2014-05-01

Transitioning Adolescents with Type I Diabetes to Adult Care

Kathyann Kenny Marsh PhD
University of San Diego

Digital USD Citation

Kenny Marsh, Kathyann PhD, "Transitioning Adolescents with Type I Diabetes to Adult Care" (2014). *Dissertations*. 459.
https://digital.sandiego.edu/dissertations/459

UNIVERSITY OF SAN DIEGO

Hahn School of Nursing and Health Science

DOCTOR OF PHILOSOPHY IN NURSING

TRANSITIONING ADOLESCENTS WITH TYPE I DIABETES TO ADULT CARE

by

Kathyann Kenny Marsh

A dissertation presented to the

FACULTY OF THE HAHN SCHOOL OF NURSING AND HEALTH SCIENCE

UNIVERSITY OF SAN DIEGO

In partial fulfillment of the

requirements for the degree

DOCTOR OF PHILOSOPHY IN NURSING

May 2014

Dissertation Committee

Cynthia D. Connelly, PhD, RN, FAAN, Chair

Jane Georges, PhD, RN

Ruth Bush, PhD

Abstract

Background: Care transitions, defined as hospital discharge or movement from one healthcare setting to another, are currently a major concern for healthcare providers and policy makers alike. These care transitions are occurring in the context of increasingly fragmented care and have been known to result in hospital readmissions, adverse events, and medication errors. The adolescents' transition between pediatric and the adult care system is not only fragmented but occurs at a time when they are most vulnerable and ill equipped for change.

Objectives: The purpose of this research was to conduct a feasibility study to examine if the use of a diabetes transition program, SMILE (Self-Management In Living Everyday), improves glycemic control in adolescents with type I diabetes mellitus (TIDM). The aims of the study were to examine 1) pre and post scores in diabetes knowledge, diabetes distress, and glycemic among a sample of adolescents with TIDM participating in the SMILE program, 2) relationships between diabetes knowledge, diabetes distress, and glycemic control among a sample of adolescents with TIDM participating in the SMILE program, and 3) the feasibility and acceptability of an individualized transition program utilizing technology, health care advocates, and home education visits among a sample of adolescents with TIDM participating in the SMILE program.

Methods: A descriptive, correlational, repeated measures design was used for this feasibility study. Both quantitative and qualitative data were collected from a purposive sample of 14 adolescents recruited from patients who received care in the endocrine clinic at a large academic children's hospital located in Southern California. Data were collected during the spring of 2012 and participants' total time in the program was three months. Study measures included The Diabetes Knowledge Test (Fitzgerald, et al., 1998), Diabetes Distress Scale (DDS17), (Polonsky et al., 2005), Hemoglobin A1c, Frequency of Self Monitored Blood Glucose Testing (SMBG), and selected demographics. Statistical analysis included descriptive and inferential statistics.

Results: A statistically significant difference was found in the pre mean = 12.57 (SD = 1.61) and post mean = 10.97 (SD=1.62) intervention HbA1c, t (13) = 3.94, p =.002; the pre mean, M = 72.4 (SD = 5.2) and post mean 87.5 (SD = 3.8) diabetes knowledge scores t (13) = - 6.47, p < .001, and mean DDS pre-SMILE score was 2.6 (SD = 1.02) and the mean DDS post-SMILE was 2.0 (SD = 0.99), t (13) = 3.63, p = .003.

Qualitative Findings: Adolescents, Parents, and Health Care Advocates were queried at the conclusion of the SMILE intervention. Qualitative content analysis was used to guide the interpretive description of the data (Sandelowski, 2000). Study participants and parents overwhelming gave positive feedback about the SMILE program.

Conclusion and Implications for Nursing Science: Transition experiences are not one-dimensional but each transition is characterized by its uniqueness, complexities, and multiple dimensions. Training and education on transition care for both healthcare personnel and patients is the first essential step to ensure smooth and effective transition

from pediatric to adult service. Clinicians, administrators, and researchers should focus future efforts on developing more comprehensive transition programs that take place over time and maximize the use of health care advocates as well as technology.

THIS PAGE INTENTIONALLY LEFT BLANK.

Acknowledgments

The time spent in my doctoral studies has provided me with the opportunity to learn from a number of exceptional professors. Dr. Cynthia Connelly, my dissertation chair and mentor, is one of these exceptional professors. There are no words to describe how thankful I am for her support and encouragement. I appreciate the time she spent answering my questions and challenging me in scholarly discussion, to say nothing of her rapid fire edits. I would also like to thank the other members of my committee, Dr. Ruth Bush and Dr. Jane Georges, for their commitment to my success. The committee has my gratitude and respect.

My USD colleagues have been exceptional role models. They exemplify what a PhD nurse researcher should be and sparked my interest in pursuing PhD education. I cannot imagine a group of harder working people and their support and encouragement along the way has been imperative to my success in this program. For over twenty years, Dr. Patricia Roth has been a constant presence in my nursing education. Her unwavering support and encouragement has been a gift. Special thanks go to my Dean, Dr. Sally Hardin, for encouraging me to pursue a PhD and for providing a faculty grant to fund my research.

Spending the last several years in class with the members of my PhD cohort has been an inspirational and humbling experience, and I am honored to know this group of exceptional nurse researchers.

To my husband and children I would like you to know this is not only my accomplishment, but yours as well. I am forever indebted to my husband, David for encouraging me to pursue a Master's degree and twenty years later for encouraging me to pursue a PhD. He has supported me in ways too numerous to list here and has been a tremendous motivator helping me meet each challenge. I could not have done this without him, nor would I have wanted to. To Ally, Rob, Liz, Melissa and their families; you have been a welcome distraction and a daily reminder that work is just one of the many important things we do in life. I hope I have been a good role model for you and have shown you first hand the importance of education. I want you to always remember to shoot for the moon, because even if you miss, you'll land among the stars.

My parents, up on cloud nine, have been instrumental in my success. It was because of their not so gentle guidance that I became a nurse. They told me early on that nursing would prove to be a rewarding career and they were absolutely correct. Today, they are smiling down on me with an extra sparkle for this new achievement in my nursing career. To my sister Patti, her family, and my brother, Vince, I just want to say your honesty and humor along this journey have helped keep my feet firmly planted on the ground. I am so thankful for your love and support.

I know that my efforts spent on my PhD studies have taken up much of my time, and I have missed several engagements along the way, therefore, I would like to thank my numerous friends, and family, for the compassion, understanding and encouragement they have shown me.

This research would not have been possible without access to the participants of the endocrine practice. Special thanks go to nurse practitioners Laura and Giana, for first approaching me with concerns about their patients and suggesting that together we could develop an intervention program that might benefit adolescents with high-risk diabetes. Finally, I would like to thank the participants in the study who gave of themselves to assist others to understand their experiences, and to benefit other adolescents in the future.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF ILLUSTRATIONS

LIST OF APPENDICES

CHAPTER I

INTRODUCTION

The transition from pediatric to adult healthcare is a major milestone in the life of a young person and his or her family and may be fraught with insidious and complicated problems. Parental and patient concerns are enmeshed, and include financial concerns, separation anxiety, and unfamiliarity with an adult practitioner (Flume, Anderson, Hardy, & Gray, 2001; Owen & Beskine, 2008). Adolescents with type 1 diabetes mellitus (T1DM) often struggle to keep diabetes management a priority and many find it challenging to maintain optimal glycemic control during this developmental stage. All of these stressors and anxieties foster challenges that may impede the successful and continuous care needed for wellness and prevention of secondary complications related to exacerbations of chronic childhood diseases (Flume et al., 2001). For adolescents with T1DM, this transition is made more difficult because it is accompanied by changes in their healthcare delivery systems (Pai & Ostendorf, 2011). When the transfer to adult care occurs, some patients opt out of care altogether, only to reappear in the medical system when they develop complications that may have been prevented (Kipps et al., 2002). In the past decade, the simple matter of transferring the care of the adolescent with T1DM to an adult care provider has presented challenges including adherence, family concerns, developmental issues, provider issues, as well as economic costs (Kelly, Kratz, Bielski, & Rinehart, 2002).

Background

Transferring adolescents with diabetes from pediatric to adult care remains a challenge and the outcome is often unknown (Anderson & Wolpert, 2004). The transition of patients with T1DM from pediatric to adult care services is difficult not only for patients but also for pediatricians, nurse practitioners, and subsequently the adult-care providers. At the time of transition for young adults with diabetes, metabolic control is often unstable and psychological comorbidities, social background, and education or employment issues are significant concerns. Typical differences between pediatric and adult health services may hamper a successful transition. The handing off of healthcare should be planned early, involving both youth and their parents, with timing adapted to the medical and psychological condition of the patient (Busse et al., 2007). Lack of preplanned, supported transitional care undertaken at an appropriate time and involving parents may result in many young people “dropping out” of adult diabetes clinics. This action may affect the young person’s health, education, and vocation, thus increasing the risk of clinical and psychiatric complications (Owen & Beskine, 2008).

Young adults with diabetes face a significantly increased risk for premature morbidity and mortality. The British Diabetic Association Cohort Study (Laing et al., 2003) found in the 20 to 29 year age group, mortality in T1DM was increased threefold in men and sixfold in women compared with the general population. Acute complications were the major cause for mortality in this age group, with 68% of diabetes deaths being certified as due to hypoglycemia and ketoacidosis (Laing et al., 2003). In another study, adolescents, after transfer from the pediatric clinic, had 52.5% incidence of changing their healthcare provider at least once. There was also a significant decrease in clinic attendance rate after transition and many patients assumed their metabolic control as measured by glycated hemoglobin (HbA1c) was better than recorded (Weissberg-Benchell et al., 2009).

Advances in Medical Science

For many children with chronic illnesses the advances in medical science, within the last 20 years, have beneficially prolonged their lifespan and improved their quality of life. Historically, children with genetic and autoimmune diseases were not expected to live into adulthood. The discovery of insulin, approximately ninety years ago, provided some longevity to children who were near death (Simoni, Hill, & Vaughn, 2002). Today, with the advances of recombinant deoxyribonucleic acid (DNA) insulin, insulin of varying peaks, durations, and the rapidly evolving sophistication of insulin pumps and continuous glucose monitors, these patients are living far into adult life (DeVries, Snoek, & Heine, 2004).

Children with chronic illnesses are experiencing fulfilling and extended life spans (Eiser, Vance, Horne, Glaser, & Galvin, 2003; Flume et al, 2001); however, adult medical practitioners have not been adequately trained in the treatment of chronic childhood illness, resulting in the shortage of medical practitioners who focus on the needs of the emerging young adult patient transitioning from the pediatric-focused care model into the adult care model (McDonagh, 2005). Most healthcare systems have the needed technology but are poorly prepared in the one-on-one care needed for adolescents to segue into receiving continuity-of-care into adulthood (Bowen, Henske, & Potter, 2010).

There are evolving models for adult transition programs; however, there is no standard protocol consistently used or evidence based (Reiss & Gibson, 2002). Literature has shown some countries, for example the United Kingdom and Australia, are more proactive in providing continuous care across the lifespan and thus proving a cost savings in prevention of diabetic complications (Busse et al., 2007). Many professional organizations have identified the need to provide guidelines to ease the transition from pediatric to adult care. It has been over a decade since a hallmark consensus statement issued a goal for 2010, stating primary and subspecialty physicians understand and facilitate the transition process from child-centered to adult-oriented health care (American Academy of Pediatrics [AAP], the American Academy of Family Physicians [AAFP], & the American College of Physicians [ACP-ASIM], 2002). This statement noted the goal of an effective transition plan is to provide developmentally appropriate health care services that continue uninterrupted into adulthood. Similarly, in 2003, the Society for Adolescent Health and Medicine (SAHM) published a position statement identifying the importance of organized and coordinated transition programs, stating programs should identify a transition coordinator who reaches out to the adolescent using multiple means including telephone, text messages, and social media (Rosen, Blum, Britto, Sawyer, & Siegel, 2003). Debate continues regarding best practices and processes for preparing youth with chronic and special health care needs to transition to adult care (Modi, et al, 2012).

Economic Consequences of Diabetes

Diabetes can be a significant financial drain for an individual with diabetes, his/her family, and the health care system. The total estimated cost of diagnosed diabetes in the United States during 2012 was $245 billion, including $176 billion in direct medical costs and $69 billion in reduced productivity (American Diabetes Association, 2013). People with diagnosed diabetes incur average medical expenditures of approximately $13,700 per year, of which about $7,900 is attributed to diabetes. People with diabetes, on average, have medical expenditures approximately 2.3 times higher than what expenditures would be in the absence of diabetes. Providing care for people with diabetes accounts for more than one in five healthcare dollars in the United States. Cost expenditures from 2002, 2007, and 2012 show the economic burden is increasing even after controlling for population growth and inflation (American Diabetes Association, 2003, 2008, & 2013). These trends underscore the importance of prevention and the efforts to mitigate the complications of diabetes.

In summary, adolescence is a period in an individual's life highlighted by significant physical, social, behavioral, and psychological changes. During these pivotal periods, adolescents establish behavioral patterns that determine current and future health outcomes (Anderson & Wolpert, 2004). Moreover, these periods are windows of opportunity for the healthcare providers, parents, and caregivers to teach, support, and foster healthy behaviors, encourage independence and active decision making, and usher adolescents into the adult-centered healthcare system. Despite agreement that transitioning is necessary, no single model for transitioning has emerged as the "gold standard" or the most cost-effective method of transitioning adolescents to adult healthcare. Lack of a unified transitioning model for adolescents was highlighted by Scal and colleagues (2009) when they identified 126 different interdisciplinary transition programs for youths with a variety of chronic conditions. Consistent observations throughout the literature demonstrate when operationalized, successful transitioning principles enable some transition models to be more effective than others (McDonough, 2005; Reiss & Gibson, 2002; Viner, 2008).

This researcher's study was developed in response to the above position statements as well as the 2011 American Association of Pediatrics guidelines for design and implementation of transition programs. The study focus is on the needs of the adolescent with T1DM preparing for transition from adolescence to adult care. This researcher attempted to develop a sustainable, coordinated, and individualized transition program utilizing technology, health care advocates, and home education visits to assist adolescents with the transition to adult care. The **S**elf-**M**anagement **i**n **L**iving **E**veryday (**SMILE**) program was guided by the use of a conceptual framework and research evidence in cooperation with adolescent patients and their parents, as well as the health care providers employed in a hospital-based endocrine clinic. Focus areas of the intervention are disease process, goal setting, nutrition, and medications.

Purpose

The purpose of this research was to conduct a feasibility study to examine if the use of a diabetes transition program, SMILE (Self-Management In Living Everyday), improves glycemic control in adolescents with T1DM. Due to the individuation of an adolescent and the consequences of non-adherence, this study sought to answer the following general research questions:

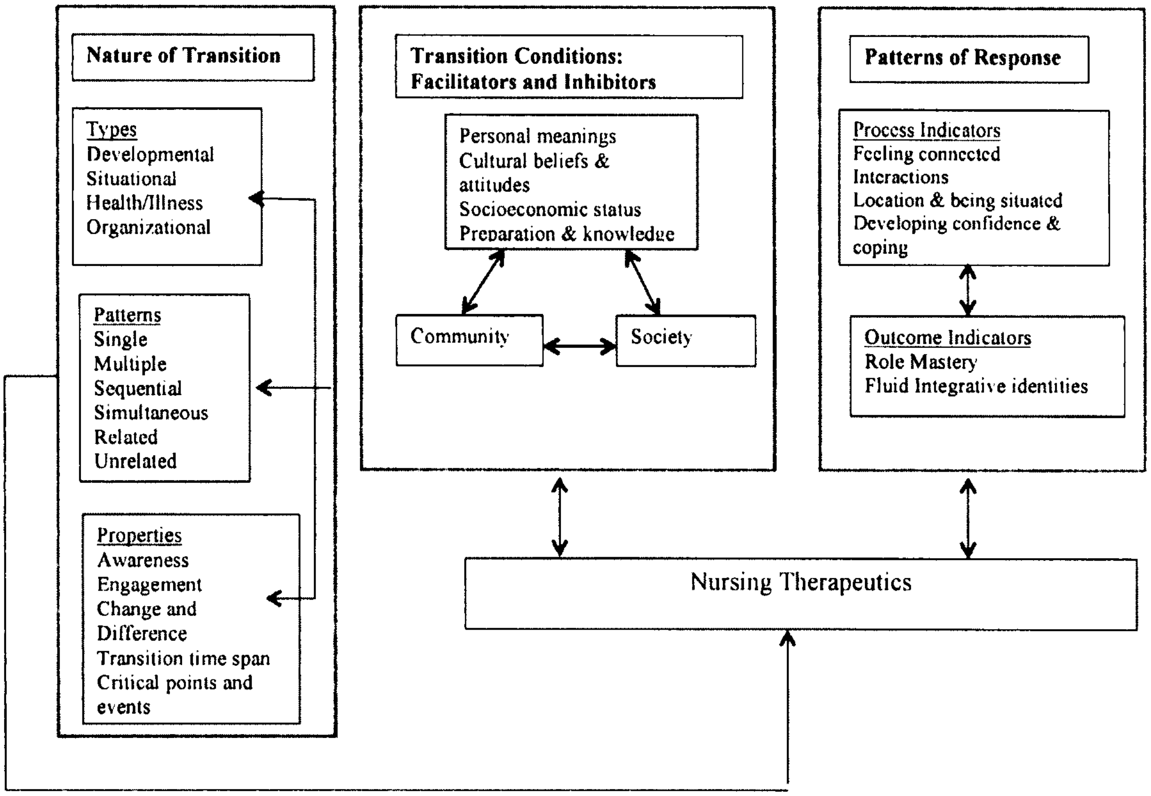
1. Is there an improvement in diabetes knowledge, diabetes distress, and glycemic control among adolescents with T1DM participating in the SMILE program?
2. What is the relationship between diabetes knowledge, diabetes distress, and glycemic control in adolescents with T1DM participating in the SMILE program?
3. Is a transition program, which utilizes technology, health care advocates, and home education visits, feasible and acceptable to adolescents with T1DM?

Specific Aims

- Aim #1: Examine pre and post scores in diabetes knowledge, diabetes distress, and glycemic control among a sample of adolescents with T1DM participating in the SMILE program.
- Aim #2: Examine the relationships between diabetes knowledge, diabetes distress, and glycemic control among a sample of adolescents with T1DM participating in the SMILE program.
- Aim #3: Examine the feasibility and acceptability of an individualized transition program utilizing technology, health care advocates, and home education visits among a sample of adolescents with T1DM participating in the SMILE program.

Conceptual Framework

According to Polit and Beck (Polit & Beck, 2012), theories serve to make research findings meaningful and interpretable by explaining not only the 'what' of natural phenomena, but also the 'why' of their occurrence. The conceptual framework for the proposed study is guided by Meleis' Transitional Theory, a Middle-Range Theory that focuses on a guided approach of care for anyone in various types of transitions (Meleis & Trangenstein, 1994). The types and patterns of transitions affecting well-being include developmental, health and illness, situational, and organizational. Many individuals experience at least two types of transitions in a time of crisis, and they often overlap (Meleis, Sawyer, Im, Schumacher, & Messias, 2000). Recognition of the multitude of transitional events and the relationship between each event is paramount. Life events, stress, illness, and change all contribute to the stress and challenge of moving through life's transitions.



Meleis, A.I., Sawyer, L., Im, E-O., Hilfinger, M., K., DeAnne, & Schumacher, K. (2000). Experiencing Transitions: An Emerging Middle Range Theory. *Advances in Nursing Science. 23*(1). 12-28

Figure 1. Transitions: A middle range theory.

There are many key points in the phases and types of transitional change. Features of the transition experiences are awareness, engagement, change and difference, time span, and critical points and events (Alligood & Marriner-Tomey, 2010). Feeling different and being perceived as different may strongly affect adolescents, and it is useful for nurses to consider a client's developmental stage and associated coping skills during a time when there might be a change in healthcare providers.

Transition conditions are the surroundings and environment experienced by the patient that may facilitate transition or delay transition. Thoughtful considerations of changes in school, work, and living arrangements should influence the timing of the transition process.

Significance to Nursing

The nation is in the midst of unprecedented healthcare reform, similar to the 1960's enactment of Medicaid and Medicare. Healthcare reform is driving innovative approaches to meet the nation's healthcare agenda and needs of the people. The Patient Protection and Affordable Care Act (ACA) is at the forefront of this change and has recognized transition as an essential health service (Democratic Policy Committee [DPC], 2010). In addition to offering affordable healthcare, the ACA is encouraging disease prevention and public health through innovative health promotion proposals and will incentivize healthcare providers to target assessment of self-management behaviors, resulting in improved patient outcomes (DPC, 2010). The National Committee on Quality Assurance, in its 2011 Patient-Centered Medical Home Standards, included a specific requirement to address care transitions for improving primary care (Bojadzievski, & Gabbay, 2011). In the same year, the American Academy of Pediatrics, the American

Academy of Family Physicians, and the American College of Physicians published a clinical report on practice-based implementation of transition for youth beginning in early adolescence (Cooley & Sagerman, 2011). Most recently, Healthy People 2020 incorporated a new public health goal on transition planning from pediatric to adult health care (United States Department of Health and Human Services, 2012).

For more than a decade, the Department of Health and Human Services' Maternal and Child Health Bureau (MCHB) has articulated transition as one of six core performance outcomes necessary to create a comprehensive system of services for all children with special health care needs such as T1DM. This core outcome specifies youth with special healthcare needs should receive the services necessary to make transitions to all aspects of adult life, including adult healthcare, work, and independence (Maternal Child Health Bureau, 2013).

In youth with T1DM, transition from the pediatric to the adult clinic can represent a major obstacle to adequate medical care. A considerable proportion of adolescents encounter various difficulties during this transition period, that can negatively affect psychosocial adjustment and glycemic control, leading to patients dropping out of care, increased hospitalizations for diabetic ketoacidosis, as well as morbidity and mortality. To achieve effective transition to adult care, it must be recognized that transition in healthcare is but one part of the wider transition from dependent child to independent adult and should be a guided educational and therapeutic process, rather than an administrative event. Current models have been ineffective in helping adolescents make the transition from pediatric to adult diabetes care (Bryden et al., 2001; Pacaud, Yale, Stephure, Trussell, & Dele, 2005). A transition process which is more individualized and responsive to adolescent concerns, aspirations, and social aptitude, can result in better health and treatment outcomes for adolescents transitioning to adult diabetes care.

There is a deficiency of planned, facilitated, and individualized transition programs for adolescents with T1DM. Nurses are well suited to plan, implement, and evaluate transition programs. Data from this study will facilitate the development, refinement, and implementation of an individualized transition program for youth with T1DM.

CHAPTER II

REVIEW OF THE LITERATURE

This chapter describes the literature pertaining to the various barriers, facilitators, and psychosocial aspects of transitioning the adolescent with diabetes from the pediatric care environment to an adult centered, chronic illness care environment. Prior to the review of literature, a basic overview of diabetes mellitus, including current standards of treatment is provided. Meleis' Transitional Theory, a middle-range theory, as well as adolescent development theory, were used to guide and organize the study and are discussed in the literature review.

Published research was reviewed from the following computerized databases: MEDLINE, PubMed, Cumulative Index to Nursing and Allied health (CINAHL), Wiley InterScience, and Google Scholar using the following search strategy key words: *Type 1 diabetes, transition to adult care, self-management*. Each key term was matched with the term *adolescence or adolescent.* The literature obtained was gleaned from articles published from 1998-2013. Reference lists from each article were examined for additional articles pertinent to the phenomenon of interest, and were also retrieved.

Background

Diabetes Mellitus: An Overview

Diabetes mellitus (DM) is a chronic endocrine disorder characterized by abnormalities in glucose metabolism related to abnormal production and/or utilization of the hormone insulin. Insulin is essential for the utilization and storage of nutrients by the body. Diabetes is considered to be present when there is an elevation of blood glucose concentration. Depending on the etiology, diabetes has been classified as either Type I or Type II.

Formally known as adult-onset diabetes mellitus or non-insulin-dependent diabetes mellitus (NIDDM), Type II diabetes is characterized by a gradual onset, usually after age 40, and insulin resistance. It may be one component of several abnormalities, including obesity, hypertension, hyperlipidemia, abnormal concentrations of blood coagulation factors, and premature cardiovascular disease. This combination of abnormalities has been termed Syndrome X or the Metabolic Syndrome (Ford, Giles, & Dietz, 2002). These individuals may or may not require insulin to control blood glucose levels. Type II DM is by far more common than T1DM and accounts for 80% to 90% of all cases (Dewitt & Hirsch, 2003).

Type I diabetes mellitus (T1DM) is characterized by absence of insulin production. Now considered a chronic autoimmune disease; T1DM is characterized by destruction of beta cells in pancreatic islets and eventual failure to synthesize sufficient insulin (Court, Cameron, Berg-Kelly, & Swift, 2009). Type I diabetes has been termed insulin-dependent diabetes mellitus, ketosis-prone diabetes, brittle diabetes, and juvenile-onset diabetes mellitus. This last term is misleading, because even though T1DM is usually diagnosed in childhood, it can occur at any age. Type I diabetes is thought to account for approximately 10% to 20% of all cases in the United States. There is clearly a genetic susceptibility to Type I disease, but environmental influences are also a factor. Current research findings support the role of viruses as the most likely environmental trigger of TIDM, however, the exact pathogenesis of T1DM is unknown (Jun & Yoon, 2003). To maintain normal growth and development, individuals with T1DM must establish a balance between insulin administration, dietary intake, and physical activity on the basis of glucose self-monitoring results (Tang et al., 2007).

Treatment: An Overview

The discovery and purification of insulin in 1921 by Banting and Best, created the first effective treatment for diabetes mellitus. While this new therapy allowed patients to survive a previously fatal illness, additional complications became apparent. These included acute hypoglycemia and significant morbidity and mortality caused by long-term diabetes-associated microvascular and macrovascular complications. It is now known that improved control of hyperglycemia decreases the risk of developing these complications (Simoni, Hill, & Vaughn, 2002). Therefore, current treatment goals involve a tradeoff between normalized blood glucose levels and the risk of hypoglycemia. In younger children, it can be more difficult to identify hypoglycemia because the symptoms may be too subtle for caregivers, and the child may be less able to identify the symptoms of hypoglycemia in him/herself (Weinzimer et al., 2004).

One of the most common concerns in providing care for a child with T1DM is glycemic control. Poor glycemic control has been shown to substantially increase risk for future cardiovascular complications. These cardiovascular complications include endothelial dysfunction, activation and maintenance of the proinflammatory immune response, and poor quality of life secondary to vascular changes (Voulgari et al., 2011). Tight glycemic control through the use of insulin pump therapy, increased physical fitness, and a diet that includes carbohydrate counting and decreased saturated fat intake are recommended therapeutic modalities in the management of diabetes (Johnson, Cooper, Jones, & Davis, 2013).

Results of the Diabetes Control and Complications Trial (DCCT) (DCCT Research Group, 1993) and its follow-up Epidemiology of Diabetes Interventions and Complications (EDIC) study (DCCT/EDIC Research Group, 2001) have clearly demonstrated the importance of maintaining near-normal blood glucose control to avoid long-term microvascular complications in people with T1DM. Therefore, for the past several years, the aim of management for people with diabetes is to maintain blood glucose levels as close to the normal range as possible in order to avoid long term complications (Hirsch & Brownlee, 2010). Glycosylated hemoglobin (HbA1c) is formed when the hemoglobin is exposed to glucose in the blood and can be measured in a blood test, expressed as a percentage, allowing for an assessment of how well the individual's diabetes is being managed (Phillips & Phillipov, 2005). The relationship between exposure to elevated blood sugar over time and the development of macro- and microvascular complications was identified through a prospective observational study in the United Kingdom (Stratton, Adler, & Neil, 2000). For each 1% reduction in HbA1c, the risk of microvascular complications decreased by 37% and the risk of any end-point or death related to diabetes decreased by 21%.

Insulin Pumps. Introduced over 35 years ago, continuous subcutaneous insulin infusion (CSII), also known as insulin pump therapy, has within the last 10 years been increasingly utilized to achieve tight glycemic control (Weinzimer et al., 2004). CSII is an alternative to multiple daily injections (MDI) for delivering insulin as a basal-bolus regime. Pumps have been in use since the late 1970's but have become smaller and far more technologically sophisticated. Theoretically, the portable pump offers the most physiologic appropriate method of insulin delivery because it simulates the normal pattern of insulin secretion, namely continuous 24-hour "basal" delivery superimposed by prandial-related boosts or "boluses". It is also more flexible and precise than MDI. The insulin pump is not an implanted device; rather, it is a syringe connected to tubing mechanically driven to infuse insulin at a prescribed rate. The tubing is attached to the syringe at one end and connects to a catheter at the other. The catheter is inserted under the skin by means of a metal introducer needle that is removed, leaving the Teflon catheter in the subcutaneous tissue. The pump wearer usually changes the catheter every two to three days. Although, intensive CSII originally was assumed to provide better glycemic control than MDI, with a lower risk for severe hypoglycemia and less weight gain, a recent randomized controlled study yielded similar results in terms of HbA1c and adverse effects (Shalitin et al., 2010).

Along with a prescribed pharmacological regimen (i.e. insulin), increased physical fitness, and proper nutrient intake are required self-management practices for children with T1DM. The American Diabetes Association (ADA) and The American Heart Association (AHA) recommend improving lifestyle strategies in youth to optimize glycemic control and to reduce cardiovascular risk, albeit physical activity has been prescribed to youth with T1DM for decades (American Heart Association; American Diabetes Association, 2007).

Developmental Psychology

Developmental psychologists argue individuals pass through a sequence of stages throughout their lifetime; transitions are periods between these stages. For example, childhood and adulthood are both developmental states and some theorists would consider them stable states of human development. For other developmental psychologists, however, the entire period of adolescence is viewed as a time of transition.

Fuhrmann (1990) stated every definition of adolescence includes the word transition, indicating the entire period of adolescence is frequently seen as a bridge between childhood and adulthood, or a period of transition. Fuhrmann viewed adolescence as a 20th century social invention in the United States that emerged following the occurrence of historical events over the past 150 years. This came primarily from the change in society's economic structure. Before 1900, society was agrarian-based, but advances in industry and technology resulted in a society in which youth have greater educational opportunities, such as high school, college, or technical schools, and more career choices (Fuhrmann, 1990). The social change redefined the transition from adolescence to adulthood for individuals who were physically mature but socially and educationally immature, economically dependent on their parents, and not ready to assume adult roles.

The modern transitional stage of adolescence differs from tribal cultures and agrarian societies in which adulthood was ceremoniously marked with clear rites of passage with no differentiation between sexual maturity and adulthood. Before the puberty rite, the person was a child; after the ritual he or she was accepted as an adult, with the status being clear to both the person and society (Fuhrmann, 1990). In Western societies, adolescence is not about puberty and physical development, rather, it is a social invention dependent on the surrounding culture to define the tasks of adolescent development.

Developmental psychologists describe a number of developmental tasks associated with adolescence. According to Dacey and Travers (1999), one cognitive task is the establishment of formal operations originally described by Piaget in which the ability to think abstractly becomes established by 15 to 16 years of age. Formal operations are defined as the understanding of abstract characteristics that enable a person to operate on a level of a theory instead of observable facts and to analyze purely hypothetical situations and statements.

Along with cognitive development, Baltes and Silverberg (1994) described the developmental tasks of autonomy and self-identity belonging to this period. Autonomy can be viewed as disengagement from parental control and confidence in self-governance Baltes and Silverberg stated typical rebellion is most likely an indicator of problems in the development of autonomy rather than the demonstration of autonomy. Moreover, teens who appear most competent in later adolescence are those who have maintained close and supportive relationships with their parents. Thus, the developmental task of adolescence is a negotiated balance between an emerging sense of self as competent on one hand and a feeling of connection with significant others on the other.

The young-adult period begins at approximately 16 or 17 years of age or older. The developmental tasks of this period are different from the developmental tasks of adolescence (Dacey & Travers, 1999). These include stabilization of ego identity or one's feelings of self, resulting in personal relationships that are less centered on one's own desires. Young adults are more concerned with the deepening of their interests and the expansion of caring outside their immediate self or peer group. Young adults are searching for meaning in their lives and involvement of self into society. They seek growth and expansion. Dacey and Travers noted the transition into adulthood raises questions, for individuals about what they will become, including family, employment, and careers.

Adolescent Development

When looking at adolescents with T1DM, it is important to remember they are developing and changing physically, emotionally, and mentally. This time period can be tumultuous to any adolescent. Barker and Galambos (2005) found in a survey of 170 adolescents, 71 percent indicated independence as a crucial part of their development toward adulthood. Adolescents not only go through chronological aging but they also attempt to achieve individuality and other changes that can have an effect on their psychological and emotional well-being. For instance, some adolescents seek out peers, rather than adults, as their main source of information (Carroll & Marrero, 2006).

Autonomy can be a vital part of growing up and a difficult situation for those adolescents who have a disability (Crittenden, 1990). Crittenden examined adolescent development as a main component in determining choices and developing autonomy. Due to the severity of TIDM, adolescents have many choices in determining if they are going to adhere to medical recommendations or not. As adolescence is a time period where many changes are occurring for an individual, this stage of development can have the most lasting impact on the life of an individual. The choices made can have repercussions later in the individual's life with regard to health and well-being.

Adolescents with chronic illnesses, such as T1DM, go through the typical changes in their transition toward adulthood; however, they must also learn how to adapt to the extra responsibility of their illness. Adolescents with diabetes can face the stigma of having a disease they will have for the rest of their lives, a disease that could eventually kill them. In a 2007 study, Debono and Cachia (2007) found adolescents who feel stigmatized and do not fit into the regular adolescent society have a self-reported lower quality of life. The psychological impact of being an adolescent with type-1 diabetes can be damaging. Cottenceau and associates (2012) found approximately 17 percent of Americans will have a depressive episode in their lives. However, adolescents with T1DM have an 18 percent chance of having a depressive episode during this developmental stage alone. The number of adolescents with T1DM is increasing; thus it would stand to reason the number of depressed adolescents would also increase.

Though there are studies and other literature about TIDM, adherence is something discussed from a theoretical perspective, with few actual studies published, regarding motivational factors for adherence. Challenges regarding stressors to adherence were first examined by Olsen and Sutton (1998). They utilized surveys to explore the role of how formal and informal supports assist with adherence. Study findings indicated there were no direct links between the type of support an adolescent receives, but rather the motivation to adhere from the adolescent. A deeper understanding of the influences in an adolescent's life that influence their choices of following medical recommendations for controlling their T1DM is needed. Once these factors are identified and explored, more effective approaches could be developed to help these adolescents with their diabetes. The literature is starting to demonstrate a shift in thinking in developing individualized medical plans to incorporate the view of the patient (Christie, Romano, Thompson, Viner & Hindmarsh, 2008; Knight, Dornant, & Bundy, 2006). While this is a good start, an additional focus on incorporating the unique life influences of the adolescent is needed. Each individual has the ability to make decisions for him/herself and become empowered to make those that best serve his/her specific need. Each adolescent, especially with a chronic illness such as T1DM, has an idea of what motivates them to adhere to the regimen of treatment including self- management techniques. Allowing adolescents to have input into their medical treatment may be a good way to gain or maintain self-management (Tang et al., 2005).

Adolescents with T1DM are taught about the complications that can arise from poor control of their glucose and insulin. However, some adolescents still have low adherence to their medical recommendations (Court, Cameron, Berg-Kelly, & Swift, 2009). There may be many reasons adolescents do not adhere to medical recommendations, including: 1) choosing to express their freedom as a natural part in the life span development; or 2) pressures society, their family, or some other entity places on them to fit into societal norms. Societal norms of being “normal” or “not ill” are unattainable to those with TIDM since diabetes has no cure nor does it ever go away. Often the opposite is true. It can become more intrusive on an individual’s life as they age. The best an adolescent with T1DM can hope for is the complications will not begin to affect him/her until later in life. However, no matter how good the control is, the disease does affect the body and could result in death through body system failure

(National Institute of Health, 2006). Knowing these inevitable facts, it is possible for an adolescent to express and become an individual while still maintaining control of his/her diabetes. When, if ever, an adolescent should gain complete control over his/her diabetes is not a definite, but it is an individual pursuit, as each adolescent is a unique individual (Luyckx, Seiffge-Krenke, & Hampson, 2010).

As previously stated, literature focusing on motivational factors with adolescents for or against adherence with TIDM is scarce. There are studies that have focused on gaining better adherence, but many of them have sampled participants with type II diabetes and did not involve adolescents (Bogner, Morales, deVries, & Cappola, 2012; Viklund, Ortqvist, & Wikblad, 2007). Type II diabetes can be more easily controlled by changing the individual's environment. This can include more exercise or better nutrition and rarely does type II diabetes require insulin regulation. Among individuals with type II diabetes, the body is resistant to insulin, or may not utilize insulin efficiently, so an oral medication may be effective in helping both of these situations. In TIDM, the pancreas does not produce insulin, so changes in exercise, nutrition, or a medication will not help the insulin utilization unless the insulin is injected into the body for use.

There are studies focusing on adolescent adherence to a medical regimen with regard to chronic illness; however, they do not focus specifically on TIDM (Barlow, Bancroft, & Turner, 2005; Gray, Denson, Baldassano, & Hommel, 2012; Sawin, Bellin, Roux, Buran, & Brei, 2009). Most of these studies have been conducted outside the United States (Kettunen, Liimatainen, Villberg, & Perko, 2006; Viklund, Ortqvist, & Wikblad, 2007). Though studies conducted outside of the United States may be suitable for use in this nation, there is still a great deal of room for the exploration of adolescents with TIDM specific to the United States and the identification of factors that influence their choice to adhere or not adhere to the medical recommendations of their diabetes care providers. The United States has a unique framework of family dynamics, economics, and eating habits that shape how adolescents interact with their environment (Grey, Knafl, & McCorkle, 2006). Studies conducted outside the United States may not share these same framework elements resulting in a lack of direct correlation. Since these studies may not apply directly to adolescents within the United States, there is a need for further United States specific research, including replication of these studies within this country's societal and medical norms.

In an article by Hirsch and Brownlee (2010), the issue of adherence in adolescents and young adults with diabetes was explored. They suggest one of the major inhibitors of proper adherence is medical professionals do not spend enough time with the patient and are too burdened to actually make effective changes if they are needed in the individual's diabetes regimen. Physicians are commonly confined by policies that require many patients to be seen in a short amount of time. Due to these policies the quality of care can begin to diminish. When a doctor uses his or her power and influence over the patient, the patient may feel as if they have little input into the situation and determining what solutions may be most beneficial. Despite how much information physicians tell patients, the patient is ultimately the one who decides to adhere or not. This concept is starting to influence how healthcare providers interact with their patients, but it can be a slow process.

The motivational factors that go into whether or not an adolescent adheres to medical recommendations are numerous. Hysing, Elgen, Gillberg, and Lundervold

(2009) suggest adolescents go through many changes, physically, emotionally, and mentally during this time period in their lives which can be difficult to handle. Those with chronic illnesses, like T1DM, often face many other factors that influence their lives. There is evidence the idea of helping the patient to have an influence in the medical recommendations given to him/her has a stronger influence on overall adherence to the goals set forth (Dahan & McAfee, 2009; Karnieli-Miller & Eisikovits, 2009). By increasing patient involvement and participation in treatment decisions, there is greater follow through with the decisions made. No literature was found indicating specific motivational factors impacting adolescents with T1DM decisions to adhere or not adhere to medical recommendations.

Conceptual Framework

Transition Theory

Transition theory has a long history within other disciplines. Sheehy (1977) highlighted the importance of socio-cultural rituals celebrating the rites of passage throughout the stages of life. This worked was based on the early 20th century work of Van Gennep (1960). Van Gennep's theory describes the way people move through life's stages in three distinct phases. The first phase is the rite of separation which is characterized by removal of the individual from their normal social life which may occur through the use of customs and rituals. Rites of transition refer to the second phase which is characterized by customs and rituals of the individual when they are in a liminal state, such as experiencing a feeling of confusion or alienation. Lastly, rites of incorporation occur when the individual is brought back into society and takes up their new status. Van

Gennep's (1960) three-phase approach to transition continues to influence current transition thinking in the social and health literature.

Meleis' transition theory focuses on five conditions of transition: types and patterns of transition, properties of the transition experience, transition conditions, patterns of response, and nursing therapeutics. The types and patterns of transitions affecting well-being include developmental, health and illness, situational, and organizational. In an article by Meleis, Sawyer, Im, Schumacher, and Messias (2000), many individuals experience at least two types of transitions in a time of crisis and they often overlap. It is important to recognize the multitude of transitional events and the relationship between each event. Life events, stress, illness, and change all contribute to the stress and challenge of moving through life's transitions

Patterns of response monitor the healthy or unhealthy process of moving through a transitional crisis. Process indicators and outcome indicators are assessment tools used by healthcare providers to determine whether a patient is at risk for an unhealthy response to transition (Aligood & Marriner-Tomey, 2010). Some of these processes, as suggested by Meleis et al (2000) are feeling connected, interacting, developing confidence, and coping skills. Nursing therapeutics encompasses assessment, readiness, education of the client, and timing (Aligood & Marriner-Tomey, 2010). The nurse must have an all-inclusive understanding of the patient, resources, and multidisciplinary input to best facilitate any health-related transition.

Psychosocial Factors Affecting Transition

Psychosocial factors play a significant role in the management of adolescents with T1DM. According to the Consensus Guidelines 2009 of the International Society of

Pediatric and Adolescent Diabetes (as cited in Court, et al., 2009), psychosocial factors are among the most important influences affecting the care and management of diabetes, especially in the transitioning adolescent client.

It is important to meet the young patient's requirement for support and information, not just about the illness but also in other areas of young adult life, such as school or college, social life, drug taking, alcohol, smoking, sexual relations, and career prospects (DeBeaufort et al., 2010). Preparation for change and transfer should be more inclusive of psychosocial issues relevant to adolescents, as well as setting the scene for independence and the transfer to the adult setting. The aim would be to create individuals who are confident enough, when they actually go to an adult clinic, to demand respect, and to know what is needed for them to maintain a degree of well-being and empowerment (Peters & Laffel, 2011).

Barriers to Transition

There are three dominant themes identified by Rasmussen and colleagues (2001) as barriers to continuity of care from adolescence to adulthood in the patient with diabetes: (a) access to a familiar diabetes specialist, (b) multidimensional aspects (emotional, social, and parental) of transition from adolescence, and (c) prenatal and obstetric care with access to and treatment by an endocrinologist or diabetologist specializing in obstetrics.

The time of transition can be fraught with a combination of psychological growth, physical growth, conflicting dependence, and social risk behaviors, all of which can be problematic. During the transition from pediatric to adult diabetes care, there is often a high medical dropout, failure to keep or cancel appointments, and increased rates of acute and chronic complications. The Maestro Project, implemented in Winnipeg, Canada, examined the achievability and receptivity of an advanced support system to maneuver through the myriad health services for young adults with T1DM (Van Wallehgem, MacDonald, & Dean, 2011). The project demonstrated a suitable and adaptable transition liaison was viable in this model of service for young adults with diabetes as they transitioned from pediatric clinic care to adult care. In a United Kingdom study, Kipps et al. (2002) noted a significant decrease in clinical attendance and missed appointments around the time of transfer to adult services. Some young adults tend to drop out of medical care for extended periods because they feel they have the experience and expertise to handle their diabetes. Also, the young adult is impatient with long wait times, multiple specialist visits off-site, and the financial implications of multispecialty services. In the study, this decline in clinic attendance was correlated with high HbA1c and higher comorbidities with unexpected death in this age group, which is concerning and unwarranted. Infrequent encounters with the medical team and a loss to follow-up are known to contribute to both adverse glycemic control and increased hospitalizations and long-term detrimental out-comes (Holmes-Walker, Llewellyn, & Ferrall, 2007).

Transition and Nursing

Chick and Meleis (1986) analyzed the concept of transition related to knowledge development in nursing. They identified universal properties related to transition as seen through a nursing perspective. Later, Schumacher and Meleis (1994) suggested intervention during transition should be directed toward alleviating the disruption in relationships and promoting the development of new relationships. They identified three nursing activities widely applicable during transitions. Initially, nurses should begin with an assessment of readiness that includes the indicators of subjective well-being, role mastery, and well-being of relationships. The second activity is preparation for the transition and includes some form of education for creating optimal conditions in anticipation of the transition. An example of this activity is the home educational visits provided in the SMILE program and explained in chapter three. The third activity is role supplementation. An example of this activity is the role of a healthcare advocate or the use of text messaging to supplement other medical activities in the SMILE program.

More recently, Meleis et al. (2000) described the emerging middle-range theory of transition. They identified five studies in which the original framework by Chick and Meleis (1986) was used to guide the development of the studies. From these studies, they concluded transitions are complex and multidimensional. Although none of the studies examined the adolescence to young adult developmental transition, points of interest these studies make invite further research to identify whether transition supports the theory.

Identified Gaps in Literature

Although transition of care was first discussed in the literature in 1984, Blum (2002) states, there have been few, if any, real strides made since that time. There is still no system in place to guarantee youth with chronic conditions will successfully transition to adult care.

Published literature reviews have addressed different aspects of transition. Some articles describe how the main participants involved in the transition process (patient, family, pediatric, and adult practitioners) may facilitate or impede the process. Several describe the different transition models and the importance of the timing of transition.

Generally, authors agree the timing of transition should be individualized and should not be concurrent with any medical crises. Some authorities suggest age is not the best predictor of transition readiness (Cooley & Sagerman, 2011).

It is evident there is a need for further study in this field. Literature surrounding transitioning the care of young adults with chronic illnesses from pediatric to adult care is limited. Although there are many recommendations regarding who should be transitioned, when transitioning should occur, and how it should happen, empirical data providing evidence of successful implementation are limited. The literature included in this review do not offer any instances in which guidelines or suggestions put forth have proven to be effective. Additional studies are needed to examine transition models, transition program outcomes, and most importantly, clinical outcomes. The intent of the current study is to fill a gap in the literature by developing and implementing a transition program and examine its feasibility, acceptability, and preliminary outcomes.

CHAPTER III

METHODOLOGY

The purpose of this research was to conduct a feasibility study to examine if the use of a diabetes transition program, SMILE (Self-Management In Living Everyday), is acceptable to teens and their families and if the SMILE program improves glycemic control in adolescents with type 1 diabetes mellitus. This chapter includes a description of the design, study sample and sampling methods, data collection, and analytic procedures. The protection of human subjects is also presented.

Study Aims

- Aim #1: Examine pre and post scores in diabetes knowledge, diabetes distress, and glycemic control among a sample of adolescents with type 1 diabetes mellitus participating in the SMILE program.
- Aim #2: Examine the relationships between diabetes knowledge, diabetes distress, and glycemic control among a sample of adolescents with type 1 diabetes mellitus participating in the SMILE program.
- Aim #3: Examine the feasibility and acceptability of an individualized transition program utilizing technology, health care advocates, and home education visits

- among a sample of adolescents with type 1 diabetes mellitus participating in the SMILE program.

Research Questions

1. Is there an improvement in diabetes knowledge, diabetes distress, and glycemic control among adolescents participating in the SMILE program?
2. What is the relationship between diabetes knowledge, diabetes distress and glycemic control in adolescents with T1DM participating in the SMILE program?
3. Is a transition program, which utilizes technology, health care advocates, and home education visits, feasible and acceptable to adolescents with T1DM?

Research Design

A descriptive, correlational, repeated measures design was used for this study. A correlational design is appropriate for use in this study to describe the relationship between self-care and glycemic control for the intent of generalizing from a sample to a population (Polit, 2010). A descriptive correlational design is a study conducted in a natural setting without any attempt to modify or control the environment (Shadish, Cook, & Campbell, 2002). Furthermore, a correlational study observes the size and the direction of relationships among variables.

Sample and Setting

A purposive sample of adolescents living with T1DM and their parents were recruited from a large metropolitan pediatric hospital-based endocrinology practice, serving a patient population of over 1000 patients with Type 1 diabetes, located in Southern California for participation in the SMILE program. In purposive sampling the researcher chooses the sample based on who they think would be appropriate for the study because of the nature of the questions to be answered by the investigation (Huck, 2012). This is used primarily when there are limited numbers of people who meet the enrollment criteria.

Inclusion criteria for enrollment in the SMILE program were (a) diagnosis of T1DM for at least one year, (b) adolescent aged 13-19 years (c) HbA_{1c} greater than 10%, or inpatient admission for diabetic ketoacidosis (DKA) within the previous year (d) ability to speak and read English, and (e) ability to send and receive text messages. Approximately 5% of patients seen in this practice were expected to meet inclusion criteria for the proposed transition program. Participants were referred by nurse practitioners, as well as endocrinologists practicing in the endocrine group.

Power, Effect, and Sample Size

A pilot feasibility study was designed to collect preliminary data for this population of subjects. Therefore, a power analysis was not conducted for this study. However, for a future study, sample size will be determined by calculating the effect size, the desired power, and an acceptable significance level. Monroe (2005) states in order to determine significance of statistical results, an adequate sample size must be utilized to minimize the possibility of drawing the wrong conclusion. Polit (2010) states it is probably wise to anticipate a new intervention being tested against ‘usual care’ rarely will have greater than a small-to-moderate effect, which would mean an effect size in the vicinity of .35. With an alpha of .05, a power of .80, and three variables identified (HbA1c, diabetes knowledge, and diabetes distress) a sample size of 89 patients would be needed to detect significance.

Protection of Human Subjects

A waiver of consent, permission, and assent in accordance with 45 CFR 46.408 and 45 CFR 46. 116(d) and a waiver of HIPAA authorization in accordance with 45 CFR 164.512 has been granted by Institutional Review Board from a local children's hospital in Southern California allowing examination of pre-collected data from patients who were enrolled in the SMILE program (Appendix A).

Risks associated with participation in the intervention included mild psychological distress from discussion of topics related to the self-management of diabetes. If distress occurred participants were encouraged to let the nurse practitioner or health care advocate know so arrangements could be made to refer the participant to the social worker assigned to the pediatric endocrinology team. No other risks were noted.

Participants were reminded they could bypass answering questions that made them uncomfortable, halt participation in the program, or withdraw from the program at any time at any time. Participants were notified prior to participating in the SMILE program that any answers which made the health care advocate concerned about the personal safety of the adolescent would be reported to the nurse practitioner.

All intervention data collected in paper and pencil format were stored in a locked cabinet. Participant numbers were utilized and no identifiers were linked to data. All data will be maintained in a locked cabinet by the PI for a period of seven years and then destroyed per institution IRB protocols. All study personnel completed required human subjects training and Health Insurance and Portability and Accountability Act (HIPAA) education specific to the IRB of the local children's hospital requirements (Appendix B).

Data Collection Procedures

A cohort of 14 adolescents who participated in a transition intervention program at a local children's hospital in Southern California provided data for this analysis. Pre-collected data were obtained from retrospective data abstraction from the patient chart and electronic medical record was examined.

Qualitative data regarding participation, feasibility, and diabetes knowledge were collected via written responses to open ended survey questions which were obtained from adolescent participants, participating parents, and Health Care Advocates when the SMILE program was completed (Appendix C).

Definition of Terms

- Adolescent: ages 13-19 years (Fuhrmann, 1990).
- Health Care Advocate: A non-judgmental person able to empower patients to exercise their individual rights to self-determination (Altun & Ersoy, 2003). This role was filled by prelicnesure nursing students, who had completed at least two academic semesters and had provided care for patients with diabetes in an acute care setting. The HCA received a four hour tutorial on adolescent diabetes care from the researcher.
- Duration of diabetes: Time since initial diagnosis of TIDM. Participants must have diabetes for at least one year in order to participate in the SMILE program
- Diabetic Knowledge: Measured as the score obtained on the Diabetes Knowledge (Redman, 2003)
- Diabetic Distress: Measured with the DDS17 (Fisher, Hessler, Polonsky, & Mullan, 2012)

- Glycemic Control: Defined as the HbA1c result (Benhalima, Standl, & Mathieu, 2011)
- Frequency of SMBG: Number of times per day in which the participant performs blood glucose readings with personal glucometer.

Data Collection Instruments/Measures

Demographics

Demographic data including age at enrollment, gender, race, and duration of diabetes, were abstracted from the patient medical record.

Diabetes Knowledge Test

For many years the assessment of diabetes-related knowledge has been as important component in the overall assessment of patients with diabetes. The Diabetes Knowledge Test includes 23 items (Appendix D). The general segment of the test has 14 items and additional 9 questions are directed to insulin management. It is appropriate for adolescents and adults with type 1 and type II diabetes and can be self-administered. The 23-item test takes approximately 15 minutes to complete. The test's reliability was measured by the Flesch-Kincaid grade level, and the reading level for the test items is at the 6th grade level. Although knowledge is not a good predictor of patient behavior, it is a prerequisite to perform appropriate self-care (Fitzgerald et al., 1998). The coefficient α values for the general test and the insulin-use subscale indicate both are reliable, ($\alpha \geq 0.70$).

Diabetes Distress Scale

Developed in 2005, the Diabetes Distress Scale (DDS17) assesses different types of diabetes-related emotional distress. The DDS17 builds on the strengths of previously developed instruments and addresses some of their limitations. This total scale is a 17-item scale which yields a total diabetes distress scale score comprised of four sub-scale scores, each addressing a different kind of distress, including emotional burden, physician-related distress, regimen-related distress, and interpersonal distress. Internal consistency has been computed for the total 17-item scale and for each subscale. Cronbach's α for the 17-item scale is 0.93 (Polonsky et al., 2005). (Appendix E)

Hemoglobin A1C

Medical management of diabetes aims to keep HbA1c as close to the normal range as possible (4% - 7%), with lower levels reflecting better metabolic control (Benhalima, 2011). Glycated hemoglobin, or HbA1c, is considered the gold standard for long term metabolic control and is widely used for patients with diabetes. HbA1c reflects the average blood glucose level over the past two to three month period and is the primary indicator of whether an individual with diabetes is maintaining adequate control over their blood glucose level. HbA1c has been shown to be linearly related to the development of severe short and long-term complications. The Diabetes Control and Complications Trial (DCCT) showed in patients with T1DM, the risk of long term complications was reduced significantly when patients maintained an average HbA1c of 7.2% (DCCT Research Group, 1993). Patients typically have HbA1c measured at each clinic visit. With waiver of consent to access the patient's medical records, the HbA1c associated with the visit at which the questionnaires were completed was obtained. Additionally, an HbA1c was obtained within three weeks after completing the SMILE program.

Frequency of Self Monitored Blood Glucose Testing (SMBG)

Self-monitoring of blood glucose (SMBG) is an important component of modern therapy for diabetes mellitus. SMBG has been recommended for people with diabetes by their health care professionals in order to achieve a specific level of glycemic control and to prevent hypoglycemia. The goal of SMBG is to collect detailed information about blood glucose levels at many time points to enable maintenance of a more constant glucose level by more precise regimens. It can be used to aid in the adjustment of a therapeutic regimen in response to blood glucose values and to help individuals adjust their dietary intake, physical activity, and insulin doses to improve glycemic control on a day-to-day basis.

Numerous trials have been conducted to determine the true impact of SMBG on glycemic control. Some, including randomized, controlled trials, have demonstrated the efficacy of SMBG. Among patients with T1DM, SMBG has been associated with improved health outcomes. Specifically, increasing frequency of SMBG was linearly correlated with reductions in HbA1c among patients in Scotland (Colhoun, 2009). Among patients with type 2 diabetes, a higher frequency of SMBG was associated with better glycemic control among insulin-treated patients who were able to adjust their regimen.

SMBG works by having patients perform a number of glucose tests each day or each week. The test most commonly involves pricking a finger with a lancet to obtain a small blood sample, applying a drop of blood onto a reagent strip, and determining the glucose concentration by inserting the strip into a reflectance photometer for an automated reading. Test results are then recorded in a logbook or stored in the glucose meter's electronic memory. People with diabetes can be taught to use their SMBG results to correct any deviations out of a desired target range by changing their carbohydrate intake, exercising, or administering more or less insulin.

The frequency with which patients with diabetes should monitor their blood glucose level varies from person to person. Most healthcare providers agree that insulin-treated patients should monitor blood glucose at least four times a day, most commonly fasting, before meals, and before bed. In addition, patients using insulin can benefit by obtaining postprandial blood glucose readings to help them more accurately adjust their insulin regimen. A positive correlation between frequency of SMBG and glycemic control among patients with insulin-treated type 1 or type 2 diabetes has been demonstrated (Blood Glucose Monitors and Data Management:Buyers Guide, 2001).

Intervention

Design of Intervention

Healthcare transition is recognized as a needed area of practice to facilitate the transfer of care from pediatric to adult healthcare and to support the adolescents acquisition of the developmental competencies needed to successfully transition to adulthood. Yet, few evidence-based and exemplary models of care exist (Reiss & Gibson, 2002). The medical community has provided leadership with the development of healthcare transition policy, practice, and research. In contrast, the influence of nursing as it pertains to these areas of professional practice is limited (Betz, 2013). This intervention is a nurse-designed, nurse-managed, and nurse-evaluated intervention. The SMILE program was designed as a result of nurses brainstorming about possible interventions for high risk adolescents with T1DM. The nurse practitioners in the endocrine clinic experienced frustration with a significant number of adolescents who were in the high-risk category. They had concerns about the adolescents turning 18 years old, transitioning to adult care and being lost to follow-up. They felt adolescents needed to be seen by a member of the healthcare team more frequently than the standard of care for the area, which is a clinic visit every three months. However, reimbursement costs do not cover additional clinic visits. This researcher was approached for consultation regarding a cost-effective way to engage the adolescent population. As a result of that meeting the SMILE program was designed.

The SMILE program was designed as a three month program in which adolescents with chronic poor metabolic control as demonstrated by an HbA1c of greater than 10%, would participate in an intervention program utilizing health care advocates, text messaging, and home education visits. The participants would be seen by a member of the healthcare team for five encounters over a three month period. The program began in early 2012. Each adolescent was assigned a personal health care advocate (HCA). The role of the HCA was to be nonjudgmental and to empower the adolescent to exercise their individual rights to self-determination (Altun & Ersoy, 2003). It was determined the HCA's would require previous knowledge related to diabetes so pre-licensure nursing students from a local private university were recruited to participate in the role of HCA. The HCA's were not paid for their services rather the SMILE program served as clinical hours for a community health course. Data were collected on the first as well as the final visit.

Adolescent participants had to agree to give their glucometer to their parent each evening so the parent could verify that SMBG was taking place. Parents had to agree to review blood glucose readings but were not allowed to question their adolescent about the reading. This was specifically incorporated into the design as a result of comments from adolescents stating a big source of family conflict was parental 'nagging'. Research states parents of chronically ill children are faced with two sets of tasks: (1) taking responsibility for management of the disease at home in order to ward off the immediate threat of medical crises and (2) helping the child take developmentally appropriate steps in managing his or her own health. The construct of 'miscarried helping', when this leads to conflict, has proven to be consistent across a diverse group of families of youth with poorly controlled diabetes (Harris et al.,2008) Yet, research suggests there is no specific 'family profile' for predicting miscarried helping in families of youth with diabetes (Harris et al., 2007). Having a HCA provide the daily text messaging or reminders was a way to decrease conflict between the parent and adolescent. The HCA was instructed to text message the adolescent 3-5 times per week. In addition to providing motivational texts to the adolescent, the purpose of the text message was to remind the adolescent patient of self-management activities such as SMBG, counting carbohydrates, and sticking to a meal and activity plan.

Two home education visits were provided by the HCA. Topics of the home education visit were; goal setting, disease process, medications, and nutrition. The nurse practitioner, health care advocate, and adolescent participant determined which of the American Diabetes Association education modules would be reviewed. The education modules were reviewed in the participants' home on a personal laptop owned by the HCA. Parents were required to be present for home visits for participants less than 18 years of age. Study fidelity was maintained by weekly email updates to the researcher and nurse practitioner from the HCA. Updates provided information regarding what had been discussed via text messaging, what had occurred during the home education visits, and overall psychosocial assessment of the participant. The researcher and/or the nurse practitioner returned a weekly email to the HCA with recommendations for future encounters with the adolescent. Adolescent participants received a $10.00 cash stipend for each visit.

Implementation of Intervention

Visit #1. The researcher, HCA as well as the NP met the adolescent patient and parent at visit #1, in the endocrine clinic. The HCA and adolescent exchanged cellular telephone information and a mutually agreed upon time for text messaging was determined. The adolescent and parent completed data collection at visit #1. (Study Timeline, Appendix F). Additional data including the Diabetes Family Conflict Scale, The Pediatric Assessment in Diabetes Survey (PAID), and the Survey of Eating Attitudes & Diabetes Management was obtained at visit #1, and will be analyzed in the future.

Visit #2. Occurring approximately two weeks after visit #1 and again taking place in the endocrine clinic, visit # 2 involved the HCA, participant, parent, and NP. Together, the educational modules which would be reviewed at the home visits were determined. Text messaging was discussed to make sure it was occurring at a mutually agreed upon time, as well as to make sure the adolescent was responding to text messages.

Visit # 3 and Visit # 4. The third and fourth visits were educational visits which occurred in the participants' home or sometimes at a local coffee shop: visit # 3 took place approximately three weeks after visit # 2 and visit # 4 took place approximately one month after visit # 3. The educational information was provided via PowerPoint presentation and viewed on the laptop computer belonging to the HCA. The home education visits lasted approximately one hour.

Visit # 5. Visit # 5 took place in the endocrine clinic. Participants included the adolescent, the parent, HCA, NP, and researcher. A program evaluation was completed by the adolescent, the parent, and HCA (Appendix C). Further data collection included; HbA1c, as well as completion of the same instruments obtained at visit #1.

Data Analysis Plan

Quantitative Analysis

The Statistical Package for the Social Sciences (SPSS version 21, Chicago, IL.) was used for quantitative data analysis. Descriptive statistics summarized the demographic items such as age at enrollment and age at diagnosis using ranges, means, and standard deviations. Percentages were used to report gender and race. The primary analysis examined Pre/Post change in diabetes knowledge, diabetes distress, and HbA1c. Diabetes knowledge and diabetes distress were assessed pre and post intervention using the previously described assessment tools and HbA1c data was abstracted from the patient's medical record. It should be noted that the device to measure HbA1c only has the capacity to return values up to 14; all values greater than 14 are reported as 14+. Therefore, in order to obtain continuous data for all participants, values reported as 14+ were rounded down to 14. This is considered appropriate because it biases the result of the test toward the null, so any demonstrated effect of the SMILE program lowering HbA1c, is likely lower than the true effect of the intervention. These three measures yielded continuous data for each participant. As such, a paired-sample t-test was conducted for each of these variables to calculate the significance of the average change from Pre to Post intervention. Using the Pre and Post values for these three variables, the change during the study period was calculated. These variables were used for correlational analysis, which yielded information about the relationship between HbA1c change and knowledge change, HbA1c change and distress change, and knowledge change and HbA1c change.

Frequency of SMBG was collected via self-report and when possible from the patient's glucometer by attaching the glucometer to the computer program in the endocrine clinic and generating a calculation. At times, the patient reported a range for the frequency of SMBG instead of an integer and as such, frequency of SMBG had to be categorized into a dichotomous variable. As a result, a paired t-test could not be performed so a *Chi*-square test with Fisher's exact test, to account for the small sample size, was performed to test whether a significant relationship between the frequency of SMBG Pre and HbA1c Pre and if there was a significant relationship between SMBG Post and HbA1c Post. The categories for frequency of SMBG were determined Post hoc based on the frequencies of the available data. Based on the reported values, the only categories of frequency SMBG that could be created were 0-3 and 3+.

In order to provide another estimate of the effect of the intervention to change in HbA1c a McNemar test with a Yates correction, again to account for the small sample size, was performed to test the difference in proportion of those with an HbA1c ≥ 14 from pre to post intervention.

Qualitative Analysis

Feasibility and acceptability of the SMILE program were primarily evaluated using qualitative thematic analysis of open-ended responses to program evaluation questions. Thematic analysis is a process of encoding qualitative information. This may be a list of themes; a complex model with themes, indicators, and qualifications that are casually related; or something in between these two forms. It is not a separate measure, such as grounded theory or ethnography, but something to be used to assist the researcher in the search for insight (Creswell, 2009). The primary researcher and a research assistant independently coded the responses and then used these codes to generate broader themes. In most cases, codes were similarly applied between the two researchers. However, when inconsistencies occurred the primary researcher and research assistant met to discuss and determine which category a response fell into.

Table 1

Research Aims, Variables, Measurement, and Method of Analysis

Research Aim	Variable	Level of measurement	Method of Analysis
Aim #1 Examine pre and post scores in glycemic control, diabetes knowledge, and diabetes distress among a sample of adolescents with T1DM	Diabetes Knowledge Diabetes Distress Glycated hemoglobin HbA_{1c}	Ratio Nominal Answers are ranked as lower than or greater than 3 Ordinal Ordered according to a criterion.	Correlation Pearson r Correlation Pearson r t-test
Aim #2 Examine the relationship between diabetes knowledge, diabetes distress, and glycemic control among a sample of adolescents with T1DM participating in the SMILE program			Contingency tables
Aim #3 Examine the feasibility and acceptability of an individualized transition program utilizing technology, health care advocates, and home education visits among a sample of adolescents with T1DM participating in the SMILE program.			Qualitative analysis

CHAPTER IV

STUDY RESULTS

The purpose of this research was to conduct a feasibility study to examine a transition program that utilizes technology, health care advocates, and home education visits with adolescents living with T1DM. This chapter provides a descriptive profile of study participants. The results related to the specific research aims will be presented.

Characteristics of the Sample

A purposive sample of 14 adolescents was recruited from patients who received care in the endocrine clinic at a large academic children's hospital located in Southern California. Data were collected during the spring of 2012 and participants' total time in the program was three months. Demographic data were abstracted from the patient medical record (see Table 2).

The sample was predominately female (86%). Age ranged from 14.5 to 17.8 years with a mean of 16.1 (SD = 1.61). The sample was diverse with slightly less than half Latino (42.9%), White (42.9%), Other (14.2%).

Table 2

Descriptive Statistics for Adolescent Sample

Characteristic	n%	Mean	Std. Deviation
Gender			
Male	12	85.7	
Female	2	14.3	
Race			
Caucasian	6	42.9	
Hispanic	6	42.9	
Other	2	14.2	
Age at Diagnosis	14	10.2	4.7
Age at Enrollment	14	16.1	1.6

Research Aim 1

Examine pre- and post- intervention scores of diabetes knowledge, diabetes distress, and glycemic control among a sample of adolescents with T1DM participating in the SMILE program.

Paired-samples t-tests were computed to examine the differences between the pre- and post- intervention scores of glycemic control (HbA1c), diabetes knowledge, and diabetes distress. T-tests comparing pre-post intervention outcomes for program participants are presented in Table 3.

Glycemic Control

Pre-intervention HbAlc (PreHbA1c) was obtained on all participants within three weeks before beginning the SMILE program. Post-intervention HbA1c (Pre HbA1c) was obtained at the last and final clinic visit which occurred approximately three months after enrollment. A statistically significant difference was found in the Pre Mean= 12.57, (SD = 1.61) and Post Mean = 10.97 (SD = 1.62) intervention HbA1c, *t (13)* = 3.94,

$p = .002$ indicating study participants successfully reduced their average blood glucose.

Diabetes Knowledge

A statistically significant difference was found in the pre mean, M = 72.4 (SD = 5.2) and post mean 87.5 (SD = 3.8) diabetes knowledge scores $t\ (13) = -6.47$, $p < .001$ indicating study participants significantly increased their diabetes knowledge throughout the course of the program.

Diabetes Distress

The Diabetes Distress Scale is an accumulation of four subscales summed to a total score of three. A score of 3 indicates a need for referral to social services. The mean DDS pre-SMILE score was 2.6 (SD = 1.02) and the mean DDS post-SMILE was 2.0 (SD = 0.99), $t\ (13) = 3.63$, $p = .003$ indicating a statistically significant decrease in the adolescents' level of distress after the SMILE intervention.

Table 3

Dependent Group t Tests: Pre- and Post-Intervention Outcomes

	Pre Mean (SD)	Post Mean (SD)	*t*	d*f*	*p*
HbA1c	12.6 (1.61)	10.97 (1.62)	3.94	13	0.002*
DK	72.4 (5.15)	87.5 (3.84)	- 6.47	13	< 0.001*
DDS	2.6 (1.02)	1.99 (0.99)	3.63	13	0.003*

Research Aim 2

Examine the relationships between diabetes knowledge, diabetes distress, and glycemic control among a sample of adolescents with T1DM participating in the SMILE program.

Correlations between continuous variables were used to examine bivariate relationships between diabetes knowledge change, diabetes distress change, and HbA1c change. Using the Pre and Post values for these three variables, the change during the study period was calculated. These variables were used for correlational analysis, which yielded information about the relationship between HbA1c change and knowledge change, HbA1c change and distress change, and knowledge change and HbA1c change.

Non-statistically significant weak positive relationships were found between DK change and DDS, $r = .175, p = .55$, DDS and HbA1c, $r = .236, p = .41$, and a non-statistically significant inverse relationship between HbA1c change and DK, $r = -0.187, p = .52$. This indicates all participants exhibit similar levels of basic knowledge about diabetes. Previous studies also found no correlation between knowledge about diabetes and glycemic control (Munhoz-Santos, Bernardo, Gabbay, Dib, & Sigulem, 2013).

Table 4

Correlation Matrix: Computed Changes in Diabetes Knowledge, Diabetes Distress, and Glycemic Control Pre and Post Intervention

	DK	DDS	HbA1c
DK	--	.175	-.187
DDS	.175	--	.236
HbA1c	-.187	.236	--

Note: n=14; * p = .05

In order to assess the relationship between HbA1c and frequency of SMBG the data was divided into groups and *chi*-square tests were performed. HbA1c was grouped 0 = <14% and 1 = >14%. Frequency of SMBG has variation in the way scores are reported: integers and ranges. Since it is impossible to approximate the values for a range the continuous variable, or integers, SMBG was categorized 0-3 times/day and > 3 times/day. Table 5 provides percentage of youth's frequency of pre/post SMBG by pre/post HbA1c. A Fisher's Exact Test was performed because of the small sample size. Results of the Fisher's Exact indicated there was not a statistically significant relationship ($p = 0.99$) between frequency of blood glucose testing and HbA1c, prior or after ($p = .357$) enrollment in the SMILE program.

Table 5

Percentage of Youths' Frequency of Pre/Post SMBG by Pre/Post HbA1c

SMBC	Pre HbA1c < 14 n (%)	Pre HbA1c > 14 n (%)	x^2	p
>3	2 (25)	2 (33.3)		
<3	6 (75)	4 (66.7)		
			0.12	0.99
>3	4 (30.8)	1 (100)		
<3	9 (69.2)	0 (0.00)		
			1.94	0.36

Note: n = 14

McNemar's Test, a repeated measure *chi*-square test was performed to assess the proportion of participants with HbA1c greater than 14 versus those participants with an HbA1c less than 14%. Eight (57.1%) of the 14 participants had pre and post HbA1c <14%, 5 (35.7%) had a pre HbA1c >14%, there were no participants who had a pre HbA1c < 14 % who had a post intervention HbA1c >14%, and 1 participant had an HbA1c >14% pre and post intervention, $p = .063$ approached significance. Table 6 provides percentage of participants in HbA1c group's pre/post intervention. Since the composition of males and females was disproportionate, it was decided not to test for differences between males and females.

Table 6

Percentage of Participants in HbA1c Groups Pre vs. Post

		Post HbA1c	n (%)
		<14	>14
Pre HbA1c n (%)	<14	8 (57.1)	0 (0)
	>14	5 (35.7)	1 (7.1)

To examine the relationship between Race and HbA1c change a Univariate Analysis of Variance was performed. Results of The Tests of Between Subjects Effects revealed there was not a significant relationship between Race and HbA1c ($R^2 = 16.7$, $p = .935$), indicating the model does not explain the variability of the response data around its mean.

Post Hoc tests were performed using Bonferroni correction which controls for false positives. Again, results indicated there was not a statistically significance relationship between any of the races reported and HbA1c change ($p=1.0$).

Research Aim 3

Examine the feasibility and acceptability of an individualized transition program utilizing technology, health care advocates, and home education visits among a sample of adolescents with T1DM participating in the SMILE program.

Adolescents, Parents, and Health Care Advocates were queried at the conclusion of the SMILE intervention. Qualitative content analysis was used to guide the interpretive description of the data (Sandelowski, 2000). Qualitative description involves staying close to the participants responses without extracting additional meanings beyond the participant responses (Sandelowski, 2000). Program evaluation forms were coded by identified key words and phrases reflecting aspects of the adolescent, the parent, and the Health Care Advocate response to each question.

Adolescent Experiences

Adolescent participants described positive experiences when participating in the SMILE program. Ten adolescents stated they enjoyed working with the Health Care Advocate. Comments received include the following:

- "I loved having a HCA to talk to throughout the week"
- "I liked that the HCA was so willing to learn and help me. I was not expecting her to actually care as much as she did, and I appreciate that more than she knows."
- "It was nice to have someone to talk to about my diabetes"
- "I liked that I had the confidence talking with my HCA about the things I was going through and how I felt"
- "I had someone, my HCA, who actually understands me" and
- "I enjoyed building a relationship with the HCA. She really had a big impact on my life in general. It really helped me improve."

Improved control of diabetes was the impetus for joining the program, emerged as a theme from nine respondents. Examples of responses included the following:

- "So I could control my diabetes."
- "To learn how to take care of my diabetes so my A1c would go down."
- "I needed help with my uncontrolled diabetes."

- "To look for a new way to get help with my diabetes from a non-biased point of view" and
- "To get my bs (blood sugar) under control".

Only one participant response indicated the SMILE program was not his choice. When answering the question "Why did you agree to participate in the SMILE program, the participant answered "...because my mom told me to".

When adolescents were queried about what three things they learned while in the program the responses varied widely. Each adolescent had specific learning needs and several themes emerged from their responses. These themes included improved diabetes management resulting from increased knowledge of hypoglycemia awareness, nutrition, carbohydrate counting, and frequency of blood glucose monitoring.

"Others comments were concerned about their (youth's) well-being" emerged as a second theme. For example statements included:

- "Everyone cares greatly"
- "I have someone who actually understands me (HCA)",
- "I learned to be more patient with my family".

Only one participant responded "nothing" to the question asking what was learned during the program.

In an effort to determine how to improve the program, participants were asked what would make the SMILE program better. Four participants indicated they would like the program to last longer, three participants indicated they would like to have group meetings with other teens and HCA's. Other responses included, "I don't know" and two respondents stated, "Nothing, its perfect."

Parent Experiences

While not all parents chose to complete the questionnaire, parent responses indicated a need to "help" their adolescent manage diabetes. In responding to what was learned during the SMILE study, most parents did not reflect on their personal knowledge acquisition, but more on the increased knowledge they observed in their adolescent. Responses included:

- "She started to check her bs (blood sugar) four times a day"
- "She now remembers to wear a medic alert bracelet", and
- "She learned how to get a more accurate reading when checking her bs".

One parent stated she had learned to manage her emotions related to her adolescents' blood glucose readings and another parent stated she learned the entire family had to work together to manage diabetes.

Honesty, support, encouragement, and mentoring were words used by parents when describing what they liked about the SMILE program. "The HCA was honest with my child" and "I liked that my daughter could communicate with someone with a great deal of information about diabetes."

Five respondents recommended the SMILE program be longer in time. One parent suggested HCAs send weekly email reports to the parent and another parent suggested group activities for the adolescent participants and HCAs. Finally, one parent stated the SMILE program was "... a good refresher for me, kind of a wakeup call for my daughter to really work on her diabetes and knowing how important it is for her life."

Health Care Advocate Experiences

The two major themes emerging from Health Care Advocate responses to the questions were (1) participation to increase own knowledge related to T1DM and (2) gain experience working with an adolescent population. When responding to what they learned while participating in the SMILE program responses varied, HCAs (n= 13) reported an increase in their knowledge related to carbohydrate counting, activity regulation, and insulin adjustment, ten HCAs responded along a developmental approach stating;

- "I learned how it could be difficult (for the adolescent) going out with friends and having to manage diabetes",
- "Compliance in teens is more than lack of education. It is social factors and fear of being judged", and
- 'The teenagers have such a high degree of responsibility for their age".

All HCA respondents stated they were interested in a career in pediatric nursing and thought participation in the SMILE program would make them a more desirable candidate for a job offer in a pediatric setting.

CHAPTER V

CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

Summary of the Problem

Healthcare transition, although acknowledged as a service need for the past two decades, has yet to become a reality. Clinicians and researchers have highlighted the complex difficulties inherent in the transition from pediatric to adult care. Even for healthy individuals, the transition and independent management of general healthcare can be complicated. In addition to the typical challenges of entering adulthood, this particular period of development is especially difficult for adolescents with chronic conditions, including T1DM. Few exemplary and evidence-based models of healthcare transition exist that have been sustained with revenue generated from the services provided.

Summary of the Purpose

In the clinical setting intervention programs are not designed with theoretical underpinnings nor are they evidence based. This is especially true when working with the adolescent population because this group wants to 'fit in', and therefore traditional support group activities tend not to be sustainable. The intervention was based on transition theory, in concert with developmental theory. The study had three aims; (1) examine the pre and post intervention scores of diabetes knowledge, diabetes distress, and glycemic control (2) examine the relationships between diabetes knowledge, diabetes distress and glycemic control, and (3) examine the acceptability of a transition program which included the use of healthcare advocates in the role of coach and supporter to adolescents with T1DM.

Discussion of Findings

Study Findings Related To Conceptual Framework

Mid-range nursing theories are useful tools in helping to understand the scope of nursing practice in a range of contexts and situations. The extent to which the study findings were found to be linked with the domains of the theory of nursing transitions is shown in tables seven through ten.

Table 7

The Nature of Transitions

Element	Description	Relevance to Current Study
Types		
Developmental Situational Health/Illness Organizational	Nurses regularly encounter four main types of transition Interventions must be tailored to type of transition	While experiencing a developmental transition (becoming a teenager), a person may be going through a situational transition (being referred to adult care).
Patterns		
Single Multiple Sequential Related Unrelated	Transitions are commonly patterns of complexity, with individuals experiencing more than one type of transition concurrently.	Adolescent participants were not only dealing with the situational transition of a change in care providers, but also with the developmental changes occurring during adolescence.
Properties		
Awareness Engagement Change and Difference Transition Time Span Critical Points and Events	Engagement is the degree to which a person demonstrates involvement in the processes inherent within the transition.	Adolescents and HCAs varied in their degree of engagement in the process. Those who were proactive in text messaging tended to evaluate the program more positively.

Table 8

Transition Conditions

Element	**Description**	**Relevance to Current Study**
Personal Meanings	These emerge from subjective appraisal of an anticipated or experienced transition and the evaluation of its likely effect on one's life.	Parents stated they allowed their adolescent to participate in the program so their child might get a better understanding of their diabetes.
Cultural Beliefs and Attitudes	Diverse patient populations require individualized programs.	SMILE participants were a diverse group of patients and the educational modules were tailored to individual learning needs.
Socioeconomic Status	Socioeconomic status has an important impact on transition experience.	Socioeconomic status was not a variable in this study.
Preparation and Knowledge	Extensive planning helps to create a smooth and healthy transition.	Participants met with the P at visit #1 to review a detailed assessment and develop an individualized home education plan.

Table 9

Indicators of Healthy Transitions: Process Indicators

Element	Description	Relevance to Current Study
Process Indicators		
Feeling Connected	This is concerned with making new contacts and continuing old connections.	This was reflected in the adolescents' comments about knowing the HCAs cared about them.
Interacting	The meaning of the transition and the behaviors developed in response to the transition are clarified and acknowledged.	The importance of effective communication at all stages of the program was significant. This included text messaging as well as email follow up from the HCA.
Location and Being Situated	Location involves understanding the new way of life; being situated involves finding justification for how or where they came, where they are, and where they have been.	The study variables did not examine whether participants reached an understanding of acceptance of diabetes.
Developing Confidence; Coping	The extent to which the participants experienced an increase in confidence and coping	While coping was not measured in this study, distress was measured. Overall distress decreased during the program.

Table 10

Indicators of Healthy Transitions: Outcome Indicators

Element	Description	Relevance to Current Study
Outcome Indicators		
Role Mastery	The sense of achievement of skilled role performance and comfort with the behavior required in the new situation.	The extent to which adolescents demonstrated mastery was measured in the Diabetes Knowledge Test. Overall, participants increased diabetes knowledge.
Fluid, Integrative Identities	Transition experiences have been characterized as resulting in identity reformulation.	In order for participants to develop a bicultural perspective participants would need to complete the transition to adult care and only then could they comment on both perspectives.

As presented, the use of this framework provides a useful guide to examine the aims of this study. Study findings indicate the usefulness of this model in understanding the relationships between study concepts and the acceptability of an innovative intervention designed to assist adolescents with T1DM healthcare transitions.

Quantitative Discussion

Aim #1. Study participants successfully reduced their average blood glucose throughout the course of the intervention. Diabetes knowledge increased as a result of participating in the program and diabetes distress decreased after participating in the program. These conclusions may suggest offering home educational programs increased the acquisition of knowledge. As far as a decrease in diabetes distress it is difficult to determine what specifically contributed to the decrease. The combination of text messaging and the two home educational visits by the HCA may have provided the right balance of support for the adolescent resulting in a decrease in diabetes distress. This however, is speculation and difficult to quantify with this limited sample.

Emerging information and communication technologies have considerable potential to aid patients with long-term conditions, and young people with diabetes report using many of these to serve their information and support needs (Skinner, Biscope, Poland, & Goldberg, 2003). For example, analysis of messages submitted to online diabetes forums suggests adolescents use these in order to obtain social support, information, advice, and shared experiences (Ravert, Hancock, & Ingersol, 2004). The literature suggests text messaging via mobile phones has become an integral component of teenage culture in many parts of the world, providing an inexpensive, portable, and widely used for of communication (Linhart, Nadden, & Hitlin, 2005). The medium of text messaging with adolescents is increasingly being used to deliver healthcare information, reminders, and lifestyle interventions; it has obvious potential to engage young people with diabetes (Gimenez et al., 2002).

Aim #2. A weak positive relationship was found between diabetes knowledge and diabetes distress meaning as diabetes knowledge increased diabetes distress decreased, however this was not statistically significant. This is interesting to note and draws upon adolescent development theory. One would infer as a person learns more about diabetes his/her related distress would increase because of the newly acquired knowledge of the severity of the disease. On the other hand, one might argue the distress decreased as a result of participating in the intervention because participants increased their knowledge and therefore felt more confident with their diabetes self-management resulting in decreased distress. Ellis and colleagues (2005) found greater diabetes distress to be significantly related to poor glycemic control. Further studies by Hains and colleagues (2007) found negative attribution of friends' and peers' reaction and teachers' reaction had a significant indirect effect on glycemic control through associations with diabetes-related stress.

Correlations between knowledge and HbA1c change were negative (-.187) not statistically significant (p = 0.523), in other words there is not a significant relationship between an increase in knowledge and level of HbA1c. For many years, the knowledge each patient has about diabetes is a basic element in educational programs for TIDM patients (Miller, Goldstein, & Nicolaisen, 1978). The patient is required to have basic knowledge about insulin, carbohydrate counting, diet, etc. Knowledge is one of the many important variables involved in diabetes education. One study has demonstrated the positive impact knowledge has on glycemic control (Heisler, Piette, Spencer, Kieffer, & Vijan, 2005). However, others suggest the level of knowledge about diabetes is not a good predicator of good glycemic control and generally recommend need for further research in this field. (Munhoz-Santos et al., 2013). Despite the advancement in diabetes therapy during recent decades, the quality of diabetes care, in general requires improvement. Effective educational program aimed at managing glycemic control need to address not only the knowledge about the procedures, but also address psychosocial factors (American Diabetes Association, 2008).

Qualitative Discussion

Aim # 3. Study participants, as well as parents, overwhelmingly gave positive feedback about the SMILE program. Positive feedback about transition programs has not been well documented in the literature, however negative experiences with transition are well known. A large qualitative study including 49 adolescents and young adults, ages 13-35 years, with special healthcare needs, 44 family members, and 50 healthcare providers, report young adults have negative experiences with transition (Reiss, Gibson, & Walker, 2005). The young adults involved in the study perceived their adult providers to lack knowledge and experience needed to provide care for childhood-onset chronic conditions. Young adults had difficulties establishing a trusting relationship with the adult care providers (Reiss, Gibson, & Walker, 2005).

In a study conducted by Tuchman and colleagues (2008) adolescents perceived benefits from a structured transition program and expected clinic practices to be consistent and fairly applied, which may be unrealistic given the spectrum of disease severity and developmental readiness. In their study, few adolescents interviewed expressed ideas about how to improve the transition process; however several adolescents suggested starting the transition process at an earlier age.

Adolescents' participating in the SMILE program remarked how much they valued having a healthcare advocate remind them about diabetes tasks instead of a parent to 'nag' them. This supports the literature regarding family conflict during adolescence. The technologic advances for diabetes, including more physiologically exact replacement methods with basal-bolus therapy or subcutaneous insulin infusion, insulin analogs, and continuous glucose monitoring, promote more optimal glycemic control while adding to the burden of care for youths and their families. Although these approaches offer significant opportunities for improved diabetes management, the increased demands placed upon patients and families associated with these therapies provide an environment rich for conflict. General family conflict is unavoidable and in fact some general family conflict is normal (Holmbeck, 1996), nonetheless diabetes-specific conflict is counterproductive to effective diabetes management (Hood, Butler, Anderson, Laffel, 2007).

Study Limitations

The findings of this study must be viewed in the context of its limitations. The sample under investigation, while ethnically diverse, was a small group of patients receiving care at one institution. Nevertheless, many of the findings overlap those reported in the small number of transition-focused studies. Further research is needed to assess whether identified concerns translate to global issues rather than regional issues.

Data were obtained through retrospective review of patient records. Using medical records and clinic charts as data sources introduces potential error resulting from the quality of data entry.

The use of nursing students as healthcare advocates, while favorably received from participants and the parents, may have skewed the results related to diabetes knowledge and diabetes distress. While all HCAs participated in the standardized training program, it is difficult to determine if delivery of the educational modules were consistent by each HCA. The text messaging was not standardized and therefore may have influenced study outcomes. Future studies might consider standardizing the text messages. Despite these limitations this study provided preliminary data and support for tailored transition programs for adolescents with chronic conditions.

Implications for Nursing Practice, Nursing Education, Future Research and Policy

Nursing Practice

The past two decades have been a period of quiescence by pediatric and adult health nursing associations and nursing leaders. The lack of involvement and participation in efforts to define the scope of nursing practice roles and responsibilities in healthcare transition has been noticeable. During that time, one pediatric organization provided input on the role of nursing in healthcare transition, the National Association of Pediatric Nurse Practitioners (NAPNAP) (2008). In 2008, NAPNAP reaffirmed its original statement published in 2002, its Position Statement on the Parameters for Pediatric Nursing Practice recommended 21 years of age be the upper age limit for care provided by pediatric nurse practitioners (PNP) except in special circumstances as agreed upon by the emerging adult, family members, and the PNPs.

There are opportunities for pediatric and adult nurses to furnish needed leadership in transition programs. Such leadership will advance integration of nursing philosophies of care into the development of the healthcare transition field. Policy making, practice, and research will be positively influenced. This is a clear opportunity for nursing leaders to formulate visions of the contributions nurses can make to the field of healthcare transition. By doing so, practicing nurses and nurse scientists will be encouraged to engage in this emerging and growing area of specialization.

Nursing Education

Nurses in diverse practice settings assist people to navigate transitions when illness and change disrupts their lives (LeVasseur, 2002). Education of patients, families, and healthcare providers on the issue of healthcare transition is critical. Understanding transition enables nurses to move towards a more holistic approach to the provision of care (Kralik, Visentin, & Van Loon, 2006).

Research and Policy

Relatively few nursing studies have been conducted pertaining to healthcare transition. Published studies conducted by nursing, the medical community and interdisciplinary colleagues have relied primarily on descriptive designs (Ridosch et al., 2011), with limited use of randomized control trial (Betz, Smith, & Macias, 2011). The nursing framework of practice which is based on the application of comprehensive care to address youth and family biological, developmental, behavioral, and psychosocial needs is well suited to investigate the phenomenon of healthcare transitions. Nurse scientists can contribute in important aspects, given their reliance on theoretical models, to guide the selection of variables for study, their appreciation to use instrumentation with strong psychometric properties and their understanding of applied research designs for clinical investigations.

This feasibility study raises several issues which need to be addressed in future research. First, this study indicates several implications for the design of transition care programs: implementation and evaluation with a larger sample can lend further support to transitional programs. Additional studies should be performed to examine the clinical outcomes of different models of transitioning care from pediatric to adult care. Transition models which utilize a transition coordinator and/or a healthcare advocate to aid in the transition process should be studied and evaluated. Secondly, time is an essential element in transition and therefore longitudinal studies are required to explore experiences during the transition process that result in news ways of living and being as the outcome of the transition experience.

Finally, future studies should also focus on the relationship between costs related to chronic health issues and national standards for patient education which will ultimately guide policy makers. For example, self-management education is now understood to be a critical part of diabetes care and the medical treatment of diabetes. Without a system wide approach to self-management education the education provided is considered inadequate. The National Standards for Diabetes Self-Management Education and Support establish specific criteria against which diabetes education programs can be measured, and a quality assurance program has been developed and subsequently revised (Haas et al., 2014). To achieve optimal glycemic control, thus achieving long-term reduction in healthcare costs, individuals with diabetes must have access to the integral components of diabetes care, such as healthcare visits, diabetes supplies, self-management education, and diabetes medications. Notably, insurers must be required to reimburse for diabetes-related medical treatment, as well as for self-management education programs that have met the accepted standards. Furthermore, these same standards should apply to organizations that purchase healthcare benefits for their employees, as well as managed care organizations that provide service to participants.

Conclusions

Transition experiences are not one-dimensional. Rather, each transition is characterized by its own uniqueness, complexities, and multiple dimensions. The question of how best to transition youth with TIDM to adult care remains unanswered, in part due to the lack of randomized control trials evaluating models of transition from pediatric to adult care. Training and education on transition care for both healthcare personnel and patients is the first essential step to ensure smooth and effective transition from pediatric to adult service. Clinicians, administrators, and researchers should focus future efforts on developing more comprehensive transition programs which take place over time, and maximize the use of healthcare advocates, as well as technology.

It is an opportune time for nursing leaders in pediatric and adult nursing to initiate more visible efforts to infuse this area of practice with nursing and interdisciplinary perspectives. In collaboration with our interdisciplinary colleagues, nursing leaders can initiate the process of developing relevant policy and practice standards to inform the healthcare community of the role nurses and interdisciplinary professionals can have in healthcare transition.

References

Alligood, M.R., & Marriner-Tomey, A. (2010). *Nursing theorists and their work*: Mosby/Elsevier.

Altun, I., & Ersoy, N. (2003). Undertaking the role of patient advocate: a longitudinal study of nursing students. *Nursing Ethics, 10*(5), 462-471. doi: 10.1191/0969733003ne628oa

American Academy Of Pediatrics, American Academy of Family , & American College Of Physicians, Transitions Clinical Report Authoring Group (2011). Clinical Report-Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics*. doi: 10.1542/peds.2011-0969

American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians-American Society of Internal Medicine. A consensus statement of health care transitions for young adults with special health care needs. (2002). *Pediatrics, 110*, 1304-1306.

American Diabetes Association. (2002). Economic costs of diabetes in the U.S. in 2002. *Diabetes Care, 26,* 917- 932.

American Diabetes Association. (2008). Economic costs of diabetes in the U.S. in 2007. *Diabetes Care, 31,* 596-615.

American Diabetes Association. (2008). Standards of medical care in diabetes. *Diabetes Care,* 31, S12-S54.

American Diabetes Association. (2013). Economic costs of diabetes in the U.S. in 2012. *Diabetes Care, 36,* 1033-1046.

American Heart Association; American Diabetes Association. (2007). Primary prevention of cardiovascular diseases in people with diabetes mellitus. *Diabetes Care, 30*(1), 162-172.

Anderson, B. J., Wolpert, H.A. (2004). A developmental perspective on the challenges of diabetes education and care during the young adult period. *Patient Education and Counseling, 53*, 347-352.

Baltes, M., Silverberg, S. (1994). The dynamics between dependency and autonomy: Illustrations across the life span. In D.L. Featherman & R.M. Lerner (Eds.), *Life-span development and behavior* (Vol.12, pp. 41-90). Hillsdale, NJ:Eribaum.

Barker, E. T., & Galambos, N. L. (2005). Adolescents' Implicit Theories of Maturity Ages of Adulthood, Freedom, and Fun. *Journal of Adolescent Research, 20*(5), 557-576.

Barlow, J. H., Bancroft, G. V., & Turner, A. (2005). Self-management training for people with chronic disease: A shared learning experience. *Journal of Health Psychology, 10*(6), 863-872.

Benhalima, K., Standl, E., & Mathieu, C. . (2011). The importance of glycemic control: How low should we go with HbA1c? Start early, go safe, go low. *Journal of Diabetes and its Complications,* 25(3), 202-207.

Beskine, D., Owen, P. (2008). Review of transitional care for young people with diabetes. *Journal of Diabetes Nursing, 12*(1), 35-38.

Betz, C. L. (2013). Health care transition for adolescents with special healthcare needs: Where is nursing? *Nursing Outlook, 61*(5), 258-265.

Betz, C., Smith, K., Macias, K. (2011). Testing the transition preparation training program: A randomized controlled trial. *International Journal of Child and Adolescent Health,* 3, 595-608.

Blood Glucose Monitors and Data Management : Buyers Guide (2001). *Diabetes Forecast, Jan.*, 71-88.

Blum, R. (2002). Introduction: Improving transition for adolescents with special care needs from pediatric to adult-centered care. *Pediatrics, 110*, 1301-1303.

Bogner, H.R., Morales, K.H., de Vries, H.F., & Cappola, A.R. (2012). Integrated Management of Type 2 Diabetes Mellitus and Depression Treatment to Improve Medication Adherence: A Randomized Controlled Trial. *The Annals of Family Medicine, 10*(1), 15-22. doi: 10.1370/afm.1344

Bojadzievski, T., & Gabbay, R. A. (2011). Patient-centered medical home and diabetes. *Diabetes Care*, 34(4), 1047-1053.

Bowen, M.E., Henske, J.A., Potter, A. (2010). Health care transition in adolescents and young adults with diabetes. *Clinical Diabetes,* 28, 99-106.

Bryden, K.S., Peveler, R.C., Stein, A., Neil, A., Mayou, R.A., & Dunger, D.B. (2001). Clinical and psychological course of diabetes from adolescence to young adulthood: a longitudinal cohort study. *Diabetes Care, 24*(9), 1536 - 1540.

Busse, F.P., Hiermann, P., Galler, A., Stumvoll, M., Wiessner, T., & Kiess, W. (2007). Evaluation of patients' opinion and metabolic control after transfer of young adults with type 1 diabetes from a pediatric diabetes clinic to adult care. *Hormone Research in Pediatrics, 67*(3), 132 - 138.

Carroll, A. E., & Marrero, D. G. (2006). The Role of Significant Others in Adolescent Diabetes: A Qualitative Study. *The Diabetes Educator, 32*(2), 243-252. doi:10.1177/0145721706286893

Chick, N., & Meleis, A. (1986). *Transitions: a nursing concern* (P. L. Chinn Ed.). Aspen, Rockville, MD.

Christie, D., Romano, G. M., Thompson, R., Viner, R. M., & Hindmarsh, P. C. (2008). Attitudes to psychological groups in a paediatric and adolescent diabetes service–implications for service delivery. *Pediatric diabetes*, *9*(4pt2), 388-392.

Cohen, J. (1998). *Statistical power analysis for the behavioral sciences*. Hillsdale, NJ: L. Eribaum Associate.

Colhoun, HM. (2009). Use of insulin glargine and cancer incidence in Scotland: a study from the Scottish Diabetes Research Network Epidemiology Group. *Diabetologia, 52*(9), 1755-1765.

Cooley, W.C., Sagerman, P.J. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics, 128,* 182-200. doi:10.1542/peds.2011-0969

Cottenceau, H., Roux, S., Blanc, R., Lenoir, P., Bonnet-Brilhault, F., & Barthélémy, C. (2012). Quality of life of adolescents with autism spectrum disorders: comparison to adolescents with diabetes. *European Child & Adolescent Psychiatry, 21*(5), 289-296. doi: 10.1007/s00787-012-0263-z

Court, JM, Cameron, FJ, Berg-Kelly, K, & Swift, PG. (2009). Diabetes in adolescence. *Pediatric Diabetes, 10*(Suppl 12), 185 - 194.

Crittenden, P. M. (1990). Internal representational models of attachment relationships. *Infant Mental Health Journal, 11*(3), 259-277. doi: 10.1002/1097-0355(199023)11:3<259::AID-IMHJ2280110308>3.0.CO;2-J

Dacey, J., & Travers, J. (1999). *Human Development across the lifespan* (4th ed). Boston: McGraw Hill.

Dahan, A., & McAfee, S. G. (2009). A proposed role for the psychiatrist in the treatment of adolescents with type I diabetes. *Psychiatric quarterly*, *80*(2), 75-85.

De Beaufort, C., Jarosz-Chobot, P., Frank, M., De Bart, J., & Deja, G. (2010). Transition from pediatric to adult diabetes care: smooth or slippery? *Pediatric Diabetes, 11*(1), 24-27. doi: 10.1111/j.1399-5448.2009.00524.x

Debono, M., & Cachia, E. (2007). The impact of diabetes on psychological well being and quality of life. The role of patient education. *Psychology, Health and Medicine*, *12*(5), 545-555.

Democratic Policy Committee (2010). Affordable care act: Detailed summary. Retrived from http://www.dpc.senate.gov/healthreformbill/healthbill95.pdf

DeVries, J.L., Snoek, F.J., Heine, R.J. (2004). Persistant poor glycaemic control in adult type 1 diabetes. A closer look at the problem. *Diabetic Medicine, 21,* 1263-1268.

DeWitt, D. E., & Hirsch, I. B. (2003). Outpatient insulin therapy in type 1 and type 2 diabetes mellitus: scientific review. *Jama*, *289*(17), 2254-2264.

Diabetes Care. (2012). Position Statements. *Diabetes Care*, *35*(1), 1364-1379

DCCT Research Group (1993). Results of Diabetes Control and Complications Trial (DCCT). *Diabetes Care*, 10(1): 1-19.

Eiser, C., Vance, Y.H., Horne, B., Glaser, A., & Galvin, H. (2003). The value of the PedsQLTM in assessing quality of life in survivors of childhood cancer. *Child Care Health Dev, 29*(2), 95-102. doi: 10.1046/j.1365-2214.2003.00318.x

Ellis, D.A., Frey, M.A., Naar-King, S., Templin, T., Cunningham, P. & Cakan, N. (2005). Use of Multisystemic therapy to improve regimen adherence among adolescents with type 1 diabetes in chronic poor metabolic control: A randomized controlled trial. *Diabetes Care, 28*(7), 1604-1610. doi: 10.2337/diacare.28.7.1604

Fitzgerald, J., Funnell, M., Hess, G., Barr, P., Anderson, R., Hiss, R., & Davis, W. (1998). The reliability and validity of a brief diabetes knowledge test. *Diabetes Care, 21*(5), 706-710.

Flume, P.A., Anderson, D.L., Hardy, K.K., & Gray, S. (2001). Transition programs in cystic fibrosis centers: perceptions of pediatric and adult program directors. *Pediatric Pulmonology, 31*(6), 443-450.

Ford, E. S., Giles, W. H., & Dietz, W. H. (2002). Prevalence of the metabolic syndrome among US adults: findings from the third National Health and Nutrition Examination Survey. *Jama*, *287*(3), 356-359.

Fuhrmann, B.S. (1990). *Adolescence, Adolescents.* Glenview, IL: Scott Foresman & Co.

Gimenez-Perez, G., Gallach, M., Acera, E., Prieto, A., Carro, O., Ortega, E., . . . Mauricio, D. (2002). Evaluation of accessibility and use of new communication technologies in patients with type I diabetes mellitus. *Journal of Medical Internet Research, 20*(4). doi: 10.2196/jmir.4.3.e16

Gray, W. N., Denson, L. A., Baldassano, R. N., & Hommel, K. A. (2012). Treatment Adherence in Adolescents With Inflammatory Bowel Disease: The Collective

Impact of Barriers to Adherence and Anxiety/Depressive Symptoms. *Journal of Pediatric Psychology, 37*(3), 282-291. doi: 10.1093/jpepsy/jsr092

Grey, M., Knafl, K., & McCorkle, R. . (2006). A framework for the study of self- and family management of chronic conditions. . *Nursing Outlook, 54*(5), 278–286.

Haas, L., Maryniuk, M., Beck, J., Cox, C. E., Duker, P., Edward, L...., & Youssef, G. (2014). National Standards for diabetes self-management education and support. *Diabetes Care, 37*(Supplement 1), S144-S153.

Hains, A.A., Berlin, K.S., Davies, W.H., Smothers, M.K., & Sato, A.F. (2007). Attributions of adolescents with type I diabetes related to performing self care around friends and peers: the moderating role of friend support. *Journal of Pediatric Psychology, 32*, 561-570.

Harris, M.A., Antal, H., Oelbaum, R., Buckloh, L.M., White, N.H., & Wysocki, T. (2008). Good intentions gone awry: Assessing parental 'miscarried helping" in diabetes. *Families, Systems, & Health, 26*, 393-403.

Harris, M.A., Oelbaum, R., Antal, H., Buckloh, L.M., Sadler, M., & White, N.H. (2007). Miscarried helping in families of youth with diabetes:demographics and diabetes-related profiling. *Diabetes, 56*(A496).

Helgeson, V. S., Reynolds, K. A., Escobar, O., Siminerio, L., & Becker, D. (2007). The role of friendship in the lives of male and female adolescents: does diabetes make a difference? *Journal of Adolescent Health, 40*(1), 36-43.

Heisler, M., Piette, J.D., Spencer, M., Kieffer, E., & Vijan, S. (2005). The relationship between knowledge of recent HbA1c values and diabetes care understanding and self-management. *Diabetes Care, 28*, 816-822.

Hinkle, D., Wiersma, W., & Jurs, S. (2003). *Applied Statistics for the Behavioral Sciences* (5th ed.). New York: Houghton Mifflin.

Hirsch, I. B., & Brownlee, M. (2010). Beyond hemoglobin A1c—need for additional markers of risk for diabetic microvascular complications. *JAMA*, *303*(22), 2291-2292.

Holmes-Walker, DJ, Llewellyn, AC, & Farrell, K. (2007). A transition care programme which improves diabetes control and reduces hospital admission rates in young adults with type 1 diabetes aged 15-25 years. *Diabet Med, 24*(7), 764 - 769.

Holmbeck, G.N.(1996). A model of family relational transformations during the transition to adolescence: parent-adolescent conflict and adaption. In J.A. Graber, J. Brooks-Gunn, A., & A.C. Petersen (Eds.), Transitions through adolescence: Interpersonal domains and context (pp. 167-199). Mahwah, NJ: Erlbaum Press

Hood, K.K., Butler, D.A., Anderson, B.J., & Laffel, L. (2007). Updated and Revised Diabetes Family Conflict Scale. *Diabetes Care, 30*(7), 1764-1769.

Huck, S.W. (2012). *Reading Statistics and Research* (6th ed.). Boston,MA: Pearson Education, Inc.

Hysing, M., Elgen, I., Gillberg, C., & Lundervold, A. J. (2009). Emotional and behavioural problems in subgroups of children with chronic illness: results from a large-scale population study. *Child: Care, Health and Development, 35*(4), 527-533. doi: 10.1111/j.1365-2214.2009.00967.x

Johnson, S., Cooper, M., Jones, T.W., Davis, E.A. (2013). Long-term outcome of insulin pump therapy in children with type 1 diabetes assessed in a large population-based case-control study. *Diabetologia*, *56*(11), 2392-2400.

Jun, H. S., & Yoon, J. W. (2003). A new look at viruses in type 1 diabetes. *Diabetes metabolism research and reviews*, *19*(1), 8-31.

Karnieli-Miller, O., & Eisikovits, Z. . (2009). Physician as partner or salesman? Shared decision-making in real-time encounters. *Social Science & Medicine 69*(1), 1-8.

Kelly, A., Kratz, B., Bielski, M., & Rinehart, P. (2002). Implementing transitions for youth with complex chronic conditions using the medical home model. *Pediatrics, 110*(6), 1322-1377.

Kettunen, T., Liimatainen, L., Villberg, J., & Perko, U. (2006). Developing empowering health counseling measurement: Preliminary results. *Patient education and counseling*, *64*(1), 159-166.

Kipps, S., Bahu, T.,Ong, K., Ackland, F., Brown, R., Fox, C., Griffin, N., Knight, A., Mann, N., Neil, H., Simpson, H., Edge, J., Dunger, D. . (2002). Current methods of transfer of young people with Type 1 diabetes to adult services. *Diabetic Medicine, 19*(8), 649-654. doi: 10.1046/j.1464-5491.2002.00757.x

Knight, S., Northam, E., Cameron, F., & Ambler, G. (2011). Behaviour and metabolic control in children with Type 1 diabetes mellitus on insulin pump therapy: 2-year follow-up. *Diabetic Medicine, 28*(9), 1109-1112.

Koh, H. K. (2010). A 2020 vision for healthy people. *New England Journal of Medicine*, *362*(18), 1653-1656.

Kokkonen, J., & Kokkonen, E. R. (1995). Mental health and social adaptation in young adults with juvenile-onset diabetes. *Nordic Journal of Psychiatry*, *49*(3), 175-182.

Kralik, D., Visentin, K., & Van Loon, A. (2006). Transition: a literature review. *Journal of Advanced Nursing, 55*(3), 320-329. doi: 10.1111/j.1365-2648.2006.03899.x

Kralik, D. (2011). The quest for ordinariness: Transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing* 39(2), 146-154.

Laing, S. P., Swerdlow, A. J., Slater, S. D., Burden, A. C., Morris, A., Waugh, N. R., ... & Patterson, C. C. (2003). Mortality from heart disease in a cohort of 23,000 patients with insulin-treated diabetes. *Diabetologia*, *46*(6), 760-765.

Lenhart, A., Madden, M., & Hitlin, P. (2005) Teens and Technology: Youth are leading the transition to a fully wired and mobile nation. (Washington DC: Pew Internet & American Life Project) Retrieved from http://www.pewinternet.org/pdfs/PIP_Teens_Tech_July2005web.pdf.

Lerner, R.M., Boyd, M.J., & Du, D. (2010). Adolescent development. *Corsini Encyclopedia of Psychology*.

LeVasseur, J. (2002). A phenomenological study of the art of nursing: Experiencing the turn. *Advances in Nursing Science* 24(4), 14-26.

Luyckx, K., Seiffge-Krenke, I., & Hampson, S.E. (2010). Glycemic Control, Coping, and Internalizing and Externalizing Symptoms in Adolescents With Type 1 Diabetes A cross-lagged longitudinal approach. *Diabetes Care, 33*(7), 1424-1429.

Maternal Child Health Bureau (2013). *Child and Adolescent health Measurement Initiative, Data Resource Center on Child and Adolescent Health website.* Retrieved from http://mchb.hrsa.gov/cshcn0910/core/pages/co6/co6tahc.html

McDonough, J.E. (2005). Growing up and moving on: Transition from pediatric to adult care. *Pediatric Transplant, 9*, 364-372.

Meleis, A.I., Sawyer, L., Im, E-O., Hilfinger, M., DeAnne K., Schumacher, K. (2000). Experiencing Transitions: An Emerging Middle Range Theory. *Advances in Nursing Science, 23*(1), 12-28.

Meleis, A. I., & Trangenstein, P. A. (1994). Facilitating transitions: Redefinition of the nursing mission. *Nursing Outlook, 42*(6), 255-259.

Miller, L.V., Goldstein, J., & Nicolaisen, G. (1978). Evaluation fo patients' knowledge of diabetes self-care. *Diabetes Care, 1*, 275-280.

Modi, A., Pai, A.L., Hommel, K., Hood, K.K., Cortina, S., Hilliard, M.E.,...Drotar, D. (2012). Pediatric self-management: A framework for research, practice, and policy. *Pediatrics, 129,* 473-485. doi: 10.1042/peds.20111635

Munhoz-Santos, F.R., Bernardo, V., Gabbay, M., Dib, S., & Sigulem, D. (2013). The impact of knowledge about diabetes resilience and depression on glycemic control: A cross sectional study among adolescents and young adults with type I diabetes. *Diabetology & Metabolic Syndrome, 5*(55).

Olsen, R., & Sutton, J. (1998). More hassle, more alone: Adolescents with diabetes and the role of formal and informal support. *Child: Care, Health, and Development 24*(1), 31-39.

Owen, P., & Beskine, D. (2008). Factors affecting transition of young people with diabetes. *Paediatric Nursing, 20*(7), 33-38. doi: 10.7748/paed2008.09.20.7.33.c6706

Pai, A., & Ostendorf, H. . (2011). Treatment Adherence in Adolescents and Young Adults Affected by Chronic Illness During the Health Care Transition From

Pediatric to Adult Health Care: A Literature Review. *Children's Health Care, 40*(1), 16-33. doi: 10.1080/02739615.2011.537934

Pacaud, D., Yale, J.F., Stephure, D., Trussell, R., & Dele, D.H. (2005). Problems in transition from pediatric care to adult care for individuals with diabetes. *Canadian Journal of Diabetes, 29*(1), 13-18.

Peters, A., Laffel, L. (2011). Diabetes Care for Emerging Adults: Recommendations for Transition From Pediatric to Adult Diabetes Care Systems: the American Diabetes Association Transitions Working Group. *Diabetes Care, 34*(11), 2477-2485.

Phillips, P., & Phillipov, G. (2005). A1C-Frequently asked questions. *Australian Family Physician, 34*, 663-667.

Polit, D. (2010). *Statistics and data analysis for nursing research* (2nd Ed.). San Francisco: Pearson.

Polit, D., & Beck, C. (2012). *Nursing Research: Generating and Assessing Evidence for Nursing Practice* (Ninth Ed.). Philadelphia: Wolters Kluwer/Lippincott Williams & Wilkins.

Polonsky, W. , Fisher, L., Earles, J., Lees, J., Mullan, J., & Jackson, R. (2005). Assessing Psychosocial Distress in Diabetes. *Diabetes Care, 28*(3), 626-631.

Rasmussen, B., Wellard, S., & Nankervis, A. (2001). Consumer issues in navigating health care services for type I diabetes. *Journal of Clinical Nursing, 10*(5), 628-634. doi: 10.1046/j.1365-2702.2001.00550.x

Ravert, R., Hancock, M.D., & Ingersol, G.M. (2004). Online forum messages posted by adolescents with type I diabetes. *Diabetes Educator, 30*(5). doi:

10.1177/014572170403000518

Redman, B. (2003). *Measurement Tools in Patient Education* (2nd ed.). New York: Springer Publishing Company.

Reiss, J.R., & Gibson, R.W. (2002). Health Care Transition: Destinations Unknown. *Pediatrics, 110*(6), 1307.

Reiss, J.R., Gibson, R.W., & Walker, L.R. (2005). Health Care Transition: Youth, family, and provider perspectives. *Pediatrics, 115*, 112-120.

Ridosch, M., Braun, P.,Roux, G., Bellin, M., Sawin, K. (2011). Transition in young adults with spina bifida: a qualitative study. *Child: Care, Health, and Development, 37,* 866-874.

Rosen, D.S., Blum, R.W., Britto, M., Sawyer, S.M., Siegel, D.M. (2003). Transition to adult health care for adolescents and young adults with chronic conditions: Position paper of the society for adolescent medicine. *Journal of Adolescent Health, 33*(4), 309 - 311.

Sandelowski, M. . (2000). Focus on research methods-whatever happened to qualitative description? *Research in Nursing and Health, 23*(4), 334-340.

Sawin, K.J., Bellin, M.H. , Roux, G. , Buran, C.F. , & Brei, T.J. (2009). The Experience of Self-Management in Adolescent Women with Spina Bifida. *Rehabilitation Nursing 34*(1), 26-38.

Scal, Peter. (2002). Transition for Youth With Chronic Conditions: Primary Care Physicians' Approaches. *Pediatrics, 110*(Supplement 3), 1315-1321.

Scal, P., Horvath, K., & Garwick, A. (2009). Preparing for adulthood: health care transition counseling for youth with arthritis. *Arthritis Care & Research, 61*(1), 52-57.

Schumacher, KL, & Meleis, AI. (1994). Transitions: A central concept in nursing. *Image Journal of Nursing Scholarship, 26*, 119-127.

Shadish, W., Cook, T., & Campbell, D. (2002). *Experimental and Quasi-Experimental Designs for Generalized Causal Inference*. Belmont, CA.: Wadsworth Cengage Learning.

Shalitin, S., Gil, M., Nimri, R., De Vries, L., Gavan, M. Y., & Phillip, M. (2010). Predictors of glycaemic control in patients with Type 1 diabetes commencing continuous subcutaneous insulin infusion therapy. *Diabetic Medicine*, *27*(3), 339-347.

Shalitin, S., & Phillip, M. (2007). The role of new technologies in treating children and adolescents with type 1 diabetes mellitus. *Pediatric diabetes*, *8*(s6), 72-79.

Sheehy, G. (1977). *Passages Predictable : Crisis of Adult Life*. Toronto: Bantam Books.

Simoni, R.D., Hill, R.L., & Vaughan, M. (2002). The discovery of insulin: the work of Frederick Banting and Charles Best. *Journal of Biological Chemistry, 277*(26), e15-e15.

Skinner, H., Biscope, S., Poland, B., & E., Goldberg. (2003). How adolescents use technology for health information: Implications for health professionals from focus groups studies. *Journal of Medical Internet Research, 18*(5).

Stratton, I., Adler, A., & Neil, A. (2000). Association of glycemia with macrovascular and microvascular complications of type 2 diabetes: Prospective observational study. *British Medical Journal, 321*, 405-412.

Tang, T. S., Gillard, M-L., Funnell, M. M., Nwankwo, R., Parker, E., Spurlock, D., & Anderson, R. M. (2005). Developing a New Generation of Ongoing Diabetes Self-management Support Interventions: A Preliminary Report. *The Diabetes Educator, 31*(1), 91-97. doi: 10.1177/0145721704273231

Tuchman, L. K., Slap, G. B., & Britto, M. T. (2008). Transition to adult care: experiences and expectations of adolescents with a chronic illness. *Child: Care, Health & Development, 34*(5), 557-563.

United States Department of Health and Human Services, & Office of Disease Prevention and Health Promotion. (2012). Healthy People 2020. Washington, DC.

Van Gennep, A. (1960). *The Rites of Passage*. London: Routledge and Kegan Paul.

Van Walleghem, N., MacDonald, C.A., & Dean, H. J. (2011). The Maestro Project: A Patient Navigator for the Transition of Care for Youth With Type 1 Diabetes. *Diabetes Spectrum, 24*(1), 9-13. doi: 10.2337/diaspect.24.1.9

Vervloet, M., van Dijk, L., Santen-Reestman, J., van Vlijmen, B., Bouvy, M., & de Bakker, D. (2011). Improving medication adherence in diabetes type 2 patients through Real Time Medication Monitoring: a Randomised Controlled Trial to evaluate the effect of monitoring patients' medication use combined with short message service (SMS) reminders. *BMC Health Services Research, 11*(1), 5.

Viklund, G., Ortqvist, E., & Wikblad, K. . (2007). Assessment of an empowerment education programme. A randomized study in teenagers with diabetes. . *Diabetic Medicine 24*(May), 550-556.

Viner, R.M. (2008). Transition of care from pediatric to adult care services: one part of improved health services for adolescents. *Archives of Disease in Childhood, 93*, 160-163.

Voulgari, C., Psallas, M., Kokkinos, A., Argiana, V., Katsilambros, N., & Tentolouris, N. (2011). The association between cardiac autonomic neuropathy with metabolic and other factors in subjects with type 1 and type 2 diabetes. *Journal of Diabetes and its Complications*, *25*(3), 159-167.

Weinzimer, S. A., Ahern, J. H., Doyle, E. A., Vincent, M. R., Dziura, J., Steffen, A. T., & Tamborlane, W. V. (2004). Persistence of benefits of continuous subcutaneous insulin infusion in very young children with type 1 diabetes: a follow-up report. *Pediatrics*, *114*(6), 1601-1605.

Weissberg-Benchell, J., Nansel, T., Holmbeck, G., Chen,R., Anderson, B., Wysocki, T., & Laffel, L. (2009). Generic and diabetes-specific parent-child behaviors and quality of life among youth with type I diabetes. *Journal of Pediatric Psychology*, *34*(9), 977-988.

Williams, R., Freedman, & Edward, L. (1998). Supporting autonomy to motivate patients with diabetes for glucose control. *Diabetes Care, 21*, 1644-1651.

Wdowik, Melissa J, Kendall, Patricia A, Harris, Mary A, & Auld, Garry. (2001). Expanded health belief model predicts diabetes self-management in college students. *Journal of Nutrition Education, 33*(1), 17-23.

Appendix A

IRB Waiver

12008C
Initial Approval

Rady Children's
Hospital
San Diego

Office for Human Subjects Protection
3020 Children's Way, MC 5074
San Diego, CA 92123
(858) 966-4008
(858) 499-0248 - fax

June 28, 2012

Cynthia Connelly, PhD
c/o Kathy Marsh, MSN, RN
5998 Alcala Park
Hahn School of Nursing
San Diego, CA 92110

Re: Study number 12008C (2480): Transitioning to adult care: The use of health care advocates to improve glycemic control in teenagers with Type I diabetes mellitus

Dear Dr. Connelly,

The above referenced study was re-reviewed at the May 17, 2012 meeting of the Rady Children's Hospital Institutional Review Board, in accordance with the requirements of the Code of Federal Regulations on the Protection of Human Subjects (45 CFR 46 and 21 CFR 50 and 56), including its relevant Subparts. Your study was determined to meet the criteria set forth in 45 CFR 46.404, research not involving greater than minimal risk.

This letter serves as notice that this new study request has been approved based upon the response and revisions you submitted. The regulations require that continuing or final review be conducted and approved on or before the study's expiration date of **May 16, 2013**, even though the activity may not begin until some time after the IRB has given approval. Please submit requests for continuing review at least 30 days prior to the expiration date. If the project is completed by the expiration date, please submit a final report to the IRB.

You must use the enclosed approved parent permission form, consent form, and adolescent assent form with the IRB approval stamp. The parent or legal guardian of each minor subject must sign the parent permission form, and the minor subject must sign the adolescent assent form, or the adult subjects must sign the consent form, before ANY research activity begins, be given a copy of the form, and Subject Bill of Rights. The parent/legal guardian or adult subject must also sign the IRB approved HIPAA authorization form at the time of enrollment.

A waiver of consent, permission and assent in accordance with 45 CFR 46.408 and 45 CFR 46.116(d) and a waiver of HIPAA authorization in accordance with 45 CFR 164.512(i) has been granted for phase 1, the retrospective review portion of the study. The PHI for which use was determined necessary includes patient name, medical record number, date of birth, date of service, date of diagnosis, lab results, pre and post questionnaire results from patients see between January 2011 through April 4, 2012.

The IRB must be notified and review all recruitment materials, including advertisements, serious adverse events, amendments or changes in the protocol, protocol violations, patient deaths, or termination of the study. You may not implement the changes until you have received the Board's approval. However, changes involving patient safety may be implemented prior to approval by the IRB, if necessary.

12008C
Initial Approval
06/28/2012
Page 2 of 2

Please be aware that while you have IRB approval, you may not start your project until you have completed the administrative approval process and have been issued a Ready to Accrue letter by Research Administration.

Please contact the Office for Human Subjects Protection at (858) 966-4008 if you have any questions or require further information.

On behalf of the RCHSD Institutional Review Board,

Anthony Magit, MD, MPH
Chair, Institutional Review Board
Rady Children's Hospital – San Diego

Appendix B

Human Subjects Training

SDSU Human Subjects Tutorial
Certificate of Completion

This certifies that Kathy Marsh
has demonstrated compliance with
SDSU training in the ethical and regulatory
issues associated with the protection
of human subjects in research.

Date of Certification : *Tuesday, January 3, 2012*
Expires : *Friday, January 3, 2014*

Please keep this certificate in your records so that you may verify completion of training.
You may print this certificate by right clicking anywhere on the page and selecting print from the menu that appears. You will probably find it best to print the certificate as landscape.

Appendix C

SMILE Program Evaluation

Please circle one: Parent Teen Healthcare Advocate

1. Why did you participate in the SMILE program?

2. Name at least three things you learned which have changed how you manage diabetes after being in the SMILE program?

3. What did you like about the SMILE program?

4. What do you think would make the SMILE program better?

5. Any other thoughts or suggestions?

Appendix D

Diabetes Knowledge Test

ID #: ____________________

Date: ____________________

Michigan Diabetes Research and Training Center

1. The diabetes diet is:
    - a) The way most people eat
    - b) A healthy diet for most people *
    - c) Too high in carbohydrate for most people
    - d) Too high in protein for most people

2. Which of the following is highest in carbohydrate?
    - a. Baked Chicken
    - b. Swiss Cheese
    - c. Baked Potato *
    - d. Peanut Butter

3. Which of the following is highest in fat?
    - a) Low fat milk *
    - b) Orange juice
    - c) Corn
    - d) Honey

4. Which of the following is a "free food"?
    - a) Any unsweetened food
    - b) Any dietetic food
    - c) Any food that says "sugar free" on the label
    - d) Any food that has less than 20 calories per serving *

5. Glycosylated hemoglobin (hemoglobin A1) is a test that is a measure of your average blood glucose level for the past:
    - a) Day
    - b) Week
    - c) 6-10 weeks *
    - d) 6 months

6. Which is the best method for testing blood glucose?
   a) Urine testing
   b) Blood testing *
   c) Both are equally good

7. What effect does *unsweetened* fruit juice have on blood glucose?
   a) Lowers it
   b) Raises it *
   c) Has no effect

8. Which should not be used to treat low blood glucose?
   a) 3 hard candies
   b) ½ cup orange juice
   c) 1 cup diet soft drink *
   d) 1 cup skim milk

9. For a person in good control, what effect does exercise have on blood glucose?
   a) Lowers it *
   b) Raises it
   c) Has no effect

10. Infection is likely to cause:
    a) An increase in blood glucose *
    b) A decrease in blood glucose
    c) No change in blood glucose

11. The best way to take care of your feet is to:
    a) Look at and wash them each day *
    b) Massage them with alcohol each day
    c) Soak them for one hour each day
    d) Buy shoes a size larger than usual

12. Eating foods lower in fat decreases your risk for:
    a) Nerve disease
    b) Kidney disease
    c) Heart disease *
    d) Eye disease

13. Numbness and tingling may be symptoms of:
    a) Kidney disease

  b) Nerve disease *
  c) Eye disease
  d) Liver disease

14. Which of the following is usually not associated with diabetes:
  a) Vision problems
  b) Kidney problems
  c) Nerve problems
  d) Lung problems *

15. Signs of ketoacidosis include:
  a) Shakiness
  b) Sweating
  c) Vomiting *
  d) Low blood sugar

16. If you are sick with the flu, which of the following changes should you make?
  a) Take less insulin
  b) Drink less liquids
  c) Eat more proteins
  d) Test for glucose and ketones more often *

17. If you have taken intermediate-acting insulin (NPH or Lente), you are most likely to have an insulin reaction in:
  a) 1-3 hours
  b) 6-12 hours *
  c) 12-15 hours
  d) More than 15 hours

18. You realize just before lunch time that you forgot to take your insulin before breakfast. What should you do now?
  a) Skip lunch to lower your blood glucose
  b) Take the insulin that you usually take at breakfast
  c) Take twice as much insulin as you usually take at breakfast
  d) Check your blood glucose level to decide how much insulin to take *

19. If you are beginning to have an insulin reaction, you should:
  a) Exercise
  b) Lie down and rest
  c) Drink some juice *

   d) Take regular insulin

20. Low blood glucose may be caused by:
    a) Too much insulin *
    b) Too little insulin
    c) Too much food
    d) Too little exercise

21. If you take your morning insulin but skip breakfast your blood glucose level will usually:
    a) Increase
    b) Decrease *
    c) Remain the same

22. High blood glucose may be caused by:
    a) Not enough insulin *
    b) Skipping meals
    c) Delaying your snack
    d) Large ketones in your urine

23. Which of the following will most likely cause an insulin reaction?
    a) Heavy exercise *
    b) Infection
    c) Overeating
    d) Not taking your insulin

*Correct answer

From Redman, B. (2003). *Measurement Tools in Patient Education* (2nd ed.). New York: Springer Publishing Company.

Appendix E

Diabetes Distress Scale

DIRECTIONS: Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 17 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 17 items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number.

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, not whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle "1". If it is very bothersome to you, you might circle "6".

	Not a problem	**A Slight Problem**	**A Moderate Problem**	**Somewhat Serious Problem**	**A Serious Problem**	**A Very Serious Problem**
1. Feeling that diabetes is taking up too much of my mental and physical energy every day.	1	2	3	4	5	6
2. Feeling that my doctor doesn't know enough about diabetes and diabetes care.	1	2	3	4	5	6
3. Feeling angry, scared, and/or depressed when I think about living with diabetes.	1	2	3	4	5	6
4. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.	1	2	3	4	5	6
5. Feeling that I am not testing my blood sugars frequently enough.	1	2	3	4	5	6
6. Feeling that I am often failing with my diabetes routine.	1	2	3	4	5	6
7. Feeling that friends or family are not supportive enough of self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods)	1	2	3	4	5	6
8 Feeling that diabetes controls my life.	1	2	3	4	5	6

9. Feeling that my doctor doesn't take my concerns seriously enough.	1	2	3	4	5	6
10. Not feeling confident in my day-to-day ability to manage diabetes.	1	2	3	4	5	6
11. Feeling that I will end up with serious long-term complications, no matter what I do.	1	2	3	4	5	6
12. Feeling that I am not sticking close enough to a good meal plan.	1	2	3	4	5	6
13. Feeling that friends or family don't appreciate how difficult living with diabetes can be.	1	2	3	4	5	6
14. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
15. Feeling that I don't have a doctor who I can see regularly enough about my diabetes.	1	2	3	4	5	6
16. Not feeling motivated to keep up my diabetes management.	1	2	3	4	5	6
17. Feeling that friends or family don't give me the emotional support that I would like.	1	2	3	4	5	6

DDS17 SCORING SHEET

Instructions for Scoring:

The DDS17 yields a total diabetes scale score plus 4 sub scale scores, each addressing a different kind of distress. To score, simply sum the patient's responses to the appropriate items and divide by the number of items in that scale. The letter in the far right margin corresponds to that item's subscale as listed below. **We consider a mean item score of 3 or higher (moderate distress) as a level of distress worthy of clinical attention.** Place a check on the line to the far right if the mean item score is ≥ 3 to highlight an above-range value.

We also suggest reviewing the patient's responses across all items, regardless of mean item scores. It may be helpful to inquire further or to begin a conversation about any single item scored 3 or higher.

Total DDS Score:

a. Sum of 17 item scores. __________
b. Divide by: 17
c. Mean item score: __________ ≥3 _____

A. Emotional Burden:

a. Sum of 5 items (1,3,8,11,14) __________
b. Divide by: 5
c. Mean item score: __________ ≥3 _____

B. Physician-Related Distress:

a. Sum of 4 items (2,4,9,15) __________
b. Divide by: 4
c. Mean item score: __________ ≥ 3 _____

C. Regimen-related Distress:

a. Sum of 5 items (5,6,10,12,16) __________
b. Divide by: 5
c. Mean item score: __________ ≥ 3 _____

D. Interpersonal Distress:

a. Sum of 3 items (7,13,17) __________
b. Divide by: 3
c. Mean item score: __________ ≥ 3 _____

Fisher, L., Hessler, D.M., Polonsky, W. H., & Mullan, J. (2012). When Is Diabetes Distress Clinically Meaningful?: Establishing cut points for the Diabetes Distress Scale. *Diabetes Care, 35*(2), 259-264. doi: 10.2337/dc11-1572

Appendix F

SMILE Study Timeline

Measure	Visit #1	Visit # 2	Visit # 3	Visit # 4	Visit # 5
		2 weeks after visit # 1			Closure visit
	Weeks 1 - 2	**Weeks 3 - 4**	**Weeks 8-10**	**Weeks 10-12**	**Weeks 14 - 16**
Routine clinic visit with NP	X	X			X
Review study requirements with NP	X				
Teenager to sign assent	X				
Parent to sign consent	X				
Introduced to HCA, exchange contact info with HCA	X				
Teen & Parent to complete questionnaires (approximately 20 min.)	X				X
Schedule home visit with HCA		X	X		
Clinic Visit- Review educational module (teen & HCA)		X			
Home visit Review educational module (teen & HCA)			X	X	
Weekly texting between teen & HCA	X	X	X	X	X
HCA to email visit summary to NP & PI			X	X	