An Exploration of Diabetes Self-Care Among Older Adolescents with Type 1 Diabetes: A Focus Group Study

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LOYOLA UNIVERSITY CHICAGO

AN EXPLORATION OF DIABETES SELF-CARE AMONG OLDER ADOLESCENTS WITH TYPE 1 DIABETES: A FOCUS GROUP STUDY

A DISSERTATION SUBMITTED TO THE FACULTY OF THE GRADUATE SCHOOL IN CANDIDACY FOR THE DEGREE OF DOCTOR OF PHILOSOPHY PROGRAM IN NURSING

BY KELLY K. ZINN

CHICAGO, ILLINOIS
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ABSTRACT

Background: Type 1 diabetes (T1DM) is a chronic illness that requires intensive treatment to improve glycemic control and limit the risk of diabetes-related complications. The management of T1DM is challenging for adolescents as the diabetes self-care activities invade all aspects of their life. Older adolescents frequently have poor glycemic control which places them at increased risk for diabetes-related complications.

Study Aim: The goal of this study was to explore diabetes self-care practices among older adolescents, 15 through 18 years old, with T1DM. Specifically, this study sought to determine if there was a difference in diabetes self-care practices between adolescents who exhibited good (HbA1c < 9%) versus poor (HbA1c > 9%) glycemic control.

Study Design: This study used an exploratory, focus group design to gain a better understanding of diabetes self-care among older adolescents and how they integrate diabetes self-care activities into their lives. Six focus groups were conducted and adolescents (n = 21) participated in either a good (HbA1c < 9%, n = 13) or poor (HbA1c > 9%, n = 8) control focus group according to their reported HbA1c.

Results: Inductive analysis revealed 17 themes for adolescents in good control and 16 themes for those with poor glycemic control which were categorized as life with
T1DM; diabetes self-care; interactions with parents, teachers/coaches, or others; or interactions with the healthcare team.

*Nursing Implications:* Understanding the older adolescent’s views about having diabetes and incorporation or lack thereof of diabetes self-care provides valuable information for nurses to develop a trusting relationship with them which may assist with improvement of glycemic control.

*Conclusions:* Teens with good control believed they were stronger than the disease and that diabetes self-care is something they have to do to feel good physically. In contrast, teens with poor control often forgot to perform diabetes self-care activities and had to adjust their lifestyle to fit their chronic hyperglycemia. Teens in good control have accepted the disease and diabetes self-care as part of their identity where teens in poor control described having diabetes and its self-care activities as a burden and something that made them different from their peers.
CHAPTER ONE

PROBLEM STATEMENT

Diabetes is one of the most common chronic diseases in children and adolescents. Annually, approximately 15,000 youth are diagnosed with type 1 diabetes (T1DM) in the United States. It is estimated that approximately 1 in every 357 youth, 10 to 19 years, have T1DM (American Diabetes Association [ADA], 2008). According to the most recent data from the SEARCH for Diabetes in Youth Study Group (2009), a multi-center, population-based study, the prevalence of T1DM for non-Hispanic white youth, 15 to 19 years, is 3.22 per 1000, 2.32 for African-American youth, and 1.71 for Hispanic youth. The medical expenditures associated with management of T1DM and its complications are 2.3 times higher than what expenditures would be in the absence of diabetes amounting to nearly $132 billion annually (Centers for Disease Control [CDC], 2008; National Institute of Diabetes & Digestive & Kidney Diseases [NIDDK], 2005).

Diabetes self-care is multifactorial and intense invading all aspects of the adolescent’s life making it difficult for them to appear normal among peers. The current intensive treatment regimen including multiple daily injections or an insulin pump, frequent blood glucose monitoring, and management of diet are necessary to prevent acute and chronic complications associated with the disease. Developmentally, adolescents are in the process of individuation where peers become more important and normalcy is expected. Type 1 diabetes, because of its intensive self-care regimen,
permeates all aspects of the adolescent’s life (Delamater, 2000), thereby making them
different from their peers.

Another complication for this age group is that diabetes self-care and glycemic
control deteriorate during adolescence with HbA1c increasing 0.7% for every year of age
(Bryden et al., 2001; Greening, Stopelbein, & Reeves, 2006; Helgeson, Siminerio,
Escobar, & Becker, 2008; Leonard, Jang, Savik, & Plumbo, 2005; Lernmark et al., 1996;
Paris et al., 2009; Pound, Sturrock, & Jeffcoate, 1996; Urbach et al., 2005). In
comparison to other age groups, the poorest glycemic control occurs among older
adolescents, 15 to 19 years (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997).
Although much research has been done addressing the issue of adolescent diabetes self-
care, ambiguity remains as to reasons why this age group exhibits decreased performance
of diabetes self-care and poorer glycemic control than any other age group.

**Background and Significance**

**Type 1 Diabetes**

Diabetes mellitus is a disease of inadequate insulin production or action which
leads to hyperglycemia (ADA, 2007). There are two types of diabetes mellitus, type 1
and type 2. Type 1 diabetes (T1DM) is most frequently diagnosed in youth and
adolescents where type 2 more often is diagnosed in adults and is associated with
overweight and obesity (ADA, 2007; Seleman, Scofield, & Swenson-Brousell, 1999).
Control of diabetes requires monitoring blood glucose, dietary changes, exercise, and
medications. Changes in diet and increased exercise often lead to control of T2DM but
not T1DM. Type 1 diabetes is the result of an autoimmune process that causes
destruction of the beta cells in the pancreas leading to decreased insulin production. Insulin is necessary for the body to maintain homeostasis and steady blood glucose levels. The decreased insulin production by the pancreas necessitates administration of exogenous insulin as part of the T1DM treatment regimen (ADA, 2009; Silverstein et al., 2005). In addition to insulin administration, the treatment regimen for T1DM includes frequent blood glucose monitoring, dietary management, and exercise to attain and maintain blood glucose within the recommended range (ADA, 2009; Silverstein et al., 2005).

**Treatment of T1DM**

A landmark longitudinal study, the Diabetes Control and Complications Trial (1994), dramatically changed the treatment regimen of T1DM. Prior to release of the results of this trial, usual care of T1DM involved one or two daily insulin injections, once daily self-monitoring of blood or urinary glucose, and diet and exercise education. The intensive treatment regimen that involved three or more daily insulin injections, blood glucose testing at least four times per day, diet modification, and exercise resulted in substantially decreased HbA1c (p < .001) and a lower frequency in progression of chronic complications than those in the usual care group (DCCT Research Group, 1994). The differences associated with progression of chronic complications between participants who received the usual and intensive diabetes treatment regimens were sustained throughout the eight-year follow-up study, the Epidemiology of Diabetes Interventions and Complications trial (DCCT/EDIC Research Group, 2001).
Diabetes Self-Care

There are many medical, psychosocial, and cognitive aspects involved in the diabetes self-care regimen to control blood glucose levels thereby decreasing the risk for diabetes-related acute and chronic complications. A primary component of the medical aspect of diabetes self-care involves the administration of exogenous insulin. This aspect of the medical regimen most commonly uses a basal-bolus regimen through either multiple daily injections or a continuous subcutaneous insulin infusion pump. Multiple daily injections often involves six to seven shots per day in contrast to the insulin pump which provides a continuous basal rate and insulin boluses through a needle placed in the subcutaneous tissue of the abdomen (Silverstein et al., 2005).

Proper insulin administration relies on knowledge of preprandial blood glucose levels, obtained through self-monitoring, and the amount of carbohydrates that will be consumed to achieve or maintain postprandial blood glucose within the recommended range, 90 to 130 mg/dL (Silverstein et al., 2005). Self-monitoring of blood glucose should occur at least 4 times per day in concordance with meals and snacks. In addition, adolescents should be checking their blood glucose before going to sleep and before driving because of the potential for hypoglycemia. Blood glucose levels and glycosylated hemoglobin (HbA1c) are medical measures used to assess T1DM control and risk for diabetes-related complications (Krishnamurti & Steffes, 2001). Currently, HbA1c ≤ 7.5% is the recommended target goal for adolescents (ADA, 2009), but there is no universal number that has been used as the definitive boundary of good versus poor glycemic control. Further, without the intense multidisciplinary support that was provided for
participants in the DCCT, this level may be difficult to attain (Silverstein et al., 2005). In addition, although use of a basal-bolus regimen leads to a greater decrease in HbA1c, achievement of recommended HbA1c goals is obtained only by families where the parent and adolescents are highly motivated to perform diabetes self-care (ADA, 2009).

Like their peers, adolescents are encouraged to adopt a healthy lifestyle including a healthy diet and physical activity most days of the week. Although they are encouraged to maintain an active and normal lifestyle, adolescents with T1DM must check their blood glucose before and after activity and every hour, if participating in prolonged physical activity (Silverstein et al., 2005) to prevent hypoglycemia. Further, they must monitor and should limit the amount of carbohydrates in their meals and snacks. Insulin is necessary for the digestion of carbohydrates, fat, and protein (ADA, 2009). Normally, the pancreas secretes enough insulin to maintain a homeostatic environment, but this does not occur in persons with T1DM and, therefore, they must administer an appropriate amount of exogenous insulin to account for the current blood glucose level and the amount of carbohydrates that will be consumed (ADA, 2009).

Diabetes self-care also involves cognitive and psychosocial skills. Cognitively, advanced decision making and problem solving skills are necessary to determine the timing of and how much insulin to administer according to blood glucose results and the amount of carbohydrates to be consumed. The medical diabetes treatment regimen is intense and pervasive; impacting all areas of the adolescent’s daily life at a time when appearing normal is expected. Thus, in relation to the psychosocial aspect of diabetes
self-care, a major decision is whether or not to perform diabetes self-care activities around peers and whether or not to tell their friends that they have T1DM.

**Diabetes-Related Complications**

The diabetes self-care activities of insulin administration, blood glucose monitoring, dietary management, and physical activity are necessary to maintain glycemic control and lower the adolescent’s risk for acute and chronic diabetes-related complications. Acute complications associated with T1DM include hypoglycemia, hyperglycemia, and diabetic ketoacidosis. Hyperglycemia and hypoglycemia can lead to decreased neurological function where hyperglycemia relates to an excess of glucose and hypoglycemia is a deficit (Murphy, 1998). Hypoglycemia leads to tremors, dizziness, and fainting. Some youth with T1DM have decreased awareness of hypoglycemic symptoms and may progress to fainting where usually the symptoms of hyperglycemia, such as polyuria, polydipsia, polyphagia, and extreme fatigue are identified before the person reaches a level of glucose that causes decreased level of consciousness (Murphy, 1998). In addition to symptoms of hyperglycemia, diabetic ketoacidosis, a result of untreated severe hyperglycemia, leads to symptoms associated with dehydration, ketonuria, Kussmaul respirations, tachycardia, worsening mental status changes, and abdominal and muscle pain (Murphy, 1998).

Micro- and macrovascular chronic diseases associated with diabetes include retinopathy, nephropathy, neuropathy, cardio- and cerebrovascular disease. Poor glycemic control, HbA1c ≥ 10.0%, leads to a four to eight times increased risk for retinopathy, nephropathy, and macrovascular disease (Greene, 2002). Several studies
have shown that some chronic complications present within five to eight years of onset of T1DM (Krantz, Mack, Hodis, Liu, & Kaufman, 2004; Mohsin et al., 2005; Peppa-Patrikiou et al., 1998; Schultz et al., 1999; Svensson, Eriksson, & Dahlquist, 2004) and as few as five to seven years of poor control during adolescence and young adulthood, even after improvement of glycemic control, leads to increased risk for micro- and macrovascular complications (DCCT/EDIC Research Group, 2001; Rewers et al., 2007; Silverstein et al., 2005).

Several studies have found the presence of risk factors for micro- and macrovascular disease in adolescents, 10 to 19 years old, where 23% of females and 19% of males had 2 or more cardiovascular disease risk factors, such as hypertension, elevated triglycerides, elevated total cholesterol and low-density lipoprotein cholesterol (LDL-C), decreased high-density lipoprotein cholesterol (HDL-C), and increased waist circumference (Petitti et al., 2007; Rodriguez et al., 2006; SEARCH for Diabetes in Youth Study Group, 2006). In addition, children with T1DM as young as 10 years have developed arterial stiffness (Haller et al., 2004). A longitudinal study that followed adolescents (n = 65) with T1DM for eight years found that 27.6% had diabetes-related complications including severe retinopathy, nephropathy, and hypertension (Bryden, 2001).

Adolescents in fair or poor metabolic control have lower exercise capacity, lower pulmonary ventilation (Komatsu et al., 2005); decreased parasympathetic and sympathetic neural modulation (Faulkner, Hathaway, Milstead, & Burghen, 2001); subclinical vascular changes (Mahmud et al., 2006); and increased nocturnal blood
pressure (Krikovszky et al., 2002). In addition, adolescents with poor metabolic control exhibited distal polyneuropathy and autonomic nerve dysfunction (Riihimaa et al., 2001); microalbuminemia (Schultz et al., 1999); and dyslipidemia (Schwab et al., 2006). Furthermore, increased HbA1c was significantly related to occurrence of stroke and development of heart disease and retinopathy (Klein et al., 2004) in later life. The International Diabetes Foundation (2005) estimates that about half of all the money spent on diabetes care goes towards the costs of managing diabetic complications.

**Adolescent Developmental Issues**

The period of adolescence is characterized by rapid growth, along with advancement in physical, psychosocial, and cognitive abilities. Adolescents with T1DM are different from other adolescents because they have a chronic condition that requires performance of self-care tasks to maintain control of their disease and decrease their risk for complications.

**Psychosocial Development**

Psychosocial development during adolescence involves increased responsibility for self and increasing independence (Erikson, 1968). Adolescents with T1DM, however, must also assume responsibility for performance of necessary diabetes self-care tasks. During this period, adolescents develop their own identity, choose their lifestyle, and gradually separate from their parents (Gardiner, 1997) that may lead to increased family conflict and decreased family communication (Weissberg-Benchell & Antisdel, 2000). Adolescents with T1DM desire to have complete independence and control over their lives and diabetes self-care as they mature and begin planning for the future. But, they
may have unrealistic expectations and deny limitations in regard to planning for their future, which sets them up for failure. In addition, they may develop a sense of futility or lose hope due to an exaggeration of the potential barriers of diabetes (Vessey & Mebane, 2000).

Peers begin to exert a greater role in the life of the adolescent and adolescents have a great desire to conform and belong to a group (Weissberg-Benchell & Antisdel, 2000; Woodman, 1999; Zeltzer, 1985). Adolescents become more self-conscious and concerned with how others, especially their peers, perceive them. Adolescents with T1DM have difficulty hiding their condition from peers which makes them ‘different’. However, adolescents with T1DM are psychosocially no different than their peers and their desire to be accepted can outweigh the desire to perform diabetes self-care and negatively affect glycemic control (Timms & Lowes, 1999; Woodman, 1999; Wysocki, Buckloh, Lochrie, & Antal, 2005).

**Cognitive Development**

Advancement of cognitive development is necessary in order for the adolescent to become fully independent and is especially important for the adolescent with T1DM. Diabetes self-care requires advanced problem-solving skills and decision-making capabilities so the adolescent can make adjustments in their diabetes self-care based on available data. Cognitive development during adolescence encompasses the advancement of ability to think, use of abstract thinking, information processing, and use of deductive reasoning (Piaget & Inhelder, 1969; Taylor, Lillis, & LeMone, 1989). As a result of cognitive advancement, adolescents experience improvement in problem-solving ability.
(Weissberg-Benchell & Antisdel, 2000; Williams, Holmbeck, & Greenley, 2002), use
logic for problem solving, and can predict the costs associated with their actions
(Weissberg-Benchell & Antisdel, 2000).

**Neuropsychological Functioning**

Cognition and intellect are impacted by brain development and its level of
functioning. Neuropsychology addresses the use of cognition and intellect as it relates to
learning, memory, and attention. Recently neuroanatomical studies using functional
magnetic resonance imaging (fMRI) to assess brain development have found that
prefrontal cortex development is not complete until the mid-20s (Casey, Tottenham,
Liston, & Durston, 2005). This area of the brain is responsible for sophisticated thinking
abilities such as planning, decision making, goal setting, and metacognition, all of which
are needed in daily diabetes self-care (Steinberg, 2008).

**The Impact of Adolescence on Glycemic Control**

In youth with T1DM, there are 2 periods during childhood in which issues
relating to poor glycemic control most frequently occur. The first occurs with the onset of
puberty in which fluctuating hormone levels creates difficulty in controlling blood sugars
requiring frequent changes to the treatment plan and increased daily exogenous insulin
requirements (Helgeson et al., 2008). The second most difficult period is that of middle to
late adolescence, between 15 to 19 years of age. During this time adolescents exhibit
varying degrees of diabetes self-care and subsequently experience worse glycemic
control than any other age group (Anderson et al., 1997; Bryden et al., 2001; Dashiff,
Bartolucci, Wallander, & Abdullatif, 2005; Lernmark et al., 1996; Mortensen et al., 1998; Pound et al., 1996; Urbach et al., 2005; Ianotti et al., 2006; Springer et al., 2006).

A qualitative study (Chien et al., 2007) with adolescents, 10 to 19 years, found that 84.2% had poor or very poor glycemic control. Further, > 50% had no meal plan, 36.8% had difficulty following the treatment regimen, and 26.3% could not accept the illness or its regimen. Among adolescents with poor glycemic control, 74% reported fair to bad diabetes management; 16% did not take insulin every day; 16% did not take the right amount of insulin, and 26% were not always careful when drawing up their insulin (Frey, Ellis, Naar-King, & Greger, 2004). In addition, 25% reported missing insulin at least once a week, 29% made up blood test results because they did not test or the result was too high, and 81% ate inappropriate food. When asked why they missed shots, adolescents reported that they forgot or were away from home and had forgotten to take insulin with them (Weissberg-Benchell et al., 1995). A retrospective study found that the poor eating practices of adolescents counterbalanced the positive effects experienced with use of an insulin pump (Nimri et al., 2006).

The prevalence of risk factors for diabetes-related chronic diseases and the prevalence of noncompliance with the diabetes self-care regimen are disturbing. The results of studies examining the risks associated with poor glycemic control leads one to wonder why adolescents, knowing they are at increased risk for development of diabetes-related complications even within the next 10 years, do not adhere to the necessary treatment regimen.
Specific Aims

The purpose this study was to explore diabetes self-care among older adolescents, 15 to 18 years of age. Qualitative research with this population has focused on their experience of having diabetes, assuming responsibility for diabetes self-care, and coping methods. Quantitative research has focused on factors associated with performance of diabetes self-care or glycemic control and the transfer of responsibility for diabetes self-care from parents to adolescents. Interventions that have been developed have not shown sustained improvement in glycemic control or aspects of diabetes self-care such as blood glucose testing (Anderson, Brackett, Ho, & Laffel, 1999; Channon, Smith, & Gregory, 2003; Cook, Herold, Edidin, & Briars, 2002; Ellis et al., 2005; 2007; Greco, Pendley, McDonnell & Reeves, 2001; Grey, Boland, Davidson, Li, & Tamborlane, 2000; Grey, Boland, Davidson, Yu, & Tamborlane, 1999; Grey et al., 1998; Harris, Greco, Wysocki, & White, 2001; Laffel et al., 2003; Lawson, Cohen, Richardson, Orrbine, & Pham, 2005; Nansel, Iannotti, Simons-Morton, et al., 2007; Wysocki et al., 2000; 2001; 2006; 2007; 2008). Further, interventions that were developed were based on expert knowledge regarding the disease and its treatment without input from adolescents with T1DM.

The nature of diabetes self-care among older adolescents is best understood from their perspective. This study used an exploratory design with a focus group methodology to explore diabetes self-care, topics related to performance or nonperformance of self-care activities, and what adolescents want in a diabetes self-care program. The aim is to develop a better understanding of diabetes self-care and explore the adolescent’s
perspective of what should be contained within a program designed to assist them with diabetes self-care. The study is designed to answer the following research questions:

1. How do adolescents, 15 to 18 years, manage life with T1DM?

2. What is diabetes self-care among older adolescents, 15 to 18 years, with T1DM?
   a. Is there a difference between adolescents with good vs. poor glycemic control and, if so, what is it?
   b. Why do some older adolescents exhibit incorporation of diabetes self-care into their daily lives while others do not?

3. What do adolescents want in a diabetes self-care program?
CHAPTER TWO
LITERATURE REVIEW

Theoretical Framework

Orem’s self-care deficit nursing theory (SCDNT) was used to guide and organize the review of literature. The development of the theory of self-care began in 1958, was formulated in 1970, and is currently in its 6th edition (Orem, 2001). The SCDNT contains three constituent theories: the theories of 1) self-care, 2) self-care deficit, and 3) nursing system. The theory of nursing system is informed by the theories of self-care deficit and self-care to provide a framework for the process of nursing. The theories of self-care and self-care deficit speak more directly to the issues surrounding adolescent diabetes self-care while the theory of nursing system encompasses interventions designed for adolescents with T1DM.

Theoretical Concepts & Definitions

Basic conditioning factors are attributes that influence self-care agency and self-care demands. Basic conditioning factors can be personal, within or relating directly to the individual, and environmental. Personal basic conditioning factors include: age, gender, developmental and health state. Environmental basic conditioning factors relate to sociocultural characteristics, patterns of living, the family system, and the social environment (Orem, 2001).
Self-care agency is “the complex acquired capability to meet one’s continuing requirements for care of self that regulates life processes, maintains or promotes integrity of human structure and functioning and human development, and promotes well-being” (Orem, 2001, p. 254). An adolescent’s self-care agency is impacted by self-perception, motivation, self-efficacy, self-esteem, coping abilities, and knowledge. Mental or emotional illness or impairments in perception, memory, or attention also affect adolescent self-care agency (Orem, 2001).

Self-care, a “human regulatory function, is the performance of activities necessary to maintain life and health, both mental and physical that must be learned and deliberately performed” (Orem, 2001, p. 43, 45, 143). Self-care requisites are the processes of actions, conscious and unconscious, involved in the individual’s function, development, and promotion of well-being. Health deviation self-care demands are those actions needed for functional integrity and well-being that arise from an illness or disability (Orem, 2001).

The theory of nursing system is the reason for nursing where persons with specialized education to assist patients use their knowledge to assist patients with the performance or maintenance of self-care (Orem, 2001). An alteration in health state, such as T1DM, and the self-care measures required to manage the disease are termed health-deviation self-care requisites. The health deviation self-care requisites associated with T1DM include cognitive and physical activities, such as decision making and administration of insulin. Self-care agency, knowing what is necessary, and self-care
demands, the resultant knowledge leading to initiation of action to meet self-care requisites, are necessary for the control and management of T1DM (Orem, 2001).

Orem’s self-care deficit nursing theory (SDCNT) will guide the review of literature. Concepts of this theory particularly applicable for the adolescent with T1DM include basic conditioning factors, self-care agency, and self-care.

**Method for Retrieval of Literature**

Adolescent self-care of type 1 diabetes is a phenomenon that has been of interest for many years to researchers and clinicians. As has been previously elaborated on, adolescents with T1DM often exhibit poorer glycemic control than youth of other age groups. In the quest for information relating to this phenomenon, the following computerized databases were searched: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, PsychINFO, ProQuest, and Google Scholar. All searches were performed without limits. Keywords used were adolescent or adolescence, diabetes, self-care, self-management, and self-responsibility. Much overlap was found between databases. In an attempt to capture the many aspects relating to diabetes self-care among adolescents, abstracts of articles in English were reviewed and those that related to adaptation, quality of life, emotions, mood, and glycemic or metabolic control were retrieved. In addition, reference lists of each article were examined for additional articles pertinent to the phenomenon of interest, which were also retrieved.

The ensuing review of literature is organized according to the major concepts of Orem’s SCDNT, basic conditioning factors, self-care agency, self-care, and nursing system. Interventions across disciplines that have been developed in an effort to improve
glycemic control among adolescents with T1DM are included within the nursing system section. For purposes of this literature review, only studies that used a measure of diabetes self-care or self-management, adherence, or responsibility are included. Further, a wide participant age range was found across studies, 6 to 25 years. Therefore, this review includes only studies with youth, 10 to 20 years, or those that reported findings specific to adolescent participants.

**Basic Conditioning Factors**

Basic conditioning factors are nonmodifiable characteristics of the adolescent that influence their self-care agency and performance of self-care. These include gender, age, development, health states, family system, sociocultural and external environmental factors (Orem, 2001). This section will review and critique studies addressing the relationship of basic conditioning factors, including race/ethnicity, socioeconomic status (SES), development, health state, family systems, and sociocultural factors, with self-care agency and diabetes self-care among adolescents with T1DM.

**Race/Ethnicity**

There are contrasting findings regarding the relationship between race/ethnicity, diabetes self-care and glycemic control. Only two studies regarding race/ethnicity and its relationship with diabetes self-care or glycemic control among adolescents, 10 to 20 years, were found.

A cross-sectional study with adolescents (n = 224), 9 to 17 years, (Souter et al., 2004) found that race/ethnicity predicted blood glucose testing where being Caucasian predicted better blood glucose testing [Beta = .19, p < .05]. However, age (Beta = -.35, p
< .001), and memory (Beta = .25, p < .01) more significantly predicted blood glucose testing than racial/ethnic classification (Souter et al., 2004). In contrast, Faulkner and Chang (2004) found that although African-American (n = 23) adolescents exhibited poorer metabolic control (t = 2.19, df = 18.7, p = .04), there were no significant race/ethnicity differences in diabetes self-care.

The numbers of racial/ethnic participants in both studies were similar, 26% (Souter et al., 2004) versus 23% (Faulkner & Chang, 2007). However, diabetes self-care was measured using different instruments, a 24-hour recall interview (Souter et al., 2004) vs. the Self-Care Questionnaire ([SCQ], Faulkner & Chang, 2007). Further, data was collected from multiple sources, parents and adolescents, in Souter et al. (2004) but only adolescents were the source of information regarding diabetes self-care in Faulkner & Chang (2007). The 20-item SCQ exhibited adequate reliability with the participant population (Cronbach’s alpha = .78) and content validity was established through use of a panel including a diabetes nurse educator, a pediatric endocrinologist, and a statistician (Faulkner & Chang, 2007). In contrast, reliability of the 24-hour recall interview with the participant population was not assessed and reference to the original psychometric data showed questionable reliability, with subscale reliability coefficients ranging from .37 to .76. However, only findings regarding blood glucose testing were included and this subscale exhibited acceptable reliability coefficients (.72 to .76). Further the 24-hour recall interview does not allow for different treatment regimens and it is difficult to appropriately assess insulin administration (Souter et al., 2004).
In summary, methodological issues exist and the association of race/ethnicity with performance of diabetes self-care activities is unclear. Within both studies, unequal ethnic group sizes, with a low population of participants from ethnic/racial minority groups, could skew the results. Further, in both studies, participants were primarily from two-parent families and of middle socioeconomic status.

Additional studies finding relationships between racial/ethnic classification and diabetes self-care or glycemic control in all youth ages 6 to 16 years were not included in this review due the range of participants and no classification of findings specific to the adolescent population (Greening et al., 2007; Harris et al., 1999; Wysocki et al., 2003). Two additional studies that found relationships between race/ethnicity and glycemic control were not included because diabetes self-care, treatment adherence, nor responsibility was included as research variables (Faulkner, 2003; Hoey et al., 2001).

**Socioeconomic Status**

The socioeconomic status (SES) of families is often classified using the Hollingshead Four Factor Index, but this is not always the case. Only one study reported findings addressing the relationship between SES and diabetes self-care. Additional studies found significant relationships between SES and glycemic control (Harris et al., 1999; Helgeson et al., 2008).

Baseline cross-sectional data from adolescents (n = 74), 12 to 18 years, found a significant but weak relationship where poorer dietary self-management existed among adolescents with parents in manual or unskilled occupations \( r = .23, n = 64, p < .05; \)
However, similar to studies of race/ethnicity, unequal group sizes existed where only 23% had parents in less-skilled occupations.

**Development**

Studies have found a reciprocal relationship between normal adolescent development and performance of diabetes self-care (Christian et al., 1999; Davidson et al., 2004; Meldman, 1987). This relationship is reciprocal in that normal psychosocial tasks of adolescence, such as fitting in with peers, affects their performance of diabetes self-care activities. And, the intense diabetes self-care regimen interferes with normal adolescent psychosocial development.

An exploratory design was used in all of these studies where two were descriptive (Davidson et al., 2004; Meldman, 1987) and the third used grounded theory (Christian et al., 1999). The descriptive studies sought to describe diabetes management from the perspective of older adolescents (n = 12), 15 to 18 years (Meldman, 1987) and the other to describe the stressors and self-care challenges faced by adolescents (n = 6), 13 to 17 years, as they transitioned to the intensive diabetes treatment regimen (Davidson et al., 2004). Christian and colleagues (1999) examined the meaning of the chronic illness experience in relation to assuming responsibility for diabetes self-care among older adolescents (n = 4), 15 to 17 years. Constant comparative analysis was used in data analysis for all studies, however; only Christian et al. (1999) indicated additional techniques used to maintain trustworthiness of their findings.

The studies revealed similar psychosocial themes that could relate to adolescent performance of diabetes self-care (Christian, D’Auria, & Fox, 1999; Davidson, Penney,
Muller, & Grey, 2004; Meldman, 1987). Adolescents stated they were conflicted regarding telling peers about their disease. They realized it would be important for peers to know about the disease in case help was needed. However, telling others would expose their difference at a time when being normal is expected (Christian et al., 1999; Meldman, 1987). Further, adolescents stated the diabetes treatment regimen was pervasive in their lives and negatively impacts their ability to meet their developmental needs (Christian et al., 1999; Meldman, 1987) and made them different from their peers (Davidson et al., 2004).

**Emotional Health**

Altered emotional states can negatively impact glycemic control and well-being among adolescents with T1DM. One quantitative study was found that investigated the effect of depression and anxiety on frequency of blood glucose measurement and glycemic control among adolescents 13 to 18 years (n = 145; Hilliard, Herzer, Dolan, & Hood, 2011). Researchers found that more depressive symptoms, as measured by the Children’s Depression Inventory (α = .90), and higher anxiety, measured with the State-Trait Anxiety Inventory for Children ([STAIC] α = .87) correlated with higher HbA1c (r = 0.22, p < .01; r = 0.30, p < .001) and decreased frequency of blood glucose measurement (r = -0.33, p < .001; r = 0.19, p < .05). Multivariate regression found that depressive symptoms at baseline were not a significant predictor of glycemic control or frequency of blood glucose measurement 12 months later. Higher anxiety levels at baseline significantly predicted glycemic control where a 14 point increase in STAIC scores led to a 1% increase in HbA1c (r = 0.25, p < .01; Hilliard et al., 2011).
In their discussion section, the researchers of this study concluded that depressive symptoms predicted decreased frequency of blood glucose measurement (Hilliard, Herzer, Dolan, & Hood, 2011). However, review of the table that provided the statistical results of multiple regressions revealed that depressive symptoms “trended toward significance” (Hilliard, et al., 2011, p. 42).

Two additional studies that studied the impact of emotional or behavioral health on glycemic control follows (Bryden et al., 2001; Goldston et al., 1994). Although these studies do not relate emotional health to glycemic control or performance of diabetes self-care, this researcher felt they provided valuable information in regards to the effects of T1DM on adolescents.

Bryden and colleagues (2001) followed adolescents for eight years and found that those with behavioral problems had higher HbA1c during the study period ($t = 3.61$, $p < .001$). In addition, at follow up as young adults, 27% of females and 8% of males suffered from a psychiatric disorder (Bryden et al., 2001). Findings from a 12-year longitudinal study support these findings (Goldston et al., 1994). Interviews with adolescents ($n = 95$), 8 to 13 years, 2 to 3 weeks after diagnosis indicated that 29.5% had a history of suicidal ideation with 53.5% of these occurring after diagnosis. The majority of participants ($n = 94$) were re-interviewed 12 years after diagnosis as young adults (Goldston et al., 1994). It was found that 46% had a history of suicidal thoughts and 6.4% had attempted suicide, with a cumulative attempted suicide rate of 7.3%. In addition, adolescents who had suicidal ideation exhibited pervasive noncompliance (Chi-square = 8.97, df = 1, $p <$
Suicide was first attempted between 15 to 18 years and insulin overdose (36%) was the most common method (Goldston et al., 1994).

**Family Composition**

The composition of families is associated with glycemic control, but the relationship of family composition and diabetes self-care is unknown. Only two studies were found that included family composition and diabetes self-care as research variables.

The relationship between family composition, health outcomes, and psychosocial functioning was the focus of a study whose participants (n = 119), adolescent 12 to 17 years, were recruited for a larger, randomized controlled trial (Harris et al., 1999). There were no significant relationships with diabetes self-care but poorer metabolic control was found for adolescents of single-parent families \[F(1, 111) = 7.18, p < .05\], and especially African-American adolescents in single-parent families \[F(1, 111) = 4.76, p < .03\]. The Conflict Behavior questionnaire and Diabetes Responsibility and Conflict Scale were used to evaluate family conflict. Families with at least one member whose scores indicated moderate or greater general conflict were invited to participate in this study which limits generalization of results beyond this population. Further, the majority of participants were Caucasian (79%), from 2-parent families (68%), and there were significant differences in SES between groups.

Family dynamics, parental involvement in diabetes self-care, and metabolic control were variables of interest in the Hvidøre Study Group on Childhood Diabetes that includes 21 centers in 19 countries in Europe, Japan, Australia, and North America (Cameron et al., 2008). Adolescents (n = 1,973), 11 to 18 years, whose biological parents
were still living together ($t = 4.1$, $p < .001$) and whose father was employed ($F = 7.2$; d.f. $= 3$; $p < .001$) had lower HbA1c (Cameron et al., 2008). However, it was indicated that 79% of the participants had biological parents still living together. Although level of responsibility was measured in this study, no information regarding its relationship with family composition was provided. No demographic information regarding race/ethnicity or SES was provided.

Additional studies that showed a relationship between family composition and glycemic control, where adolescents in two-parent families exhibited better glycemic control, did not include diabetes self-care as a variable (Hoey et al., 2001; Leonard et al., 2002), and, thus, were not included in this review.

**Family Relations**

The type of support an adolescent receives from their family, primarily parents, is related to their performance of diabetes self-care and glycemic control. Family relations and its relationship to adolescent diabetes self-care were included as variables in a focus group study and five quantitative studies.

Early adolescents ($n = 24$), 13 to 15 years, were participants in a focus group study regarding parent-adolescent diabetes-related conflict and support (Weinger, O’Donnell, & Ritholz, 2001). Negative parental behaviors such as worry, intrusive behaviors, lack of understanding, and blaming behaviors were a common precursor for parent-adolescent conflict. In addition, a difference in time orientation between parents and adolescents, future vs. present, further contributed to conflict. Although negative interactions were the primary focus of the discussion, adolescents also identified some
positive parental behaviors. Parents who understood the demands of diabetes and
provided reassurance about diabetes and normal functioning were behaviors these
adolescents identified as supportive (Weinger et al., 2001). Validity of analyses was
supported by discussion among researchers regarding analysis and coming to a consensus
on the coding procedure that would be used.

Adolescents (n = 21), 11 to 18 years, were participants in a descriptive study
regarding the transfer of responsibility for diabetes self-care activities (Hanna, Juarez,
Lenss, & Guthrie, 2003). Checklists that addressed independent functioning and decision
making regarding diabetes management along with measures of parental support and
communication regarding diabetes management were completed by the participants. It
was found that adolescents who received higher levels of parental support were less
independent in decision making (r = -.45, p = .019). Although, independent functioning
in diabetes management was measured, no data regarding its association with parental
support was presented.

More recently, research was conducted to determine if family conflict was
associated with or predicted frequency of blood glucose measurement and glycemic
control among adolescents 13 to 18 years (n = 145, Hilliard, Guilfoyle, Dolan, & Hood,
2011; Ingerski, Anderson, Dolan, & Hood, 2010). It was found that increased adolescent
responsibility for diabetes self-care (β = 0.18, p < .05) and family conflict (β = -0.19, p < .05) predicted frequency of blood glucose measurement six months later (F[13,146] =
3.55, p < .001, R² = .26). Further, family conflict (β = .19, p < .05) predicted glycemic
control six months later (F[13,146] = 3.13, p < .001, R² = .23; Ingerski et al., 2010) and at
12 months ($\beta = 0.08$, $p = .02$; Hilliard et al., 2011). Blood glucose measurement frequency at six months explained 24% of the variance in association between family conflict at baseline and glycemic control at 12 months ($\beta = -0.24$, $p = .007$; Hilliard et al., 2011). Participants in this study were younger ($\bar{x}$ age $= 15.5$ years), used an insulin pump (63%), and had higher HbA1c ($\bar{x} = 8.8$).

Two additional studies found relationships between family support, family communication, and diabetes self-care (Faulkner & Chang, 2007; Skinner & Hampson, 1998). General family support moderately correlated with dietary self-management ($r = .40$, $p < .01$) while diabetes-specific family support correlated with blood glucose monitoring ($r = .24$, $p < .05$), and insulin administration ($r = .27$, $p < .05$) where more support led to better diabetes self-management behaviors (Skinner & Hampson, 1998). Similarly, Faulkner and Chang (2007) found that adolescents in families with more positive emotional support and communication had higher levels of diabetes self-care (Beta $= .25$, $R^2 = .08$, $p = .005$). However, although both studies had fairly large sample sizes, the majority of participants were male (57%). Further, Faulkner and Chang (2007) identified unequal subgroup sizes and lack of homogeneity in variances, along with large standard deviations for HbA1c, as study limitations.

Additional studies found negative correlations between adolescent age and family relations (Hanson, Henggeler, & Burghen, 1987; Hanson, De Guire, Schinkel, & Kolterman, 1995). However, because they were completed before the change in treatment regimen, they were not included.
Sociocultural

Peers. The relationship of sociocultural factors, such as peer support, with diabetes self-care and metabolic control is vague. Peer relationships are of increasing importance to adolescents who desire to fit in with the group and may negatively affect adolescent performance of diabetes self-care.

Findings regarding the impact of peers on diabetes self-care from two qualitative studies in nursing were similar (Dickinson & O’Reilly, 2004; Kyngas et al., 1998). Dickinson & O’Reilly (2004) found that adolescents with T1DM have difficulty socially because the intensive treatment regimen is difficult to hide. Adolescents reported that fitting in with their peers was more important and they often chose to do what their friends were doing without thinking of its effects on their diabetes (Dickinson & O’Reilly, 2004; Kyngas et al., 1998), especially among adolescents whose friends dominated their lives (Kyngas et al., 1998). In contrast, adolescents who received silent support, such as friends changing their lifestyle to fit more closely with the adolescent’s diabetes lifestyle, were more likely to comply with the treatment regimen. Similarly, adolescents who viewed diabetes as a normal part of their life were less likely to be pressured by friends and more likely to comply with the treatment regimen (Kyngas et al., 1998).

Methodological differences between these studies exist. A phenomenological design used unstructured interviews with females (n = 10), 16 to 17 years, who were participants in a diabetes camp counselor-in-training program to understand their lived experience (Dickinson & O’Reilly, 2004). In contrast, Finnish adolescents (n = 51), 13 to
17 years, completed questionnaires regarding their compliance with the treatment regimen and semistructured interviews regarding their perception of the influence of peers in relation to compliance (Kyngas et al., 1998).

A study with early adolescents (n = 127), 10 to 15 years, examined the nature of friendship between adolescents with T1DM and healthy peers at two time periods 1 year apart (Helgeson, Reynolds, Escobar, Siminerio, & Becker, 2007). Among adolescents with T1DM, negative peer relations were associated with worse metabolic control (Beta = .35, p < .05) with a stronger association 1 year later (Beta = .59, p < .001). Adolescents with T1DM completed the Self-Care Inventory which measures how well adolescents followed the treatment regimen recommended by physicians; however there were no significant relationships with peer support or negative peer relations.

In summary, qualitative data indicated that peers have a significant impact on the performance of diabetes self-care activities (Dickinson & O’Reilly, 2004; Kyngas et al., 1998), but the quantitative study did not find a relationship with peer relations, however these participants were younger (Helgeson et al., 2007). A study with German 14-year-old adolescents (n = 98) found a relationship between peer relations and metabolic control, but did not include diabetes self-care as a variable (Seiffge-Krenke & Stemmler, 2003).

**Healthcare.** The interaction of healthcare providers with adolescents with T1DM can also impact their performance of diabetes self-care. Findings regarding this relationship were included in three qualitative and one quantitative study.
Qualitative studies (n = 3) with adolescents, 13 to 18 years, revealed important information regarding the influence of health care providers, especially physicians and nurses, on adolescent performance of diabetes self-care (Carroll & Marrero, 2006; Davidson, Penney, Muller & Grey, 2004; Kyngas, Hentinen, & Barlow, 1998).

Physicians and nurses who displayed interest in the adolescent’s opinion and how they integrated the treatment regimen into their lives were more likely to motivate adolescents to comply with the treatment regimen. In contrast, physicians and nurses who seemed to be working from a predetermined regimen and discounted adolescents’ views did not necessarily influence the adolescent’s compliance with the treatment regimen (Kyngas, 1998).

Similarly, adolescents who felt they had a good relationship with their physician were more careful about their diabetes management before and after clinic visits. A good relationship existed when physicians saw the adolescent as an individual, not the disease, spoke directly to the adolescent, or were more accessible (Carroll & Marrero, 2006). Further support was provided by adolescents (n = 6) who were participants in coping skills training. These adolescents, who were beginning the intensive treatment regimen wanted more input into treatment decisions (Davidson et al., 2004).

Although the majority of participants in the Carroll and Marrero study (2006) were older adolescents (n = 17/31, 55%), across all of these studies, older adolescents were the minority (Davidson et al., 2004; Kyngas et al., 1998). Additional methodological differences for these studies relates to data collection. Open-ended questions formed the interview guide for individual interviews (n = 51; Kyngas et al.,
1998) and were used with the focus groups (Carroll & Marrero, 2006). In contrast, transcripts from coping skills training sessions with adolescents (n = 6) were used to determine self-care challenges and stressors (Davidson et al., 2004).

A cross-sectional quantitative study with Finnish adolescents with T1DM (n = 289), 13 to 18 years, studied predictors of good adherence to the diabetes treatment regimen (Kyngas, 2007). The majority of findings related to adolescent perceptions of diabetes, thus more information regarding the study can be found in this subsequent section. A newly-developed adherence measure included questions regarding support from healthcare providers. Logistic regression analysis found that adolescents who reported receiving support from physicians [Exp(B) = 6.69, p = .0008] and nurses [Exp(B) = 6.28, p = .0006] were more likely to adhere to the recommended diabetes treatment regimen (Kyngas, 2007). It should be noted, however, that the majority of participants (94%) indicated that they fully or satisfactorily adhered to the treatment regimen.

In summary, health care providers including physicians and nurses can positively or negatively influence the diabetes self-care of adolescents with T1DM. The recommendations for diabetes care from the American Diabetes Association (2009) further support the need for health care providers to collaborate with their adolescent patients regarding treatment decisions.

**Summary of Basic Conditioning Factors**

In summary, the basic conditioning factors of development, health states, family systems, race/ethnicity, socioeconomic status, and sociocultural factors have an important
role in adolescent diabetes self-care and metabolic control among adolescents.
Nonmodifiable conditioning factors, such as race/ethnicity, SES, or living in single-parent families were associated with adolescent performance of diabetes self-care and glycemic control (Cameron et al., 2008; Faulkner & Chang, 2004; Harris et al., 1999; Skinner & Hampson, 1998; Souter et al., 2004). Further, the normal psychosocial development tasks influenced performance of diabetes self-care and having the disease affected adolescent cognitive and psychosocial development (Christian, D’Auria, & Fox, 1999; Davidson, Penney, Muller, & Grey, 2004; Meldman, 1987).

Additional conditioning factors such as family, peer, and healthcare relations also affected adolescent performance of diabetes self-care. Family relations, including support of parents and communication, worsened as adolescents aged which influenced their diabetes self-care (Faulkner & Chang, 2007; Hanna et al., 2003; Hanson et al., 1987; Hanson et al., 1995; Skinner & Hampson, 1998; Weinger et al., 2001). The influence of peers and the pressure to conform increases during adolescence, however, the impact of peer relations on diabetes self-care is unclear (Helgeson et al., 2007). Although adolescents recognize that they should tell peers about their disease, they are reluctant to because it would reveal their difference (Dickinson & O’Reilly, 2004; Kyngas et al., 1998). The manner in which healthcare providers, especially physicians, interact with adolescents with T1DM also influences their performance of diabetes self-care. Adolescents want to be recognized as knowledgeable partners in decision making regarding the treatment regimen, but need assistance fitting it into their lives. Further support is provided by recommendations from the ADA who state that healthcare
providers should collaborate with adolescents regarding treatment decisions (ADA, 2009).

**Self-Care Agency**

Self-care agency, which includes autonomy, problem solving, self-efficacy, perceptions, and coping, also affects adolescent’s performance of diabetes self-care. This section will discuss the research relating these characteristics to diabetes self-care or glycemic control among adolescents with T1DM.

**Autonomy**

An adolescent’s level of autonomy can impact decisions they make and performance of diabetes self-care. However, only two studies addressing this relationship have been conducted.

A cross-sectional study with youth (n = 100), 5 to 18 years, examined the relationship between youth self-care autonomy and psychological maturity (Wysocki et al., 1996). The autonomy-to-maturity ratio (AMR) is a measure of the extent of developmentally appropriate self-care. Constrained AMR involves the adolescent not having developmentally appropriate autonomy where adolescents with excessive AMR have too much self-care autonomy. Participants with excessive AMR were older ($r = .29$, $p < .001$). Multivariate analysis, controlling for age, revealed a significant group effect where increased self-care autonomy related to worse self-care [$F(3,96) = 4.47$, $R^2 = .14$, $p < .01$; (Wysocki et al., 1996)]. Although youth were recruited from three pediatric diabetes centers, the enrollment rate was low (30%). In addition, the evaluation sessions were long (3.5 hours) which could lead to fatigue among participants that could
negatively impact their performance on maturity tests or the way they responded to questionnaire items.

A phenomenological method was used to examine the transition towards autonomy in Swedish teens (n = 32), 13 to 17 years with T1DM, two weeks after they participated in empowerment education (Karlsson, Arman, & Wikblad, 2008). The core, “hovering between individual actions and support of others” (p. 565) was affected by “growth through self-reliance” (p. 566) and “growth through confirmation of others” (p. 567). “Hovering” related to adolescent’s trying to separate from parents but feeling insecure in taking on some of the responsibilities of diabetes self-management which led to confusion. “Growth through self-reliance” related to the development of self-determination, advancing psychological maturity, and increased motivation as a result of self-management successes. “Growth through confirmation of others” related to parental encouragement and support from the diabetes team that encouraged decision-making and progression toward increased self-responsibility (Karlsson et al., 2008). The validity of the interview guide was established through interviews with two teens who were not participants in the study. Researchers reported that they used the Vancouver School of doing phenomenology where two or more interviews are conducted with each participant. However, this procedure was not followed. Instead, interviews and discussion of the themes and subthemes were conducted with two of the teens to validate findings.

**Problem Solving**

The diabetes self-care measures necessary to control blood glucose and prevent chronic complications are intense, requiring advanced decision-making and problem-
solving skills. This section will review two studies that investigated decision making or problem solving.

A cross-sectional design was used to study the relationship of problem solving with diabetes self-care and glycemic control among youth (n = 67), 8 to 17 years (Thomas, Peterson, & Goldstein, 1997). The Social Problem-Solving for Diabetic Youth measure was a structured interview that presented youth with several vignettes of situations they might encounter during interactions with peers in their daily lives. As would be expected, older adolescents were able to define problems, provide more solutions, and identify consequences for their diabetes better than prepubertal youth \[F (10, 112) = 4.39, p < .005\]. However, older youth were more likely to choose actions that were acceptable to peers but less adherent to the diabetes treatment regimen \(r = -.46 \text{ and } -.58, p < .0001\). Alpha coefficients of the measure ranged from 0.63 to 0.90 and average inter-rater reliability was 0.86 (Thomas et al., 1997). Persons who were unaware of the literature or the study’s hypotheses conducted the interviews and were provided with written instructions that included a set structure and wording of questions and prompts.

A second study from psychology with adolescents (n = 63), 11 to 17 years, found that maladaptive decision making, which includes hypervigilance, passing the buck, and procrastination was associated with lower report of adherence by parents \(r = -.33, p < .01\); (Miller & Drotar, 2007)). Further, adolescent use of negative communication, such as criticizing and discounting the other’s points, was associated with decreased parental \(r = -.28, p = .022\) and provider report \(r = -.26, p < .03\) of treatment adherence and poorer metabolic control \(r = .29, p < .03\). The Self-Care Inventory was completed by parents
and adolescents and exhibited low coefficient alphas (.66 adolescent and .70 parents). Adolescent report of treatment adherence, because of the low reliability, was excluded from analyses (Miller & Drotar, 2007).

In summary, although older youth could identify problem situations and more solutions than younger children, they were more likely to choose peer-acceptable actions that often negated diabetes self-care (Thomas et al., 1997). In addition, older adolescents were more likely to use maladaptive decision making which led to decreased diabetes self-care which was also related to the use of negative communication (Miller & Drotar, 2007). Similar to the majority of studies conducted with adolescents with T1DM, these studies used a cross-sectional design with participants who were primarily Caucasian and of middle SES.

**Self-efficacy**

Adolescent performance of diabetes self-care behaviors can be affected by their self-efficacy, or belief in themselves to perform diabetes self-care. Two studies that used Bandura’s self-efficacy theory as the guiding framework found a relationship between self-efficacy and adolescent diabetes self-care.

Adolescents (n =168), 10 to 16 years, were participants in a study that evaluated the psychometrics of the revised Diabetes Self-Management Profile [DSMP; (Iannotti et al., 2006)]. In this study, diabetes-specific self-efficacy correlated with youth- (r = .37, p < .001) and parental-reported (r = .29, p < .01) adherence. In addition, adolescents with higher diabetes-specific self-efficacy exhibited lower HbA1c [r = -.21, p < .05; (Iannotti et al., 2006)]. The second study evaluated diabetes self-care with the Summary of Self-Care
Activities (SSCA) questionnaire (Ott et al., 2000). Similarly, diabetes-specific self-efficacy was associated with diabetes self-care \( (r = .21, p < .01) \) and adolescent’s age \( [r = .24, p < .005; (Ott et al., 2000)] \).

Both studies had large sample sizes, but SSCA total scores indicated adolescents in Ott et al. (2000) were fairly adherent to diabetes self-care (mean = 33, range = 22 to 42). Although psychometrics of the DSMP had previously been conducted, major modifications of the measure were completed to make it suitable for younger children and make it standardized so non-medical interviewers could administer the instrument. In addition, instruments were developed to assess self-efficacy and outcome expectations of diabetes self-management (Iannotti et al., 2006). Further, there was no indication of examination of convergent validity with instruments with established and acceptable reliability and validity. Parents and youth completed the self-care measures in both studies, however the SSCA assesses the level of adherence to the prescribed treatment regimen (Ott et al., 2000) and the DSMP assess adherence to an optimal diabetes treatment regimen (Iannotti et al., 2006).

**Perceptions**

How an adolescent perceives themself, their environment, and diabetes can impact their performance of diabetes self-care. This section will review eight studies that investigated the relationship between adolescent perception, diabetes self-care, and glycemic control.

Three qualitative studies, two that used phenomenology and one with focus groups, provided information regarding adolescent perceptions of diabetes (Dickinson &
Female adolescents, 16 to 17 years, did not let diabetes define who they were as a person, therefore it was easier for them to blend in with the adolescent culture (Dickinson & O’Reilly, 2004; further information regarding this study can be found within the Sociocultural section under Basic Conditioning Factors). Elaboration of adolescent perceptions regarding diabetes was provided in a focus group study with adolescents, 13 to 18 years (Carroll & Marrero, 2006). They described diabetes as a daily hassle that exerted control over their lives but that they were more mature and responsible than their peers. Focus groups were separated according to adolescent age and contained participants who were using insulin injections or an insulin pump. Although the principles of the diabetes self-care regimen remain the same whether using injections or a pump, the differences potentially could affect an adolescent’s response. Further, negative feelings could emerge among adolescents who use injections because they would rather have the pump, but cannot due to nonpayment by insurance and/or lack of pump affordability.

The third qualitative study used phenomenology to interview Swedish adolescents (n = 8), 14 to 18 years, about their experience of living with T1DM (Huus & Enskar, 2007). Data analysis revealed five themes that described the adolescent’s desire to live like peers. Adolescents felt they were different and were treated differently than others and could not live a regular life due to the treatment regimen. Further, knowing their body and taking care of themself was important to adolescents in this study.

A cross-sectional design was used to study illness beliefs and how adolescents with T1DM define themselves (Helgeson & Novak, 2007). Among this population of
early adolescents (n = 132), 10 to 15 years, females who viewed their illness negatively exhibited more depressive symptoms, had higher anxiety, and were more angry (all variables had Beta = .32, p < .01). Worse metabolic control was found in adolescents who viewed their illness more negatively (Beta = .25, p < .05) but only a marginally significant relationship was found between illness perception and diabetes self-care (Beta = -.17, p = .07). The Self-Care Inventory, used to measure diabetes self-care, exhibited acceptable reliability (alpha = 0.78) in this population. However, the Self-Perception Profile, used to determine illness centrality, exhibited poor reliability [Cronbach’s alpha = 0.51; (Helgeson & Novak, 2007)]. As such, it cannot be determined whether illness perceptions affect metabolic control or vice versa.

The self-regulation theory was used to guide a one-year longitudinal study by psychologists of the relationship between illness beliefs, diabetes self-care, and metabolic control among adolescents, 12 to 18 years, with T1DM (Skinner & Hampson, 1998; Skinner & Hampson, 2001). Baseline data found that beliefs regarding the consequences of diabetes were not related to total self-care, however beliefs regarding treatment effectiveness in controlling complications correlated with dietary self-care (r = .46, p < .001) and blood glucose monitoring [r = .23, p < .05; (Skinner & Hampson, 1998)]. Follow-up data indicated that change in beliefs regarding treatment effectiveness (baseline score minus follow-up score) predicted dietary self-care [R^2 = .39, F = 13.92, p < .0001; (Skinner & Hampson, 2001)].

At baseline, participants (n = 74) completed the Summary of Diabetes Self-Care Schedule which is a 12-item questionnaire that measures diabetes self-management for
the previous seven days. They also completed six other measures assessing well-being, family support, diabetes family behavior, peer support and beliefs regarding diabetes (Skinner & Hampson, 1998). However, at one-year follow-up, participants (n = 54) only completed three measures, diabetes self-care, well-being, and beliefs regarding diabetes (Skinner & Hampson, 2001). In addition, only 72% of participants were retained and according to parents’ occupation, were of higher SES.

A cross-sectional study with Finnish adolescents with T1DM (n = 289), 13 to 17 years, tested and used a new measure of adherence (unnamed) to determine factors that predict good adherence to the treatment regimen (Kyngas, 2007). Logistic regression revealed several significant predictors. Adolescents who viewed diabetes as a threat to their mental well-being [Exp(B) = 7.68, p = .0001] or physical well-being [Exp(B) = 2.95, p = .0032] were more likely to adhere to the recommended diabetes treatment regimen. In addition, good adherence was more likely among adolescents with good motivation [Exp(B) = 5.52, p = .0004] or who had energy and willpower [Exp(B) = 3.69, p = .0007; (Kyngas, 2007)]. However, although participants were randomly selected from the Finnish Registry, 94% reported full or satisfactory compliance with the treatment regimen and 81% reported good adherence with insulin treatment. It is important to note, however, that only 56% of adolescents with HbA1c < 7.0% showed good adherence and among the 6% that reported poor adherence, 57% exhibited HbA1c > 8.9% (Kyngas, 2007). Considering this data, the relationship between adherence and HbA1c in this study is questionable.
In a five-year longitudinal study, adolescents (n = 132) were interviewed annually to determine if stressful life events related to glycemic control and diabetes self-care (Helgeson, Siminerio, Escobar, & Becker, 2010). Cross-sectional data and multi-level modeling found that stressful life events predicted poorer self-care (-.04, SE = .007, p < .001), interacted with age to predict blood glucose frequency (-.03, SE= .012, p < .05) and to predict glycemic control (.03, SE = .011, p < .01). Longitudinal analysis found that stressful life events predicted changes in self-care behavior (-.044, SE = .023, p = .05), blood glucose frequency (-.015 SE = .005, p < .005) and change in glycemic control over time (.042, SE = .019, p < .05). At study entry, participants were 10 to 14 years (x̄ = 12.1) and the majority used injections.

In addition to these studies, a focus group study regarding perceptions was reviewed but not included in this review due to the large age range, 16 to 25 years, with no findings reported specifically related to the adolescent population (Dovey-Pearce et al., 2007). A second study measured diabetes self-care, but analyses regarding its relationship with perceptions were not included, thus the study was not included in this review (Faulkner & Chang, 2007).

Coping

There are many positive and negative coping behaviors that adolescents with T1DM use to help them deal with having the disease. Across studies, it has been found that adolescents with T1DM frequently use negative coping strategies, such as avoidance or disengagement, to deal with stressors and their disease. Avoidance coping includes behaviors such as using drugs or other substances to escape, and avoiding people or
issues that cause problems (Hanson, Harris, Relyea, Cigrang, Carle, & Burghen, 1989). Ventilation coping styles include behaviors such as blaming others, complaining, yelling at others, and saying mean things (Hanson et al., 1989). Unfortunately, the only study that could be found that assessed the relationship between diabetes self-care and coping was conducted prior to the change in diabetes treatment.

Coping styles and their relationship with health outcomes among adolescents (n = 135), 10 to 20 years, was the focus of a cross-sectional study from psychology (Hanson et al., 1989). Diabetes self-care was assessed using an unnamed adherence instrument that exhibited a small negative correlation with HbA1c \((r = -0.20, p < 0.011)\) but had strong three month test-retest reliability \((r = 0.70, p < 0.001)\). However, findings related to adherence should be used cautiously because the Cronbach’s alpha was low (0.62). Use of ventilation/avoidant coping negatively correlated with adherence \((r = -0.37, p < 0.001)\), age \((r = 0.35, p < 0.001)\), and duration of diabetes \((r = 0.14, p < 0.05)\). Further, older adolescents (Beta = 0.207, \(\text{F(1,128)} = 7.16, p = 0.008\)) were more likely to use ventilation/avoidant coping if they had high life stress (Beta = 0.189, \(\text{F(1,128)} = 6.27, p = 0.014\)) and low family cohesion \([\text{Beta} = -0.298, \text{F(1, 128)} = 13.97, p = 0.000]\). Positive coping behaviors, such as using personal and interpersonal resources were not associated with treatment adherence or other health outcomes, including metabolic control (Hanson et al., 1989).

Two additional studies that reported findings regarding coping and metabolic control for participants, 8 to 18 years, were not included because adolescent-specific data was not provided (Grey, Lipman, Cameron, & Thurber, 1997; Reid, Dubow, Carey, &
In addition, two studies that assessed the association of coping with metabolic control among adolescents with T1DM were not included because diabetes self-care was not included (Graue, Wentzel, Larsen, Bru, Hanestad, & Sovik, 2004; Hema, Roper, Nehring, Call, Mandleco, & Dyches, 2009). The relationship between coping and diabetes self-care among adolescents remains unclear.

**Summary of Self-Care Agency**

Several factors, such as autonomy, self-efficacy, perceptions, and coping affect an adolescent’s self-care agency or capability to perform self-care. Adolescent’s with too much autonomy for diabetes self-care exhibited poorer performance of diabetes self-care, poorer glycemic control, and increased hospitalizations (Wysocki et al., 1996). Adolescents stated self-management successes positively contributed to a sense of security regarding taking on the responsibility for diabetes self-care but that self-determination and increased motivation were also necessary (Karlsson et al., 2008). In addition, adolescents described diabetes as a daily hassle that exerted control over their lives (Carroll & Marrero, 2006).

Research addressing problem-solving abilities of adolescents found that older adolescents were more likely to choose peer-acceptable solutions that negated diabetes self-care (Thomas, Peterson, & Goldstein, 1997). Further, use of maladaptive decision-making and negative communication correlated with decreased parental report of adherence which predicted poorer glycemic control (Miller & Drotar, 2007). Use of positive coping behaviors was not related to diabetes self-care. But, adolescents who used
avoidance or ventilation coping behaviors were less likely to adhere to the recommended diabetes treatment regimen (Hanson et al., 1989).

**Self-Care**

Self-care is a key concept in the diabetes treatment regimen and is necessary to maintain blood glucose and HbA1c at acceptable levels to decrease the risk and prevent development of acute or chronic complications of the disease. Previous sections provided information regarding adolescent diabetes self-care in relation to several other factors (e.g. basic conditioning factors, self-efficacy, coping, etc.). This section will discuss research related specifically to diabetes self-care.

**Self-Care Style**

A qualitative, descriptive study identified division of responsibility self-management styles among a purposive sample of youth, 8 to 19 years (Schilling, Knafl, & Grey, 2006). This study used semistructured interviews and interviewed a parent and the adolescent individually to determine the level of parental involvement and the transfer of responsibility for diabetes self-care to the adolescent. Content analysis of interviews identified three self-management styles, parent-dominant, transitional, and adolescent-dominant. Among mid-adolescents (n = 5), 15 to 17 years, some exhibited an adolescent-dominant self-management pattern (n = 3) while others exhibited transitional self-management. Within the adolescent-dominant self-management pattern, adolescents performed daily self-management activities including contacting health care providers, without parental assistance. However, parents provided support, encouragement, and assistance with nondaily diabetes self-management activities such as making clinic
appointments. In contrast, within the transitional self-management pattern, parents are involved in counting carbohydrates, were involved in insulin corrections, and changed the basal rate for those adolescents that used an insulin pump. The mid-adolescents (n = 2) in this pattern desired more responsibility, but parents were reluctant because the adolescents exhibited inconsistent performance of diabetes self-care activities (Schilling et al., 2006).

The classification of self-management styles was the focus of a study that used a profile-based approach with participants from an observational study and randomized controlled trial (Schneider et al., 2007). Baseline data for adolescents (n = 156), 10 to 17 years, were analyzed using cluster analysis to identify and evaluate a self-management classification system (Schneider et al., 2007). Among these participants, three self-management styles were found, methodical, adaptive, and inadequate. Adolescents recently diagnosed with T1DM [F(2, 153) = 4.06, p < .05] were more likely to exhibit methodical self-management with a precise, consistent routine for insulin administration and dietary management with few self-care adjustments. In contrast, adolescents with a longer disease duration exhibited an adaptive self-management style with autonomous decision making and a more active lifestyle that included frequent blood glucose testing (≥ 5 times per day) and frequent adjustments to the treatment regimen. Older adolescents, the majority of participants with inadequate self-management, exhibited fewer blood glucose tests, irregular insulin and food intake [n = 33, F(2, 15) = 8.13, p < .001] and higher HbA1c (9.6% vs. 8.0%, p < .0001) than adolescents who were methodical or adaptive (Schneider et al., 2007).
The Diabetes Self-Management Profile (DSMP), a structured interview, was standardized so non-medical persons could act as interviewers. The DSMP – youth version exhibited acceptable subscale reliability; insulin administration (alpha = .70), self-care adjustments (alpha = .73), and meal planning (alpha = .73 for flexible insulin regimen, alpha = .57 for conventional insulin regimen). Total scores (r = .52, p < .0001) and subscale scores (r = .37 to .69, p < .0001) for parent- and adolescent-completed measures were moderately correlated. Further research is needed regarding self-management styles and variables impacting an adolescent’s assumption of responsibility for diabetes self-care tasks.

**Responsibility for Self-Care**

Results from two qualitative studies provided information regarding the process of assuming responsibility and its effect on adolescent’s perceptions. An exploratory grounded theory study used a semistructured interview to guide discussion of self-responsibility among adolescents (n = 4), 15 to 17 years, beginning with their earliest memory (Christian, D’Auria, & Fox, 1999). The central phenomenon, “gaining freedom”, depicted the process of assuming responsibility. “Making it fit” began the process of assuming responsibility. However, adolescents had to “be ready and willing” and receive support and validation to take on responsibilities. In addition, “having a safety net of friends” was necessary for adolescents to assume responsibility. As adolescents assumed more responsibility they felt more confident, had more freedom, and received approval from family and healthcare providers. Several techniques were used to establish
credibility and trustworthiness of data analysis including constant comparative analysis, data reduction, and reflection and paraphrasing.

A second exploratory study interviewed adolescents (n = 16), 11 to 18 years, regarding the benefits and barriers of assuming responsibility for diabetes self-care. Analysis revealed 66 descriptions of benefits and barriers, however the results section was brief and participant responses were contained within paragraphs. Similar to the previous study (Christian et al., 1999), these adolescents described a sense of confidence, freedom, and receiving approval as benefits to assuming responsibility for diabetes self-care. However, they stated that being independent and having more responsibility was a burden that could negatively affect their metabolic control (Hanna & Guthrie, 2000).

Three quantitative studies regarding the division of responsibility between adolescents and their parents and its effect on adherence and metabolic control had similar findings (Anderson et al., 1997; Cameron et al., 2008; Dashiff, McCaleb, & Cull, 2006).

Parental involvement in insulin administration correlated with adolescent performance of blood glucose testing ($r = .29, p < .006$) but was not significantly associated with metabolic control. Further, parental involvement in diabetes self-care activities decreased as adolescents aged [$\chi^2 = 14.2, df = 3, p < .003$; (Anderson et al., 1997)], however adolescent performance of diabetes self-care also decreased as they aged [$R^2 = .59, F(1,149) = 9.281, p < .01$; (Dashiff et al., 2006)].

In the first study, adherence was assessed through physician report, using a four-point scale where higher scores indicated more parental responsibility, to rate the
adolescent’s and family’s level of treatment adherence. In addition, the division of responsibility for diabetes management activities was assessed through a joint interview with parents and adolescents (Anderson et al., 1997). Psychometric data of the instruments used in this study was not provided. In contrast, adolescents were asked to rate their self-care behavior over the previous two months through use of the Self-Care Adherence Inventory (SCAI), a semistructured interview (Dashiff et al., 2006). The total scale exhibited low Cronbach’s alpha (.49) with this population. Discussion of the reliability of the SCAI in the methods section referred to Hanson (1989). The Hanson et al. (1989) study was reviewed and internal consistency was moderate (Cronbach’s alpha = .62) which researchers attributed to the “diverse areas of adherence assessed with this instrument” (p. 645). It was found that the SCAI correlated with metabolic control \[ r(134) = -0.20, p < .011 \] and 3-month test-retest reliability was adequate \[ r(17) = 0.70, p < .001; (Hanson et al., 1989) \].

In 2005, the Hvidøre Study Group on Childhood Diabetes collected data from adolescents (n = 1,973), 11 to 18 years, regarding their perception of parental over-involvement in diabetes care and level of responsibility, where both the adolescent and a parent completed the responsibility questionnaire (Cameron et al., 2008). Adolescents reported their parents were too protective (26%), worried too much (36%), and acted as if it was their diabetes (22%). It was reported that parental over-involvement was associated with adolescent report of responsibility \( r = .14, p < .01 \), parental report of responsibility \( r = .15, p < .01 \), and parent-adolescent disagreement \( r = .13, p < .01 \). HbA1c was significantly associated with parental over-involvement \( r = .11, p < .01 \), parent report of
responsibility ($r = .06, p < .01$), and parent-adolescent disagreement regarding responsibility ($r = .08, p < .01$). Researchers reported that family variables are “robust determinants of HbA1c” (Cameron et al., 2008, p. 467). Review of the results does not seem to support this statement. In the report of the results, researchers only noted that parental over-involvement and parent report of responsibility exhibited a weak association when all relationships have a weak association.

In summary, the level of parental involvement in diabetes self-care activities decreases as adolescents age (Anderson et al., 1997; Dashiff et al., 2006) as does the adolescent level of diabetes self-care (Dashiff et al., 2006). As has been the case with the majority of studies reviewed, the studies regarding adolescent responsibility included participants who were primarily Caucasian, from two-parent families and of middle SES. An additional study was not included in this review as it was published prior to the change in the diabetes treatment regimen (La Greca, Follansbee, & Skyler, 1990).

**Quality of Life**

The relationship between quality of life and diabetes self-care among adolescents with T1DM is unclear. Only one study could be found regarding the relationship between quality of life and diabetes self-care or treatment adherence.

This study evaluated the PedsQL which measures the youth’s and parent’s perception of the youth’s quality of life and provided information regarding its psychometrics and one-year stability (Laffel et al., 2003). Assessment of treatment adherence was completed in two ways, clinician-rated adherence and a semiquantitative, joint interview that assessed the division of responsibility for diabetes self-care activities.
Although a large age range, 8 to 17 years, was included in this study, participants were grouped according to younger, 8 to 12 years, and older, 13 to 17 years, adolescents. A similar level of quality of life was found between younger and older adolescents and was not associated with diabetes management or parental involvement in diabetes activities (Laffel et al., 2003). Similar to previous studies that provided results according to age group, unequal group sizes (early = 66, older = 34) existed which can skew findings. Sociodemographic information indicated 85% of participants were from two-parent homes and of middles SES.

Additional studies that assessed the relationship between quality of life and metabolic control were not included in this review because diabetes self-care was not included (Faulkner, 2003; Hoey et al., 2001; Nardi, Zucchini, D-Alberton et al., 2008)

**Summary of Self-Care**

In summary, several studies included findings specifically related to adolescent performance of diabetes self-care or treatment adherence. Older adolescents are primarily responsible for daily diabetes self-care activities (Anderson et al., 1997; Cameron et al., 2008; Dashiff et al., 2006; Schilling et al., 2006) but were more likely to exhibit inadequate diabetes self-care and poorer metabolic control (Schneider et al., 2007). Qualitative studies provided information regarding the process of assuming responsibility for diabetes self-care and the benefits and barriers to assuming responsibility. As adolescents began to assume more responsibility, they had to figure out how to fit diabetes self-care activities into their normal adolescent lives (Christian et al., 1999). Benefits of assuming responsibility included freedom, self-confidence, and receiving
approval from others (e.g. family) but being independent and having responsibility was a burden and barrier to assuming responsibility for diabetes self-care activities (Hanna & Guthrie, 2000).

Lastly, quality of life was thought to impact performance of diabetes self-care, but there is scant data regarding this relationship. The one study that addressed this relationship found no significant relationship between quality of life and diabetes management or parental involvement (Laffel et al., 2003).

**Nursing System**

The theory of nursing system, according to Orem’s self-care deficit nursing theory, encompasses the theories of self-care deficit and self-care and forms the framework and content of nursing practice (Orem, 2001). The relationship between adolescents with T1DM, metabolic control, and diabetes self-care has been the focus of interventions across disciplines such as nursing, medicine, and psychology. Although a nursing concept, this section will review interventions from multiple disciplines designed to impact diabetes self-care performance among adolescents with T1DM.

**Educational Interventions**

Diabetes-related education was the primary focus of interventions discussed in this section. However, only one study could be found that assessed the impact of an educational intervention on adolescent performance of diabetes self-care.

A single-blinded randomized controlled trial evaluated the effect of 6 months of regular telephone contact with a diabetes nurse educator among adolescents (n = 46), 13 to 17 years, with poorly-controlled T1DM, defined as HbA1c > 8.5% (Lawson, Cohen,
Richardson, Orrbine, & Pham, 2005). Computer-generated sequencing was used to randomize participants to either the telephone or usual care groups. The intervention involved weekly standardized, telephone contact that centered on blood sugar levels and insulin adjustment, but began with discussion of the adolescent’s life that week. Adherence to the treatment regimen was assessed through downloads of the adolescent’s blood glucose meter and the Compliance with Diabetes Management questionnaire. At six months, it was found that adolescents who received weekly telephone contact had slightly better adherence, however statistical data regarding this association was not provided.

**Problem-Solving Interventions**

The hypothesis that improved problem-solving ability among adolescents with T1DM would improve metabolic control and/or diabetes self-care was the basis for the four studies. One study implemented a peer-group intervention. The remaining studies incorporated the Choices diabetes program, a cognitive-behavioral therapy program, and an internet-based problem-solving self-management support program.

A peer group intervention that included peers of adolescents with T1DM was designed to help adolescents (n = 21) with T1DM, 10 to 18 years, to include peers in diabetes management (Greco, Pendley, McDonnell, & Reeves, 2001). The intervention was administered by a psychologist and included four 2-hour group sessions that addressed diabetes education, reflective listening and problem-solving skills, and stress management. Adolescents with T1DM completed the Self-Care Inventory along with measures regarding diabetes-related support, adjustment, division of responsibility and
family conflict. Researchers referred to the original study for reliability of all measurement instruments, except the education and support measure where reliability and validity was ongoing. Measures were completed at pre- and post-intervention periods and took approximately two hours to complete (Greco et al., 2001).

The peer-group intervention led to increased diabetes knowledge for adolescents with T1DM (t = -6.13, p < .0001) and their peers (t = -12.77, p < .0001), decreased family conflict as reported by parents (t = 2.25, p < .05), and peers’ self-perception (t = -3.07, p < .01). Peers indicated increased peer support (t = 4.32, p < .001), but, according to adolescents with T1DM, there was not a significant increase in peer support. In addition, there was not a statistically significant change in mean scores for diabetes self-care (Greco et al., 2001).

A pilot study, that used a repeated-measure control group design, evaluated the Choices diabetes program which used findings from a critical incident study as the basis for development of this intervention; however, adolescents were not actually involved in development of the intervention (Cook, Herold, Edidin, & Briars, 2002). The Choices program which included cognitive and behavioral skills was designed to enhance adolescent motivation and integration of the skills into their daily lives. The program included six 2-hour weekly group sessions and adolescents were provided a workbook for each session. After completion of baseline measurements, participants were randomized to either the Choices program (n = 23) or the control group (n = 26) who received standard diabetes care, clinic visits every three months. Data was collected at baseline and six months after enrollment from both groups. Intent-to-treat analyses revealed no
significant difference in problem-solving, degree of responsibility, or HbA1c between groups (Cook et al., 2002). However, participants in the Choices program exhibited increased frequency of blood glucose testing ($\bar{x} = 3.8$ vs. $3.0$, $p < .02$). Within-group analysis revealed increased problem-solving ($p < .03$) and decreased HbA1c ($p < .01$). There was not a significant effect of the intervention on diabetes self-care (Cook et al., 2002). Participants were primarily Caucasian, but, although not statistically significant, the control group contained more participants who were African-American or Hispanic (Exp: $n = 3$ vs. Control: $n = 5$).

A pilot study with adolescents, 11 to 18 years ($\bar{x} = 13.6$), studied a cognitive-behavioral intervention aimed to help adolescents with cognitive restructuring and problem-solving skills (Salamon, Hains, Fleischman, Davies, & Kichler, 2009). The intervention included one session with a graduate student therapist followed by three phone contacts. Participants completed measures that assessed adherence in social situations and peer-related diabetes stress. Repeated measures ANOVA revealed no significant changes; however, it is important to note that participants had few concerns about performing diabetes self-care around peers (Salamon et al., 2009).

An 11-week internet-based problem-solving program used block randomization to randomize adolescents ($n = 72$), 13 to 17 years, to participate in the intervention ($n = 34$) that was developed by a multidisciplinary team and young patients (Mulvaney, Rothman, Wallston, Lybarger, & Dietrich, 2010). Intent-to-treat analyses did not reveal a statistically significant change over time. Among participants in the intervention, self-management adherence, as measured by the Diabetes Behavior Rating Scale, improved (d
Although glycemic control among the intervention participants remained the same (- 0.01%), it worsened among those in the control group (+0.33%; Mulvaney et al., 2010). The range of HbA1c among participants in this study is unknown as only the mean at baseline was provided. By the end of the study, there was a large decrease in the number of participants (n = 52) which potentially negatively impacted statistical significance of changes that occurred as a result of participation in the internet-based self-management program.

In summary, the internet-based self-management program was the only program that improved diabetes self-care among adolescents, 13 to 17 years old, but had no effect on glycemic control. The other interventions that focused on problem-solving skills among adolescents had minimal effects on glycemic control and no effect on diabetes self-care. Methodological issues including lack of randomization, small sample sizes, and little participant variability in ethnicity or SES preclude the use of findings that were statistically significant.

**Motivational Interviewing**

A pilot study of motivational interviewing with adolescents (n = 22), 14 to 18 years, used the Readiness to Change questionnaire and invited those whose scores indicated they were contemplating change (Channon, Smith, & Gregory, 2003). Motivational interviewing is a counseling technique and adolescents were allowed to choose the frequency and location of sessions and the presence of others. Although the intervention was designed to last six months, sessions were discontinued if the adolescent so desired. Topics related to awareness building, alternative behaviors, problem solving,
goal setting, and avoidance of confrontation. Self-care was assessed through use of the Summary of Diabetes Self-Care Activities but researchers provided no information regarding the measure or its psychometrics. In addition, measures of well-being, diabetes knowledge, beliefs about diabetes, family relations, and family responsibility were collected pre- and post-intervention. At immediate post-intervention, 79% (n = 16) of the adolescents reported making a positive change and 64% (n = 14) reported being more active in seeking change. Further, although adolescents reported diabetes was easier to live with (p = .03), there was no effect on other psychosocial outcomes (e.g. well-being, diabetes self-care) or metabolic control (Channon, Smith, & Gregory, 2003).

A diabetes personal trainer intervention was based on principles of motivational interviewing, applied behavior analysis, and problem solving (Nansel, Iannotti, Simons-Morton, et al., 2007). Adolescents (n = 81), 11 to 16 years, were randomly assigned to the personal trainer intervention or usual care after they were stratified by age and HbA1c. The intervention was delivered over two months and included six semistructured sessions and supplemental telephone contact. Diabetes self-care was measured through use of the Diabetes Self-Management Profile (DSMP) which exhibited acceptable reliability at baseline (Cronbach’s alpha = .70 for youth, .75 for parents). Post-intervention data collection revealed a significant decrease in HbA1c especially for older adolescents (F = 4.78, p = .03) which, at one-year follow-up, remained significantly lower than at baseline (F = 4.53, p = .04). However, there was not a significant impact of the intervention on parent- and youth-reported diabetes self-care (Nansel et al., 2007).
Multisystemic Therapy

Multisystemic therapy (MST) is an intense, home-based family-focused therapy that was originally designed for use with youth with antisocial behaviors (Ellis et al., 2005; 2007). In this study, therapists met with families for approximately 6 months or until treatment goals developed by the therapist were met. In this randomized, controlled trial with a repeated-measures design, adolescents (n = 127), 10 to 17 years, with poor metabolic control were randomized to the MST plus standard medical care or standard care groups after baseline data collection. Randomization was stratified by adolescent’s HbA1c level according to baseline level of glycemic control (Ellis et al., 2005; 2007).

Immediate post-intervention assessments, seven months post-enrollment, revealed an increased frequency of blood glucose testing [F(1,125) = 16.75, p = .001], improvements in metabolic control (-.60%), and decreased hospital admissions [F(1,125) = 6.25, p = .014]. But, there were no improvements in insulin [F(1,125) = 1.90, p = .171] or dietary [F(1,125) = .04, p = .847] adherence (Ellis et al., 2005). A second article, also reporting seven-month data, found increased frequency of blood glucose testing which was decreased in the SC group [F(1,116) = 16.25, p < .001]. In addition, youth from single-parent families who participated in MST exhibited decreased HbA1c (-0.92%, p = .003). While there was no significant difference in diabetes-specific relationships with the primary caregiver, youths in 2-parent families experienced increased diabetes-specific support by the secondary caregiver (t = 2.67, p < .05). Although there were small improvements, no differences in general family relationships were found (Ellis et al., 2007).
**Teamwork Intervention**

The teamwork intervention includes four modules, is family-focused, conducted at quarterly clinic visits, and lasted 20 to 30 minutes. The focus of the teamwork intervention was sharing responsibility for diabetes self-care activities within the family and ways to avoid conflict (Anderson, Brackett, Ho, & Laffel, 1999; Laffel et al., 2003). The first evaluation of the teamwork intervention used a three-group design but, data from the attention-control and standard care groups were combined to form a single comparison group since there were no significant differences between these groups (Anderson et al., 1999). Random assignment of adolescents (n = 85), 10 to 15 years, involved stratification of participants by age and gender and data was collected at baseline, 12 months, and 24 months, however metabolic control was the only variable measured at 24 months post-enrollment. At 12 months, more parents in the comparison vs. teamwork group exhibited deterioration in involvement in insulin administration (Chi-square = 4.95, df = 1, p < .03), but there was not a statistically significant difference in regarding parental involvement in blood glucose testing (Chi-square = 3.17, df = 1, p < .075). A primary goal of the teamwork intervention was decreased diabetes-related family conflict. At 12 months, families in the teamwork vs. comparison group exhibited significantly decreased diabetes-specific conflict (F = 4.97, df = 1, p < .02) and unsupportive behaviors (F = 5.66, df = 1, p < .02). Although not statistically significant, more adolescents in the teamwork group (68%) vs. comparison group (47%) improved their HbA1c at 24 months [Chi-square = 3.17, df = 1, p < .07; (Anderson et al., 1999)].
The second study of the teamwork intervention was somewhat different in that participants (n = 100) were of a wider age range, 8 to 17 years, and randomized to either the teamwork or comparison group stratified by age (8 to 12 years vs. 13 to 16 years) and duration of diabetes (Laffel et al., 2003). In addition, physicians rated adherence for the previous 3 to 4 months. Similar to the previous study, division of responsibility for diabetes management tasks was assessed through a joint interview. After completion of measures at the end of the intervention period, families in the comparison group received the teamwork educational materials. At 12 months, among all youth, the frequency of blood glucose testing decreased (66% vs. 58% SC and 60% TW). Metabolic control (HbA1c) significantly deteriorated among youth in the standard care group ($R^2 = .17, p = .04$), but teamwork youth exhibited no change from baseline. No differences were found in family responsibility, conflict, or youth’s quality of life at 12 months. But, more teamwork families increased or maintained involvement [Chi-square = 3.73, df = 1, p = .05; (Laffel et al., 2003)]. In this study, there were more single-parent families in the teamwork group vs. comparison group (22% vs. 8%).

**Behavioral Family Systems Therapy**

Adolescents (n = 119), 12 to 17 years, were participants in a randomized controlled trial that evaluated the effects of Behavioral Family Systems Therapy (BFST) on diabetes-related family conflict (Harris, Greco, Wysocki, & White, 2001; Wysocki et al., 2000; Wysocki, Greco, Harris, Bubb, & White, 2001). BFST consisted of 10 family therapy sessions with a doctoral-level psychologist that targeted problem solving, communication skills, irrational beliefs, and structural family problems. It was found that
BFST significantly affected mothers report of diabetes-related family conflict (Delta = 1.06, p < .001), however, there were no other statistically significant changes (Harris et al., 2001). There was no significant impact for T1DM treatment adherence (Wysocki et al., 2000) post-intervention, but the BFST group showed improvement at 6- and 12-months while the adherence of the SC and ES groups deteriorated. In addition, there were no significant interaction effects on glycemic control which was elevated at all time periods for all participants (Wysocki, et al., 2001).

The BFST intervention was revised to make it more specific for diabetes (BFST-D). Revisions included identification of barriers to diabetes management or control, behavioral contract training, advanced use of blood glucose test results education, and parents simulated living with diabetes for one week (Wysocki et al., 2007). The BFST-D intervention was evaluated in a longitudinal study that randomized adolescents (n = 104), mean age 14.2 years, with HbA1c > 8.0% to standard care (SC), educational support (ES), or BFST-D groups (Wysocki et al., 2007). Although there was no significant group by time effect for diabetes-related family conflict, it was lower in BFST-D families $[F(2,82) = 3.27, p < .03]$ but only at six months post-intervention. Adolescents in BFST-D exhibited improved diabetes self-care, as measured by the Diabetes Self-Management Profile, $[F(2,81) = 3.62, p < .03]$ than those in the SC group at each follow-up evaluation, but no with those in the ES group. Further, a significant group by time effect $[F(12,600) = 4.29, p < .001]$ for HbA1c was found for BFST-D participants. However, although there was a significant difference with SC participants, it was only significantly different than ES participants at 9, 15, and 18 months post-intervention (Wysocki et al., 2007).
Two additional studies of BFST-D with adolescents included adolescents with T2DM who were treated with insulin (Wysocki et al., 2006; Wysocki et al., 2008). Demographic data did not indicate how many of the participants had T2DM and presented findings encompassed the entire participant population. Thus this study was not included in this review.

**Coping Skills Training**

Coping skills training was developed in an effort to improve quality of life and metabolic control among adolescents who were initiating the intensive diabetes treatment regimen. Diabetes self-care was not included as an outcome variable. However, it is included in this review due to the significant effects CST on improvement of HbA1c among adolescents beginning intensive treatment. Coping skills training is a small-group intervention that was designed to increase adolescent’s competence and expertise regarding diabetes self-care. The program involves eight 1 to 1 ½ hour weekly sessions and six monthly booster sessions. The program addresses social problem-solving, communication skills, cognitive behavior modification, and conflict resolution. Further, adolescents are given the opportunity to participate in role-play to practice application of the skills.

A longitudinal, prospective, randomized, controlled trial of coping skills training (CST) with adolescents, 12 to 20 years old, with T1DM was conducted and led to findings reported in four separate studies (Grey Boland, Davidson, Li, & Tamborlane, 2000; Grey et al., 1998; Grey, Boland, Davidson, Yu, & Tamborlane, 1999; Grey, Davidson, Boland, & Tamborlane, 2001). The recruitment time period was reported
differently between articles, [i.e.: November 1995 to December 1997 (Grey et al., 2000) and November 1995 to September 1998 (Grey et al., 2001)]. In addition, the sample size increased across articles [n = 65 (Grey et al., 1998); n = 77 (Grey et al., 1999; Grey et al., 2000); n = 81 (Grey et al., 2001)]. Review of each article revealed major similarities that indicate the four articles are based on one study that continued to add participants across time.

Adolescents who were beginning the intensive treatment regimen, multiple daily injections or insulin pump, were randomized to the intense therapy only or intense therapy plus CST groups. Intensification of treatment led to improved HbA1c at 1, 3, 6, and 12 months post-intervention for all participants (Grey et al., 1998; Grey et al., 1999; Grey et al., 2000, Grey et al., 2001). However, there was a faster and greater decrease among those who participated in CST. Statistically significant differences in HbA1c were found at 3 months [F = 2.56, df = 2, p = .04; (Grey et al., 1998)], 6 months [F = 3.89 (2, 124), p = .02; Grey et al., 1999)], and 12 months [F = 5.89, df = 3, 213, p = .001; (Grey et al., 2000)].

In addition to changes in metabolic control, CST led to improvements in psychosocial measures such as coping and self-efficacy. At 12 months post-intervention, medical (F = 2.79, df = 3, 213, p = .04) and diabetes-specific self-efficacy (F = 5.33, df = 3, 213, p = .002) was improved. In addition, the impact of diabetes on quality of life (F = 4.41, df = 3, 213, p = .005) was decreased for CST participants (Grey et al., 2000). Approximately 33% of all participants achieved the treatment goal (HbA1c ≤ 7.2%)
which was more likely for participants who used an insulin pump or who had lower
baseline HbA1c and participated in CST (Grey et al., 2001).

The Coping Skills Training program was developed as a five-week internet-based
program (Whittemore, Grey, Lindemann, Ambrosino, & Jaser, 2010). Adolescents (n =
12), 13 to 16 years, were randomized to the five-week CST program or a 4-week diabetes
education program. Quality of life, stress, coping, self-efficacy, psychosocial adjustment,
and glycemic control were measured at baseline and three and six months after the
intervention. The study found improvement in all measures except glycemic control at 3
months, some of which were maintained at six months. However, none of the
improvements reached statistical significance (Whittemore et al., 2010). This is only the
second intervention that incorporated adolescents and parent feedback in the design of the
website.

**Summary of Nursing System**

In summary, the effects of nine separate interventions, two with participants who
exhibited poor metabolic control, on diabetes self-care were reviewed. The many
interventions had varying effects on adolescent performance of diabetes self-care or
glycemic control. In most cases, however, if there were short-term improvements in self-
care or glycemic control, they often were not maintained.

**Summary of the Review of Literature**

This review of the literature relating to diabetes self-care among adolescents with
T1DM used Orem’s SCDNT as a guiding framework. Adolescents with T1DM are at
significant risk for devastating health outcomes, especially when they exhibit poor
glycemic control. The self-care measures necessary for controlling the disease are intense, invading every aspect of the adolescent’s life.

Synthesis of the literature indicates basic conditioning factors significantly increase the risk for poor glycemic control among adolescents with T1DM. Adolescents who are members of a racial/ethnic minority or have low SES, altered emotional states, decreased family support and cohesion, or who would rather fit in with peers are more likely to exhibit poor control. An adolescent’s diabetes self-care is also affected by self-care agency characteristics. Although adolescents desire autonomy, having too much independence or freedom can lead to poor control. Having worse perceptions of diabetes can lead to decreased self-efficacy and negative coping behaviors which, in turn, lead to decreased self-care and increased HbA1c.

Several other issues were also found the further contribute to the confusion regarding adolescent diabetes self-care. Information specifically identifying the research design used was rarely provided. Quantitative studies primarily used cross-sectional, descriptive, and exploratory designs while qualitative studies contained in this review primarily used a phenomenological or focus group methodology. In addition, the majority of studies primarily included participants who were Caucasian, living in 2-parent families, or of middle SES. The majority of researchers addressed this issue by stating that their sample reflected the population from which the participants were recruited. Also, a wide age range of participants, most using youth 10-19 years old, creates difficulty in narrowing down correlates of and rationale for poor glycemic control among older adolescents, 15-18 years. Further complicating the issue, varying levels of HbA1c,
ranging from 7.6% to > 9.5%; have been used to define poor metabolic control. If the studies included an outcome related to adolescent diabetes self-care, it was usually one specific task, namely frequency of blood glucose testing. Further, the majority of studies did not include and report results specifically to the population of good vs. poor glycemic control. Lastly, only one intervention included adolescent patient as part of a multidisciplinary team in its development. All other interventions contained within this review did not include adolescents with T1DM in the development of the intervention.

**Gaps in the Literature**

It is evident, from this literature review, that ambiguity regarding adolescent diabetes self-care remains and gaps in the literature exist. Adolescent diabetes self-care has been a phenomenon of interest across all health care disciplines. A major contributor to ambiguity and gaps is the lack of a universal definition or term that clearly defines diabetes self-care and lack of inclusion of operational definitions in studies. Self-care and self-management have been terms used interchangeably (Schilling et al., 2002) which creates further confusion.

Review of the literature leads to assumptions regarding diabetes self-care among adolescents, but does not provide conclusive evidence regarding the concept of diabetes self-care and specifics such as why some older adolescents exhibit poor glycemic control while others do not. Further research including participants at both ends of the glycemic control spectrum within the same study would minimize limitations and appropriately allow for comparison of findings between groups. More specifically, this author has remaining questions relating to adolescents and diabetes self-care. 1) How do
adolescents, 15 to 18 years, manage life with T1DM? 2) What is diabetes self-care among adolescents with T1DM? 3) Why do some older adolescents exhibit incorporation of diabetes self-care into their daily lives while other do not? 4) Is there a difference between adolescents with good vs. poor glycemic control and, if so what is it? 5) What do adolescents want in a diabetes self-care intervention?

Additional study of self-care of T1DM among adolescents, especially those 15 to 18 years of age, is important because this population continues to have the highest incidence of poor glycemic control than any other age group which increases their risk for early onset of diabetes-related complications. Further research regarding the performance, or nonperformance, of diabetes self-care is necessary to try to understand the issues surrounding this phenomenon so new directions of service and support can be identified, implemented, and evaluated. Nurses can be influential in the improvement of glycemic control among adolescents. However, if nurses want to make an impact on the incidence of poor glycemic control among adolescents and/or decrease the incidence of complications associated with T1DM, further research “hearing from the adolescents” is necessary. Only the adolescents can provide insight into the phenomenon of poor glycemic control and what can be done to prevent or minimize it.
CHAPTER THREE

METHODS

Purpose and Research Questions

The purpose this study was to explore diabetes self-care, topics related to performance or nonperformance of self-care activities, and what adolescents believe would be important components to include in a diabetes self-care program. The aim was to develop a better understanding of diabetes self-care practices and explore the older adolescent’s perspective of what should be contained within a program designed to assist them with diabetes self-care. The study is designed to answer the following research questions:

1. How do adolescents, 15 to 18 years, manage life with T1DM?
2. What is diabetes self-care among older adolescents, 15 to 18 years, with T1DM?
   a. Is there a difference between adolescents with good vs. poor glycemic control and, if so, what is it?
   b. Why do some older adolescents exhibit incorporation of diabetes self-care into their daily lives while others do not?
3. What do adolescents want in a diabetes self-care program?

Study Design

This study used a qualitative exploratory research design. Qualitative research could provide further depth and understanding of factors that contribute to diabetes
management (Frey et al., 2004) and is interactive and human-centered (Marshall & Rossman, 2006). Exploratory research seeks to discover or define problems and is flexible and insightful (Brink & Wood, 1998). There is scant literature regarding performance of diabetes self-care among older adolescents. Further, the literature does not provide information regarding integration of the demands of diabetes self-care into their normal lives as adolescents. Thus, this study used open-ended questions with few parameters to explore diabetes self-care among older adolescents with T1DM in order to gain a better understanding and description of the concept.

This study used a focus group method which was chosen due to the social nature of adolescents. A focus group design collects data about a phenomenon from a group of participants with experience in the area of interest. Focus groups are used to engage participants in a conversation, encourage interaction, and provide a range of opinions and experiences (Morgan, 1998). Interactions among the group often stimulate individual reflection of something they may not have thought of on their own (Freeman et al., 2001). Focus groups are an especially appropriate methodology when working with adolescents because being a member of the group is less intimidating and more relaxing than individual interviews (Peterson-Sweeney, 2005). In addition, focus groups can act as a type of support group (Gulanick & Keough, 1997) which was valued in one study with adolescents because it helped them to learn more about themselves and gave them insight into their coping behaviors and other options (Davidson et al., 2004).
The criteria for establishing trustworthiness of focus group data include credibility, dependability, transferability, and confirmability (Morrison-Beedy, Cote-Arsenault, & Feinstein, 2001). Credibility of data was established through the use of multiple focus groups, setting guiding group principles, such as “everyone’s view is important”, and use of debriefing sessions after each focus group. Although it is recommended that detailed interview guides are used to establish dependability of data (Morrison-Beedy et al., 2001), this study used open-ended questions because the richness and depth of information was necessary to understand diabetes self-care practices among older adolescents with T1DM. Dependability was also established through verbatim transcription of audio recordings and comparison of transcripts to audio recordings. In addition, use of field notes and debriefing session notes were used during data analysis. Transferability relates to the application of findings to and meaning for others (Morrison-Beedy et al., 2001). Transferability primarily relates to the reporting of results in that direct quotes from participants were used and the sample is described in regards to their demographics and diabetes-related characteristics. Lastly, confirmability was established through use of researcher field notes, bracketing, and memoing (Brink & Wood, 1998).

**Strengths and Limitations**

There are several advantages to using focus groups. Focus groups allow researchers to collect concentrated data from several people in a more efficient, cost-effective manner than individual interviews (Morgan, 1998; Stewart, Shamdasani, & Rook, 2007). In addition, the direct interaction the researcher has with participants allows for clarification and further explanation. Further, focus groups allow researchers to
collect a large amount of data that contributes to richness and depth of findings. The focus group also allows researchers to observe group interactions and gain important data regarding motivations and behaviors (Morgan, 1998).

There are also several limitations to the use of focus groups. The group environment may influence responses of participants in the group where some may not feel comfortable sharing specific information except during private conversations. Further, there is the potential that one person may dominate the conversation or present views that are extremely different (Morgan, 1998; Stewart et al., 2007). Also, there is a potential for loss of control of the conversation when working with a group of participants. However, this potential weakness was limited by using a primary moderator who had experience leading support groups and experience working with adolescents. In addition, focus groups often produce a large amount of data which can make summarization and interpretation of the data difficult (Stewart et al., 2007).

Procedure

Setting

The setting for this study is Omaha, Nebraska which is the home of the primary investigator. Omaha is the 42nd largest city in the United States (City of Omaha, 2009) with a population of approximately 843,000 where approximately 42% have an annual household income less than $50,000. Although Omaha’s population is primarily Caucasian (84.9%), there has been an increase of racial/ethnic minorities since 1990 such as a 139.8% increase in Hispanics, 73.9% increase in Asian/Pacific Islanders, 15.9% increase in American Indians, and 15.6% increase in African-Americans. Currently,
youth 15 to 19 years are 6.6% of the population but there has been an 18.8% increase among this age group since 1990 (Greater Omaha Economic Development Partnership, 2009).

The healthcare providers and staff of the Children’s Hospital and Medical Center Diabetes Clinic assisted in recruitment of participants. This clinic is the only pediatric-specific diabetes program recognized in the State of Nebraska (Children’s Hospital & Medical Center, 2009), thus it provides diabetes care for youth from across the state and Eastern Iowa. A multidisciplinary team of pediatric endocrinologists, pediatric nurse practitioners, nurse educators, social workers, dietitians, and child life specialists provide care for youth with diabetes and other endocrinology illnesses.

**Sample Recruitment**

The target population for this study was adolescents, 15 thru 18 years, with T1DM. Older adolescents were chosen as participants for this study because this is the period when glycemic control deteriorates (Bryden et al., 2001; Greening, Stoppelbein, & Reeves, 2006; Helgeson, Siminerio, Escobar, & Becker, 2008; Leonard, Jang, Savik, & Plumbo, 2005; Lernmark et al., 1996; Pound, Sturrock, & Jeffcoate, 1996; Urbach et al., 2005) and is the poorest in comparison to other age groups (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997). Further, surprisingly little is known about what constitutes self-care of diabetes in this age group (Sawyer & Aroni, 2005).

A purposive sampling method was used to recruit participants. Purposive samples are used when specific members of a population are desired as study participants (Brink

![Recruitment process diagram]

Figure 1: Recruitment process

<table>
<thead>
<tr>
<th>Mailing #1 = 220</th>
<th>Response = 17</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mailing #2 = 220</td>
<td>Response = 10</td>
</tr>
<tr>
<td>Mailing #3 = 220</td>
<td>Response = 8</td>
</tr>
<tr>
<td>Not Eligible = 3a</td>
<td>Unable to Connect with = 6b</td>
</tr>
<tr>
<td>Enrolled = 26</td>
<td>Withdrawn/ Dropouts = 5c</td>
</tr>
<tr>
<td>Participants = 21</td>
<td></td>
</tr>
</tbody>
</table>

- aNot Eligible: 1 not diagnosed for 6 months, 2 had other chronic conditions that required daily self-care activities.
- bPotential participant had made initial contact but this researcher was unable to connect with through subsequent phone calls.
- cWithdrawn/Dropouts: 1 official withdrawal, 4 unable to attend focus groups scheduled that were appropriate for their level of control.

The office manager of the Children’s Diabetes Clinic provided this researcher with a list of 220 clinic patients, without identifying information, who were 14 thru 18 years old, had been diagnosed with T1DM, and lived within 30 minutes of the Omaha, Nebraska/Council Bluffs, Iowa metropolitan area. The recruitment process involved three separate mailings (depicted in Figure 1). For the first mailing, completed in January 2010, this researcher prepared 220 recruitment packets (Appendix A) which included a letter of support from the medical director of the Children’s Diabetes Clinic and letter from this researcher providing an overview of the study with the researcher’s contact information. The stamped packets were taken to the office manager who printed address labels, which were affixed to the envelopes by clinic staff and then taken to the post office by the clinic manager. This mailing resulted in 17 contacts from potential participants.
The same patient list was used for a second mailing which was conducted in April 2010. For this mailing, the recruitment flyer developed for the study was prepared for mailing and 220 were delivered to the clinic manager who printed address labels which were affixed by clinic staff. The fliers were then taken to the post office by the clinic manager. This mailing resulted in 10 contacts from potential participants.

A third mailing was conducted in October 2010. Prior to this mailing, the clinic manager developed a new list of clinic patients who were 15 thru 18 years old with T1DM. The clinic manager advised this researcher there were a few new names on the list, however, a de-identified list was not provided to this researcher. The clinic manager advised this researcher to prepare 220 mailing packets. The third mailing included the letter of support from the medical director of the Children’s Diabetes Clinic and this researcher’s study letter that contained contact information. The packets were prepared as they were with mailing #1. This mailing resulted in 8 contacts from potential participants.

Interested families/participants contacted this researcher who conducted a phone interview to determine eligibility (Appendix B) of the adolescent. This phone screening determined that three adolescents were not eligible for this study; one had not been diagnosed with T1DM for at least six months, two had other chronic conditions that required daily self-care activities. There were six additional initial contacts made, however, this researcher was not able to connect with them. This resulted in 26 eligible adolescents with whom this researcher scheduled an appointment to meet with the adolescent and his/her parents in their home or a location of their choice. At this meeting, this researcher provided in-depth study information and reviewed and obtained signed
consent (Appendix C) and assent forms (Appendix D). In addition, adolescents were asked to complete the Demographic and Diabetes Questionnaire (Appendix E) developed for this study. Subsequent to these meetings and prior to participation in a focus group, 1 adolescent withdrew from the study and 4 were subsequently unable to participate in a focus group scheduled for their level of glycemic control which netted 21 participants.

Adolescents were assigned to 1 of 6 focus groups based on their reported glycemic control where good control was < 9% (3 groups) and poor control was > 9% (3 groups). Although the ADA recommends HbA1c < 7.5%, it is generally accepted that this level may not be possible for many, especially adolescents, unless they have intense multidisciplinary support (Silverstein et al., 2005). Further, there is no universal number that has been used as the definitive boundary of good versus poor glycemic control and a review of this data in the literature has shown that HbA1c of 9.0% has been used most frequently. The rationale for dividing groups according to glycemic control was to prevent feelings of inadequacy among adolescents with poor glycemic control.

Although it is recommended that focus groups contain 6 to 8 participants (Morgan, 1998), there were many difficulties associated with scheduling adolescent participants thus each focus group consisted of 2 to 5 participants. In order to gather the full range of experiences and complexities associated with adolescent diabetes self-care, 6 total focus groups were conducted with 3 for each level of glycemic control. Saturation of data was reached when no new information was generated and researchers can anticipate responses (Morgan, 1998).
When this study was designed, this researcher intended to conduct a separate group for adolescents who use the insulin pump and separate them from adolescents using injections. The rationale for this was because insulin pumps are expensive and are not always covered by insurance policies thus it was felt that adolescents who are using multiple daily injections would feel frustrated because they would rather have the pump but cannot due to insurer limitations. In addition, although the concept of diabetes self-care is the same whether using multiple daily injections or an insulin pump, there are additional issues that may be specifically related to use of an insulin pump that could impact data collection and analysis. This occurred with the first focus group, but due to recruitment and scheduling difficulties, insulin pump users were subsequently mixed with participants who used multiple daily injections and no animosity was found.

**Inclusion/Exclusion Criteria**

The primary inclusion criterion was adolescents who were at least 15 years old but who have not reached their 19th birthday. As previously mentioned, this age group is the one that exhibits the poorest glycemic control above all other age groups. Further, this is the period where adolescents are spending more time away from home and, theoretically, are primarily responsible for diabetes self-care activities. In addition, adolescents must have been diagnosed with T1DM for at least six months. This criterion was established because the majority of youth diagnosed with T1DM experience a ‘honeymoon period’ where the pancreas continues to excrete some insulin, but within six to eight months it is no longer able to perform this function (Silverstein et al, 2005). Lastly, adolescents must be able to read, write, and speak English.
Adolescents with a significant cognitive or developmental disability were excluded from the study. In addition, adolescents with a co-committant psychological diagnosis, other than poor glycemic control, and those with other chronic illnesses that require daily treatment were excluded from the study. These exclusion criteria have been established because each of them could alter their engagement in focus group discussions.

**Protection of Participants**

Adolescents who were 15 thru 18 years old at time of enrollment were participants in this study. When working with adolescents extra precautions must be taken to protect them during the research process. Youth less than 18 years old are considered a vulnerable population, therefore parental consent in addition to youth assent is necessary (Fisher, 2004). Prior to recruitment of participants, Institutional Review Board (IRB) approval was sought from the Loyola University Health System, where the primary investigator is a doctoral student, and the University of Nebraska Medical Center, with which the recruitment site is affiliated. In addition, the dissertation committee of the primary investigator oversaw all procedures throughout the research study.

In order to protect the identity of clinic patients, the list provided to this researcher of potential participants did not contain identifying information. In addition, as discussed previously (with Sample Recruitment), clinic staff printed and affixed mailing labels to packets provided by this researcher and delivered them to the post office. Interested participants then contacted this researcher who screened them and met with the
adolescent and his/her parent to review study information and complete consent/assent forms, and the Demographic and Diabetes Questionnaire, which was previously discussed under sample recruitment.

A study that examined the capacity of adolescents to understand their rights in research found that the majority understood the purpose and nature of the research, its risks and benefits, the voluntary nature, and confidentiality (Bruzzese & Fisher, 2003). Consent and assent forms were developed according to IRB protocols and provided information regarding the study and potential risks and benefits of participation. Minimal risk to the adolescent was anticipated. Adolescents are emotionally self-conscious and sensitive to appraisal from others (Dashiff, 2001). No physical harms endangered the adolescents. However, there was a potential risk of affective/emotional harm in that adolescents may experience emotional distress due to the nature of the interactions or when sharing personal thoughts and feelings and things that have happened to them. In addition, when working with a group of adolescents, there was the potential for negative verbal and nonverbal interactions between group members. These interactions could affect the adolescent’s self-esteem and lead to emotional distress. An experienced moderator conducted the focus groups, but none of the participants demonstrated distress during focus group participation. Focus group ground rules including, “everyone’s opinion is important” and “everyone deserves respect and to be treated with dignity” were provided at the beginning of each focus group session and throughout sessions as necessary. In contrast, there were potential benefits for the adolescents in that interaction with others with T1DM can help them see they are not alone. Further, there was a
potential for establishing new friendships or support systems if the adolescents chose to share contact information with others after the focus group session is completed.

Several steps were taken to ensure confidentiality of participants. Information containing the participant’s name and contact information was stored in a locked file cabinet in the primary investigator’s home office. During travel to and from participant meetings, completed paperwork was kept in a locked, portable file cabinet or locked in the glove box of the researcher’s vehicle. Participants were assigned a code based on their focus group participation that was used on the transcribed data and in a Microsoft Excel file where information from the Demographic and Diabetes Questionnaire was input. In order to access this researcher’s computer, where the data was stored, a unique password known only to this researcher had to be entered. Due to the nature of a group discussion, confidentiality could not be guaranteed (Carey, 1994; Smith, 1995), however, ground rules that established the necessity for maintaining group confidentiality were provided before beginning the focus group session. Further, the statement, “I understand that information shared in focus group sessions is confidential and I will not share anything heard in the focus group outside of the focus group”, was included on the adolescent assent form and that adolescents were asked to initial and date.

To further protect participants, the digital recorder was kept in a locked portable file and MP3 files were uploaded to this researcher’s computer which required a password to access. Once all data has been analyzed and reported, recordings will be deleted from the digital recorder and MP3 computer files will be deleted. Electronic
transcript files did not contain participant identifiers, however, they were stored on this researcher’s computer that required a password to access.

**Focus Group Sessions**

Once parents consented and adolescents assented, the primary investigator scheduled the adolescent for a focus group session appropriate for their reported HbA1c and that was convenient for them. Reminder phone calls or emails were made one week and two days in advance of the adolescent’s scheduled focus group session. On the day of focus groups, the primary investigator and moderator arrived approximately 30 to 45 minutes prior to the scheduled focus group start time to get the room and equipment set up and equipment tested prior to the arrival of the adolescents.

It was planned that each focus group session would involve a moderator and this researcher, who acted as the assistant moderator, which was done for the first five focus groups. Focus group six was conducted by this researcher because there were only two participants able to attend and it was felt having another adult might have limited the information shared by these participants. The moderator was a psychiatric nurse with experience in conducting groups with adolescents. Although the literature recommends that the assistant be silent during focus groups, this researcher felt it was important to ask clarifying questions as needed to gather a richer description from participants as this researcher has become an expert in T1DM. In addition, the primary moderator did not have this expertise and thus did not always know when to probe further.

Focus groups were conducted at a centrally-located private college. The location was selected because of its central location and focus groups were scheduled at a time
that was convenient for parents and adolescents (Peterson-Sweeney, 2005). Adolescents and their parents were consulted regarding scheduling of focus groups during the primary investigator’s initial meeting and subsequent phone calls or email communications. All focus groups were conducted in a classroom with tables and chairs arranged in a conference-style arrangement so that the moderator and participants sat around the tables and could see each other.

Upon the adolescent’s arrival, the primary investigator checked adolescents in and directed them to the room where focus groups were held. Participants were asked to arrive at least 20 minutes prior to the scheduled start time to allow time for them to introduce themselves to and become comfortable with fellow participants. Snacks were provided during this social period and adolescents were consulted in advance regarding the type of snacks.

At the scheduled focus group start time, the moderator asked participants to sit down and began the session. The session began with introductions of the moderator, assistant moderator, and participants followed by an introduction to the focus group including its purpose. At this time, focus group rules were established and participants were instructed regarding their participation in the group. Digital recording of the focus group session began at the start of the focus group to include recording of focus group rules.

A moderator guide (Appendix F) was developed that included focus group ground rules, the primary open-ended questions, and suggested probing questions. Open-ended questions were used, rather than a detailed interview guide, because the purpose of this
study was to explore diabetes self-care and how older adolescents incorporate it into their daily lives as adolescents. Participant checking of information provided in focus groups was performed with subsequent focus groups in an attempt to determine if information gathered was specific to the previous group or was a theme among adolescent participants. The following questions and suggested probes were developed to try to gain an understanding of diabetes self-care practices and life among older adolescents.

1. Please tell me about your life as a teenager who has type 1 diabetes. (Probe: What types of things do you do every day to take care of your diabetes? What successes or frustrations regarding incorporating the diabetes treatment regimen into your life as an adolescent have you had? What is the most difficult aspect of living with type 1 diabetes?)
   a. What are some positives associated with having type 1 diabetes?
   b. What are some negatives associated with having type 1 diabetes?

2. Now, please tell me about what it’s like with your… (Probe: including positives and negatives)
   a. Parents
   b. Teachers/coaches
   c. Peers/friends

3. Now, I’d like to know about your interactions with the health care team, including positives and negatives. (Probe: How do you feel about the healthcare team [doctors, nurses, social worker, and/or dietician? How are treatment decisions made?)
4. Sometimes teens know different ways to do things [i.e. insulin administration, blood glucose checking, diet, exercise]. After you were told what you should do to manage your type 1 diabetes, how did you make it work for you?

The second aim of this study was to gain adolescent input regarding what should be included in an educational and management program to assist adolescents with incorporation of diabetes self-care into their daily lives. The following questions were developed to guide the diabetes self-care program discussion.

1. What kinds of things do you think might be helpful regarding an education and management program for teens with diabetes?
2. How would you like to learn?
3. How would you like to have the program offered? Where would you like to meet?
4. What would make you want to come?
5. What would prevent you from coming?

After completion of the focus group session, this researcher provided a summary of the session and asked for verification from the participants. This step is necessary to establish trustworthiness of data (Krueger, 1998). Once this was completed, the digital recorder was shut off and adolescents were given a $15 gift card. During the initial meeting with the adolescent and their family, the adolescent was asked to identify locations from which they would like a gift card. Incentives are important to acknowledge and thank participants for their time and participation (Morgan, 1998; Krueger & Casey, 2000; Peterson-Sweeney, 2005).
Data Analysis

Focus group sessions were digitally recorded and later transcribed by this researcher, who has experience in transcribing qualitative data recordings. Participant and other names were eliminated from the transcript. Participants were assigned a number based on the group in which they participated and the order in which they responded to the first question posed during the focus group. Once transcription was completed, line numbers were added and transcripts were reviewed while listening to the recordings to check for accuracy of transcription. Once accuracy was verified, data analysis used the transcripts, along with focus group session and debriefing notes. Transcripts were printed on different colored paper which aided in comparison across groups (Krueger, 1998).

The analysis team consisted of this researcher who has significant experience in caring for adolescents with T1DM and was prepared in the focus group methodology; the moderator, a psychiatric nurse who was doctorally-prepared, and a doctorally-prepared educator experienced in qualitative analysis. Inductive analysis, where categories are developed from the data collected rather than categories decided before data collection as is done in deductive analysis, was used (Marshall & Rossman, 2006). Analysis of data in exploratory research requires intuitive flexible interactions with the data (Brink & Wood, 1998).

Data analysis followed the process for analyzing focus group data described by Krueger (1998). Analysis team members read each transcript to become familiar with and immersed in the data. During analysis team meetings, the team focused on data from one focus group at a time. Categories were developed based on the questions asked during the
focus groups. The categories included: 1) life with diabetes; 2) diabetes self-care; 3) unclear division between #1 and #2; 4) interactions with others, which was further subdivided into parents, school/peers, and healthcare team; and 5) program development. One copy of each transcript was cut apart and content was sorted into the established categories. Themes were generated for each category and exemplar quotes were identified. The analysis team reviewed and discussed the generated themes and quotes for each group. The same process was used for each focus group then across the groups for good control and poor control. Based on this process, 34 themes were developed overall for the good control groups and 27 themes overall for the poor control groups. After discussion, the analysis team condensed the themes to 17 themes for the good control groups and 16 themes for the poor control group. Once the process was completed, the analysis team compared and contrasted themes between those for the good and poor control groups in order to answer the underlying research question, “is there a difference between adolescents who maintain good control versus those who do not?”

During the analysis process, the primary investigator wrote notes and memos regarding insights and reflective thoughts (Marshall & Rossman, 2006). These notes, along with detailed notes of the analysis process, supported confirmability of the findings. Once the transcripts from all focus groups were analyzed and themes were developed, the primary investigator reread the transcripts in their entirety to search for alternative explanations for the generated themes and links between concepts (Marshall & Rossman, 2006). This process assisted with interpretation and reporting of the data and identification of plausible explanations for this researcher’s conclusions. Dependability
was further established by having this researcher’s dissertation advisor review the transcripts and themes generated by this researcher and the analysis team.

**Summary**

There is scant literature regarding diabetes self-care among older adolescents and how they incorporate its intense requirements into their daily adolescent lives. During the older adolescent period, 15 to 18 years, glycemic control deteriorates and is the poorest over all age groups. This study used an exploratory research design with focus groups to gather data regarding diabetes self-care and its incorporation into their daily lives among older adolescents. It is hoped that information from this study will be used to guide interactions, diabetes education, and support of adolescents in an effort to prevent deterioration in glycemic control thereby lessening their risk for acute and chronic diabetes-related complications.
CHAPTER FOUR

RESULTS

Introduction

The purpose of this research study was to develop a better understanding of diabetes self-care among older adolescents, 15 through 18 years old, with type 1 diabetes (T1DM). More specifically, this study sought to determine if there was a difference in diabetes self-care between adolescents who exhibited good versus poor glycemic control. A secondary purpose of this study was to gain adolescent insight as to what they think should be included in a diabetes self-care program.

Adolescents with type 1 diabetes (T1DM) participated in 1 of 6 focus groups, divided according to HbA1c, with the primary research aim to gain a better understanding of diabetes self-care and what impacts performance or nonperformance of diabetes self-care activities among teens who exhibit poor (HbA1c > 9%) versus good (HbA1c < 9%) glycemic control. The purpose of this chapter is to present participant demographic and diabetes information, the themes associated with living with T1DM, including diabetes self-care, and for teens who exhibited good and poor glycemic control. Themes addressing their interactions with parents and peers, within the school environment, and with the healthcare team will also be presented. Lastly, participant insight regarding a diabetes self-care program will be presented.
Demographics/Diabetes Data

This study included adolescents (n = 21), 15 through 18 years old at initial meeting with the primary researcher. The demographic information for the participants is summarized in Table 1. The average age of participants was 16.4 years. They were primarily white (85.7%), female (52%), had an annual household income > $60,000 (57%), and lived in a 2-parent household (76.2%). Participants in this study who exhibited good glycemic control were more likely to be from families with household income > $60,000 where those with poor glycemic control were from families with household income < $60,000.

Table 1: Demographic Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Good Control (n = 13)</th>
<th>Poor Control (n = 8)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td><strong>Mean Age (years)</strong></td>
<td>16.2</td>
<td>16.5</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td>Black</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Mixed</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Household Income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; $20,000</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>$20,000 to $40,000</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>$40,001 to $60,000</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>&gt; $60,000</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td><strong>Family Composition</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One Parent</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Two Parents</td>
<td>11</td>
<td>5</td>
</tr>
</tbody>
</table>

Data was also collected about the adolescent’s diabetes using the Demographic and Diabetes Questionnaire which is summarized in Table 2. Control was determined by
level of HbA1c with good control quantified as HbA1c < 9% and poor control as HbA1c > 9%. The mean HbA1c was 7.7% compared to 11.4% and the mean diabetes duration was 5.8 versus 7.8 years among teens in good and poor glycemic control respectively. In addition, 23.8% of teens in good glycemic control compared to 50% in poor glycemic control used an insulin pump. Lastly, 42.8% versus 25% of teens in good and poor glycemic control respectively participated in extracurricular activities (such as sports or theater).

<table>
<thead>
<tr>
<th>Table 2: Diabetes Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Good Control</strong> (n = 13)</td>
</tr>
<tr>
<td><strong>Mean HbA1c (%)</strong></td>
</tr>
<tr>
<td><strong>HbA1c Range</strong></td>
</tr>
<tr>
<td><strong>Mean Diabetes Duration (years)</strong></td>
</tr>
<tr>
<td><strong>Diabetes Duration Range (years)</strong></td>
</tr>
<tr>
<td><strong>Insulin Delivery</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td><strong>Extracurricular Activities (Yes)</strong></td>
</tr>
</tbody>
</table>

*Participant stated usually < 9% so included with good control group; if would have been in poor control group, would have been an outlier.

**Participant could not remember exact number, just knew was > 9%.

Focus Group Characteristics

At initial enrollment, adolescents completed the Demographic and Diabetes Questionnaire which included a question asking them to note their most recent HbA1c, which was verified by parents. The adolescent’s HbA1c at enrollment was used to assign them to focus groups where teens with HbA1c < 9% were considered in good control and those with HbA1c > 9% were classified as poor control. Adolescents were scheduled for
participation in focus groups according to their HbA1c and availability. Adolescents participated in 1 of 6 focus groups (see table 3) held within a classroom in a small, private college in an urban setting. During each focus group, classroom tables were arranged so that the teens and moderator faced each other and were sitting in a conference-style set up.

Table 3: Focus Groups

<table>
<thead>
<tr>
<th>Good Control (HbA1c &lt; 9%)</th>
<th>Poor Control (HbA1c &gt; 9%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Group #1</strong> (n = 4)*</td>
<td><strong>Group #2</strong> (n = 3)†</td>
</tr>
<tr>
<td>Mixed group (M = 2; F = 2)</td>
<td>All Males = 3</td>
</tr>
<tr>
<td>Insulin pump = 4</td>
<td>Insulin shots = 2</td>
</tr>
<tr>
<td><strong>Group #3</strong> (n = 5)</td>
<td><strong>Group #5</strong> (n = 3)</td>
</tr>
<tr>
<td>Mixed Group (M = 1; F = 4)</td>
<td>All Females = 3</td>
</tr>
<tr>
<td>Insulin pump = 1</td>
<td>Insulin pump = 2</td>
</tr>
<tr>
<td><strong>Group #4</strong> (n = 4)</td>
<td><strong>Group #6</strong> (n = 2)</td>
</tr>
<tr>
<td>All Males = 4</td>
<td>All Females = 2</td>
</tr>
<tr>
<td>Insulin pump = 1</td>
<td>Insulin pump = 1</td>
</tr>
</tbody>
</table>

* Group 1-Participant #1 reported most recent HbA1c as 9.3% but stated usually < 9% so was included with good control participants.

† Group 2-Participant #1 reported that he was using oral pills to control his diabetes. “Some patients cannot be clearly classified as having type 1 or type 2 because clinical presentation and disease progression vary in both types” (ADA, 2011, p. S12). Further, the medical director of the Children’s Diabetes Clinic stated, “we use Metformin if patient is obese and insulin resistant with T1DM” (K. Corley, personal communication, March 19, 2012).

Focus Group Questions

Focus group discussions revolved around a set of questions that were developed based on the review of the literature and were designed to elicit the adolescent’s description of life with type 1 diabetes. A focus group moderator guide was developed in order to maintain consistency of content and questions between groups. The adolescents were asked general, open-ended questions in an effort to gain a rich description of life with diabetes and information about their interactions with people whom they come in
contact with and who could potentially affect the adolescent’s performance of diabetes self-care. When needed, probing questions were used to gain specific information or further details. There were two parts to the focus group discussion. The first revolved around being a teenager with T1DM and included the following questions:

1. Please tell me about your life as a teenager who has type 1 diabetes.
2. Please tell me about what it’s like with your …
   a. Parents
   b. Teachers/coaches
   c. Peers/friends
3. I’d like to know about your interactions with the health care team, including positives and negatives.
4. Sometimes teens know different ways to do things [i.e. insulin administration, blood glucose checking, diet, exercise]. After you were told what you should do to manage your type 1 diabetes, how did you make it work for you?

The second aim of the focus groups was to gain adolescent input regarding program development and involved the following questions:

1. What kinds of things do you think might be helpful regarding an education and management program for teens with diabetes?
2. How would you like to learn?
3. How would you like to have the program offered? Where would you like to meet?
4. What would make you want to come?
5. What would prevent you from coming?

**Overview of Themes**

Review of transcripts from the focus groups revealed some commonalities and differences in themes between teens who exhibited good and poor control of T1DM. Table 4 contains the themes identified for the questions asked during the focus group sessions. Discussion of the identified themes will be arranged according to the questions asked during focus groups. Quotes from the participants are included to illustrate the identified themes. Participant quotes will begin with a code to identify good (GC) or poor (PC) control followed by a participant number that was assigned during transcription to indicate speaker position in response to the first question posed by the moderator.

**Table 4: Identified Themes**

<table>
<thead>
<tr>
<th>Question Topic</th>
<th>Theme for Good Control</th>
<th>Theme for Poor Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life as Teen with Type 1</td>
<td>Life with Diabetes is a</td>
<td>Having Diabetes Interferes with My Life</td>
</tr>
<tr>
<td>Diabetes</td>
<td>Struggle</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(They are) Stronger</td>
<td></td>
</tr>
<tr>
<td></td>
<td>than the Disease</td>
<td></td>
</tr>
<tr>
<td>Diabetes Self-Care</td>
<td>Something Have To Do</td>
<td>It’s A Burden</td>
</tr>
<tr>
<td></td>
<td>Adjust Diabetes Self-Care to Fit Lifestyle</td>
<td>Poor Control Leads to</td>
</tr>
<tr>
<td></td>
<td>Integration of Diabetes into</td>
<td>Adjustments in Lifestyle</td>
</tr>
<tr>
<td></td>
<td>Identity</td>
<td>Struggle with Having Diabetes</td>
</tr>
<tr>
<td>Interactions with Parents</td>
<td>Parental Support Important</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Power Struggle</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I’ve Got It</td>
<td>Leave Me Be</td>
</tr>
<tr>
<td>Interactions with</td>
<td>Supportive Teachers/Coaches Important</td>
<td></td>
</tr>
<tr>
<td>Teachers/Coaches</td>
<td>Check in with the Nurse</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mistake Equipment for Popular Technology</td>
<td></td>
</tr>
</tbody>
</table>
Life as Teen with Type 1 Diabetes

The first aim of this study was to learn about the life of older adolescents with T1DM. Thus, after comfort was established during focus groups, teens were asked to talk about their life as a teenager who has type 1 diabetes. Teens who exhibited good control of diabetes described life with diabetes as a struggle, but that they were stronger than the disease. Teens with poor control, however, felt that diabetes interfered with all areas of their life as a teenager.

Life with Diabetes is a Struggle vs. Having Diabetes Interferes with My Life

Teens in good control identified living with diabetes and its complex treatment regimen as a struggle. The need to control the disease by performing diabetes self-care made it difficult for them to appear normal and be like their peers. Further, teens in good control struggled with the reciprocal relationship in which diabetes negatively impacts their daily activities and the activities in which they participate often wreak havoc with their blood sugar.

GC3-P4(F): I think it’s still a constant struggle though because when I go to friends’ houses, they have food just laying out. They all eat it throughout the whole night and sometimes I do to because it’s hard not to.
GC3-P5(F): I had this big presentation in one of my classes and I was pretty nervous for it and then after that class I had lunch and my sugar was like 300. It really had no reason to be that because I hadn’t eaten since breakfast and it was fine at breakfast. So I figured all my nervousness from the presentation stuff; it can just easily go up.

GC1-P2(F): It’s really hard with tests and stuff too if you’re all over the place [blood sugar numbers] ‘cause I went through like a month where I was like all over the place and my grades were all over the place too.

In contrast, teens in poor control felt diabetes and the diabetes self-care activities interfered with their teenage lifestyle. Teens in poor control demonstrated a strong desire for normalcy and to be like their peers and having diabetes interfered with their daily life. Thus they often forgot or actively chose not to perform diabetes self-care measures.

PC6-P2(F): I used to try to ignore it like “oh nah I don’t need to check, I’m gonna go be a teenager go do what my friends do. I don’t have diabetes. I don’t know what you’re talking about.” It’s just difficult being a teenager and going through high school and junior high and everything, just having diabetes. It’s different from everyone else.

PC2-P3(M): If I go out for a whole day to skateboard, I really don’t think about it [diabetes self-care]. I’d rather just not stop and [take] the time to do it when I could I just don’t. I just want to do my day like I want to do it really. I don’t think to stop and do this.

In the majority of participants with poor control, the physical symptoms the teens experienced because of their hyperglycemia forced them to decrease participation in sports and socializing with peers. One male (participant PC2-P3), however, when probed about the presence of physical symptoms, stated "no otherwise I wouldn’t go out and skate."

(They Are) Stronger than the Disease

Although they identified life with T1DM as a struggle, several teens in good control exhibited strength. Many of them participated in sports and did not allow diabetes
to hold them back. One male, in particular, exuded a strong sense of being stronger than
the disease and did not allow it to stop him from playing football.

GC3-P3(M): I don’t really want to admit defeat to the disease because I feel
above it. You know not like it’s holding me back. I feel like I’m stronger than the
disease.

GC4-P1(M): I never really see it as a disease that limited me in any way.

In summary, teens with T1DM get frustrated with having the disease. Teens in
good control identified having diabetes as a struggle where teens in poor control felt that
having the disease interfered with their lives. Further, teens in good control exuded a
sense of “being stronger than the disease” and many of them participated in sports and
other extracurricular activities.

**Diabetes Self-Care**

During focus groups, teens were asked to describe what they did every day to
manage their diabetes. Among the good control focus groups, this question created a
lengthy pause where participants had to stop and think about this. Many had difficulty
answering the question because they viewed diabetes self-care activities, such as
checking blood sugar and administering insulin, as part of their life. Before this, however,
teens in good control had come to the realization that diabetes self-care had to be done
and figured out how to adjust it to fit their lifestyle although they stated having diabetes
was still a struggle. In contrast, teens with poor control had difficulty discussing their
diabetes self-care because it was something that they did not want to do and many days
forgot to perform diabetes self-care activities. Teens with poor control identified diabetes
self-care as a burden and often adjusted their lifestyle because of the way poor control
made them feel physically.
Something Have To Do vs. It’s a Burden

Teens in good control stated they often struggled with incorporation of diabetes self-care into their day and various activities. However, they came to the realization that performance of diabetes self-care was important in order for them to feel good, which allowed them to participate in activities with peers such as sports, theater, or just hanging out with friends.

GC4-P1(M): If you don’t take care of yourself, that’s your own fault. I mean nobody [else] can make a difference. I didn’t take care of myself for awhile. I just gotta put the foot down.

GC1-P1(F): it’s pretty much something you just have to get used to.

GC3-P5(F): you have to take that extra work to…

GC3-P3(M): you want to feel normal.

GC3-P5(F): yeah

GC3-P1(M): it’s like you want to be like everybody else and the better your blood sugars are then the more normal you are.

For teens who exhibited poor metabolic control, diabetes self-care activities were a burden and interfered with their daily life. A few teens felt it was not difficult to adjust their lifestyle to accommodate the necessary diabetes self-care activities. However, further discussion revealed they were frustrated with having to interrupt their lives to perform diabetes self-care, thus they actually did view diabetes self-care as a burden.

PC5-P3(F): …you have to check your blood sugars you know 4+ times a day; you have to take insulin every time you eat 4+ times a day with meals you know and then it’s just there’s a lot more that goes into it than I think people really understand.
Adjust Diabetes Self-Care to Fit Lifestyle vs. Poor Control Leads to Adjustments in Lifestyle

Teens in good control stated they did not always perform diabetes self-care as instructed by the healthcare team. Instead, they made adjustments in performance of diabetes self-care based on their lifestyle and what works for their body.

GC3-P3(F): There are sometimes I don’t always count the carbs and just take insulin based on usually how much I eat and how much I usually give myself. Sometimes…it works for me most of the time. It’s just kind of faster sometimes and at least more in the morning.

GC3-P5(F): I don’t always check either sometimes. I have had that where I know I’m gonna be high just because I’ve been snacking or something so you kinda are just like “oh I’ll just give a couple extra [units of insulin]”

GC1-P2(F): Well, I probably don’t check myself as much as I should. I mean like I do at breakfast, lunch, dinner, and then usually before I run and then after. But usually with a snack, I’ve just kind gotten used to knowing how much insulin to give for it so I’m just like “okay well I’ll just eat this.” I guess that’s kind of bad but it’s worked for me. I don’t really need to do extra blood tests. I just kind of know my numbers now.

In contrast, many of the teens in poor control adjusted their lifestyle to fit how they felt physically because of their chronically high blood sugars and poor control. The majority of the teens in poor control commented that they withdrew from sports or other activities because of the way they felt physically.

PC6-P1(F): When I wake up in the morning it’s really hard to wake up because I feel sick. I feel sick all the time.

PC6-P2(F): My A1c was up to like 12 and 13 last year so I was just like, “oh sports I can’t do it.” I was tired all the time. I just couldn’t do it.

However, when probed, one male was adamant that he felt no different between periods when he had better performance of diabetes self-care than when he did not.
PC2-P3(M): When I got out of the hospital, I was really good about it. Probably like the first year I was really good about it because I was kind of scared, but then I realized if I have a bad day, nothing really significant happens to me. I don’t feel bad. So I realized that I could skip out once in a while and there’s not really any physical consequences so I just progressively got worse. I had a period for like 3 months when I just didn’t do anything for it and nothing really happened…I usually sleep a lot anyways so I really don’t feel the difference from being on medication or being off.

**Integration of Diabetes into Identity vs. Struggle with Having Diabetes**

 Teens with good control demonstrated several behaviors that provided evidence of the development of independence and responsibility for themselves, their actions, choices, and their diabetes. For the teens in good metabolic control, the activities necessary to monitor and control their diabetes have been integrated as part of their normal routine, thus diabetes and its necessary self-care activities have become part of their identity. In addition, for the teens in good control that use an insulin pump, there was a common theme of the pump becoming a part of them.

GC3-P5(F): At first I didn’t think life’d be normal, but it’s kind of just become more routine now. It’s just part of my day giving shots and poking my fingers.

GC3-P2(F): Since I’ve been diagnosed, I just find it amazing how registered it is. Just any time I think about eating and how many carbs…it’s just in there now and it happened really quickly. So I just found it weird how quickly I adapted.

GC4-P4(M): There’s been times where it’s like I’ll wake up in the morning forget that I have it [pump] just hanging out so I’ll get out of bed and it starts hanging and I’ll walk with it and I’ll be like “oh.”

The majority of teens with poor control of T1DM demonstrated struggling with having diabetes, its complex self-care requirements, and their desire to be a normal teenager. This struggle created inner conflict for the teenager which was most evident among the females. The males who participated and exhibited poor control were not concerned with their poor control or blood sugars.
PC2-P2(M): … but if it’s [blood sugar] a bad thing it doesn’t really bother me like it should.

PC5-P3(F): I’m really working hard in both those things [dance and school] and yet I’m not taking care of my diabetes and yet if I don’t do that then what’s the point in going to school and doing dance and having my parents spend so much money for me to be able to do that and yet like I said before there’s something stopping me. I don’t know and it’s my fault. I don’t know why but like I’ll like go to bed one night and I’ll be like “okay tomorrow I’m going to start out fresh. I’m going to start taking care of it. It’ll all be really great.” And in the morning I’ll forget about that and then I’ll be like “okay I’ll start tomorrow” and just keep on pushing it back further and further.

In summary, teens with good control have learned that diabetes self-care is “something they have to do” in order to feel normal and participate in activities with peers. However, they have adjusted some diabetes self-care activities which, along with their attitude toward diabetes self-care, facilitated integration of the disease and its necessary self-care activities into their identity. In contrast, because teens with poor control view diabetes and its self-care activities as a burden, they struggle with having diabetes. Further, many have decreased participation in activities with peers because of the way they feel physically.

Interactions with Parents

During focus groups, participants were asked to talk about their interactions with their parents. The primary theme associated with this interaction related to teens in good and poor control struggling with their parents. Between the groups, though, there was a difference in the dynamics of the power struggle where teens in good control wanted parents to recognize that they have control of their diabetes and those in poor control desired independence and normality. However, there were some positive behaviors parents exhibited that both groups of teens appreciated.
Parental Support Important

Several teens stated having parental support was important in helping them deal with the intricacies of living with T1DM. Teens with T1DM who were female, whether in good or poor control, identified the importance of talking with parents about their diabetes. For these teens, parents provided emotional support which assisted them in dealing with the complexities associated with living with the disease.

PC5-P1(F): I don’t talk about it to anybody and then once I did talk about it to my mom and I told her everything about how I felt, I woke the next morning I felt so much better and things have just been going really good since then.

GC3-P3(F): My parents usually know I have the capacity to take care of it myself and so I usually will come to them about anything just like anomalies or anything like that and we’ll get it taken care of.

Parents are also a source of physical support for teens with T1DM. However, only teens in good control discussed these parental interactions. Teens in good control valued the physical support parents provided in various situations, such as when the teen experienced hypoglycemia or equipment issues.

GC1-P3(M): yeah finals last semester, first day I walked in and my blood sugar was like 500. We had like 10 minutes in between periods so my dad came and changed the [insulin pump] site in 5 minutes and get ready for my next period… Then my mom um you know obviously I’m not home during the day so she’ll call and order supplies and that kind of thing.

GC4-P3(M): I go over to check my blood sugar and I’m standing there with the blood sugar and I can’t do it because I can’t think because my blood sugar’s so low. My mom comes over and she had to do it for me. She told me five times when she was sitting on the couch to check my blood sugar and I was like “all right” and just stare at it and she came over and checked it and it was 32. It was bad.
**Power Struggle**

The primary theme involving parental interactions for teens in good and poor control revealed the teen’s desire for independence. There was similarity in the wording used by the teens in good versus poor control where they stated parents “nagged and worried too much.” However, there was a subtle difference in the theme of the discussions between the groups where the theme among teens with good control was “I’ve got it.” In contrast, teens in poor control demonstrated a “leave me be” attitude.

“**I’ve Got It.**” The message from the teens who exhibited good control of their T1DM was “I’ve got it.” Within this theme, teens wanted parents to recognize that they had good control of their diabetes, as evidenced by their HbA1c and blood glucose numbers, and to stop checking on their performance of diabetes self-care activities.

GC3-P1(F): What really drives me nuts is when my parents think I can’t handle it. It’s like I’ve been dealing with this for five [times] a day. I’ve been dealing with this for six years. I kinda know what I’m doing. You don’t need to interfere as much as you do.

GC4-P3(M): They worry too much. It’s like one time my mom actually, not one time but a lot of the times, my mom texts me and said you know, while I’m at school, and she’s like “did you check your blood sugar? How was it? Was it high?” “It’s fine mom.”

**Leave Me Be.** In contrast, the power struggle was more evident among teens in poor control. The parental behaviors described by the teens depicted actions by their parents that could be construed as protective behaviors where the parent is trying to prevent the complications associated with poor control of T1DM. Parental actions ranged from reasoning with the teen to performing diabetes self-care activities.

PC5-P2(F): … I didn’t do anything and I just totally stopped caring in general. And I know my mom was really worried and she was really upset and she was really hurt because she’s like “I don’t want anything to happen to you and if you
keep this up, you’re going to seriously harm yourself and you’re going to get complications” and my parents threatened to take me to the hospital so I can see people that have amputated limbs.

PC2-P1(M): either that [make self do it] or my mom has to stand over me looking over my shoulder making sure I’m doing it she’s always bugging me like “did you do it” and “what was it”. She always asks me to see my notebook.

PC6-P1(F): … well my mom, she comes in every morning when I’m sleeping and gives me my Lantus and checks my blood… I hate it when she comes over when I’m eating supper and tries to do it. I’m like, “just wait until I’m done eating I might eat some more”

Teens in poor control resented their parents’ intrusive behaviors, but recognized they would be in worse control if not for these parental actions. However, they also responded with rebellious behaviors. A strong message of “leave me be” was evident in the comments made by teens in poor control. Further, teens felt if his/her parent knew what life with diabetes was like, they might back off. Within the parent-adolescent struggle, teens in poor control have a strong desire for independence and control over their life and choosing not to perform diabetes self-care activities is one form of control.

PC2-P3(M): I like to be independent and I don’t like people always there telling me what I gotta do or how I gotta do it or always checking up on me. But if [it] wasn’t for them checking up on me I probably you know wouldn’t be doing as good as I am even though I’m not doing incredibly well.

PC6-P2(F): My mom gets on my back about diabetes, I’m like “that sucks [there] goes a day now when I’m not going to do what you want.”

PC5-P3(F): Sometimes I wish that my mom could do everything I have to do every day, like give herself a site change but not put any insulin in you know just see okay live with this for like a day. You know, how much of it do you actually want to do now?

In summary, teens in good and poor control value and need parental support in order to deal with the complexities associated with living with T1DM. Females identified the importance of the “sounding board” role of their parents in which they could talk to
their parents about issues and not worry about being reprimanded. Among teens in good control, they were appreciative of their parent’s assistance in times of need, especially when they experienced hypoglycemia. However, the discussion regarding parental interactions mostly revolved around the teen’s struggle with their parents over control over their lives. The major developmental task for adolescents, 15 through 18 years, is to develop independence and separation from their parents. The teens in this study felt their parents nagged them too much about performance of diabetes self-care activities with a subtle difference in the message between teens in good (I’ve got it) versus poor (Leave me be) control.

**Interactions with Teachers/Coaches**

Teens spend much of their time in a school environment. Thus, teens were asked, “please tell me what it’s like with your teachers/coaches.” In most groups, there was little depth surrounding this topic. During this discussion teens described interactions with teachers/coaches where most were aware of their diabetes status and supported the teen. In addition, teens also talked about school requirements in regards to carrying diabetes self-care supplies and performing diabetes self-care while in school. Themes that occurred for teens in good and poor control include “supportive teachers important,” “checking in with the nurse” and “mistaking equipment for popular technology.”

**Supportive Teachers/Coaches Important**

During the discussion regarding interactions with teachers/coaches, both teens in good and poor control identified situations that teens felt were supportive or not. Since teens spend much of their day in school, the teens felt it was important to have a
supportive school environment. In order to garner support and make their school life easier, some teens in good and poor control worked with nurses to email teachers at the beginning of each school year to inform them of the teen’s diabetes and make them aware that special accommodations or assistance occasionally may be needed.

GC1-P1(F): Every year before school starts the nurse and I and my mom, we email my teachers and make sure they know that I’m diabetic and sometimes I have to leave the classroom... and I know some teachers keep like juice boxes in their little refrigerators so that makes it kinda easy.

GC3-P5(F): Our school nurse ...teach[es] some teachers to give the glucagon and stuff and so my coach is like “well if you need me to know how to do that then I’ll have the nurse teach me how to do that.

PC6-P2(M): I have a pass that says, “whenever ___ needs to go” I just show it to my teacher, I’m just like, “can I go?” they’re all, all my teachers know. They’ve been with me all year so they’re just, “okay go down come back whenever.”

Check in with the Nurse

During the discussion regarding their school environment, it was found that some schools required teens with T1DM to visit the health or nurse’s office before lunch to check or report their blood glucose and administer insulin, if the teen did not use an insulin pump. Among the teens that discussed this, there were no easily identifiable characteristics between teens that stated they were required to check in versus those who were not. Teens in good and poor control, on shots or the pump, or from large or small schools were required to check in with the school nurse/health office daily.

PC2-P1(M): If I don’t check in, she [school secretary] comes to whatever class I’m in and asks me “did you check it?”

GC3-P3(M): She [nurse] does require me to write it down what it was for lunch like my blood sugar and how many units I took. I usually do that everyday for school.

GC1-P4(M): If you don’t go to the nurse every time you go to lunch, yeah you get ISS [in-school suspension].
Mistake Equipment for Popular Technology

Although the teens commented that teachers/coaches supported their performance of diabetes self-care activities as needed in the classroom, they stated that teachers frequently mistook their insulin pump or other equipment for popular technology (ie: cell phone). This was a source of frustration for the teens because they had to stand up for themselves to persons in authority and risk discipline.

GC1-P4(M): I was sitting at the lunch table and I had my pump out and I was taking insulin, he [Assistant Principal] comes over and he’s like “I’m gonna take your ipod from you” and he pulls right on the cord right as I’m taking insulin. I tried to explain to him that it was a pump after he pulled it and he was like ‘I still need to take it from you’. I’m like ‘this is for diabetics. I’m a diabetic. I need insulin.’ He looked at me like ‘oh.’

PC5-P1(F): I know in high school they would think it was a cellphone, “put it away, put it away” and I’m like, “I can’t put it away” and then I’ll try and tell them and they’ll just send me out and I’ll come right back with a note and they’re like, “oh sorry”.

In summary, teens in good and poor control had similar experiences within the school environment. They felt having supportive teachers/coaches was important in helping them deal with the disease while at school. In addition, many teens stated they had to check in with the school nurse or health office on a daily basis, an action which frustrated some because it did not allow them independence. Lastly, a major source of frustration for teens with T1DM, in good and poor control, was teachers and school staff mistaking their diabetes self-care equipment for popular technology and trying to confiscate it which forced the teen to stand up for themselves and pointed out their difference to peers.
Interactions with Others

While teens were asked to talk about what life is like with their peers and friends, the discussion also included interactions with others. As teens discussed their interactions with peers and friends, the males in all groups (good and poor control) contributed little to the discussion. The majority of the information contained within the subsequent themes came from the females.

Misconception Creates Stigmatization

The majority of the teens in good and poor control exhibited frustration with society’s misunderstanding about diabetes. As teens discussed this, it was evident they were frustrated with the stigma that surrounds the word “diabetes” and thus felt stigmatized by society which led to frequent questions, misconceptions, and sometimes mocking of the teen by peers.

GC1-P4(M): I get that “is that the really bad one?” It’s like “you’re right but the other one’s completely fine.

GC1-P3(M): my sister, when she was in college, she told a friend of hers that she had a diabetic brother. My sister told me later that her friend had said “oh I was expecting your brother to be fat.”

PC5-P3(F): this lady gave me this gift that was a bunch of candy and she’s like, “there’s a lot of candy in there sorry you probably can’t have any of it.” I’m like, “yeah I can.”

PC6-P1(F) and P2(F): sometimes if somebody really wants to hurt your feelings, that’s what they’ll say. Because they know that’s [diabetes] the only thing that’s different like that’s only thing that they have against you that’s different.

Openness with Others

Although some teens with good control commented that they were proactive and open with friends about their diabetes, the prevailing theme for teens in good and poor
control was that their friends were aware and “pretty cool with it” but did not know much about it. The teens were conflicted about whether or not to tell others about their diabetes because of the stigma associated with it. This conversation was mostly held among female participants. Male participants did not share specifics about their interactions with others, especially 2 males in poor control group #2 who felt that their diabetes was “no one else’s business” (PC2-P1).

PC2-P3(M): I don’t really talk about mine to anybody. It never really comes up... I never really talk about it. There’s really no reason to.

GC1-P2(F): that’s the problem like I’m always scared to tell new people like I don’t tell people until I get really comfortable.

GC3-P4(F): I don’t even know if my boss at work knows because, like I said earlier it’s just awkward. I don’t even know when I would tell them that like it wouldn’t just come up in conversation like “oh by the way I have diabetes” like I don’t know I guess I should just tell them up front but it’s just awkward.

PC5-P1(F): my close friends it’s not really a big thing to them. They don’t say anything. So they don’t really know much about it.

Supportive Network

Close Friends. Teens with good and poor control felt that having a network of close friends was important. Females with T1DM, whether in good or poor control, discussed the emotional support provided by friends. In one case, the teen’s friend went as far as mimicking wearing an insulin pump for a day. Males identified situations where peers gave them nicknames because of their diabetes which was revealed acceptance of the teen with diabetes by peers.

PC6-P2(F): One of my best friends, I had the Cosmo pump and she’s always like, “I want a pump” so we pretended to stick one of the things on and she carried it around for a day and she’s like, “this sucks I feel bad for you.”
PC5-P2(F): I have a really supportive group of friends and if anything was wrong, like earlier this year, I was hospitalized with ketoacidosis and quite a few of my friends came to visit me and it was not a very good circumstance but it made me feel good to know that no matter what they’d be there for me.

GC4-P3(M): I got my nickname at school from when I was in gym once and I passed out on the track they called me ‘sweet bloods’.

GC1-P1(F): You can hold your feelings all you want, but they’re still going to be there and I think talking to your peers is a big thing and then you also have to have close friends that you can talk to too. I mean, if they don’t have diabetes, they’re not exactly going to understand your point of view, but at least they can be there for you.

**Diabetes Camp.** Several teens in both good and poor control, male and female, discussed attending diabetes camp. All described this as something positive that assisted them in dealing with having T1DM and the many diabetes self-care activities. One teen in poor control was especially appreciative of the diabetes camp experience because it allowed her to see others who were worse than her at performance of diabetes self-care and control of the disease.

PC5-P2(F): Girls that I was rooming with told me they don’t check outside of camp really and so, I know that sounds terrible, but it makes me feel better, “oh I’m better than you are, I actually do check.”

GC4-P4(M): Camp helped. It was kind of like an eye opener like “oh” you know. It wasn’t this horrible disease.

PC6-P2(F): I like diabetic… camp like I can’t picture myself without my friends from camp they’re like [my] best friends. At camp it’s just a whole other family so I couldn’t picture not having diabetes and not meeting those people ever.

**Intrusive Behaviors**

As teens discussed their interactions with friends, they stated that peers often questioned their dietary choices or reminded them to perform diabetes self-care. This was evident among teens in good and poor control, however, females in poor control
described more intrusive behaviors by friends or boyfriends such as not letting them eat until they administered insulin. Friends’ intrusive behaviors were described as annoying but the teens with T1DM were less frustrated when friends interfered than when their parents did.

PC6-P2(F): She [friend] really likes knowing, “oh what’s your blood sugar?” and she’ll be like, “you can’t eat that, that has way too much sugar.” She’s on my back about things but she doesn’t do it in like a parenting way. It’s different hearing it from a parent because it feels like they’re ruling you, controlling you but from a friend it’s just like talking so it’s different.

GC1-P1(F): I dated a guy who told me what I could eat and what I couldn’t eat like (giggle from group) if we would go to a restaurant and he’d be like “up, we can’t order dessert” or something like that so like I finally had to tell him “okay you have to stop telling me what I can and cannot eat” which is like really hard too.

In summary, teens with T1DM believe having close friends who support them is important in order for them to deal with the complexities of the disease. Even though their friends interfere in regards to the teens’ diabetes self-care, which was frustrating for the teens, the emotional support and acceptance friends provided was more important to the teen with T1DM, whether in good or poor control. For those who had the opportunity, attendance at diabetes camp was identified as an invaluable source of support and friends who actually understood the complexities and stigma associated with living with diabetes.

**Interactions with the Healthcare Team**

Teens in all groups were also asked to describe their interactions with the healthcare team. The response to this question primarily focused on the endocrinologist and described negative interactions. However, the teens described interactions with the nurses and other members of the healthcare team more positively. The themes evident in
the discussion surrounding the healthcare team related to trusting members of the healthcare team with diabetes and the physician’s communication style.

**Trust Those with Diabetes vs. Dismissive of Those Who Don’t**

The one commonality between the two groups of teens was their appreciation for nurses and other members of the healthcare team who have diabetes. Teens from both good and poor control groups felt they could trust what these healthcare team members said. Teens also commented they were more likely to believe staff who had diabetes because they felt these staff knew what the teen was going through.

GC2-P1(F): I like it some of the doctors I’ve had they’ve actually had diabetes and I really like that. It’s like okay you know what I’m going through.

PC6-P2(F): I feel like there’s someone [dietitian from camp] actually on my side and gets it more… when she tells me critical things like, “oh you need to do this.” I’m like, “oh, okay well obviously because you’ve been here, you’ve known me for how long like I should probably, you know try.” I mean it might not be perfect but I try I listen to them more than just the normal doctor who doesn’t have it who just went to school for it.

PC5-P2(F): I think it’s (nurses with diabetes) made a greater impact because you know they know what you’re going through and they try to encourage you and tell you “you know it’s not that hard.”

Teens in poor control were vocal about their distrust of the physicians because they did not know what it was like to live with the disease. They recognized the physician’s education but were dismissive of this and anything the physician said about them or what they should be doing to improve their diabetes control.

PC2-P3(M): They [doctor] only look at it from a medical standpoint…not like social or like how you function as a person. They don’t know really. They don’t know what you do every day or how you do it.

PC6-P2(F): I just feel like doctors like all they went to school and studied and …if they don’t have it, it’s just like “you don’t know”. Don’t say that you know what I’m going through, you understand because you don’t. Like you don’t have
diabetes. You don’t have to wear my pump. You don’t have to go through what I go through what I have to do every day...”

Physicians Impersonal vs. Condescending

The majority of teens, both good and poor control, described interactions with the physicians negatively. Review of the data indicated a difference in the way the physicians treated teens based on their level of control. Teens in good control felt physicians were impersonal and detached where teens in poor control felt the physicians were condescending toward them. Throughout this discussion, teens in good and poor control demonstrated a desire to be heard and included in decision making regarding their treatment regimen and the complexities they face with trying to incorporate diabetes self-care into their daily lives.

Impersonal. The teens in good control described their interactions with the physicians as impersonal where the doctors just came into the examination room, asked the same questions as they did during the previous visit, dictated changes in the treatment regimen without involving the teen, and then moved onto the next person.

GC1-P2(F): When I would go they’d spend like 30 minutes just checking up and it’s not even … it just seemed like they never really had time to put [in].

GC3-P1(F): … it’s like they’ll come in and they’ll look at it and they’ll go “oh okay you’re good” and they’ll like so you’d be like “oh see you in 3 or 6 months” or whatever.

GC3-P5(F): Every three months doesn’t seem like that often but then when you go there they just ask you the same questions and everytime you feel like it’s gotten shorter because you’re just like “yep”, “no”, OK then up two of Lantus; like it’s just the same.

Condescending. In contrast, teens who exhibited poor control felt that the demeanor of the physicians was condescending. These teens felt that the physicians
judged them based on their blood glucose and HbA1c numbers; judgments the teens believe are wrong because it is based on only one part of them.

PC2-P3(M): I just don’t like it when I get a bad report and they [doctors] sit across the room and talk down to me about it…they don’t really ask me what the problem is they just accuse me of not doing anything; they just say “well, you must not be doing anything at all” and it’s like “but I am” and then they go “well, that’s not what the data shows” and it’s like “well, then come watch me for a week”… I think that they should help you work through it, not just put you down over it.

PC6-P1(F): Because they [doctors] just sit there and tell what you’re doing wrong never what you’re doing right and like I usually just don’t even listen just sit there I just kind of sit there in the background.

PC5-P2(F): I feel like when he sees your numbers you know they’re not the best like he kind of throws you a guilt trip like makes you feel bad.

**Nurses Treat Me Like a Person**

Adolescents with T1DM in both good and poor control preferred interacting with nursing staff over the physicians. They felt the nurses were more positive toward them and treated them like a person. In addition, the teens identified that many of the nurses also had T1DM and, thus, the teens were more likely to listen to them because they understood what it was like to live with the disease and its complex treatment regimen.

GC1-P1(F): if I have a problem or something then like [a doctor] will step in and we’ll talk about it but for the most part she [nurse practitioner] does really well talking to me about the ups and downs of it. She’s (a) person that you’re on the exact same level as she is. She doesn’t treat you like some kid who’s not doing what you’re supposed to be doing.

GC3-P5(F): I think at the clinic that we go to, they still have 80% of the nurses have diabetes so it helps what they know and stuff.

PC5-P2(F): Like that’s what I want to do. I want to work with people that are diabetic as a nurse as well because from my experience I think it’s made a greater impact because you know they know what you’re going through and they try to encourage you and tell you “you know it’s not that hard.”
PC6-P1(F): They [nurses] understand (sighing), they’re way nicer about it. They don’t sit there and tell you what you’re doing wrong and stuff, well sometimes they do, but not as much I guess.

In summary, all teens with T1DM felt they could trust members of the healthcare team who also had diabetes as the teens believed they understood the difficulties they face as they try to navigate the complexities associated with the disease and its treatment regimen. Teens in poor control were dismissive of the physician because they did not have "real life" experience. Further, there was a difference in the way teens described their interactions with the physician where teens in good control described impersonal interactions and teens in poor control described the physician communication as condescending and judgmental.

**Program Development**

The second primary aim of this study was to get input from teens with T1DM regarding what they think should be included in an intervention designed to assist older adolescents who have T1DM. When the teens were asked to provide input on an education and management program for teens with T1DM, most of them felt a program should be designed for teens newly diagnosed with the disease. Some teens who were older demonstrated a future orientation where they desired more information regarding the long-term complications associated with the disease as they felt this would prevent worsening or improve glycemic control. When probed further, teens felt that having a group where teens with type 1 diabetes could gather and share information with each other might be beneficial. Teens in poor control thought it might be helpful to be included in a group with teens who have good control as they felt this might provide them with helpful advice in how to improve incorporation of diabetes self-care into their day.
Several teens felt participation in the small focus groups was beneficial as it provided them insight and provided them with a form of support they normally do not get.

PC2-P3(M): I think that if there is a program, I’d like to hear it from another teenager that does do well because I think they understand what you do in your life as a teenager better and they can help you figure out ways to…

PC5-P3(F): I think this discussion has really opened up my mind about things that I don’t know how to explain it, I never really thought about some of this stuff and it’s like “wow” you know you need to start thinking about what can happen later.

GC1-P2(F): I don’t really know anyone else with diabetes my age. At my school I’m pretty much the only one and so talking tonight, it’s kind of nice knowing that other people go through the same thing and know what I’m talking about because my friends, yeah they know about it, but they don’t know like what goes on like with it.

Further probing questions were asked of participants to garner insight into specifics of timing and group make-up. Teens stated groups should be held approximately once a month and should include a mix of teens in good and poor control.

The most important characteristic of any program that the teens identified was that it must be led by someone who actually had T1DM because they would understand what the teens dealt with on a daily basis in trying to incorporate the complex treatment regimen into their teenage lifestyle.

Conclusion

In conclusion, teens with type 1 diabetes described living with the disease as stressful and struggle with incorporation of the complex diabetes self-care activities into their lives as teenagers. The various groups of people and environments in which the teen interacts with daily can positively or negatively influence incorporation of diabetes self-care into the teen’s daily life. However, factor that most influenced whether or not the
teen incorporated diabetes self-care into their daily lives was their attitude toward having the disease.

Review of the data and the themes generated reveals an overarching domain among the teens of “desiring normalcy”, but a difference regarding what “normalcy” is between teens in good versus poor glycemic control. Teens with good control exuded a belief that they were stronger than the disease and that, in order to participate in activities with their friends, diabetes self-care is something they have to do in order to feel good physically. In contrast, teens with poor control often forget to perform diabetes self-care activities and thus have to adjust their lifestyle to fit their chronic high blood sugar. Teens in good control came to accept having the disease and that performance of diabetes self-care as part of who they were where teens in poor control described having diabetes and its self-care activities as a burden and something that made them different from their peers.
CHAPTER FIVE

DISCUSSION

The goal of this research study was to develop a better understanding of diabetes self-care among older adolescents, 15 through 18 years old, with type 1 diabetes (T1DM). More specifically, this study sought to determine if there was a difference in diabetes self-care between adolescents who exhibited good (HbA1c < 9%) versus poor (HbA1c > 9%) glycemic control. The purpose of this chapter is to compare and contrast results from focus groups held with adolescents who exhibited good or poor glycemic control and correlate significant findings with the literature. Study limitations along with implications for practice and further research will also be discussed.

Discussion of Findings

The findings from this study expand on the knowledge gained regarding diabetes self-care among older adolescents with T1DM in good and poor glycemic control. First and foremost, this is the first study the specifically identified using adolescents from both groups within the same study which facilitates comparison of the data. Analysis of content for each focus group question revealed similarities and differences between teens in good and poor glycemic control. The subsequent discussion of findings will highlight the themes that contributed most to understanding why some teens are able to maintain
good glycemic control and others are not. In addition, the subsequent discussion will correlate the findings of this study with the literature.

**Demographics**

It was interesting to note that the majority of adolescents who exhibited good glycemic control in this study lived in households with an income > $60,000 while those with poor glycemic control were from households with an income < $60,000. Previous studies have found that adolescents from families with higher SES (Helgeson, et al., 2008) exhibited better glycemic control; while adolescents with lower SES have a poorer diet and HbA1c (Harris et al., 1999).

**Life with Diabetes and Diabetes Self-Care**

The themes for living with T1DM and performance of diabetes self-care were presented separately in the previous chapter. However, this discussion will integrate these themes as analysis revealed that the way the teen viewed having diabetes correlated with whether or not they were able to incorporate diabetes self-care into their life as a teenager.

The participants who exhibited good control have gotten through the process of accepting that they have diabetes which led them to take ownership of the necessary diabetes self-care activities. The culmination of this process of acceptance was demonstrated by the teen accepting diabetes as part of their identity. Teens in good control realized that performance of diabetes self-care was “something they had to do” in order to feel normal and have learned how to “adjust diabetes self-care activities to conform to their lifestyle” which enhances “integration of diabetes into their identity.”
Previous studies have found that the adolescent’s perceptions about themselves and diabetes can impact their performance of diabetes self-care. Older adolescent females found it easier to blend in with adolescent culture because they did not let diabetes define who they were as a person (Dickinson & O’Reilly, 2004). Similarly, Kyngas (2007) found that good adherence was more likely among adolescents with good motivation or who had energy and willpower.

Adolescents with diabetes also view diabetes as a hassle that exerts control over their lives (Carroll & Marrero, 2006). In this study, among teens who exhibited poor metabolic control, it was evident that they had not incorporated the diabetes diagnosis into their identity. Teens in poor control viewed “diabetes as a burden” and were more likely to forget to perform diabetes self-care activities. Since they have not incorporated diabetes self-care into their life, most of the teens in poor control have “been forced to adjust their lifestyle.” The teen’s view towards diabetes and diabetes self-care contributes to their continued “struggle with having diabetes.” Similarly, a phenomenological study with Swedish adolescents revealed that adolescents felt they could not live a regular life due to the treatment regimen (Huus & Enskar, 2007).

**Interactions with Parents**

In previous studies, adolescents reported their parents were too protective and worried too much which contributed to parent-adolescent disagreement (Cameron et al., 2008). In addition, parental worry and intrusive behaviors were precursors to parent-adolescent conflict (Weinger et al., 2001). Further, higher parent-adolescent conflict correlated with or predicted poorer diabetes self-care (Hilliard et al., 2011; Ingerski et al.,
2010). But, parental support and positive parent-adolescent communication correlated with better diabetes self-care behaviors (Faulkner & Chang, 2007; Skinner & Hampson, 1998).

In this study, teens were asked about their interactions with their parents. Overall, the teens in good control described their parents as nagging or worrying too much about their performance of diabetes self-care. They were frustrated by these parental behaviors because they did not convey parental trust which the teens felt they had earned by maintaining good glycemic control and incorporation of the diabetes treatment regimen into their busy teenage lifestyles. Teens in good control wanted their parents to recognize their good control and to let them handle performance of diabetes self-care without so much interference.

In contrast, teens with poor glycemic control described parental behaviors as intrusive. Except for a few females, no specifics were provided where this researcher was able to definitively identify parent-teen conflict. Nor, for the most part, could it be concluded that performance of diabetes self-care decreased as a result of parent-teen conflicts. However, one female participant specifically described not performing diabetes self-care because of a conflict with her parent. There was also one other female who described constant conflict between herself and her mother, who also has T1DM. In this case, the mother has taken over performance of the daughter's diabetes self-care such that she wakes her every morning to check her blood sugar and administer insulin. In addition, there is conflict between the two at dinner where the daughter describes mom standing over her with insulin drawn up ready to give and the daughter is verbally trying
to fight her off stating that she might want to eat more. With this data, it is evident that
parent-teen conflict exists more frequently for adolescents who exhibit poor glycemic
control; however a definitive conclusion cannot be made.

**Interactions with Teachers/Coaches**

Teens in good and poor control felt it was important to have teachers/coaches who
were supportive. Teens stated that teachers/coaches supported them by allowing them to
perform diabetes self-care measures as needed in the classroom and accommodating or
assisting them during periods of hypo- or hyperglycemia. In order to garner support from
teachers, some teens were proactive at the beginning of each school year by working with
the nurse to notify teachers of their diabetes status. No previous studies were found that
related interactions in the school environment with diabetes self-care among adolescents.

**Diabetes Camp**

In this study, teens in good and poor control discussed the value of attending
diabetes camp. They stated this experience assisted them with dealing with the
complexities of managing T1DM. For many participants, they did not know other
adolescents with T1DM, thus attending diabetes camp provided them with a source of
support they could not get otherwise. Review of the literature did not reveal any studies
that investigated the impact or correlation of attendance at diabetes camp with
performance of diabetes self-care.
Interactions with Peers/Others

This study expands upon the literature in regards to peer relations. Previous studies found that teens with diabetes often chose to do what their friends were without thinking about the effect on their diabetes (Dickinson & O’Reilly, 2004; Kyngas et al., 1998; Thomas et al., 1997). In this study, teens with good control identified circumstances where they struggled with situations where they had to choose to frequently perform blood glucose monitoring and insulin administration or eat like their peers. Frequently, teens in good control actively chose to wait to administer insulin when they were done snacking.

Previous studies found that teens with T1DM were conflicted about telling peers about their disease, recognizing the value and importance of being open with friends, but not wanting to reveal a difference at a time when being normal is expected (Christian et al., 1999; Meldman, 1987). Adolescents in this study, whether in good or poor glycemic control, also identified the inner struggle they faced in regards to telling others about having T1DM. They realized the importance of sharing the information with friends in order to garner support. However, they frequently dealt with intrusive behaviors and frequent questions by peers. These behaviors, such as trying to control what the teen eats or preventing them from eating until insulin has been administered, are a major source of frustration for the teen with T1DM as they feel they have enough people trying to control or hover over them. However, several teens identified that they were more accepting of intrusive behaviors when they were exhibited by friends than when their parents
exhibited the same behaviors. In addition to intrusive behaviors exhibited by peers, another possible explanation for the conflict associated with telling others relates to the societal misconceptions and misunderstandings about diabetes. Teens in this study described experiencing stigmatization because society associates having diabetes with obesity and poor diet. Further, some teens experienced mocking by peers, which could also relate to societal misunderstandings about the disease.

**Interactions with Healthcare Team**

Previous studies discovered that the adolescent’s interactions with the healthcare team can influence performance of diabetes self-care. Adolescents in previous studies identified being more likely to comply with the treatment regimen if physicians and nurses displayed interest in them as a person and if they felt they had a good relationship with the healthcare team (Carroll & Marrero, 2006; Davidson et al., 2004; Kyngas et al., 1998, Kyngas, 2007). Adolescents in this study did not specifically correlate performance of diabetes self-care with their relationship with the healthcare team. However, all teens were vocal about their frustrations with the physician. Teens with good glycemic control identified the physician as impersonal and detached. These teens wanted to be acknowledged as someone with valuable information and wanted to be included in decision making regarding the treatment regimen.

In this study, adolescents in good and poor control positively described their interactions with the nurses and nurse practitioners at the diabetes clinic. They were comforted that many of the nurses also have T1DM thus the participants trusted what the
nurses told them. Further, the teens felt the nurses had a better understanding of the difficulties they face with incorporation of the complex treatment regimen into their lives.

**Self-Care Program Development**

Currently there are no programs for older adolescents with T1DM in the area where this study was conducted. Thus this researcher felt it was important to ask the teens their opinion on this and to gain their input regarding an education and management program. Many teens in this study felt they did not need an education and management program. One explanation for this, for adolescents with good glycemic control, is that they have incorporated diabetes self-care as part of their daily lives and, for many, had been performing diabetes self-care for several years, thus had it under control and did not feel the need for additional education. For those participants with poor glycemic control, while they believed they did not need an education and management program, some expressed interest in being in a group with adolescents with good control as they felt they could learn ways to incorporate diabetes self-care into their lives and potentially improve their glycemic control.

When asked for their opinion regarding an education and management program, the participants in this study felt it would be more important to have a group for adolescents who were newly diagnosed. However, further discussion of this revealed that females thought a support group would be good as many had gained much from the focus group discussions.
Discussion of Research

Group Dynamics

This research study used six focus groups, three each for participants in good control and poor control. Of the six groups, two were mixed groups in which both males and females participated in the group. The first mixed group contained two females and two males in which one of the females seemed to dominate the conversation while one of the males was quiet. The moderator was able to draw out the quiet male in order to gain his perspective on the majority of topics. There were some challenges associated with moderating this first group that were discussed in the subsequent debriefing session and implemented as needed in subsequent focus groups. The second mixed group contained four females and one male who was somewhat quiet, but again, the moderator was able to draw him out and interesting information was obtained from him. He may have been more comfortable in the all-male, good control group, however, he participated in sports like some of the females thus they were able to relate to each other.

The first focus group contained only adolescents who used an insulin pump whereas adolescents who used an insulin pump were mixed with those who used multiple daily insulin injections in subsequent groups. It was initially thought that adolescents who used insulin injections would be envious of those who used pumps and experience negative feelings because they were not able to have the pump. Although specific questions that addressed this were not posed to participants, this did not appear to be the case. In one group, one participant who used injections asked questions of those who used a pump to gain information on their use.
Lastly, neither the focus group moderator nor the assistant moderator has T1DM which potentially could have affected interactions with the adolescent participants. Overall, this researcher does not believe this impacted the information shared by the participants except possibly with the all-male, poor control group. This group was fairly vocal that they did not trust physicians who did not have T1DM and were dismissive of anything they said regarding treatment decisions or about the adolescent and their poor control. This group was the most difficult to conduct, which could be associated with lack of trust. However, this did not seem to impact the discussions with the other focus groups.

**Challenges**

This research study posed many challenges for this researcher. The first challenge was associated with recruitment of participants. This researcher decided to only use the Children’s Diabetes Clinic for recruitment of adolescents since the list generated 220 potential participants. This researcher met with the clinic manager who asked that the study be presented to the staff thus this researcher attended a nursing and clinic staff meeting and the physician/nurse practitioner meeting. This researcher asked the clinic manager to hang the study flyer in exam rooms and, during presentation of the study at the staff meetings, asked staff to mention the study to potential participants. It was later discovered that the flyer was not posted in exam rooms, but rather on the desk where patients checked in with the receptionist. Further, due to busy schedules, staff did not refer to the study with clinic patients. The low response rate also presented a challenge for this researcher. Participants were not asked why they chose to respond to the
mailings, however a few volunteered that they nearly overlooked the research information letter(s) because they appeared to be a form letter from the clinic.

Scheduling of focus groups also presented a major challenge for this researcher. The participants in this study were busy with extracurricular activities, family obligations, and etc. The first group was held in February 2010 but subsequent groups were unable to be scheduled until November 2010 and the last in March 2011 because of the many scheduling difficulties. This researcher thought adolescents would be more available during the summer, however, this was not the case and they actually had more commitments that prevented scheduling of focus groups during this time.

Study Limitations

This study used an exploratory, focus group methodology. The nature of qualitative, focus group research does not lend itself to generalizability of findings. Generalization beyond the participants is further limited by the low response rate and the homogeneity of the participant population. Participants in this study were primarily white, living in two-parent households with an annual household income > $60,000.

In addition to the above, the size of the focus groups in this study created another limitation. It is recommended that focus groups contain six to eight participants (Morgan, 1998) which was not possible with this study due to the low response rate, difficulties in trying to schedule groups around the busy schedules of the adolescent participants, and adolescents who forgot to attend. Thus, the size of focus groups in this study ranged from two to five participants. Few difficulties were encountered in groups with four to five participants. The group in which the most difficulties were encountered was the all-male,
poor control group that included only three participants. There were many conversation lags during this focus group where the focus group moderator had to ask more probing questions than in other groups. In addition, the length of this group was approximately 20 minutes shorter than all other groups, including the poor control group with only two participants.

Another limitation associated with focus group research relates to the amount of data collected which makes summarization and interpretation of data difficult (Stewart et al., 2007). This study was no different. Additional study limitations related to time gaps for the transcription and analysis process. The nature of qualitative, exploratory research is dynamic such that focus groups should build on analysis of previous groups which was not possible because of time gaps; however the moderator was able to refer to field notes during subsequent focus groups and analysis team meetings. Member checking of generated themes was not conducted thus internal validity was impacted. But, at the end of each focus group, the moderator and this researcher reviewed themes heard during the group discussion with participants.

**Implications for Nursing**

Although generalizations cannot be made about older adolescents, 15 through 18 years, with T1DM, several implications for nurses can be made. First and foremost, all of the participants, whether in good or poor control, younger or older, want to be treated like an individual not the disease. Most of the adolescents recognize that the nurses’ and other healthcare professionals’ time is valuable but they believe it is important for all members of the healthcare team to treat the teen like a person who understands the importance of
T1DM. They recognize that they do not have as much knowledge about the disease, but do know their own body and how it responds in different situations and to different foods. Thus, the participants in this study expressed a strong desire to be treated like a person and to be included in treatment making decisions.

Most of the teens with poor glycemic control identified negative interactions with the physician and described feeling judged as a bad person because the numbers are not where they should be. Thus, they dislike going to clinic appointments. Further the teens in poor control were more dismissive of the physician and other staff who tried to tell them what to do but do not have diabetes themself. Part of the dismissiveness related to lack of "real world" knowledge but also the negative, judgmental demeanor expressed toward them. Similar to teens with good control, teens in poor control want to be viewed as a person and want to be included in treatment decision making. In contrast, they want nurses and other healthcare professionals to have a helpful, nonjudgmental attitude and to help them figure out how to incorporate diabetes self-care measures into their teenage lifestyle.

In the area where this study took place, there are no regular support groups for older adolescents. However, there has been an educational seminar arranged by the local Juvenile Diabetes Research Foundation office with breakout sessions designed for adolescents with diabetes. But, these occur infrequently and would require the adolescent to skip participation in other activities, such as sports, work, or hanging out with friends, all of which contributed to difficulties with scheduling focus groups for this study. Thus, some other support group method would be important to investigate further.
Implications for Research

The results of this study answered an important question - why are some older teens with T1DM able to maintain good glycemic control while others are not? Analysis of data from 6 focus groups (Good = 3, n = 13; Poor = 3, n = 8) revealed a difference in the way the teen views having T1DM and the necessary diabetes self-care. Finding out more specifics regarding this and how the teen came to this realization is important. Is there something about the teen's personality or interactions with others that contribute to how the teen views having diabetes? In addition, although one of the goals of this study was to determine what diabetes self-care is among older adolescents, the teens in this study struggled with this concept possibly because of the wording, but also equally possibly due to the fact that teens in good control have incorporated diabetes self-care activities into their daily life while teens in poor control often forget to perform diabetes self-care activities. Thus, further research, on a larger scale, needs to be conducted to determine what teens understand about diabetes self-care and specifically what they do to manage their T1DM.

Further research should be conducted with adolescents and emerging adults to study performance of diabetes self-care and their view about having T1DM. In addition, research using focus groups for adolescents and separate groups for their parents should be conducted to try to understand the teen-parent relationship, potential conflict or support, and correlation with the teen’s performance of diabetes self-care.

In addition, an intervention program led by an emerging adult with T1DM would be important to study to see if it improved performance of diabetes self-care measures.
The teens in this study felt it was important that a group be led by someone with the disease who understands the inherent difficulties. According to the information provided in this study, it appears the content of a program should include some education on how to make insulin and carbohydrate ratio adjustments. In addition, content on coping with the disease through the many life changes the adolescent will experience and time for social activities should also be included as components of a program for older adolescents with T1DM.

Lastly, other methods of communication and support for adolescents with T1DM should be investigated. Many adolescents use technology as a form of communication. Thus, support using online support groups should be investigated and outcomes compared with face-to-face support groups. Further, adolescents with T1DM must be involved in the development of education/management or support programs.

**Summary and Conclusions**

This study used an exploratory, focus group methodology to explore diabetes self-care among older adolescents, 15 through 18 years, with T1DM who exhibited good and poor glycemic control. The ultimate aim of this study was to try to understand why some adolescents with T1DM are able to maintain glycemic control (HbA1c < 7.5%) as recommended by the American Diabetes Association (2009) and others are not. Findings revolved around living with diabetes, diabetes self-care, interactions with teachers/coaches, parents, peers/friends, and the healthcare team. The most important finding to come out of this study was the way the adolescent with T1DM views having the disease and its complex treatment regimen. All of the participants identified
struggling with the complex treatment regimen and frustrations and interruptions in their lives. However, adolescents who exhibited good glycemic control demonstrated an acceptance of the disease as part of who they were as a person, thus diabetes self-care was part of their daily routine like brushing their teeth or taking a shower. In contrast, teens who exhibited poor glycemic control viewed having diabetes as a burden thus they often forgot to perform diabetes self-care activities and had to adjust their lifestyle to conform to the way they felt physically because of their poor control. Further research needs to be conducted to study this dynamic and factors that impact adolescent acceptance of the disease and incorporation of diabetes self-care into their daily life.

Further, healthcare professionals must develop a trusting relationship with these adolescents, one that recognizes the teen as an individual with valuable information and insight. Only by treating the adolescent with T1DM in a nonjudgmental manner and including them in treatment decisions will we be able to facilitate their acceptance of the diabetes diagnosis and its complex treatment regimen.
Dear Parent and Teen;

We are writing to invite you and your teen to participate in a research project being planned by Kelly K. Zinn, MSN, RN. Mrs. Zinn has been a nurse for 15 years and is interested in improving healthcare for teens with type 1 diabetes. The project is titled "An Exploration of Diabetes Self-Care among Older Adolescents with Type 1 Diabetes: A Focus Group Study." In order to better understand diabetes self-care and how older teens incorporate it into their normal lives, Mrs. Zinn plans to invite teens to discuss their diabetes self-care in small groups, which will take approximately two hours.

The Children's and University of Nebraska Medical Center Diabetes Clinic, Dr. Kevin Corley, and staff have approved this study. Our role is to make information available to families and teens to see if you are interested in participating. Your name and contact information is confidential. Mrs. Zinn does not have your name or contact information. Attached please find a letter from Mrs. Zinn providing more information about her study so you can decide if you and your teen would like to participate in the study. If you are interested in participating, you should contact Mrs. Zinn. Her contact information is included with this letter.

Mrs. Zinn is planning on having these groups meet within the next few weeks, and she would like to have your teen participate in one of the groups. We believe the information from this project will assist healthcare providers to better serve teens with type 1 diabetes. We hope you will consider joining.

Sincerely,

Kevin P. Corley, M.D.
Children's Diabetes and Endocrinology Clinic
Department of Pediatrics
University of Nebraska Medical Center

IRB Approved
Valid until 12-18-10
Dear Parent and Teen;

I have been a nurse for 15 years and teach nursing at Nebraska Methodist College. I am currently conducting a research project as part of my doctoral studies at Loyola University Chicago. I would like to invite you and your teen to participate in my project. The purpose of my study is to learn about diabetes self-care among older teens and how they incorporate it into their normal lives. For this study, older teens are at least 15 years old but have not reached their 19th birthday. The information gained in this project could inform healthcare practice or serve as the basis to develop a program to help teens with diabetes self-care with the ultimate goal of improving or preventing decreased metabolic control which could help delay or prevent diabetes-related complications.

I became interested in diabetes self-care among adolescents after my son was diagnosed with type 1 diabetes and demonstrated difficulties in performing the necessary activities. He has had difficulty incorporating the diabetes self-care activities into his daily life which has led to several episodes and hospitalizations related to diabetic ketoacidosis and chronic poor metabolic control. I would like to be able to help other teens learn how to incorporate the necessary diabetes self-care activities into their daily lives. This project is an important first step in reaching this goal.

In order to find out what teens think about diabetes self-care, I am holding several small group sessions, called focus groups, with older teens who have had type 1 diabetes for at least 6 months. There will be about 8 teens per group, along with a group moderator and myself. The sessions will last approximately 2 hours. Information discussed in these sessions will be audio taped and later typed out so that I can focus on everything the teens discuss during the session. My interpretation of these discussions will be written in a research report. All of the information from the groups and the demographic information sheet that I will ask your parents to complete is confidential; no names will be used in any reports. In addition, information from the teens contained in the research report will be general and will not focus on any one teen.

Several focus groups will be held within the next few weeks. If you are interested in participating, please contact me via phone or email. I will then contact you to discuss the project and answer any questions you or your teen have. If you and your teen decide to be a part of this study, I will schedule your teen into a focus group at a day, time, and location that is convenient for you. The focus group sessions will contain teens 15 to 18 years, but will be separated according to your teen’s latest HbA1c. The purpose of dividing in this manner is to decrease the potential of emotional distress. In
addition, I suspect there are different issues between adolescents according to their level of metabolic control. In order to determine which group would be appropriate for your teen to attend, I will ask for permission to get his/her latest HbA1c from the Diabetes Clinic. In order to keep your information confidential, codes will be assigned to teen’s who will be participating in the study.

The focus group session will last about two hours, beginning with time for socialization among the teens. There will be an area for parents to wait for your teen if you wish and free parking will be provided. Refreshments will also be available for teens. Teens who participate in a focus group will be offered a $15 gift card as a thank you for participating.

If you or your teen are interested in participating in the teen type 1 diabetes focus groups, or you would like more information, please contact me at 402-599-3207 or email me at kkzinn@yahoo.com or you may simply return the enclosed self-addressed, stamped card. I will contact you to tell you more about the project and schedule a group if you would like to participate. Once we have talked further about the project and you and your teen have decided to participate, I will send you the forms that will be needed for the study. This will include a parental permission form, teen agreement form, and a type 1 diabetes information form.

I hope to hear from you soon.

Sincerely,

Kelly K. Zinn, MSN, RN
Cell: 402-599-3207
kkzinn@yahoo.com
ATTENTION TEENS !!

YOUR HELP IS NEEDED FOR A RESEARCH PROJECT ABOUT TEENS WITH TYPE 1 DIABETES

PURPOSE: To learn about diabetes self-care among older adolescents and how they incorporate its requirements into their daily lives.

WHO: Teens, 15 through 18 years of age, with type 1 diabetes

WHAT: Teens join a small group of other teens to talk about their diabetes self-care

HOW LONG WILL IT TAKE? Only 2 hours of your time (at a time convenient for you and your parents)

WHAT'S IN IT FOR ME?
- It will be fun – refreshments provided.
- Opportunity to talk with other teens about having diabetes.
- You may choose a gift card as a Thank You for being in the group.
- You may help doctors and nurses understand what works best for you.
- You may contribute to the development of a program to help teens like you.

HOW DO I JOIN?
Contact: Kelly Zinn
402-599-3207
Email: kkezinn@yahoo.com
APPENDIX B

PHONE SCREENING SCRIPT
An Exploration of Diabetes Self-Care among Older Adolescents with Type 1 Diabetes: A Focus Group Study (UNMC IRB #540-09-EP)

TENTATIVE SCRIPT FOR TELEPHONE CALLS FROM INTERESTED PARTICIPANTS

Hello. May I speak with _______?

Yes, this is ____________.

My name is Kelly Zinn and I am calling you since you had expressed interest in my research study on the diabetes self-care of older adolescents with type 1 diabetes.

Is this a good time to talk about the study? It will take about 15-20 minutes.

Yes. (If no, ask them when would be a convenient time) and best phone number.

We know that type 1 diabetes is a very serious disease that can lead to chronic diseases, such as heart disease and blindness. We also know that older adolescents, 15 through 18 years old, are more likely to exhibit poor metabolic control than other age groups which increases their risk for development of diabetes-related complications. I am doing a study to learn about diabetes self-care among older teens and how they incorporate it into their normal lives. Research has been done regarding diabetes self-care among adolescents. But, there has not been any research asking adolescents about the disease and its treatment regimen. The information gained in this project could inform healthcare practice or serve as the basis to develop a program to help teens with diabetes self-care with the ultimate goal of improving or preventing decreased metabolic control which could help delay or prevent diabetes-related complications.

The study will require that your teen participate in one focus group session that is convenient for your and/or his/her schedule. The focus group session will last approximately 1 ½ to 2 hours during which 6 to 8 teens will share what it’s like to have type 1 diabetes and its impact on their life.

Does this sound of interest to you?

Yes. (If no, ask them why not, and thank them for their time)

In order to participate in the study, I need to ask you some questions. Some are personal and this information will not be shared with others.
1. **How old is your teen?** ________ **What is his/her birthdate?** ________
   (Must be 15 through 18 years, but have not reached their 19th birthday.)

2. **How long has your teen had diabetes?** ________
   (Must have diabetes for at least 6 months)

3. **Does your teen have a developmental disability?**
   Yes _____ No _____
   (Must not have cognitive or developmental disability.)

4. **Does your teen currently have any other physical or psychologic conditions other than diabetes?** Yes _____ No ______
   If yes, what are they? (Must not have a chronic illness that requires daily treatment.)

If the individual does not meet the above criteria, thank them for their interest in the study, and ask if you can have their phone number and address to share information about future studies.

If the individual meets the above criteria: **Thank you for your interest and time. I would like to schedule a time to meet with you and your teen to discuss further details regarding the study. If you and your teen are interested in participating in this study, I will ask you to complete a demographic questionnaire, diabetes questionnaire, and to sign consent/assent forms. At that time, I will schedule your teen for participation in a focus group session that is convenient for your schedules.**

_I greatly appreciate the time that you have given to talk to me. Do you have any questions?_

(If yes, then the questions will be answered before closing.)
APPENDIX C
PARENTAL CONSENT FORM
PARENTAL CONSENT FORM

Title of this Research Study

AN EXPLORATION OF DIABETES SELF-CARE AMONG OLDER ADOLESCENTS WITH TYPE 1 DIABETES: A FOCUS GROUP STUDY

Invitation

You are invited to allow your teen to take part in this research study. The information in this form is meant to help you decide whether or not to allow your teen to take part. If you have any questions, please ask.

Why is your teen being asked to be in this research study?

This study is being conducted to gain knowledge of diabetes self-care among older teens, 15 through 18 years of age. Your teen is being asked to participate in this study because he/she is 15 through 18 years of age and has been diagnosed with type 1 diabetes for at least 3 months.

What is the reason for doing this research study?

The purpose of this study is to explore 1) how adolescents manage their life with type 1 diabetes, 2) what makes up diabetes self-care among older adolescents, 3) successes or frustrations regarding incorporating the diabetes treatment regimen into their life, 4) the most difficult aspect of living with type 1 diabetes, and 5) what adolescents recommend be included in a diabetes self-care program.

What will be done during this research study?

Your teen will be asked to complete a questionnaire regarding his/her diabetes self-care and general information about his/her lifestyle. Your teen will then be asked to participate in a focus group consisting of 6 to 10 teens for a discussion of diabetes self-care and its impact on their life. The focus group will be conducted by a moderator. The interview will last approximately 1 1/4 hours.

The discussion will be recorded and then transcribed. The recordings will be shared with members of the research team and the dissertation committee to generate the research data. Your teen’s first name will be included in the recordings, however, your teen’s last name and any identifying information about them will not. The recordings will be erased after the data has been transcribed and checked which should take no longer than one year.

What are the possible risks of being in this research study?

There are minimal risks associated with the study. There is no physical harm that will endanger the teen who participates in this study. However, there is a potential risk of emotional distress due to the nature of the interaction and the sharing of personal thoughts, feelings, and things that have happened to them. If you or your teen decides they would like to further discuss their findings, a resource sheet about counseling services can be provided.

Consent Version: CON-MR 0010 (Rev. 7/08)

RB Approved
Valid until 12-16-10

CONSENT FORM

CONSENT

Initials: ________
What are the possible benefits to your teen?

Your teen may not get any benefit from being in this research study. But, the interaction with other teens with type 1 diabetes may help them see they are not alone. Further, there is a potential for establishing new friendships or support systems if your teen chooses to share contact information with others after the focus group session is completed.

What are the possible benefits to other people?

The information provided by your teen may advance knowledge of diabetes self-care among older adolescents that may lead to changes in practice for future patients. Also, the information from this study may be used to develop a program to assist teens with type 1 diabetes in incorporating diabetes self-care into their lives and prevent decreased performance of diabetes self-care and decrease their risk for poor metabolic control.

What are the alternatives to being in this research study?

Instead of being in this research study you can choose that your teen not participate.

What will your teen being in this research study cost you?

There is no cost to you to have your teen be in this research study.

Will you or your teen be paid for being in this research study?

After participation in a focus group, your teen will receive a $15 gift card as a thank you for participating in this project.

Who is paying for this research?

The costs associated with this research study are being paid by Kelly K. Zinn, MSN, RN.

What should you do if your teen is injured or has a medical problem during this research study?

If your teen is injured or has a medical problem as a result of being in this study, you should immediately contact one of the people listed at the end of this consent form.

How will information about your teen be protected?

You have rights regarding the privacy of your teen’s medical information collected before and during this research. This medical information, called “protected health information” (PHI), typically may include, depending upon the nature of this research, demographic information (like your teen’s address and birth date), the results of physical exams, blood tests, x-rays and other diagnostic and medical procedures, as well as your teen’s medical history.

By signing this consent form, you are allowing the research team to have access to your teen’s PHI. The research team includes the investigators listed on this consent form and other personnel involved in this specific study at UNMC, The Nebraska Medical Center and Tenam’s Hospital and Medical Center.

Your teen’s PHI will be used only for the purpose(s) described in the section “What is the reason for doing this research study?”

Consent Version: I3 Approved
Valid until 12-16-10
Initials ________
What are the possible benefits to your teen?

Your teen may not get any benefit from being in this research study. But, the interaction with other teens with type 1 diabetes may help them see they are not alone. Further, there is a potential for establishing new friendships or support systems if your teen chooses to share contact information with others after the focus group session is completed.

What are the possible benefits to other people?

The information provided by your teen may advance knowledge of diabetes self-care among older adolescents that may lead to changes in practice for future patients. Also, the information from this study may be used to develop a program to assist teens with type 1 diabetes with incorporating diabetes self-care into their lives and prevent decreased performance of diabetes self-care and decrease their risk for poor metabolic control.

What are the alternatives to being in this research study?

Instead of being in this research study you can choose that your teen not participate.

What will your teen be doing in this research study cost you?

There is no cost to you to have your teen be in this research study.

Will you or your teen be paid for being in this research study?

After participation in a focus group, your teen will receive a $15 gift card as a thank you for participating in this project.

Who is paying for this research?

The costs associated with this research study are being paid by Kelly K. Zinn, MSN, RN.

What should you do if your teen is injured or has a medical problem during this research study?

If your teen is injured or has a medical problem as a result of being in this study, you should immediately contact one of the people listed at the end of this consent form.

How will information about your teen be protected?

You have rights regarding the privacy of your teen's medical information collected before and during this research. This medical information, called "protected health information" (PHI), typically may include, depending upon the nature of this research, demographic information (like your teen's address and birth date), the results of physical exams, blood tests, x-rays and other diagnostic and medical procedures, as well as your teen's medical history.

By signing this consent form, you are allowing the research team to have access to your teen's PHI. The research team includes the investigators listed on this consent form and other personnel involved in this specific study at UNMC, the Nebraska Medical Center and Children's Hospital and Medical Center.

Your teen's PHI will be used only for the purpose(s) described in the section "What is the reason for doing this research study?"

Consent Version: R3 Approved
Valid until 12/15/10

Initials ________
PARENTAL CONSENT FORM

Your teen's PHI will be shared, as necessary, with the Institutional Review Board (IRB) and with any person or agency required by law. You are also allowing the research team to share your teen's PHI with other people or groups listed below. All of these persons or groups listed below are obligated to protect your teen's PHI.

You are authorizing us to use and disclose your teen's PHI for as long as the research study is being conducted.

You may cancel your authorization for further collection of PHI for use in this research at any time by contacting the principal investigator in writing. However, the PHI which is included in the research data obtained to date may still be used. If you cancel this authorization, your teen will no longer be able to participate in this research.

The results of clinical tests and therapy performed as part of this research may be included in your medical record. The information from this study may be published in scientific journals or presented at scientific meetings. Your teen's identity will be kept strictly confidential.

What are your teen's rights as a research subject?

Your teen has rights as a research subject, and you have rights as the parent of a research subject. These rights have been explained in this consent form and in The Rights of Research Subjects that you have been given. If you have any questions concerning your rights or complaints about the research, talk to the investigator or contact the Institutional Review Board (IRB) by:

- Telephone: (402) 559-6485
- Email: IRB0RA@unmc.edu
- Mail: UNMC Institutional Review Board, 987830 Nebraska Medical Center, Omaha, NE 68198-7830

What will happen if you decide not to allow your teen to be in this research study?

You can decide not to allow your teen to be in this research study. Deciding not to allow your teen to be in this research study will not affect his/her medical care or his/her relationship with the investigator, the University of Nebraska Medical Center, the Nebraska Medical Center or the Children's Hospital and Medical Center. The doctor will still take care of your teen and he/she will not lose any benefits to which he/she is entitled.

What will happen if you decide to have your teen stop participating once he/she has started?

Your teen can stop being in this research study (withdraw) at any time before, during, or after the research begins. The doctor will still take care of your teen. Deciding to withdraw will otherwise not affect your teen's care or your teen's relationship with the investigator, the University of Nebraska Medical Center, The Nebraska Medical Center or the Children's Hospital and Medical Center. Your teen will not lose any benefits to which he/she is entitled.

Your teen may be taken off the study if he/she doesn't follow instructions of the investigator or the research team.

Consent Variants: 

CON-IRB-0019 (Rev. 7/09) 

Initials __________

CONSENT FORM

CONSENT
If the research team gets any new information during this research study that may affect whether you would want to continue being in the study you will be informed promptly.

Documentation of informed consent

You are freely making a decision whether to allow your teen to be in this research study. Signing this form means that (1) you have read and understood this consent form, (2) you have had the consent form explained to you, (3) you have had your questions answered and (4) you have decided to have your teen be in the research study.

If you have any questions during the study, you should talk to one of the investigators listed below. You will be given a copy of this consent form to keep.

Signature of Parent: ___________________________ Date: ___________ Time: ___________

You are agreeing to be in this research study. You have had someone explain the study to you, and answer your questions.

Signature of Subject: ___________________________ Date: ___________ Time: ___________

My signature certifies that all the elements of informed consent described on this consent form have been explained fully to the subject’s parent and, as appropriate, the subject. In my judgment, the parent possesses the legal capacity to give informed consent to have the teen participate in this research and is voluntarily and knowingly giving informed consent to participate.

Signature of Person obtaining consent: ___________________________ Date: ___________

Authorized Study Personnel

Principal Investigator: Kelly K. Zinn, MSN, RN (402-599-5207)

Consent Version: ________________  IRB Approved  ______/____/____  Valid until 12/18/10

Initials: ___________________________
You are being invited to take part in this research study. The information in this consent form is meant to help you decide whether or not to take part. If you have any questions, please ask.

You are eligible to participate in this research study because you are 15 through 18 years of age and have had type 1 diabetes for at least 6 months.

The goal of this study is to collect information regarding diabetes self-care among older teens to develop a better understanding of diabetes self-care among older teens and how they incorporate the necessary diabetes self-care activities into their normal lives as teenagers.

You will participate in a focus group with other teens to discuss diabetes self-care and its impact on your life. Your parents will complete a questionnaire providing demographic information (age, race, gender, etc.) and information about your type 1 diabetes.

Participation in the focus group discussion will not cause you any physical harm but minimal emotional discomfort may occur.

After you have participated in the focus group discussion, you will be given a gift card as a thank you for participating in this research study.

You may not get any direct benefit from being in this research study. We hope the information learned will benefit other teens with type 1 diabetes in the future.
APPENDIX E

DEMOGRAPHIC AND DIABETES QUESTIONNAIRE
DEMOGRAPHIC AND DIABETES QUESTIONNAIRE
An Exploration of Diabetes Self-Care among Older Adolescents with Type 1 Diabetes: A Focus Group Study

The following requested information will assist with data collection and analysis. All information you provide will be kept confidential and in a locked file cabinet in the researcher’s office. Only the researcher and dissertation committee will have access to the information.

Name: ______________________________________________________________

Parents’ Name(s):_____________________________________________________

Address: ____________________________________________________________

Phone Number(s): __________________________

Email: ________________________________

Demographic Information:

Gender: _______ Date of Birth: _________

Family Composition: Parents (1 or 2) _________

Siblings (gender & age only, no names) ___________________________________

Race/Ethnicity: □ Caucasian (White)
□ African-American
□ Hispanic
□ Other: ____________________________

Approximate Household Income:
□ < $20,000
□ $20,001 to $40,000
□ $40,001 to $60,000
□ > $60,001

Do you participate in any extra-curricular activities (e.g., sports, band, other school activities)?
Do you have a job? □ Yes □ No

Where? ____________________________

How many hours per week (on average)? __________

How much time do you spend away from home on a usual school day? Weekend day?

**Diabetes Information:**

At what age were you diagnosed with type 1 diabetes? __________

What was your most recent HbA1c? ________ When was this? __________

In the last 6 months, have you had any periods of high or low blood sugar? If yes, please identify frequency for each and highest or lowest blood sugar.

Have you missed school because of diabetes in the last year? If yes, how many days?

Have you visited the emergency room because of diabetes in the last year? If yes, how many visits?

Have you had any overnight hospital stays because of diabetes in the last year? If yes, how many & how long was each stay?

Please describe the treatment regimen recommended by your health care provider:
(#/shots or insulin pump, insulin regimen, #/blood glucose checks per day or continuous glucose monitor)

Are you primarily responsible for the daily diabetes management tasks? Which tasks?

Do your parent(s) assist with or perform any daily diabetes management activities? Which ones?
An Exploration of Diabetes Self-Care among Older Adolescents with Type 1 Diabetes: A Focus Group Study (UNMC IRB #540-09-EP)

FOCUS GROUP MODERATOR GUIDE

(As you greet the focus group participants, ask them to write their FIRST name only on a place card. Also ask them to introduce themselves to each other – and tell them they will be introducing the person that sits next to them, and tell something they like to do for fun.)

Introduction (10 minutes)

MODERATOR: “I’d like to welcome you to this focus group session. Thank you for coming. Your participation in this group is very important, and we appreciate your coming here today. We have asked you to come here today because we need your help with a research project. The goal of this project is to develop a better understanding of diabetes self-care among older adolescents and how they integrate the necessary diabetes self-care activities into their normal lives as adolescents. Diabetes self-care refers to the activities necessary to control type 1 diabetes and decrease the risk for diabetes-related complications. The four main areas that make up diabetes self-care include: insulin administration, blood glucose monitoring, dietary modifications, and exercise. When you answer the questions, please consider these areas and how they relate to your activities and interactions with others.

My name is ______________ and I will be leading our discussion today. Also present is Kelly Zinn, the researcher for this study. She will be taking notes throughout this discussion and may participate in the discussion.

This study is being conducted by Kelly Zinn who is a doctoral student at Loyola University Chicago. This research project is part of her doctoral studies. Mrs. Zinn became interested in diabetes self-care among adolescents with type 1 diabetes after her son was diagnosed with the disease at age 16. He has had difficulty incorporating the diabetes self-care activities into his life and, as such, exhibits chronic poor metabolic control. The information you provide today may assist Mrs. Zinn in helping other adolescents with type 1 diabetes.

There are several parts to what we will be doing today. First, we are interested in finding out how you include the type 1 diabetes treatment regimen into your life and any successes or frustrations you have experienced. Second, we would like to talk about what you think would be important to include in a program to help adolescents with type 1
diabetes live better with the disease and incorporate its treatment regimen into their life and how that program should be carried out.

We realize that having type 1 diabetes and including its treatment regimen is challenging. Thus, we would really like to know everything about how the disease and its treatment challenge you. You are the experts, and we would like to know what YOU think. We are not judging you or anything that is said today. There may be something innovative that you are doing that others are not. There are no right or wrong answers, so please feel free to say whatever you like. This group discussion will last about 1 1/2 hours.”

Ground Rules for the Discussion

**MODERATOR:** “Before we get started, I would like to go over a few ground rules for our discussion:

1. In our discussion, we want to know what everyone in the group thinks. Mrs. Zinn and I will be taking notes while we talk. It will help me if only one person talks at a time, and we need to make sure that everyone gets a chance to talk. Even if you have an opinion that is different from other people, it is important to tell me about it. In fact, I especially need to know when there are different opinions or when people don’t agree. You don’t need to answer any questions that you don’t want to, and, if you become uncomfortable, you can leave the room at any time.

2. We will be recording your voices on tape – no pictures, just voices. The tape recording will help us to remember exactly what was said during our discussion. So I need you to speak clearly so that the tape can pick up your voice. If you feel uncomfortable, let me know, and we can stop the tape recording. The tape will be transcribed onto paper and be reviewed by the researchers of this project. But your names won’t be included. Later the tape will be erased.

3. The things that the focus group members say here should stay in this room. After you leave, I need to ask you not to talk about anything that was said in this room.”

**MODERATOR:** “Prior to attending this focus group, Mrs. Zinn reviewed the consent forms that described what this focus group is about as well as your rights as a research participant with you and your parents. In order to participate in this focus group you and your parents must have completed a consent form and submitted it to Mrs. Zinn. Before we begin the discussion, does anyone have any questions regarding this research project and your participation?”

“Let’s now go around the group and introduce ourselves Please tell us your first name - first name only - and one thing that you like to do for fun. I will start. My name is_____ and I like to ______”

**PART 1: Adolescent life with type 1 diabetes (50 minutes)**

**MODERATOR:** “The primary purpose of our meeting is to learn about the life of older adolescents with type 1 diabetes, including daily diabetes management activities, success
or frustrations, and the most difficult thing about having diabetes. Let’s start with your life as a teenager with type 1 diabetes.”

1. Please tell me about your life as a teenager who has type 1 diabetes. (Probe: What types of things do you do everyday to take care of your diabetes? What successes or frustrations regarding incorporating the diabetes treatment regimen into your life as an adolescent have you had? What is the most difficult aspect of living with type 1 diabetes?)
   a. What are some positives associated with having type 1 diabetes?
   b. What are some negatives associated with having type 1 diabetes?

2. Now, please tell me about what it’s like with your… (Probe: including positives and negatives)
   c. Parents
   d. Teachers/coaches
   e. Peers/friends

3. Now, I’d like to know about your interactions with the health care team, including positives and negatives. (Probe: How do you feel about the healthcare team [doctors, nurses, social worker, and/or dietician? How are treatment decisions made?)

4. Sometimes teens know different ways to do things [i.e. insulin administration, blood glucose checking, diet, exercise]. After you were told what you should do to manage your type 1 diabetes, how did you make it work for you?

Examples of probing questions:

- Can you tell me more about that?
- Can you explain that (why or why not)?
- Does anyone have a different experience/opinion?
- Using synonyms for questions not understood or alternate form questions.
- Use phrases supplied by the teens.

PART 2. Developing a Program (10 minutes)

MODERATOR: “Now that we have information regarding the life of older adolescents with type 1 diabetes, we would like your input regarding an education and management program for teens like you.”

1. What would you like to learn about your diabetes and how to take care of yourself? (Probe: For example, stress management, communication or coping skills, or something else.)
2. How would you like to learn? (e.g., Lecture with discussion, reading literature, watching videos, listening to audiotapes, working on the computer, or other ways.)

3. How would you like to have the program offered? Where would you like to meet?

4. What would make you want to come?

5. What would prevent you from coming?

Summary and Closing (15 Minutes)
MODERATOR: “We would like to thank you for sharing your thoughts with us today”.

These are some of the themes/main points you shared: (summarize discussion)
   Is there anything we missed?

If 2nd or subsequent group, these are some additional themes from previous groups: (briefly provide themes from previous groups that are different from this group). What are your thoughts regarding these?

Is there anything more that you would like to share with us about your experiences?

“Thank you for taking time to participate in this research study. If you have any questions, please contact Kelly Zinn. Her contact information is on the [board?]”
APPENDIX G

RESEARCH APPROVAL DOCUMENTS
December 24, 2009

Kelly Zinn
424 G County Road D
Tekamah, NE 68061

IRB # 540-09-EP

TITLE OF PROPOSAL: An Exploration of Diabetes Self-Care Among Older Adolescents with Type 1 Diabetes

DATE OF EXPEDITED REVIEW: 12-18-09
DATE OF FINAL APPROVAL: 12-24-09
VALID UNTIL: 12-18-10

EXPEDITED CATEGORY OF REVIEW: 45 CFR 46.110; 21 CFR 56.110, Category 5 and 7

SUBPART B, C, AND/OR D CATEGORY OF REVIEW: Subpart D category 46.404

The Institutional Review Board (IRB) for the Protection of Human Subjects has completed its review of the above-titled protocol, including any revised material submitted in response to the IRB’s review. The IRB has expressed its approval of the protocol and consent forms after reviewing the proposal in compliance with 45 CFR 46.110; 21 CFR 56.110, and the institution’s HRPP Policies and you have provided adequate safeguards for protecting the rights and welfare of the subjects to be involved in this study. This letter constitutes official notification of the final uncondition approval and release of your project by the IRB, and you are authorized to implement this study as of the above date of final approval.

Please be advised that only the IRB approved and stamped consent forms or consent assent forms can be used to make copies to enroll subjects. Also, at the time of consent all subjects/legal authorized representatives (LARs) must sign a copy of The Rights of Research Subject and “What Do I Need to Know?” forms. The IRB wishes to remind you that the PI is responsible for ensuring that all legally and ethically sound informed consent has been obtained from all research subjects.

Finally, under the provisions of this institution’s Federal Wide Assurance (FWA00002039), the PI is directly responsible for submitting to the IRB any proposed change in the research or the consent/assent document(s). In addition, any adverse events and unanticipated problems involving risk to the subject or others must be promptly reported to the IRB.

In accordance with HRPP Policy, this project is subject to periodic review and surveillance by the IRB and, as part of their surveillance, the IRB may request periodic progress reports. For projects which continue beyond one year, it is the responsibility of the PI to initiate a request to the IRB for continuing review and update of the research project.

Sincerely,

Ernest D. Prentice, Ph.D.
Executive Chair, IRB

ECPI dqdk
NOTICE OF FULL APPROVAL OF A RESEARCH PROJECT
Date: 12/28/2009

Investigator: RVELSOR

LU Number: 202166

TITLE: An Exploration of Diabetes Self-Care among Older Adolescents with Type 1 Diabetes: A Focus Group Study

Dear Investigator,

The above-referenced research project was given Full Approval by the Institutional Review Board on 12/28/2009.

YOUR PROJECT MAY NOW BEGIN.

Results from the Board Review and required conditions applied to the project can be accessed through the online Research Portal.

The following is for your information and will help you meet local and federal IRB requirements.

1. You must use the final IRB-approved version of the Consent Document. Spelling and grammatical changes may be made as necessary, but any other changes require prior review and approval.

2. You are required to maintain complete records of this project. Any changes in the protocol and the Consent Document must receive prior IRB approval. Use the online Research Portal's Project Amendment form to report changes. A change to the protocol necessary for the immediate safety and welfare of a research participant may be implemented prior to IRB review and approval.

3. Federal Regulations require that projects undergo periodic review of research activity at least once a year. This review must be substantive. The frequency of review and next scheduled date of periodic review for your project can be found under the "Annual Review" tab in the Research Portal's IRB section.

You will receive notification 4-8 weeks prior to the scheduled date of review. At that time, you must provide information regarding the status of the project.

If the information is not received, the project will be suspended. It is important that you not let approval lapse.
4. The IRB must be notified any time that the project temporarily or permanently stops enrolling participants along with the reason. Use the online Closure form to submit these notifications.

5. Any notices or advertisements soliciting participation must receive prior IRB approval. Use the online Amendment reporting form.

6. The IRB must be notified PROMPTLY of all serious and any unanticipated adverse events associated with the project (or the device or the drug). This includes any notification received of adverse events occurring at other performance sites. Further guidance on adverse event reporting may be found at the Office for Human Research Protections web site; http://www.hhs.gov/ohrp/policy/AdvEvntGuid.htm#Q5

Reportable events include, but are not limited to:
   a) a serious adverse event (including events that produce injury or death, an event leading to hospitalization or lead to prolongation of a current hospital stay);
   b) the enrollment of a patient on a study that is no longer enrolling participants;
   c) pregnancy occurring on the study where the study excludes pregnancy;
   d) any patient reporting a billing problem as a result of project participation;
   e) any participant who has voiced a complaint about some aspect of the project or the consent document;
   f) any unanticipated, untoward, or unexpected adverse event not covered above including rare adverse events or adverse events that occur at an unexpected rate
   g) protocol deviations
   h) investigational drug/device brochures, revisions

Adverse Protocol Events are reported through the online Research Portal.

7. The IRB may suspend the project to new participant enrollment or may suspend the participation of current subjects if there is a perceived safety and/or regulatory issue.

8. Prospective consent must be obtained from all research participants.

9. The IRB may review your records relating to this project, including signed consent documents.

10. The Institutional Review Board of Loyola University Medical Center is appropriately constituted and has been granted Federal Wide Assurance Number FWA00009471 (Effective Dates: 12/13/2005 - 12/13/2008).
11. If you are unsure of your reporting requirements or of what is expected of you during the conduct of this research, please call the IRB Office (708-216-4608) or Dr. Kenneth Micetich (708-327-3144).

12. The Loyola Institutional Review Board is appropriately constituted as stipulated in 45cfr46 and is in compliance with Good Clinical Practice Guidelines insofar as those guidelines are consistent with the U.S. Food and Drug Administration regulations (21 CFR Parts 50 and 56) and the Department of Health and Human Services regulations (45 CFR 46) pertaining to the protection of human subjects in research.

Thank you for your cooperation.

Kenneth Craig Micetich, M.D.
Chairman, Institutional Review Board for the Protection of Human Subjects
Loyola University Medical Center
REFERENCES


Hanson, C. L., Henggeler, S. W., & Burghen, G. A. (1987). Model of associations between psychosocial variables and health-outcome measures of adolescents with IDDM. *Diabetes Care, 10*(6), 752-758.


VITA

Kelly K. Zinn graduated in 1995 with a Bachelor of Science degree in Nursing from Clarkson College in Omaha, Nebraska. She worked as a staff nurse from 1995 until 2002 finishing as a pediatric nurse. She also worked as a private duty nurse for children with special needs from 1997 until 2002. In 2001, Mrs. Zinn graduated with a Master’s Degree in Nursing with a focus on Pediatrics from the University of Nebraska Medical Center in Omaha, Nebraska. She worked as a clinical instructor for Children’s Hospital in Omaha, Nebraska from 2001 to 2002 and was an Assistant Professor in the Bachelor’s of Science in Nursing program at Clarkson College in Omaha, Nebraska. She transferred to Nebraska Methodist College in Omaha, Nebraska in 2007, where she is currently employed, teaching as an Assistant Professor for the Bachelor’s of Science in Nursing program, RN-BSN completion program, and Master’s of Science in Nursing program. Mrs. Zinn began her doctoral studies at Loyola University Chicago in 2006. Mrs. Zinn resides in Tekamah, Nebraska.