” Interview #1 p. 10

1.421 Using a scale is defined as weighing food products to correctly measure the amount of carbohydrates in them. Initially the parent helps the adolescent in using the scale to learn how many carbohydrates are present.

“we have my scale, which has like a booklet with numbers and then you type in the numbers and it tells you what carbs it has So like pizza, no bread I think whole wheat bread is 301 and so you type it in and we put my plate on first and then turn it on so it is like zeroed, and then we type in 301 and then like bread so it tells us like 20” Interview #1 p.10

1.422 Using a measuring cup is defined as using measuring cups to measure out the appropriate serving size of food choices to correctly carb count them. Some adolescents say they never measure their food with measuring cups or scales.

“we never did the measuring and the scales” Interview #11 p. 7

“well I’m not sure how I started getting onto the measuring stuff ...go to the cupboard and get a cup and measure it out ...for 1 cup it has 24 grams and if you have 2 cups...it’s like this much for 2 of that it equals that is how I started doing that” Interview #4 p. 17

1.423 Looking up information in the book is defined as using a printed reference to review information on food items to obtain the correct carb count.

“calorie king book for the carbs...it has like fast food and stuff when you go to restaurants you can look things up in there like if they don’t have the nutrition information available” Interview #1 p. 9

“I got this really cool book that had like every chain restaurant and everything in there so I could look at that and it pretty much had like every food on the planet so like if I would go get a milkshake I could look it up in there...it had the amount of food – like 1 cup of cereal – that is 23 carbs for cheerios or whatever” Interview #12 p. 2

1.424 Eyeballing the food is defined as estimating the amount of carbohydrates in foods based on approximate size of food choices. Adolescents share that this is a skill that is learned over time, but sometimes is not as accurate and is more of a guess.

“it was more of a guess... you know this looks right and we would just do that” Interview #11 p. 6

“I am an expert, I feel like I deserve a medal or something that says carb counting expert – I can eyeball it, my friends will give me stuff at lunch and they will say how many cars are in it and I’ll look and I’ll say there is like 62 and they will say 62 good job, I have learned over the years” Interview #11 p. 7

1.425 Using hand values to estimate amount of carbs is defined as estimating food choices by approximate size using your hand. Adolescents share that this method is particularly useful when you do not have the scale or measuring cups available.

“how to carb count certain foods so I do it like value, like on your hands – the size of your fist or a handful of pasta is about half a cup which is about 15 so like even at the restaurant if you look silly it’s like ok, here’s a half a cup, here’s another half a cup, here’s another half a cup (showing motion of scooping up handfuls of pasta) but you know that’s a big thing that they teach you is how to do it by measurement when you don’t have scales and you don’t have actual measuring cups” Interview #11 p. 7

1.426 Memorizing certain foods is defined as learning the carbohydrate count of food choices that are eaten often.

“this has this much carbs you know we learned everything one year about how much carbs are in a serving of fruit so like I have this little song in my head about how much carbs a 2” apple is, how much a 3” apple is, it’s ridiculous but it works because you remember it” Interview # 11 p. 7

“you just start to memorize that a cup of pasta is 40 and a cup of milk is 12 and you just kind of start to memorize that a piece of bread is like 15” Interview #12 p. 1

1.427 Eating prepackaged foods is described by the adolescents as a way to obtain a correct carbohydrate count by eating foods that have a label on the side of the package; this helps them to eliminate the guessing.

“I would have food that was packaged snacks like fruit snacks, the all natural stuff, and it would say (the carbs) on the side so you would know...we never did the guess sort of thing” Interview #11 p. 7

“I can look at serving sizes on the amount of carbs on the package for example if I wanted to have half of a chocolate milk I would look at the back and it would say if there was 20 carbs and the serving size was 2 so there would be 40 carbs if I had the whole thing but if I only had half then it was just 20 and I would just cover for half” Interview #12 p. 2

1.43 Learning to add the total carbohydrates is defined as adding up the total amount of carbohydrates for the meal or snack to be consumed The adolescents describe a number of steps they take to help in adding the total carbohydrate

intake including: **a) using the calculator, b) creating a log, and c) writing amounts on a sheet.**

1.431 Using the calculator is defined as using technology to quickly divide the amount of carbohydrates by their carb ratio to come up with the insulin dose needed.

“I have a spot for like every blood sugar I check ... they'd have my um my insulin to carb ratio... you'd write your carbs right here and divide them on the calculator 'cuz it told you what to divide by” Interview #1 p. 3

1.432 Creating a log is defined as writing information about carbs on a special log sheet created to help in calculating correct doses of insulin for food.

“mom made these spread sheets and we have and like I have a spot for like every blood sugar I check like the normal ones, and then if they were like at lunch and breakfast and dinner” Interview #1 p. 3

1.433 Writing amounts on a sheet is defined as writing carb information on a note to provide with a lunch or other meal so it is already calculated for adolescents. Adolescents state that sometimes the parent is helping with this step as a way to get them to learn the value of each food they are eating.

“normally I help like today she wrote down what I was going to have for lunch like bread, apple, crackers and they would just be like shorthand or something like bread is just BR and I would weigh out the crackers and write down the carbs and she might write down the carbs for an apple and then she might tell me the carbs for bread and I would write them down” Interview #1 p. 11

1.44 Calculating the correct dose of insulin for carbohydrates is defined as doing the math calculations needed to figure out the correct dose of insulin for

foods eaten. The adolescents describe carb counting as challenging for them at times and often double check the information with their parent. Several steps are involved that help the adolescents to calculate this dose including: **a) memorizing the scale and b) using the insulin pump.** An example of calculating the correct dose of insulin is seen below.

“I have to see like how many carbs are in the food and then I have my carb ratio is 1:10 and I have to divide by 10 to see how many units I have to give” Interview #3 p. 2

1.441 Memorizing the scale (for insulin dosing) is defined as learning the scale used to calculate insulin dosing The adolescents share how this sometimes takes a long time, how writing it on paper can help them, as well as the difficulties when it changes.

“(I needed to) make sure I knew how much insulin for a certain amount of carbs, that took me like a really long time to memorize and ‘cuz you have these scales and you have to know what the scales are and it took me a really long time that was probably one of the last things I started doing ‘cuz I would mostly be like mom, how much is this I really don’t know” Interview #4 p. 18

1.442 Using the insulin pump is defined as a method used by adolescents to calculate insulin doses, by entering their blood sugar and food into the pump, the math is then done for them automatically.

“you would put in the amount of carbs you are taking, put in the amount that your blood sugar is and it does all the math for you which is great” Interview #11 p. 7

1.45 Learning from blood sugar results how food affects body is defined as learning about how food affects the body by testing the blood sugars and altering the values the next time.

“it’s a lot of last time I had this – did I go high or low, it’s just a lot of trial and error” Interview #11 p. 11

“so if I guess when I try something new for the first time I’m like this sounds about 50 carbs ok, well then if I go high then next time I have it I’ll try like 60 or 70 or if I go low well maybe I’ll do 45 or 40 it really, it’s very much this is too much this is too little” Interview #11 p.11

1.46 Learning how to create a balanced diet is defined as learning about how to eat a healthy balanced diet or meal plan. The adolescents share two different ways that help them to create a balanced diet which includes: **a) using the plate plan and b) cooking for yourself.**

1.461 Using the plate plan is defined as a way to quickly visualize food items to eat balanced meals.

“the FDA has a plate plan...like half your plate is supposed to be vegetables and a quarter of it is supposed to be meat and a quarter of it is supposed to be your grain and then you are supposed to have some like fruit and milk and all that sort of good stuff...I do that because you feel better” Interview #11 p. 10

1.462 Cooking for yourself is defined as learning more healthy eating and choosing types of foods by creating your own meals.

“I cook dinner for myself sometimes now so it’s a lot easier to do all of it when you can decide what you put in your body as well as like medicine and what goes in with it” Interview #11 p. 10

1.47 Remembering to take insulin for food is defined as the ability to remember to take an insulin dose for food eaten. Adolescents state they have trouble remembering their insulin for their food, especially when snacking or when they are out with others.

“I wouldn’t remember that it was there and that I needed to take insulin ‘cuz I was just like, oh well does it matter, it’s just a little bit of food” Interview #4 p. 5-6

1.48 Developing strategies for carb counting is defined as finding things that assist the adolescents in carb counting easier, these include eating the same foods, eating staples in your diet, and by using the insulin pump as a way to remember their ratios since they are programmed in the pump. Eating staples in your diet is defined as eating the same foods over and over.

“I ate the same thing for breakfast, lunch, and dinner every single day for a very long time...I had waffles with peanut butter for breakfast every single day so it was like really easy to calculate” Interview #11 p. 6

“I make this soup with noodles in and I know a ladle is this much carbs...that’s helpful when you kind of know some staples in your diet that you are always going to have” Interview #11 p. 10-11

“it’s easier ‘cuz I don’t have to remember my carb to insulin ratios...(the pump) is easier, my carb to insulin ratios were changing like every 3 weeks so we had to adjust them and it was hard to keep track of” Interview #1 p. 2

Conditions when the adolescents are able to manage their diet independently include:

a) when they understand how to carb count correctly, b) when they are able to learn how much insulin to give for their food, c) when they understand the effects of their diet choices on their blood sugar, and d) when they structure their eating times and choices. Conditions when the adolescents are not able to manage their diet independently include: a) when they guess at their carbohydrate totals, b) when they are not able to understand the process of how to identify and count the foods they are eating, c) when they are out with others, and d) when they eat foods that they are not familiar with. A hypothesis is that by helping the adolescent to feel comfortable with appropriate carb counting methods, and once they have developed the skills needed for carb counting, they will be more successful in giving the correct dose of insulin.

1.5 Managing activity independently is defined as learning to assess effects of activity on the blood sugar values and make appropriate adjustments to insulin or food.

Adolescents shared two things they do to help manage activity including: **a) assessing effects of activity and b) managing insulin dosing for exercise.**

1.51 Assessing effects of activity is defined as being able to learn about how activity affects the blood sugar levels. Some adolescents state they do not check their blood sugars; they just go run.

"I have found that I go high right after I exercise...my first reaction is oh, my BS is high and I need to give myself insulin but if you give yourself insulin then you are going to hit the low from the exercise and then you are going to go really low so exercise is like really hard for me...if I go for a walk, that is like nothing... if I'm running or lifting or doing any sort of circuit I have to stay with a high BS for a while because or if you it is just you don't know if you are going high, high or if you are just doing that exercise go high go low" Interview #11 p. 11

"there is nothing really special with exercise that I do with diabetes I will just go and run like any other kid" Interview #6 p. 10

1.52 Managing insulin dosing for exercise is defined as learning how to adjust insulin dose based on activity levels. Some adolescents share that they don't understand why they have high or low blood sugars when they exercise.

"I sometimes will take my basal rates down about an hour or so after I exercise because that's when the lows will start so and then I'm not taking way less insulin when I am running high" Interview #11 p. 11

"she needs to exercise, so then I would like go high and then I would plummet and so it too a couple runs of why is this happening why is this happening" Interview #11 p. 12

Conditions when the adolescents are able to independently manage their activity include: a) understanding the effects of exercise, and b) having the ability to make a judgment on the amount of insulin to be given to keep their blood glucose levels balanced. Conditions when the adolescents are not able to independently manage their activity include: a) when they are not monitoring their blood glucose with their activity, and b) when they do not understand the effects of how activity affects their blood glucose control. A hypothesis is that by developing

an awareness of the effects of activity on blood sugars adolescents will then learn to better manage their blood sugars when active.

The major goal of the adolescents in taking over care is to become independent in their diabetes management tasks. As the adolescents take on more of these tasks they simplify their regimen to try and maintain as much normalcy in their life as possible. In trying to accomplish normalcy and independence, the adolescents begin to experience more conflict with their parent as they make choices about how they are going to manage their diabetes that may not fit with the parent's view of maintaining their health.

2.0 Experiencing Conflict with Parents

Experiencing conflict with parents is defined as the parent and adolescents not agreeing on diabetes management or arguing over care being done. Codes that will be discussed include the following: **a) struggling for independence, b) experiencing nagging from parent, and c) building trust.** Adolescents share that they begin experiencing increased conflict with their parents as they try to transition to independent care of their diabetes. The adolescents and parents have disagreements about their care, what is expected from them, and how to help their parent trust their abilities to care for themselves.

2.1 Struggling for independence is defined as trying to take on more independent care by having parents too involved or checking in too often is a struggle. Adolescents share that while they are attempting to become independent from their parent, they feel like they are in a tug of war with their parent wanting to retain control over the diabetes management. Adolescents state that they believe they are doing their own care, but their parents are constantly trying to stay involved. On the other hand, once the adolescents are older they begin to understand that this is a difficult transition for their parents, and their parents want them to stay healthy. A code that will be discussed is

worrying about the reaction of parents or others. An example of struggling for independence follows.

“it is the tug of war that happens when you have a sick child that you have been taking care of since she has been like an infant and I completely understand...but it’s just hard for her but at the same time it kind of just needs to be like a band-aid - just rip it off quick, I mean and just let me go” Interview #11 p. 15

2.11 Worrying about the reaction of parents or others is defined as worrying about the parents reactions to blood sugar values. Adolescents share that as they do care independently, they have high blood sugars at times and worry about what to tell their parent or doctor to avoid getting into trouble. They sometimes lie about their blood sugar value or do not test ketones with high blood sugar just to avoid conflict.

“we had installed the fear that if like you don’t have a perfect number you were going to get yelled at and like I still have that fear ‘cuz even now if I have a high number and I know mom is going to get on me I might be like just tell her it’s a little lower even though I am like going to take care of it” Interview #7 p. 10

2.2 Experiencing nagging from parent. Adolescents define nagging as when the parents ask them over and over again about their blood sugars and always wanting to check in with them about how their blood sugars are doing. The adolescents relay how at times the nagging causes them to not want to do their blood sugars and that as they get older they just ignore the nagging more. Codes that will be discussed include: **a) avoiding testing from nagging, b) wanting to be 18 to not deal with parent nagging, c) understanding parent means well, d) getting used to parent nagging, and e) experiencing the parent not nagging.**

2.21 Avoiding testing from nagging is defined as not testing the blood sugar because the parent is reminding them so often to do it.

“you don’t want to nag because it just wants to not make them want to do it more ‘cuz there is a difference between did you check your BG and you need to check your BG, you need to check your BG, you need to check your BG” Interview #6 p. 8

2.22 Wanting to be 18 to not deal with parent nagging is defined as wanting to be older so you no longer need to deal with the parent constantly nagging.

“I can actually remember myself doing the calculations and finding out just how many days till I turned 18 so I didn’t have to deal with mom or dad nagging on me anymore, I mean all the time” Interview #6 p. 4

2.23 Understanding parent means well is when the adolescents come to realize that their parent is asking them about their blood sugars and diabetes care to try and help them to stay healthy, and because they care about them.

“I mean all the time, I know they do it for the best. . .It’s not that easy but something tells me that I’m ignoring you and then you get angry for me asking you all the time and then ignoring your help. . . it’s just something that I have to deal with I mean” Interview #6 p. 4

“Even though it is annoying to have your parents and everyone on you and stuff I’d rather have them on me then being you know lazy with their caring, I guess it just shows that people care” Interview #7 p. 2

2.24 Getting used to parent nagging is when the adolescents finally just gets used to their parent’s reminders to do their care, but this helps when their parent is not reminding them as often.

“Kind of just after hearing like hearing it so repetitive you just kind of getting used to the point that you’re going to hear it at some point, just don’t get angry at it, it won’t get you anywhere you are going to hear it again, just go do it and then well you don’t have to hear it again, she doesn’t quite say it as much as she used to I mean like I do my BS most of the time now, it’s just maybe like 2 or 3 times a day now she’ll tell me ... go do your BS” Interview #4 p. 10

2.25 Experiencing the parent not nagging is defined as a time the adolescents feel their parent is not nagging. They find some of the reminders about checking blood sugars helpful to them so they don’t forget to check, and even find it

reassuring by having their mom help them. If they do not want to check, and their mom reminds them, then they will usually go ahead and check their blood sugar. Adolescents state that sometimes their moms have to remind them several times before they finally test.

“Well it’s helpful for me for my mom to remind me so I don’t forget to do it, she like reassures me and tells me to do it so I don’t forget and then I can get to my food” Interview #3 p. 10

“Sometimes I don’t want to check my blood sugar, but my mom is just like check your blood sugar” Interview #1 p. 1

“if I don’t check my blood sugars she says go check your blood sugar before you eat, she is just on me about that, it is a help for her to remind me, sometimes I’ll forget I’ll just like hear it and then I forget her saying that and then she’ll like yell at me and then I remember and I go and check” Interview #3 p. 8

Conditions when the adolescents experience less nagging from their parents include: a) when they are older, b) when they believe their parent is trying to help, and c) when they know they need reminders from their parent. Conditions when the adolescents are more likely to experience nagging from their parent include: a) when they are young adolescent’s age (10-12), b) when they first are doing more on their own, c) when the parent repeatedly asks about diabetes management, and d) when the adolescents do not believe the parent trusts them to make a good decision. A hypothesis is by decreasing nagging between adolescents and their parent the adolescents will be more willing to do their care.

2.3 Building trust. The adolescents share that building trust is part of the process in decreasing conflict with their parent. Building trust is defined as having a relationship with their parent that allows the parent to trust that the adolescents are able to independently manage their diabetes. Codes that will be discussed include the following: **a) demonstrating care being done, b) affirming care is done, c) having a**

conversation with parent, d) demonstrating truthfulness in care, and e) showing parent you are doing well.

2.31 Demonstrating care being done is when the adolescents show their parent that they are testing their blood sugar and giving themselves a shot.

Adolescents share that when the parents are checking on them more the parent trusts they are going to do their care.

“they had to see my check my blood and they had to see my log and they had to see me give my shot” Interview #7 p. 9

2.32 Affirming care is done is when the adolescents responds to their parent that they have already done their blood sugar and insulin when asked.

“they will be like hey did you check your blood and I’d be like yeah and hey did you give yourself a shot and I’d be yeah and they’d say how much and I’d tell them, I guess there is a lot more trust on me that I’m doing what I’m supposed to be doing” Interview #7 p. 9

2.33 Having a conversation with parent is when the adolescents are able to have a conversation with their parent to help build trust that they know how to handle their diabetes and will be able to manage a high blood sugar or low blood sugar.

“you just need to have the conversation with your parent that like if my number is like 425 because I had a bag of chips and I didn’t bolus for it you will just have to trust me that I am going to get that number down because I know what it’s like to be sick and I’m not going to do that to myself...I guess some points they lose trust but you just have to let them know that you know how to handle it...you know what you are supposed to be doing” Interview #7 p. 10

2.34 Demonstrating truthfulness in care is when the adolescents are telling their parent the correct blood sugar that can be verified in the meter and that builds trust.

“she is not going to go check my meter some days she does and some days she doesn’t but she just trusts in me that I checked my blood and it was 125 so it makes it less of a burden if we are doing what we are saying truthfully compared to just lying about it” Interview #7 p. 10

“there is less and less of checking in so I’m sure as I’m getting older there is going to be less and less concern that I’m doing it right and more trust that I’m doing what I’m supposed to be” Interview #7 p. 11

2.35 Showing parent you are doing well is when the adolescents feel that their parent or nurse is able to trust them because they have been doing their care appropriately without assistance from others. Adolescents share that they believe this helps to build trust with their parent when they show them they are able to manage on their own.

“I would always get really good reports, oh, your numbers look great, and so my parents kind of trust me they do trust me and I do pretty well on my own, so just kind of over time they just kind of let me do my thing” Interview #10 p. 10

“I don’t have to go check in with the nurse...they just trust me to do it...not having to be at the beck and call of someone a certain time every single day or get yelled at ‘cuz I didn’t do it” Interview #7 p. 10

Conditions when the adolescents are able to build trust include: a) when they are doing their care, and b) when their parent is monitoring the adolescent and assuring care is done.

Conditions when the adolescents are not able to build trust include: a) when they lie to their parent, b) when they do not test or take their insulin when their parent asks, and c) when they are younger. A hypothesis is that when parents trust the adolescents they are more likely to allow the adolescents independence with providing their own care and adolescents are more likely to be truthful in sharing information.

The goal for the adolescents during this step is to decrease the conflict and nagging from their parents by building trust in their ability to manage their diabetes. Part of the struggle for the adolescents as they are trying to find a sense of normalcy and balance in their life is the

realization that diabetes is hard, and finding they often experience the management tasks as a burden on their life that leads to problems in maintaining blood sugar control.

3.0 Realizing diabetes is hard

Realizing diabetes is hard is defined as struggling to manage diabetes independently all day every day, not having blood sugars respond as expected, and the emotional burden of having diabetes and just wanting to give up. Adolescents share challenges they have in managing their diabetes independently once they begin to separate from their parents and realize they are different from their peers. They state that when their blood sugars are out of control is when they feel diabetes is hard and when their blood sugars are in control they are better. Codes include: **a) experiencing burnout, b) juggling diabetes with other responsibilities, c) getting frustrated, d) getting annoyed, and e) getting stressed.**

“Sometimes it is kind of hard, you just have those days where like it seems like everything is harder than it really is, when you are young and when you have those days, basically when you have diabetes it’s like you just want to give up” Interview #4 p. 13

“when you first start doing it yourself it is a harder thing because you’re not sure what you are doing because you know you have always had someone else kind of doing it for you and so it’s like ok, what am I supposed to do, how am I supposed to do it” Interview #4 p. 17

3.1 Experiencing Burnout is defined as the adolescents not being able to focus on doing their diabetes care in an appropriate way due to their feelings about having diabetes and feeling it is a burden in their life. Codes that will be discussed include the following: **a) realizing that diabetes is a pain, b) believing diabetes is a burden, and c) experiencing trouble taking care of diabetes.**

3.11 Realizing that diabetes is a pain is defined as feeling that diabetes is just always there and not being able to take a break from taking care of it.

“(being a pain) goes with diabetes being hard it’s just always there” Interview #6 p. 16

“living with diabetes is definitely an interesting experience. . . it’s almost like continually riding a bike and you cannot stop or else. . .it’s just a pain, I will put it that way, it’s definitely a pain” Interview #6 p. 1

3.12 Believing diabetes is a burden is defined as the adolescents believing that diabetes is something they have to deal with that is very difficult and time consuming to manage. Adolescents shared how feeling diabetes is a burden leads to their not always manage their diabetes as they would like to. Codes that will be discussed include the following: **a) not checking blood sugars, b) lying about blood sugar numbers, c) running out of insulin, d) acting lazy, and e) needing a break.**

“you have to check your blood every hour or two hours, and you have to give injections or change your sites or fill your reservoirs, or if you get sick you have to go to the hospital, or the feeling of when you’re sick of how nauseous you are, it’s a burden any disease is a burden” Interview #7 p. 2

3.121 Not checking blood sugars is defined as when the adolescents are tired of the day to day work in managing their diabetes and do not always do their blood sugar checks in a way they know will help them to control their diabetes. They state they also are trying to fit in with their peers.

“for a while I wasn’t checking my blood sugars or staying on it...I think it is just part of being a teenager you know what teenager wants that burden all the time” Interview #7 p. 1

“like not checking your blood, like some days I check my blood like twice I know that is horrible... you realize you are different from everyone else and you are trying to fit in...if you are going to a movie and are going to eat popcorn you don’t want to stop and check your blood or if you are hanging out with friends you are going to get food after school you don’t want to be hold on I’ve got to check my blood” Interview #7 p. 3

3.122 Lying about BS numbers is defined as when the adolescents know they are not doing what they are supposed to and do not want others to find out their blood sugars are not in the range they would like them.

“not being honest with your doctor’s I mean I remember when I was like littler and we had the little logs that I would write down everything in and I mean I would lie in that thing all the time” Interview #7 p. 5

“we are in the car and mom is like did you check your blood and like if I do I will say it was 125, I could lie about that number she is not going to go check my meter some days she does and some days she doesn’t” Interview #7 p. 10

3.123 Running out of insulin is defined as when the adolescents are not keeping up with their diabetes and do not make sure they have insulin in their insulin pump which leads to DKA.

“I did know what was going on...like from ketoacidosis...I ran out of insulin and then I went in” Interview #7 p. 1

“one of the biggest things for me is like I will go to bed and forget that my reservoir is empty and I’ll be like so comfy and I will be like you just need to get up, I did that last night, I mean I do that all the time and it is like the biggest bummer” Interview #7 p. 12

3.124 Acting lazy is defined as not doing what you are supposed to be doing to manage your diabetes because some days you just are not as motivated to take care of it, which leads to poor blood sugar control.

“I obviously know when I’m not like checking my blood enough and I know when I’m being lazy with it but I’m like a teenager and teenagers are lazy and I know that I’m not supposed to be lazy but I think that is a natural human habit to be lazy when you are a teenager but I know it’s not an excuse...I know there is nothing drastically wrong with me I’m just lazy” Interview #7 p. 3

“I have to check my blood sugar and ahhh, I have to change my site, and that is when I started to get really lazy and just not and I would leave sites in for like 2 weeks because I was just no, I don’t want to do it so there was that I mean as terrible as that sounds you just get lazy and your blood sugars just go like really high and really low and their A1C’s get all messed up” Interview #11 p. 8

3.125 Needing a break is defined as just wishing you could have one day when you do not have to take care of your diabetes, and so some days you do not do all the care to give yourself a break.

“you do get burnt out, you get tired of doing the same thing every single day, you want to know take a break from it even though you know you can’t and so I guess you try to just get around it” Interview #7 p. 3

3.13 Experiencing trouble taking care of diabetes is defined as not being able to keep up with doing the blood sugars and giving the insulin resulting in a rise in HbA_{1c}. The adolescents shared that when their parents stopped helping them as much they had, more problems keeping their blood sugars controlled.

“I started doing it on my own and for the first few years my A_{1c} went up a bit but it was still ok, then maybe a year or two ago it actually started becoming harder for me to be able to keep up with you know doing blood sugars and insulin” Interview #4 p. 1

3.2 Juggling diabetes with other responsibilities is defined as the adolescents trying to maintain balance in their daily life. This balance includes their school work, chores, friends, sports, and their relationships, yet still being able to manage their diabetes.

“there are just so much, school, relationships and everything and I just think this just adds that much more stress...some days I just like cry about this... and then I get frustrated” Interview #10 p. 11-12

“I’m overwhelmed trying to juggle school, and sports and diabetes and stuff” Interview #10 p. 17

3.3 Getting frustrated is defined as the adolescents not feeling successful in their management of diabetes and trying to manage their blood sugars while keeping up with

their other responsibilities. The adolescents view diabetes as hard when they have problems managing their blood sugars.

“if I’m really, really high or something...if it’s just one of those days that I’m not in a good mood and then my BS is off and it just kind of like piles up like one thing after another, I mean maybe they are just little things but... if my BS are way off then it just makes it worse (frustrating)” Interview #10 p. 12

3.4 Getting annoyed is defined as being irritated when others are always checking in on them because of their diabetes, as well as because they have diabetes and caring for it is interfering in their day.

“suffocating...smothering...It’s annoying honestly and she knows it she I just don’t think she’s physically capable of stopping what’s your BS now what’s your BS now” Interview #11 p. 4

“people were annoying in middle school and it was just like I don’t want to worry about this ‘cuz I’ve got my social life to worry about” Interview #11 p. 8

3.5 Getting stressed. Adolescents discuss how stressed out they get from diabetes, from life, from all the responsibilities they have, and how that makes it hard to juggle everything and the effects on their blood sugar from stress.

“I have been stressed out about family things and school things especially with fast pitch because I have been practicing all day... then coming home and doing my chores and my homework and it’s hard and then it just stresses me out so then my blood sugar goes high and that’s pretty much why my blood sugar goes high lately” Interview #2 p. 3-4

Conditions when the adolescents feel that diabetes is not hard include: a) when they have more parental assistance, b) when their blood sugars are in better control, c) when they are older, and d) when they do not believe diabetes is a burden. Conditions when the adolescents feel that diabetes is hard include: a) when they are having difficulty controlling their blood sugars, b) when they want to fit in with their peers, c) when they feel like they need a break, d) when they are younger adolescents, and e) when their parent is not helping as much.

A hypothesis is if adolescents were able to take a break from diabetes for a few hours or a day when they feel it is a burden they will be more in control on other days.

Emotions are an important part of this phase of the journey moving the journey to independence. Negative emotions that adolescents discussed on their journey to independence include: a) feeling worried, b) feeling sad/depressed/suicidal, c) feeling not recognized by their parent and d) feeling overwhelmed. Adolescents discuss how they wish they could just forget they had diabetes and struggle with having to worry about their blood sugar all the time.

The adolescents described **feeling depressed** about having diabetes, having an overwhelming sadness that causes them to wonder what is the point, and stating they think about suicide.

“I don’t even know what I’m sad about anymore, you just get to the point that it’s like what is the point of being sad, you know? You know what I’m talking about right, committing suicide” Interview #6 p. 4

Adolescents describe **feeling not recognized** by their parents; they would like approval from their parents instead of always hearing negative comments.

“I want to please my parents and mom’s not exactly the person to come to and say oh wow! It’s great! She will say well that looks nice, but ... you missed this... sometimes I don’t feel recognized by mom for being mature” Interview #6 p. 5

Adolescents discussed feeling **overwhelmed** about their diabetes and how their parents respond to events that happen with their diabetes. Adolescents share how they have to say they are fine just to calm their parents down.

A key component for adolescents in normalizing during this phase is how they are able to manage ‘taking on the burden of care’. The process of taking over care from their parents and becoming independent, the conflict they experience with their parents, as well as when they have difficulty controlling their blood sugars leads them to feel very frustrated and out of control. Adolescents share that diabetes is hard, a burden, and they experience burnout while trying to

juggle all the responsibilities they have in life which just adds to this burden of care and their ability to normalize during this crucial time of moving to independence.

Summary

During this fourth phase, the axial code **moving the journey towards independence**, the major codes include taking over care, experiencing conflict with parents, and realizing diabetes is hard. Some of the key conditions that occur during this phase include: fear of needle pain, forgetting to give insulin, the ability to make judgments on insulin dosing affects outcomes, feeling self-conscious or embarrassed about doing care in front of others, conflict with parents occurs more when they are frequently asking about blood sugars, the rate of transition affects how the adolescent does (too soon, too slow), and diabetes is hard when adolescents just want to fit in with peers.

Key hypotheses include: a) insulin pump use increases independence and improves care for adolescents and the alarm feature can help adolescents remember to do their blood sugars and insulin, b) creating strategies to decrease needle fear and help adolescents achieve success in administering their own insulin and placing their own pump sites will enhance independent care, c) an awareness of the effects of activity on blood sugars will help the adolescents to learn to manage their blood sugars better when they are active, d) creating strategies the adolescents like to help them remember their blood sugar tests will improve adherence to care, e) helping the adolescents to feel comfortable with appropriate carb counting methods, they will be more successful in giving the correct dose of insulin, f) decreasing nagging between adolescents and their parents, the adolescents will be more willing to do their care, g) helping the adolescents to have appropriate knowledge and assisting the parent and adolescents in a smooth transition will decrease conflict and improve care, h) when the adolescents do not feel diabetes is a burden, they have less emotional trouble with managing their diabetes and i) creating a climate of trust between adolescents and their parents may

reduce lying about blood sugar numbers. The major task for adolescents in managing their diabetes is **separating from their parent and independently managing diabetes** with the normalizing task of **'taking on the burden of care'**. Phases 2, 3, and 4 are cyclical, and adolescents revert back and forth through them before finally coming to phase 5.

Phase 5. Figuring It Out

In this phase of the journey, **figuring it out**, adolescents begin to realize that things need to change and begin to learn how to manage their diabetes as they take on even more responsibility for their care. The definition of figuring it out is the ability to come to the realization that you can manage your diabetes and maintain your glucose control, when you are able to accept diabetes and stay on track. This also includes having developed the skills to simplify and integrate diabetes into the activities of normal daily living. The adolescents have a shift in their mental framework that helps them to understand that diabetes is a part of who they are, and finally accepting and realizing their life with diabetes is their 'new normal'. The adolescents begin to realize that diabetes is not so hard, and they begin to believe that they can manage diabetes. This changing awareness allows them to now make positive changes in taking on more responsibility in caring for their diabetes. The adolescents gain an understanding that they know how to care for themselves and develop the confidence required to stay on track and keep their blood sugars balanced. The **major task** during this stage is **learning to cope with diabetes**. The normalizing task during this phase is termed **'accepting the new normal'**. During this phase the codes that will be discussed include: **1) accepting diabetes, 2) believing it's possible to manage diabetes, 3) showing responsibility, and 4) staying on track.**

"I started trying to figure out what Type 1 diabetes was" Interview #4 p. 2

“you don’t think about it as being extremely hard you kind of thing about it, you start to figure out it’s not as hard as people think, once you start to get used to the motion of it, it becomes just a really simple thing” Interview #4 p. 13

1.0 Accepting Diabetes

Accepting diabetes is defined as developing an understanding that diabetes is part of you and that having diabetes is normal. When the adolescents are able to move past the grief, anger, sadness, denial, and rebellion of having diabetes, they develop a realization that diabetes is not going away and they must start accepting diabetes. They begin to understand the consequences for them in not taking care of the diabetes and feel that once they have achieved a certain age or level of maturity, they are then capable of dealing with diabetes and feeling like this is normal for them. The adolescents share the steps they go through as they learn to accept diabetes, learn ways to cope with having diabetes, and accept that how their life “is” their new normal. Major codes of accepting diabetes include the following: **1) realizing diabetes is forever, 2) believing you are trapped, 3) realizing things need to change, 4) learning to cope, and 5) accepting the new normal.** Several examples of accepting diabetes follow.

“It (diabetes) is there, it will never go, but it is just how much you let it get to you is just the key to it, it never goes away it is always a part of you, until you just accept it, it is always just there” Interview #6 p. 16-17

“once I learned to accept it ‘cuz I think like early on my friends kind of accepted it, but I still didn’t want to, but like once my friend did and I started to” Interview #10 p. 14

1.1 Realizing diabetes is forever. The adolescents share that during their course of having diabetes they come to the realization that diabetes is forever. This is defined as knowing that you will not be able to get rid of the diabetes and must learn to live with it.

“you are sitting alone at night and you are like shit, I’m going to have this forever – like FOREVER and then you are sitting there and like, oh boy, how am I going to do that, and you get that panic moment of oh my God, what am I going to do” Interview #11 p. 12

“you have a disease, when you have diabetes you have a disease that you have to monitor all the time and it is never going away” Interview #11 p. 14

A condition when adolescents are more likely to realize diabetes is forever is when they come to realize that diabetes is not going away. A condition when the adolescents are not able to realize diabetes is forever is when they are in denial about having diabetes. A hypothesis is that by helping adolescents understand the permanence of diabetes through education, they will then be able to move forward with acceptance.

1.2 Believing you are trapped. The adolescents described that they feel trapped by diabetes, and that it is difficult for them to learn to accept it. Believing you are trapped is defined as believing there is no way out, and you are stuck with this forever: therefore, you may as well adjust to having diabetes and accept it.

“(it’s) ridiculously hard sometimes because you feel like trapped, then you are just like, well people deal with a lot worse” Interview #11 p. 12

1.3 Understanding things need to change is defined as developing an awareness that it is the high blood sugars that cause illness, and they need to do something different to control their diabetes to prevent getting sick, yet the realization that this task is not easy to accomplish.

“It was just really horrible because my BS were just constantly running high and it didn’t even seem like insulin would really get it down and it was like they were up in the 500’s and my A1C’s were way up there and I was like throwing up almost every day and it was just it was just horrible it was like you know you have those times when you like know that this is one of those times that you know that you need to start thinking about what you are doing and see that if you don’t do it something could go wrong and that was one of the points of time that I was doing it by myself and I saw that it wasn’t going to be easy peasy” Interview #4 p. 8-9

Conditions when adolescents understand that things need to change include: a) when they have multiple high blood sugar crisis leading to DKA and hospitalization, b) when they do not like being sick, and c) when they understand that by taking their insulin they are less likely to

get sick. A hypothesis is that by helping adolescents understand that crisis can be prevented by taking insulin and monitoring blood sugars regularly will decrease DKA admissions.

1.4 Learning to cope is defined as the steps necessary to help find ways to emotionally handle having a chronic illness. Once the adolescents realize that they will have diabetes forever and it is not going away, they have to figure out how to cope with living with diabetes daily. Adolescents share that learning to cope is a process that takes time, and happens as they get older. Codes that will be discussed include the following: **a) gaining a positive outlook, b) seeing diabetes as not scary, c) talking to a friend with diabetes, d) finding solutions, and e) realizing it's not a big deal.** An example of learning to cope is below.

“the longer I live with it the more I can kind of find ways to kind of cope with it easier” Interview #10 p. 1

1.41 Gaining a positive outlook. As adolescents learn to accept diabetes they share that part of the process of coping is in their attitude. The definition for gaining a positive outlook is the belief that your life is going well, and you can view life events in a positive manner. Adolescents share that by maintaining a positive outlook on life, diabetes is easier for them. A code that will be discussed is **understanding you are important.** An example of gaining a positive outlook is seen below.

“I’m just like it’s like half full, not half empty, that’s just kind of how I try and see things, I think the more positively you look at things the easier they get” Interview #10 p. 17

1.411 Understanding you are important is defined as believing you have self-worth and viewing yourself from a positive perspective.

“people don’t think we are important, but they think that everyone else is so important you know and if you think that it mostly means that you think about yourself in that way...it is one of those things that if you think they are thinking that but actually you are the one thinking it” Interview #4 p. 16

1.42 Seeing diabetes as not scary is defined as when diabetes is no longer viewed as something scary but manageable. Adolescents share that parent’s reactions to blood sugars sometimes make it hard for them to not be scared.

“It’s not scary anymore for me, it’s just life I guess” Interview #10 p. 14

1.43 Talking to a friend with diabetes is defined as being able to receive support and understanding from friends who have diabetes to help with coping. Adolescents share that this support is helpful to them.

“one thing I found really helpful...to talk about it with someone who really knows exactly what you are going thru...I’ve found one way to cope with like if I get mad or upset, I’ll talk to a friend that has diabetes” Interview #10 p. 7-8

1.44 Finding solutions is defined as finding ways to manage diabetes or situations that occur. Adolescents share that this helps them to feel more confident in their ability to handle difficulties.

“it’s hard to think about the good or the bad or the troubles you’ve had if you’ve just lived with it forever and you’ve learned to cope and deal and find your solutions” Interview #7 p. 11

1.45 Realizing it’s not a big deal is defined as understanding that diabetes is not as hard as it once seemed and it is now manageable. Adolescents share that once they believe diabetes is no big deal, they are able to handle situations when they are with their friends.

“if you are put in the situation where you think you can’t do something you’re just going to – I was with all my friends I just wasn’t going to make a big deal about it but I just learn to cope” Interview #7 p. 12

Conditions when adolescents are able to learn to cope include: a) when they have support from family and friends, b) when others are accepting of their diabetes, and c) when others are able to help them see diabetes care is easy by knowing how to keep blood sugars balanced. Conditions when adolescents are not able to learn to cope include: a) when others are not supportive, and b) when parents are afraid of high or low blood sugars. A hypothesis is that by helping adolescents to cope with diabetes sooner they will have less problems during transition to self-care.

1.5 Accepting the new normal is defined as realizing that my life includes diabetes which is now a 'part of my being' and 'who I am'. Adolescents discuss that now diabetes is part of 'who they are', and that mind frame helps to make diabetes part of their life. The adolescents discuss that they understand they cannot go back to the way it was before diabetes, but have incorporated diabetes into their new self. Codes that will be discussed include the following: **a) getting used to having diabetes and b) realizing that diabetes is part of my life**. An example of accepting the new normal is below.

"it just felt normal after the first few days, I just felt normal and I'm like I am going to have this the rest of my life, why fight it" Interview #3 p. 8

1.51 Getting used to having diabetes is defined as accepting diabetes as part of me and just learning to deal with having diabetes. Adolescents share that this process takes time.

"after working for so long with diabetes it just becomes kind of a natural thing and that is just what I kind of tell them once you get used to it" Interview #4 p. 2

1.52 Realizing diabetes is part of my life is incorporating diabetes into their life, and accepting that this IS now their life. Those adolescents who were diagnosed very young feel that diabetes is part of them as it is all they know.

“having diabetes has always just kind of been part of my life ‘cuz I’ve had it since I have been 2 so it’s kind of just something I grew up with, it is just a normal part of life, it’s just kind of been a normal thing for me” Interview #4 p.1

“after a few years I started to get used to the thought that diabetes was a part of me, yes it wasn’t something good but sometimes things just happen and you’ve got to work with it” Interview #4 p. 2

Conditions when adolescents are more likely to be able to accept diabetes as the new normal include: a) when they are very young when diagnosed with diabetes, b) when they can get a positive attitude about having diabetes, and c) when they realize that this is their life. A condition when adolescents are not able to accept diabetes as the new normal is when they are in denial. A hypothesis is that by assisting adolescents to view diabetes as a normal part of their life through mentoring with others who are successful in diabetes management allows them to accept diabetes into their own life and to be able to move forward.

The major goal in this stage is accepting diabetes and understanding that diabetes is not going to go away and you must learn to deal with it and make it part of your life. This is a key turning point for the adolescents in their ability to normalize diabetes into their life and accept it.

2.0 Believing it’s possible to manage diabetes

Believing it’s possible to manage diabetes is defined as the ability to have the confidence to know how to manage your diabetes, in your decision making skills, and in your desire to control your diabetes successfully. Part of this process is when adolescents begin to make diabetes a priority in their life instead of trying to ignore it to ‘fit in’ with their friends as was seen in the last phase. Codes that will be discussed include the following: **a) changing the attitude, b) knowing how to do everything, c) realizing diabetes is manageable, d) making diabetes a priority, and e) gaining confidence that you can do what you want.** Examples of believing it’s possible and when adolescents do not are below.

“I think now that I am starting to think about where I am going to go to college and start to transition to where I’m going to move out and do my own thing, I feel like I can do it on my own” Interview #11 p. 12

“I am not healthy, the diabetes is not healthy, that means I am not a healthy person, that runs through my head...embrace your sickliness, you can do it, but there is that overwhelming sense of I am not healthy which is kind of scary” Interview #11 p. 13

2.1 Changing the attitude is defined as a willing emotional state that allows one to believe in their capability to manage diabetes. Adolescents share that as they start having success in their blood sugar control they begin to believe in themselves. They describe a distinct attitude change that they have that includes coming to the realization that diabetes is not hard which coincides with their being able to keep their blood sugars in better control. This is a distinct change from the previous phase where the overwhelming thoughts of taking care of their diabetes and juggling all their responsibilities made them feel that diabetes was hard. A code that will be discussed is **realizing it’s not hard**. An example of changing the attitude is below.

“I was kind of all over it (my diabetes), my blood sugar leveled out so I felt better which was really nice and so that kind of changed my attitude and everything turned around” Interview #11 p. 9

2.11 Realizing it’s not hard is defined as the understanding that diabetes is not difficult to manage or control.

“managing it...it really isn’t a hard thing I guess you could say ‘cuz I guess you would say it was really hard to do mostly towards the beginning” Interview #4 p. 16

“I guess now it’s not really a hard thing it’s just kind of an everyday thing, it’s something that you can’t just forget about one day, but it’s mostly not a hard thing anymore because I’ve just gotten used to it” Interview #4 p. 18

Conditions when adolescents do not believe that diabetes is hard include: a) when they are older, b) when they get used to having diabetes, and c) when they are able to keep their blood sugars more in control and they have simplified and mastered the skills needed to

manage their diabetes. A condition when adolescents believe diabetes is hard is when their blood sugars are out of control. A hypothesis is that by supporting adolescents in keeping their blood sugars controlled by helping them to learn the skills needed and to simplify the tasks of diabetes management to make their life with diabetes feel normal they will then be able to see that it is not hard.

2.2 Knowing how to do everything. This second step is defined as when you feel you have adequate knowledge and are capable of managing your diabetes. Adolescents share that it takes a while to not only understand how to do the tasks needed to do their blood test and take the insulin, but also learn how their choices are going to affect their blood sugar value. Once the adolescents believe they have mastered these skills, they share this is when they believe they can truly be independent in their care. Adolescents discuss that when they are given too many responsibilities early or first go on the pump, they do not always know what they are supposed to be doing.

“that’s where the independence thing comes in that you know what you are supposed to be doing” Interview #7 p. 10

“when you first start doing it yourself it is a harder thing because you’re not sure what you are doing because you have always had someone else kind of doing it for you and so it’s like ok, what am I supposed to do” Interview #4 p. 17

A condition when adolescents know how to do everything is when they understand the process of how to take care of themselves and all the steps needed. Conditions when adolescents do not know how to do everything are: a) when they are not supported when first going on the insulin pump, b) when they do not know how to carb count appropriately, and c) when they have not learned to simplify their care. A hypothesis is that by supporting adolescents in learning how to simplify their regimen, remember their blood sugars and learning carb counting as they transition to self-care and going on the insulin pump will help them to be more self-sufficient.

2.3 Realizing diabetes is manageable is defined as developing an understanding of the steps necessary to take care of diabetes in order to keep blood sugars controlled.

The adolescents shared that they do not feel that diabetes was as hard as other things people have to do, and as long as they take their insulin every day, it no longer feels like such a burden to them.

“I always think there are a lot of people that have a lot harder stuff too deal with than diabetes mine is manageable, I take insulin every day – I am good to go” Interview #11 p. 12

2.4 Making diabetes a priority is defined as an attitude change that includes stopping a current activity to manage diabetes instead of ignoring it. Adolescents discuss that when they are able to understand that there are consequences to their body from high blood sugars they are more likely to focus on staying healthy and keeping their blood sugars controlled and this usually happens when they get older.

“taking care of myself is my top priority...I don’t have a problem like stopping what I’m doing now to make sure my blood sugar is ok and it is just a priority so I just make sure that my health comes first” Interview #10 p. 17

Conditions when adolescents make diabetes a priority are: a) when they are older and b) when they have the ability to understand that taking care of their diabetes will affect their health and long term condition.

2.5 Gaining confidence that you can do what you want is defined as believing you have the ability to successfully manage your diabetes to be able to meet whatever goal or aspiration you have in life.

“you can take care of yourself a lot better than you did before...I could do these things” Interview #4 p. 13

“You can be anyone you can be, who you want to be” Interview #4 p. 15

3.0 Showing responsibility

Adolescents share that they take on more responsibility for their own care as they get older and more mature. Showing responsibility is defined as the mental ability to see the consequences of their actions and understand why being responsible is important. The adolescents discuss how being more responsible and mature than their peers is important. The adolescents describe showing responsibility comes when they are not exhibiting as much rebellion in separating from their parent, but in showing the maturity to take on this task of managing their diabetes. A code that will be discussed is **putting in an effort**. An example of showing responsibility is shown below.

“if you’re older you are more responsible, you are more mature you don’t have hormones messing with you and you aren’t in your well, maybe not as much, you don’t have as much rebellion” Interview #6 p. 1

3.1 Putting in an effort is defined as taking the time to care for oneself. The adolescents share that they begin to put in an effort to take care of their diabetes as they take on additional responsibility for care, and that is seen in their ability to keep their blood sugar more level. They share that they need to stop being lazy and take care of their diabetes.

“I was putting an effort in and it was showing I was putting an effort it keeping my blood sugar level” Interview #11 p. 9

Conditions when the adolescents are more likely to be able to show responsibility include: a) when they are older and b) when they understand there are consequences to their actions. Conditions when the adolescents are not likely to show responsibility include: a) when they are experiencing rebellion and b) when they are still being lazy and not putting forth effort. A hypothesis is that by assisting adolescents in taking on responsibility by decreasing rebellion

and encouraging their efforts in self-management, they then will be able to manage their diabetes independently.

4.0 Staying on track

The definition of staying on track is learning to manage diabetes in a way that is physically and emotionally healthy. In the previous phase the adolescents were gaining independence in their care yet struggled with blood sugar control. In this phase adolescents share the steps they take to stay on track. Some of the steps in this process include the following: **a) maintaining health, b) setting goals, and c) maintaining motivation.**

Examples of staying on track are included below.

“after you are done with the doctor like the next week, boom, they are just like on track, and the week after that they are probably back to the old ways” Interview #7 p.5

“you don’t want to start having too many abnormal blood sugars I guess you kind of want to keep them at an even rate, checking them it helps me to keep in on track” Interview #4 p. 7

4.1 Maintaining health is defined as the ability to control diabetes by taking the necessary steps to address blood sugars to meet goals. Codes that will be discussed include the following: **a) understanding how to control blood sugars and b) overcoming fear.** An example of maintaining health follows.

“now if I take care of myself later on I’ll be a lot healthier and so it’s just one of my biggest goals is just to maintain my health while I am young” Interview #10 p. 16

4.11 Understanding how to control blood sugars is defined as the ability to understand that habits in testing blood sugars regularly, counting carbohydrates carefully, taking the right doses of insulin, and staying active are an important part of keeping blood sugars controlled. Codes that will be discussed include the following: **a) testing blood sugars, b) giving insulin, c) managing diet, d)**

managing exercise, and e) making diabetes part of your routine. Examples are below.

“doing BS, taking insulin, watching food, that took me a long while to actually get down ‘cuz knowing how much is there, how much that amount is that took me awhile to get down, ‘cuz it was like how do I do this, I got that down like 6 months ago like since I’ve gotten that down it’s like wow, it’s a lot easier to keep your BS down, ‘cuz you know what you are doing” Interview #4 p.17

“I have to be sure I correct my carbs that I eat correctly, and I have to be sure that I remember to correct for my blood sugar ...and I have all the right foods...that’s mostly what I do to keep my blood sugar balanced” Interview #2 p. 5

4.111 Testing blood sugars is defined as testing the blood sugar to keep it within a desired range. Adolescents describe how testing their blood sugar regularly and being older has helped them with this.

“as I grew older now my blood sugar has been more level since I am on my pump” Interview #2 p. 1

“you need to check your blood sugar like at least 5 times a day just to make sure that your blood sugar is ok...that it’s in the right range that you want it to be” Interview #2 p. 4

4.112 Giving insulin is defined as taking insulin regularly to keep blood sugar balanced.

“mostly just take my insulin and make sure you take your insulin (to keep my blood sugar balanced)” Interview #4 p. 19

“I take my blood sugar and put it in my pump and then it gives me insulin” Interview #2 p. 4

4.113 Managing diet is defined as choosing healthier food options and not snacking as often.

“I will try and not snack and stuff so I can keep my blood sugar where I want it to be” Interview #2 p. 5

“choosing healthier food types I used to eat a lot of junk, but I mean I like I still kind of do but I keep it in moderation and I eat healthier now and I noticed that it has kept my blood sugar better” Interview #2 p. 2

4.114 Managing exercise is defined as adjusting insulin for activity to prevent low blood sugars during activity. The adolescents state that by exercising regularly they see improved glucose values.

“I’ll have to sit out of volleyball games and soccer games ‘cuz I was low...that just kind of pushed me to be more careful and keep my numbers steady so that doesn’t happen anymore” Interview #10 p. 11

“I turn my basal rates down about an hour or so after I exercise...I figured that out when I started exercising like frequently with my mom...it took a couple of runs of why is this happening, why is this happening” Interview #11 p. 11

4.115 Making diabetes part of your routine is defined as doing diabetes management tasks at set times each day. The adolescents describe that keeping a daily routine, what they do, and how they do it helps them to stay on track.

“It is just something you kind of need to be part of your daily routine” Interview #10 p.1

“(my routine is) just check my BS, do my insulin, eat, wait 2 hours, check it again, do my insulin, eat, wait do it again, do that for 6 times I think, when I wake up, during school I get out before lunch, then during dinner again and usually for snacks too” Interview #3 p. 10

4.12 Overcoming fear is defined as mentally preparing oneself to give a shot. With the needle fear that the adolescents have described throughout this process of their journey of diabetes, the adolescents share that it is an important step for them when they are finally able to overcome their fear of needles. Adolescents share how they have to get used to the pain, think they can do it, and giving the shot.

“something came over me and I just wasn’t scared anymore (about taking shots), I just overcome my fear and that was the best day of my life actually because I took control and it was nice to know that I came over my fear, one of my biggest fears” Interview #2 p. 9

“and me getting used to it, of the pain, it didn’t hurt as much anymore and I thought that if they could do it I could do it and one day my grandma was giving me a shot and I just took it out of her hand and I was like no I want to do this and so I just started doing it and I gave myself my shot” Interview #2 p. 9

4.2 Setting Goals is defined as making a decision about what outcome are attainable in diabetes care to maintain health. Adolescents describe how setting and either meeting or exceeding their goal is rewarding to them and others describe that they do not set goals for themselves. Codes that will be discussed include the following: **a) recognizing blood sugars are high or low, b) demonstrating to others you can meet recommendations, c) encouraging myself, d) setting goals for HbA₁C and blood sugars, e) measuring success by attaining goal, and f) seeing effects of your actions.**

4.21 Recognizing blood sugars are high or low is defined as the adolescents realizing that their blood sugar is out of control and setting a goal to keep it in a normal range. They share that they do not like feeling sick or going to the hospital and that is a reason for them to keep their blood sugars more in control.

“I have problems with high blood sugars ... sometimes I go low in the morning ... mostly during the rest of the day it’s ok it stays pretty even I try to keep my BS at 100 it’s my goal” Interview #4 p. 2

4.22 Demonstrating to others you can meet recommendations is defined as showing others that you can meet the set target goal for diabetes they have given to you.

“well my doctor wants me to have my BS like between 100 and 150 ... and my A1C ... like 7% is good well that is what I had last time and my doctor was really proud of me because I had a 7 something she’s always proud whenever I have a

7 something, but like if it gets in the 9's or something that's high" Interview #9 p. 10

"well I've always tried to keep my A1C- my goal is to keep my A1C under 7.5% usually um but my doctor has recommended well she says under 8.0% but I try and keep it pretty low so it's kind of cool" Interview #10 p. 17

4.23 Encouraging myself is defined as giving yourself positive feedback or a reward when you are able to meet or exceed the goal you have set.

"I try to like try to encourage myself like if I can get my A₁C down to 8.1 then I can do this or I can have this because I was able to get to my goal or exceed my goal and that kind of encouraged me to keep going, I don't really do that so much anymore but it's kind of like yes I did it now I'm going to go do it again" Interview #4 p. 16-17

4.24 Setting goals for HbA₁C and blood sugars is defined as keeping the blood sugar and HbA₁C value in a target they have set for themselves. These are very concrete goals the adolescents describe in being able to stay on track. Some adolescents discuss not setting goals but having an overall idea of where they would like their blood sugars to be. They share that they are disappointed when they are not able to achieve the results they want and this helps them to do better with their care.

"my goal is to try to keep it (A₁C) at least under 9 and I try and keep it in the 8 zone so if it like gets to 9 I'll be ok, well like I didn't do this so I need to get it back down" Interview #4 p. 14

"I don't really have any goals, I mean I have my BS target- 150 to 150 like I have a range of where I want my BS to be but I don't have any set goals in my mind of what I want them to look like I'm not that in to it, as long as they are good I'm not going to complain" Interview #7 p. 15

4.25 Measuring success by attaining goal is defined as setting a target to then show if you have met that goal to achieve success.

"I measure my own success rate so basically approval or achievement so when I set myself a goal and I know when I reach that I'll have that and it just feels good to achieve your own goal" Interview #6 p. 6

4.26 Seeing effects of your actions is defined as the ability to visualize a change in outcome when attaining a goal helps with motivation to continue.

"in the summer when I'm off and family vacation when I'm off I mean I do try and keep a routine but it's a lot harder so I think one of my goals is to actually like this summer to try and keep testing around the same times every day 'cuz I find that does help, I think having structure throughout the day really helps" Interview #10 p. 18

"I saw a change when I started not exercising and started eating worse 'cuz when I went to the doctor they had to up everything again ...that is something I hated seeing so I guess knowing that that is a goal too 'cuz I want to get my stuff down 'cuz I know when it is down I have better control" Interview #7 p. 15

Conditions for setting goals include: a) when you want to avoid being sick or are going into a crisis and b) being disappointed in results of HbA_{1c} or blood sugars. A condition for not setting goals is not seeing the value in goal setting. A hypothesis is that by helping adolescents to test their blood sugar regularly, take the correct dose of insulin, count carbohydrates carefully, and stay active they will be better able to maintain blood sugar control.

4.3 Maintaining motivation is defined as the ability to maintain the energy and focus and gather resources needed to consistently maintain a positive attitude. The adolescents describe ways that help them stay motivated with their diabetes care. The adolescents described not being motivated during the previous phase of their diabetes journey which is partly what led to their difficulties in their diabetes management. Adolescents share that one thing that helps to motivate them is by not wanting to have their legs amputated. Adolescents share steps in the process of what is helpful for them in maintaining motivation that include: **a) encouraging myself, b) urging yourself, c) receiving offerings of help from others, d) pushing myself, and e) receiving urging from others.**

4.31 Encouraging myself. Adolescents describe that by encouraging themselves to do the care they are more motivated.

“well with my motivation I try to like try to encourage myself like if I can get my A1C down to 8.1 then I can do this” Interview #4 p. 17

4.32 Urging yourself is defined as giving yourself positive encouragement to keep going. Adolescents share that praise from doctors, parents, and others is helpful and nagging and criticism is not. They also discuss that when they are constantly told they are doing things wrong it is also not positive for them in trying to maintain their motivation.

“you just have to remind yourself to do it you have to just keep urging yourself to keep going, I’m not sure exactly how to put that but with taking care of it is really I just try to keep my motivation up and that helps to keep me going” Interview #4 p. 16

4.33 Receiving offerings of help from others is defined as others being there for you and offering help, is supportive and motivating.

“I think it has mostly been my friends ad stuff (keeping my motivation up)...they have always just kind of been there for me to say do you need any help or be there for me if something is going wrong” Interview #15 p. 2

4.34 Pushing myself is defined as telling myself that you can do this and gain a sense of accomplishment from staying motivated.

“to stay motivated I just keep pushing myself, just keep telling myself no you are not like everybody else...just keep doing it and you will accomplish everything you want...I’m very, very proud of myself, I feel very accomplished for all the things I have done” Interview #14 p. 3

4.35 Receiving urging from others is defined as others telling you what you must do to get something.

“dad was like you can’t be on the pump unless you can give yourself a shot...I’m a big carrot on the stick kind of person, I mean like if I need a motivator and I need something to punish me if it doesn’t happen.” Interview #11 p. 5

Conditions that allow the adolescents to stay motivated include: a) having support from others, b) not wanting to have things amputated off you, and c) not wanting to hear nagging from others. A condition that does not allow the adolescents to stay motivated is being told they are doing everything wrong. A hypothesis is that by motivating adolescents to care for themselves with a positive attitude and encouragement will allow them to stay on track with their diabetes care and control their blood sugars.

The major goal in this stage was to keep the blood sugars balanced and maintain motivation to stay in this phase of figuring it out and not revert back to previous phases 2, 3 and 4 where the adolescents were struggling to maintain blood sugar balance. The primary steps in this effort include maintaining health, setting goals, and maintaining motivation. The key process to normalizing is ‘accepting the new normal’. As adolescents proceed through this phase they learn to cope and maintain their motivation to accept that diabetes is their new life. An important condition for this acceptance is when they start achieving some success in their blood glucose management and believe in themselves.

Summary

There are four major codes: a) accepting diabetes, b) believing it’s possible to manage diabetes, c) showing responsibility, and d) staying on track phase in the axial code **‘figuring it out’**. Some of the key conditions that occur during this phase include: realizing diabetes is forever, having multiple illnesses leading to DKA, understanding that not taking insulin leads to feeling sick, support from family and friends is key, reactions from parents affects adolescent adjustment, diabetes is easier when blood sugars are controlled and harder when they are not, the transition process is important in how the adolescent is able to manage diabetes, adolescents knowledge is a key component, rebellion and being lazy are conditions that do not

lead to success, and recognition of consequences from poor diabetes care helps adolescents. Key hypotheses include: a) by helping adolescents see that illness can be prevented by taking insulin will decrease DKA admissions, b) by helping adolescents to cope with diabetes sooner they will have less problems during transition to self-care, c) that by assisting adolescents in taking on responsibility they will be able to manage their diabetes independently, d) by helping adolescents to set and achieve goals they will be better able to maintain blood sugar control, and e) by motivating adolescents to care for themselves they are more likely to have a positive attitude about diabetes and be able to maintain their care. The major task for adolescents in managing their diabetes is **learning to cope with diabetes** and the normalizing task during this phase is **'accepting the new normal'**.

Phase 6. Helping Others

The definition of **helping others** is to provide information, assistance, and compassion to those around them in a manner that improves their future. Once adolescents reach the phase in their diabetes journey where they have accepted diabetes and 'figured it out' they discuss the importance of helping others. By giving back or talking to little kids about their diabetes, they hope to make it easier for them and help them to understand that diabetes is doable and not scary or impossible to take care of. Normalization during this stage is labeled **'hoping for a normal future'**. Codes that will be discussed include the following: **a) mentoring others, b) showing compassion to others and c) planning for a future helping others**. The **major task** for the adolescents in this phase is **sharing with others to improve their lives**. An example of helping others is seen below.

*"actually growing up with diabetes I have actually been able to help some people too"
Interview #4 p. 1*

1.0 Mentoring others

The definition of mentoring is to give back to others through education, motivation, and role modeling to help younger children with diabetes cope and adjust to their illness.

Adolescents discussed that by sharing their experiences with diabetes they hope to improve the lives of others by motivating them to take control of their own diabetes management.

Adolescents that were more recently diagnosed, and those who were still struggling with their own diabetes, did not share information about helping others. Codes that will be discussed include the following: **a) teaching others about diabetes, b) motivating others to take care of their diabetes, c) sharing with others was to accept diabetes, d) acting as a role model, e) participating in advocacy boards, and f) participating as camp counselor.**

1.1 Teaching others about diabetes. The goal of the adolescents in teaching others about diabetes is to help them to better understand what diabetes is. This differs from previous teaching others because it is primarily focused on teaching others with diabetes to better understand their own care. The adolescents also share that helping others around them gain a better understanding of diabetes is important to them. Codes to be discussed include: **a) teaching others with diabetes and b) teaching others who need to learn more about diabetes.**

1.11 Teaching others with diabetes is defined as sharing knowledge of diabetes with peers with diabetes to help them feel confident in their own care or learn things they may not know about diabetes.

“I have people coming up to me (at camp) and ask me, like some people are new and they come up to me and ask me things and it is nice to be able to help them out if they need something” Interview #2 p. 10-11

“I can help them with their diabetes and I can explain it to them” Interview #2 p. 11

1.12 Teaching others who need to learn more about diabetes is defined as teaching others about diabetes helps them to improve their knowledge about diabetes and about themselves.

“(I talk to others) I’m like, there is a difference between type 1 and type 2 and I can eat sugar and I can eat whatever I want” Interview #7 p. 9

“my teacher...would ask me about stuff with diabetes and questions about like the pump or something” Interview #9 p.12

1.2 Motivating others to take care of their diabetes is defined as the ability to help others care for their diabetes by setting an example or sharing ideas with them.

Adolescents discuss the importance of being honest with others that diabetes is difficult and stressful but not impossible, and that they really want others to have the desire to want to take care of themselves and stay healthy.

“(others) say if they can do it I can do it... If you say you were not doing good it would be like discouraging them about things like it’s so hard it’s not going to be easy well it’s not easy but you shouldn’t make it sound like it’s going to be horrible and impossible and you aren’t going to be able to do it I can do it they can do it but I’m not going to say I can do it but you can’t do it because that’s not going to make them feel that they can do it, it’s going to make it harder for them” Interview #4 p.13

“now one of my things is kind of like helping kids want to take care of themselves...I can show kids like I want them to want to take care of themselves and want to be healthy” Interview #10 p. 18

1.3 Sharing with others ways to accept diabetes is helping others emotionally to cope with diabetes or not feel scared about diabetes. Adolescents share that they accept diabetes, and they want to help others move to this same place in their own lives.

Adolescents share some of the strategies they used for accepting diabetes with their peers to help them in these same endeavors. The following codes will be discussed: **a) helping others to cope, b) helping others not feel scared, and c) helping others to see diabetes as part of life.**

1.31 Helping others to cope is defined as finding ways to assist others in coping with diabetes. The adolescents share information for others with diabetes on ways they can learn to cope with diabetes by: **a) explaining it to them, b) understanding they can manage diabetes, and c) understanding diabetes is not hard.**

1.311 Explaining it to them.

"I ... can explain to them um how they can deal with it" Interview #2 p. 11

1.312 Understanding they can manage diabetes

"I don't want them thinking that the world is ending because of diabetes" Interview #2 p. 12

1.313 Understanding diabetes is not hard

"I could help with kids ... help them to deal with it and cope with it because it's not as bad as they think it is" Interview #2 p. 11

1.32 Helping others not feel scared is defined as sharing with others not to be afraid about having diabetes and assisting them in finding ways to not be afraid.

"I could help with kids with diabetes to help them to understand more and make them less scared, because it is a scary thing" Interview #2 p. 11

1.33 Helping others to see diabetes as part of life is defined as helping others accept diabetes and see it as part of your life. Adolescents shared that talking with others helps them to understand this concept and strive towards that in their own acceptance of diabetes.

“after working for so long with diabetes it just becomes kind of a natural thing and that is just what I kind of tell them once you get used to it, it just becomes an everyday part of life” Interview #4 p.2

1.4 Acting as a role model is defined as demonstrating to others the ability to care for oneself. Adolescents state that by promoting a healthy attitude and positive example to others shows them they do not have to struggle with managing their diabetes.

“I really enjoyed being that role model character for kids and being able to help people and so that kind of pushed me more to trying to make a difference” Interview #10 p. 18

“showing that I can take care of myself and just kind of being a role model by doing rather than talking actions rather than words and kids see that and they’ll be like oh, she is pretty cool and she likes to take care of herself” Interview #10 p. 18

1.5 Participating in advocacy boards is defined as mentoring others by participating in diabetes advocacy boards where their voice and experiences can be heard.

“you have more opportunities...you are going to get involved with things more, I am more involved with the advocacy board I am still working on” Interview #7 p. 2

1.6 Participating as camp counselor is defined as staying involved in camps by becoming counselors. Adolescents shared that they found camp to be valuable for them when they were younger in how others mentored them and want to make sure others have that same experience. Adolescents also shared that camps that provided leadership experiences were helpful to them in learning to help others.

“last year I was chosen to participate in a leadership weekend...the camp directors...pick the people they would like to have as counselors and I was chosen to be a counselor” Interview #10 p. 15

“camps made me feel a lot better about having diabetes...when I go to LIT/CIT weekend...once I get my own cabin I can help them with their diabetes” Interview #2 p. 11

Conditions when the adolescents are more likely to be able to mentor others include: a) when they are older, b) when they have accepted diabetes and believe they can manage their

blood sugars, c) when they have had a positive camp experience, d) when they have leadership qualities, e) when they have faced challenges they have overcome, and f) when they have seen value in others mentoring or encouraging them. Conditions when the adolescents are less likely to be able to mentor others include: a) when they are younger, b) when they are still having difficulty managing their own diabetes, and c) soon after their own diagnosis. A hypothesis is that having adolescents mentor others younger than them is a positive experience for both parties in coping with diabetes.

2.0 Showing Compassion To Others

The definition of showing compassion to others is the ability to understand how others are feeling and making a connection with them. Adolescents know how they feel to have a disease that makes them feel different and have to learn to manage their diabetes on a daily basis. Adolescents then develop compassion for others as they recognize how others may feel who have other disabilities like cancer or deafness, or even those with diabetes. Many adolescents had not reached the phase of wanting to connect with others and just discussed feeling alone and isolated. Sub-codes in this section include: **1) knowing how others feel, 2) helping others feel special, and 3) trying to connect with others.**

2.1 Knowing how others feel is defined as a compassion for others with illness and how they want to be treated. Adolescents state that this leads to them have more compassion for others around them as they open up and try to share or be friends with others.

“because with actually growing up with diabetes I guess you could say in a way it makes you more knowledge to how people see you, it is actually a strength to having any illness ‘cuz you have to you actually know how other people feel, and you can actually help others, ... I have a friend who was just diagnosed with cancer ... I just know if I didn’t have diabetes I would just think like well that’s nothing, but I have diabetes and I can say that I have diabetes and he has cancer and we both have hard times, and you can help

people I guess with any problem I guess that you have learned to control” Interview #4 p. 20

2.2 Helping others feel special is defined as working with other people with diabetes to help them feel special and know that they are not alone in trying to deal with their diabetes.

“it is better for the kids to know that it is not as bad as they think and that um they are really special because they have diabetes and they are not the only person” Interview #2 p. 12

2.3 Trying to connect with others is defined as helping others feel they are not alone and that they are connected in some way with people around them.

“I try and see if someone is all alone and go and say hi to them or try and help them out. Like in math class last year there was this deaf girl... and no one really talked to her I would chat with her thru her interpreter and sometimes I would write on a piece of paper to talk to her, try to connect with her on a personal level” Interview #6 p. 17

Conditions when the adolescents are likely to show compassion to others include: a) when they have experienced feeling alone or isolated from others, b) once they have control over their diabetes, and c) if they have experienced feeling like they are the only one. A condition when the adolescent is less likely to show compassion to others is when they have not reached the phase of their diabetes where they are in control of their diabetes. A hypothesis is that helping adolescents feel less isolated and alone is important to them in adjusting to having a chronic illness.

3.0 Planning For a Future Helping Others

Adolescents share the last step of this phase of helping others is moving into their own future and realizing the possibilities that exist for them in giving back to other children. The adolescents expressed the value that they received in managing their own illness and how this

has made them want to give back and help others in this way. A definition of planning for a future helping others is seeking life goals that will allow one to help others in their career.

“I want to be a radiologist and I want to work at a (children’s hospital) for my future I think that um I could help with kids with diabetes” Interview #2 p. 11

“I’ve always kind of had a goal of going into the medical field but now I think now one of my biggest goals is to just either be a researcher or be an endocrinologist because I see what she has done for me and how much she has helped me and I want to be able to do that for other people” Interview #10 p. 15

Conditions when the adolescents are more likely to plan for their future include: a) when they are older, b) when they have had positive experiences in others helping them, and c) when they believe they can make a difference in others’ lives. A condition when the adolescents are less likely to plan for their future is when they do not feel they are in control of their diabetes. A hypothesis is that by encouraging adolescents to help others and get involved in camp or other mentoring programs will improve their self-esteem and self-efficacy.

As adolescents normalize during this phase they are **‘planning for a normal future’**. This phase is reached when the adolescent is able to have hope in their future and see that living with diabetes is possible. Once they reach this phase of wanting to give back, they begin thinking not only about ways to help others now but in their future careers as well.

Summary

In the sixth phase the axial code **‘helping others’**, there are three major codes: a) mentoring others, b) showing compassion to others, and c) planning for a future helping others. Some of the key conditions related to the codes include the following: a) feeling isolated and alone are common in adolescents with diabetes and lead to poor self-esteem, b) having positive experiences of others helping them allows adolescents to want to help others, c) adolescents are not ready to help others if they are overwhelmed or do not feel in control of their diabetes, and d) when adolescents have accepted diabetes, they are able to give back to others. Key

hypotheses include: a) helping adolescents feel less isolated and alone are important to them in adjusting to having a chronic illness, b) encouraging adolescents to help others and get involved in camp or other mentoring programs will improve their self-esteem and self-efficacy, and c) having adolescents mentor others younger than them is a positive experience for both parties in coping with diabetes. The major task for adolescents in managing their diabetes is **sharing with others to improve their lives** and the normalizing task during this phase is **'hoping for a normal future'**.

Summary

In this chapter the characteristics of the study participants were defined. The grounded theory data analysis was discussed with axial codes, sub-codes and categories and processes that were found in the data were also discussed. A total of 15 interviews were completed using 11 adolescent's ranging in age from 11 to 15 participated in the study. There were 3 boys and 8 girls. All of the participants had Type 1 diabetes, diagnosed for more than 6 months, on insulin therapy with no other conditions except controlled hypothyroidism. All study participants attended school and were from Western Washington.

A major task being addressed by the adolescents in this study was **"normalizing"**. Once the adolescents were diagnosed with diabetes they sought to return their life to normal while they were transitioning to self-management and independence. The aim of this study in adolescents ages 11 to 15 years was to gain a greater understanding of the adolescent's perspective of their experiences in living with diabetes, and associated challenges and management issues they faced. The goal was to learn more about the conditions that were related to management behaviors in order to generate hypotheses to guide both research and nursing practice in the design of interventions to support the adolescents in making the transition to self-care in diabetes management. The ultimate purpose was to build a theoretical paradigm that captured the main categories and moving processes in the experiences of

adolescents to provide much needed information and hypotheses in order to support interventional design.

A substantive theory “normalizing” was developed. The definition of normalizing in adolescents with diabetes that emerged as the adolescents told their story was the ability of the adolescent to integrate diabetes into the background of their daily life by creating routines to make diabetes ‘part of me’. Included is the ability to take on the diabetes management tasks of blood glucose monitoring, insulin administration, monitoring diet and activity in order to feel diabetes is manageable and that they are in control. This also included an attitude of acceptance and the ability to cope, thus allowing them to independently manage their diabetes. This theoretical model illustrates the main categories and moving processes that adolescent’s experienced during their journey with diabetes and normalizing their life as well as the conditions that were related to these behaviors. The six axial codes of diabetes management that are part of this model include: a) remembering the beginning of the journey, b) balancing blood sugars/preventing a crisis, c) integrating diabetes into the world outside the home, d) moving the journey towards independence, e) figuring it out, and f) helping others. The tasks that are related to the concept of normalizing with diabetes during adolescence include the following: a) ‘recognizing life is changing’, b) ‘taking action to prevent a crisis’, c) ‘disclosing to engage support’, d) ‘taking on the burden of care’, e) ‘accepting the ‘new normal’’, and f) ‘hoping for a normal future’. Integral to this process of normalizing during this time are the normal developmental tasks of adolescence.

A major hypothesis that was developed was that helping adolescents normalize their lives while managing the tasks of diabetes during adolescence will lead to decrease in hemoglobin A₁C (HbA₁C) levels showing improved blood sugar control, a decrease in hospitalizations from DKA, and an increased ability to cope with this difficult chronic illness. Other key hypothesis that were found during this study include: a) helping adolescents cope

with their feelings of loss of their 'normal life' they had previous to the diagnosis will help them to adapt to having a chronic life changing illness that is permanent, b) creating strategies to decrease needle fear and help adolescents achieve success in successfully administering their own insulin and placing their own pump sites will enhance independent care, c) decreasing nagging between adolescents and their parents will allow adolescents to be more willing to do their care, d) helping the adolescents feel comfortable disclosing their diabetes to close friends will allow them to seek assistance when needed, e) by modifying the reactions, and interactions of their friends, teachers, and others around them will decrease feelings of embarrassment or self-consciousness and assist adolescents in viewing their life as normal, f) by helping adolescents cope with diabetes sooner will lead to less problems during transition to self-care, g) helping adolescents feel less isolated and alone are important to them in adjusting to having a chronic illness, h) by assisting adolescents to view diabetes as a normal part of their life through mentoring with others who are successful in diabetes management will allow them to accept diabetes into their own life and be able to move forward, i) by supporting adolescents in keeping their blood sugars controlled by helping them to learn the skills needed and to simplify the tasks of diabetes management to make their life with diabetes feel normal they will then be able to see that it is not hard, and j) by encouraging adolescents to help others and get involved in camp or other mentoring programs will improve their self-esteem and self-efficacy.

Based on the findings from this study it is important to note that: a) needle fear is a significant and ongoing major issue in allowing adolescents to normalize their experience and independently manage their care, b) the manner in which transition happens is a major part of how adolescents are able to normalize their life during puberty, c) conflict between the parent and adolescent is a significant deterrent and social support is a significant positive factor in the smooth transition to independent management, and d) the ability of the parent to 'let go' of monitoring the adolescent during puberty is a significant influence on the ability of the

adolescent to normalize his or her life. It is important to focus support for adolescents on wellness and having a normal life rather than on illness. Teaching adolescents to simplify their diabetes while maintaining their diabetes control is a crucial step during transition. Supporting adolescents in addressing these tasks and helping them to achieve normalcy in their life is dependent on the actions taken to support and create conditions for their success during adolescence and their transition to independence.

CHAPTER 5 – CONCLUSIONS

The purpose of this chapter is to provide an overview of this study by giving a brief summary of the findings, the major tasks, and axial codes. These findings will then be compared to the literature review that was done in Chapter 2 to see how these findings are similar or different and then reviewed with new literature to see how normalizing is described in adolescents. The contribution to nursing science, hypothesis generated, limitations of this study, and recommendations for further study will be included.

Summary of Findings

A key concept that emerged from this study is “**normalizing**”. Normalizing in adolescents with diabetes is defined as the ability of the adolescents to integrate diabetes into the background of their daily life by creating routines to make diabetes ‘part of me’. The conceptual codes developed that describe normalizing for adolescents with diabetes include: a) ‘recognizing life is changing’, b) ‘taking action to prevent a crisis’, c) ‘disclosing to engage support’, d) ‘taking on the burden of care’, e) ‘accepting the ‘new normal’’, and f) ‘hoping for a normal future’.

The normal developmental tasks of adolescence are closely related to each step of this normalizing process for the adolescents with diabetes and help to explain why adolescents struggle with diabetes during this phase of adolescence. The first step of normalizing for the adolescent, ‘recognizing my life is changing’, fits with the developmental task of coping with loss (EHSNRC, 2013; Neinstein, 2008). Once adolescents are old enough to recognize that their life is changing, they need to reconcile that in their mind and go through some of the stages of grief such as denial and anger as they grieve the loss of their normal life and begin their process of coping. The second step of normalizing, ‘taking action to prevent a crisis’, fits the developmental tasks of being interested in the present with little thought to the future (EHSNRC,

2013; Neinstein, 2008), and concrete thinking that is prevalent in early adolescence. This is particularly apparent during the early phase of adolescence where they are focused on their day to day blood sugars yet are unable to see the effects of their actions or inactions when they do not manage their blood sugars appropriately. The third step of normalizing, 'disclosing to engage support', fits with the developmental tasks of adolescents who are struggling with their identity, their body image, wanting more privacy, and wanting to be normal (EHSNRC, 2013; Neinstein, 2008). This helps to explain why adolescents are so cautious about sharing their diabetes with others, avoid blood testing, and avoid insulin injections in an attempt to 'be normal' and 'fit in' with their friends. The fourth step of normalizing, 'taking on the burden of care', fits with the developmental tasks of wanting independence, having conflict with parents, rule and limit testing, and increasing influence of their peer group (EHSNRC, 2013; Neinstein, 2008). This is evident by the conflict adolescents describe during phase 4 of this study where they want independence and more self-care which causes increasing conflict with parents and not always following parents' requests. The fifth step of normalizing, 'accepting the new normal', fits with the developmental tasks of increasing abstract thinking with the ability to set goals (EHSNRC, 2013; Neinstein, 2008). In older adolescence they become more able to see the consequences of their actions, worry about their health, have increased problem solving skills, and are able to set and achieve goals as they learn to manage their diabetes. The sixth and final step of normalizing, 'hoping for a normal future', fits with the developmental tasks of having an increased sense of identity and an increased concern for others (EHSNRC, 2013; Neinstein, 2008). This is seen by the adolescents now being comfortable with their diabetes and wanting to help others to achieve the same feeling of success and accomplishment with their diabetes management.

The six axial codes and major tasks that are part of this model include: a) remembering the beginning of the journey with the major task being learning about diabetes and going home

from the hospital, b) balancing blood sugars/preventing a crisis with the major task being learning to keep blood sugars balanced, c) integrating diabetes into the world outside the home with the major task being enlisting support from others, d) moving the journey towards independence with the major task being separating from parents and independently managing diabetes, e) figuring it out with the major task being learning to cope with diabetes, and f) helping others with the major task being sharing with others to improve their lives.

Findings relating to previous literature

Many of the codes that were described by adolescents during this study have previously been described by a variety of authors. During adolescence there is a decrease in blood glucose monitoring (B. Anderson et al., 1997), resulting in higher blood glucose and hemoglobin A₁C (HbA₁C) levels (B. Anderson et al., 1997; B. J. Anderson et al., 2002; Evans et al., 1999; Levine et al., 2001; Morris et al., 1997), and higher risk for diabetic ketoacidosis (DKA) (Angus & Waugh, 2007; Levine et al., 2001; Palta et al., 1997). Behavioral and psychological factors such as anxiety (Di Battista et al., 2009; Edgar & Skinner, 2003), depression (Edgar & Skinner, 2003), poor self-esteem (Grey et al., 1991; Jacobson et al., 1987), fear of needles (Simmons et al., 2007), poor coping skills (Jacobson et al., 1987; Leonard et al., 2002; Northam et al., 2010), and increased family conflict (B. Anderson, 2009; B. J. Anderson et al., 2002; Ingerski et al., 2010; Weissberg-Benchell et al., 2009) are also described in previous literature. Each of these studies focused on identifying factors that lead to poor adherence or control in diabetes but did not focus on these from the adolescent's perspective.

Issues such as parental support (Hanna & Guthrie, 2001; Kyngas & Rissanen, 2001) and transition to self-care (B. Anderson et al., 1997; Ingerski et al., 2010; Schilling, 2006) have been addressed. One study that focused on adolescent experiences with type 1 diabetes was focused on independence (Marshall et al., 2009) but did discuss that some of the adolescents felt different and worked on trying to be 'normal'. Another study of adolescents (Hanna &

Guthrie, 2000) explored their perspective on transferring to self-care, and the adolescents described gaining approval from others and having difficulty with adding on all the responsibility for self-care. The meta-analysis focusing on interventions to improve adherence (Hood et al., 2010) showed benefit in interventions working on behavior change along with those that focused on either coping, problem-solving, or family issues.

These studies and similar others focused primarily on adolescent behavior change and psychological components for addressing adherence to care. Many of the themes or factors that have been addressed in the literature are certainly discussed by the adolescents in this study as processes that are important in their journey of diabetes. What is missing from these studies is the understanding of the process that the adolescents go through and the behaviors they experience as well as the conditions that are more likely to help or hinder those behaviors.

In this study I focused on the adolescent's experiences of living with type 1 diabetes using a grounded theory approach that has led to the development of a theory that helps to better explain this process of living with diabetes from the adolescent's own experiences. Wanting to be normal was only described in one study (Marshall et al., 2009), and now this theory of defining normalizing for the adolescent helps to provide a strong basis for increased understanding about adolescent's experiences during transition to self-care. Linking the steps of normalizing with the developmental tasks allows researchers to view this time of transition from a very different perspective, and new interventions can now be designed utilizing this model. Previous interventional work has not focused on the transition process, helping the parents in this process, the developmental aspects of the adolescent, or from a framework that understands that the adolescent is trying to 'be normal' and 'fit in'.

Finding relating to new literature search

A new literature search was conducted at the end of this study to learn about normalizing in particular in the context of chronic illness management, with adolescents, as well

as in diabetes Type 1 or 2. Normalizing has been described previously in a variety of settings, but often it is just listed as a term and has not been related to a definition or process. In the classic text and early work in grounded theory on chronic illness *Chronic Illness and the Quality of Life* (Strauss, 1984), the authors describe not only the process and work of living with chronic illness such as managing their disease and preventing a crisis, maintaining a regimen, experiencing social isolation, and seeing their illness as a burden, but also specifically describe normalizing as a strategy. The authors describe normalizing in the life of someone with chronic illness as an important process in returning their life to normal. Some of the strategies that are described include rebelling against illnesses that are very restrictive by concealing their illness, and if this is not possible, they note that study participants talk about feeling awkward or embarrassed by their disease. They also discuss how they tell or don't tell others about their disease partly to protect themselves as well as coming to terms with their illness and learn to accept their illness into their life. These are very similar to some of the steps that are described in normalizing in this current study – 'taking action to prevent a crisis', 'disclosing to engage support', 'taking on the burden of care', and 'accepting the new normal'.

Other studies that also described normalizing and shared similar aspects as this study usually only had one similar category each. A detailed concept analysis of the literature to define normalizing was done (Deatrick, Knafel, & Murphy-Moore, 1999), but this was on how parents normalize a chronic illness in their family. The first step is 'acknowledging the condition and its potential to threaten the lifestyle', which is similar to this study of 'recognizing my life is changing'. Other researchers (Peck & Lillibridge, 2005) focused on how fathers normalize their life when their child has a chronic illness, and they describe 'focusing energies on a day to day basis', which is similar to this study of 'taking action to prevent a crisis' and the developmental task of focusing in on the present. In the chapter on normalizing by Strauss (Strauss, 1984) he discusses how the patients with chronic illness often conceal their disorder to appear normal,

which is similar to adolescents in this study who are 'disclosing to engage support', but developmentally often do not want to disclose during the adolescent years so others do not know. In another study the researchers discussed helping parents to normalize their life with a child who has a chronic genetic illness (Knafl, Darney, Gallo, & Angst, 2010); they found that a stage of normalizing was 'living a difficult life' which is similar to this study of adolescents 'taking on the burden of care'. In another study, the researchers noted that parents of chronically ill children 'altered their therapeutic regimen to normalize their life' (Bossert, Holaday, Harkins, & Turner-Henson, 1990). In research on normalizing among those with cystic fibrosis who were not diagnosed until after age 20 (Widerman, 2004), discussed the importance of 'maintaining routines' which is similar to this study of 'accepting the new normal' where the adolescents also find that building routines becomes important for them. In another study written about adults with a child with chronic illness (Robinson, 1993), the researchers discuss the benefits of normalizing which include 'having hope for a brighter or more livable future' which is similar to this study of adolescents 'hoping for a normal future'.

While this research provides greater understanding of the concept of normalizing, the work does not provide the depth of normalizing among adolescents with Type 1 diabetes. Grounded theory was an important methodology that provided the depth and understanding of the processes of diabetes management for adolescents with Type 1 diabetes which allowed normalizing to emerge as the primary task of their journey. This important work contributes to the advancement of the understanding the concept of normalizing in adolescents with Type 1 diabetes and leads to the design of interventions for nursing practice. These are very important findings to support the adolescents during this time and to help them to find strategies to normalize their life during their journey to independence.

Unique contribution to advance nursing science

This theory of normalizing for the adolescent with a chronic illness, in particular with diabetes, is a very important novel contribution in the diabetes literature. No one has described and defined normalizing, or the concepts that are part of normalizing, for the adolescent with Type 1 diabetes. These steps of normalizing and how they relate to the developmental tasks of the adolescent help to describe and define the process of the experiences of adolescents as they are progressing through adolescence towards independence of care. These steps are critical in helping adolescents to normalize their life and reach the stage of 'accepting the new normal' with minimal risk during their phases of 'taking action to prevent crisis', 'disclosing to engage support', and 'taking on the burden of care' where they often are so focused on being normal; they have a difficult time managing their blood sugars as they try to fit in with their peers. As researchers and clinicians view this difficult stage of adolescent diabetes care in an attempt to normalize their life, it places a very different and positive perspective on this process with a focus on wellness and maintaining a normal life rather than a focus on illness. This creates many new opportunities to provide education and interventions to not only help the adolescents normalize but also assist their parents, peers, schools, and communities to help them normalize their life as well.

The uniqueness of describing and identifying the process of normalizing in the adolescent with the link of each task to normal adolescent development is an exciting step in understanding adolescent diabetes care. This creative view of linking the steps of normalizing in diabetes with adolescent development and how they are interconnected, not only creates positive but negative influences on the ability of the adolescents to normalize their life during this time of transition. The hypotheses that were generated in this study allow researchers to take a fresh look at the behavioral, psychological, and emotional issues during this phase and create novel new interventions to assist the adolescents in normalizing.

Hypotheses

A major hypothesis that was developed was that helping adolescents normalize their lives during adolescence will lead to a decrease in hemoglobin A₁C (HbA₁C) levels showing improved blood glucose control, a decrease in hospitalizations from DKA, and an increased ability to cope with this difficult chronic illness. Additional key hypotheses that are noted include:

- a) if adolescents were taught skills to decrease needle fear they would be able to better cope with injections and site changes and independently manage their care,
- b) if parents and adolescents were taught a smooth transition process then adolescents would be better able to normalize their life during puberty,
- c) if parents and adolescents were taught conflict resolution skills they would better be able to manage or prevent the conflict that arises during their interactions with diabetes care,
- d) if parents were taught how their interactions, reactions, and emotions affect the adolescents then they would be able to modify those behaviors to be less influential on adolescent reactions,
- e) by training school personnel and staff more about adolescents with diabetes would improve their knowledge and tolerance of those with chronic conditions and better help them support adolescents in the school setting at a time in their life when they want increased independence and privacy,
- f) if the community and particularly peers of adolescents with diabetes were trained about their perceptions and reactions to those with diabetes, and how to better support them adolescents would then be better able to feel normal around others, and
- g) by supporting the ability of the parent to 'let go' of monitoring the adolescents during puberty and teaching them more about transition would enhance the adolescent's ability to make the transition to self-care.

Supporting adolescents in addressing these tasks and helping them to achieve a normal life is dependent on the actions taken to support their endeavors and create conditions for their success during adolescence and their transition to independence. Incorporating interventions at multiple levels including parents, peers, schools, and communities are more likely to achieve success in normalizing and achieving good glucose control with positive outcomes. In this study it has been shown that

interventions need to be directed at individual behavior change with parents, providers, adolescents and school teachers, as well as changes in policies and structures.

Study Limitations

In this study, the participants were largely 14 and 15 years old and female; while these study participants remembered their younger years and the process of normalizing; it is possible that they may not have remembered many painful and important details of experiences from their younger years. In this study more females than males signed up to participate, thus further studies with males may be of value. There were no 13 year olds at all, and few subjects were 11 and 12, so additional studies could also focus on younger adolescents or even children with Type 1 diabetes to add to the depth of codes identified in this study or the addition of further codes.

Future Directions

This grounded theory study on normalizing in adolescents with type 1 diabetes led to the generation of multiple hypotheses that now can lead to further study. Recommendations for future research for not only the adolescents but their parents, peers, school, communities, and system changes are included.

Adolescent – Further research might be done with transcultural populations as well as other adolescents with chronic illness during transition to see if these same concepts of normalizing fit in other groups. Needle fear was recognized as a significant ongoing barrier to care and needs a great deal of further research. Interventions are needed to decrease needle fear and increase the ability of adolescents to cope with self-injecting and self-insertion of pump sites. Additional work utilizing novel techniques developing phone apps to help adolescents remember and log their blood sugars in a device they are already carrying will assist them in normalizing their life with diabetes.

Parent – Further research might be of value for parents to support their understanding of normalizing in adolescent's with diabetes, the developmental tasks they are going through during this stage, as well as assisting them in separating/transitioning to independence in a way that decreases conflict. Developing an educational protocol about parental reactions and emotions would help the parents to be aware of their fears and reactions. Providing an intervention on transition of care from parent to adolescent would enhance supportive behaviors of parents and the ability of adolescents to take on care when ready. Additional studies should be completed on the parents' perspectives during this time of transition.

Peers – Further education and support of peers in school or in the community can help them to develop a broader understanding of what diabetes is, how to relate and include those with chronic illness, and learn about comments that may be hurtful. Helping the peers to gain skills in supportive behaviors and knowledge about risks from diabetes would also be beneficial.

School- Developing an intervention in the school setting to enhance awareness of chronic illness and improve attitudes of staff and educators towards those with diabetes should be beneficial in improving adolescent's perceptions of support from those in the school setting.

Communities- Future research and education to communities will assist in knowledge of adolescents with chronic illness, and how these members can support them in taking care of their diabetes in places such as restaurants, sporting events, activities, and helping to integrate adolescent's with diabetes into the community. Developing interventions that engage diabetes camps and other types of programs (i.e. mentoring, peer to peer, and leadership training) to build adolescents support network are essential during this transition period.

System Changes – Future research that will allow the adolescents to stay as normal as possible include ongoing improvements in glucose monitoring, insulin administration, and decreased work and effort on the adolescents part to keep their blood glucose levels normal is critical. Engaging the policy makers, funding agencies, as well as individual choices by health

care companies that influence choices for adolescents in being allowed to use today's new technologies to manage their diabetes are even more critical than ever during this stage of adolescence.

Summary

In this study I have provided new information that advances nursing science in chronic illness management as well as provides a definition and a model of normalizing in the adolescent with Type 1 diabetes. This information has generated multiple hypotheses that now can lead to additional interventions. Normal adolescent developmental tasks, along with these steps in normalizing, create a new paradigm which focuses on wellness and normal growth and development rather than an illness model and provides a basis for ongoing research to increase knowledge for the diabetes community in novel new ways to work with adolescents to help them to normalize their life.

APPENDIX A

This interview will be done by phone to determine eligibility of the study participant. I will provide an introduction to the study (See appendix C) and explain that the purpose for the call is to determine eligibility for the study but that not all eligible individuals may be selected. Details of the introduction are provided in the Human Subjects application.

In determining eligibility, I will also determine if the person with whom I am speaking has primary custody of the child and could provide consent for this study.

QUESTIONS for parent or legal guardian about adolescent participation in the study:

1. How old is your child? (ages 11-15 target)
2. Does your adolescent identify as Caucasian?
3. Is your adolescent male or female?
4. Does your adolescent have a medical (physician and clinical) diagnosis of type 1 diabetes?
5. Is your adolescent currently taking insulin?
6. Has your adolescent been diagnosed with diabetes for more than 6 months?
7. Do both you and your adolescent read and speak English fluently?
8. Are you willing to learn more about this research study and possibly allow your adolescent to participate?
9. Does your adolescent have any other diagnosed medical conditions besides diabetes? If so list.
10. Has your adolescent been diagnosed with a mental health condition or been under treatment for a mental health condition in the past year such as depression, attention deficit disorder (ADD), schizophrenia, bipolar, anxiety or any other mental health conditions?

11. Has your adolescent had a medical appointment with the researcher Elizabeth Babler, ARNP for their diabetes within the past year?
12. Is your adolescent currently in a special education program (for children with learning disabilities or extra help at school) or has your child ever been placed in special education due to learning challenges?

If you have questions about your rights as a research patient you may contact the MultiCare Health System Institutional Review Board (MHS IRB) directly by calling the MHS IRB Office at (xxx) xxx-xxxx.

APPENDIX B

Demographic information to be collected from the parent after the parent and adolescent have consented to being in the study.

1. Please list your adolescent's current age _____ date of birth _____
2. Is your adolescent _____ male _____ female
3. Indicate your adolescent's current grade. _____
4. Please list any other medications your adolescent takes besides insulin

5. When was your adolescent's last office visit? _____
What was his or her Hemoglobin A₁C at their last visit? _____
6. Where do you live? _____
Address (city and state)
7. Does your adolescent live with his or her biological mother? _____
8. Does your adolescent live with his or her biological father? _____
9. If you answered no to item #7, 8 who does the adolescent live with?
_____; who has primary custody for this child? Who can provide a formal consent for this child to participate in this study:

- Name and phone number.
10. Does the adolescent's mother have (please mark the highest completed schooling)
 - a. Did not finish high school _____
 - b. High school diploma _____
 - c. Some college _____
 - d. Graduated college _____
 - e. Graduate or professional degree _____
11. Does the adolescent's father have (please mark the highest completed schooling)
 - a. Did not finish high school _____
 - b. High school diploma _____
 - c. Some college _____
 - d. Graduated college _____
 - e. Graduate or professional degree _____
12. Please mark the box closest to your combined family annual gross income (before taxes)

- a. Less than \$20,000 _____
- b. Between \$21,000-\$50,000 _____
- c. Between \$51,000 –\$75,000 _____
- d. Between \$76,000 – \$99,000 _____
- e. Over \$100,000 _____

If you have questions about your rights as a research patient you may contact the MultiCare Health System Institutional Review Board (MHS IRB) directly by calling the MHS IRB Office at (xxx) xxx-xxxx.

APPENDIX C

Interview Guide. These are beginning interview questions. Additional questions/probes will be determined based on information needed to fill out and saturate categories after the beginning themes and categories have been determined.

1. Let's discuss your experiences of living with diabetes.
2. Now let's talk more specifically about taking care of or managing your diabetes. Can you tell me about that? Probes that may be used include: a) What is it like for you to take care of your diabetes? b) Tell me more about taking your insulin and testing your blood sugar. c) What do you have to do to keep your blood sugar balanced? d) How do you manage your diet? e) How do you manage exercise? f) What, if any, challenges have you experienced? g) What strengths do you have for this situation?
3. Subsequent interviews will start with these initial questions and as codes are identified, additional questions will be included at the end of the interview to further saturate emerging codes. In some cases, an interview might be about only one code as appropriate.

If you have questions about your rights as a research patient you may contact the MultiCare Health System Institutional Review Board (MHS IRB) directly by calling the MHS IRB Office at (xxx) xxx-xxxx.

APPENDIX D**Counseling services available**Bremerton area

Golnar Ansari, PhD
7500 Old Military Rd. NE Suite 103
Bremerton, WA 98311
(360) 698-9258

Candido Trujillo, PhD
32 NE Silver Pine Dr.
Suite 300
Bremerton, WA 98311
(360) 271-6966

Peninsula Counseling Center
9201 Silverdale Way Northwest
Silverdale, WA 98383-8563
(360) 698-4860

Dr. Anthony Hwang
Front Street Clinic
20174 Front Street NE
Poulsbo, WA 98370
(360) 339-4716

Keri Acker-Peltier,
Sunday Farr
Russell Bragg
237 6th St
Bremerton, WA
(360) 377-0181

Olympia area

Jeff Hansen, PhD
1800 Cooper Point RD SW
Suite 17
Olympia, WA 98502
(360) 754-4662

Lynne Dearing, ARNP
1211 4th Ave E
Suite 200
Olympia, WA 98506
(360) 570-1161

Jennifer Shannon, MD
2100 Caton Way SW, Olympia
(360) 455-4571

David Callies, PSYD
Gyro Psychology Services, Inc.
2101 4th Ave East
Suite 202
Olympia, WA 98506
(360) 236-0206

Puyallup area

Good Samaritan Behavioral Health
325 E Pioneer Ave, Puyallup
(253) 445-8120

Dr. Timothy Ernst MD
Lisa Hardebeck, PhD
Woodcreek Pediatrics
1706 S. meridian
Suite 120
Puyallup, WA 98371
(253) 848- 8797

Tacoma area

Melanie Barnes, PhD
Chris Ladish, PhD
Robert Beilke, PhD
Mary Bridge Psychology Department
315 Martin Luther King Jr Way
Tacoma, WA 98405
(253) 403-1465

MENTAL HEALTH CRISIS LINES:

Pierce County: (253) 798 4333, 1 (800) 576 7764
Pierce Crisis Triage Center: (253) 798 4357
Pierce Mobile Outreach Crisis Team: (253) 798 2709, psychiatric placement
King County: (206) 461 3222, 1 (866) 427 4747, Teen Link (206) 461 4922
Kitsap County: (360) 479 3033, 1 (800) 843 4793
Lewis County: (360) 748 6601, 1 (800) 244 7444
Mason/Thurston County: (360) 586 2800, 1 (800) 627 2211
Grays Harbor County: (360) 532 4357, 1 (800) 686 6556

APPENDIX E

Letter to families to be mailed out to eligible subjects from clinic

Greetings,

You are being contacted to see if you are interested in having your adolescent participate in a research study. This research study is being conducted to learn more about adolescent experiences with Type 1 diabetes. Your adolescent has been identified by Mary Bridge Endocrinology Clinic as possibly fitting the criteria to be involved in this study. The hospital has identified your adolescent as a possible eligible participant for this study through the epic system and has mailed you this letter. The researcher does not know who this letter has been mailed to but if you are interested in participating please contact the researcher directly (her information is provided below).

Why this study is important:

This study is being conducted in adolescents with Type 1 diabetes who are ages 11 to 15. Adolescent's often take on more of their own care during this age. Many adolescents do not always continue to test their blood or take their insulin as regularly as needed to keep their blood sugar steady. There are many things that are part of how the adolescent is able to manage their diabetes. Researchers are interested in learning more about the adolescent's experiences in living with diabetes so we can learn new ways to support the adolescent in managing their diabetes and engaging in the daily normal growth and development activities for their age.

How can you help:

You are being contacted to see if you think your adolescent would be interested in helping researchers from the University of Washington learn more about what it is like for them

to have diabetes. It is necessary to get your permission before talking to the adolescent. If you would like to have more information about this study or would like to find out how your adolescent can participate you can contact Elizabeth Babler, ARNP from the University of Washington directly at (xxx) xxx-xxxx by (date will be inserted for 1 month after letter is mailed to families).

Other information:

This study is being conducted as part of a doctoral program and is the dissertation research being conducted through the University of Washington. It has been approved by the University of Washington and MultiCare. Your participation in this study will not affect the care that your adolescent receives for their diabetes at Mary Bridge.

Thanks for taking the time for reading this letter. Please contact the researcher directly as soon as possible to set up a time to see if your adolescent is able to participate in this study.

MultiCare health systems and Mary Bridge Children's Hospital on behalf of
Elizabeth Babler, PhC, ARNP, CDE
University of Washington
(xxx) xxx-xxxx

APPENDIX F

(script to talk to parents about the study)

You have expressed interest in learning more about the research study that is being conducted. The researcher is currently doing research in a doctoral program at the University of Washington. The researcher is interested in learning more about adolescent's who are ages 11 to 15 that have Type 1 diabetes and their experiences with having diabetes. In order to conduct this study the researcher needs to ask you a few questions to make sure that your adolescent meets the requirements to be in this study. If your adolescent does meet the requirements necessary to be in the study the researcher would like to further discuss the study with you so that you will be able to consent to your adolescent participating in this research study. After you consent to your adolescent being in this study the researcher will also need to speak with them about the study and get their consent to be in this research study as well. In doing this study the researcher hopes to learn more about what having diabetes is like for your son or daughter, any challenges they face with having diabetes as well as what it is like for them to take care of their diabetes. The researcher is also interested in knowing how having diabetes affects your adolescent's normal daily life, activities, and relationships with friends and family. The hope of the researcher in doing this study is that more can be learned about the experiences that adolescents with diabetes are experiencing so that researchers can better support adolescents in managing diabetes and in addressing the normal activities and needs for their age. Are you interested in letting the researcher ask you some questions to see if your son or daughter would be eligible to be in this study? It should only take a few more minutes. If you have questions about your rights as a research patient you may contact the MultiCare Health System Institutional Review Board (MHS IRB) directly by calling the MHS IRB Office at (xxx) xxx-xxxx.

(If the parent agrees to let me do the screening questionnaire [Appendix A] over the phone with them and their adolescent meets the eligibility criteria I will then obtain contact information from the parent in order to meet with them to go over the study consent in person.)

APPENDIX G

STATEMENT OF MUTUAL AGREEMENT

Adolescent Experiences with Type 1 Diabetes

This statement of mutual agreement documents the essential elements between the Mary Bridge Children's Health Center Endocrinology Clinic a part of Multicare and the PhD student researcher; it is intended to describe the shared view between the agency and the student concerning the student's research project.

Description of the Research Project and Resulting End Products

The goal of this research project is to learn about the experiences of adolescents with type 1 diabetes, ages 11 – 15 years. The student researcher would like to learn more about the adolescent's perspective of living with diabetes and any associated challenges and management issues they may face. The student researcher is interested in learning more about the diabetes management behaviors and how diabetes affects the adolescent's relationships with his or her parents, peers, and school. The student researcher is hoping to build a theoretical paradigm to develop a better understanding of the adolescent's experience and to gain insight/generate hypotheses about ways to support adolescents that can be translated into more effective nursing practice

On-Site Activities

1. It is agreed that the agency will identify potential study participants and send a letter to the parent or legal guardian to support recruitment.

2. It is agreed that Multicare will furnish mailing labels of eligible patients for this research project and that clinic staff will be hired by the researcher to label stuffed envelopes (provided by the researcher) ready for mailing.
3. It is agreed that the student researcher will be able to post flyers in the pediatric endocrinology clinic at all locations (Tacoma, Olympia, Silverdale and Puyallup).
4. It is agreed that flyers will be available for distribution during clinic by the clinic staff for patients who are eligible to participate in the study.
5. It is agreed that interviews may be conducted onsite in the agency as needed in a private conference room, based on room availability if the parent does not wish for the interview to take place in their home.
6. It is agreed that a focus group may be held onsite in the agency in a private conference room at the end of the study based on room availability.

Ownership and Intellectual Property

7. It is agreed that the interviews recordings and transcripts will remain confidential and the agency will not have access to those recordings or hard copy transcripts.
8. It is agreed that the final theoretical paradigm and findings from this research study will remain the intellectual property of the student researcher and information from this research study may be used by the student researcher for publication in professional journals, presentations or abstracts. This work will not include Multicare staff as authors or coauthors. The agency will be provided a copy of any related publications and given an opportunity to provide appropriate feedback to assure that the name and identity of the agency has been protected/not disclosed.

Reference to Agency

9. It is agreed that the Mary Bridge Children’s pediatric endocrinology clinic will be named as a small urban Children’s Hospital and will not be named directly in any publication or presentations.
10. It is agreed that the student researcher will honor the privacy and confidentiality of the Mary Bridge Children’s Endocrinology Clinic and Multicare when discussing the research project; neither the agency nor any staff will be disclosed in any related publications and the agency will be provided an opportunity to review related publications before submission.
11. It is agreed that the student researcher will not access the medical record of any research participant for study purposes.
12. By signing below, these non-disclosure agreements are understood by all and each will comply with the conditions of this memorandum.

Signatures

Elizabeth Babler, ARNP, PhD student	
Dr. Barbara Marshall – clinic director	
Dr. Jim Polo – Mary Bridge medical director	

APPENDIX H

Interview Guide. These are beginning interview questions. Additional questions/probes will be determined based on information needed to fill out and saturate categories after the beginning themes and categories have been determined. **Additional questions and probes added to this interview guide seen in red will be now used. These questions and probes are based on codes that have emerged from the first interviews conducted and are being added to gain more in-depth information to saturate codes or to explore areas the adolescents have identified that were not in the original interview guide.**

1. Let's discuss your experiences of living with diabetes.

New Probes: When you heard you had the diagnosis of 'diabetes', tell me about that time.

Tell me about learning about your diabetes

2. Now let's talk more specifically about taking care of or managing your diabetes. Can you tell me about that? Probes that may be used include: a) What is it like for you to take care of your diabetes? b) Tell me more about taking your insulin and testing your blood sugar. c) What do you have to do to keep your blood sugar balanced? d) How do you manage your diet? e) How do you manage exercise? f) What, if any, challenges have you experienced? g) What strengths do you have for this situation?

New probes that may be used: Talk about transitioning to self-care (or taking care of diabetes more by yourself). What pieces are you doing, what pieces are your parents doing (re BS, insulin, carbs, exercise, other)

Some people talk about things being hard. How do you define hard, what makes it hard (covering BS, insulin, carbs, exercise, other)

People talk about goals they have (how to be healthy or in control) with their BS, insulin, carbs, exercise and other, tell me about that

Tell me about your experiences in balancing your BS, your insulin, carbs, exercise and anything else about balancing or staying in control

Some people talk about coming to a place that says "I can take care of my diabetes", tell me if you have come to that place and what that is like.

Tell me about any special routines or schedules that you have for your diabetes

NEW question: People talk about their emotional experiences with having diabetes (such as being overwhelmed, being scared, being worried, etc.), talk about your experiences with any of these feelings or others about having diabetes and please give me an example. (note: these are words that have been used by previous study subjects)

NEW question: Tell me about your relationship with others.

Probes that may be used include: People talk about the support of friends and how they help to remind them, stand up for them or help them to not feel different, tell me about that

NEW question: Talk to me about your parents and your diabetes.

NEW question: Talk to me about other people you are in contact with (such as teachers, coaches, and other classmates) and your diabetes.

3. Subsequent interviews will start with these initial questions and as codes are identified, additional questions will be included at the end of the interview to further saturate emerging codes. In some cases, an interview might be about only one code as appropriate.

If you have questions about your rights as a research patient you may contact the MultiCare Health System Institutional Review Board (MHS IRB) directly by calling the MHS IRB Office at (xxx) xxx-xxxx.

Revised 6.14.12 Elizabeth Babler

APPENDIX I

Axial Code	Code	Sub—code	Sub— Code	Sub-code	Sub-code
Phase 1. Remembering the beginning of the Journey	1.0 Getting Diagnosed	1.1 Realizing you are sick 1.2 Going to the doctor or ED			
	2. Learning about diabetes and it's management	2.1 Reading 2.2 Learning from others 2.3 Practicing skills 2.4 Demonstrating how to care for self 2.5 Asking the doctors 2.6 Learning quickly 2.7 Getting scared 2.8 Experiencing feeling alone			
	3.0 Recognizing my Life is Changing				
Phase 2. Balancing blood sugars/preventing a crisis	1.0 Recognizing Symptoms of low and high BS	1.1 Recognizing symptoms of low BS 1.2 Recognizing symptoms of high BS			
	2.0 Monitoring	2.1 Testing Blood sugars 2.2 Testing ketones	2.1.1 Experiencing difficulty with testing BS		
	3.0 Taking action	3.1 Treating low BS			

Axial Code	Code	Sub-code	Sub-Code	Sub-code	Sub-code
Phase 2. Balancing blood sugars/preventing a crisis (continued)	3.0 Taking action (cont.)	3.2 Treating high BS	3.2.1 Taking insulin/responding to the blood sugar	3.2.11 Using the insulin pump	3.2.11.1 Going on the pump 3.2.11.2 Evaluating the pump as easy
				3.2.12 Experiencing needle pain from shots/pump set	3.2.12.1 Coping with injection pain -3.2.12.1.1 using different spots on body -3.2.12.1.2 using self-talk -3.2.12.1.3 engaging parent to help -3.2.12.1.4 using new size needles
			3.2.2 Responding to ketones in urine		
	4.0 Adjusting Diet and Activity to Balance Blood sugars	4.1 Adjusting Activity	4.1.1 Staying Active		
			4.1.2 Monitoring for effects of activity on BS	4.1.2.1 Testing extra during activity 4.1.2.2 Changing insulin dose	
			4.1.3 Stopping activity		

Axial Code	Code	Sub—code	Sub—Code	Sub-code	Sub-code
Phase 2. Balancing Blood sugars/Preventing a Crisis (cont.)	4.0 Adjusting diet and Activity to Balance Blood sugars (cont.)	4.2 Adjusting diet	4.21 Counting carbs	4.211 ID foods with carbs 4.212 Learning to decide how many carbs in food 4.213 Knowing correct ratio 4.214 Avoiding carbs to not take a shot	
			4.22 Recognizing foods that elevate BS		
			4.23 Establishing routines/schedules		
			4.24 Snacking		
			4.25 Eating healthier foods		
	5.0 Evaluating Results from trying to balance BS	5.1 Assessing effects of low BS txt			
		5.2 Addressing effects of high BS txt	5.21 Leaving school early		
	6.0 Seeking help and experiencing Consequences	6.1 Experiencing a seizure/low BS			
		6.2 Experiencing ketones/going to hospital in DKA			

Axial Code	Code	Sub-code	Sub-Code	Sub-code	Sub-code
Phase 2. Balancing Blood sugars/Preventing a Crisis (cont.)	6.0 Seeking help and experiencing Consequences (cont.)	6.3 Seeking assistance from others	6.3.1 Seeking assistance with low BS 6.3.2 Seeking assistance from others with high BS		
Phase 3. Integrating Diabetes Into the World Outside the home	1.0 Building Support	1.1 Disclosing/Not disclosing	1.1.1 Telling Friends 1.1.2 Telling Teachers 1.1.3 Telling others		
		1.2 Teaching and Explaining	1.2.1 To Friends 1.2.2 To teachers 1.2.3 To others		
		1.3 Answering questions			
		1.4 Engaging others to help	1.4.1 Keeping BS balanced	1.4.1.1 Testing BS	
				1.4.1.2 Taking insulin	1.4.1.2.1 In restaurants 1.4.1.2.2 In school 1.4.1.2.3 In front of others 1.4.1.2.4 At parties
			1.4.2 Dealing with crisis	1.4.2.1 Explaining need to go to office 1.4.2.2 To others diabetes comes first 1.4.2.3 Engaging help with low BS	

Axial Code	Code	Sub-code	Sub-Code	Sub-code	Sub-code
Phase 3. Integrating Diabetes Into the World Outside the home (cont.)	1.0 Building Support (cont.)	1.4. Engaging others to Help (cont.)	1.43 Counting Carbohydrates		
	2.0 Realizing I'm different	2.1 Feeling like you don't fit in/ have friends			
Phase 4. Moving the Journey Towards Independence	1.0 Taking over care	1.1 Transitioning from parental care	1.11 Depending on your parent 1.12 Taking over some responsibility gradually 1.13 Needing to separate from parent 1.14 Assuming full responsibility		
		1.2 Independently monitoring BS	1.21 Reaching independence in BS monitoring 1.211 Knowing how to use equipment 1.212 Keeping up with equipment 1.213 Doing the blood test 1.214 Interpreting the result 1.215 Understanding when the BS testing needs to be done		
			1.22 Remembering / Forgetting		

Axial Code	Code	Sub-code	Sub-Code	Sub-code	Sub-code
Phase 4. Moving the Journey Towards Independence (cont.)	1.0 Taking over care (cont.)	1.2 Independently monitoring BS (cont.)	1.23 Creating Strategies for remembering	1.231 Keeping a log 1.232 Setting an alarm 1.233 Using app on ipod touch or phone 1.234 Keeping a schedule 1.235 Using a planner	
		1.3 Taking over administration of insulin	1.31 Determining amount of insulin needed		
			1.32 Giving the insulin	1.321 Knowing how to use equipment 1.322 Keeping equipment available 1.323 Giving insulin independently	
			1.33 Remembering to give insulin		
			1.34 Experiencing high BS	1.341 Addressing high BS	
			1.35 Developing strategies to address issues	1.351 Creating a schedule 1.352 Carrying a bag	
			1.36 Seeking assistance from others		
		1.4 Managing diet independently	1.41 Learning to ID foods with carbs		

Axial Code	Code	Sub—code	Sub- Code	Sub-code	Sub-code
Phase 4. Moving the Journey Towards Independence (cont.)	1.0 Taking over care (cont.)	1.4 Managing diet independently (cont.)	1.42 Learning to ID amount of carbs in products	1.421 Using a scale 1.422 Using a measuring cup 1.423 Looking up information in the book 1.424 Eyeballing the food 1.425 Using hand values to estimate amount of carbs 1.426 Memorizing certain foods 1.427 eating prepackaged foods	
			1.43 Learning to add the total carbs	1.431 Using the calculator 1.432 Creating a log 1.433 Writing amounts on a sheet	
			1.44 Calculating the correct dose of insulin for carbs	1.441 Memorizing the scale 1.442 Using the insulin pump	
			1.45 Learning from blood sugar results how food affects body		
			1.46 Learning how to create a balanced diet	1.461 Using a plate plan 1.462 Cooking for yourself	
			1.47 Remembering to take insulin for food		

Axial Code	Code	Sub-code	Sub-Code	Sub-code	Sub-code
Phase 4. Moving the Journey Towards Independence (cont.)	1.0 Taking over care (cont.)	1.4 Managing diet independently (cont.)	1.48 Developing strategies for carb counting		
		1.5 Managing activity independently	1.51 Assessing effects of activity		
			1.52 Managing insulin dosing for exercise		
	2.0 Experiencing Conflict with Parents	2.1 Struggling for independence	2.11 Worrying about the reactions of parents or others		
		2.2 Experiencing nagging from parents	2.21 Avoiding testing from nagging 2.22 Wanting to be 18 2.23 Understanding parent means well 2.24 Getting used to nagging 2.25 Experiencing parent not nagging		
		2.3 Building trust	2.31 Demonstrating care being done 2.32 Affirming care is done 2.33 Having conversation with parent 2.34 Demonstrating truthfulness in care 2.35 Showing parent you are doing well		

Axial Code	Code	Sub—code	Sub— Code	Sub-code	Sub-code
Phase 4. Moving the Journey Towards Independence (cont.)	3.0 Realizing that diabetes is hard	3.1 Experiencing burnout	3.1.1 Realizing that diabetes is a pain		
			3.1.2 Believing diabetes is a burden	3.121 Not checking blood sugars 3.122 Lying about BS numbers 3.123 Running out of insulin 3.124 Acting lazy 3.125 Needing a break	
			3.1.3 Experiencing trouble taking care of diabetes		
		3.2 Juggling diabetes with other responsibilities			
		3.3 Getting frustrated			
		3.4 Getting annoyed 3.5 Getting stressed			
Phase 5. Figuring it out	1.0 Accepting Diabetes	1.1 Realizing diabetes is forever			
		1.2 Believing you are trapped			
		1.3 Understanding things need to change			
		1.4 Learning to cope	1.4.1 Gaining a positive outlook	1.411 Understanding you are important	

Axial Code	Code	Sub—code	Sub— Code	Sub-code	Sub-code
Phase 5. Figuring It out (cont.)	1.0 Accepting Diabetes (cont.)	1.4 Learning to cope (cont.)	1.42 Seeing diabetes as not scary		
			1.43 Talking to a friend with diabetes		
			1.44 Finding solutions		
			1.45 Realizing it's not a big deal		
		1.5 Accepting the new normal	1.51 Getting use to having diabetes		
			1.52 Realizing diabetes is part of my life		
	2.0 Believing it's Possible to manage diabetes	2.1 Changing the attitude	2.11 Realizing it's not hard		
		2.2 Knowing how to do everything			
		2.3 Realizing diabetes is manageable			
		2.4 Making diabetes a priority			
		2.5 Gaining confidence that you can do what you want			
	3.0 Showing responsibility	3.1 Putting in an effort			
	4.0 Staying on track	4.1 Maintaining health	4.11 Understanding how to control BS	4.111 Testing BS 4.112 Giving insulin 4.113 Managing diet 4.114 Managing exercise 4.115 Making diabetes part of your routine	

Axial Code	Code	Sub-code	Sub-Code	Sub-code	Sub-code
Phase 5. Figuring It out (cont.)	4.0 Staying on track (cont.)	4.1 Maintaining health (cont.)	4.12 Overcoming fear		
		4.2 Setting goals	4.21 Recognizing BS are high or low 4.22 Demonstrating to others you can meet recommendations 4.23 Encouraging myself 4.24 Setting goals for A1C and BS 4.25 Measuring success by attaining goal 4.26 Seeing effects of your actions		
		4.3 Maintaining motivation	4.31 Encouraging myself 4.32 Urging yourself 4.33 Receiving offerings of help from others 4.34 Pushing myself 4.365 Receiving urging from others		
Phase 6. Helping others	1.0 Mentoring others	1.1 Teaching others about diabetes	1.11 Teaching others with diabetes 1.12 Teaching others who need to know more about diabetes		

Axial Code	Code	Sub—code	Sub— Code	Sub-code	Sub-code
Phase 6. Helping others (cont.)	1.0 Mentoring others (cont.)	1.2 Motivating others to take care of their diabetes			
		1.3 Sharing with others ways to accept diabetes	1.31 Helping others to cope	1.311 Explaining it to them 1.312 Understanding they can manage diabetes 1.313 Understanding diabetes is not hard	
			1.32 Helping others not to feel scared 1.33 Helping others to see diabetes as part of life		
		1.4 Acting as a role model 1.5 Participating in advocacy boards 1.6 Participating as camp counselor			
	2.0 Showing compassion to others	2.1 Knowing how others feel 2.2 Helping others feel special 2.3 Trying to connect with others			
	3.0 Planning for a Future helping others				

APPENDIX J

Characteristics of Population

Male	3	27.3%
Female	8	72.7%

HbA1C Ave	8.2%
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Highest education of parent	Mother	Percent	Father	Percent
Did not finish HS	0	0	0	0
HS Diploma	1	9.1	2	18.2
Some College	2	18.2	3	27.3
Graduated college	6	54.5	5	45.5
Graduate or professional degree	2	18.2	1	9.1

Gross Income of Parent	Number	Percent
<\$20,000	1	9.1%
\$21,000— \$50,000	3	27.3%
\$51,000— \$75,000	4	36.4%
\$76,000- \$99,000	3	27.3%

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