ASSESSING HEALTH-SEEKING BEHAVIORS OF RURAL YOUTH WITH TYPE 1 DIABETES THROUGH PARTICIPATORY ACTION RESEARCH

By

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ABSTRACT

Type 1 diabetes mellitus (T1DM) occurs in 1 in 400 children and is most prevalent among rural, non-Hispanic whites (SEARCH, 2004, 2006; CDC, 2009). Growth and hormonal changes during puberty can cause insulin resistance, a reaction that makes it difficult for adolescents to maintain optimal glycemic control. Adolescents typically have poorer glycemic control with HgbA1c blood levels of 1% or higher than most adults, thus increasing complications. Poor glycemic control accounts for ten percent of the health care economic burden and short-term hospitalizations for 18 to 44 year-olds with diabetes, ranking fourth behind child birth, mental health issues, and injury (CDC, 2006; Kaiser, 2003).

This study addresses following questions: “What does it mean to be healthy while living with a chronic disease such as T1DM in a rural community?” “What are positive health-seeking behaviors an adolescent with T1DM needs to display to reflect health?” What support do adolescents with T1DM require to be independent in successful management of their chronic illness?”

The study reveals that, for adolescents, “being healthy” means successfully completing medical tasks that prevent negative symptoms, “no nausea, and no shakiness.” Positive health-seeking behaviors reflect these tasks: eating properly, exercising, checking blood sugars regularly, and using insulin appropriately. Adolescents
value face-to-face time with a known health care provider and report needing information at the time questions arise rather than waiting for scheduled appointments or contacting health care providers through social media.

The study also illuminates the adolescent’s perspective on living in a rural area with T1DM. First, adolescents value face-to-face time with their health care provider. Second, adolescents value and perceive as essential the support they receive from a primary family member who reminds them of their many daily task-management activities. Third, adolescents do not view living in a rural area a burden, and they value the time with a family member during travel to health care appointments.

The form and content of this abstract are approved. I recommend its publication.

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CHAPTER I

INTRODUCTION

Chapter I focuses on the impact of diabetes in rural adolescents. I describe the challenges of maintaining health with type 1 diabetes mellitus (T1DM) as a chronic health condition, and I identify the challenges adolescents face as they manage their own health. The transitional period of adolescence is a developmental risk factor. I also discuss the impact T1DM may have on the adolescent in a rural geographical area, including the additional barriers adolescents face as they try to manage living with T1DM.

Introduction to Problem

This study describes the needs and health-seeking behaviors of adolescents in rural Colorado and identifies concepts they view as important in their daily management of diabetes. Health care professionals are keenly aware of several issues related to adolescents who must seek medical assistance: a) enhancing or maintaining self-management behaviors; b) identifying opportunities perceived as gaps in health care, including control of T1DM as a chronic disease; c) identifying health-seeking behaviors that are present in adolescents who feel they have stable glycemic control, and d) exploring independent behaviors which lead to positive self-management of their chronic disease. This study addresses the knowledge that complications of mismanaging diabetes during adolescence profoundly affect young adults with diabetes. For example, short-term hospitalizations for 18 to 44 year-old young adults with diabetes ranks fourth behind childbirth, mental health issues, and injury (Diabetes, CDC/cdc.gov., 2006; Kaiser, 2008). A range of factors influence adolescents’ decisions about whether to
adhere to treatment, including knowledge about their condition, the social support they receive, the quality of their relationships with health professionals, and the complexity or burden of their treatment regimen (Fotheringham & Sawyer, 1995; Diabetes Control and Complications Trial (DCCT) 1995; 2000). The situation requires research to address the reasons adolescents in rural areas do or do not adhere to a treatment plan during the transitional period to adulthood.

Health care providers report a decline in diabetic complications in many areas when medical institutions provide specialized pediatric endocrinology clinics and when a collective environment provides centralized specialty care for children with T1DM (Donaghue, Chiarelli, Trotta, Allgrove, & Dahl-Jorgensen, 2009). Declines in complications also occur when providers make major changes in diabetes management, improve identification of risk factors, and institute regular screening for complications. However, no evidence exists demonstrating that this improvement in care is a worldwide occurrence. For example, in rural areas where health care resources are often limited, complication risks from diabetes do not change (Donaghue, Chiarelli, Trotta, Allgrove, & Dahl-Jorgensen, 2009). As a result, we need to evaluate barriers and facilitating factors that influence adolescents’ access to health care, especially in rural areas where specialty clinics are often nonexistent.

In rural areas of western Colorado, medically underserved areas limit specialty clinics and specialized diabetes care teams. For example, Mesa, Delta, and Montrose counties are designated medically-underserved counties for low-income populations (hpsafind.HRSA.gov., 2011). The goals to improve health care outcomes of all patients, including adolescents with T1DM, are important but often unattainable with the limited
resources. The purpose of this study is to identify perceived gaps adolescents encounter in rural settings, as they become independent young adults managing a burdensome chronic illness (CDC. 2006; Kaiser, 2003). The knowledge gained from the study will improve program design and address the unique needs of the rural adolescents with T1DM.

Aims of the Study

My research has several goals:

1. Explore the health-seeking behaviors of adolescents in rural western Colorado.

2. Identify health-seeking behaviors of adolescents who are positive and reflect stable self-management of their T1DM.

3. Define developmental transitional behaviors that adolescents perceive as positive and lead to independent and collaborative disease management.

Scope of the Problem

The diagnosis of T1DM is highest in ten to fourteen year-old females. T1DM is most prevalent among non-Hispanic whites and least prevalent among Hispanic and Asian/Pacific Islander youth. In Colorado, health care providers diagnose 1 in 400 annually with T1DM, with the highest rates in some of the more rural counties (Search, 2004, 2006; CDC, 2009). Type 1 diabetes mellitus (T1DM) is often referred to as insulin dependent diabetes mellitus (IDDM). Other terms used are type 1 diabetes or T1D, juvenile diabetes, and insulin dependent type 1 disease. For the purpose of this study, I will use T1DM, and I will limit the use of IDDM to reports specifically using this term.
Justification for study

The incidence of T1DM is a worldwide concern, affecting the youth of many different cultural groups. Estimates extrapolated from three large United States registries reveal the highest incidence among non-Hispanic white females age ten to fourteen years old. The trend of increasing diagnosis of T1DM in Colorado adolescents, with the highest prevalence in some of the more rural counties, parallels trends of increasing incidence that medical providers observe in Europe, Japan, and New Zealand, with an overall incidence of 3% to 10% of the population (Search, 2004, 2006; CDC, 2009). Similarly, Denmark has seen a threefold increase in the diagnosis of T1DM in preschool (<5 years old) children (Dyrlov, 2000). The trend in younger children in Denmark may soon reflect an increase in diagnosis among this age group in the United States as well. This trend is also consistent with our observation of T1DM in children less than eight years of age in a rural setting. In rural areas in the United States with high prevalence rates, researchers report a bimodal variation of incidence that shows a peak among those aged four to six years and a second, much greater peak during early puberty in those aged ten to fourteen (Felner, Klitz, Ham, Lazaro, Stastny, & Dupont, 2005).

Definition of successful diabetic care

Health care workers typically manage diabetes by measuring blood levels of glycol-hemoglobin (HgbA1c), a laboratory test that measures the blood sugar fluctuations over a three-month period. The glycol-hemoglobin test (HgbA1c) reflects the amount of glucose that is irreversibly bound to the red blood cell. The binding of the hemoglobin molecule is measured in a blood test to monitor long-term diabetic management. A blood level of 7 % mg/dl indicates optimal glucose control (Goldstein, Little, Lorenz, Malone,
Nathan, Peterson, & Sacks, 2004). At present, to improve glycemic control in children, doctors try to maintain the lowest HgbA1c that a body can sustain without causing disabling or severe hypoglycemia. Avoiding blood glucose levels less than 70 mg/dl while also avoiding prolonged periods of significant hyperglycemia and episodes of diabetic keto-acidosis remains the goal of management of T1DM (Rewers, Pihoker, Donaghue, Hanas, Swift, & Klingensmith, 2007). Adolescents can achieve these goals by frequently monitoring their blood glucose and adjusting food intake, insulin administration, and exercise. These adjustments in self-management can help blood glucose levels remain in targeted ranges.

Adolescents typically have HgbA1c blood levels of 1% or higher than most adults with T1DM. An increase in HgbA1c blood levels in the 8-9 % range can increase renal, ophthalmic, and neurologic complications later in life (DCCT, Research group, 2001; Danne, Mortensen, Hougaard, Lynggaard, Henk-Jan, Chiarelli, Daneman, Dorchy, et al., 2001). Growth and hormonal changes during puberty can cause insulin resistance. These physical maturational changes make it difficult for adolescents to maintain optimal glycemic control. Poor glycemic control increases the risk for complications of diabetes such as retinopathy, nephropathy, thyroid and celiac disease, hypertension, dislipidemia and diabetic ketoacidosis (Hampson, et al., 2000; Silverstein, et al., 2005; DCCT, 1995; Skinner & Hampson, 2001; Hamilton & Daneman, 2002; Wolfsdorf, 2002). Of all age groups, adolescents are currently the least likely to achieve the recommended goal based on DCCT trials of a HgbA1c of 7.5% or less (DCCT, 2000). This situation demonstrates how challenging it is for teens to manage their diabetes independently while they also
face the effect of psychological and hormonal changes that occur during adolescence (Rewers, Pihoker, Donaghue, Hanas, Swift, & Klingensmith, 2007).

Diabetic support-group blogs reveal that the focus on the HbgA1c laboratory blood value often frightens adolescents, and as a result, they avoid medical visits. (TuDiabetes.org., Hernandez, M., 2010). The health care team must find unique ways to help young people manage their diabetes and reduce the swings in glucose levels. Compared with twenty years ago, better formulations of insulin, insulin pumps, and glucose monitors are now available (DCCT, 1993). However, adolescents may still be unable to achieve a lower HgbA1c level than their previous control participants without novel approaches (Rewers, Pihoker, Donaghue, Hanas, Swift, & Klingensmith, 2007).

The challenges of adolescence complicate not only their physiology, but also emotions and cognitive levels as well. The focus on achieving a targeted HgbA1c level may not be sufficient motivation to improve health-seeking behaviors of adolescents. A secondary challenge to glycemic control is the onset of puberty which causes insulin resistance that is antagonistic to achieving optimal metabolic control. Adolescent rebellion and experimentation become a psychological challenge that reduces adherence to treatment regimens that complicate the transition to independent care of their diabetes (Weissberg-Benchell, Glasgow, Tynan, Wirtz, Turek, & Ward, 1995).

Diabetes is a lifelong disease that requires daily management and vigilance. The addition of a chronic illness complicates the already challenging life of adolescence. Studies focus on the benefits of, and barriers to, diabetes self-management among adolescents. By managing their diabetes, adolescents report that their parents are relieved of responsibility and worry. On the other hand, these teens also feel that the burden of
personal responsibility is a barrier to self-management (Hanna & Guthrie, 2000). Participants describe the benefits of diabetes self-management in terms of gaining confidence in their abilities to care for themselves, achieving greater freedom, and gaining approval from family members. In interviews with teens and their parents, directive guidance (behavior to aid performance) and tangible (physical) assistance are the most important factors to positive self-management behaviors (Schilling & Grey, 2002).

This transition from dependent teenager to independent adult is particularly complex, for an individual will encounter more health and social risks during this period than any other time in his or her life. (Ingersoll, Orr, Herrold, & Golden, 1986; Silverstein, Kingensmith, Coleland, Plotnick, Kaufman, Laffel, Deeb, Grey, et al., 2005). The addition of a chronic illness makes the transitional developmental stage more complex than any other time of change in the human life span. Rural, white youth with T1DM are at significant risk of developing complications as they transition into adulthood for many reasons that I will discuss below.

**Rural Issues Unique to the Western Colorado**

Located 250 miles west of Denver, Colorado, and separated by the Rocky Mountains and two significant canyons to the east, western Colorado is a unique geographical area. Specialty medical care is available in Denver (250 miles east) and Salt Lake City (250 miles west), and this distance poses a geographical challenge for those who need to access pediatric endocrinology care. Situated between these two metropolitan areas, Mesa County often forces patients to travel up to 10 hours, often with adverse road and weather conditions. The challenge of traveling to medical specialty
health care clinics is difficult and sometimes dangerous (if not impossible) many times of
the year. Economy, fuel prices, employment status, and the condition of vehicles all
complicate the family’s ability to make appointments with specialty clinics.

Mesa County has a higher number of uninsured and unemployed workers in
relation to other counties in Colorado (Center for Disease and Control (CDC), 2010).
Unemployment rates can affect who has access to private insurance in Colorado because
insurance is primarily an employer-based system (Colorado Health Institute, 2011).
Compared to the average person in Colorado, Mesa County has a higher percentage of
uninsured and individuals with Medicare. The Medicaid population of Mesa County and
other western Colorado counties is almost twice as high as those of other Colorado
counties. (See Appendices A.) Poverty levels in rural Colorado reach 40% in some areas
(Search, 2004, 2006; County prevalence data, CDC, 2009; Colorado Health Institute,
2011). This situation becomes an important issue as adolescents reach the age of 18 and
may lose Medicaid eligibility that affects the transition to adult diabetic health care.

The Colorado Health Survey (COHS) provides a rich source of data for
policymakers and researchers to understand how insurance status and household income
influence where and if residents use health services (Colorado Health Institute, 2011). A
larger proportion of individuals living in Mesa County cite a hospital emergency room as
a usual source of care compared to other individuals in the state. The findings from
COHS suggest reactive care is associated with worse outcomes in comparison with
planned care at the physician’s office.

The burden for youth with a chronic illness increases in rural areas. For example,
40% percent of all rural families in the United States live below the poverty level as
defined by the Center for Disease Control (CDC, 2010). Minority families who live in poverty experience greater rates of substandard housing, poor sanitation, inadequate nutrition, contaminated water, and a lack public health services. Additionally, lack of health care is associated with lower rates of prenatal care, immunizations, health screening, and health education (Kaiser Foundation, 2008).

In general, rural residents are not as healthy as those living in urban areas. Medically underserved communities that are designated as such for geographical or socioeconomic reasons have higher rates of infant and maternal morbidity, chronic illnesses (e.g. hypertension and cardiovascular disease), and mental illness. Rural Americans have less health insurance and are less likely to have pharmacy coverage plans. Consequently, they spend 25% more on prescription drugs compared to those living in urban areas (Gamm, Hutchison, Dabney, & Dorsey, 2003; Gamm, 2007). The added burden of poverty in a rural area affects those with diabetes. Missed appointments, geographical distance to health care facilities, and cost of travel all impact these families for both diabetic as well as general health care.

**Transitional Care**

Transitional health care is a multi-faceted process that focuses not only on the medical care needs, but also on the psychosocial, educational, and vocational needs of adolescents as they move from the child-focused to the adult-focused health-care system. Transitional health care affects other areas of life as well, such as work, community, and school. Transitional health care tries to anticipate areas that pose risks for the adolescent, and the practice suggests an increase in independent behavior and personal autonomy while improving an ability to care for oneself (Reiss, & Gibson, 2002).
As adolescents become more independent and manage their T1DM, health care has largely been reactive rather than proactive (Donaghue, et al., 2009). Daily fluctuations of cognitive and physical abilities challenge adolescents who tend to think in the moment rather than consider future consequences. This situation can challenge a health care team as well because researchers have developed models of care for children and adults, not the unique needs of the adolescents (Reiss, & Gibson, 2002; Donaghue, et al., 2009). We lack research and guidance for health care related to chronic disease management of T1DM in adolescents. We need to understand the transitional years and explore how adolescents perceive health-seeking behaviors for their T1DM. During the transition phase, we see a greater desire to be independent, an aspiration that extends to self-management of their T1DM. This transitional period can challenge and confuse, thus making health care provided in a supportive and consistent manner all the more pressing.

While studies focus on the need for better glycemic control, especially through the adolescent years (Diabetes Control and Complications Trial, DCCT, 1993, 2000, 2001), little research describes what adolescents with T1DM need in order to “feel healthy” (i.e. not feeling labeled as having a chronic illness and still sustain glycemic control.) Understanding the challenges teens face on a daily basis requires researchers to explore the skills required to independently manage T1DM. Recognizing what it is like to live with a chronic illness, rather than explore what is needed to change behaviors when complications arise, enables us to identify target areas where health care providers can intervene.
Adolescence as a Developmental Risk

Arnett (2007a) finds that youth who lack financial, educational and emotional support lag in indicators of success. For example, they are less likely to have stable jobs, income, health insurance, and the ability to compete effectively for employment. These stressors complicate the transition of adolescents with T1DM who must develop psychological maturity, accept responsibility, generate motivation for their own wellbeing, and develop skills that allow them to manage their diabetes (Karisson, Arman, & Wikblad, 2006).

Developmental Transition

According to the *Merriam Webster Dictionary*, transition is a “process or period in which something undergoes a change and passes from one state, or stage, form, or activity to another” (p. 1254). The word transition is frequently used to describe a process of change in life’s developmental stages, or alterations in health and social circumstances rather than peoples’ responses to change (Kralik, Visentin, & Van Loon, 2006).

Transition is relevant to a wide range of phenomena or human experiences across many clinical and substantive areas in nursing. A variety of conditions may influence the transitional experience. An individual must negotiate expectations that others may have of and for that person. The level of knowledge and skill a person processes shapes how he or she may navigate the change. The physical and supportive environment may ease or complicate the transition. The presence or lack of planning affects how well one adapts to the new situation. Finally, the emotional and physical well-being of the person plays a key role. Successful transition may be evident in increased self-management skills of the
adolescent with T1DM leading to improved glycemic control (Meleis, Sawyer, Im, Hilfinger, Messias, & Schumacher, 2000; Meleis, 2010).

Meleis’ (2010) Transitional Theory provides a framework for nurses who work with adolescents with T1DM, because the protocols are fundamentally rooted in the tenets of holistic nursing. The first concept in this theory requires a better understanding of the human experience during the transition process. The second concept suggests that nurses need to anticipate interventions at appropriate moments in the experience. Nurses can use both of these concepts to understand the adolescent in the “transition” of becoming independent. The view of adolescence as a developmental period requiring understanding and anticipation of the physiological and psychological changes create a framework that is fluid and consistent with this process (Meleis, 2010).

Adolescence is not only a physical time of change, but a process of becoming and learning to be an adult. Researchers often describe the change as a process and not a “stage.” Several authors describe change as a time of learning to live and incorporate consequences in to everyday life or becoming ready (Dalton & Gotlieb, 2003; Kralik, Koch, Price, & Howard, 2004). Using the meta-paradigm of nursing’s central concepts (Fawcett, 1984) of nurse, patient, health and environment may help health care providers anticipate ways to improve young adults’ ability to control glycemic levels as they move from one stage of life to another (Meleis & Trangenstein, 1994). The holistic nursing approach encompasses the emotional, social, physical, and psychological needs in the transitional process. As the young adult matures, nurses can anticipate specific needs and offer positive choices. Meleis and Trangenstein (1994) suggest that nursing “is concerned
with the process and the experiences of human beings undergoing transitions where health and perceived well-being is the outcome” (Meleis & Trangenstein, 1994, p. 257).

Situations that can place a person at risk for delayed or complex transitions include illness experiences, rehabilitation and recovery, developmental and lifespan transitions such as adolescence, and chronic illness during developmental transition periods (Chick & Meleis, 1986; Meleis & Trangenstein, 1994; Meleis, 2010). A need exists to understand the transition of adolescents with T1DM as they become independent and develop a supportive health care environment that could assist this process. Research related to transition of adolescents has been reactive. The literature explores the transition process, but not how to promote a sustainable health care environment to produce positive health outcomes (Dyrlov, Povlesn, Solvkaer, Marinelli, Olsen, Hougaard, & Mortensen, 2000; Schoeni, & Ross, 2005; Skinner, & Hampson, 2001).

Nursing interventions can influence human experience at many points in the developmental and transitional process. One of the most important times nursing interventions can affect health is during the adolescent years. There is limited knowledge of how to promote healthy interactions with adolescents in the health care once they leave the home (Carson, 2007; Harris, Freeman, & Duke, 2009; Park, Mulye, Adams, Brindis, & Irwin, 2006). Once the young adult leaves home, their encounters with the health care system usually occur in times of crisis, rather than at preventive health visits. Young people may also delay medical treatment due to finances, geographical locations, and time constraints of work, school and social life (Park, Mulye, Adams, Brindis, & Irwin, 2006). After the age of 18, limited contact for preventive services occurs. Therefore, understanding health-seeking behaviors of adolescents with T1DM may result in
strategies that improve their contact with the health care team. This impact may lead to positive health outcomes.

Arnett’s (1997, 1998, 2000, & 2007) studies of the emerging adult show that demographic characteristics, such as finishing education and settling into a career, are not as important for the adolescent during the transitional time. The characteristics that matter most to the young person attaining adulthood are individual qualities of character (Arnett, 1998). Specifically, the two major characteristics include 1) accepting responsibility for one's self and 2) making independent decisions (Arnett, 1997, 1998). A third, less tangible criterion identified is becoming financially independent. Using these criteria, Arnett’s (2000) work reveals it is not until age 35 that 90% of young adults surveyed feel they reached adulthood (Arnett, 2000). The noted delay of adulthood reinforces the need to provide health care that addresses adolescent issues well into their twenties.

The situation requires a new way to think about the transitional health care issues that young people encounter in multiple settings. Until now, researchers who study young adults limit their work to adolescents with T1DM into the college setting. As a result, new research needs to address access to care, delivery of care models, and ways to help adolescents develop necessary skills, for we know that this population often encounters irregular life styles and erratic access to health care (Van Welleghem, MacDonald, & Dean, 2008; Weissberg-Benchell, Wolpert, & Anderson, 2007).

A biological process defines puberty and adolescence. Visible physiological changes mark differences between infancy, early childhood, and other stages of growth and development. In contrast, the transition to young adulthood is defined by changes in
social roles, notably within the institutions of family, education, employment, and society (Hamilton & Hamilton, 2009). The institutions of education, employment, society, and family (families of origin and the new families formed by new adults) shift from dependence to independence. No other life course transition is so fully defined by social institutions as the transition from adolescence to adulthood (Hamilton & Hamilton, 2009). Seldom is the word adolescence defined without including the descriptor of transition, indicating that the entire period of adolescence is a bridge between childhood and adulthood, or a period of transition (Fuhrmann, 1990).

**Transition as a Concept for Improving Glycemic Control**

Meleis, et al. (2000) suggest that transitions can be described as types, patterns, or properties such as transition experiences, facilitating and inhibiting conditions, process indicators, outcome indicators, and nursing therapeutics. These experiences are part of an emerging middle-range theory. These diverse, complex, and multiple dimensions of transitional experiences require exploration, and we need to incorporate them into research and nursing interventions (Meleis, et al., 2000). Meleis’ Transitional Theory is an excellent framework to research the transition of dependent adolescents with T1DM to independent young adults with adequate skills to facilitate control of their diabetes.

Transitional events entail perception or reflections on how the self interprets the process of transition and how the self assigns meanings to these changes (Chick & Meleis, 1986). Perceptions vary among persons, communities, and societies. They influence one’s responses to transition events, making each transitional event less predictable. Simply put, “transition is a personal phenomenon that offers unique
meanings for the individual; it offers the linkage of change with the experienced time” (Chick & Meleis, 1986, p. 238).

Chick and Meleis’ (1986, 2000) model of transition describes factors that influence the process of change. (See Appendix B). These factors are individual responses, environmental factors, and nursing therapeutics. We can observe patterns of individual response, and examples include disorientation, distress, and displays of happiness. The particular environment in which the transition occurs (e.g. rural) may inhibit or facilitate the transition. In planning nursing therapeutics or interventions, we should consider antecedents and consequences related to the transition.

The goal of nursing is to anticipate times when an individual is most vulnerable with respect to health (Lenz, 2001). The use of Meleis’ theory supports the process and journey of becoming an adult. The framework allows for the fluidity of changes as acquisition of new roles and responsibilities occur. Nursing applies transitional theory extensively in recent nursing research (Meleis, A., Interview, January 25, 2011).

**Summary**

Adolescence is a challenging developmental stage marked by emotional, intellectual, social, and psychological changes. For some adolescents, social pressures and peer influences coupled with the desire to “fit in” can be a higher priority than performing the constant diabetes care tasks associated with self-management (Keogh, Sullivan-Bolyal, Crawford, Schilling, & Dixon 2011). Adolescents may have physical skills to administer their insulin before they have the cognitive maturity to make the required judgments in their daily insulin doses. This maturity is particularly challenged in times of stress, illness, and when decision-making is inconsistent with their life styles
(Ingersoll, Orr, Herrold, & Golden, 1986). Understanding the health-seeking behaviors of adolescents with T1DM in rural area may help to inform interventions, and this new direction may help patients adjust insulin levels until individuals develop cognitive maturity and self-management skills.

The human experience of transitioning from a dependent adolescent to an independent young adult is a journey. We can explain the journey by holistic approaches that reflect the challenges and opportunities youth encounter as they transition to learning independence. Health concerns, environmental challenges, poor social support, and lack of essential resources can challenge adolescent growth. The addition of a chronic, demanding illness makes identifying innovative strategies for T1DM in adolescents a priority in the ongoing effort to improve self-management and help youth adapt to daily demands. Growth and developmental changes during adolescence can influence an adolescent’s view and consequently shape how he or she manages his or her chronic condition (Sawyer & Aroni, 2005). The adolescent period is an optimal time to guide perspectives on chronic disease and understand how adolescents view their diabetes in the context of their daily life and overall health experience. A positive outlook could have a lasting impact on their adult perspective of the disease (Sawyer & Aroni, 2005; Keough, Sullivan-Bolyai, Crawford, Schilling, & Dixon, 2011). Health care teams must develop supportive and developmentally sensitive techniques to work with adolescents. By viewing the transition of adolescents with T1DM as a human experience, those who care about teens can provide the support necessary to ensure a healthier outcome for young adults with T1DM. The ability of linking teens to a health care team that would follow them through their young adult lives could help reduce complications that thirty to
forty-year-old individuals with T1DM often encounter. Researchers need to examine what this linkage of health care resources to adolescents with chronic illness would entail.

The next two chapters describe the evolution of the research project and analyze gaps in research for transitional care of adolescents with T1DM. I address the need to support the intermediary stage or early to late adolescence more directly, especially in rural geographical areas. Chapter II describes the challenges of adolescents with T1DM living in a rural area. The literature I review in Chapter II encompasses challenges that adolescents with T1DM must face.

Chapter II explains the framework of Transitional Theory as a way to investigate the health-seeking behaviors of high school-eligible adolescents who are typically 14 to 18 years of age with T1DM. Chapter III describes the methodology of Participatory Action Research (PAR) and the strategy for the research dissertation. The chapter also outlines interviews of singular paired and group discussions and describes questions and group process in detail. Chapters IV and V outline my findings and discuss future implications for research, education, and practice.
CHAPTER II

REVIEW OF LITERATURE

Chapter I describes adolescent transition to young adulthood as a complex developmental transition or process. Adolescents encounter additional burdens if they have a chronic illness. This situation is especially true for adolescents with T1DM living in a rural geographical area. A number of conditions may influence the transitional experience: expectations, level of knowledge and skill, environmental challenges, social support and access to essential resources, planning, and emotional and physical well-being. Understanding health-seeking behaviors and transitional changes of adolescents in rural contexts may improve their interaction with the health care team in early adult years and facilitate overall diabetes control. This chapter reviews the research literature across the following key themes related to the issues of adolescents with T1DM living in a rural area:

1. **Diabetes**: T1DM significance, self-efficacy and self-management; adolescents with T1DM; complications of T1DM; adolescent complications.

2. **Environmental**: Access; rural health; medically underserved populations.

3. **Support**: Health behavior support; chronic care model; health belief model; adaptation model; stages of change; adolescent support through text messaging and social media.

4. **Gaps**: New directions; and transitional theory as a conceptual framework for adolescent health.
Evolution of the Study

The thesis focus arises from the hypothesis that using text messages to remind adolescents with T1DM to test blood glucose and bolus may improve glycemic control. Prior observation of text messaging by two adolescents in a primary care setting provide the incentive for this study. The positive effects of text messaging was evident in three forms: teens continued to respond to text messages from the provider (up to five times per week); teens notified the provider if glucose readings were over 400 mg/dl; and Hgba1c was reduced over a six month period of time by 2% for both patients.

I reviewed the literature to determine what researchers have published on text messaging as a form of health support, evaluating the use of text messaging in adolescents with T1DM for glycemic control. The review focuses on research that supports the clinical intervention of text messaging and evaluates long-term outcomes or impact on diabetes control in adolescents with T1DM living in a rural geographical area in the United States.

Review of Literature Process

I searched the University of Colorado Health Science library's webpage, CINAHL, Pub Med, FindIt, and Google Scholar for text messaging and health care for adolescents with ‘type 1 diabetes’ (T1DM) without quotation marks. I placed parameters to limit the number of publications to include articles in scholarly publications, including peer review articles. Exclusion criteria included newspaper articles, non-human studies, and non-English resources. Defining the search process to articles focusing on health care for adolescents with T1DM narrowed the search to three research studies.
These three studies report using text messaging with adolescents who have T1DM. Two of these articles report text messaging via cell phone (Franklin, Waller, Pagliar, & Greene, 2003 Franklin & Waller, 2006). The third article by (Kollmann, Riedl, Kastner, Schreier, & Ludvik, 2007) evaluates the feasibility of phone-based service for T1DM. The study addresses acceptance and participation of using a phone-based service, but does not explore outcomes or improvement of glycemic control and changes in behavior to improve self-management.

Franklin’s et al. (2003, 2006) work studies the use of text messaging for adolescents with T1DM to improve glycemic control. Franklin et al., (2003, 2006) designed and piloted a unique text messaging system (Sweet Talk) in Edinburgh, Scotland. The motivational support program designed a software package to deliver automated messages for patients in clinics in Tayside, Scotland, for the medical practice (Franklin, Waller, Pagliari, & Greene, 2003). The program delivered individually targeted messages from a database of 400 messages containing general diabetes information to teenagers with T1DM. Researchers used individualized motivational strategies to intensify insulin therapy and increase contact with the diabetes team between clinic visits. The concept is based on social cognition theory, health belief model, and goal setting. These theories form the theoretical basis of the message content sent by text messaging to the teenagers with T1DM (Franklin & Waller, 2003).

Franklin et al. (2006) studied 126 patients with T1DM, ages 8-18. Ninety-one participants qualified and were randomized to three groups: one conventional insulin therapy (n=28); two conventional therapy and “Sweet Talk” (n= 33); or three intensive insulin therapy and “Sweet Talk” (N=31). Intensive insulin therapy (IIT) is the use of
multiple daily injections of insulin or a continuous subcutaneous insulin infusion via a pump. Clinic visits established goals for groups two and three, and daily text messages from the Sweet Talk software system reinforced these goals by sending personalized, goal-specific prompts and messages tailored to the patients’ age, sex, and insulin regimen (Franklin, Waller, Pagliari & Greene, 2006). The primary outcomes for the study are glycemic control measured by HgbA1c blood levels. Psychological assessment tools measure behavioral changes. The adolescent’s view of self-management competence, diabetes knowledge, and diabetes social support indicate these changes. Mean glycemic control did not change in the patients who remained on conventional insulin therapy alone (10.3± 1.7%), or the conventional therapy plus Sweet Talk (10.1±1.7%). Glycemic control improved in patients allocated to intensive therapy plus Sweet Talk (9.2 ± 2.2%, 95% CI - 1.9, -0.5, P < 0.001) (Franklin, Waller, Pagliari & Greene, 2006). Previous studies show intensive insulin therapy in specialized clinics focusing on adolescents with T1DM does improve glycemic control (Donaghue, Chiarelli, Trotta, Algrove, & Dahl-Jorgensen, 2009).

Franklin et al. (2006) find that self-efficacy improves as a result of text messaging (P= 0.003), and texting improves self-reported adherence score (P= 0.042). Sweet Talk increases patients’ perception of the quantity of support they receive from the diabetes team. However, the impact on diabetes knowledge score does not influence patients’ perceptions of support from family and friends (Franklin, Waller, Pagliari & Greene, 2006). Support from family to the adolescent has been a key area described in the literature for adolescents who maintain adequate control of their T1DM (Ingersol, Orr, Herrold, & Golden, 1986; Weissberg-Benchell, Glasgow, Tynan, Wirtz, Turek, & Ward,
Researchers do not note any behavioral changes that improve glycemic control. The behavioral changes are pivotal to independent self-management.

Sweet Talk tested a new e-health intervention for adolescents with diabetes. Researchers did not observe any difference in glycemic control between patients on conventional insulin therapy (group 1) or patients on conventional insulin therapy plus Sweet Talk support (group 2). There was an overall decrease in HgbA1c of approximately 1% between these groups and patients who received intensive insulin therapy and Sweet Talk (Franklin, Waller, Pagliari & Greene, 2006). Researchers do not know if this difference is due to the Sweet Talk application or to intensive insulin regimen. Research shows that intensive insulin regimen is a cornerstone to achieve glycemic control in T1DM patients. However, there is a lack of research in what health care providers need to do to change behaviors of adolescents with T1DM to independently maintain intensive insulin therapy regimens (Mortensen, Villumsen, Volund, Petersen, & Nerup, 1992; White, Cleary, Dahms, Goldstein, Malone, & Tamborlane, 2001).

Given the limited information obtained in the prior search, I expanded the literature review to a second phase using the following key words and phrases: T1DM; adolescents; insulin adherence; missed insulin doses; behavioral issues in adolescence; text messaging for education in diabetes; text messaging in disease management; and text messaging in the health care. I used Google scholar, Pub Med, and Article Link. I gathered articles from electronic sources, then downloaded and copied them for review. I also scanned Diabetes Care, Diabetes Medicine, Diabetes Education and Journal of Pediatrics online for articles relating to the above key words from 2009-2011. I filtered
the search with the following inclusion criteria: type 1 diabetes, text messaging, methods, health, pediatrics, diabetes, adolescent, self-care psychology, and chronic illness. The exclusion criteria included the following terms: infancy, childhood treatment, medicine, infant, newborn, surgery, children, child, preschool, and therapy. The inclusion and exclusion criteria narrowed the results to 1300 journal articles.

I added key words to this phase of the search: adolescence; text messaging to improve health outcomes; text messaging in chronic disease management; self-care, self-efficacy and self-management of adolescents with type 1 diabetes; and transitional issues of adolescents. I eliminated articles focusing on type 2 diabetes or subjects outside the range of interest. I found no articles in Pub Med on insulin-dependent diabetes mellitus and text messaging for improved outcomes. Google Scholar lists 1700 articles linking telemedicine, tele-care, and chronic disease management; however, I found the same three articles reported earlier that explored text messaging. I then reframed my major question as, “Can text messaging improve T1DM glycemic control in adolescents living in a rural setting?” I collected content related to the key issues of text messaging and adolescent adherence, as well as the standards of diabetic care for the adolescent.

Researchers have written little about theory development in the use of text messaging and improvement in diabetic control of the teenager with T1DM. Many studies investigate behavioral theory in medication adherence. Franklin (2003) evaluates social cognition theory; however, the small number of participants limit the results. The use of text messaging to provide diabetes behavior modification through education and support is new and must be evaluated. However, it is unknown what strategies
researchers need to influence independent self-management behaviors of adolescents with T1DM in a rural setting.

The limited number of relevant research articles on adolescents with T1DM and text messaging led to the expansion of the literature review to include several supplementary areas: T1DM and its significance in adolescence; theoretical frameworks identified for research of adolescents T1DM; the impact of self-care, self-efficacy and self-management of an adolescent; adolescents with T1DM and issues specific to this population.

**Diabetes**

**Type 1 diabetes and its significance in adolescence**

Research on adolescents with T1DM focuses on the following themes: self-management, self-efficacy, improving transitional care, adolescences as a risk factor, parental support for improved outcomes in glycemic control, and metabolic risk factors. I will discuss the summaries of these pertinent themes. I did not consider literature in adaptation and mental illness in this review due to the confounding role they play as secondary conditions in diabetes management. Limited research describes diabetes as a risk factor for developing psychological problems in youth with T1DM. In a Nordic population study, rates of depressive symptoms and other psychological problems were up to three times as high as those without diabetes (Kokkonen & Kokkonen (1995). This study compared 63 patients to 123 aged-matched healthy controls. Present state examination (PSE) measured the depressive symptoms. The overall prevalence of mental disorders in this study was 17 % in the patients with diabetes, with a confidence interval (CI) of 8-26% and 20 % among the controls with a CI of 13-27 %. The two groups
differed: patients with diabetes increased severity of affective disorder, and the diabetic group saw an increase in neurotic symptoms based on PSE sub scores. The diabetic group also encountered increased social development problems. Schooling issues and separation from parents were the main social development problems. The study concludes that diabetes is not a risk factor for mental health in young adulthood; however, diabetes increases the severity of psychological symptoms, especially depression. In one of the few longitudinal studies to follow youth with T1DM into young adulthood, 42% developed at least one episode of psychiatric disorder, with the most common being depressive disorders (26%), followed by anxiety disorders (20%), and behavior disorders (16%) (Kovacs, Goldston, Obrosky, & Bonar, 1997).

The presence of clinical depression complicates a desire to control and adhere to a medical plan for diabetes. SEARCH for diabetes is a multi-center study founded in 2000 and projected to continue through 2015. To date, there are over 20,000 participants in the research study at sites in Washington, Colorado, California, South Carolina, and Ohio. SEARCH (2006) explored depressive mood in 2672 participants, ages 10-21, who had a mean duration of diabetes for five years. Researchers measured the level of depressed mood using the Center for Epidemiologic Studies Depression Scale (CES-S). Results find the prevalence of depressed moods similar to those of adolescents without diabetes. SEARCH results find fourteen percent of adolescents with T1DM have mild depressive symptoms and nine percent of adolescents with T1DM have moderate or severely depressed moods. Females are affected more than males 10.9 % and 6.1 % respectively (p .001) and depressed moods are associated with poor glycemic control and a higher likelihood of emergency room visits (Bell, Klingensmith, Lawrence, Liese, Loots, &
McKeown, 2006). The research from SEARCH (2006) data suggests that 15% of all patients’ with diabetes suffer some form depression. Research also shows that individuals with depression or depressed mood have a significant impact on Hemoglobin A1c, in individuals with T1DM but not in those with type 2 diabetes.

Several theories relevant to working with transitional issues of adolescence include Bandura’s work using Social Cognitive Theory and Prochaska’s Stages of Changes. Both of these theories reflect a linear process that gives the perception that the individual will complete a defined stage from a beginning to an end (Bandura, 1997; Prochaska, 2011). However, in adolescence, the process is circular or a continual process. The literature now supports the idea that adolescence could take years to become self-sufficient and independent with adequate decision making skills. These theories are not, therefore, relevant to the study of adolescents in a transitional process.

Multiple studies use self-efficacy for an adolescent with diabetes and other chronic health conditions as a framework. Bandura’s theory has implications with regard to self-efficacy. The premise of the Self-Efficacy Theory demonstrates that people will engage in activities when they feel they have competent skills (Bandura, 1986, 1997). Adolescents can manage fine motor skills, but they periodically feel incompetent with their skills. Adolescents are not equipped with the cognitive ability to sort through physiological symptoms. The addition of emotional and bodily changes to a chronic illness complicates and challenges a teenager, a situation that also affects compliance and self-management of his or her disease process.
Chronic care model

Approximately 131 million Americans suffer from a chronic condition (Improving Chronic Illness Care-ICIC, 2008). Nursing uses a chronic care model (Appendix E) to describe how the community and health care system can improve outcomes in patients with chronic disease. The large number of patients that United States health care system encounter with chronic conditions is growing rapidly. Unfortunately, there is limited success in the management of chronic illness in relationship to improved health outcomes. Wagner (1998) notes that “Usual care is not doing the job” (p. 2). The failure to improve health care outcomes for patients with chronic illness generates the evolution of the chronic care model (CCM) (Improving Chronic Illness Care, 2008).

A combination of health care team and system issues challenge those with a chronic illness. For example, practitioners feel rushed or do not follow standards of practice. Coordination of care is often absent. Patients encounter poor follow-up. Finally, health care providers do not inadequately train patients to manage their chronic illness (ICIC, 2008). Some of these deficiencies, such as inadequately educated patients, provide evidence for the need to transform health care to a proactive and patient-focused system. Many times the care is reactive, responding only when patients become ill. In effect, researchers created CCM to improve care in health systems at varying levels: the community, organization, practice, and patients. To function at optimum levels, these patients need constant adjustments to manage their health, a situation that requires ongoing interaction with the health care system.
The CCM model offers simple, concise statements and provides complete and comprehensive explanations of chronic illness care. The CCM is based on adult care models, and the model may eventually be useful in the care of the adolescent. However, at present the CCM model is based on systems of care that already challenge the adolescent and prevent smooth transitional care. Therefore, I do not consider this model for the transitional process of the adolescent with T1DM.

**Stages of change theory**

I reviewed Stages of Change Theory, but I do not apply it because the framework suggests a stage or process ends or is completed (Prochaska, 2011). In terms of chronic illness, this theory does not fit, for medical treatment rarely cures chronic illness. The five stages addressed in Stages of Change Theory lead to action and maintenance suggesting resolution of issues. Researchers conducted extensive research using the theory in drug and alcohol addiction and smoking cessation, demonstrating resolution with cessation of the problem behavior (Prochaska, 2011). However, I determine that the theory is not appropriate as a framework for holistic care for an adolescent with a chronic illness.

**Self-efficacy and self-management**

The literature for T1DM management has a plethora of research addressing the concepts of self-efficacy and self-management. The central concept observed in diabetes is self-efficacy. Self-efficacy believes that one can execute behavior to produce a desirable outcome (Bandura, 1986, 1997). Studies also identify self-efficacy as an important factor in diabetes for adolescents (Innotti, Schneider, Nansel, Haynie, Plotnick, Clark, Sobel, & Simons-Morton, 2006; Littlefield et al., 1992). Researchers find self-
efficacy can mediate the relationship between responsibility for diabetes and self-reported adherence (Holmes et al., 2005; Ott, Greening, Palardy, Holderby, & DeBell, 2000). Medical literature disagrees on ways to increase self-efficacy and accordingly increase self-management of T1DM in adolescents (Littlefield et al., 1992; Griva, Myers, and Newman, 2000; Innotti, Schneider, Nansel, Haynie, Plotnick, Clark, Sobel, & Simons-Morton, 2006). For example, research suggests that increased family support increases the adolescent’s self-efficacy, and that change increases the self-management skills. To examine critical parenting relationships and adherence of the medical regimen in youth with T1DM, researchers asked 120 participants to complete instruments of diabetes specific functioning and adherence interviews. Through regression analysis, research demonstrates that critical parenting reduces adolescent adherence which in turn reduces glycemic control (p<.001) (Duke, Geffken, Lewin, Williams, Storch, & Silverstein, 2008).

In a study to examine family factors and metabolic control in T1DM, researchers asked 109 children age 8 to 18 and a parent to complete the following: a questionnaire on diabetes specific family functioning; a diabetes family behavior scale (Waller, 1986); and an adherence interview with each child and parent separately. Through regression analysis, results show that family factors account for 34% of the variance in metabolic control (p < .001). Overall, families with higher conflict and decreased roles addressing the responsibility of diabetes management have poorer glycemic control (Lewin, Heidgerken, Geffken, Williams, Storch, Gelfand, & Silverstein, 2006).
Self-efficacy

Self-efficacy refers to an individual’s perceived ability to perform a specified behavior or set of behaviors. This ability is a construct central to social cognitive theory that proposes that behaviors are determined not solely by knowledge, but rather by the outcome and confidence related to performing them. Self-efficacy is a behavior-specific construct. The issue with researching self-efficacy in the adolescent is the confounding conditions and changes that occur through adolescence. Self-efficacy is not a general trait, but is instead a condition varying across distinct groups of behaviors (Bandura, 1986, 1987).

According to Bandura (1997), four sources generate self-efficacy beliefs: performance accomplishments, vicarious experiences, verbal persuasions and social influence, and a physiological state. Performance accomplishments are the most influential source of self-efficacy information and are based on internalized mastery of experiences. For example, for the patient with T1DM, it takes time to master judgment and decision-making in response to glycemic swings. Mastery of specific skills occurs at ages much younger than mastery of the experiences of living with T1DM in adolescence.

One of the primary concerns for children with T1DM is the age they become physically, as well as cognitively, competent to perform tasks needed for self-management of their disease. Ingersoll et al. (1986) show that children as young as seven or eight years of age can perform the tasks (skills) for T1DM but are not ready for the judgment and cognitive challenges until much later in adolescence (Ingersoll, Orr, Herrold, & Golden, 1986). To evaluate self-management behaviors and cognitive maturity, researchers asked 41 adolescents age 12 to 21 and one of their parents to
complete instruments designed to evaluate self-adjustment guidelines in their T1DM management (Ingersoll, Orr, Herrold, & Golden, 1986). An adolescent whose family has increased knowledge concerning diabetes and attends to the adolescent’s glycemic fluctuations is better able to maintain long-term glycemic control (Follansbee, 1989).

Arnett’s (2007) more recent work questions the age when adolescents are ready to assume care of their diabetes. Differences in age further compound the time frame when adolescents cognitively mature, driving the age of competent self-management with T1DM into the mid-twenties of many young adults (Arnett, 2007b). The age when an adolescent or young adult acquires self-efficacy may be even older.

Vicarious experience refers to learning that occurs through observation of events and/or other people. Mentoring or role modeling behaviors that support glycemic control can be an important means of learning diabetes management in this group. Adjustments in daily routines can be simple, or they can be quite complicated in times of illness and stress. During these periods, missed doses of insulin and episodes of sustained hyperglycemia or diabetes keto-acidosis (DKA) can occur. Without capable role models, adolescents may not experience the opportunity to learn appropriate adjustments of their medications or modifications in their diet.

Verbal persuasion and related types of social can strengthen an individual’s belief that he or she possesses certain capabilities. Adolescence is a time of significant peer pressure (and social influence), and these forces may affect the ability to manage diabetes. Adolescents are known for their rushed decisions and spontaneous reactions, rather than planned and controlled choices for the management of their T1DM.
Physiological state, according to Bandura, (1996) is the magnitude of visceral arousal that increases in stressful situations. The physiological awareness is the final source of increased self-efficacy (Bandura, 1986, 1997). The physiological awareness is complicated in adolescents by symptoms of hypoglycemia and hyperglycemia competing against hormones their bodies experience as they go through adolescence. Adolescents are not equipped with the cognitive ability to sort through physiological symptoms as their body changes with emotional, hormonal, and physical development. The additional demands of a chronic illness challenge adolescents and affect their ability to adhere to protocols and manage the disease.

Using a social cognitive theory framework, Iannotti et al., (2006) examine the interaction of self-efficacy and outcome expectancies (a combination of perceived consequences and treatment effectiveness beliefs) on self-care behavior and metabolic control. The results show that the effect of self-efficacy is greatest when adolescents have stronger beliefs in the beneficial effects of overall diabetes self-care activities (p< .05). The researchers assessed 168 adolescents ages 10 to 16 to determine self-efficacy of diabetes management, outcomes of adherence to the diabetes regimen, and control of glycemic levels. In children thirteen and older, both parent and youth-reported diabetes self-management adherence were significantly associated with HgbA1c. Consistent with previous research, diabetes self-management and glycemic control decrease significantly as the age of the child increases (p < .001).

The literature is sparse in research that addresses confidence and self-efficacy in adolescents with T1DM. I found no studies that support increased self-efficacy with health outcomes of a chronic disease in an adolescent, especially with T1DM (Schilling,
Grey, & Knafl, 2002). I searched for dietary compliance and self-efficacy, and currently, no study explores the interaction of self-efficacy and illness representations on both dietary self-care behavior and diabetes distress (Griva, Myers, & Newman, 2000; Iannotti et al. 2006). Griva, Myers, and Newman (2000) find that only the belief in treatment effectiveness is a significant predictor of intended dietary adherence in adolescents with T1DM (p < 0.001). In their study of 64 patients, ages 15 to 25, in two United Kingdom hospitals, researchers administered participants instruments to assess self-efficacy, adherence, and illness perception. Generalized and diabetes specific self-efficacy correlates only with adherence to diet (p < 0.001) and blood glucose monitoring (p < 0.01). These findings may relate more to self-management and skill acquisition rather than enhanced self-efficacy.

Research demonstrates that self-efficacy mediates the relationship between social support and exercise. When studies control for the effects of self-efficacy, social support is no longer a significant independent predictor of self-care. The difficulty in using this relationship in research with adolescents is the variability of measuring self-efficacy in the teenage population. Williams and Bond (2002) suggest that programs designed to increase confidence in self-care abilities are likely to be effective because indirectly they may increase self-efficacy. It is equally possible that a history of successfully controlling diabetes builds the patients’ confidence in their self-care abilities (Williams & Bond, 2002). This history, in turn, may influence self-management, but it is unclear if self-confidence translates into improvement of diabetes control.
Self-management

Self-management is a multidimensional concept that includes activities that youth and their parents perform together to control the day-to-day activities needed to balance the chronic disease process. Collaboration between youth, their parents, and healthcare providers is necessary to help adolescents assume full responsibility for managing their diabetes (Schilling, Grey, & Knafl, 2002).

The literature often uses “self-management” and “adherence” interchangeably. To clarify the conceptual confusion about the definitions of adherence and utilize a working definition for both terms, I will use following definitions. I employ “adherence” to describe the degree to which an individual follows medical advice (Greening, Stoppelbein, & Reeves, 2006). Researchers often measure adherence in relation to medication or use of devices. Self-efficacy correlates with self-rated and physician-rated adherence in medication administration (Padgett, 1991). Distinguishing between the two concepts provides a more nuanced understanding of how youth care for their T1DM.

Significant research addresses the complications of poor management, including, for example, early parental withdrawal of support for management of T1DM and lack of transitional resources for adolescents in self-care (Ingersoll, Orr, Herrold, & Golden, 1986). The gap in the literature focuses on research relating to what motivates adolescents to care for themselves with T1DM. We still need to differentiate the tasks and behaviors that motivate adolescents to adhere to their diabetes regimen.

Problems of Researching Self-management of T1DM in Youth

According to Shillings (2002) several problems exist with self-management of T1DM in children and adolescents. First and foremost is the lack of standardized
terminology in relation to self-management. Some researchers write about “self-management” while others write about “self-care,” “compliance with self-care,” “self-care management,” or “illness management.” Second, researchers often do not define self-management, and when they use a definition, the consistency is not uniform with the concept of self-management (Shillings, 2002). Third, some writers insist that self-management is distinctly different from compliance and adherence while others equate those latter concepts with self-management. For example, Glasgow (1997) equates self-management and adherence, but in a later paper his colleagues distinguishes between the two concepts (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997). Wysocki and Greco (1997) use treatment adherence as part of the larger construct of self-management. Lastly, the literature rarely distinguishes self-management in children and in adults, yet researchers are aware that age and developmental status are powerful contextual variables that influence self-management (Harrigan, Faro, VanPutte, & Stoler, 1987; Wysocki, Meinhold, Cox, & Clarke, 1990; Ingersoll et al. 1986). Understanding what self-management signifies to an adolescent is an equally important aspect of care that requires additional research.

Finally, diabetes research identifies self-efficacy as a key psychosocial variable (Charron–Prochownik, et al. 1993; Glasgow & Osteen, 1992). Glasgow and Osteen (1992) note that self-efficacy predicts adherence with self-care in areas that the health belief model does not predict (Glasgow & Osteen, 1992). Researchers tested the health belief model in a small study of 56 adolescents with Type 1 diabetes. The model reveals that adherence to exercise and injections of the regimen decreases as age increases (Bond, Aiken, & Somerville, 1992). Self-efficacy is a stronger predictor of self-care for insulin
self-injection and later adherence to injection regimen than diet or exercise. While research correlates self-efficacy with adherence in medication administration (Padgett, 1991), it is unknown if self-efficacy predicts future adherence (Skelly, 1995).

How we define the population complicates how we apply concepts of self-efficacy, self-management, and self-care. Adolescents are a changing population, with unique individual needs that a variety of constructs define. It may not be possible to correlate constructs that define their self-efficacy.

Innovative approaches to self-management education in adolescence must consider the current social climate relevant to young people. Social networking and text messaging has rapidly become a form of communication for many teens in the world. New surveys indicate that 75% of all teens in the United States have cell phones and send text messages (30 per day for boys and 80 per day for girls), exceeding phone calls and other forms of communication (Goldberg, 2010). Studies are beginning to examine this form of communication as a way of delivering education, support, and information. For example, technology is available to send reminders to check blood glucose levels.

However, the need for a strong connection with parents to facilitate effective management confounds the adolescent’s need for independence. Additional research needs to explore ways to facilitate communication with the adolescent when parental support diminishes. A need to understand what type and amount of social networking adolescents need is indicated.

**Adolescence and T1DM**

In the context of T1DM, adolescents may experience deterioration in metabolic control due to erratic meals, little or no exercise patterns, poor adherence to treatment
regimens such as multiple injections of insulin per day, hazardous and risk taking behaviors, and eating disorders. Endocrine changes associated with puberty lead to greater insulin resistance (Court, Cameron, Berg-Kelly & Swift, 2009). The challenges adolescents face with T1DM can be daunting. Lack of parental support, irregular schedules, and missing doses of insulin can challenge the health and well-being of these youth. Lack of cognitive maturity and intellectual ability can burden teens even more. The following section will discuss the challenges of managing T1DM as an adolescent from the perspective of parental support, effect of missed insulin doses, and metabolic challenges.

**Lack of parental involvement**

Studies demonstrate that affirmative family communication and conflict resolution skills strongly predict T1DM outcome. This correlation suggests that families living with a member who has T1DM could derive health and behavioral benefits from interventions that improve parent-adolescent-communication (Wysocki, 1993). In particular, the extent of family support available to the adolescent may affect their adherence to the prescribed treatment regime. Follensee (1989) finds that adolescents whose parents maintain some guidance and supervision in the management of diabetes have better metabolic control (Follensee, 1989). In contrast, parent-child conflict is related to worse diabetes outcomes in several studies (Anderson, 2002; Wysocki, 1993; Miller-Johnson, 1994). Follanase’s (1989) work is cited as the landmark study for improved health outcomes in teens with T1DM.

Adolescents have the fine motor control to competently perform most self-management activities. However, they still require help adjusting insulin in times of
stress, illness, and prolonged periods or swings in their diabetes control. The degree a family assists an adolescent is a delicate balance between control that creates conflict and neglect that leads to poor diabetes outcomes (Seiffge-Krenke, 1998). Routine care should incorporate behavioral interventions that enhance the ability for youth and their families to self-manage diabetes.

The adolescent's assumption of responsibility for insulin adjustments does not balance parental withdrawal. Cognitive ability plays a huge role in self-management. In a study of 41 adolescents and their parents, Ingersoll, Orr, Herrold, & Golden (1986) indicate that parents withdraw from the insulin adjustment process as their adolescents grow older. Parental participation nearly ceases by the time the adolescent reaches age fifteen. Older adolescents are statistically no more likely than younger adolescents to self-adjust insulin doses. The more cognitively mature adolescents are, the more likely they are to perceive themselves controlling their illness. Thus, older adolescents who are less cognitively mature than their peers are sometimes given responsibility for self-management behaviors that they are unable to assume (Ingersoll, Orr, Herrold, & Golden, 1986; Schwarzer & Luszczynska, 2005).

Research affirms the need to understand the health-seeking behaviors of adolescents between the ages of 14 to 18 years of age. Evaluating self-management behaviors during adolescence as parental withdrawal of support occurs allows us to understand how to enhance the ability of adolescents independently manage their T1DM.

Arnett’s work (2000) suggests adolescents need to acquire two skills to become an adult: a) accept responsibility for one's self and b) make independent decisions. These skills are greatly complicated for adolescents with chronic illness who attempt to become
an independent member of society and acquire important self-management skills needed
to improve their health (Schilling & Grey, 2002; Innotti, et al., 2006; & Wysocki et al.,
2003). Developing proactive, developmentally current interventions for adolescents with
T1DM requires additional research in the process of becoming mature and gaining
confidence with a chronic health condition.

**Missed insulin doses**

Missing insulin injections (resulting in poor glycemic) is the behavior researchers
most observe in adolescent’s with T1DM. Up to 25% of adolescents report missing
insulin injections. At the same time, parents tend to underestimate adolescent
mismanagement, especially with missing insulin boluses or injections. The missed insulin
doses are significantly related to poor glycemic control (Weisberg & Benchell, 1995).
The older adolescents frequently engage in more mismanagement behaviors than their
younger cohorts, leading to wider swings in diabetes control. Patients who miss less than
one mealtime bolus per week had a mean HgbA1c of 8.0% compared with 8.8% for
patients who missed more than one bolus per week. Research correlates missed mealtime
insulin boluses with one of the major cause of suboptimal glycemic control in youths
with diabetes receiving continuous subcutaneous insulin infusion therapy (Burdick,
Chase, Slover, Knievel, Scrimgeour, Maniatis, & Klingensmith, 2004).

Reminders to adolescents to decrease the number of missed boluses may improve
diabetic control. The question remains how to facilitate daily reminders to sustain
adherence to the medical regime of T1DM in this population. Underestimating behaviors
by parental dyads speaks to the need for outside support systems for the adolescent
separating from parental control. The frequency of missed doses of the older adolescent
suggests lack of maturity and/or social support for self-management. It is in the area of missed dosages that tele-health and reminders could impact glycemic control. Researchers have yet to study the specifics of using tele-health to impact areas of medication adherence and social support in this population.

The Diabetes Control and Complications Trial-DCCT (DCCT, 1995; 1998; 2000) demonstrates the importance of control of T1DM with the reduction of nephropathy and retinopathy (Burdick, Chase, Slover, Knievel, Scrimgeour, Maniatis, & Klingensmith, 2004). Metabolic control during adolescence reduces the risk of progression of microvascular complications in T1DM. A range of factors, including improved knowledge, the nature of the social support, the quality of relationships with health professionals, and the nature of the treatment regimen influence adolescents’ decision about whether to adhere to treatment (Fotheringham & Sawyer, 1995). It is the constant, daily demands of diabetes that make adherence difficult for adolescents who have many other priorities in their daily routines (Burdick, Chase, Slover, Knievel, Scrimgeour, Maniatis, & Klingensmith, 2004). The difficulty adhering to the medical plan further complicates the transition to independent self-management of the adolescents with T1DM (DCCT, 1995; 2000, & 2001). Studies link missed appointments to poor glycemic control (Karter, Parker, Moffet, Ahmed, Ferrara, Liu, & Selby, 2004). The adolescent in rural areas must travel hundreds of miles to see endocrinologists. Change in travel plans can impact the time between appointments adding to missed or skipped appointments. Interventions that prevent common mismanagement practices would significantly reduce risk in this population.
Metabolic changes

An additional factor that complicates the care and control of diabetes during adolescence is nutritional stability with health food choices. Nutritional consistency affects control. Research links consistency in the amount and source of carbohydrate intake from day-to-day with improved blood glucose control in people with T1DM (Wolever & Hamad, 1999). Nutritional intake in many adolescents with diabetes mellitus is poor and does not follow current recommendations. Support for continued educational efforts to achieve adherence to a diabetes diet plan, especially in adolescence. Day-to-day reminders to eat healthy snacks prove helpful in small research studies in adults with type 2 diabetes (Chen, Fang, Chen, & Dai, 2008; Kim, & Kim, 2008). The day-to-day reminders may benefit adolescents; however, current research has not explored the best mode to deliver reminders.

Only ten percent of youth with T1DM meet recommendations for total dietary fat intake, and only seven percent meet recommendations for saturated fat (SEARCH, 2006). In addition to problems with adherence with diet, adolescents with poor metabolic control often have problems accessing health services, further impeding the implementation of intensive insulin therapy (Couper, 1999). DCCT trials demonstrate the benefits of intensive insulin therapy, consisting of four or more insulin injections or boluses of insulin per day (DCCT, 1995, 2000). The study also reveals that intensive management, requiring the adjustment of insulin to fluctuating amounts of nutritional and physical variations and checking blood glucose levels frequently multiple times per day, improve metabolic control in adolescents (DCCT, 1995, 2000). However, adolescents with poor family support and metabolic control often have difficulties adhering to their diabetes

**Environmental**

**Economic and insurance needs of adolescents**

The economic burden on families with a member who has T1DM can be substantial. A study undertaken by Kaiser Foundation to determine the out-of-pocket health care costs of families with a child with T1DM finds that most families with a child with T1DM have health insurance. However, the families incur out-of-pocket health care costs that are 56% higher than those in the control families without diabetes (Kaiser, 2008). According to the Kaiser Family Foundation (2008), approximately one-third of all uninsured Americans are between the ages of 19 to 24, a number twice that of 30 to 64 year-olds. In addition, according to Gallup’s annual survey on health and health care, conducted in November 2005, one in five 18 to 29 year-olds is uninsured (Kaiser, 2008). The differences in the statistics reflect the insured eligible and the general public.

Having a chronic health condition such as T1DM does not assure access to routine health care. The economic burden with high out-of-pocket health care costs affects access to care. The frequency of health care interventions based on the decreased appointments and increased time between appointments of young adults with T1DM indicates these economic issues with young people (Weisberg-Benchall, 2007). As stated previously, research links missed appointments to poor glycemic control (Karter, Parker, Moffet, Ahmed, Ferrara, Liu, & Selby, 2004).
Diabetic complications account for 10% percent of the health care economic burden and correspond to short-term hospitalizations for 18 to 44 year-olds. Diabetes ranks fourth behind childbirth, mental health issues, and injury (CDC, 2006; Kaiser, 2003). Medical providers need to improve access to health care for this young adult population to prevent poor control and hospitalizations. Of the 108 million Americans ages 19 to 64 who have private insurance for the full year, only eight percent have insurance they purchased through the individual or private market. The remaining 100 million adults have coverage through employer-sponsored health plans that are directly tied to their employment. This population is a moving target in the employment field to assess the actual coverage for health benefits. In 2011, it was difficult to estimate how many young adults are employed with health insurance. Most studies group 19 to 64 year-olds together, thus making it difficult to determine if those under the age of thirty have adequate health care coverage. With the unemployment rate being the highest in the age group between 19 to 24, many of these individuals choose to go without health insurance and skip scheduled appointments for their chronic illness (Court, Cameron, Berg-Kelly, & Swift, 2009). The statistics are also hard to track because of short-term employment. Data from emergency room (ER) visits provide some information as to the economic burden in this group. Uninsured may use the ER for the regular care or may wait until serious complications arise before seeking care. Complications arise from inadequate care with kidney failure, myocardial infarctions, and blindness in the adults age 30 and 40 years-old with diabetes (Laing, Swerdlow, Slater, et al., 1999; Kaiser, 2008).
A study of type 1 diabetes in the United Kingdom followed 24,122 eligible patients with insulin-treated diabetes. The mortality rates from acute complications of diabetes are much higher than any other cause-specific rates in the under 20 age group and are similar in each sex during the teenage years, accounting for 37% of the male and 49% of the female deaths. The overall deaths and mortality rates for all ages are considerably higher than rates for the general population, accounting for a total of 949. Acute metabolic complications of diabetes are the greatest single cause of excess death under the age of 30 (Laing, Swerdlow, Slater, et al., 1999).

Many suggest that universal health care is a solution, but that path is not an economic reality. Many of the insurance plans, including Cover Colorado, have premiums ranging from $110 to $900 dollars per month, making it unaffordable for the working poor (Cover Colorado, 2010). The Affordable Health Care Act (2010) legislates continued coverage of a student up to age 26; however, some health insurance companies stipulate the student must remain in school to obtain this coverage (HealthCare.gov., 2010). Recent data show that seventy-five percent of high school students graduate (CDC, 2010). Only 57.8 of high school graduates go directly to higher education. As a result, there is a greater likelihood of youth entering lower-paying jobs without health insurance (CDC, 2010).

The average weekly income for 19 to 24 year-olds who need health insurance most are the working poor making a medium income of $800 per week (CDC, 2010). With insurance rates $110 to $900 dollars per month, income will no doubt go for housing, food, utilities, and mandated car insurance. The Affordable Health Care Act (2010) provides five billion dollars in federal funding to support pre-existing condition
insurance plans in every state. Some states designate that the U.S. Department of Health and Human Services run their pre-existing condition insurance plan (HealthCare.gov., 2010). While insurance coverage provides greater availability of health care coverage, the policies do not address access to care, transition to adult care, and access to health care in rural communities.

Studies estimate the cost of diabetes care in the United States at $174 billion in 2007. This figure includes $27 billion directly to treat diabetes, $58 billion to treat diabetes-related chronic complications, and $31 billion in excess general medical costs. The average daily cost for a hospital inpatient stay due to diabetes-related chronic complications, including neurological, peripheral vascular, cardiovascular, renal, metabolic, and ophthalmic complications is $1831 and $2231 (Congressional Diabetes Caucus, 2010). The average medical expenditures among people diagnosed with diabetes are 2.3 times higher than for those without diabetes. Additionally, research estimates the reduced national productivity to account for $58 to $105 billion.

Challenges mark the period of transition to adulthood. As morbidity increases with age, better access to health care may prove to greatly reduce the economic burden of people with diabetes in their forties and older. In the age group of 18 to 44 year-olds, the medication, insulin, does not even make the top fifteen medications for which this group seeks medical attention (Goldman, Joyce, Escarse, Pace, Solomon, Laouri, Landsman, & Teutsch, 2004). This absence speaks to the relative low cost of the medication, but high cost of not using medication correctly or missing insulin injections. However, as cited previously, the impact of diabetes and complications accounts for ten percent of the health care burden in this age group, and short-term hospitalizations contribute the most
(CDC, 2006; Kaiser, 2008). By addressing the health-seeking behaviors of the adolescent population with T1DM, we may understand the challenges the rural adolescent faces and the effects on disease management.

Weisberg & Benchall (2007) describe the issues of transitional care to adulthood. They identify a need to hire a “transitions coordinator” to facilitate transition. Increasing telephone and e-mail contact with young adults as well as developing a website or newsletter improves communication in the transitional phase. Small pilot studies demonstrate that email and phone-call contacts are acceptable and useful for patients. Programs that fund early screening for micro-vascular complications and that fund collaboration with patients and their families to develop individualized written transition plans at least two years prior to the transition date improve contact between health care teams and adolescents. It is unknown on a large scale if this approach is a practice-specific strategy. We require research to discern if this practice leads to sustainable positive outcomes and determine how to access the financial resources needed to carry out the transitional process and incorporate the plan into current health care in rural settings (Weisberg & Benchall, 2007). Future studies need to ask whether or not rural youth access care similar to their urban counterparts during these transitional times.

**Access to health care for rural adolescents**

Problems associated with transition to adult health care systems are numerous. Many health care providers do not provide the specific care needed for the emerging adult who is eighteen to twenty-five years old. Young adults can be lost to health care systems due to changes in health care providers, living arrangements, economical support, and geographical locations. Using a questionnaire, Pacuald & Yale (2005)
surveyed 154 patients with diabetes who had been transferred from the diabetes clinic at the Alberta Children’s Hospital to adult care services from June 1992 to June 1997 in Montreal Canada. (n=154). Challenges noted by Pacuald & Yale (2005) reveal that 46% of adolescents responding (N=75) with diabetes report difficulty with transitional care. One in three acknowledge a greater than six-month span of time between appointments with a medical provider. Eleven percent of adolescents with T1DM are lost to follow up care for their diabetes. Fifty-two percent of the respondents, (N=75) either experience a problem, a delay of >12 months between their transition of care, or no current follow-up. Some studies report as long as two years before medical providers reestablish care (Pacuald & Yale, 2005; VanWellgenham, MacDonald, & Dean, 2008; Harris, Freeman, & Duke, 2009). Understanding the issues that create the gap in care in rural youth, particularly health-seeking behaviors of youth with T1DM, may improve diabetic outcomes in young adults.

**Transitioning to adult care in rural areas**

The challenges for youth with a chronic illness increase in rural geographical areas due to limited resources. Individuals living in rural areas are less likely to engage in preventive behaviors such as regular blood pressure checks, Pap smears, and breast examinations (Kaiser, 2003). In addition, rural adults engage in high-risk lifestyle behaviors such as smoking, refusal to wear seat belts, and failure to exercise regularly (Kaiser, 2003). The addition of a chronic illness impacts health outcomes for young adults with T1DM in these rural areas.

Since 2009, inquiry is expanding in the area of technology and chronic disease management. Much of the research focuses on the acceptance, delivery of care, and
follow-up using telemedicine and other forms of technology. The potential, therefore, to reach youth in rural areas has improved.

I reviewed the transitional period of adolescence living in rural areas, yet the research adds very little information on adolescent health needs. A secondary literature search on the health care needs in rural adolescents produced 1,212 articles from PubMed and 137,000 hits from Google scholar. Very few studies report on youth’s perceptions about health-related issues and even less give voice to youth with disabilities, chronic health conditions, or youth in therapeutic foster care (Broussard, 2011).

Through a more focused literature review of research in health needs of rural adolescents, the majority of articles focus on access to health care, sexual health, and mental health issues. When I limited the search to diabetic care and health needs of rural youth, I only identified five articles. Three of the studies were conducted outside of the United States and involved a difference in health care systems. One paper described earlier, Franklin et al. (2006), identifies studies that evaluate cell phone voice and text messaging interventions, and this article is the only experimental research noted in the literature review.

In a meta-analysis review, Krishna and colleagues (2009) find twenty-five studies that meet criteria for their research on the role of cell phones and text messaging interventions to improve outcomes or processes of care. Their findings show that health outcomes and care processes improve when health care providers enhance standard care with reminders, monitor and manage disease, and educate through cell phone voice and short message service (Krishna, Boren, & Balas, 2009). The use and acceptance small studies report do support a role for cell phones and text messaging. However, research
has yet to determine how to use text messaging, with what population to use text messaging, and when such practices are appropriate.

**Support**

The literature reveals adolescent struggles, need for transitional support, and financial support, but lacks awareness of what would make a successful journey of the transitional stage to young adulthood. The problem requires additional research, and Meleis’ Transitional Theory can provide a framework to research health-seeking behaviors in adolescents and identify themes of success that youth define as important. Studies synthesizing rather than describing the adolescent’s state of mind during the transition process will further the development of knowledge in this area.

Previous research defines adolescence as a biological process known as puberty. My work addresses how visible physiological changes mark differences of growth and development. Changes in social roles, notably within the institutions of family, education, employment, and society characterize the transition to adulthood. The need to study what we can do to make this transition less complicated is important. Particularly difficult to determine is how the structure of educational, employment, social, and family institutions help adolescents move from dependence to independence. No other life-course transition is so fully defined by social institutions as the transition from adolescence to adulthood (Hamilton & Hamilton, 2009). Seldom is the word “adolescence” defined without including the descriptor of transition, indicating that the entire period of adolescence is a bridge between childhood and adulthood, or a period of transition (Fuhrmann, 1990). The addition of a chronic illness complicates this difficult period. Researchers have not
adequately explored the health-seeking behaviors for adolescents, especially in a rural setting.

**Gaps in the Literature and Future Research Opportunities**

Nurse researchers are keenly interested in “transition” because the concept applies to a wide range of phenomena across many clinical areas in nursing. Universal properties of transitions are process, direction, and change in fundamental life patterns. At the individual and family levels, transitions include changes to the identity of the person going through the transition and the roles the person represents in relationships. The ability to develop skills to alter the roles and patterns of behaviors contribute to success (Meleis, Sawyer, Im, Hilfinger, Messias, & Schumacher, 2000).

Transitions result from changes in lives, health, relationships, and environments (Schumacher & Meleis, 1994). Meleis’ Transitional Theory supports the framework to research adolescents with type 1 diabetes. In addition to the taxing responsibility of managing a chronic disease, a number of transitional events make individuals especially vulnerable: illness experiences such as diagnosis, surgical procedures, rehabilitation and recovery, as well as developmental and lifespan transitions such as pregnancy, childbirth, parenthood, adolescence, and menopause (Meleis & Chick, 1986; Meleis & Trangenstein, 1994).

Meleis, Sawyer, Im, Hilfinger, & Schumacher, (2000) suggest that transitions consisting of types and patterns of transitions, properties of transition experiences, facilitating and inhibiting conditions, process indicators, outcome indicators, and nursing therapeutics are all part of an emerging middle-range theory. Gaps in understanding require additional exploration of diverse, complex, and multiple dimensions of
transitional experiences (Meleis, Sawyer, Im, Hilfinger, & Schumacher, 2000). Thus, I will use Transitional Theory to research the transition of dependent adolescence to independent young adults with a chronic illness specifically T1DM.

The meanings and expectations a person internalizes during the transition may influence the quality of the transition experience and the consequences of transitions. A person’s level of knowledge and skill within a particular transitional environment determines whether or not the transition is positive or negative. Finally, the level of planning and the person’s emotional and physical well-being influence the outcome of the transitional event. Indicators of successful transitions are subjective well-being, role mastery, and the well-being of relationships (Meleis, Sawyer, Im, Hilfinger, Messias, & Schumacher, 2000). In terms of the adolescent with T1DM, signs of successful transition include increased self-efficacy and self-management skills resulting in successful diabetes management. The success of the diabetes management reflects optimal glycemic control.

An inadequate understanding of the transition process requires additional research of family systems therapy, cognitive behavioral therapy, motivational interviewing, and frequency of contact with health care professionals and the effects on the Hemoglobin A1c that measures glycemic control. Randomized control studies with larger numbers, for longer periods of time, are needed to evaluate these areas and specify standards of care for education and follow-up with the age group of 13-18 year-olds. The context and environment that provides education is crucial to adolescents. Research has not quantified the frequency of successful communications to adolescents via text messaging or any mode. Researchers have not fully identified key components in the environment that
provide adolescents with a positive health-care setting or what adolescents perceive as positive health-seeking behaviors.

Research has also neglected the effect of interventions and the impact of diabetes on the quality of life in adolescent years. Limitations to previous studies result from outcome measures of the diabetes itself and not the impact on the adolescent’s life. The Diabetes Control and Complications Trial (DCCT) and several subsequent reports show the benefit of intensive diabetes management on HgbA1c in children and adolescents, but additional studies need to examine the aspects of interventions that improve outcomes with intensive management approach, especially as adolescents become more independent in their self-management of T1DM. Follow-up of the previous DCCT cohort by the Epidemiology of Diabetes Interventions and Complications study (EDIC) find that the HgbA1c rises over time in a person with diabetes. We need to explore education interventions that might decrease deterioration of this glycemic control (DCCT, 1993, 1995; Dabelea, 2007; Hanna, 1999; Wysoki, 1993) and improve independent self-management effectiveness in the transition of adolescence to young adults.

General themes of nutrition, exercise, and medication characterize diabetes education, but researchers pay little focus to why adolescents do not comply. Adolescents whose parents are less involved with the decision-making tend to have worse diabetic outcomes. The research questions include 1) How can health care providers replace the lost support in this age group? 2) How can those interested in improving an adolescent’s health motivate adolescents to adhere to a medical management regimen to improve glycemic control, thereby reducing long-term complications with their diabetes?
3) Could professional health care teams in contact with the adolescent via text messaging or other modes of social support supplement lost parental support?

The thesis study initially aimed to improve glycemic control by increasing communication with adolescents by using text messaging. However, it was unknown if improved diabetic outcomes require a change in the mode of treatment, the delivery of information, or the information itself. Therefore, the primary goal of this study transitioned to an exploration of the health-seeking behaviors of adolescents with T1DM in rural areas. Research needs to focus on rural adolescents with T1DM because they must travel great geographical distances to specialty endocrine clinics and because adolescents often increase the time between medical visits.

Advanced medical practice has not effectively changed the outcomes of T1DM. As research communicates medical advances and supports patients with chronic diseases, a desire for positive lasting outcomes requires that we address how well a patient accepts and adheres to that information. Health care teams struggle to personalize diabetic education complicated by time constraints, travel to endocrine centers, and lifestyles of busy families with teenagers. The challenge left for the health care team is to find innovative ways to provide support and diabetes education to adolescents in a developmentally appropriate method. Navigating health care for young adults is challenging even without a chronic illness. Adolescents struggle to access help when systems are rigid and require advance planning. A population learning to adapt to independent new systems needs flexible, creative opportunities to access health care. Systems requiring financial responsibility penalize a young person who may miss or
arrive late to medical appointments by delaying rescheduling or conveying a judgmental attitude.

Increasingly, sophisticated computer interfacing with blood glucose (BG) meters, continuous glucose sensors, insulin pumps, and insulin pens allow patients to interact directly with the diabetes team between visits, a technological advance that may improve diabetes management (Jansa, Vidal, & Viaplana, 2006). A combined adolescent/young adult clinic with both pediatric and adult diabetes specialists may be the optimal model of transition to adult care. Recent studies suggest declining incidence of complications in many areas with specialized clinics (Donaghue, Chiarelli, Trotta, Allgrove, & Dahl-Jorgensen, 2009). A decline in complications occurs over a period of time when medical providers substantially change ways to manage diabetes, identify risk factors, and regularly screen patients for complications. There is no evidence that improved screening for complications is a worldwide occurrence. However, in areas where health care is not optimal, greater risks of complications remain (Donaghue, Chiarelli, Trotta, Allgrove, & Dahl-Jorgensen, 2009). The nearest pediatric endocrine centers available to rural western Colorado are 250 miles in both directions. Specialty clinics with telemedicine capabilities could greatly improve outcomes of the young adult population who come to rural areas to work, play, and obtain education.

The American Diabetes Association advertised promising technology in July, 2010, when the organization announced the arrival of the first diabetic magazine mobile application, Diabetes Health Mobile (Diabetes health.com, 2010). The application offers extensive up-to-date data content, forums, and DHTV via the iPhone® and iPod®. The technology is available; however, both a well-trained medical community that knows
how to employ this technology as well as opportunities to embrace the e-health to its maximum potential remain a distant reality in rural areas. Evidence that technology improves long-term outcomes in the adolescent with T1DM is also missing.

**Health-Seeking Behaviors**

Justification exists to identify what adolescents need to improve their health-seeking behavior in diabetes care. Much of the literature focuses on prevention or reaction to health care issues. We know little about what adolescents perceive they require to manage their diabetes independently. Through my own clinical practice I began text messaging two adolescents with T1DM. After searching the literature, I found little that addresses how well text messaging as a form of chronic disease management sustains and improves health outcomes. Through individual appointments and support groups, I identified a need to ask adolescents what they require to improve diabetic self-management. By planning interventions through text messaging, there was a perception on the clinician’s perspective that adolescents prefer the contact through text messaging. I found little in the literature to support the use of text messaging with adolescents. This discrepancy led to the decision to research strategies and methods that may improve health-seeking behaviors from the perspective of the adolescent.

Descriptive and exploratory studies demonstrate positive outcomes related to the use of text messaging or mobile phone use as a source for communicating, notifying patients of appointments, reminding patients to take medications, and educating the study participants (Chen, & Fang, 2008; Downer, Meara, & DaCosta, 2005; Ferra, Rocca, et al., 2004; Franklin, Waller, Pagliari, & Greene, 2003, 2006; Howells, et al., 2002; Kim & Kim, 2008; Kollman & Riedl, 2007; Mao, Zhang, & Zhai, 2008; Saoke-Joo & Bom-
Taeck, 2007). However, researchers have conducted very little research that explores adolescent youth who use text messaging as a means to improve health-seeking behaviors. As adolescents simultaneously separate with their families and struggle to find their own identities, they require additional education and support. The complications that accompany separation demand a focus on adolescents, and we need to ask, “What do they require to have a positive identity with a chronic illness?”

We need solutions to increase access to health care for the young adult population. In a technological society, an increase in telemedicine or electronic health (e-health) could well be an answer to meet this age group at their own level by using technology that is part of their everyday life. The questions become what route, method, or source of media would youth like to use, and what impact would this have on health-seeking behaviors?

By instituting mobile communications as a tool for medical providers to use, including email, text messaging, Facebook, and Twitter to communicate with young adults in the time of transition, interested parties could create and coordinate seamless health care. The communication could decrease the length of time adolescents face to access their health care team. Health care providers could reduce complications by using these social networking tools to address medical concerns, and they could also educate and support at-risk young people during long periods away from known medical care. Establishing medical communication via social networking for young adults who have been well established in a primary care setting lends itself best to this transitional practice and may reduce liability concerns. Exploring adolescent interest in this type of intervention will be part of the future progression of research. Training more nurse
practitioners and primary care physicians in management of chronic illness and prevention of complications in the use of social networking tools will reduce the lack of access to routine health visits. Addressing issues of risky behavior early in the adolescent’s care via e-health and tele-health in an effort to establish lifelong healthy practices may well break down barriers youth perceive when coming to formal and private practice offices in rural settings.

The main focus in chronic disease management has been on medical care, with less attention being paid to psychosocial aspects of life with a chronic disorder. Nevertheless, the role of educational interventions in facilitating adaptation to chronic disease is receiving growing recognition, and current care policies advocate greater involvement of patients in self-care (Timpka, Eriksson, Ludvigsson, Ekberg, Nordfeldt, & Hanberger, 2008). The need to utilize research that gives voice to participants is the key reason for using Participatory Action Research (PAR) for adolescents. A model of care for adolescents largely focuses on either a pediatric model of care or an adult model of care. Health care providers place little attention on the transition model of care and the proactive needs of the adolescent. PAR supports inquiry into the health-seeking behaviors of adolescents. Listening to adolescents voice their spontaneous reflection of the health care system provides opportunities to increase access and health-seeking behaviors. We should examine evidence of their perception of health and physical and psychological needs as they live with chronic illness.

Participatory Action Research (PAR) is a key method to identify which behavioral interventions are successful for adolescents. Through the personal voices of adolescents, researchers can identify themes for success and develop interventions to
support and increase self-management skills. I will explain details of using PAR to examine health-seeking behaviors in adolescents with T1DM in great detail in Chapter III under “methods.” There is an absence in Action Research literature for theory building (Dick, 2004) with the exception of Koch and Kralik’s work on transition. By using the cyclical nature of PAR, the promotion, reflection, and reconstruction of experiences and stories enhance people’s lives. Through PAR, collaborative action enables the development of theory building with the aim to make a difference in health care. Thus, practical effects define theory (Koch & Kralik, 2006). This study will add to the understanding of Transition Theory, for we can apply the theory to the context of rural adolescents with T1DM.

Assumptions, Biases, Experiences

The relationship participants have with the researcher is one of the most important aspects of PAR methodology. Being a health care provider in the community will encourage personal, cooperative relationships, including familiarity with communication norms and expectations associated with rural adolescents. Adolescence is a time of change and growth for normal healthy individuals. Prior to the research process, researchers must outline personal assumptions, biases, and experience to protect the quality of the research process. The following are my assumptions and biases.

1. Normal growth and development is difficult for adolescents under the best circumstances with family and educational support.

2. A challenging disease such as type 1 diabetes adds increased stress and burden to adolescents.

3. Family support improves diabetic control in adolescence.
4. We don’t know what factors encourage families with children with chronic illness to participate with the health care team and with health care professionals.

5. Technology can be an effective tool for communication with patients with a chronic disease.

6. It is unknown if health care providers can be an effective support to families who do not support their teenager with type 1 diabetes.

7. Research is limited on the role of replacing parental support with education via text messaging multiple times a week and the impact on teenagers with poor glycemic control.

8. Increasing social support will improve glycemic control in adolescents with T1DM.

9. Improved glycemic control in the teenage years will reduce long-term cardiac, neurological, retinal, and nephrological complications in later years, thus reducing the cost and burden of type 1 diabetes.

Adolescents are a unique and vulnerable group. They are difficult to categorize by specific demographic characteristics. Add a chronic disease to the scenario and every adolescent with T1DM is potentially unique. PAR is an important method to use with adolescents to summarize their distinctive needs and concerns. Chapter III describes the methodology of Participatory Action Research (PAR) and the strategy for the research dissertation. I will outline interviews of singular, paired, and group discussions, and I will describe questions and group process. Chapters IV and V outline the study results and discuss future implications for research, education, and practice.
CHAPTER III
PARTICIPATORY ACTION RESEARCH

Method of Inquiry

Participatory Action Research (PAR) fits under an umbrella of terms used for methodologies since the 1970’s. Using PubMed and Google Scholar, I completed a literature search of “PAR in youth with T1DM,” retrieving twelve articles from PubMed, 4600 articles through Google Scholar, and 380 articles through Find It on the University of Colorado Health Sciences library search engine. I searched secondary sources cited in the five main articles with inclusion criteria of adolescents, T1DM, and PAR. Three articles pertain to rural youth with a chronic illness and the use of community action research. By focusing on PAR, I expanded the search to include other disease processes, and this search led mainly to issues pertaining to social injustice in the educational and counseling literature. Using the same sites noted above, a search under Kralik and Koch, who are known Australian PAR researchers, yielded 160 articles. I examined twelve articles using the research methodology PAR in adolescents. I used these articles as a guide to develop questions for the research proposal.

PAR utilizes a group process that brings together community members and professionals to raise and examine issues relevant to community. In this case, the community is composed of adolescents with type 1 diabetes (T1DM), and the relevant issues include health-seeking behaviors adolescents need to acquire to support glycemic control. PAR uses knowledge that the process generates to create action plans. Traditional research explores community members, whereas in PAR, community members themselves are equal participants in the research team. They partner with
researchers to identify the problems that are most important to their local community. The process can identify the community at the micro or macro level. In the study of adolescents with T1DM, this unique community requires clarification of their health care options. Together, the community forms research questions that apply to their issues or concerns. The research participants, along with the researcher, develop action results or an intervention related to the problems they identify. The participants create ways to put the results to work through actions the PAR process identifies (Smith, Davis, & Bhowmik, 2010). PAR has an elemental foundation of community-based action research; PAR is interested in the issues of a group, a community, or an organization (Stringer 1996, 1999; Koch & Kralik, 2006). PAR is a process of inquiry that has a social context with life-enhancing characteristics that enable the expression of a person’s full potential (Koch & Kralik, 2006).

PAR is a potentially democratic process that gives a participant an equal voice. The process can be liberating as participants construct meaning during facilitated group discussions (Koch & Kralik, 2006, p. 6). Research needs to explore ways to include teenagers in their own care by using an adolescent’s perspective. The PAR process can encourage reflection and reconstruction of experiences leading to the acquisition of new knowledge, and these insights can improve understanding of a group’s needs and health-seeking behaviors (Kock & Kralik, 2006). By telling stories and reflecting, the participants can identify health-seeking behaviors in their day-to-day lives. As researchers focus on adolescent experiences, guiding questions will explore what works for this unique population.
Kemmis and McTaggart (1987) write the goal of social justice into the steps of McKernan’s (1988) definition of action research. Kemmis and McTaggart (1987) describe action research as a form of “collective, self-reflective inquiry undertaken by participants in social situations in order to improve the rationality and justices of their own social or educational practices” (Kemmis & McTaggart, 1987, p. 6). McKernan (1988) expands this definition by describing action research as “a form of self-reflective problem solving, which enables practitioners to better understand and solve pressing problems in social settings” (McKernan, 1988, p. 6). This methodology is an appropriate method for research because adolescents are a social group. The ability to understand why adolescents feel disconnected from their health care team can provide medical teams with ways to respond to this unique group’s health challenges. By studying the adolescent perspective of how they manage, access, and engage in their health care, researchers may develop new strategies to improve the health of adolescents with T1DM.

Using PAR in research involving youth (yPAR) (Cammarato and Fine, 2008) creates an environment that allows youth to develop solutions that address their concerns. Knowledge production or knowledge from youth leads to different perspectives than adults would generate. The democratization and group process can empower youth. Cammarato and Fine (2008), for example, observe that yPAR goes beyond actions and products to have important implications for youth development. In yPAR, young people study problems and derive methods to overcome obstacles that deter their own well-being and progress. Understanding how to overcome these obstacles becomes critical knowledge for the discovery of one's own efficacy to produce personal as well as social
change. Once young people discover that they can effect change through engaged citizenship, oppressive systems and subjugating discourses no longer have the same power to persuade them (Cammarato & Fine, 2008). Youth find their voice and ability to navigate unpredictable and sometimes oppressive institutional systems.

PAR takes its cues (questioning, puzzles, problems, and solutions) from the observations offered by health care providers with community roots and context. This method can create conflict between rigor and relevance of the research (Herr, 2005). The advantage to using PAR for this research study is that identifying the local culture and needs in a rural setting effect social change. Action research demands a form of intervention or “action,” a change that makes this methodology relevant to the small community of adolescents who will have a voice in how health care providers meet their health care needs.

Using PAR as a method to inquire into the needs of adolescents in rural areas is a research model based on work by Freire, Olrlando, Fals, & Borda, (2000). Freire et al., (2000) frame participatory research as a thematic, inductive process. Issues important to the community become more visible, and participants engage the researcher in social critique (Herr, 2005). PAR provides a method to work with subordinated populations to solve unique local problems with local resources of knowledge (Denzin, & Lincoln, 2008; Kamberlis & Dimitriadis, 2005). PAR is a multidimensional approach to knowledge-building and action that includes the following principles: intend liberation from oppressed cultures or systems, participate in a dynamic process of action and reflection, develop a compassionate culture, use the present as a starting point, collectively investigate and act, and develop new knowledge (Smith, 2007).
Researchers asked adolescent support groups on a quarterly basis over the last year an important question: “What is needed to make your health care more of a collaborative effort?” The responses were consistent: “It does not matter how hard we try.” “It never seems good enough” (Diabetes Counts, support group GMMS, 2011).

These responses invite two key questions. First, how can technology improve glycemic control? What health-seeking behaviors do adolescents with T1DM need to improve when they have a chronic illness such as T1DM?

PAR may limit certain communities. However, by using PAR as a more inclusive method for researching a vulnerable population such as adolescents, the group may express context-rich experiences. Many studies struggle with recruitment and retention while researching vulnerable populations. The use of PAR has the potential to gain valuable, context-rich information from adolescents with T1DM in western Colorado. The PAR methodology invites adolescents to voice their insights in ways that allow researchers to discover new areas of health-seeking behaviors and encourage adolescents to engage in their health care.

I engaged in group processes and support groups for over fifteen years. The need to facilitate group discussion is imperative when using PAR methodology. Rooted in the local community, I have experience with group process in multiple settings and experience with adolescents.

**Methodology**

I used PAR as the methodology to examine health-seeking behaviors of adolescents in a rural community who have T1DM. This chapter describes the aim,
methods, retention, informed consent, compensation, internal review board approval, sampling, group process, instrument selection and usage, and data analysis techniques.

**Aims**

The aims of the study include the following inquiries:

- Explore the health-seeking behaviors of adolescents in rural western Colorado.
- Identify health-seeking behaviors of adolescents with T1DM that lead to positive glycemic health.
- Define independent behaviors that adolescents perceive as positive and lead to collaborative disease management with their health care team.

I base the focus of the research study on the participants’ described needs and issues they identify as most important in their health and management of glycemic control. The process uses a “look, think, and act cycle” (Stringer, 1999, Koch & Kralik, 2006).

**Method**

Stringer and Genat’s (2004) work influences Koch and Kralik (2006) with the “look, think, and act” framework. The basic research model gathers relevant information, builds a picture of the information, and explores and interprets what the picture means. The action phase plans, reports, implements or evaluates interventions, thoughts, and themes researchers find in the process.

The purpose of PAR methodology is to investigate a problem or issue (Koch and Kralik, 2006). Through the process of inquiry, explanations of the inquiry enable individuals to understand the nature of the problems. Engaging in action research of this nature allows participants to share in the solutions of the process. Collaborative
exploration helps practitioners, agency workers, client groups, and other stake-holding parties to develop increasingly sophisticated understandings of the problems and issues (Stringer, 2007). PAR guides my research using the procedures, “look, think, and act” as a model to describe a systematic, cyclical action process. (See Appendix C.)

I used the PAR process to explore the aims described above in four iterative cycles by paired and singular interviews of adolescents with T1DM. Over a three-month period, I described the health-seeking behaviors of adolescents with T1DM and identified issues in collaboration of their health care needs. I detail the phases for the focus groups as well as questions, information, and a model for the process in the following discussion.

I administered a Quality of Life survey (QOL Peds 4.0) to each participant during the first focus cycle. The PedsQL™ consists of brief, practical, generic core scales suitable for use with healthy school and community populations, as well as with pediatric populations with acute and chronic health conditions. PedsQL™ condition-specific modules complement the generic core scales for use in designated clinical populations. The Peds QOL 4.0 is specific to adolescents age 13-18 with T1DM. For the purposes of this study, the QOL Peds 4.0 for diabetes age 13-18 tool is a broad starting point for understanding youth quality of life when living with T1DM. I discussed descriptive and thematic analysis of the survey results with the participants, and I used broad direction to the second focus group conversations and subsequent probing of health-seeking behaviors in the questions. I organized the agenda for subsequent interviews based on comments from the previous focus group sessions. I organized the reflections from the participants into themes and sub-themes to discuss at the next focus group. I also addressed pre-planned formal questions in each focus group and interview. Finally, I
continually reflected on participant’s responses with themes and discussion details generating the next focus group agenda. These summaries provided a starting point for the conversation for the next focus group. I organized questions added at each focus group meeting for consistency in each setting of the participants.

**Participatory Action Research Cycle**

**Look phase**

The first phase in PAR is the *look* phase. The *look* phase gathers participant information and demographics and sets goals to describe and evaluate concerns or issues that adolescents reveal. In-depth discussions with a group of seven, high-school eligible adolescents with T1DM formed the basis for data generation. In the first cycle of data generation, the focus builds a basic picture or “looking.” In the model, researchers gather relevant information to construct a representation of needs or issues from the group. In this study, I pose the following question: “What are health-seeking behaviors of adolescents with T1DM in a rural western Colorado?” I then reframe the question in developmentally appropriate language for the adolescent focus group: “What does it mean to be healthy while living with T1DM?” Reframing the question is necessary because adolescents do not understand the term “health-seeking.” The questions define and develop basic goals for the group to compile a common theme.

After I obtained adolescent assent and parental consent in the first focus group meeting, I completed baseline data including demographics and the pediatric quality of life questionnaire. The questionnaire results provided a catalyst for discussion in the first focus group. However, adolescents were not able to meet for a pre-group meeting to sign consent and complete the QOL questionnaire. We discussed exploratory data describing
what it means to be an adolescent with T1DM and “What does my health care team need to know about myself?”

In the first group it is important to develop norms that permit the participants to share and work through emotions and experiences that may be uncomfortable (Koch & Kralik, 2006). I asked participants to identify what is important to them in a group environment. They agreed that confidentiality and listening to the other adolescents were the group rules. We revisited these norms for each subsequent focus group, and I reminded participants to not share information learned about another participant. A safe environment is imperative to allow honest discussion and maintain respect for all group members.

A paper chart and a review of norms at each meeting maintained respect and confidentiality of the group. I placed data generated by the focus groups on a paper chart for the participants to review. I securely locked these paper charts and field notes in my office. I generated these field notes during the discussion group, and I analyzed them immediately after the group session. I taped and password-protected interviews on my iPhone® which I then transcribed. The iPhone® remained in my possession at all times. At the conclusion of the research process, I downloaded interviews to a locked computer that I stored in my home. I then erased the interviews on the iPhone®.

The first focus group addressed the following questions:

- What would you like the group to know about you?

- How has having T1DM affected the way you live, socialize, play, study, sleep and work, and think about yourself and or your body?

- What are important issues for you?
• What did you learn about the Quality of Life survey you completed for the group?
• What does health-seeking behavior mean to you?
• What do you feel your health care team should know about you?
• What is a definition of QOL in general for this group?

Think phase

The second phase, *thinking*, in the PAR model describes the picture or situation. The *think* cycle interprets and explains the information the participants express. In the *look* phase, I categorized responses that surfaced into themes and areas of need. I asked participants to reflect on the picture, “What does it mean to have T1DM as an adolescent”? I analyzed the description of “why are things as they are” (Koch & Kralik, 2006). In the second focus group, I analyzed and described what was happening in the group. I then explained the collected data, the themes of the first group, to each of the participants.

The importance of using PAR in the setting is actually hearing and understanding the voice of the community of adolescents. Through the *thinking stage*, the participants and I compared and contrasted their interpretations of their story or picture of being healthy while living with T1DM (Koch & Kralik, 2006). Feedback was ongoing, and emerging data from the previous group guided the conversation and structure of the following focus groups. I supplied each participant with a summary of themes generated by other participants to compare and contrast. Many of the participants agreed upon some of the themes, and some of the themes differed for each participant. Chapter IV will discuss in detail the results of these themes.
By studying data and feedback, I analyzed the emerging themes and clustered them into groups. I validated these themes when I returned responses to each participant in the subsequent session. The cyclic feedback loop is crucial in PAR and preserves distinctive features and common discussions from each participant interview or group meeting.

In the second focus group, I reviewed the themes from the first group meeting. Direction for the second group focused on how participants could improve quality of life, and the group explored how values affected quality of life. In the second setting, we explored common issues, and we completed goal setting for session three. I sent participants home with one goal: Explore what interventions by the health care team might facilitate quality of life transitions. I posed several questions that helped them address that goal: What has worked for you in your health care, and what do you need in your health care? What do you need in order to improve your quality of life? How can your health care team help? I asked them to reflect on certain interventions available to them that impacted their access to health care. Finally, I asked them to think about ways they could improve their health-seeking behaviors.

**Act phase**

The third stage, or *act* phase in PAR, is plan, implement, and evaluate what the process reveals. Koch and Kralik (2006) state, when contemplating action, participants question what is important in their lives and consider the available options. It is important to retain both the distinctive features of each group and find recurring themes within the group. In this case, it may be a change in the way professionals deliver health care to the adolescent or an effective media source health care providers use to deliver education and
information about the care to the adolescent. Researchers address the setting or method of the education and follow up for the adolescent needs by planning actions to address these needs. Action may also include the “act” of reflecting on their transition experience and the impact of the process of PAR on the participants. Involvement of participants ensures constructs are congruent with their lived experiences (Koch and Kralik, 2006). Assurance of acceptance improves if doctors, nurses, nurse practitioners, and certified diabetes educators use the adolescent’s own ideas in the act phase.

The act cycle can define interventions the group participants discover. A health care provider then evaluates and addresses the effectiveness and appropriateness of the interventions. For example, a nurse may gather the solutions the group identifies, and then describes and presents the conclusions to the group for accuracy. The cycle will return to the look phase to identify the validity of group information and accuracy of the interventions proposed. Such interventions could include support groups for the adolescents via social media or modification or alteration of communication strategies in health care, such as email, text messaging, or Skyping for one of two office visits. A health care provider may change the structure for health care visits, such as group visits with other adolescents, or include other activities, such as educational opportunities to understand the characteristics of individual disease issues, options for nutrition, or alternative insulin options.

In the act phase, I reexamined the participant’s view of what it means to have T1DM. This transitional process created meaning and provided a chance to act or label certain issues explored in earlier meetings. Questions addressed in the third focus group included the following:
• What do our health care providers, teachers, and friends, need to know about our health?
• What is the most important information that is not understood about me?
• My greatest obstacle in having T1DM is...?
• What actions would enhance quality of life for you?
• What was it like to be involved in the research process?

**Opportunities Using PAR**

PAR as a methodology presents the opportunity to gain a deep theoretical and clinical understanding of transition. PAR is an opportunity to develop knowledge. Through informed and constructed dependent information, I can design a course of action. By exploring the perspectives of the adolescents living in rural areas of the western Colorado, my study anticipates new knowledge that will improve health care. Thus, understanding the behavioral needs of the adolescent will lead to the implementation of new interventions that connects adolescents to the health care community.

PAR translates knowledge into action and produces knowledge-in-action. Central to the process is a cycle of critical thinking and reflection (Koch & Kralik, 2006). Reflection encourages adolescents to discuss, write, or tell their own stories. An adult researcher summarizing their discussions may inhibit what adolescents say. Research participants find PAR cycles appealing because they can interpret their own behavior (Koch, Mann, Karlik, van Loon, 2005).

In my study, the fourth session was an individualized telephone interview with each participant. A telephone interview was appropriate, for my three previous interviews
with the paired and individual participants established rapport. Adolescent development involves belonging to a group, yet participants also value privacy and confidentiality. The PAR process provides both for the emerging adult. I recorded the phone interview on an iPhone® and then transcribed the interviews, which I then analyzed for themes and social interactions. Again, it was imperative to hear the voice of the research participants to accurately describe their experience (Grover, 2004). By giving them a confidential interview, I could address concerns or comments that participants did not feel they could express in a group setting.

During the focus groups, I provided the participants with opportunities to reflect on issues emerging from the quantitative survey data collected in the first group sessions. I used Varni’s (2008) instrument for Pediatric Quality of Life in T1DM for ages thirteen to eighteen (QOL Version 4.0) to measure baseline data. The review of these results in the second focus groups generated community-specific qualitative data that allow for a more in-depth understanding of emergent themes and trends from initial survey data. The third focus group solicited general and population-based ideas for possible program and policy development areas related to access of care and understanding health-seeking behaviors.

The participants’ ideas shaped the final focus groups. I explored opportunities to evaluate group dynamics to see if any of the participants would initiate contact between groups via social networking meetings. At this point, the group decided to continue with an informal, bi-monthly support group. For the study purposes, the telephone interviews concluded the research proposal study. Future research may study the progression and support the group generates if future group contact continues.
I audio-recorded focus groups to review accuracy and messages that I may have missed from group interaction. I then reviewed and transcribed interviews and themes generated from the interviews to clarify each of the subsequent focus groups. This method provided a mechanism to check ongoing members. During the last telephone interview, I asked participants to identify what methods worked and to identify if they gleaned information from the group process that would influence their health-seeking behaviors. I posed the following questions: “Why did you join the research group?” and “Do you have examples of a change you would make after being involved in the group process?” I provided a final chance for individual participants to express what they did not feel comfortable expressing in the group process. I also examined opportunities to explore the appropriate setting for support (i.e. individual or group) for adolescents in a transitional process and the use of social media.

**Sampling**

I gathered a convenience sample of high school eligible adolescents in Mesa County through a central medical group. To recruit participants, I contacted, via phone calls to parents, adolescents who met inclusion criteria of being a type 1 diabetic for longer than two years and who were eligible for high school (grades 9-12). A local pediatric endocrinologist helped me obtain phone numbers (Koch & Kralik, 2006). The general office billing department provided a list of phone numbers that were faxed to my office in a confidential format. The office staff called at the same time I faxed the phone numbers, and I immediately picked up the faxed papers with the phone numbers on them. I did not know demographics or the participant’s background, only phone numbers. I completed recruitment by talking to parents on the phone. Then, if parents
agreed to let me talk to the adolescent, I invited the individual to join the study. I made a second phone call to one family who agreed to participate but did not attend two focus group meetings. Using a local medical office helped legitimize the first meeting because the site is frequently used for educational meetings.

Koch and Kralik (2006) find the ideal number of participants in a group session to be between eight and twelve. If there are less than eight participants, then participants feel more vulnerable and less inclined to share their stories. If there are more than twelve participants, the discussion of multiple participants or conversations can dilute or perhaps lose key constructs of information.

The research population of interest was high school eligible adolescents who are typically fourteen to eighteen years old, with T1DM, who are transitioning to self-management skills. There are two important reasons why participants should have T1DM for longer than two years. First, the honeymoon period of insulin fluctuations after diagnosis is over. Second, participants are aware of their self-management skills because they have had the chronic condition for a specified length of time.

Data in the literature review suggests most parental support of the adolescent for diabetes management withdraws by age fifteen, leaving most adolescents to self-manage their own chronic illness (Hamilton & Daneman, 2002). This shift in responsibility makes the research population of interest an appropriate group to study. Many young adolescents are not equipped with the foresight to make decisions that contribute to long-term and healthy outcomes. In the life of an adolescent, management of her or his diabetes can simply be a day-to-day survival function. Increasing long-term
complications observed in thirty to forty-year-olds living with diabetes provide evidence of this situation (Laing, Swerdlow, Slater, et al., 1999; Kaiser, 2008).

**Recruitment**

I asked local health care providers, at two medical practices that manage children with T1DM in Mesa County, Colorado, for referrals. These practices include eight pediatricians and two endocrinologists who provide health care to potential participants. I also accessed Colorado Diabetes Resource Nurse Program, (DRN). The DRN program is a state-funded program that supports school nurses and children with diabetes in the schools. I am a regional DRN and have support and assistance from local and regional school nurses involved in the program in rural Colorado to aid in recruitment. I also have access to approximately 45 Mesa County adolescents with T1DM in the high school systems who are fourteen to eighteen years of age. However, only one local pediatric endocrinologist provided access to participant names for recruitment.

The Diabetes Resource Nurse Initiative and primary care providers connected me to the target population, adolescents with T1DM. I had previously established an ongoing professional connection with local health care providers. To protect the integrity of the study in a rural area, I excluded participants who were actively visiting me in a private practice setting. I maintained and promoted anonymity and confidentiality by relying on the medical office to screen participants who had a previous relationship with me. The collaboration with health care providers I already established enhanced the participants’ trust and promoted the quality of the study (Koch, Mann, Kralik, van Loon, 2005).

Students were scattered over a broad area of 3327 square miles (US Census Data, Mesa County, Colorado, 2011), thus influencing participation in the study. The region
hosts a central medical facility with most services within a five-mile radius. However, twenty of the students traveling from two large high schools were within the five-mile radius of the office location and enhanced participation. Using a central primary care office allowed a connection and safe zone for the participants. Participants and parents were cautious with the research process. By having the first group meeting at a known location, all but one participant joined the focus group.

Two of the greatest challenges in research are recruiting adequate numbers of participants and assuring the availability of these participants throughout the follow-up period (Stringer, 2007). Recruitment of adolescents is particularly difficult due to their inconsistent lifestyles. Action research produces knowledge grounded in local realities that is also useful to local participants (Stringer, 2007; Koch & Kralik, 2006). Using PAR as the methodology and involving local participants may be a unique “buy in” for youth, thus increasing recruitment and retention. Finding a common meeting time and place for all of the adolescents made the recruitment process especially difficult. The challenge changed the format of a single focus group to multiple individual and paired interviews. (See Figure 4.2 for dates and places of interviews).

Retention

Previous studies note a decline in participant retention (Wiemann, Chacko, Tucker, Velasquez, Smith, DiClemente, & Sternberg, 2005). Strategies to enhance retention gleaned from these studies include anticipating a decline in recruitment and expanding the pool of participants to counter the concern. Flexibility in scheduling group sessions and providing food for the group during the focus sessions enhance participation. The flexibility of place and time of interviews is key to recruiting and
retaining participants. Following the academic school year may also improve retention.

Establishing a positive recruitment tone at the beginning of each session and adjusting to barriers by allowing the group to direct the session increases flexibility and interactions (Wiemann, et al., 2005). In my particular study, I provided an additional incentive by providing an iTunes® card of $10.00 dollars to each participant who completed each focus group. Each participant received a total of $30.00 dollars.

**Inclusion and exclusion criteria**

The inclusion criteria:
- T1DM for greater than two years
- High school eligible students (may be home schooled)
- Male or female
- Parental consent
- Adolescent assent
- Permission of primary care provider

The exclusion criteria:
- New onset or T1DM less than 1 year
- Decline of a parent or guardian
- Decline of primary care physician
- Age 19 or older (due to change in insurance with Medicaid)
- A current patient of the researcher

**Timing**

I conducted four, one to two-hour, semi-structured single and paired interviews called focus groups (FG) during the 2012 school year and summer. The interviews took place every two to three weeks during a four-month time frame. I established schedules so each student was able to meet at a desired time and location. I drove to two different sites, 45 miles and 60 miles respectively, to meet participants at a public place due to transportation issues of the participants. This decision helped adolescents and parents participate. Koch and Kralik (2006) recommend extra time for informal opportunities for
participants to meet and build relationships. Therefore, I structured an extra hour into the schedule for housekeeping and discussion after each meeting. Discussion with parents occurred on separate occasions, a development that enhanced rapport with both adolescent and parent. Field notes captured this “off camera” contribution to the PAR process.

**Location**

The location of the medical practice is centrally located in Mesa County and within a five square-mile radius of the two largest high schools. The medical practice is familiar to most high school eligible students due to the location of Docs on Call. The location is well-lit for security and provides adequate parking. Health care resources are available through Docs on Call, an urgent care clinic, if needed. The sites provide access to toilets and a kitchen for snacks. After the first group met, meetings were relocated to public school and libraries in the participant’s hometown.

**Informed consent**

Participation was voluntary and rewarded by an offer explained in the “compensation” section below. The “rights” agenda of the last two decades creates an impetus to increase use of participative research (Freeman, 2007). The right of children, age less than eighteen, to participate in decisions that affect them (Article 12 of the United Nations Convention on the Rights of the Child [UNCRC]) gives political and quasi-legal strength to the promotion of research that directly engages with children (Holland, Renold, Ross, Hillman, 2010). Canella and Lincoln (2007) remind researchers of their ethical responsibilities:
By mandating ongoing attention to ethical concerns, ethical reflexivity reminds researchers that few research projects proceed as expected; many ethical issues are unforeseen; participants have their own concerns regarding ethical behavior that cannot be predicted by institutional review boards; ethics, as a general concern, reside in specific situations with the complex histories of individuals. (p. 327)

I advised adolescents that participation is entirely voluntary, that the information they provide is confidential, and that I would code data in a manner that ensures anonymity. Group participation, however, does not guarantee anonymity, but group norms were identified to enhance confidentiality beyond the group interview (Stringer, 2007). I asked participants to sign an assent form indicating that they understood the purpose and goals of the research and acknowledge how I would use the information they provide in the focus groups and individual interviews. Due to the conservative nature of the community, I asked parents to sign a consent form. I asked participants to treat information presented in the room confidentially; I also reminded participants to be cautious of sharing information that they do not want their peers to know.

**Compensation**

Participants received a $10.00 iTunes® card if they completed the initial focus group and an additional $10.00 iTunes® card for each focus group completed. I provided snacks and beverages during the interviews.

**Approval**

I obtained approval from the Colorado Multiple Institutional Review Board (COMIRB) before I initiated any recruitment or gathered information for the study. It was imperative that COMIRB recognize the results of the research could reduce risk for
adolescents with T1DM in a rural setting. The study allowed teenagers to choose to participate. I anticipated risks such as severe hypoglycemia or hyperglycemia symptoms, and I screened for emotional issues during the focus groups. There was no need for subsequent referrals to the health care provider during the research process. However, contacts were available if participants needed any resources. A local Institutional Review Board was not active in Mesa County at the time of the research; therefore, I used COMIRB for local and educational approval. I connected with local care providers through collegial relationships that allowed for quick collaboration if needed for a participant. I sent letters to primary care providers prior to recruitment to enhance collaboration in the project. (See appendix F for letter.)

**Position of the Researcher**

I am a Family Nurse Practitioner, and I have been a health care provider within the community for the past fourteen years. Working as a professional within the community for thirty-one years has enhanced occupational relationships. My professional status is also an inherent risk for bias in the study due to my thorough knowledge of the community. I outlined previous assumptions and biases in the beginning of this chapter. I have clinical knowledge of adolescence and type 1 diabetes, and I am a resource in the health care systems. I am a Certified Diabetes Educator and Regional Diabetes Nurse Consultant for the western region of the state, a position that enhances the context knowledge of rural health care for focus group discussion. This expertise can be a risk if I do not clarify statements from the group for accuracy of their meaning. Also continual awareness of my role in this setting and not as a clinician is imperative for validity and
quality in the study. I maintained a reflective journal throughout the study to enhance analysis, monitoring, and exploration of potential bias due to knowledge proximity.

**Data Management**

Confidential storage of audio and written data was ongoing during the entire research project. Given the risk for potential malfunction or human error, I used an iPhone® to digitally record the focus group sessions. I securely transported all focus group data (and related demographic information of participants) to and from the community sites. When not in use, data remained in a locked location. I password-protected computer data, and I kept the computer in a secure place in my home office. The dissertation committee and I will have access to the information coded for de-identifying data. I will allow a formal audit with written request.

**Transcription**

I transcribed all audio recordings for the purposes of coding and analysis. I verified the accuracy of transcription by conducting random and periodic checks of the transcripts against the recordings.

**Data coding and analysis**

Inductive Analysis (Thomas, 2006) is an approach that uses in-depth interpretation of raw data to derive constructs, themes, or a model through interpretations made from the raw data by a researcher. “The primary purpose of the approach is to allow research findings to emerge from the frequent, dominant or significant themes in raw data without restraints imposed by structured methodologies” (p. 238). This approach supports the premise that the participant’s voice is vital and must drive data analysis.
The process of inductive coding began with close readings of the text and consideration of the multiple meanings. I then identified text segments that contained meaningful units and created a label for a theme to which I assigned a text segment. I added additional text segments to categories when relevant. I developed an initial description of a category’s meaning and transcribed the description for review by the participants and dissertation committee. I considered the software program Atlas TiV6, as a way to support textual analysis and data management, particularly in relation to data mapping and construction of concept network functions. However, I used flip charts and reviewed data analysis with a senior qualitative researcher for themes, groupings, exemplars, and sub-groupings.

I used inductive analysis, a procedure by Thomas, (2006), to analyze the qualitative data:

1. Prepare raw data files by formatting the data in a common text format.
2. Print out the text from the focus groups and the telephone interview.
3. Read the prepared text in detail.
4. Familiarize its content while gaining understanding of the themes and events covered in the text.
5. Create categories: the researcher identifies and defines categories or themes, first by general themes, then by specific categories.
6. Create specific categories from actual phrases or meanings.
7. Among the commonly assumed rules that underlie qualitative coding, two are different from the rules typically used in quantitative coding:
   a. One segment of text may be coded into more than one category,
b. A considerable amount of the text (e.g., 50% or more) may not be assigned to any category, because much of the text may not be relevant to the evaluation objectives.

8. Revise and refine category system: Within each category, search for subtopics, including contradictory points of view and new insights.

9. Select appropriate quotations that convey the core theme or essence of a category.

I combined or linked categories under a superordinate category when the meanings were similar (p. 242).

After the first focus group took place, I analyzed the process and incorporated themes. The type of analysis involved the development of themes described by the participant’s account, in his or her own words. I combined descriptive and interpretive analysis to develop theoretical or analytical themes as described above using Thomas’ (2006) work. I analyzed and compared data in several primary ways: I accorded general codes, themes and sub-themes, and then compared members of the group with special attention to issues of similarities and differences. At this point I used the theoretical framework Meleis (2010) provides to guide a secondary analysis looking for conceptual bridges to previous work and alignment with new contextual understandings.

I encouraged the adolescents to provide concrete examples of experiences that highlighted both their challenges and successes in accessing health services, self-management, and health-seeking behaviors. The participatory approach ensured participant involvement in all aspects of the research process, from collection to analysis (Kock & Kralik, 2006).
The group process revealed issues, concerns, and ideas. Subsequent focus groups and final telephone interviews clarified reoccurring themes. Reflection and a debriefing telephone interview occurred for each participant. This study was small, with the option for participants to continue during my postdoctoral work.

The final step of this study provided feedback to appropriate groups such as area school district nurses and primary care providers to discuss follow-up research ideas. I uses Meleis’ Theory on transition to explore the themes of transition in greater depth. In the course of using the lens from Meleis’ Theory, I interpreted key elements and text using transition ideas in the final analysis.

**Rigor and credibility**

Extensive work by Lincoln and Guba (1985; 1989) provide qualitative research with standards to assess rigor and credibility. Rigor in PAR is based on checks to ensure that the outcomes of research are trustworthy. Trustworthiness ensures the researcher has established veracity and validity of the data that has emerged from the research process (Stringer, 2007). Procedures established by Lincoln and Guba (1985; 1989; & 2005) assess the credibility, transferability, dependability, and confirmability of the research process. Checks and balances through the approved proposal assure the credibility and integrity of the study with the dissertation committee faculty at the University of Colorado, Denver. I achieved successful application approval through COMIRB. (See COMIRB letter of acceptance Appendix G.) Several steps with the research participants enhanced credibility as described below.

Trustworthiness demonstrates that my interpretations of the data are credible to those who provide the data (Herr & Anderson, 2005). Participants reviewed my
clarification of the information, and I asked them to read the excerpts from the coded data for accuracy of its meaning. Finally, the thirty-minute telephone interview for each participant with debriefing questions clarified emotions, comments, and feelings that may clouded my interpretation of events or those hidden by a group setting. I offered opportunities to express ideas in all focus group interviews. Multiple occasions with the study participants illuminated the trustworthiness of the data.

The transferability in qualitative research allows other researchers to apply the results of the data to other groups (Stringer, 2007). Transferability is limited at times to the particular group or place that is part of the study. Rich, detailed descriptions of the context, events, and issues that describe the health-seeking behaviors of rural youth with T1DM may influence other research and interventions in working with adolescents in rural geographical areas with chronic illness (Creswell, 2009).

The dissertation review measures dependability. Critiquing and auditing the methodology, interview recordings, and evaluation of the final transcripts address dependability. Gibbs (2007) suggests watching for errors in transcription, constantly comparing data and confirmation of the audit by asking the dissertation committee to review the recordings and notes of the focus groups themselves. The cross checks were reviewed with Dr. J. Jones, Ph.D., and the process was carried out as proposed and agreed upon (Gibbs, 2007). I will keep data collection and field notes securely locked and available for an audit if needed for seven years.

Quality of PAR is derived from useful inquiry and initiates a difference or actions that researchers can sustain and document. Meeting with stakeholders such as parents of the adolescents and previous adolescents who are now adults over the age of twenty-one
have revealed stories of disconnect between the families’ perceptions, their disease, and health care. These stories exemplify the research’s importance by reflective concern for practical outcomes while caring for families and adolescents with T1DM (Koch & Kralik, 2006).

Working principles from Stringer’s (2007) body of work enhances the quality of PAR. Key principles from Stinger’s work (2007) include participant involvement, thus enabling the participants to perform significant tasks, provide support for people as they learn to act for themselves, encourage plans and activities that people are able to accomplish themselves, and deal personally with people rather than their representatives, a vital method when working with adolescents (Stringer, 2007). My relationship with participants is one of the most important aspects of PAR. Being a health care provider in the community will encourage personal, cooperative relationships thanks to familiarity with communication norms and expectations associated with contemporary rural adolescents. Effective collaboration of health care agencies within the community are present, as I have practiced in the community for thirty-one years. Appendix E outlines the steps for protection of data, participants and storage of the research data through the COMIRB application form.
CHAPTER IV

RESULTS

Introduction

In my study of research adolescents with T1DM, I use PAR as a group process to examine issues relevant to their community. PAR creates action plans in response to the knowledge generated by research participants to inform research, practice, and policy which I will discuss in Chapter V. In Chapter IV I discuss the results of PAR gleaned from in-depth group and individual interviews of adolescents with T1DM. I will now describe the analysis of the results and address the following themes:

- Distraction
- Taking time to deal
- It’s a challenge
- Quality of life is good
- Rurality is not an issue
- Make diabetes easier
- Listing to me
- Struggles
- Relationships

Qualitative research findings are integrated descriptions or explanations derived from the analysis of data obtained from interviews, observations, documents, and artifacts. The validity of data-based studies depends primarily on the ability of researchers to ground their findings or results in the data they collect in those studies (Sandelowski, 2004). In the process of my research, I identify preliminary themes from
over 140 pages of text from transcribed interviews. I transcribed the interviews to remain close to the data and continually reflect on words and themes repeated in the transcriptions.

Data analysis consists of data reduction and data display while constantly moving between the parts and the whole of the textual and audio data. The first step was data reduction, which theorists describe as the “process of systematically searching and arranging the data” into primary codes (Bogdan & Biklen, 2003, p. 147). I then read the transcripts to gain a general sense of the consistency identified in the interviews (Creswell, 2009). The ongoing process involved continual reflection about the data (Creswell, 2009). My analysis of the data consisted of moving between the parts and the whole, generating codes and themes, as well as identifying pertinent quotes. I prepared the data by transcribing the interviews verbatim and organizing the data into manageable units of themes and quotes. Organizing, preparing, and checking the data for accuracy enhanced the authenticity of the data analysis. I completed the member checking by reflecting on the themes I derived from the statements made by individual participants. I completed the data analysis with the supervision and oversight of an experienced, doctoral-prepared qualitative researcher (J. Jones, 2012).

Analysis continued by reflecting and cataloging data by hand. This process identified themes and quotes using the actual participant language (called an in vivo code or theme) (Creswell, 2009, p186). I coded the data with general themes and organized the information into sections of text before I ultimately settled on the specific themes from each focus group interviews (Rossman & Rallis, 1998, p.171; Creswell, 2009). (See themes from interviews in summary table A page 140).
After I coded the data from each focus group, I further analyzed themes using Meleis’ Transitional Theory (2000) as a framework to explore and describe the nuances in participant text in terms of developmental transitions. I categorized transitional themes into four areas derived from Meleis’ theory: awareness, engagement, change, and difference. I will describe these categories of transition in greater detail later in this chapter. Themes found through a theoretical framework increase the depth of the analysis of this study (Creswell, 2009). (See table B, page 149 for theoretical framework themes).

**PAR: The Entry Process**

I am a nurse practitioner and doctoral student working as a certified diabetes educator with an interest in adolescents and T1DM. I developed these interests after spending thirty years in the community working as a health care professional where I completed the research. The entry process into PAR depends considerably on building relationships and negotiating with the community of interest (Kerr, 2005). The initial steps in this process are important in rural communities where individuals tend to be cautious of outsiders (Long & Weinert, 1989). I built relationships over a three-year time frame as key members of the diabetes medical and lay communities learned that I am a doctoral student. As a result of these associations, the research developed through a number of networks: the medical community, continuing education programs, previous doctoral practicums, and volunteer activities with diabetes support groups.

I improved recruitment by first establishing credibility with the parents of the research participants. Initially, the parents were cautious about the research process. By clarifying the goals of the research, explaining the concept of consent, and discussing my connections in the community, parents agreed to participate. Aligning with the local
endocrinologist enhanced my credibility. Once I established credibility with the parents, I then invited the adolescents to participate, and I provided an incentive in the form of an iTunes® card. One participant did not have access to a computer or music player, so I substituted a generic gift card. Statements like “it will be fun” and “I was curious about the process” were common reasons why participants agreed to join the study.

In retrospect, the parents of the teens encouraged participation. While picking up adolescents from the focus groups, several parents stated, “There were no available diabetic support groups in western Colorado.” The ability for adolescents to meet peers with T1DM motivated both parents and two study participants.

The purpose of many PAR studies is to advocate or provide emancipatory action for the identified group. For adolescents with a chronic illness, the emancipatory process parallels the transitional process. Enhancement of self-efficacy in their disease process leads to increased self-management of their diabetes (Innotti, Schneider, Nansel, Haynie, Plotnick, Clark, Sobel, Simons-Morton, 2006). PAR provides the ideal methodology to research the transition process in adolescents with T1DM. As adolescents become more independent in their roles, they learn to self-manage their T1DM. PAR illuminates the voice of the adolescent in this transitional process while living with a chronic illness.

Creating Participatory Structure

Recruitment

The recruitment population is a specific group of individuals who possess particular characteristics and who live with relevant social phenomenon of the study process. I identified participants in three ways: first by their disease process (T1DM), second by their age (14-18 years of age), and third by their high school eligibility.
Recruitment was challenging due to a variety of reasons. A desire for privacy is a discernible characteristic in the rural area. Health care providers are aware of confidentiality concerns in rural communities. Many are wary of referring patients.

I first attempted to recruit adolescents with T1DM by posting fliers in schools with a diabetes resource nurse (DRN). However, no participants responded to the fliers. No local diabetes educators and pediatricians whom I queried referred patients. The sole pediatric endocrinologist in western Colorado became the active source of recruitment. The office staff of the endocrinologist searched their database to find eligible adolescents, and they contacted the families willing to grant me permission to call and recruit. The database generated a list of nineteen possible participants.

The families of the adolescents with T1DM posed many questions. Participants wanted to know who referred them to the research study and how I was able to obtain their phone numbers even after the office staff had informed them of the referral process. My personal connection with the pediatric endocrinologist enabled me to locate and recruit the teenagers to join the study. I doubt I would have had successful connections in the community without being a member of the community and without maintaining a professional relationship with the pediatric endocrinologist. Participatory Action Research acknowledges that a willingness to participate in a group study poses limitations. Gaining access to a community of interest, to research specific needs, can be a challenging process. As noted above, the process of relationship building is imperative in PAR (Koch & Kralik, 2006).
Sample size

I accessed nineteen participants from the endocrinologist’s database. I didn’t recruit five participants because they were less than fourteen years old. One adolescent recently started home school and declined to participate in the study. Two phone numbers had been disconnected and provided no forwarding contact numbers with local pediatric endocrinologist staff. Staff members reviewed contact information and attempted to reach the families on multiple occasions without success. The staff twice contacted three potential participants and left messages to contact me. However, participants did not return phone invitations. One participant agreed to participate in the study after two phone calls, the invitation and confirmation call. However, the individual did not attend the first focus group. I placed a second phone call to enroll the individual in the next focus group, but the person did not reply. The final individual of seven participants lives in a town sixty miles south of the research area. The participant is at a new support group, “Diabetes Counts,” started at a local university. “Diabetes Counts” is a night out for kids with T1DM between the ages of 6-18 years of age. The local university hosts the event and encourages students to meet with peers with T1DM under the supervision of nursing students, certified diabetes educators, and faculty.

Seven participants consented to the study and focus groups. The seven participants resulted in twenty-eight participant interactions that built on repeated contacts within the study over time. The repeated contacts led to an adequate sample size to verify themes and collect data. The value of the twenty-eight interviews supported the need to reflect multiple themes with an adequate number of participants.
The sample group consisted of three males and four females. I made no attempt to provide gender balance in this study. The age distribution is between 14-17 years of age. None of the participants were driving independently at the time of the study. Participants self-identified socio-economic indicators. Three participants expressed worries about financial issues on multiple encounters; three self-identified as “middle class” and stated that “they did not worry about money.” One participant did not identify with a formal comment of socioeconomics.

The adolescents represent differing time periods identified by Arnett (2000) and Hamilton (1990) as early, middle, and late adolescence. The grade level corresponding with these periods include eighth and ninth-grade participants in early adolescence, tenth and eleventh-grade participants as middle adolescence, and twelfth-grade as late adolescence. (See Table IV.I for focus group demographics of the participants.

**Table IV.I Demographics of Study Participants**

<table>
<thead>
<tr>
<th>Chosen Name</th>
<th>Grade</th>
<th>Age of Onset</th>
<th>Gender</th>
<th>BG checks per day</th>
<th>Last HgbA1c</th>
<th>Missed doses per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bryce</td>
<td>8th</td>
<td>3 years</td>
<td>M</td>
<td>7-8</td>
<td>Don’t recall</td>
<td>4-5</td>
</tr>
<tr>
<td>Esme</td>
<td>10th</td>
<td>3 years</td>
<td>F</td>
<td>6-7</td>
<td>9.1</td>
<td>6-7</td>
</tr>
<tr>
<td>Jessica</td>
<td>12th</td>
<td>13 months</td>
<td>F</td>
<td>5-6</td>
<td>high</td>
<td>4</td>
</tr>
<tr>
<td>Hayden</td>
<td>12th</td>
<td>6 years</td>
<td>M</td>
<td>8</td>
<td>high</td>
<td>12</td>
</tr>
<tr>
<td>Super Girl</td>
<td>10th</td>
<td>6 years</td>
<td>F</td>
<td>5-6</td>
<td>7’s</td>
<td>7-14</td>
</tr>
<tr>
<td>Ash</td>
<td>10th</td>
<td>8 years</td>
<td>F</td>
<td>1-2</td>
<td>9.8</td>
<td>5</td>
</tr>
<tr>
<td>Joel</td>
<td>8th</td>
<td>16 months</td>
<td>M</td>
<td>15</td>
<td>7.7</td>
<td>5</td>
</tr>
</tbody>
</table>

I arranged individual interviews with the seven participants in a private conference room at a local medical practice. However, due to geographical distance, I changed interview locations to accommodate participants and their travel needs. (See
Table IV.I for demographics describing the research participants and the location of group and individual meetings. I conducted interviews at alternative sites in private settings that participants choose.

**Focus group recruitment**

The recruitment for the specified population of T1DM challenged me more than I anticipated. Due to time constraints of the adolescent participants and the vast geographic distance between the participants’ residences, I designed focus groups for pairs and individual sessions. I attempted to locate a time and place so that all seven participants could meet at once. However, with scheduling conflicts and geographic distance, this arrangement did not work for the research process. Collaboration with a senior qualitative researcher (J. Jones, 2012) resulted in a virtual group process that built and frequently added information and reflections to the participants. I generated and summarized themes and ideas, and I then reflected these back to individuals and paired group members. The virtual group process was not a synchronous process, but I developed an asynchronous process that refuted and confirmed group thinking, and through this process an interactive understanding emerged from pairs and individual interviews. The process responded to the adolescents’ “way” to participate in a rural setting. The ability to share ideas, test the themes, and generate responses from interviews generated the sense of group process. The group process appeared virtual, and each participant tested all themes and responded to other participants’ comments within a certain time frame or the next interview setting.

Two of the families had only one vehicle, and that situation created transportation and scheduling difficulties. Three of the families had multiple children with competing schedules. I changed the site of the last focus groups to meet the participants in their
hometown public library with a private setting. Although two of the participants attended the same school, their different ages and involvement in different activities continued to cause time constraints for focus groups.

The total geographic distance between the families in this study is 120 miles. One of the participants lives 45 miles east of the research site, and three participants live 65 miles south of the research site. Three participants live in the research town. However, they attend different schools and are involved in different activities leading to additional scheduling issues. I scheduled focus groups around school, family, and extracurricular activities. These activities included seminary, track, lacrosse, marching band, music, basketball, football, softball, activities with raising and breeding livestock, and other social and family activities.

The third challenge became scheduling each focus group. The first focus group included two participants. I contacted five families to gain permission and ask if their adolescent would participate in the research study. Two of the adolescents requested individual interviews, stating they are shy and do not want to discuss their T1DM in a group setting. However, both of the participants agreed to discuss their T1DM in a private setting with me. I arranged interviews for the two other participants in their hometown as described above. See Table IV. II, for flow chart of recruitment.

**Data collection phase two**

By the second focus group, the research process became familiar to the participants. Three were willing to meet with other participants in a focus group I organized by gender due to the connection in sports and age. I considered using primary residence due to geographical distance and travel time for the second focus group. By
becoming familiar with each other, participants were willing to discuss personal
experience with T1DM in the third focus group.

**Figure IV.1 Recruitment Flow Chart**

Iterative Cycles of Inquiry: Theoretical Framework
I use a matrix of theoretical concepts as an analytical lens to explore the focus group data and emergent themes. The research question focuses on the transitional process of adolescents and the health-seeking behavior they view as positive. Meleis’ (2000) Transitional Theory framework guides this study. The framework is comprised of four concepts to successful transition: awareness, engagement, change, and difference. These theoretical themes are also connected to early, middle, and late adolescence. The matrix of these two aspects of theory then allows me to identify “concepts of successful transition.” Examples of these four concepts of successful transition surface in the varied statements of each participant according to their developmental level of adolescence.

Theorists define awareness as the level of understanding that an individual or group possesses during the transitional process. The transitional process may be conscious or unconscious. The unconscious process, such as in a developmental transition, can be influenced by health care providers who draw attention to changes as the adolescent develops skills and increases cognitive judgment. Researchers do not agree on who begins the transitional process, the nurse or the adolescent (Meleis, 2000). However, adolescents are, by definition, in a state of transition. This study seeks to further understand the transitional period of the adolescent with T1DM.

Meleis (2000) asserts that increased awareness leads to increased engagement. Therefore, looking for an awareness of T1DM in adolescent comments may guide knowledge development in the iterative cycle. Some authors suggest lack of awareness as lack of transition. However, in this research, the stage of early adolescence supports lack of awareness. The fact that adolescents largely depend on caregivers may inhibit early
awareness. The lack of awareness does not necessitate a lack of transition, only the dependent nature of diabetes self-management.

The second concept is engagement. Successful engagement occurs when adolescents look for positive role models and seek information about their T1DM. The modification of activities, including increasing self-management tasks, is both an example of and a strategy to enhance success in the transitional process. The level of a person’s awareness of physical, emotional, social, or environmental changes will differ from those who are unaware of such changes (Meleis, 2000). Only the mature adolescent will fully engage in these levels of change needed to self-manage their diabetes.

Change is the third concept in Meleis’ theoretical framework (Meleis, 2000). The nature of change and its effects and meaning in the transitional process are important when it comes to establishing successful routines that become part of a participant’s self-management behaviors. The importance or severity of the transition, as perceived by the participant, can result in critical or incapacitating events. An awareness of the severity of these events contributes to how well participants adapt. Disruption in relationships and routines can impact the change of the transitional process both negatively and positively (Meleis, 2000).

Finally, difference is the fourth concept in successful transition. How the participant perceives the world and perceives how others differ from themselves exemplify a successful transition (Meleis, 2000). I will evaluate elements of these successful transition properties in the themes the focus group summaries generate.
Focus Group One

Focus groups answered the question, “What is it like to have T1DM as an adolescent?” I held the focus group in a small, private conference room with participants seated at a table. I explained and requested confidentiality of the participants in each focus group. I audio recorded participant interviews on a password-protected digital device. I obtained demographic information during the first focus group interviews. I posed questions in a semi-structured format, and I added open-ended questions to reflect and clarify answers. I reflected back participant statements to the group to clarify and confirm content.

I posed two additional questions of each focus group member. First, “How does living with T1DM affect your life in the social, work, play, school, sleep, and physical areas?” Second, “What does it mean to be healthy while living with T1DM in a rural area?” I reflected back answers to the participant for clarification. I clarified reoccurring themes within the participants’ answers at the next focus group to assess congruence of the themes with other group participants.

The three themes that emerged from focus group one include:

1. “Diabetes is distracting” and “You forget you have it sometimes.”
2. “It takes time to deal with diabetes.”
3. “You are inhibited at times by the disease.” “It is a challenge to deal with diabetes on a daily basis.”

In the following paragraphs I will define and describe the themes that emerged during the interviews in a summary format and provide exemplars to illuminate the selected themes. The participants chose names to identify themselves in their quotes. A
characteristic in adolescence is the search for identity. Several of the participants chose given names while two participants made up names to identify their quotations.

**Theme one: Forgetting**

I define the theme “forgetting” in two ways. First, “forgetting” to the adolescent participants means they forget they have diabetes. The topic of “forgetting” they have diabetes is more apparent in the middle and late adolescent group. Often the adolescents “forget” to take care of their disease multiple times per day. These individuals have grown up with the disease. Daily activities in the adolescent’s life compete with the multiple self-management tasks involved in diabetes. For the participants, it is difficult for them to remember to take care of their diabetic needs while living an active teenage life. Several participants state they would wait until one activity is over to complete the tasks needed to take care of their diabetes.

The second part of “forgetting” is the distraction of social, school, sports, and family activities. Interviewees are often caught up in the moment of life which make them forget to take care of the self-management tasks, including checking blood sugars regularly, injecting insulin regularly (especially with snacks), counting carbohydrates, eating well, and getting routine exercise. I consistently notice “forgetting tasks” in the late adolescent participants who are more independent than their early adolescent counterparts.

Exemplars that support this theme include, “It can be a hard challenge sometimes just dealing with remembering to test, remembering to give a shot, remembering.” Esme also reveals, that “It’s part of me so I forget I have it. The pump vibrates, and I am used to it, so I forget.” Jessica states, “It is important that I deal with it, but it is just harder to
deal with it, especially when I am distracted by school or my social life; it is a challenge to do it but I have to do it.” These statements appear in the late adolescent period and reflect examples of awareness and engagement based on Meleis’ theoretical framework.

The theme of “remembering” is part of adolescence and does not necessarily stem from the diabetes itself. Esme states that diabetes is about “50% of me. It is like faith. You know you have it, but you forget about it.” Alarms on insulin pumps are set, but adolescents admit that they tune them out. Parents and grandparents text to remind them to bolus or check blood sugars, but adolescents often delay the task. This delay in task performance can impact glycemic control. Participants reflect, “I feel like I shouldn’t have to push my buttons. They should just push themselves” or “If I don’t do anything [with my insulin], maybe my pancreas will start working again.”

The awareness adolescents have about their T1DM increases as they mature. However, the difficulty in multi-tasking and balancing life issues remains a struggle even in late adolescence. Jessica believes that,

Being a diabetic is like oil and water. It doesn’t mix really well. Social life doesn’t mix with diabetic life; diabetic life doesn’t mix with school life, so it is just a big confusing type of triangle that you have to balance our and its pretty hard to balance.

The theoretical framework that Meleis (2000) provides describes “becoming aware” as part of the transitional process. As stated above, late adolescent participants increase awareness of how important it is to deal with their diabetes. Consistent engagement of the process remains the challenge.

**Theme two: Taking time to deal**

The second theme generated in focus group one is “taking time to deal.” Participants describe the interruption of activities to check their blood glucose, bolus their
insulin, or treat a symptom of low or high blood glucose. The participants sometimes do not want to deal with the task, and as a result, they skip the task until later or until they complete the activity. Ash states, “If am sitting down, I don’t get up. I will wait until I get through the activity or until lunch or dinner to check my blood sugar.” The task could be something they hate, but they hate the process of stopping to check blood glucose levels more. Esme states, “I hate taking time out to check my blood sugar, even if I am doing something I hate. I hate taking time to stop and check my blood sugar.”

The participants need to check their blood glucose before tests. If they have a blood glucose that is high (greater than 250-300 mg/dl), it could interfere with their memory and effect the test they are taking. Changes in participants’ blood sugar force them to take time out of the testing to correct the blood sugar. Rescheduling or completing the test at a later time usually takes place during the participants’ lunch or after school. This schedule impacts not only their social time, but the task also takes time away from yet another activity. Jessica states,

It’s a challenge, especially with tests, because if I am having a high blood sugar number during a test, my brain is foggy. I don’t remember as much as I would if I were having a normal blood sugar number. It kind of clouds my mind with what I have learned.

The last scenario of “taking time away” is seen in activities with sports and pleasure. “Taking time away” from play and sports, especially if there are symptoms of low glucose levels or difficulty concentrating, requires a break in the activity. Participants need to check their blood glucose and eat a snack to maintain their blood glucose levels prior to returning to the activity. Bryce states, “I have to take time off the field to make sure my blood sugar is still good.”
While most of the participants explain that they do not have any difficulty with activities, including moderate activity in sports, they do change their insulin basal or increase carbohydrate intake to maintain the energy needed to complete the activity. Hayden replies, “I have never had trouble with sports. I have always been able to go and do what I am supposed to do.” One participant went on a raft trip for two days and used long-acting insulin by syringe and took a break from their insulin pump. The blood glucose levels remained at an adequate level for the two days due to the increased and constant activity levels. The participant’s ability to engage and seek knowledge while participating in new activities reveals elements of successful transition evident in this example of an adolescent in late adolescence.

**Theme three: It’s a challenge**

The third theme from focus group one focused on “the challenge” of having T1DM. I define “challenge” as the difficulty of dealing with so many tasks of T1DM while being an adolescent. It is difficult to maintain the motivation to stay on top of a chronic illness, at any age on a daily basis. Esme states,

> It’s harder than you would think; it’s kind of like you have to practice at it to get really good at it. If you do not practice at it you are going to fail. If you fail, it can really, really, really be bad. It is going to kick you in the butt so hard, or you are going to feel like [Did not finish quote; gestured with her hand].

As the adolescent matures, awareness of the challenge of living with diabetes increases. Reflective statements that indicate the significance of not controlling blood glucose increase profoundly in the older adolescent responses. Older adolescents compare themselves with their peer counterparts and reveal the differences they experience. Engagement with their T1DM varies at all levels of the adolescent process. Some are actively involved in the self-management of their T1DM and report well-
controlled glycemic levels. However, the awareness of the need to be consistent and stay on top of the disease process is evident.

Words such as “effortful” and phrases like “it’s a challenge” and “it is so hard” are consistent in the interviews on multiple occasions. The levels describing the participants’ life while living with T1DM reflect their period of adolescence they are currently experiencing. Esme and Jessica share many similar perspectives. Esme states, “I think the main thing with having diabetes is that even if I don’t want to deal with it, even if it sucks, even if it is one of the worst things to me in the world that I have ever experienced it does make me, but it basically is me. It’s part of my life.” Jessica reveals, “It is like 50% if my life, so it is a very big vital piece of me, but then again I don’t want to let it control me, so it’s a challenge.” Both statements reflect awareness and engagement in the older adolescent.

Participants describe having diabetes as “hard,” maintaining that it is “difficult” to remember many tasks and procedures throughout the day while being an active adolescent. Jessica states, “It is really hard some days. It’s a challenge to try and deal with my diabetes and the things that are most important to me. It just inhibits me from doing a lot of the things I love.” Hayden reveals, “Diabetes is different. You don’t really get to do all the things you want to do sometimes. It feels a little unfair that you are left behind.” Two participants reveal they could not do overnight camping trips or travel great distances from their home because of their diabetes.

The underlying theme of the seven interviews compiled from focus group one is perseverance. Esme states:

I will do really, really good with checking my blood sugars every single day, and I will go really good for like two to two and half weeks. Then I will just
start slacking off. And I will go OK, so I did it for two and half weeks so where is my reward? What the heck? Then, after like two to three days my blood sugar will get really bad. And then I will start up again, and I will keep on going, and then I will be exactly where I was, when I started.

Not one participant mentions an inability to continue with the challenge or that the condition is overwhelming. The sense of humor, hope, perseverance, and commitment to the task of self-managing their disease filters through the discussions.

Super Girl states:

I still try and look at it in a positive way; this is helping me to learn and grow and be who I am; I am supposed to be here, and there will be a cure one day. Ever since I got it, me and my parents have been really close, especially me and my mom. So I think I feel it is a blessing and a burden at the same time, because there are so many good things, and there are also some not so good things.

Super Girl sees herself as part of a bigger experience, a part of the world with other connections in the world. The statement above reflects a mature response indicating an awareness of “difference” that appears in late adolescence. The participant can see the “difference” of her experience when she compares it to others in the outside world. She finds positivity in the transitional process and the changes that come with her diagnosis of T1DM.

**Pediatric quality of life questionnaire**

I distributed the Pediatric Quality of Life (PedQOL) questionnaire to participants in focus group one. Between focus group one and two, I analyzed the PedQOL to learn how these participants define quality of life. (See Appendix D, page 171). The PedQOL questionnaire is a tool that assesses quality of life, especially for adolescents with diabetes age 13-18. The PedQOL addresses four content areas: problems with health and activities, problems with feelings, sociability, and school concerns. The scale provides a
spectrum of severity for these four content areas. The parts of the scale include the following: This is never a problem for me. This is almost never a problem for me. This is sometimes a problem for me. This issue is often or always a problem for me. I used the PedQOL results as a catalyst to initiate discussion in focus group two. I discussed the responses from the tool with each participant. The majority of the participants offer the following answers: they never or they almost never had issues about walking, completing chores, lifting, or playing sports. Two participants indicate they often have trouble with running.

In the content area of feelings, participants reveal that they are scared sometimes. They are sad sometimes, and sometimes they are angry. Three participants indicate they worry about what may happen to them on the “sometimes I feel this way” scale. Many of the participants state they get along with other teens. However, two participants state that their peers tease them sometimes, and other teens do not want to be their friends because they have T1DM.

In focus group one, three of the teens reveal they often “forget” in school and have trouble keeping up with schoolwork. One participant reveals no difficulty in school or remembering things, and this individual is male and the youngest in the group. The lack of difficulty reflects several possibilities: the early adolescent is less aware and does not perceive change as an impact on the diabetes, or the early adolescent does not see the difference in themselves and the world, a perception indicating early transition. There is no way to know if this perception will change and impact the success of transition without longitudinal studies to follow the early adolescent participants through late adolescence.
Focus Group Two

Prior to scheduling focus group two, I transcribed the transcripts from focus group one. I analyzed and summarized themes at the micro level of focus group one. Focus group two addressed the Pediatric Quality of Life questionnaire results I distributed to participants in focus group one. I addressed concerns pertaining to quality of life questionnaire with the following questions in focus group two. First, “What is quality of life, and how can it be improved while living with T1DM?” Second, “What health care interventions could be enhanced to support your transition to independent self-management of your disease?” Third, “How can your health-seeking behaviors improve?” To clarify the meaning of each participant’s responses, I followed up with open-ended questions such as, “What else?” or “What do you mean?”

Three themes surface in focus group two. First, when I ask about quality of life, the participants state it is “like any other kid.” Second, “rurality” is not as big of an issue for the adolescent participants as it is for the parents. The adolescents report they do not mind driving to medical appointments or taking a day off to go into town and see their endocrinologist. They usually combine the medical visits with shopping and running errands. The last theme that surfaces is that the participants want “diabetes to be easier.” The participants do not want to think about the tasks involved with daily self-management of their diabetes. Comments surface about having their body function more effectively or their pancreas start producing insulin naturally. (See PedQOL Appendix D page 171 for summary of questions and responses).
Theme one: Quality of life

When I ask participants if diabetes impacts the quality of life, Bryce states, “I feel like I am a normal kid. Everyone else has their challenges. Diabetes is just mine. That is what I was given, and I just have to deal with it.” I ask participants to compare their quality of life with other kids who did not have diabetes. Joel states, “it is the same as any other kid without diabetes.” While both of these statements are from participants in early adolescence, there is a sense of maturity in their speech. It is unknown if the statements reflect the lack of awareness of the differences they exhibit in the transitional process. The awareness and acceptance of their differences may remain constant as they become more independent and self-manage their diabetes. This attitude may reflect their successful transition. Super Girl reveals, “We are normal people. We just have a challenge in our life that we have to work out.” Super Girl’s observation reveals the separation of herself from others in the world. Her perspective is a positive trait observed in successful transitions.

Theme two: Rurality

The second theme in focus group two is “rurality.” “Rurality” is difficult for the adolescent participant to define. I revisited the concept of “rurality” in focus group four, the final interview phone call. When I ask participants to define rural living, definitions include safety, hard work, and driving long distances. The participants state their doctors and health care are comparable to what they encounter in larger urban areas. The only concern of living in a rural area participants report is access to supplies and a closer pharmacy to purchase insulin. The interviewees do not mind driving an hour or more to appointments and view the time spent traveling as time with their caregiver. Ash states,
“We will make the appointments so we have something to do in town. My grandma and I will take a whole day and spend it by ourselves, so we get a girls day out that we hardly get at home.”

Being in a rural area has an effect on privacy and how much adolescents tell people around them about their diabetes. Participants explain that a lot of people do not know they have diabetes at school. They are not opposed to discuss their diabetes if people ask about their pump or notice they are checking a blood sugar. However, they do not outwardly tell people or explain their disease in-depth to strangers. Living in a rural area does impact the way people come together in groups. Esme states:

Because in a small area, things tend to spread around a little more. If you don’t want anybody to know about it, then obviously you’re not going to go. But if you want people to know about it, and you want to share it with the world, go right ahead. Be my guest. I would love that. I mean and I’m still a little self-conscious about everything, but, um, it’s more of, I don’t know, it’s kind of like being scared of yourself.

Esme is in middle adolescence, but many of her statements reflect emerging late adolescence with her ability to identify differences in herself and the world. Her increased awareness of her diabetes and her need to engage in self-management indicate elements of successful transition from the theoretical perspective.

I addressed access to local endocrinologists with the participants. Three participants state they wish there were more pediatric endocrinologist closer to their living arrangements. This proximity would provide more personal time with their provider. The participants do not want to substitute technology with one-on-one contact with a health care provider. I will discuss face-to-face time when I discuss focus group three under theme three, “relationships.” Jessica states:
I do think the visits are the best way. As you say, body language is very important, too. Because sometimes a text message could get read the wrong way, and I could interpret it how it’s not meant, and I could take offense, or I could take it better than it’s meant to be. I do think face-to-face is the best thing to do, especially since you have all that body language, and you can understand the tone of the voice. You could have people interaction, and you get what they are saying because they portray it by what they do with their hands or what you do with yourselves. It’s better to have the face to face than over Skype®. You could take it wrong when they don’t mean it wrong. You could take it right but they don’t mean it right; it’s just better to do it face-to-face.

**Theme three: Make diabetes easier**

The third theme that surfaced from focus group two is to “make diabetes easier.” Participants’ wording defines “making diabetes easier.” The participants want the ability to manage their diabetes easier. They wish their pancreas worked, or they wish they had an automatic button pusher (to their insulin pumps). Participants want to have something on their body to act like a pancreas. Ideally, the participants long or hope for a cure of T1DM. This theme surfaces throughout all the focus groups. Participant statements include, “I shouldn’t have to push my buttons. They should just do it themselves” or “We should have a really awesome robot, but I don’t think that is going to happen.” Esme echoes, “I think if I don’t do anything, maybe my pancreas will start working again, but it doesn’t happen.” They reiterate their frustrations with comments ranging from “I don’t want to push buttons” to more realistic statements that include “having diabetes is a reality. You are either going to live or die with it.” These statements culminate in the expression by Super Girl in focus group two, “Find me cure! I mean, overall, there needs to be a cure. I am getting better at it, but wish it would go away.”

**Focus Group Three**

The third focus group has two purposes. The first is to assess prior themes from focus group one and two. The second purpose is to ask four questions and to determine
how participants envision their future health care. I ask adolescents four questions:
“What do you need in your health care?” and “What do you need to be healthy while
managing your diabetes?” The third question is “What it was like to be in the research
study?” The final action plan in Participatory Action Research (PAR) considers planning
from the group perspective. I ask participants in the last question, “How, where, and what
type of health care do you need?”

Three themes emerge in the interviews with focus group three. First, the concept
of “listening to me” suggests an opportunity to tell their story in the research process and
explain how they want to partner in their health care. The second theme, “struggles,”
reemphasizes the challenges with diabetes and people who are close to them. “Struggles”
also reflects feelings about their health care. The final theme in group three is
“relationships.” The adolescents perceive there is a strong need for relationships to
effectively manage their disease process. Many believe they cannot manage their T1DM
alone. Family and friends, as well as face-to-face time with a familiar health care
provider are paramount.

**Theme one: Listening to me**

The adolescent participants want the health care team to understand and believe
how difficult it is to live with diabetes. The definition of “listening” to the adolescent
means the health care provider listens with acknowledgement and acceptance. The
adolescent does not want health care providers or family members to be less stringent
with their discussion about their T1DM management. They just need more understanding
and lack of judgment during their difficult days. Super Girl states:

I know that they need to tell us that we should try harder or we should try
this or a different thing. For me, I would like them to realize that I have
been trying and doing some sort of regulation. Telling me that you are doing a great job, but we need to still keep improving would be really helpful.

The wording and supportive body language convey to the adolescent a degree of acknowledgement and understanding.

The participants want to tell “their story” about living with diabetes and explain to a health care provider (HCP) what it is like to live with diabetes, rather than having a HCP tell them “it is OK” or “you are doing a good job.” Jessica states, “I think because I see my doctor more, it helps me to be able to make changes.”

The adolescent participants reveal they need their health care provider to make sure they remain on top of their diabetes. Jessica reveals:

I went to my HCP in January and there is a certain thing we changed. In March, if those changes have worked then we could keep them the same and fix other things, but if I don’t see them from January to June that is a lot of time for changes. So I like seeing my doctor every couple of months. It helps me to keep on track; it helps me with my diabetes to keep the changes that we make.

Adolescent participants want to “partner” in their health care. When I ask what makes a health care appointment a positive experience, many of the participants respond that the HCP asks about their life. Bryce states, “Asking about social life, what it is like, how you think you are doing, how our parents think [we] are doing.” They ask, “What do you think you could do to make it a lot better.” This statement reflects the partnership of the adolescent, the family, and the health care provider from a younger participant in early adolescence. Jessica, one of the older participants, observes that, “That they ask about what is going on in your life, and how that can affect your diabetes and what you can do to control that. It’s kind of like mentoring.” The partnership with the older
adolescents represents engagement in their T1DM and maturity in the transitional stage. The empowerment in this *partnership* helps the adolescent gain confidence.

The partnership with a health care provider may impact self-management in a positive manner if health care providers increase contacts. Jessica reveals,

I know a lot of times I have to make tweaks in adjustments in my pump. If something is not going right, and I am not entirely sure what I am doing, then I am kind of doing it blindly, and then come to find out I didn’t do it right, *per se*, when I go to see the doctor.

The older adolescent represents “engagement” by understanding the changes in her body as well as the need to address these changes on a consistent basis.

The research process gives the adolescents a chance to tell their story. One participant states, “I’ve never gotten the chance to explain myself to anybody so I’m really happy.” The opportunity to have an objective person (the researcher) listen to the adolescent gives meaning to their story. Jessica states,

I thought it would be a fun idea just to like share what’s going on with me and you know, to have someone listen and be really interested instead of like someone saying, oh yea that’s right, you’re having a high. Let’s do something about it.

The participants reveal they feel they are helping adults learn about their disease process. They also view the research process as a way to meet other adolescents with diabetes. Esme states:

This is going to be a chance to meet other diabetics, just so I know that I’m not the only one out there, but it kind of seems like you’re the only one out there even when you meet them. You know? It’s kind of like are you faking? But I’m pretty sure they aren’t.

**Theme two: Struggles**

The second theme from focus group three is labeled “struggles.” “Struggles” are defined as the conflicts with people close to the adolescent. “Struggles” are the
difficulties or disagreements that arise as caregiver and care providers interact with and facilitate for the adolescent with their diabetes. I also define “struggles” as the misunderstanding of the health care teams surrounding the adolescent’s perception of the doctors’ and nurses’ knowledge of diabetes or the technology used in diabetes management. The technology with devices used in diabetes, such as the insulin pumps and glucose monitors, changes frequently. To the adolescent, the health care providers do not appear to be as up to date with the devices as the participants themselves feel they need to be. This perception is quite prevalent in the rural area. One of the participants who previously lived near a large endocrine center states that her “previous nurses and doctors knew everything about diabetes.” Her statement reflects confidence in health care providers who specialized in pediatric endocrine issues, mainly kids with T1DM.

Lastly, I define “struggles” as arguments the adolescent has with his or her parents, grandparents, or friends over self-management behaviors. For example, one participant states, “They needed their caregivers to help them stay on task with their diabetes, but they frequently pushed them away or were angry to them over reminders to accomplish or complete the tasks.”

Participants want the health care provider to understand their life and the technology used with their diabetes. The understanding the adolescents look for in their health care team is to “walk the walk” with daily tasks. The participants want the health care provider to check blood glucose levels regularly and inject “saline” in place of insulin for a month to feel what it was like to live with diabetes. Joel says, “I would advise you to act as if you had diabetes with maybe fake insulin for about a month and
then you pretty much will know it all.” The adolescent participant is task-oriented and technologically savvy. Ash states:

My doctors don’t know a lot about the pump. I know more because I play around with it like a keyboard. I know what to do, where to go, and how to do it with my pump. The thing is when nurses talk about it or doctor’s talk about it, I go but you aren’t doing it.

The need to acknowledge the difficulty of day-to-day management surfaces in the discussion of technology use. The statement of “acting like you had diabetes” from the participants interrelates with the statements from the participant concerning their need to have the HCP understand the difficulty of managing their T1DM on a daily basis.

Two participants come from other states and feel their doctor or nurse knows them better in the previous states. Ash states, “They should know how to do their job. I am not saying that all doctors who don’t know about every disease and every little detail is bad. I think especially nurses and diabetic doctors should know about diabetes.” This attitude also reflects the relationships established with health care providers that I will discuss in the next section on relationships in theme three.

The last area of struggles focuses on arguments with the primary caregiver in the family. The participants reveal the need for caregivers to understand that the adolescents’ behavior is linked to their disease when teens express their frustrations or anger to their loved ones. The adolescent participants admit feeling guilty because they fight with their loved ones, and teens acknowledge they push their parent and grandparent away. Ash states,

At dinner I just usually start eating, and then I need to run and get my pump or my blood meter because I forget it. Grandpa will get mean. He drives me crazy so, but I would forget if he did not say something.
At the same time, adolescents acknowledge that family members need to keep pushing them to manage their diabetes. Ash states:

That is how my grandpa is. That is how my grandma is. They get on my nerves a lot but that is technically what I need to do my stuff. I usually regret after yelling at her because she has taken care of me, and I pay her back by yelling and not listening.

All participants reveal they get angry and argumentative with their caregivers, but they acknowledge that they need them to stay involved in their daily task management of their diabetes. The adolescents need daily reminders to keep up with self-management tasks of their diabetes.

**Theme three: Relationships**

I identify the third theme from the third focus group as “relationships.” The definition of “relationships” derives from the adolescents’ perspectives regarding their relationships with both the caregiver and care provider. The relationships the adolescent participants describe are vital to manage diabetes properly. The relationships with health care providers and parents means support. One participant maintains that, “they could not take care of their diabetes alone.” The relationships help adolescents pay attention to their self-management. The participants provide examples of this attention, and behaviors include trying to adjust their blood sugars more frequently and paying attention to, and not missing, bolus injections on a more consistent basis.

Participants indicate they need someone to “have their back.” Joel states, “I would find someone to show what I need if I were alone.” Three of the participants state, “I would not be the person I am if it were not for my mom or grandma.” “The family is everything,” states Super Girl. When I ask what could replace the parental support in the
transitional process, Esme replies, “Nothing replaces that parental support. Maybe a really awesome robot, but that is not going to happen.”

T1DM can impact “relationships” in a negative manner. Several participants reveal that school classmates often bully or mock them because of their diabetes. One participant believes conflict is really more about adolescence than their diabetes. Some adolescents indicate they maintain a sense of privacy and worry what other students might say to them about having diabetes. Ash states, “I feel normal, but other people might not see it as normal, as us being us.” Super Girl states, “They [the other people without diabetes] may see it as a contagious thing” or “you are a freak kind of thing” or say “they don’t want to be your friend because you have this.” Super Girl sums up the situation: “We are normal people, and we just have a challenge in our life that we have to work out.”

The successful transition of adolescents with T1DM becomes apparent as teens form and maintain relationships in ways that enhance positive disease management. One area of success the adolescents discuss is the process of being healthy and making choices for healthy living. Focusing on choices for healthy living, instead of task management, appears to be an area of self-identity that enhances the adolescent’s confidence in their ability to manage their T1DM.

The sense of confidence is associated with the adolescent’s perceived ability to “read” the body language of their health care provider. Adolescents acknowledge they can anticipate and discern the reaction of their health care provider in terms of accepting or acknowledging their disease management. The participants feel if they work hard on their disease management, over the last three months, the participants could discern the
heath provider’s “positive” body language at each visit. Perceiving acceptance is one of
the primary reasons adolescents do not want to carry out health care visits over the phone,
text messaging, or Skype®. They would miss the emotional connection they sense during
the visit.

I was initially interested in finding a process or technology to support an
adolescent with T1DM during the time period that parental support decreases. However,
many of the participants state they want the face-to-face time with the endocrinologist or
health care provider. Jessica states, “I wouldn’t like it on Skype® because I like the
interaction between me and my doctor and my mom that we can have in person. I enjoy
that.” All participants reveal they would like more frequent contact with health care
providers and some form of activities with peers with T1DM. There are several
declarations about the importance of the newly started support group, Diabetes Counts, a
night out for individuals with T1DM at a local university. The comments about the need
for fun and education continue throughout the focus groups.

**Focus Group Four: Telephone Interview**

The purpose of the final interview process in group four is to clarify areas of
content I found in the previous three focus groups. I reviewed four areas of content:

- Three themes from each focus group
- The opportunity for each participant to clarify any of the themes and moments
  of disagreement or agreement with the theme and definition
- The aims of the study with the participant who clarify answers to the three
  central questions of the study
- A final theme the participants decide upon in their own words.
I asked participants if they would like to make up a name I could use if I quote their response in my research results. Some of the participants adopted a pseudonym to protect their privacy. A few of the participants wanted me to use their given name while others changed their name to a pseudonym. The use of names seems to be connected with a participant’s confidence, but researchers should clarify that correlation in follow-up research. I completed the final interview phone calls over four days, with the final interview three weeks after the six previous phone interviews. I was able to contact one participant after several weeks when this individual returned a phone call after I attempted three times.

**Aims of the Study**

The aims of the study surface in the questions I ask adolescents with T1DM: First, “What does it mean to be healthy with T1DM in a rural area?” Second, “What do you do to make a positive impact for your health with T1DM?” Third, “What support do you need in a rural area to be independent with your T1DM?” I ask each participant to reflect on the questions and provide an answer.

**Aim one**

The first question identifies the struggles with living in a rural area. Participants explain that it is hard to stay healthy in a rural area because they have limited access to care, medical facilities are remote, and gas is expensive for travel. Joel states, “it means a lot of hard work. In a city you have things to do, but they are not like rock climbing; there are more and more outdoor activities you do that take more energy.” Esme states, “It is hard work and tough to succeed.”
Participants discuss time in rural living in positive terms. Super Girl states, “In a rural area, it takes time to go to a store; the pharmacy is fifteen minutes away. But on the other hand, you can take long walks and not be worried about getting hit by a car.” Joel summarizes the benefit of living in a rural area: “You have time to think.”

**Aim two**

The question of the second aim asks, “What do you do to make a positive impact for your health while living with T1DM? The answers from the participants are task-oriented and focus on remembering and participating in their diabetes management (‘engagement’ according to Meleis, 2000). The theme of “remembering” reoccurs in the three focus groups. Joel states, “I need something like an alarm clock to help me remember. I have a hard time remembering to take a test and treat for something I eat.” Participants acknowledge their awareness “to get on top of their diabetes.” Super Girl states, “I have been given a hard task in life. I am not going to let it take control of my life. I am not going to let it take over me I am going to manage it.”

**Aim three**

The third question asks, “What support do you need to be independent with your T1DM while living in a rural area?” The question exposes access issues that the previous focus groups do not reveal. The need for more doctors, pharmacies, and cheaper medical care is a consistent answer for three participants. Joel states, “We need more access to doctors. Just with basic cold support, it is easier to get sick in rural areas; there are plants and stuff to get sick from.” Access and support are consistent themes in their desire to become independent in a rural area. Super Girl states, “In a rural area, it would be great to
have a pharmacy closer to get supplies. I really need the support of friends and family, rides to a doctor and someone to be there for me.”

**Overarching theme of the research question**

Data analysis in Participatory Action Research consists of continual reflection, refinement of themes, and ongoing analysis. The final question to the participants is, “What is one theme you could identify about having diabetes and living in a rural area?” The answers are consistent with the themes surfacing from the previous focus groups. The themes difficulty, communication, family and friends, divide and conquer, doable and staying on top of it all reflect the perseverance and need for relationships. T1DM is a chronic, lifelong disease. One participant describes the process as “difficult” because of the need to balance freedom with task management. A second participant describes the need for “communication” and a desire to balance being told and being reminded to maintain tasks while increasing self-management of their diabetes.

A participant who invokes “family and friends” feels the need to have loving support to manage her diabetes on a daily basis. By taking one step at a time and one day at a time, the adolescent can “divide and conquer” her management of diabetes. The many tasks teens need to manage T1DM can be daunting. The adolescent clearly understands this challenge, and she needs to preserve a broad perspective to manage her diabetes. Likewise, a participant describing the overarching theme as “doable” also has a broad perspective. The need to balance life and the challenges life gives him is “doable.” It is simply a matter of doing what he needs to accomplish to maintain a disciplined, balanced life. Finally, “staying on top of it all” reflects the need to persevere and not let the disease get the participants down. While the participants all reflect the need for task
management, the overall theme of “staying on top of it” reflects the sense that they cannot forget about the fact they have T1DM. The results of this research demonstrate the need to address ways to support youth in transition to adulthood.

I analyze the results of the study in Chapter IV. The research uses Participatory Action Research to examine high school eligible adolescents with T1DM, ages 14-18. Focus groups address health-seeking behaviors of these adolescents, and the encounters ask them to define areas through the use of iterative group and individual interviews. I analyze themes from the interviews, overarching themes, and the Meleis’ theoretical perspectives of transition. I summarize the theoretical themes, focus themes, and summary in Tables IV.III, IV.IV, and IV.V, respectively. In Chapter V, I outline the strengths, limitations and knowledge developed from the study. In Chapter V, I identify areas that inform future knowledge in research, education, practice and policy.
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<th>Theoretical Lens: Interrelated Properties</th>
<th>Early Adolescence (8th - 9th grade)</th>
<th>Middle Adolescence (10th - 11th grade)</th>
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<td><strong>Awareness</strong></td>
<td><strong>Emerging Awareness</strong></td>
<td><strong>Increased Awareness</strong></td>
<td><strong>Increased Awareness</strong></td>
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<tr>
<td>Awareness suggests a transitional process. The question remains, “What triggers the transitional process? The nurse or the adolescent?”</td>
<td>Emerging awareness is characterized by setting Goals, (short term, two weeks, working for rewards)</td>
<td>Patients are aware of long-term complications if one does not take care of diabetes or change lifestyle.</td>
<td>There are long-term complications if one does not take care of diabetes or change lifestyle.</td>
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<td>Increased awareness leads to increased engagement.</td>
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<tr>
<td><strong>Exemplars</strong></td>
<td><strong>Exemplars</strong></td>
<td><strong>Exemplars</strong></td>
<td><strong>Exemplars</strong></td>
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<td>“Everyone has their challenges. Diabetes is just mine. There are a lot of other kids that have it a lot worse than I do.”</td>
<td>“Setting goals”</td>
<td>“With type 1, it is a life or death situation.”</td>
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<td>“I figure just let the health team do their job.”</td>
<td>“They made me think a little more about how I am doing stuff with my blood sugar.”</td>
<td>“I am not taking care of myself so I want to get myself under control before I take care of others.”</td>
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<td>“I just need to perfect waking up at night to test and then get a job and have a few minutes to test.”</td>
<td>“Parents are just going to pull you back in and help you a little bit here, like when I go downhill. That’s when they come in and help.”</td>
<td>“Just the will to take care of it.”</td>
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<td>“If I test, I can control the blood sugar.”</td>
<td>“My dad met a girl with T1DM, and she had a HGBa1C of 6.5. I think that is awesome, but what is hard is my attention span is little. I don’t think I could do that.”</td>
<td>“I am more aware that I am not doing good.”</td>
<td></td>
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<tr>
<td>“I already have diabetes. I don’t want to deal with any more health problems that could come.”</td>
<td>“If I get high, and I get permanently damaged.”</td>
<td>Just trying to grow up and be like, hey you can’t be lazy, you have diabetes.”</td>
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<td></td>
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<td>“Finding a balance between having fun and having responsibility.”</td>
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## Theoretical Lens: Interrelated Properties

### Early Adolescence (8th - 9th grade)

#### Engagement

Engage implies a desire for role models, seeking out information, and modifying activities. The level of engagement of a person who is aware of physical, emotional, social, or environmental changes will differ from that of a person unaware of such changes (Meleis, 2000).

#### Minimal Engagement

Responds to concrete tasks. “I do what I am told.” Youth struggle to be independent but do not have judgment to make changes in self-management.

### Middle Adolescence (10th - 11th grade)

#### Engagement ebbs and flows.

### Late Adolescence (12th grade)

#### Active Engagement

Engaged and responsible for self-management; understands the consequences of not being compliant which does not necessarily equate with compliance.

<table>
<thead>
<tr>
<th>Engagement</th>
<th>Minimal Engagement</th>
<th>Engagement ebbs and flows.</th>
<th>Active Engagement</th>
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<tbody>
<tr>
<td>&quot;I don’t need it.”</td>
<td>&quot;I would get people around me that know me really well and show them how to work my kit.”</td>
<td>&quot;Starting to care so I could gain independence.”</td>
<td>&quot;There are distractions that will prohibit me or distract me from taking care of my diabetes.”</td>
</tr>
<tr>
<td>&quot;I need to just take care of my diabetes”</td>
<td>&quot;With type 1 it is a life or death situation.”</td>
<td>&quot;A little more improvement it just take care of myself q little bit better, I am doing ok”</td>
<td>&quot;Make a schedule so I know what to follow. The schedule would be the thing to keep on top of everything or at lease help me with everything so that I do not make as many mistakes”</td>
</tr>
</tbody>
</table>

### Exemplars

- "My parents have never slacked off, but if they did I would be like (clapped hands). Hey guys get up. I am alone here. I don’t want to be here. I am in the spotlight and I don’t want to be here yet.”
- "Family and the health care team are helping me with my diabetes. I just don’t listen; I am not a great listener.”
- "If I’m low I need you; if I’m high I need you. If I am perfect don’t bug me.”
- "If I’m low I need you; if I’m high I need you. If I am perfect don’t bug me.”
<table>
<thead>
<tr>
<th>Theoretical Lens: Interrelated Properties</th>
<th>Early Adolescence (8th-9th grade)</th>
<th>Middle Adolescence (10th-11th grade)</th>
<th>Late Adolescence (12th grade)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes, Effects &amp; Meanings</td>
<td>Day to day; don’t want to get sick.</td>
<td>One month at a time</td>
<td>Life-long Commitment</td>
</tr>
<tr>
<td>These properties suggest a change in temporality, perceived importance or severity.</td>
<td>Youth gain confidence in ability to control diabetes. Youth start to make independent decisions.</td>
<td>Youth develop independence in a safety net.</td>
<td></td>
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<tr>
<td>Change may be related to critical or dis-equilibrating events, disruptions in relationships and routines, or ideas, perceptions, and identities.</td>
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<tr>
<td>Personal, familial, and societal norms and expectations play a role.</td>
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<tr>
<td>Responses differ from youth without diabetes.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Exemplars</td>
<td>“My parents are weaning me off, letting me gradually do more and more.”</td>
<td></td>
<td>“Touching base every three months to update and see what you need to fix if there is a problem.”</td>
</tr>
<tr>
<td></td>
<td>“It like OK. We are going to let you go and know we are going to pull you back in.”</td>
<td></td>
<td>“Stay on track or improve.”</td>
</tr>
<tr>
<td>Theoretical Lens: Interrelated Properties</td>
<td>Early Adolescence (8th -9th grade)</td>
<td>Middle Adolescence (10th -11th grade)</td>
<td>Late Adolescence (12th grade)</td>
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<tr>
<td>----------------------------------------</td>
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<tr>
<td><strong>Differences</strong></td>
<td><strong>Fear</strong></td>
<td><strong>Disappointment</strong></td>
<td><strong>Acceptance</strong></td>
</tr>
<tr>
<td>Differences suggest an ability to recognize that the world and others are different.</td>
<td>Recognizing similarity in peers.</td>
<td>Youth compare themselves to other teens.</td>
<td>Youth have an ability to understand one’s relationship with others.</td>
</tr>
<tr>
<td><strong>Environment</strong></td>
<td>Incentives include independence and an ability to go to a friend’s house.</td>
<td>Incentives include changing hair color and money.</td>
<td>Incentives include feeling good, long term plans, and trips.</td>
</tr>
<tr>
<td><strong>Exemplars</strong></td>
<td>I’m the “same as any other kid.”</td>
<td>“It’s not all about diabetes. It’s about how kids are doing, how is there social life.”</td>
<td>“I have a big responsibility I have to take care of on top of everything else.”</td>
</tr>
<tr>
<td></td>
<td>My “quality of life is similar to all other kids.”</td>
<td>“Who we are.”</td>
<td>“Basically it means I can’t live a normal, an entirely normal life, but it is possible to live as normal as I can. It’s just more challenge than I would expect.”</td>
</tr>
<tr>
<td></td>
<td>“Gaining confidence to control diabetes.”</td>
<td>“You have a disease? Like gross.” “Don’t touch me.” “It’s hurtful.”</td>
<td>“I have to take care of myself more than others might just so I don’t have any problems along the way.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Don’t tell me how to live my life because I don’t know.”</td>
<td>“You get left behind sometimes, it feels unfair.”</td>
</tr>
</tbody>
</table>
Theoretical Lens: Interrelated Properties

<table>
<thead>
<tr>
<th>Critical Time events</th>
<th>Early Adolescence (8th-9th grade)</th>
<th>Middle Adolescence (10th-11th grade)</th>
<th>Late Adolescence (12th grade)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The time of increased vulnerability</td>
<td>Pushing boundaries; striving to become independent. Vulnerability is quite critical if not social and medical support.</td>
<td>Youth “take a day off.” Vulnerability fluctuates.</td>
<td>Youth do not “slack off.” Increase in self-management The critical time event decreases as the independence and maturity increase. Vulnerability decreases.</td>
</tr>
</tbody>
</table>

Exemplars

“I am still learning about it daily. I’m still learning about how high you have to be to die and how low you have to be to die and how to keep your blood sugar regulated.”

Summary Table IV.II. Theoretical concepts of Transition PAR: Health-seeking behaviors of T1DM 2012.

<table>
<thead>
<tr>
<th>Transitional Process</th>
<th>You cannot put time on this process.</th>
<th>It is not limited by age or tasks but by change in self-identity.</th>
<th>Taking responsibility.</th>
</tr>
</thead>
</table>
Table IV.III. AIMS OF PAR: Health-Seeking Behaviors of T1DM in Rural Adolescents
EARLY, MIDDLE, & LATE ADOLESCENCE:

<table>
<thead>
<tr>
<th>Study Aim</th>
<th>Early</th>
<th>Middle</th>
<th>Late</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What does it mean to be healthy while living with T1DM in a rural area?</td>
<td></td>
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<tr>
<td>Healthy practices include task-oriented activities, including regulating blood sugars, bolusing, eating well and exercising.</td>
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<td></td>
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<tr>
<td><strong>Summaries of adolescent comments:</strong></td>
<td></td>
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<tr>
<td>Be conscious about what I eat and what I do.</td>
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<tr>
<td>There is a lot of different kinds of healthy like morally, mentally, and physically.</td>
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<tr>
<td>Eating healthy, exercising.</td>
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<tr>
<td><strong>Frequent checking of blood sugars; consistency and timing of bolusing.</strong></td>
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<tr>
<td>2. Identify health-seeking behaviors of adolescents with T1DM that are positive and reflect stable self-management of their chronic disease.</td>
<td></td>
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<tr>
<td>Changing basal rates</td>
<td></td>
<td></td>
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<tr>
<td><strong>Take care of myself. Make sure I have everything I need, and I am doing everything I should be doing. Just be healthy.</strong></td>
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<tr>
<td><strong>Don’t be constantly over 250 more in the 90-200 range.</strong></td>
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<tr>
<td><strong>Someone has a goal to be healthy; they are seeking out choices to eat healthy and exercise more.</strong></td>
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<tr>
<td><strong>Test. Bolus on time. Stay on top of my diabetes. Eat healthy. Exercise. Stay socially active.</strong></td>
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</tbody>
</table>
Study Aim

3. Define developmental transitional behaviors that adolescents perceive as positive and lead to independent and collaborative disease management.

Understanding about the whole person, who they are and what they like. As the adolescent becomes older, the depth of the relationship becomes more important with the health care provider.

Early

- Ask about my life and social issues.
- Ask about the amount of insulin I use.
- Focus on concrete data and numbers.

Middle

- The health care team should know who I am.
- The health care team should know where I have been with my diabetes.

Late

- The health care team should know that adolescents do forget. We have distractions. We don’t want to have diabetes but we will take care of it.
- Understand.
- Ask.

Table IV IV Themes from Focus Groups Summary

<table>
<thead>
<tr>
<th>Focus Groups</th>
<th>Themes</th>
<th>Exemplars</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Focus Group 1 Themes</strong>&lt;br&gt;The purpose of focus group one is to answer the questions, “What is it like to have T1DM? How does living with T1DM affect your life and what does it meant to be health while living with T1DM?”</td>
<td>Distraction /Forgetting they have Diabetes&lt;br&gt;“Distraction” to the adolescent participants means they forget they have diabetes so they forget they have to take care of their disease multiple times per day. They have grown up with the disease so it is a part of them. Remembering is difficult many times of the day with multiple activities.</td>
<td>“It’s part of me so I forget I have it.”&lt;br&gt;“The pump vibrates and I am use to it so I forget.”&lt;br&gt;“I forget.”&lt;br&gt;“I get distracted a lot.”</td>
</tr>
<tr>
<td>Focus Groups</td>
<td>Themes</td>
<td>Exemplars</td>
</tr>
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<tr>
<td><strong>Taking Time to Deal</strong></td>
<td>The adolescent participants have to stop activities to check their blood sugar or bolus their insulin. They sometimes do not want to deal with the task so skip the task until later or the activity is over.</td>
<td>“Stop to check blood glucose.”&lt;br&gt;“Check before tests.”&lt;br&gt;“Need to wake up to test blood sugar.”&lt;br&gt;“I hate taking time out to check my blood sugar, even if I am doing something I hate, I hate taking time to stop and check my blood sugar.”</td>
</tr>
<tr>
<td><strong>It’s a challenge.</strong></td>
<td>It is hard to remember so many tasks and procedures at so many times in the day while being active and being an adolescent.</td>
<td>“It is really hard some days.”&lt;br&gt;“You try and try and try and then some days you face plant in a pile of dung.”&lt;br&gt;“It really effortful.”</td>
</tr>
<tr>
<td><strong>Focus Group Two</strong></td>
<td><strong>Quality of Life is Good</strong>&lt;br&gt;Peds Quality of life tool is used to score Quality of life. All participants score high on the PEDS QOL.&lt;br&gt;Rurality is NOT an issue.&lt;br&gt;Participants do not mind the drive to appointments. They do wish there were more pediatric endocrinologists and that they could have more face to face time with their provider.&lt;br&gt;They do not want to substitute technology with the face-to-face time with an endocrinologist but would supplement the health visits.</td>
<td><strong>Quotations for Participants</strong>&lt;br&gt;“Liked the questionnaire, liked that it asked about social.”&lt;br&gt;“no one has asked questions about quality of life before”&lt;br&gt;“This group QOL is good, different from the literature.”&lt;br&gt;“This is where I live.”&lt;br&gt;“Driving is OK.”&lt;br&gt;“Want face to face no matter the distance.”</td>
</tr>
<tr>
<td>Focus Groups</td>
<td>Themes</td>
<td>Exemplars</td>
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<tr>
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<tr>
<td><strong>Make Diabetes Easier</strong>&lt;br&gt;They wish their pancreas works and they have an automatic button pusher. They wish they could just have something on their body to act like a pancreas</td>
<td>“Don’t want to push buttons on the pump. Having Diabetes is a reality. You are either going to live or die with it. Don’t want to remember so much. Sometimes my sugars just go high and there is nothing I can do about it.”</td>
<td></td>
</tr>
<tr>
<td><strong>Focus Group 3</strong>&lt;br&gt;What do you need in your health care?&lt;br&gt;What do you need to be healthy in managing your diabetes?</td>
<td><strong>Listen to “ME”</strong>&lt;br&gt;The adolescent participant wants the health care team to understand and believe how hard it is some days to live with diabetes.&lt;br&gt;The participants want to tell their story and explain to a person what it is like to live with diabetes, rather than having a HCP tell them it is OK or they are doing a good job.</td>
<td>“Liked the research process, liked telling their story.”&lt;br&gt;“Does not want to be told.”&lt;br&gt;“Wants partnership in health care.”&lt;br&gt;“I’ve never gotten the chance to explain myself to anybody so I’m really happy.”</td>
</tr>
<tr>
<td><strong>Struggles</strong>&lt;br&gt;There are difficulties and struggles with living with diabetes. The adolescent participant feels at times that doctors and nurses do not understand diabetes or understand the pumps and the technology, especially in a rural area.</td>
<td>“Fight with parents, grandparents.”&lt;br&gt;“Need health care workers to know about diabetes.”&lt;br&gt;“Need HCP to walk the walk.”&lt;br&gt;“If I don’t manage my diabetes I don’t feel well, I feel sluggish.”&lt;br&gt;“I am a teenager, and I am sporadic.”</td>
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CHAPTER V
DISCUSSION

In Chapter V, I highlight knowledge gained from the Participatory Action Research of health-seeking behaviors in adolescents with type 1 diabetes (T1DM). The participants chose the themes to describe what it is like to live with T1DM as an adolescent. The overarching themes are difficulty, communication, family and friends, divide and conquer, doable and staying on top of it all. The six overarching themes I identify in Chapter IV reveal two foundational needs. After reviewing these two needs, the participants agree that perseverance and the need for relationships illuminate the final goals they need to successfully manage their diabetes as an adolescent living in a rural setting.

The following characteristics describe the themes: Difficulty relates to the adolescent perception that living with T1DM requires a great deal of effort. Communication is imperative to stay on top of it all, and the support and help family and friends provide are essential. The theme doable relates to perseverance and suggests staying on top of it. Life with T1DM is doable; however, the adolescent must divide and conquer related tasks one step at a time to make daily living with T1DM doable. To complete each day with T1DM, adolescents need to look at the tasks as multiple parts of a whole. The adolescents describe the overall process of managing their T1DM as difficult with many steps. Consequently, taking one step at a time helps the adolescent with T1DM get through the day.

I categorize four theoretical conceptual areas gleaned from these findings into general topics to develop and improve future research, practice, education, and policy.
The four conceptual areas include technology, transition, rural, and self-identity. I will discuss these areas as they relate to the findings, the participants’ view, the implications to research practice, education and policy, and suggest actions and future research. The work of Stringer, (2008) and Herr and Anderson, (2005) guide the discussion and summaries.

**Technology**

At the beginning of this study, I questioned whether health care providers could support adolescents with poor glycemic control of their T1DM and improve daily self-management through the use of social network systems and text messaging. The present study seeks to understand health-seeking behaviors in adolescents that lead to changes in self-management or positive health-seeking goals. Adolescents, in this research, reveal that health care should be accessible, affordable, and consistent. The adolescent participants also affirm that taking time for their visits is important. The participants prefer face-to-face contact over a technology-driven health care visit through Skype® or text messaging. Descriptive and exploratory studies reveal positive outcomes when providers use text messaging or mobile phones to communicate, remind patients of appointments, remind patients to take medications, and educate the study participants (Chen, & Fang, 2008; Downer, Meara, DaCosta, 2005; Ferra, Rocca et al., 2004; Franklin, Waller, Pagliari, Greene, 2003, 2006; Howells et al., 2002; Kim & Kim, 2008; Kollman & Riedl, 2007; Mao, Zhang, Zhai, 2008; & Saoke-Joo & Bom-Taeck, 2007). However, researchers have conducted very little research that focuses on adolescent youth using text messaging to improve health-seeking behaviors. However, studies do demonstrate that telemedicine improves accessibility of health care in adult populations.
Pediatric subspecialty telemedicine consultations can provide special health care needs (CSHCN) to children living in rural, medically-underserved communities, and local providers, parents, and guardians of these children are highly satisfied (Marcin, Ellis, Mawis, Nagrampa, Nesbitt, Dimand, 2004). Health care providers should consider telemedicine as a means to facilitate care to CSHCN, for telemedicine is, relative to the customary delivery of health care, more accessible, family-centered, and coordinated among patients and their health care providers. However, my study suggests that a consistent case manager who provides medical support will benefit the adolescent. Future research should evaluate this model of care and determine whether it can improve an adolescent’s ability to maintain glycemic control.

The adolescent wants to arrange face-to-face time for health visits. While they do consider group visits as an option to increase accessibility, they still want an individual visit after the group visit to address personal issues that may arise during the group visit. The literature reveals that access to health care is limited once the young adult leaves the parental home. Visits to health care become less consistent, and visits to urgent care increase as young adults react to care rather than continue with sequentially-planned care (Carson, 2007; Harris, Freeman, & Duke, 2009; Park, Mulye, Adams, Brindis, & Irwin, 2006). The participants highlight the need to ask clinical practice a key question: What is the best way to promote healthy interactions with adolescents in the health-care setting? This study reveals an adolescent’s need for a caring, non-judgmental relationship that supports and provides anticipatory guidance in either individual or group visits. Health care providers should not underestimate the opportunity to improve the lives of
adolescents with T1DM, and health care providers should support frequent, continual visits.

The participants reveal that they use technology to make appointments or receive quick feedback, such as “check your blood sugar” or “bolus.” However, the adolescents are committed to the model of face-to-face contact with their health care provider. The adolescent participants prefer not to use text messaging as a primary source for health care or a replacement of a health visit even if driving times exceed one hour. This decision may be related to the perception that youth need to gain control and drive the creative problem solving of actions of their own concerns (Cammarato & Fine, 2008). The social network is just that, a “social” network linking people socially for communication.

Limited research discusses the understanding or lack of understanding between health care providers and adolescents. Qualitative studies shed light on the perception gap between adolescents and health care providers. Previous studies that report on the how adolescents perceive primary health care reveal that adolescents perceive a lack of respect and poor communication (Freed, Ellen, Irwin, & Millstein, 1998; Jacobson, Richardson, Parry-Langdon, & Donovan, 2001).

Studies using yPAR (Cammarato & Fine, 2008) observe how youth navigate unpredictable and sometimes oppressive institutional systems. As the participants themselves note, they feel they can “read” a health care provider’s body language, thus helping them gain control of the situation. Technology will remain useful to the participants to confirm medical appointments, relay blood glucose information, or offer an occasional reminder of an activity or meeting. However, researchers need to explore
the value of technology, especially in the adolescent population who has a better sense of ways to improve outcomes in their health. Early research is beginning to address the motivation and experiences of counseling adolescents via the Internet. Early small studies reveal that this practice is effective and positive. However, researchers need to address satisfaction levels of using the Internet long-term to manage chronic disease (King, Bambling, Lloyd, Gomurra, Smith, Reid, Wegner, 2006, King, Bambling, Reid, Thomas, 2006).

A review of the literature researched by Cole-Lewis & Kershaw (2010) focuses on outcomes of text messaging as a tool to change behavior in disease prevention and management. Only three of the studies include adolescents with T1DM. First, Franklin (2006) describes no difference in text messaging daily messages compared to a control group with no text messaging and continuous infusion therapy of insulin without text messaging. Second, Hanauer (2009) tested in a pilot study comparing phone to text messages with emails to increase blood glucose monitoring in patients with T1DM. This small study of 40 adolescents, age 12 to 25, reveals satisfaction with text messages compared to emails (Hanauer, Wentzell, Laffel, & Laffel, 2009). The phone users reply to prompts to complete blood glucose monitoring and report results more than the control group who accesses emails intervention group. (33.1 responses vs. the control group with 2.3 responses, p < 0.02). Most of the participants report that they prefer using a phone to access the office system (Hanauer, Wentzell, Laffel, & Laffel, 2009).

A study by Rami (2006) focuses on text messaging to improve glycemic control. In this study, automated text messages sent medical advice to thirty-six Austrian adolescents with T1DM, age 10-19 years. The control group kept a paper diary for three
months. The group receiving text messages from the clinic improved glycemic control based on improving hemoglobin A1c levels, (p < 0.05). Participants report the service was helpful, but did encounter technical difficulties. Researchers need larger intervention studies that measure specific outcomes and target specific behaviors in adolescents with T1DM to determine if text messaging will be useful in adolescents with T1DM. Researchers need to investigate communication tools to link adolescents with T1DM to the health care team. This area of study is especially important for teens living in remote geographical areas and for those transitioning from the parental home to areas without known health care resources or social support.

The adolescent does not want to substitute medical office visits with technology for several reasons. First, as stated previously, the participants feel they can interpret the body language of the health care provider, namely the endocrinologist, to discern how well they adhere to their diabetes management during the last two to three months. Because participants feel they are adept at reading and understanding a health care provider’s body language, they fear that social technology might deter this opportunity. Health care providers should be aware of the adolescent’s need to develop rapport and connections with a health care team, and they value these connections.

Research findings should be accessible, relevant, significant, and credible, and the results should have the potential to improve the lives of those who have a stake in them (Chambers, 2000). Participatory Action Research provides the ability to close the gap between understanding and action, but also between efficacy (or what works in research) and effectiveness (or what works in practice) (Greenhalgh, 2002). The adolescents use technology for convenience. Future research should explore different
rural settings to validate the findings of my small study. Telemedicine can increase accessibility in many populations. However, the adolescent population may be the exception.

Building a research program that develops knowledge in the field of self-management of adolescents with type 1 diabetes requires Participatory Action Research to explore communication styles and outcomes of text messaging in a group of adolescents with T1DM. The research needs to study adolescents who have been with their primary health care provider for five years. To identify what we don’t know about technology and communication, researchers should use health care providers who enjoy a positive rapport with their patients, and then researchers can focus on how well text messaging improves an adolescent’s blood glucose monitoring, glycemic control, and satisfaction over a one-year time frame. Lengthening the study assesses long-term outcomes in adolescents where glycemic control overall is often suboptimal in most adolescents with T1DM. By controlling for the length of time an adolescent has been with a known health care provider, researchers can establish relationships, thus leading to a better understanding of technology communication.

The work of Sandelowski (2004) influence the questions in this research study. In her analysis of rigor in qualitative research, Sandelowski suggests that evaluation of data is based on two questions: (a) Does it work? (b) If it works, should it be used? Technology can be an effective way to work with adolescents. However, future research needs to describe when and where using technology with adolescents with chronic illness is appropriate. Future research should explore whether satisfaction, glycemic control, and engagement in their health care in adolescents who have standard three month visits with
their Pediatric Endocrinologist differs from those who have monthly group appointments with a health care team. Future studies should also address comparisons between monthly Skype® appointments and other sources of technology. The research study could use the methodology of PAR to compare three groups of adolescents matched by socioeconomics and health care insurance.

Future research needs to determine if health care providers in rural areas view text messaging with the adolescent population as accessible and feasible. Additionally, would a subgroup of adolescents known to an established health care provider in rural areas improve their health by using communication technology to engage with the health care team and improve outcomes in overall glycemic control?

The second area of technology includes diabetes technology products. Technologies such as insulin pumps, continuous glucose monitors, and artificial pancreases are tools the participants would like to use or learn about. The participants acknowledge their confidence in new technologies and insulin pumps. They are unsure, however, of the confidence level that most health care providers exhibit in these diabetic technologies. The adolescents do reveal that the health care provider is a way to learn about what is new in the field of diabetes or technology.

Participants consistently discuss the need for health care providers to wear an insulin pump for a month. This practice may help providers understand the daunting tasks diabetics need to complete every day while managing the fluctuating responsibilities of T1DM. The participants worry that not all health care providers really understand the issues, needs, complications, and role of insulin when managing diabetes. The
participants consistently insist that they know their pump and understand the “buttons” better than health care providers.

Teen diabetics would benefit from research that identifies the training, familiarity with diabetic technologies, and confidence level of rural health care providers who work with adolescents with T1DM. These insights could, in turn, provide additional training for rural health care providers. Local health care providers could partner with larger pediatric endocrine centers, a relationship that enhances awareness of treatment and technologies applicable to adolescent populations with T1DM.

Treatment of adolescents with T1DM based on Meleis’ theory (2010) suggests a need to anticipate guidelines. Based on the findings of this study, the adolescent needs direction in their diabetes management as they become independent in self-management of their T1DM. Help through the transitional period needs to be at the pace the adolescent sets, with frequent face-to-face contacts with a knowledgeable known health care provider who is experienced with pump management of T1DM. Trained and experienced health care providers are scarce in many rural areas. Future research and policy must address creative ways to connect this scarce resource with the adolescent in a rural setting.

**Transition**

Guiding a young adult who successfully self-manages T1DM is a long process. The participants discuss the need to have a relationship with a person who could help them manage their diabetes. Only one of the participants feels independent enough to manage the disease. The participant only anticipates assistance in an emergency. The maverick independence of this young person may be partially due to normal adolescent rebellion, and the intensive management a family member has provided over the last few
years. This particular adolescent’s focus on task management rather than overall disease management may also explain why this young teen feels independent. A previous study addresses this confidence and independence. Ingersoll et al. show that adolescents have task management skills, but do not possess the cognitive judgment to critically judge specific tasks in the larger context of the disease (Ingersoll, Orr, Herrold, & Golden, 1986).

Research shows that adolescents may have physical skills to administer their insulin before they have the cognitive maturity to judge their daily insulin doses. In particular, stress, illness, and competing life styles challenge maturity and an ability to make wise decisions (Ingersoll, Orr, Herrold, & Golden, 1986). This transitional period stresses many adolescents. Educating family members in ways to stay involved and share the burden may help improve outcomes in glycemic control.

For some adolescents, social pressures and peer influences, coupled with the desire to “fit in,” can be a higher priority than performing the constant diabetes care tasks associated with self-management (Keogh, Sullivan-Bolyal, Crawford, Schilling, & Dixon 2011). However, in my study, the adolescent participants do not seem concerned with “fitting in.” The theme “taking time out from activities” to manage tasks appears frequently, and adolescents report that family and friends sometimes remind them to complete tasks. Family members, friends, and health care providers affirm the importance of “relationships” with the adolescents.

During our discussions of recruitment, the participants explained that they joined the research for two reasons. The iTunes® gift cards certainly incentivized them to participate. However, two participants wanted to experience a research study. They
expressed a desire to tell their story and meet other participants. These examples reflect the need of relationships. The theme of relationships appears in multiple areas of data analysis. Two more participants wanted to “help the researcher” gather data. The “helpers” are the two youngest participants and indicate a need to help health care providers understand their experience. The literature offers few articles on recruitment and retention of adolescents in research (Harrington, Binkley, Reynolds, Duvail, Copeland, Franklin, Raczynski (2009). The major issues in recruitment are parental consent, adolescent interest, and underrepresentation of minority adolescents.

Research indicates that the extent of family support available to the adolescent could positively influence their adherence to the prescribed treatment regimen. Follensee, (1989) finds that adolescents whose parents maintain some guidance and supervision in the management of diabetes have better metabolic control (Follensee, 1989). These results remain pertinent twenty-five years later. Follensee’s (1989) study has implications for research and practice, for health care providers need to find ways to not only support the adolescent in the transition to independent self-management, but also support their family members. Education for family members in individual meetings or in-group settings may renew involvement of the family members. Involving parents by helping them understand the importance of helping the adolescent may lead to optimal glycemic control. Research shows that family focus interventions are effective in reducing isolation, improving communication conflict, and promoting problem solving and collaboration among family members (Brackett, Ho, Laffel, 1999).

Researchers have focused on motivational interviewing (MI), a counseling-based strategy to facilitate behavioral change. Channon, Huws-Thomas, Rollnick, Hood,
Cannings –John, Rogers, Gregory (2007) researched motivational interviewing over a two-year period of time. In a randomized control trial with 66 adolescents with type 1 diabetes, researchers used MI to assess improvement of glycemic control. The results reveal MI facilitates behavioral changes in (N=67) (P=0.04) and sustains glycemic improvement N=47 with (P=0.003) at twenty-four months. Researchers need to use MI in the adolescent setting in rural areas to determine whether or not the sustained engagement supporting the adolescent can influence glycemic control.

Motivational Interviewing (MI) is a patient-centered approach using empathy, open-ended questions, reflective listening, and affirmation to elicit resistance and barriers to patient treatment in chronic disease. A variety of health care providers use the technique with adolescents to manage substance abuse and diabetes. The use of MI supports patients who identify their own reasons and need for change. Partnering with a patient appeals to adolescents who want to participate in their own health care (Miller & Rollnick, 2002; Erickson, Gerstle, & Feldstein, 2005; Channon, Huws –Thomas, Gregory, & Rollnick, 2005).

Participants affirm that relationships during the medical office visits are very important. An adolescent feels that a visit is successful to the degree that a health care professional approves of the adolescent’s efforts in their disease management. This approval indicates success more than the actual lab value or hemoglobin A1c. For example, two of the adolescents in the study acknowledge ignorance of their hemoglobin A1c numbers, but the health care provider focuses only on the successes over the last three months. If the lab values worsen, the health care provider suggests strategies to improve health choices and outcomes, but does not focus on the numbers or problem.
The participants state it is important for health care providers to ask about daily social events rather than focus on blood value numbers. All participants state they feel it is important to ask about their personal lives during the health care visit. The participants want the health care provider to know about school activities and social life. Providers need to acknowledge and emphasize how hard a patient is working over the last few months. Participants state, “I would like them to realize that I have been trying and doing some sort of regulation.” Many of the participants indicate they already know if they are not doing well with their self-management of their diabetes. As noted in Chapter III, the rights agenda over the last two decades documents the need and rights of children to participate in decisions that affect them (Freeman, 2007; Holland, Renold, Ross & Hillman, 2010).

The adolescent participants agree that health care providers could tell them that they are doing a great job, but “we as a partnership still need to keep improving.” The use of the pediatric quality of life scale (PED QOL 4.0) appeals to the adolescent. While the adolescents report that the questions are positive, many report that health care providers had never asked them these questions before. (See Appendix D for the PEDS QOL 4.0 tool and results of the participants.) These prompts allow adolescents to begin a conversation that may be difficult for the provider and the adolescent to discuss.

Adolescents with T1DM acknowledge the difficulties of day-to-day life. One participant responds, “It does tick me off when I have been trying to do everything right that I can do,” and the endocrinologist will say, “well do this and this and this.” “I just want to go like this [gesture].” “Let them [the health care providers] try this for one week. They will go crazy.” Many narratives written by patients with chronic illness echo how
adolescent participants feel. Health care providers need to be aware of daily struggles patients face while living with a chronic illness. Additionally, asking adolescents how they are coping with life challenges is an important part of any contact with teens. Responding to bullying and addressing social negative pressure is a primary developmental concern at this age.

The health care model set up for many of the participants is a system of “wait” for the health care provider, then “rush” through the appointment. Changing the model to allow time for adolescents in theory is imperative. However, researchers need to design an equitable model with scarce resources and time constraints.

Partnership in their health care is the goal set by the adolescents as they mature in their relationship with their health care provider. As Esme points out, “It is like a married couple. You suggest one thing. She suggests another thing, and then you keep on going back and forth until finally you agree on something. It might not be what you want, but it is something worthwhile so you compromise.” The rich discussion and intellect adolescents provide makes health care providers aware of the need to partner with and listen to adolescents in a time frame that addresses their desire for “immediacy.” While the knowledge gained from this research study is limited, the frankness and honesty an adolescent offers can shape new models of care. Adolescents with T1DM express a desire for health care built on collaboration, expertise, and relationships. The ability to provide care that is less system-oriented and more person-oriented needs to be available to the adolescent with type 1 diabetes.

Responses to the question, “What does my health care team need to know about a person with type 1 diabetes?” illuminates two common themes. “Fix the problem” and
“understand the difficulty.” Acknowledging the participant’s experience is an important component to building relationships and improving self-management skills of the adolescent. The confidence gained in these skills of self-management enhances self-identity, and this shift leads to successful transitions. The adolescent participant listens to the positive suggestions from the endocrinologists “to improve instead of telling” (Esme). For example, one participant describes her response when the health care provider declares that, “You have to do this and this or you are going to die.” Jessica replies, “We shut down.” One participant finds this phrase helpful: “It is not just you have to do this, but I would really like it if you would do this. You are a good person, and I don’t want to lose another person to diabetes, so do this please” (Bryce).

Lastly, participants reveal they want access to the endocrinologists’ office at the time when they, or their parents, feel like they are having “troubles or struggles.” The adolescent participants feel that three-month appointments are appropriate. However, participants note that soon after making adjustments to insulin pump settings, they realize that find these adjustments are not correct or helpful. When these situations occur, participants would benefit from frequent health care visits rather than waiting for the routine three-month evaluations. The participants feel they are making insulin adjustments “blindly” at times. To stay on the right track and prevent slippage of blood glucose levels over time, adolescents suggest more contact and a more complete response. Researchers still need to determine if increasing the frequency of face-to-face contacts in adolescents will improve glycemic control. To date, no research shows that frequency of provider contact will improve glycemic control. Research shows that continuous glucose monitoring improves glycemic control in patients greater than 25
years of age, but not in adolescents (Tamborlane, Hirch, Huang, Kollman, Kowalski, Laffel, 2008).

Other research shows that self-efficacy mediates the relationship between social support and self-care (Williams & Bond 2002; Shilling & Grey, 2002). When studies control for the effects of self-efficacy, social support is no longer a significant independent predictor of self-care. The difficulty in using this relationship in research with adolescents is the variability of measuring self-efficacy in the teenage population (Iannotti, Schneider, Nansel, Haynie, Plotnick, Clark, Sobel, & Simmons-Morton (2006). Williams and Bond (2002) suggest that programs designed to increase confidence in self-care abilities are likely to be effective because they may indirectly increase self-efficacy. However, studies cannot offer a definitive conclusion that addresses the causal order of self-efficacy and self-management from the present results. It is equally possible that a history of successful diabetes self-care builds the patients’ confidence in their self-care abilities (Williams & Bond, 2002).

Rural

Participants reveal that living in a rural area is “hard work.” Adolescent participants do not feel they lack most diabetic resources in comparison to a larger metropolitan area. They express a desire for increased access to a pediatric endocrinologist. However, travel time to a pediatric endocrinologist is not an issue for the rural adolescent participant. They report the time it takes to drive to their health care appointment is an opportunity to talk and connect with a parent or grandparent. They state that many times during the travel, they have opportunities to discuss frustrations that occurred in the previous month. Travel provides important opportunity for dialogue
between adolescents and their family members. Families often combine medical visits with shopping, eating, and entertainment, events that rarely occur at home. They state the “outing” is a primary reason to drive to appointments. They resist replacing these appointments with technological interventions. One member states, “we take the whole day and spend it ourselves. Just my grandma and I usually get a girls day out that we hardly get at home.” While taking time out for checking blood sugars is an obstacle in sports and classes, several participants value the time used to drive for appointments. I assume that family members also view these times for appointments as positive, for they are willing to make and keep these appointments at the expense of taking time from work, play, and multiple scheduling conflicts.

Research supports the notion that rural populations are people with intrinsic values (Hart, Larson, & Lishner, 2005). The adolescents in my research value the relationships they experience. Rural communities and populations ultimately define their rural nature by relationships. It is up to each individual and community to decide what its rural character is and subsequently, how they define it. Elements of characteristics rather than population numbers are commonly seen in descriptions of, and definitions of, rural character. Key characteristics may include farmlands, woodlands, clean air and water, undeveloped open space, natural stream banks, outdoor recreation opportunities, and smaller wide-spread communities.

On average, rural populations have higher percentages of poor, uninsured, underinsured, and relatively more elderly people and children. Rural populations are more vulnerable than their urban counterparts to economic downturns because of their concentrated economic specialization (Hart, Larson, & Lishner, 2005).
The environment where rural physicians and other providers practice differs both across rural areas and between rural and urban areas (Rosenblatt, 2001). Physicians who practice in smaller and more remote rural towns practice in a medical care delivery system characterized by financially vulnerable medical organizations, small populations, long distances to specialists and tertiary hospitals, longer practice hours, lack of collegial support, limited access to advanced technologies, and relatively high fixed costs per delivered service. The environment of limited resources impacts the ability for rural providers to be expert in many specialized areas of health care. The difficulty for rural providers and populations to access advanced medical systems makes it difficult to be aware of current trends in diabetes management (Rosenblatt, 2001). The adolescents’ need to stay current with advancing technology of diabetes management challenges medical providers and medical systems in rural areas that already face limited resources.

Six adolescents depend on their primary care support person in their family. The adolescent participants feel they burden their parent or grandparent, snapping at the person who reminds them to check blood sugars or bolus insulin and growing angry because of frequent reminders. However, all participants acknowledge they cannot manage their disease without their family member constantly helping or being involved. Several participants also acknowledge they do not know what they would do if the family member no longer provided help or support.

Family members provide most of the support and medical care for adolescents with T1DM. Knowledge and education are not safety nets to prevent mishaps from occurring with T1DM. One participant was hospitalized due to a parent giving the wrong kind of insulin. “It’s hard. My parents even get confused” (Esme, Bryce). Self-
management is a multi-dimensional concept that includes activities that youth and their parents perform to care for the disease. It’s essential for youth, parents, and health care providers to collaborate as youth assume full responsibility for managing their diabetes (Schilling, Grey, & Knafl, 2002). Health care providers and parents cannot underestimate the challenges and length of time it may take to successfully independently manage T1DM.

The developmental transition of adolescence is a process that takes time. The burden of type 1 diabetes, poor glycemic control, and complications of poor glycemic control in young adulthood demand interventions that support the transition of adolescents with T1DM to young adults. Chronic illness complicates the desire to become independent. Meleis’ Transitional Theory sheds light on necessary interventions and areas of research that can guide the adolescent through the transitional process.

Previous research correlates increased frequency of blood glucose monitoring with a decreased quality of life in adolescents with T1DM (Ingerski, Laffel, Drotar, Repaske, Hood, 2010). The decrease in quality of life, coupled with the lack of evidence in improving glycemic control with intense glycemic monitoring in adolescents, leave a gap in useful interventions for adolescents with T1DM at this time. The goal in clinical practice is to improve outcome of glycemic control without increasing the burden that may not make a difference in self-management. Research should focus on interventions that improve glycemic control in the adolescent.

My study participant population has ongoing family support, but additional research should repeat this study and include a group of rural adolescents without parental support. The population this study evaluates is a convenience sample. The
accessibility of the sample may lead to some participant bias. Participants expressed interest in the research process and were eager to engage in the study. Several potential participants in the endocrinology offices who were in poor control and experienced poor parental support did not participate in the study. It is likely these are the adolescents who have worse outcomes in their T1DM management in young adult life. However, this conclusion is unknown because this population is difficult to access for research.

**Factors Influencing Models of Care**

Three of the participants mentioned financial concerns during multiple interviews. Models of care and delivery of care could impact acceptance and use of technology as well as methodology of care. There is a gap in knowledge surrounding an adolescent’s awareness of care in comparison to financial access to care. In an era of changing economic and health care reform, the knowledge we gain may not directly impact practical clinical issues of the young adult with T1DM. With the large number of adolescents on Medicaid or state insurance, federal funding of chronic health issues is an area stakeholders need to address to develop education, practice, research, and policy. It is difficult to know if these issues impact adolescents in rural areas at increased levels, but the fact remains that poverty levels are higher in a rural area (Hart, Larson, & Lishner, 2005; Rosenblatt, 2001). Through this Participatory Action Research, it is clear that adolescents are aware of the cost of their diabetes and the need for medical access and supplies as they transition to independent health care as a young adult.

**Planning for the Future**

The adolescent participants supply multiple examples of living in “the present” with their T1DM. Their ability to plan for the future appears limited. Statements like,
“My health care team knows everything about me,” and “I don’t know what I would do if my family member or health care team changed” reflect the struggles of future planning for many of the participants. These reflections exemplify the concrete thinking required for healthy living. If adolescents carefully monitor their blood sugars, they will not have symptoms related to diabetes. The second area that limits future planning is evident in the theme of “not listening.” The overarching theme of “not listening” suggests participants encounter problems with their parents and their health care team. At times they choose to ignore or not listen to the advice of the parent or health care provider. The participants’ ability to acknowledge they are not listening reflects maturing cognitive skills. However, participants stating these issues are seventeen years of age. This attitude is consistent with Arnett’s (2007) work that reveals adolescent cognitive maturity develops later than we previously acknowledged.

The transition period from pediatric to adult clinical practice reflects the need for longer transitional times for adolescents with a chronic disease. A model of care that keeps adolescents with T1DM in pediatric or adolescent care longer may improve long-term outcomes at the age of forty. Research is needed to evaluate these models of care. Unfortunately, the United States has not evaluated models of care that have successfully managed glycemic control and impact long-term outcomes. Many areas with specialized pediatric endocrinology clinics, and where a collective environment performs centralized specialty care for children with T1DM, report a decline in diabetic complications (Donaghue, Chiarelli, Trotta, Allgrove, Dahl-Jorgensen, 2009). Heath care providers often develop models of medical care that stop medical training and care at an adolescent age of eighteen years, rather than considering developmental levels of maturity.
Participants view the connection with peers with T1DM as a possible source for group medical visits. Participatory Action Research illuminates the need to provide cursory group interactions first. Group visits that follow the initial meeting build on rapport that adolescents initially establish among themselves. The type and structure of group visits with adolescence suggest a need to research and develop clinical practice models of care. Adolescents report positive connections with peers when activities such as camp or overnights activities occur. Many rural communities lack overnight activities and group support. The nearest available camp for adolescents in the rural area researched is over 250 miles away, and this camp may be beyond the financial reach of many of the local adolescents with T1DM (Super Girl).

I asked study participants about the transition from family support. Six of the participants observe that they “would not know what to do if family members were not available for support.” The family is a consistent and ongoing support to the adolescent. “We thrive on more support than doing it ourselves, getting told what to do, and not just doing it. We do it, but we have to get told what to do, and we have that support system that we cling to because we feel safe with them.” A second participant reveals, “if we were apart, then we would just come crashing down.”

Family members should address the importance of support. Implications for practice include identifying opportunities to build support systems outside of the immediate family. Adolescent participants desire peer fun and interaction. Three participants enjoyed supporting and participating in a monthly fun night out, sponsored by a diabetes support group. Three participants, who live outside the area, state they would like to attend a peer support group closer to their homes. However, it is clear from
this small study that family members need to be supported during the adolescent transition. Family members need to understand they are the safe “sounding board” for harsh words and frustrations. The family members need to recognize the importance of staying involved with their child’s T1DM. The developmental swings from independence to dependence with their child are common. The support for families in a rural area becomes even more of an issue due to the extreme distance and isolation some families face. Despite the interest in primary care enhancement, very few research studies directly examine the child and family outcomes after health care providers have implemented medical home interventions. However, evidence suggests that a comprehensive, coordinated, and community-based approach improves outcomes for children with special health care needs (Farmer, Clark, Sherman, Marien, Selva, 2005).

Participants state,

My family knows I am a diabetic. My friends and my boyfriend know what to do. The people I care about the most are my family, my friends, and whoever I am with. That is an important part of the relationship with people if you can trust that person enough to tell them what is wrong with you (Ash).

As a hypothesis-generating approach, this study offers new ideas and potential connections among ideas. Medical staff could offer technological support and education for the primary family member who assists an adolescent with T1DM. The opposite view becomes evident as participants reveal that their family members are the primary support. An alternative avenue of support suggests encouraging the family members to maintain the connection and relationship with the adolescent rather than supplement the connection with health care providers.

Two important practice and research implications surface. First, family members need to stay involved in the adolescent’s life through late adolescence. According to
Arnett (2007), late adolescence can extend into the late twenties. Second, the most appropriate way to increase the contact with health care providers is through face-to-face contacts during the transitional period. Research needs to address several models of care: case management and medical home models and primary medical managers for adolescent health care, especially if a patient is chronically ill. Other emerging models include the Navigator.

The Navigator is a systems model that uses email and telephone contacts to connect adolescents moving from a pediatric practice to adult care. Through a research project (N= 82) following adolescents’ transition, we learn that more adolescents see health care providers if they connect with the Navigator model than those who do not enroll in the program (Walleghem, MacDonald, Dean, 2008). Additional research needs to explore the Navigator model and other models that connect adolescents who are in transient stages of work, school, and health care. Text messaging may be a form of support to offer parents and grandparents as they engage in the use of social networking systems as educational tools. The type of medical delivery system rural areas require depends on characteristics of the rural population. Based on this study, it is clear that researchers need to examine access, affordability, and relationships in the context of models of care with adolescents with T1DM.

Few research projects address the development of confidence and self-efficacy in adolescents with T1DM. A literature search does reveal a correlation with increased self-efficacy and athletic ability and outcomes (Dinc, 2011). However, no research has been able to support increased self-efficacy with health outcomes in diabetes. Significant research addresses the complications of poor management from early parental withdrawal
of support in the management of T1DM. The lack of transitional resources for adolescents in self-care continues to reveal gaps in the literature that future research needs to address. To date, individualized, coordinated care needs to address the transitional process of adolescents with T1DM. However, research needs to examine best-practice models for the transitional stage.

**Self-identity**

The successful developmental transition of adolescents with T1DM becomes apparent as adolescents form relationships to enhance and improve disease management. One area of success the adolescents discuss is the process of being healthy and making choices for healthy living. The change in focus from task management to choices for healthy living gives the impression that self-identity increases as confidence increases. Age and developmental status are powerful, contextual variables influencing self-management (Harrigan, Faro, VanPutte, & Stoler, 1987; Wysocki, Meinhold, Cox, & Clarke, 1990; Ingersoll et al. 1986; Comeaux & Jaser, 2010; Miller and Drotar, 2007). The change from understanding the choices the adolescent makes about their life style and the impact of these choices on the disease itself is a developmental indicator of maturity (Comeaux & Jaser, 2010). It is unknown to what extent this change indicates increasing maturity or increasing self-identity. New research must evaluate the concept of supporting transitional periods of development with an adolescent with T1DM. Research could discern if support through the transition period would increase self-identity and thus influence self-management.

For some adolescents, social pressures and peer influences, coupled with the desire to “fit in,” can be a higher priority than performing the constant diabetes care tasks
associated with self-management (Keogh, Sullivan-Bolyal, Crawford, Schilling, & Dixon 2011). However, contrary to the Keogh et. al study, the adolescents in my study do not use peer pressure to indicate a failure to manage their diabetes. They describe the need to stop what they are doing and perform the necessary tasks to manage their diabetes. Only one participant states she would wait until the activity is over to check her blood sugar. This attitude may indicate peer pressure, but my study does not discuss this issue.

**Self-management**

The adolescent participants are keenly aware that missing injections impacts diabetes management. Even though the participants reveal being conscientious about the need to inject insulin at each meal and with snacks, they admit to missing multiple doses. Missed insulin injections are at higher percentage for the participants in this study than previously noted in the literature (Burdick, Chase, Slover, Knievel, et al. 2004). However, the adolescents offer no consistent strategy to remind them to bolus insulin with each meal. The action plan generated by the adolescents consistently mentions the need for reminders to check blood sugars and bolus insulin. The participants comment that, short of tattooing “bolus” on their forehead, they do not know how they can remember. The participants acknowledge they do not want to forget the tasks; they just have trouble “remembering.”

In previous studies, teens report that being personally responsible is a barrier to self-management (Hanna & Guthrie, 2000). Continued research on the impact of missed doses could greatly change the issues with glycemic control in adolescents. Increasingly, sophisticated computer interfacing with blood glucose (BG) meters, continuous glucose sensors, insulin pumps, and insulin pens allow patients to interact directly with the
diabetes team between visits, a relationship that may result in improved diabetes management (Jansa, Vidal, & Viaplana, 2006). Two of the participants had used continuous glucose sensors and had access to these devices because family members work in the health care field. They use the devices to assess diabetes control. Four of the participants know of the technology with continuous glucose sensors. However, their insurance does not cover the technology.

To date, adolescents have used pump alarms, phone alarms, and various reminders. We expect teenagers in late adolescence to remember to practice self-management behaviors without constant reminders from parents and health care providers. However, clearly they forget and admit to needing help to remember to complete self-management tasks on a daily basis. Research and education needs to develop strategies to decrease missed doses. Missed mealtime doses of insulin are a major indicator of poor glycemic control. However, research does not show how to decrease the frequency of missed injections and boluses. (Burdick, Chase, Slover, Knievel, Scrimgeour, Maniatis, Klingensmith, 2004).

Intensive home and community-based behavioral therapy do improve adherence in diabetes self-management in a cohort study of adolescents with T1DM (N= 127). However, when the research study compares tasks, adolescents increase the frequency of blood glucose monitoring but do not change behaviors in insulin administration or eating behaviors (Ellis, Frey, Naar-King, Templin, Cunningham, Cakan, 2005). Additional studies need to determine the particular level and cost health care providers and family members can implement behavioral interventions.
Health-seeking

“Health-seeking” is a difficult term for the adolescent participants of this study to understand. Most of the participants ask what “health-seeking” means. Framing the question in terms of “What does it mean to be healthy while living with diabetes?” clarifies the issue for participants. From this question, the main theme that surfaces is “taking care of the diabetes” as a task. The care of the diabetes is defined in terms of maintaining a “blood sugar” less than 250 mg per dl. Considering normal blood glucose ranges in individuals without diabetes should be less than 120 mg/dl, this top range accounts for adequate control of diabetes in an adolescent without blood sugars going above 250 mg/dl which health professionals consider dangerous. When I ask if lab value numbers discuss what “health” means, participants’ answers change to lack of negative symptoms, “no nausea, and no shakiness.”

Research needs to clarify different definitions of health in adolescents with T1DM in comparison to those without T1DM. Much of the research on adolescent health centers on psychological health, quality of life with chronic illness, and sexual health. Research on the health of the twenty-first century adolescent is lacking. The challenges adolescents face without a chronic illness can be daunting (Grey Boland, Yu, Sullivan-Bolyai, & Tamborlane, 1998; Ingerski, Laffel, Drotar, Repaske, & Hood, 2010). Future research needs to understand this developmental risky time while promoting opportunities to engage this population in discussions about health outside the arena of quick acute care visits or health care checks for sports clearance.

Research needs to explore appropriate interventions for family support which allows family members to remain involved in their adolescent’s self management of
T1DM. The support must be balanced by opportunities for adolescents to learn decision-making skills and independence in a safe environment that do not risk complications from poor glycemic control. Family involvement must balance risking over-involvement and creating conflict and under-involvement that creates poor diabetes outcomes (Seiffge-Krenke, 1998). A successful family plan balances the increasing independent needs of the adolescent with involvement and safety from a supportive family member.

**Quality of research**

I base the themes of technology, transition, rurality, and self-identity on four conceptual areas outlined by Creswell (2009). These four conceptual areas are themes that (1) reflect current literature, (2) were not present at the beginning of the study, (3) interest readers, (4) address the larger theoretical perspective of the research (Creswell, 2009, p187). Bogdan and Biklen (1992, pp. 162-172) provide the framework for the analysis which is based on perspectives participants provide during focus groups as well as activity themes, relationship and social structure themes, and process themes (Creswell, 2009, p. 178). Using Lincoln and Guba’s criteria (1989) for rigor, credibility, and transferability, I will discuss and critique the analysis of the research. It is important to understand that action research does not automatically mean that there is a successful change to document with results. Rather the results are part of a process that produces local knowledge (Herr & Anderson, 2005). The results of this study are rich. Knowledge gleaned from difficult-to-reach populations provides ways to improve practice in many areas. While these results may not be transferable to other populations, repeated research with adolescents with T1DM and other chronic illnesses will continue to build and develop a basis for research, education, and policy development.
Rigor and credibility

Instead of asking a professional transcriptionist to work with my research, I transcribed interviews personally to remain close to the data and continually reflect on words and themes the teens repeat. The process increases the rigor and credibility of the data analysis (Lincoln & Guba, 1989). I reviewed the data with an eye on themes and descriptions with a doctoral-prepared, senior qualitative researcher (Jones, 2012). The process during data reduction reflect the continual look, reflect, and act cycles of Participatory Action Research. The transferability of qualitative research, as defined by Lincoln and Guba (1989), for this study is limited in multiple areas. However, one unexpected insight that surfaces in the study addresses the use of technology in this group. The group is a defined adolescent population living in a rural area with a defined chronic illness. I discuss this insight in the section under technology.

I tested the credibility of the data analysis with each focus group by bringing up past themes, comments, and questions from participants to all members to confirm correct or interpretive information. Lincoln and Guba (1989) refer to this process as member checks, and the protocol assures that researchers deduce data collected in a way that allows participants to confirm a researcher’s interpretation of their comments. I completed member checks with the early themes: taking time out for diabetes, the issues of access to care being hindered by distance, remembering, isolation, and use of social media as an alternative for delivery of health care. I built member checking into each focus group and final interviews.

A reduction of participants in the initial planned focus group challenged the credibility of the PAR process. I altered the planned focus group of seven participants
due to members asking me to interview them individually or in pairs. I changed the original pairing of participants during the third focus setting. I didn’t anticipate scheduling the group participants for one focus group meeting at a time in the PAR process (Lincoln & Guba, 1989). However, by reviewing each theme, each participant was able to clarify themes and statements prior to the next focus meeting or interview. In theory, this practice created virtual focus groups and allowed me to review and add the results of the interviews in the iterative cycles for analysis.

Placing two participants together in two of the focus groups challenged the process as well. The first pairing of a 10th grade female and an 8th grade male reveal the limitations of gender and age. The older female’s answers tempered the responses to questions. This effect became apparent in a second focus group that allowed the female 10th grader to fully express her ideas when I paired her with a female participant of her own age. She was even more elaborate and descriptive in her responses when she was alone during the final interview. The younger male participant was also more animated in a second focus group when paired with a male participant of similar age. Both younger male participants seemed to support each other and construct their responses by agreeing or disagreeing with each other’s response.

Paring in group two occurred due to geographical location. I paired a male in 12th grade in a higher socioeconomic status with a younger female who was home schooled and who expressed financial concerns. The interview yielded shorter and more superficial answers in comparison to a follow-up interview when the female offered considerably more in-depth comments and reflective answers.
The paring of two female participants who are close to the same age and who live in the same geographical area exposed some competition during the interview. However, I observed a more free-flowing narrative in the second interview. Participatory Action Process allowed the flow and change of group parings as these limitations and opportunities surfaced. PAR also allowed for in-depth interviews during the research process from a population that may remain superficial with single interviews.

The challenge of group dynamics in adolescents is a continual limitation in research and practice. Group cohesiveness can build ideas, but self-conscious or shy adolescents can limit interaction. Words adolescents use reflect shyness, self-consciousness, and reticence in all focus groups. The adolescent’s perspective is imperative to understand when developing new models of care. Health care providers build many models of care on adult perspectives. Cheney (2011) notes actual perspectives of adolescents are lacking when developing policy that impacts this age group (Cheney, 2011). Researchers need to consider adolescent perspectives in health care and design models with longer transition time and access to different modalities of communication.

Lessons Learned in Recruitment

The first group dismantled assumptions about recruitment during the research process. A diabetes support group had been an effective way to bring kids with diabetes together, especially the 8-14 year-old group. I anticipated participants would join the research session in a similar fashion. Participants were hesitant to join the focus group and actually preferred to meet individually before the first group setting. The consent process eased participants’ tensions, resulting in increased group participation. However,
two participants declined to participate during the initial phone contact, and one did not
attend any group meetings. Most of the participants indicate a meet and greet would have
been helpful prior to the research study.

The second difficulty for focus group process is scheduling participants to meet
for group interviews. As described above, competing activities for all adolescents were a
challenge. No one activity was consistent for all of the participants. By the third focus
group, participants were willing to meet at one scheduled time. However, geographical
issues and time constraints associated with participants’ activities prevented a single
meeting time to accommodate all participants.

The process reveals a need for prolonged engagement with adolescents. First,
adolescents do not want to be in a focus group to talk about diabetes if they do not know
other group members. They are more willing to talk individually and respond to questions
if they are interviewed alone. Second, adolescents do not want others to know they have
diabetes. The participants want to take care of their diabetes without outside help, and
except for one participant, most prefer to have family members remain involved. Third,
adolescents want to see their health care providers face-to-face for emotional support.
The adolescents are willing to drive great distances to medical visits and perceive this
time commuting as valuable time with a parent or guardian. The adolescents agree that
technology is a way to enhance information exchange between provider, parent, and
themselves, especially for blood glucose level measurements. However, the participants
do not view use of technology as a replacement of face-to-face contact or for additional
education. Finally, parents, grandparents, and guardians receive the brunt of frustrations
and anger from their adolescent. The adolescents acknowledge they cannot manage their
diabetes without their family support. The adolescents frequently and consistently push their loved ones away. Nevertheless, they need continual family support and guidance for their diabetes management.

**Implications for Education**

Health care providers should incorporate behavioral interventions that enhance the ability for youth and families to self-manage diabetes in routine care. Adolescents have the fine motor control to competently perform most self-management activities, but they still need help with decisions about insulin adjustments. Education and practice guidelines need to address the developmental issues that face adolescents with T1DM. Health care providers need to be trained in T1DM specialty care in rural areas.

**Implications for Practice**

To guide diabetes standards, pediatric clinicians at health centers use evidence-based decision support through customized electronic health records (EHR) and templates. The information is useful at the point of care, especially in terms of ordering and recommending screening tests. Clinicians can access health information technology to deliver high quality, patient-centered care to underserved populations. Growing information and research using clinical guidance to influence behavior is needed. (Naureckas, Zweigoron, Haverkamp, Obrien Kaleba, Pohl, & Ariza, 2011).

“Meaningful use” is a phrase applied to integrated systems of care to improve and measure outcomes of certain identifiable diseases. The model of central computerized systems can be useful in the diabetes model where multiple tasks over time need to be fine-tuned and individualized. By measuring processes of care, health care providers can identify implications for strategies that work with multiple-patient
populations to improve outcomes in not only glycemic control, but in standards of care, education, and practice (Renders, Valk, Griffin, Wagner, Eijk Van, & Assendelft, 2001).

**Summary**

The diagnosis of type 1 diabetes mellitus (T1DM) is highest in 10-14 year-old females. T1DM is most prevalent among non-Hispanic whites and least prevalent among Hispanic and Asian/Pacific Islander youth. In Colorado, doctors annually diagnose one in four hundred children with T1DM, with the highest prevalence in some of the more rural counties (Search, 2004, 2006; CDC, 2009). Health care workers typically manage diabetes by measuring blood levels of glycol-hemoglobin (HgbA1c), a laboratory test that measures the blood sugar fluctuations over a three-month period and reports optimal glycemic control at levels less than 7%. Adolescents typically have HgbA1c blood levels of 1% or higher than most adults with T1DM.

An increase in HgbA1c blood levels in the 8-9% range can increase renal, ophthalmic, and neurologic complications later in life (DCCT, Research group, 2001; Danne, Mortensen, Hougaard, Lynggaard, Henk-Jan, Chiarelli, Daneman, Dorchy, & et al., 2001). Growth and hormonal changes during puberty can cause insulin resistance. The physical maturational changes in adolescence make it difficult for adolescents to maintain optimal glycemic control. Poor glycemic control places the young adult at increased risk for complications of diabetes such as retinopathy, nephropathy, thyroid and celiac disease, hypertension, dislipidemia and diabetic ketoacidosis (Hampson, et al., 2000; Silverstein, et al., 2005; DCCT, 1995; Skinner & Hampson, 2001). Diabetic complications account for ten percent of the health care economic burden and short term hospitalizations for 18 to 44 year-olds with diabetes, ranking fourth behind child birth,
mental health issues and injury (CDC, 2006; Kaiser, 2003). The transition from dependent teenager to independent adult is particularly complex, for an individual will encounter more health and social risks during this period than any other time in his or her life (Ingersoll, Orr, Herrold, & Golden, 1986; Silverstein, Kingensmith, Coleland, Plotnick, Kaufman, Laffel, Deeb, Grey, et al., 2005).

Results

Diabetic support group blogs reveal that the focus on the HbA1c laboratory blood value has often scared adolescents, and as a result, they avoid medical visits (TuDiabetes.org., Hernandez, 2010). The health care team must find unique ways to help young people learn to take responsibility for the management of their diabetes and reduce the swings in glucose levels, poor glycemic control, and early young adult complications.

I used Participatory Action Research, (PAR) to explore the voice of rural geographical adolescent youth with T1DM as they navigate needed health care resources. Reading descriptions of how patients and health care providers feel disconnected from each other reveals the need to first understand how adolescents manage their health with T1DM. Perceptual gaps between how patients perceive how well they manage their health and the actual test numbers that exceed the predetermined range demonstrate a need to understand the following questions: “What does it mean to be healthy while living with a chronic disease such as T1DM on a daily basis in a rural community?” What are positive health-seeking behaviors an adolescent with T1DM needs to display to reflect health?” “What support do adolescents with T1DM require to be independent in successful management of their chronic illness?”
To better understand the needs of local youth, I conducted twenty-seven individual and paired interviews, and the results of that research reveal resources rural areas need.

It’s difficult to identify how rural youth in western Colorado manage their health. Adolescent participants frequently describe themselves as “being healthy” in terms of managing T1DM. They report the following strategies to manage their health: eat properly, exercise, check blood sugars regularly, and use insulin appropriately. As the adolescent participants mature, they repeat their health choices to maintain their diabetic health. Remembering task-oriented activities leads to independent transition in self-management of T1DM. However, decisions about what physical activities affect the glucose levels constantly challenge participants. To independently manage their T1DM, adolescents need to adhere to key protocols, including checking blood sugar, injecting insulin, exercising, and building independent social support systems.

Many professionals believe that technology would provide a solution for adolescent burdened by living in a rural area by reminding them to adhere to the medical plan. However, my study illuminates the adolescent’s perspective on technology and living in a rural area. First, adolescents value the face-to-face time with their health care provider. Second, adolescents value the support they receive from a primary family member who remind them of their many daily task management activities. Third, adolescents do not view living in a rural area a burden, and they value the time with a family member during travel to health care appointments. Fourth, at this stage in their development, adolescents typically need information quickly. When adolescent participants have questions, they want increased access to their known medical providers.
Waiting for scheduled medical visits contributes to problems with their glycemic control. Finally, relationships with a primary family member are essential because adolescents need someone to listen and to provide help when they encounter problems with their diabetes and with day-to-day life challenges.

Conclusions

Empirical knowledge indicates that adolescents with T1DM need longer transitional periods. Transitioning from dependent self-management of T1DM to independent young adult foregrounds several issues. First, health care providers must mentor adolescents to form positive relationships that help them manage their T1DM. Second, rural health care providers need to develop formal support programs for families with adolescents with T1DM to supplement current resources. Third, building formal associations to facilitate transfer from pediatric to adult health care will improve the transition from dependence to independence. Fourth, health care providers need to offer informal mentoring of adolescents with peer and group visits on a regular basis in addition to routine medical visits. Fifth, medical practices need to restructure health care visits to increase time with a known provider during the adolescent years. Finally, medical professionals need to communicate better with adolescents and families so adolescents feel that authority figures actually pay attention and listen to them. In this study, the young participants highly value personal interaction over technology when making health care decisions. The adolescents reveal a need to be “listened to” and have “relationships with” a support person and their health care providers.
REFERENCES


Anhøj, J., & Møldrup, C. (2004). Feasibility of collecting diary data from asthma patients through mobile phones and SMS (short message service): Response rate analysis and focus group evaluation from a pilot study. Journal of Medical Internet Research, 6(4), e42. Published online 2004 December 2. doi: 10.2196/jmir.6.4.e42


The red area on the left of the slide represents the area on health care access for T1DM with the majority of care being provided in Mesa County in Grand Junction.
APPENDIX B

TRANSITIONAL THEORY FRAMEWORK

Types of Transition:
- Developmental transition of adolescence
- Health and wellness while living with a chronic illness

Transition conditions:
- Level of skills
- Emotional wellbeing
- Parental and social environment
- Expectations of the adolescent, the parent, and the health care team
- Lack of ability to plan due to developmental level of being an adolescent
- Access to health care team

Universal Properties of adolescents:
- Self-management skills
- Self-efficacy
- Sense of purpose
- Human capital
- Social capital
- Cognitive abilities

Indicators of Healthy Transition:
- Glycemic control
- Independent decision-making
- Lack of mismanagement behaviors
- Forming social support systems
- Communication with health care team

Nursing Interventions:
- Anticipation of adolescent needs
- Anticipation of high-risk behavior
- Promoting self-management skills
- Communication via technology that is developmentally appropriate: i.e., social networking, text messaging, blogs, and Facebook support groups

APPENDIX B

Using Meleis’ Transitional theory as a framework for nursing with adolescents with T1DM transitioning from dependence to independence young adults.
APPENDIX C

PARTICIPATORY ACTION RESEARCH PROCESS

Pre Group meeting
Acceptance to the study
Call to participants to set up place and time to meet for study

Focus Group 1
Quality of Life Peds 4.0 handed out to participants
The following are questions to be addressed in the first focus group:
1. What would you like the group to know about you?
2. How do you feel about changes in your body and having T1DM?
3. How has having T1DM affected the way you live, socialize, play, study, sleep and work?
4. What are important issues for you?
5. What do you feel about the quality of life survey you completed for the group?
6. What does Health-seeking mean to you?
7. What do you feel your health care team should know about you?
8. What is my quality of life? (PEDS QL 4.0; Varni, 2008).

Focus Group 2
1. Summary of answers from group 1 focus sessions will be reviewed.
2. Validations of these themes occur when responses are given back to the group in the second session.
3. Reflection on the picture, “What does it mean to have T1DM as an adolescent?”
4. The question of, “How quality of life may be improved” asked.
5. Values about quality of life explored.
6. Common issues and future goal setting for session three will be completed.
7. Two statements will be sent home with the participants to journal about during the break between groups:
   a. What interventions could the health care team perform to facilitate quality of life transitions?
   b. Reflect on certain interventions available to you that could impact your access to health care and improve your Health-seeking behaviors.

Focus Group 3
1. What do our health care providers, teachers, and friends, need to know about our health?
2. What is the most important information that is not understood about me?
3. Where and when do I want my health care?
4. What was it like to be involved in the research process?
5. Why did you join the group and do you have exemplars of a change you would make after being involved in the group process?
6. What is appropriate setting for support for you?

Focus Group 4: Follow up phone call interview:

1. Clarification of reoccurring themes will be discussed at the final telephone interview.
2. Reflection and a debriefing clarify emotions, comments and feelings that may cloud the interpretation of events by the researcher.
3. What did you feel about the research process in a group setting?
4. Was there anything you would change about the process?
5. Is there anything you did not feel comfortable telling the group?

PAR MODEL (Bailey, 2011).

<table>
<thead>
<tr>
<th>Reflect back to the group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-study QOL</td>
</tr>
</tbody>
</table>

FG4

Individual telephone interview after focus groups for clarification of group process and any missed data
### APPENDIX D

**PEDIATRIC QUALITY OF LIFE INVENTORY- VERSION 4.0**

Appendix D  
PedsQL™

Pediatric Quality of Life Inventory- Version 4.0  
TEEN REPORT (ages 13-18)

**DIRECTIONS**

On the following page is a list of things that might be a problem for you. Please tell us how much of a problem each one has been for you during the past ONE month by circling:

- 0 if it is never a problem
- 1 if it is almost never a problem
- 2 if it is sometimes a problem
- 3 if it is often a problem
- 4 if it is almost always a problem

There are no right or wrong answers. If you do not understand a question, please ask for help.

*In the past ONE month, how much of a problem has this been for you...*

<table>
<thead>
<tr>
<th>ABOUT MY HEALTH AND ACTIVITIES (PROBLEMS WITH...)</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. It is hard for me to walk more than one block</td>
<td>0abdeh</td>
<td>1eg</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. It is hard for me to run</td>
<td>0abd</td>
<td>1g</td>
<td>2ef</td>
<td>3e</td>
<td>4</td>
</tr>
<tr>
<td>3. It is hard for me to do sports activity or exercise</td>
<td>0abd</td>
<td>1fg</td>
<td>2ce</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. It is hard for me to lift something heavy</td>
<td>0abdf</td>
<td>1ceg</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. It is hard for me to do chores around the house</td>
<td>0abcdef</td>
<td>1cg</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ABOUT MY FEELINGS (PROBLEMS WITH...)</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel afraid or scared</td>
<td>0ab</td>
<td>1dfg</td>
<td>2ce</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I feel sad or blue</td>
<td>0ab</td>
<td>1cef</td>
<td>2dg</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. I feel angry</td>
<td>0ab</td>
<td>1ef</td>
<td>2d</td>
<td>3eg</td>
<td>4</td>
</tr>
<tr>
<td>5. I worry about what will happen to me</td>
<td>0abg</td>
<td>1d</td>
<td>2ceef</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HOW I GET ALONG WITH OTHERS (PROBLEMS WITH...)</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have trouble getting along with other teens</td>
<td>0bf</td>
<td>1adeg</td>
<td>2e</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Other teens do not want to be my friend</td>
<td>0bf</td>
<td>1ade</td>
<td>2e</td>
<td>3g</td>
<td>4</td>
</tr>
<tr>
<td>3. Other teens tease me</td>
<td>0abf</td>
<td>1eg</td>
<td>2cd</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Appendix D Cont.  PedsQL™

Pediatric Quality of Life Inventory- Version 4.0  TEEN REPORT (ages 13-18)

<table>
<thead>
<tr>
<th>ABOUT SCHOOL (PROBLEMS WITH…)</th>
<th>Never</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Often</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. It is hard to pay attention in class</td>
<td>0abf</td>
<td>1g</td>
<td>2cde</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I forget things</td>
<td>0</td>
<td>1bcf</td>
<td>2ade</td>
<td>3g</td>
<td>4</td>
</tr>
<tr>
<td>3. I have trouble keeping up with my schoolwork</td>
<td>0bg</td>
<td>1af</td>
<td>2d</td>
<td>3ce</td>
<td>4</td>
</tr>
</tbody>
</table>

Results:
A = HT 5
B = BM 1
C = ES 6
D = KH 2
E = JW 3
F = AH 4
G = JA 7
APPENDIX E
THE CHRONIC CARE MODEL

The Chronic Care Model

Community
Resources and Policies
Self-Management Support

Health Systems
Organization of Health Care
Delivery System Design
Decision Support
Clinical Information Systems

Informed, Activated Patient
Productive Interactions

Prepared, Proactive Practice Team

Improved Outcomes

Developed by The MacColl Institute
© ACP-ANM Journals and Books
APPENDIX F

PERMISSION TO USE PEDS QOL 4.0 TOOL

Permission to use Peds QOL 4.0

Dear Debra,

We will be pleased to provide you with the PedsQL scale but first I invite you to complete and sign the User Agreement that is downloadable from the PedsQL website at: http://www.pedsql.org/conditions.html.

You will have to precise which modules and which language versions (which languages and for which countries) you would like to use.

Once completed, you have to send it to us by regular mail to the below address to the attention of my colleague Séverine Cuchet who is in charge of your request.

Regarding access and use, I would like to inform you that the cost depends upon whether your study is funded or not. Indeed, the use of the PedsQL in the framework of a non-funded academic research study is free of charge. However, the fees to access and use the PedsQL in a funded academic research study is of 800 USD per study (including one module, regardless of age-groups and language version) plus an additional fee of 250 USD (for another module) plus another additional fee of 25 USD for bank expenses is requested.

Please note that review copies are available at: http://www.mapi-trust.org/services/questionnairelicensing/cataloguequestionnaires/84-pedsql

Debra,

Thank you for sending me your completed user-agreement.
As your study is not funded, I am pleased to send you attached, for free, the requested versions of the PedsQL in US English as well as the scoring manual.
The user-agreement grants permission to reproduce the scales in as many copies as needed for use in the study described in the user-agreement, regardless of number of administration and length of study.

May I remind you that you will need to send the original executed copy of the user-agreement by regular mail to my attention at the address indicated below.

Vanessa MARTEL
Project Assistant - PRO Information Support & Databases Unit
MAPI RESEARCH TRUST
27 rue de la Villette l 69003 Lyon l FRANCE
Tel: +33 (0)4 72 13 65 75 l Fax: +33 (0)4 72 13 66 82

Envoyé : jeudi 29 septembre 2011 15:38
À : Vanessa MARTEL
Objet : RE: 22809_Permission to use tool
APPENDIX G

CERTIFICATE OF APPROVAL COMIRB

Certificate of Approval

21-Feb-2012

Investigator: Debra Bailey
Sponsor(s): 
Subject: COMIRB Protocol 12-0102 Initial Application
Effective Date: 15-Feb-2012
Expiration Date: 14-Feb-2013
Expedited Category: 6,7
Title: Improving Health Seeking Behaviors of Rural Youth With Type 1 Diabetes Through Participatory Action Research

All COMIRB Approved Investigators must comply with the following:

- For the duration of your protocol, any change in the experimental design/consent and/or assent form must be approved by the COMIRB before implementation of the changes.
- Use only a copy of the COMIRB signed and dated Consent and/or Assent Form. The investigator bears the responsibility for obtaining from all subjects “Informed Consent” as approved by the COMIRB. The COMIRB REQUIRES that the subject be given a copy of the consent and/or assent form. Consent and/or assent forms must include the name and telephone number of the investigator.
- Provide non-English speaking subjects with a certified translation of the approved Consent and/or Assent Form in the subject's first language.
- The investigator also bears the responsibility for informing the COMIRB immediately of any Unanticipated Problems that are unexpected and related to the study in accordance with COMIRB Policy and Procedures.
- Obtain COMIRB approval for all advertisements, questionnaires and surveys before use.
- Federal regulations require a Continuing Review to renew approval of this project within a 12-month period from the last approval date unless otherwise indicated in the review cycle listed below. If you have a restricted/high risk protocol, specific details will be outlined in this letter. Non-compliance with Continuing Review will result in the termination of this study.

You will be sent a Continuing Review reminder 75 days prior to the expiration date. Any questions regarding this COMIRB action can be referred to the Coordinator at 303-724-1050 or UCHSC Box F-490.

Review Comments:

This Expedited Approval Includes - v. 2/6/12 -
Application
Attachments - A, F, H
Protocol - Proposal for PhD Candidate
Consent
Appendix 1 - PedsQL - Pediatric Quality of Life Inventory
Appendix 2 - Table of Questions for Focus Group
Appendix H. HIPPA Compliance

Certificate of HIPAA Compliance

15-Feb-2012

Investigator: Debra Bailey
Sponsor(s): COMIRB Protocol 12-0102 HIPAA
Subject: Improving Health Seeking Behaviors of Rural Youth With Type 1 Diabetes Through Participatory Action Research

Effective Date: 15-Feb-2012
Title: Improving Health Seeking Behaviors of Rural Youth With Type 1 Diabetes Through Participatory Action Research

Based upon information submitted to COMIRB, this protocol meets the requirements for HIPAA Compliance in its use of:
HIPAA: Research Recruitment

Review Comments:
HIPAA: Research Recruitment

Sincerely,
UCD Panel C
APPENDIX I
FLYER FOR PAR STUDY, PARTICIPANT RECRUITMENT

PI: Debra K. Bailey RN, PhD candidate COMIRB # 12-0102

Appendix I. Flyer for Participant Recruitment
PI: Debra K. Bailey RN, PhD candidate COMIRB # 12-0102
Teenagers with type 1 diabetes T1DM needed for research study**

We are looking for:
- Adolescents with type 1 diabetes
- 14-18 years old
- Have had type 1 diabetes for greater than 1 year
- Without psychiatric or major medical illness beyond type 1 diabetes

Participants will:
1. Complete a quality of life questionnaire
2. Participate in three focus groups for 1-2 hours over a 2-month period of time
3. Receive an iTuneTM gift card for each focus group completed!

Purpose of the Study:
To answer these questions and more!!!
1. How do you want your health care provided?
2. What would help you manage your diabetes?
3. What do you need from your health care team?

For more information contact:
Debra Bailey RN, FNP, CDE at debra.bailey@ucedenver.edu or
Cell 970-261-4993