COMPLIANCE AND SELF-CARE IN ADOLESCENTS WITH TYPE I DIABETES

A RESEARCH PAPER SUBMITTED TO THE GRADUATE SCHOOL IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE MASTERS OF SCIENCE

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Abstract

RESEARCH SUBJECT: Compliance and Self-Care in Adolescents with Type I Diabetes

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Type I diabetes is a chronic illness that can lead to serious health related complications. Adolescents with type I diabetes must learn and comply with an accurate health management program to maintain good glycemic control to avoid diabetes-related complications. The purpose of this study is to describe the factors that predict compliance among adolescents with type I diabetes. This is a modified replication of Kyngas and Rissanen’s (2001) study. The framework is based on the Theoretical Model of Compliance of Adolescents with Diabetes (Kyngas, 1999). The sample will consist of 1,000 adolescents between the ages of 13 and 17 years who have a scheduled routine visit at the St. Vincent Pediatric Diabetes Clinic at Peyton Manning Children’s Hospital. A 58 item questionnaire formulated from the theoretical model of compliance will be used to measure the following: compliance; sense of normality; support from nurses, physicians, parents and friends; energy and willpower; motivation; subjective experience of results; impact of disease, attitude; fear of complications and hypoglycemia. There will also be 12 questions that pertain to background variables. Identifying factors that predict compliance with self-care will assist health care providers in transition planning for adolescents.
Chapter I

Introduction

Diabetes is a chronic illness affecting approximately 23.6 million people in the United States (American Diabetes Association, 2009). Approximately 5.7 million people are undiagnosed and unaware of having the disease, placing them at higher risk of complications (American Diabetes Association, 2009). In the population 20 years and older, 1.6 million new cases of diabetes were diagnosed in 2007 and about one in every 400 to 600 children and adolescents has type I diabetes (American Diabetes Association, 2009). Diabetes is the 7th leading cause of death in the United States (Diabetes Educator, 2009).

According to Scanlon and Sanders (2007), diabetes is the hyposcretion of insulin by the pancreas and/or the inability of insulin to exert its affects. This results in a state of hyperglycemia, increased levels of blood glucose. Excess glucose is lost through the urine (glycosuria) causing increased urine output (polyuria) and thirst (polydipsia). Additional signs and symptoms include nausea, weight loss, abdominal pain, fatigue, and blurred vision (McCann, 2006). These symptoms of hyperglycemia indicate that glucose is not moving from the blood into tissues and cells (Neighbors & Tannehill-Jones, 2006). If left untreated, or not controlled adequately, complications will arise.
Diabetes is a devastating disease associated with long-term and short-term complications. Short-term complications include hypoglycemic reactions (insulin shock) which can quickly progress to death without immediate intervention. Ketoacidosis is another short-term complication however it is associated with untreated hyperglycemia. Fats and proteins are converted to ketones for energy and acetone becomes a waste product (Neighbors & Tannehill-Jones, 2006). The pH of the blood will begin to decrease, kidneys will excrete ketones, and the individual will have a sweet “fruity” smelling breath. This state of diabetic ketoacidosis will lead to coma and death without timely intervention (Scanlon & Sanders, 2007).

The long-term complications associated with diabetes can be fatal or greatly decrease the quality of life. Long-term complications are associated with uncontrolled hyperglycemia. This leads to vascular changes that thicken capillary walls, reduce gas exchange, and diminish nutrient absorption. Organs most greatly affected include the skin of the feet, the retina, and the kidneys (Scanlon & Sanders, 2007). The individual is then at higher risk for poor wound healing, kidney failure, and atherosclerosis. Atherosclerosis can then lead to myocardial infarction, stroke, and peripheral vascular disease (Neighbors & Tannehill-Jones, 2006).

According to the American Diabetes Association (2009), heart disease and stroke account for 65% of deaths in people with diabetes and 73% of adults with diabetes have high blood pressure. Diabetes was the leading cause of kidney failure in 2005 and good blood glucose control reduced risk of kidney damage by 35% to 56% (American Diabetes
Association, 2009). The American Diabetes Association (2009) also found diabetes to be the leading cause of new cases of blindness in people 20 to 74 years of age.

Diabetes requires life long commitment to a specialized self-care regimen to reduce risk of complications associated with the disease. Good glycemic control has been shown to decrease risk of complications. The disease impacts many aspects of daily life due to the constant decision making needed for optimal blood glucose control (Hernandez & Williamson, 2004). Individuals diagnosed with diabetes must comprehend a large amount of information, make immediate lifestyle changes, and comply with a self-care regimen. Compliance with a self-care regimen is imperative since it has been claimed that 98% of diabetes management is self-care (Toljamo & Hentinen, 2001). There are many social, environmental, and personal factors that can enhance or inhibit an individual’s ability to remain compliant. Adolescence presents a growth and development period in which compliance with self-care can be particularly challenging.

**Background and Significance**

Diabetes is a chronic disease of the endocrine system. The islets of Langerhans are the hormone producing cells of the pancreas. In a functioning system, the alpha cells produce glucagon and the beta cells produce insulin (Scanlon and Sanders, 2007). When an individual eats carbohydrates or sugars, the amount not used for immediate energy is stored in the liver as glycogen (Neighbors & Tannehill-Jones, 2006). Glucagon stimulates the liver to change glycogen to glucose, raising blood glucose levels for energy production. Insulin increases transport of glucose from blood into cells by increasing permeability of cell membranes to glucose. Insulin also enables cells to take in fatty
acids and amino acids to use in the synthesis of lipids and proteins (Scanlon & Sanders, 2007).

Individuals diagnosed with diabetes have a lack of insulin production and/or decrease in insulin sensitivity. Diabetes has three general classifications that are recognized including: type I, type II, and gestational diabetes (McCann, 2006). Type I diabetes usually is diagnosed in children or young adults and accounts for 5% to 10% of all diagnosed cases of diabetes (American Diabetes Association, 2009). Type I diabetes is characterized by a destruction of beta cells and eventual complete lack of insulin production. It is an autoimmune response that perhaps is triggered by a virus. Onset is typically abrupt and insulin by injection is essential for life. There is no known way to prevent type I diabetes, however individuals are believed to be genetically predisposed if they have siblings or parents diagnosed with the disease (Scanlon & Sanders, 2007).

Individuals with type II diabetes can have impaired insulin production, inappropriate hepatic glucose production, or peripheral insulin receptor insensitivity (McCann, 2006). Type II diabetes is typically found in individuals who are overweight or have a family history. Treatment can be diet management and exercise, however if not effective, oral medications can be given that enable receptors to react with insulin more readily (Scanlon & Sanders, 2007).

Gestational diabetes is marked by glucose intolerance during pregnancy in a woman not previously diagnosed with diabetes. This may occur due to placental hormones counteracting insulin causing insulin resistance (McCann, 2006). This is more common in obese women or women with a family history of diabetes. After pregnancy, 5%-10%
are found to have type II diabetes and 40% to 60% of women with gestational diabetes will develop diabetes in the next 5 to 10 years (American Diabetes Association, 2009).

Diabetes is a life long illness that demands continuing medical care, education, and self-care to prevent acute complications and reduce the risk of long-term complications. Self-care is complex and requires many issues be addressed. Adolescents differ from adults with diabetes in many aspects. Adolescents have a change in insulin sensitivity related to sexual maturity and growth, they are gaining independence in their ability to provide self-care, and they have a unique neurologic vulnerability to hypoglycemia and diabetic ketoacidosis (American Diabetes Association, 2009).

Adolescents with diabetes also face the risk of acute and long-term complications. The American Heart Association categorizes children with type I diabetes in the highest tier for cardiovascular risk (American Diabetes Association, 2009). Retinopathy, microalbuminuria, and hypercholesterolemia are additional complications. Adolescents diagnosed with type I diabetes are also at a higher risk of developing other autoimmune diseases such as celiac disease and hypothyroidism. Hypothyroidism is the most common autoimmune disorder associated with diabetes (American Diabetes Association, 2009).

Self-care has been found to reduce a person’s chances of serious complications by 8% and chances of dying of complications by 2.3% (Diabetes Educator, 2009). Self-care behaviors that are essential for improved health include healthy eating, monitoring blood glucose levels regularly, routinely administering insulin, and exercising regularly (Neighbors & Tannehill-Jones, 2006). Health care providers must be able to evaluate the
behavioral, emotional, and psychosocial factors that interfere with compliance to self-care regimen. No matter how sound the medical regimen prescribed, it is only as good as the adolescent’s ability to comply with it (American Diabetes Association, 2009). This study is significant because it will describe factors that predict compliance in adolescents diagnosed with type I diabetes.

Problem Statement

According to Kyngas and Rissanen (2001) adolescents with type I diabetes have many difficulties complying with self-care regimens. They report approximately 50% of adolescents do not comply with the care recommendations. Compliance with self-care regimens is needed to reduce the risk of acute and long-term complications associated with uncontrolled blood glucose levels. There is a need for further research about the predictors of compliance among adolescents with type I diabetes. This study is a modified replication of the Kyngas and Rissanen (2001) study that described the factors that predict compliance among adolescents with a chronic illness.

Statement of Purpose

The purpose of this study is to examine the predictive relationship of internal and external factors and compliance with self-care among adolescents with type I diabetes.

Research Question

The study will seek to answer the research question: What factors predict the compliance of adolescents with type I diabetes?
Theoretical Framework

The study will use the Theoretical Model of Compliance of Adolescents with Diabetes (Kyngas, 1999) as a framework. The model was developed through a study conducted by Helvi Kyngas in 1999. The findings of the study were used to develop a theoretical model of compliance in young diabetics. It provides information about compliance and factors connected to it. According to the model, compliance is an active decision that the adolescent intentionally makes to work with health care personnel to improve or maintain their health (Kyngas, 1999). Factors that improve compliance are motivation, results of care, a sense of normality and adequate energy and will-power for care. Motivation is improved by support and encouragement by parents and influences energy and will-power for care. Energy and will-power for care then in turn increase through the support of parents, encouragement, and results of care. Lack of fear of complications increases energy and willpower. However, some fear improves compliance (Kyngas, 1999, p. 73). The model can be used to plan and implement care, as a framework for further research, or in development of an instrument to measure compliance and factors related to it. The model will be used in this study for instrument development and as a framework for research to identify factors that predict compliance in adolescents with diabetes.

Definition of Terms: Conceptual Definitions

Self-care Compliance: Self-care includes taking responsibility for own care, carrying out medical treatment, following recommended lifestyle, and visiting the doctor or nurse regularly.
“Compliance is the active, intentional and responsible process of care, in which the individual works to maintain his or her health in close collaboration with the health care personnel” (Kyngas, 1999, p. 73). The adolescent does not simply follow a medical regimen that is prescribed, but is actively involved in the planning and is committed to the care that is needed.

Internal factors: Internal factors are factors associated with age and adolescents themselves. This includes sense of normality, energy and willpower, motivation, subjective experience of results, impact of disease, fear of complications and hypoglycemia. Adolescents with diabetes can feel fear, guilt, shame, depression, and anxiety. They can feel that they are different and forced to live socially more restricted lives than their peers (Kyngas, 1999).

External factors: External factors are connected to the social environment. These include support from the physician and nurses, friends, and parents (Kyngas, 1999). The social setting has a great impact on how the adolescent experiences their illness and carries out treatment.

Definition of Terms: Operational Definitions

Self-care compliance: A 58 item questionnaire developed from the Theoretical Model of Compliance of Adolescents with Diabetes by Helvi Kyngas (1999). The questionnaire is formatted using a five-point Likert scale ranging from ‘definite agreement’ through ‘indecision’ to ‘definite disagreement’. Specific questions are formulated from the model to measure compliance and related factors. Items specific to compliance include questions pertaining to following medical treatment, not following medical treatment due
to side effects, taking responsibility for own care, following recommended life-style, and visiting the doctor or nurse regularly (Kyngas, 1999).

Internal factors: The Theoretical Model of Compliance of Adolescents with Diabetes Questionnaire will measure internal factors. Questions will ask if caring for the disease is a natural part of daily living, prevents normal life similar to that of others, limits everyday life, or limits independence. Questions concerning how much energy and willpower to care for self will be included as well as motivation to complete care. Impact of the disease also is measured by asking questions pertaining to fear of complications, social isolation, and hypoglycemia (Kyngas, 1999).

External factors: External factors are measured using the Theoretical Model of Compliance of Adolescents with Diabetes Questionnaire. Items include questions pertaining to parents, physicians, nurses, and friends’ acceptance of the way the adolescent performs self care and supports the adolescent’s decisions. Items also include questions about showing genuine interest, offering reminders to carry out treatment, and offering motivation to continue self-care (Kyngas, 1999).

Limitations

This study will have limitations due to the sample size and the selection from a single setting in the Midwest. Overestimation of self-care compliance can occur due to inaccurate reporting on the questionnaire due to the tendency to give socially desirable answers.
Assumptions

This study replication will be grounded by the following assumptions:

1. Improved self-care by adolescents with diabetes is desirable.
2. Self-care is essential part of diabetes management.
3. Self-care improves glycemic control.
4. Improved glycemic control prevents complications of diabetes.

Summary

Adolescence is a time of gaining independence and the life style required by the treatment of diabetes may differ from the life-style of their peers. Many social and internal factors impact the ability of the adolescent to comply with self-care. Previous studies have reported factors associated with compliance of adolescents with diabetes. The purpose of this study is to identify internal and external factors that predict compliance of adolescents with diabetes. This will be a modified replication of Kyngas and Rissanen’s (2001) study. The Theoretical Model of Compliance of Adolescents with Diabetes will be utilized to provide a framework which can measure compliance and internal and external factors affecting compliance in adolescence.
Chapter II

Review of Literature and Research Evidence

Introduction

Adolescents with diabetes require a high-level of self-care to optimize glycemic control, prevent complications, and have a high quality of life (Kulkarni, 2006). During adolescence, young diabetics are learning to care for themselves and take responsibility for management of their disease. However, research continues to show a decrease in metabolic control in this age-group (Hains, Berlin, Davies, Parton, & Alemzadeh, 2006). Family support, peer relationships, and the quality of interaction between the adolescent and health care provider have been shown to be crucial factors in the compliance of adolescents with chronic diseases (Kyngas, 2000). These factors do not however, predict good compliance to assist adolescents in planning their health care regimen. The purpose of this study is to identify predictors of good compliance among adolescents with diabetes. This is a modified replication of Kyngas and Rissanen’s (2001) study.

Organization of Literature

The following literature review consists of selected studies related to self-care of adolescents with type I diabetes. The literature is organized into four sections. The first
section will discuss the Theoretical Model of Compliance of Adolescents with Diabetes (Kyngas, 1999) which provides the theoretical framework for the study. Section two discusses education effects on self-care practices, section three examines treatment intervention effects on self-care, and section four identifies adolescents’ perceptions of self-care practices.

**Theoretical Framework**

The Theoretical Model of Compliance of Adolescents with Diabetes (Kyngas, 1999) is used as the framework for this study. Compliance is an internal process that is influenced by numerous internal and external factors. The evaluation of compliance has been difficult due to multiple definitions associated with it and the difficulty in obtaining reliable information. Kyngas defines compliance as “an active, intentional and responsible process in which young diabetics work to maintain their health in collaboration with health care staff” (Kyngas, 1999, p. 74). Interviewing and questionnaires can be used to evaluate compliance. Metabolic control is used as a criterion for compliance and is measured using hemoglobin A1C levels (Kyngas, 1999).

According to the Theoretical Model of Compliance of Adolescents with Diabetes (Kyngas, 1999), internal factors that impact compliance include the youth’s attitude, impression of the illness, feelings of the rationality of treatment, and emotions caused by the illness and its treatment. Kyngas measured these by sense of normality, energy and willpower, motivation, subjective experience of results, impact of disease, fear of complications, and fear of hypoglycemia. As the responsibility of disease management is transferred from the parent to the adolescent, conflict may occur which may promote
non-compliance. The changes that the adolescent experiences socially, physically, and emotionally compound the internal factors that impact compliance.

External factors that impact compliance according to Kyngas’s (1999) model are associated with the social setting. This includes support from family, friends, and health care staff. Treatment arrangement and guidance interventions were also considered external factors. Support versus conflict between the adolescent and family and/or friends significantly impacts compliance. This is true of the relationship with health care staff as well.

According to Kyngas’s (1999) Theoretical Model of Compliance of Adolescents with Diabetes, the internal and external factors integrate to significantly impact compliance. Motivation, the results of care, a sense of normality and adequate energy and will-power for care improve compliance. Support from parents improves motivation and motivation in turn influences energy and will-power for care. Support from parents, encouragement, and results of care also enhance energy and will-power. Lacking fear of complications enhance energy and will-power for care, but fear can also improve compliance and result in better glycemic control.

Kyngas’s (1999) model can be used to plan and implement care for young diabetics. It can also be used as a framework for research and development of an instrument to measure compliance and related factors. In this study, the model will be used as a framework and also as a tool for development of a questionnaire to measure factors that predict compliance of adolescents with type I diabetes.
**Education Effects on Self-Care Practices**

Youth diagnosed with type I diabetes lack the education needed to be able to recognize body cues for maintenance of glycemic control. Hernandez and Williamson (2004) wanted to determine if a one-hour self-awareness educational session had any short or long-term impact on adolescents and young adults with type I diabetes. The following are the research questions developed:

1. What is the effect of the educational session on the number of glucose cues detected for high, low, and normal blood glucose?
2. What is the impact of the educational session on the number of severe episodes of hypoglycemia?
3. What is the relationship between perceived quality of life and number of glucose cues?
4. What is the relationship between perceived quality of life and number of severe episodes of hypoglycemia?

The framework in which the study was conducted was Hernandez’s (1991) Theory of Integration. In this theory, integration is defined as an ongoing three phase process by which the two selves, diabetic (the new entity that emerges upon diagnoses) and personal (the person before diagnosis), more fully merge to create a mentally and physically healthy individual. This unification is manifested in the person’s thinking, being, acting, and verbalization. Phase one (having diabetes phase) begins with the diagnosis of diabetes and is characterized by a lack of knowledge about the disease and a focus on living life as normal with a disinterest in disease management. Phase two
(turning point phase) typically begins when a physiological or psychosocial life event causes the person to reassess their life with diabetes. The focus then becomes on learning about the disease and involvement in a diabetes regimen. The final phase (science of one) is a gradual progression out of the second phase. The person develops self-awareness in regards to diabetes and its impact.

The Hernandez and Williamson’s (2004) study was conducted at a retreat center in Ontario. The population consisted of young adults and adolescents who were attending a diabetes youth weekend at the retreat center in Ontario. A convenience sample of 29 participants was obtained from those attending the retreat. There were no other specific criteria for inclusion in the study. The cohort consisted of eight males and 21 females. The mean age of the participants was 22.21 years with approximately 13 years of diabetes duration. Twelve of the 29 participants completed the final questionnaire at one year post intervention.

Hernandez and Williamson (2004) used a questionnaire pre intervention, immediately post intervention, and one year later to collect data. The instruments on this questionnaire included questions about demographics, a Quality of Life Visual Analogue Scale, and items about the participants’ personal experiences and understandings related to blood glucose. Demographic measurements included age, occupation, and male or female. The Quality of Life Visual Analogue Scale was a 100 mm line with a left anchor and right anchor measuring from lowest to highest possible quality of life. Blood glucose measurements included diabetes duration in years, body cues for low, high, and normal blood glucose levels, frequency of lows and severe lows, and the circumstances under
which highs or lows are experienced. The participants completed the questionnaire and then watched a self-awareness video, participated in a facilitated group discussion, and completed a “What’s Your Blood Sugar Exercise” handout. The participants then completed the questionnaire for a second time after this one hour intervention. One year later, they were mailed the questionnaire for a third time for data collection. Statistical Package for the Social Sciences (SPSS) version 10 was used to analyze the data from the Quality of Life Analogue Scale and data from the blood glucose items to measure the impact of the intervention on number of blood glucose cues detected and number of severe episodes of hypoglycemia experienced. Correlations were also done to assess relationships between perceived quality of life and number of glucose cues and relationships between perceived quality of life and number of severe episodes of hypoglycemia. Test-retest reliability was $r = 0.94$ immediately following the educational session and $r = 0.70$ at one year post test with a $p < 0.05$ significance level (Hernandez & Williamson, 2004).

Baseline measurements of Hernandez and Williamson’s (2004) study revealed eight males and 21 females with a mean age of 22.21 years and a diabetes duration of 12.63 years. The occupation of the participants included eight students, seven blue collar workers, six professionals, 2 were unemployed, 2 were listed as other, and 4 did not list an occupation. Participants were able to identify 82 cues for hypoglycemia, 34 cues for hyperglycemia, and 11 cues for euglycemia pre-intervention. The education session resulted in an increase in the number of cues detected at one year post intervention evidenced by the following results: 93 cues for low, 53 cues for high, and 26 cues for
euglycemia detected. An insufficient amount of questionnaires were returned one year post intervention to determine the impact of the intervention on the number of severe hypoglycemic episodes. The results found no significant relationships between perceived quality of life and the number of glucose cues, or between perceived quality of life and the number of severe hypoglycemic episodes. However, one year post intervention 66.7% of the participants reported noticing some change in thinking or behavior related to body cues, 50% learned to look for other situations that may cause an increase or decrease in blood glucose levels, 41.7% talked to family or friends about self-awareness, and 33.3% reported learning the importance of looking for atypical cues of high, low, and euglycemia (Hernandez & Williamson, 2004).

Additional findings that arose as a result of the Hernandez and Williamson (2004) study included recognition of the frequency of severe episodes of hypoglycemia. All 29 participants reported having a severe hypoglycemic episode. One quarter of the 29 participants reported none of the classic signs, including weakness, shakiness, and sweating, and less than 20% reported experiencing all three during severe hypoglycemic episodes. Also, one year after the educational session 42% of the participants reported losing one or more cues for low or high blood glucose levels or both, indicating cues change over time.

Hernandez and Williamson (2004) concluded that education sessions can have short and long term effects on self-awareness knowledge regarding glycemic control. Even a short education intervention can be effective in younger clients. There are many atypical cues for varying blood glucose levels in adolescents and young adults with type I diabetes
and these cues change over time. Further research is needed to determine the relationship between the Quality of life and number of blood glucose cues or the frequency of severe episodes of hypoglycemia.

Stallwood’s (2006) study also explored the effects of education on glycemic outcomes in children with type I diabetes. The purpose of this study was to describe the relationship between caregiver diabetes knowledge and socioeconomic factors on glycemic outcomes of young children with type I diabetes by asking the research question: What is the relationship between caregivers’ diabetes knowledge and socioeconomic factors on glycemic outcomes of young children with type I diabetes?

The Double ABCX Model of Family Adaptation (McCubbin & Patterson, 1983) was used as a framework. This model states that aA (a stressor event) interacts with bB (the family’s resources) which interacts with cC (the family’s interpretation of the event) producing xX (the adaptation). This process happens over time with an accumulation of stressors.

Stallwood’s (2006) study occurred in waiting rooms of two outpatient diabetes clinics in a Midwestern children’s hospital during regular office hours. The population consisted of all the caregivers (one caregiver per child) of children diagnosed with type I diabetes that came in during regular office hours. A convenience sample of 73 caregivers (one per child) of children less than 9 years of age was derived from this population. Criteria for inclusion in the study included the caregiver must speak and understand English and be the primary caregiver for a child of 9 years of age or younger with type I diabetes. The
child could not have any other comorbid diagnosis and had to have been receiving daily insulin injections for no less than three months without the use of an insulin pump.

Stallwood (2006) used the Michigan Diabetes Research and Training Center Diabetes Knowledge Test (MDRTC) to measure the diabetes knowledge of caregivers. This consisted of 23 multiple choice questions, 14 that tested general diabetes knowledge and 9 items that tested insulin knowledge. The reliability of the questionnaire was determined to be 0.70 and 0.71 on two previous populations, one in the general community and one in a local health department sample before being used in this study. However, a pronoun adjustment was made to the questionnaire to shift the focus of the test from the affected child to the caregiver and reliability was not discussed after this adjustment. Socioeconomic factors also were measured via a demographic questionnaire and included age, level of education, annual income, length of time since child’s diagnosis, race, relationship to the affected child, and marital status. Glycemic control was then measured by hemoglobin A1C levels. Data from the demographic questionnaire and the MDRTC was collected from the caregiver while waiting in the waiting room for the child’s scheduled appointment. Hemoglobin A1C levels were drawn the same day via fingerstick by a certified phlebotomist per clinic visit protocol from the accompanying child. Reliability for the latter instruments was not discussed.

Demographic findings of the participants for Stallwood’s (2006) study were as follows: 42.5% were single, 84.9% were female, 50.7% were white, 49.3% were non-white, 59% had an annual income below $50,000, 19% had an annual income between $50,000-$200,000, 8.2% had less than a high-school level of education, and 61.6% had
attained some college education. The average MDRTC score was 74%. Additional findings for Stallwood (2006) study included higher diabetes knowledge was significantly related to higher levels of income ($r = .40, p < .01$). Caregivers with greater income had higher diabetes knowledge scores on the MDRTC. In addition, higher diabetes knowledge was significantly related to marital status ($r = .32, p < .01$). Married caregivers had a higher level of diabetes knowledge with a mean of 18.3 than unmarried caregivers whose mean was 15.8. There were no significant findings noted between marital status and hemoglobin A1C levels. A third finding was higher diabetes knowledge was significantly related to lower levels of hemoglobin A1C ($r = -.31, p < .01$). In the study, 44% of the children had hemoglobin A1C levels that fell within the target range ($M = 8.97$). The caregivers of the children whose hemoglobin A1C was within the target range had higher income levels with a mean of $39,000 and higher diabetes knowledge with a mean of 18.0. Comparatively caregivers of children whose hemoglobin A1C fell outside the target range revealed a mean income level of $20,400 and diabetes knowledge mean of 16.3 (Stallwood, 2006).

Stallwood (2006) concluded caregivers with greater income have higher diabetes knowledge scores, indicating that families from lower socioeconomic situations may be at risk for knowledge deficits. Children of caregivers with higher knowledge scores have lower hemoglobin A1C levels, supporting the need for education to improve glycemic control.

Although it has been shown through research that optimal glycemic control can decrease microvascular and macrovascular complications of diabetes, only 23-25% of
individuals with diabetes know their target hemoglobin A1C level. Approximately the same percent know how to interpret hemoglobin A1C level results in relation to their own glycemic control (Berikai et al., 2007). The purpose of Berikai et al.’s (2007) study was to investigate whether the gain in knowledge after receiving diabetes self-management education (DSME) predicts the achievement of target hemoglobin A1C levels of <7% at 6 months. Key concepts in this study include knowledge gain and glycemic control.

Berikai et al.’s (2007) retrospective study’s population consisted of adults with diabetes who received DSME in the Diabetes Center of John H. Stroger, Jr. Hospital in Chicago, Illinois, between 2001 and 2004. Inclusion criteria was English speaking and baseline hemoglobin A1C levels of ≥ 7% measured within one month of receiving the DSME and with follow up hemoglobin A1C measurement ranging 3-12 months later and at least 3 months from the baseline hemoglobin A1C. A total of 155 participants made up the sample.

Knowledge gained was the first key concept of Berikai et al.'s (2007) study. It was measured using a five-item questionnaire on glycemic control, blood pressure, and LDL cholesterol targets that is recommended by the American Diabetes association. This was administered before and after the DSME. A score of 20% was given for each correct answer. The author stated the test was validated by a method similar to the one developed by Paddock et al. (2000). Pretest scores of ≤ 40% were considered low baseline knowledge and those with > 40% pretest were considered high baseline knowledge. Knowledge gainers were those who scored a posttest score of ≥ 80% and 100% for low and high baseline knowledge groups, respectively. The second key
concept, glycemic control, was measured using hemoglobin A1C levels. Hemoglobin A1C was measured via high performance liquid chromatography method. Logistic regression using SPSS version 12.0 was used to test knowledge gain as a predictor of target hemoglobin A1C achievement. The authors reported the tests were two sided with a 5% significance level.

The findings of Berikai et al.’s (2007) study showed a higher percentage of knowledge gainers achieved target hemoglobin A1C versus non-gainers (46% vs. 29%, P=0.032). Knowledge gained remained an independent predictor of target hemoglobin A1C achievement after adjusting for baseline hemoglobin A1C, duration of diabetes, sex, ethnicity, BMI, and the number of visits to the diabetes center. Subgroup analysis showed the low baseline knowledge group attained a higher target hemoglobin A1C level than nongainers. In the high baseline knowledge group the gainers also had a higher target hemoglobin A1C level than nongainers but the difference was not statistically significant.

Berikai et al. (2007) concluded knowledge gain, measured in relation to baseline knowledge, was found to be a good indicator of the impact of diabetes education on glycemic control. The gain in knowledge after DSME independently predicted achievement of target hemoglobin A1C levels. However, the difference in the target hemoglobin A1C achievement level between knowledge gainers and nongainers was significant in the low baseline knowledge group but not the high baseline knowledge group. The researchers suggest that patients with low baseline knowledge should receive special attention in DSME programs to improve glycemic control and special
interventions need to be considered for individuals who do not gain knowledge after traditional DSME.

*Treatment Intervention Effects on Self-Care Practices*

Current diabetes education programs use approaches suited to individuals who are ready for change and therefore only reach a selection of the population in need. The purpose of Jones et al.’s (2003) study was to compare diabetes treatment as usual (TAU) with Pathways to Change (PTC) to determine whether the PTC intervention would result in greater readiness to change, greater increases in self-care, and improved glycemic control. The study was based on the Transtheoretical Model of Change (TTM). The TTM model consists of five stages people pass through when changing health behaviors. Pre-action, the individual is not planning on making any changes in the next 6 months. Contemplation, the individual is not prepared to make changes but is intending to change in the next 6 months. Preparation, the individual is planning on changing in the immediate future. Action, the individual has actually made a change in the recent past however the behavior is not well established. Maintenance, the fifth stage, the individual is working to sustain the change after the first 6 months.

The population of Jones et al.’s (2003) study consisted of individuals with type I or type 2 diabetes not engaging in optimal self-care practices living in Southern Ontario, Canada or Nova Scotia. The sample consisted of 1,029 individuals with type I or type 2 diabetes. One-third was from Nova Scotia and two-thirds were from Southern Ontario. Criteria for inclusion in the study included self-monitoring of blood glucose (SMBG) less than four times per day if using insulin and less than two times per day if using oral
antihyperglycemic agents, and/or a BMI > 27 kg/m², and/or smoking cigarettes.

Participants also had to be English speaking, have a working telephone, and not require more than usual care due to health status (e.g., pregnancy or dialysis).

Jones et al. (2003) used a variety of instruments to measure variables. Glycemic control was assessed by hemoglobin A1C levels measured from a venous blood sample using an immunoturbidometric method. Height and weight were measured and used to assess BMI. The NCI block, a validated food frequency instrument, was used to measure dietary intake. Stage of change was measured at baseline, 3, 6, 9, and 12 months, through a questionnaire addressing intent to change and current behavior based on the TTM. According to the researchers, the TTM measures were developed using exploratory and confirmatory analyses, structural equation modeling, and spit-half cross-validation. Blood glucose data was collected by a memory meter that was downloaded by a phone modem. Data about visits with family physician, medications used, and diabetes education received was collected at baseline and 12 months by meeting at the diabetes center for assessment.

Jones et al.’s (2003) comparisons were between participants in the PTC and TAU groups’ stages of change and self-care. The researchers found a significant treatment effect for PTC versus TAU on self-monitoring of blood glucose stage of change. In the PTC group, 12.1% moved to action and 18.4% moved to maintenance of SMBG; compared to the TAU group, in which only 10.9% moved to action and 7.5% moved to maintenance. This effect was found in healthy eating as well. The PTC group was associated with more movement toward action and maintenance than those in the TAU
group. There were significantly more participants in the PTC group who quit smoking than the TAU group. There were 17.8% PTC participants who moved to action in quitting smoking and 5.5% to maintenance compared to 11.6% moved to action and 0% to maintenance in the TAU group.

Jones et al. (2003) also found a significant treatment effect in the PTC group compared to the TAU group for SMBG. PTC participants increased testing from 1.4 to 1.6 times per day compared to TAU participants who decreased testing from 1.46 to 1.41 times per day. PTC participants also consumed fewer calories from fat and more fruits and vegetables than the TAU group. People in the PTC group also participated in diabetes education programs more frequently than those in the TAU group (47.7% and 37.7% respectively, P=0.002). There were no differences found between the groups in visits to the physician or changes in medications.

Jones et al. (2003) found a significant reduction of hemoglobin A1C levels in those participants who reached the action or maintenance stage for SMBG over the course of the study. The hemoglobin A1C for those in action stage was 7.78% compared to 8.30% in those who remained in pre-action. The healthy eating group also demonstrated similar findings. The hemoglobin A1C for those in action was 7.83% but 8.38% for those who remained in pre-action.

Jones et al. (2003) concluded that PTC intervention is better than TAU in assisting individuals move into action stages of self-care behaviors needed for diabetes management. Changes in SMBG and healthy eating behaviors had a significant improvement on glycemic control. Increased testing frequency improves hemoglobin
A1C levels. The researchers further concluded that this study, in combination with other recent studies, support the importance of self-care behavior change interventions for improved glycemic control.

Maintenance of glycemic control is needed to delay onset and slow progression of long-term complications of type I diabetes in youth. This can be done through intensive therapy (IT) but is very costly in comparison to usual care (UC) (Wysocki et al., 2003).

The purpose of Wysocki et al.’s (2003) study was to evaluate effects of IT versus UC on hemoglobin A1C levels of youth with type I diabetes. The stated hypothesis for the study was as follows: “Patients with moderate self-management competence (SMC) will benefit more from intensive therapy than those with either high or low self management competence” (Wysocki et al., 2003, p. 2043). The key concepts are self management competence, intensive therapy, and usual care. Self management competence is defined as skills needed for effective family management of type I diabetes including: diabetes knowledge, treatment adherence, and quality of health care interactions. Intensive therapy (IT) includes three or more daily insulin injections or pump therapy, 4 to 6 daily glucose tests, weekly 3 am glucose tests, weekly telephone contact with the diabetes nurse, access to dietician and psychologist without monetary charges, monthly clinic visits with diabetes nurse, quarterly visits with endocrinologist, advanced diabetes education, and access to a diabetes support group. Intensive therapy also has target parameters of hemoglobin A1C <6.5%, pre-prandial blood glucose (BG) 70-120mg/dl, and postprandial BG < 150mg/dl. Usual Care (UC) is defined as two or three daily insulin injections, 3 to 4 daily glucose tests, annual visits with the dietician and
psychologist, quarterly clinic visits with the diabetes nurse and endocrinologist, and participation in systematic diabetes education. Usual care has parameters of hemoglobin A1C <8.0%, pre-prandial BG 70-140mg/dl, and postprandial BG < 180mg/dl.

The population for Wysocki et al.’s (2003) study was youth between the ages of 6 and 15 years of age with type I diabetes who received care at Children’s Hospital at Washington University in St. Louis, Missouri, or Nemours Children’s Clinic in Jacksonville, Florida. A total of 446 families were contacted and a sample of 142 consented to the study. To be eligible youth had to be 6 to 15 years of age, diagnosed with type I diabetes for a minimum of 2 years, free of other chronic diseases with the exception of well controlled asthma or Hashimoto thyroiditis, have normal cognitive development, reside in a family situation with telephone services, and could not have been a psychiatric inpatient in the prior 6 months. The caregivers had to be literate in English, and could not have been treated for psychosis, major depression, bipolar disorder, or substance use in the prior 6 months.

Wysocki et al. (2003) used hemoglobin A1C levels to measure glycemic control. Hollingshead Four-Factor index of Social Status was used to measure demographics and medical history. SMC was measured using the Diabetes Information Survey for Children (DISC). This is a 98-item test of diabetes knowledge for 6 to 17 year old youth and parents. Split-half reliability (0.92), test-retest reliability over 4 weeks (0.88), convergent validity, and construct validity were confirmed in previous studies. SMC also was measured using the Diabetes Self-Management Profile (DSMP) to assess five domains of type I diabetes self-management: exercise, diet, blood glucose testing, management of
hypoglycemia, and insulin administration/adjustment. The researchers reported the internal consistency for this sample as 0.76 and state that validation data have been previously published. The Physician Satisfaction Questionnaire (PSQ) also was used to measure SMC and consisted of a 20-item scale completed by the health care provider after a clinic visit, rating the quality of the patient-provider relationship, adequacy of clinical information collection, and efficiency of the visit. Internal consistency of the total scale was 0.94 for this sample. The DISC, DSMP, and PSQ scores were summed and incorporated into a composite SMC index for each family. Scores for each individual measure were transformed into standardized T-scores based on sample data.

Wysocki et al. (2003) categorized families as low, moderate or high SMC based on a tertile split of resultant SMC score findings. IT and UC groups had the following significant differences in demographics: there were 65 males in the IT group compared to 47 in the UC group, children in the low SMC group were older, more likely to be members of a racial minority, and in families that were smaller and of lower socioeconomic status than those in the other SMC groups. Hemoglobin A1C was 7.8 ± 0.9% for IT and 8.6 ± 1.1% for UC. All three SMC groups receiving IT had lower hemoglobin A1C levels than those receiving UC. The low SMC group showed the most improvement in hemoglobin A1C levels during IT compared to the moderate or high SMC groups compared to the UC counterparts. Hemoglobin A1C levels increased with UC among the low SMC group however there was no change in the levels among the moderate or high SMC groups receiving UC.
Wysocki et al (2003) concluded that this study combined measures of diabetes knowledge, treatment adherence, and health care interactions into a composite score evaluating a family’s ability to manage type I diabetes. These self-management behaviors were then well correlated with hemoglobin A1C levels, a finding that has been inconsistent in past studies. The authors further concluded that self-management competence predicts metabolic outcomes of usual care but not of intensive therapy for youth with type I diabetes, and patients with low SMC should not be denied access to intensive therapy since they may derive the most glycemic benefit from this added support.

A variety of initiatives have been attempted to improve care and outcomes of young people with diabetes, however despite these efforts improvements in control have not been consistent. It is generally accepted that in the adult population, being involved in a clinical trial offers opportunities for improvements not available in regular clinic settings. The purpose of McGuinness and Cain’s (2007) study was to determine if participation in research can have a positive effect on education and management of disease of children and young people with diabetes. The key concepts included self-management, advising, reassuring, and empowering.

McGuinness and Cain’s (2007) study involved children and young people from pediatric clinics in the UK and Ireland. This international multi-center pediatric clinical trial had a sample of 44 participants between the ages of 6 and 17 years of age with type I diabetes. The inclusion criteria were participants must be aged between 6 and 17 years and diagnosed with type I diabetes for a minimum of 12 months. The study was
conducted via questionnaire mailings to participants’ homes, telephone contacts, and clinic visits.

A questionnaire was used by McGuinness and Cain (2007) to measure the impact of involvement in the study. A total of 23 questions evaluated two aspects: the impact of the subject’s involvement on management of their own diabetes; and their view of clinical trial participation. The questionnaire was mailed to the participant with a pre-paid envelope to be returned to a central location so the subject did not have to identify themselves. Questions with a numerical response were tested for differences using the Kruskal-Wallis test. Questions measured on a categorical scale were tested for differences using the Chi-squared test. Reliability and validity were not reported.

In McGuinness and Cain (2007) study 36 of the 44 participants returned the questionnaire. A total of 58% of the respondents were between the ages of 12 and 14 years. Findings showed that one third of the young people already had four or more injections per day before the trial and 64% tested blood glucose levels at least four times per day. Older children had a significantly higher rate of injections per day. The majority (83%) from all the age groups did not express any concerns about the multi-injection regimen required in the trial, and 97% indicated they intended to continue with the multi-injection regimen at the completion of the trial. Respondents also indicated that they would continue the same glucose monitoring routine post trial.

McGuinness and Cain (2007) also found that 56% of participants indicated they had an increased knowledge and understanding of diabetes as a direct result of their participation. Specific knowledge included an improved understanding of blood sugar
control, insulin dose flexibility, and better understanding of hemoglobin A1C and basal insulin action overnight. All participants reported satisfaction with regular telephone contacts and 86% indicated a positive response to more frequent clinic visits.

The researchers, McGuinness and Cain (2007), concluded that in this population there is a desire for better self-knowledge and management of diabetes. Past studies have shown that intensive therapy leads to better glycemic control, which in turn leads to a reduction in associated complications. The researchers stated that this study supports that many young people were already participating in intensive therapies and were willing to increase the number of injections per day. Increased contact with providers that offered support and guidance was perceived as positive by participants and believed to enhance compliance, this finding supports other studies as well.

Research has shown that adolescence is a time of poor glycemic control. The purpose of Nansel et al.’s (2007) study was to assess cognitive, behavioral and physiological outcomes of a self-regulation intervention for youth with type I diabetes. The researchers also examined intervention effects between pre- and middle adolescence. The Self-Regulation Model was used as the basis for this study. In this model, health-related behavior is explained as a function of the appraisal of the situation, perceived choice of actions, and evaluation of the outcomes of those actions.

The population of Nansel et al.’s (2007) study consisted of 113 youth and their parents who attended their routine clinic visit at two pediatric endocrinology clinics in Baltimore, Maryland. A sample of 81 youth-parent dyads consented to participate (72%). Random assignments were stratified for a total of four strata: age 11-13 vs. 14-16 years and
hemoglobin A1C <8.0 vs. ≥8.0. A total of 41 subjects were assigned to educational control and 40 to intervention groups. Inclusion criteria were age of 11 to 16 years, diagnosed with type I diabetes for at least one year, and could not have any other major chronic illnesses or psychiatric diagnoses.

Measurement tools used in Nansel et al’s (2007) study include the Diabetes Self-Management Profile, the Self-Efficacy for Diabetes Self-Management Scale, the Outcome Expectations of Diabetes Self-Management Positive and Negative Scales, and the Diabetes Quality of Life Scale. Adherence was measured using the Diabetes Self-Management Profile. The profile consists of 29 items that represent adherence to insulin administration, self-care adjustment, dietary practices, blood glucose monitoring, and exercise. The average score across each domain represents the proportion of adherence to an optimal diabetes regimen. Confidence in one’s ability to carry out the diabetes regimen in the face of situational barriers was measured using the Self-Efficacy for Diabetes Self-Management scale. To measure the strength of the participant’s beliefs in positive and negative outcomes of diabetes management activities the Outcome Expectations of Diabetes Self-Management Positive and Negative Scales were used. These measurement tools are consistent with the perceived choice of actions and the evaluation of the outcome of those actions of the self-regulation model. The Diabetes Quality of Life scale has three sub scales for measurement. These subscales include: impact, worry, and satisfaction.

Cronbach’s alpha coefficient for the Diabetes Self-Management Profile was reported as 0.70. Cronbach alpha coefficient for Self-Efficacy for Diabetes Self-Management
Scale was reported as 0.93. Outcome Expectations of Diabetes Self-Management Positive and Negative Scales Cronbach alpha coefficients were reported as 0.87 and 0.90 respectively. The three subscales of the Diabetes Quality of Life Scale had the following Cronbach alpha coefficients: impact =0.79, worry=0.84, and satisfaction=0.92 (Nansel et al., 2007).

Additional measurement tools used in Nansel et al.’s (2007) study were hemoglobin A1C levels and an intervention satisfaction questionnaire. Hemoglobin A1C levels were the primary outcome for this study and obtained via standard protocol from the clinic. Results were then recorded from the participant’s medical records for the duration of the study. The questionnaire measured the youths’ and the parents’ satisfaction with the program and the helpfulness of the personal trainer on a scale from 1-6 (strongly disagree-strongly agree). Baseline assessments were conducted in person in the participant’s home or in a location chosen by the parent. Data from the parent and child was collected simultaneously by two separate interviewers in separate rooms. Telephone interviews were done immediate post intervention and at 6 months post baseline assessment. At one year post baseline an in-person interview was conducted for final data collection. ANCOVA was done with each outcome variable (hemoglobin A1C, adherence, self-efficacy, outcome expectations, and quality of life) following each interview with baseline value of the outcome variable and age as covariates.

Nansel et al.’s (2007) findings showed at short-term follow-up, youth in the control group had an increase in hemoglobin A1C levels. The control group showed a 4.15 increase from baseline in hemoglobin A1C percent over normal and the intervention
group had a 4.76 decrease from baseline in hemoglobin A1C percent. Results of the ANCOVA indicated the intervention had a greater effect on lowering hemoglobin A1C levels in older youth (14-16 years) than in younger youth (11-13 years) both short term and at one year follow up. There were not significant differences between control and intervention groups adherence at any time period. There also was no intervention-by-age interaction for adherence revealed at short term or one year follow up. Youth in the intervention group did report lower positive outcome expectations and higher diabetes impact but no differences on worry or satisfaction on the Quality of Life scale one year follow up. Findings from the program satisfaction scale showed an overall mean of 5.32 for youth and an overall mean of 5.34 for parents on a 6 point scale. All participants indicated they would recommend the program to others and provided positive comments in regards to the trainers.

Nansel et al. (2007) concluded that behavioral self-regulation intervention, mediated by trained non-professionals, is an effective approach for preventing decline in glycemic control during middle adolescence. Those in pre and early adolescence would benefit from an intervention in which parental involvement is used due to the youth’s dependence on the caregiver for disease management at this stage of growth and development. Findings of lowered adherence do not support the observance of lowering hemoglobin A1C levels. Nansel et al (2007) concluded this was due to the intervention raising awareness and causing youth less tendency to overestimate adherence compared at baseline. This raised awareness also was concluded to be the cause of the intervention group reporting higher diabetes impact and lower positive outcome expectations. The
researchers concluded that self-management skills are important for improving glycemic control during middle adolescence.

*Adolescents’ Perceptions of Self-Care Practices*

Adolescents need to comply with long-term care recommendations for diabetes management to prevent diabetes complications. The purpose of a study by Kyngas (2000) was to examine compliance of adolescents with diabetes diet, home monitoring, visits to the doctor or nurse, and insulin treatment. Research questions included: 1) To what extent do adolescents with diabetes comply with the health regimen? and 2) What kind of factors are connected with the compliance of adolescents with diabetes? The study was based on the Theoretical Model of Compliance of Adolescents with Diabetes (Kyngas, 1999).

The population for the Kyngas (2000) study included 1,754 adolescents with insulin dependent diabetes mellitus, aged 13 to 17 years, registered by the Social Insurance Institution in Finland. The sample consisted of 300 randomly selected individuals that met sample selection criteria. Every fifth person on the list was included in the sample. Criteria were that the diagnosis of diabetes had occurred more than one year prior and the adolescent was 13 to 17 years of age.

Variables of the Kyngas (2000) study were measured using a 58 item questionnaire formatted with a 5-point Likert Scale that contained items on compliance, sense of normality, support from nurses; physicians; friends; and parents, energy and willpower, motivation, subjective experience of results, impact of care and treatment, attitude, fear of complications, and fear of hypoglycemia, self-care behaviors, collaboration with health
care staff, and responsibility and activity in care. Background variables also were measured by 12 questions. The questionnaire was pretested using factor analysis, LISREL analysis, correlation and covariance coefficients, face validity, and Cronbach alpha values, supporting construct and content validity and reliability to be good (Cronbach alpha value = 0.94). The questionnaire was mailed to adolescents within the sample. A total of 289 questionnaires were returned.

Kyngas’s (2000) findings showed adolescents most fully complied with insulin treatment (81%). Dietary regimen was the second behavior adolescents were most compliant to follow with 25% in good compliance and 38% in satisfactory compliance. Home monitoring had the least compliance with 51% of the adolescents reporting poor compliance. There was a significant relationship (p<.001) between increased compliance in adolescents and the following background variables: having the disease for no more than 1 to 3 years, regular exercise, no smoking, no drinking of alcohol, and hemoglobin A1C levels of less than 7%. Adolescents who exercised regularly, 90% demonstrated good compliance. Good compliance was demonstrated by 64% of adolescents who didn’t smoke and 56% of adolescents with hemoglobin A1C levels less than 7%. Compliance and support from friends also had a statistically significant (p<.001) relationship with 48% of adolescents having good compliance that reported support from friends. Other factors found by the researcher to improve compliance include: good motivation (39%), a strong sense of normality (29%), energy and willpower (39%), support from parents (33%); physicians (39%); and nurses (37%), a positive attitude toward the disease and its treatment (31%), no threat to one’s social well-being (36%).
Kyngas (2000) concluded that compliance reported by young people with diabetes and their hemoglobin A1C values were very similar. Adolescents who reported poor compliance also showed poor glycemic control. However, the researcher stated previous research has supported and disputed the use of hemoglobin A1C levels as a reliable predictor of compliance. There is a need for improvement in positive feedback, involvement of significant others at a level acceptable to the adolescent, and emotional support when caring for adolescents with diabetes. According to Kyngas (2000), adolescents should be actively participating in the planning and decision-making processes as they relate to transition planning.

Crucial factors related to compliance of adolescents with a chronic disease include family support, close peer relationships, and the quality of interaction between the patient and healthcare provider. However, very little is known about the factors that predict compliance in adolescents with a chronic disease. The purpose of Kyngas and Rissanen’s (2001) study was to identify predictors of good compliance among adolescents with a chronic disease such as asthma, epilepsy, juvenile rheumatoid arthritis (JRA), and insulin dependent diabetes mellitus (IDDM). The research question posed was: What factors predict the compliance of adolescents with chronic disease? The study was based on the Theoretical Model of Compliance of Adolescents with Diabetes (Kyngas, 1999). The concept of compliance is defined as “an active, intentional and responsible process of care, in which the individual works to maintain his or her health in close collaboration with the health care personnel“ (Kyngas, 1999, p. 74).
The population for Kyngas and Rissanen’s (2001) study consisted of 8671 adolescents, ages 13 to 17 years, diagnosed with asthma, epilepsy, IDDM, or JRA, registered by the Social Insurance Institution in Finland. The sample was made up of 1200 adolescents from ages 13 to 17 years. Criteria for sample inclusion were that the adolescent was between 13 and 17 years of age and had been diagnosed with the chronic illness as least one year prior.

Kyngas and Rissanen (2001) used a 58 item questionnaire formatted with a 5-point Likert scale that ranged from definite agreement-indecision-definite disagreement to measure dependent and independent variables. This questionnaire was used to measure compliance, sense of normality, support from parents; nurses; physicians; and friends, motivation, energy and willpower, attitude towards the disease and treatment, subjective experience of results, and a feeling that the disease was not a threat to one’s social well-being. Cronbach alpha values were as follows for each section of items on the questionnaire: for asthma, 0.92; IDDM, 0.93; and JRA, 0.94. Statistical Package for Social Sciences (SPSS) version 8.0 was used to complete logistic regression on the data and the values show the model to be a good fit. Questionnaires were mailed to the adolescents and returned directly to the researcher.

Kyngas and Rissanen (2001) found the most powerful predictor of compliance of adolescents with a chronic illness is support from nurses. Adolescents with support were 7.28 times more likely to comply with a health regimen compared to those who did not receive nurse support. The second most powerful predictor is energy and willpower. Adolescents were 6.69 times more likely to comply if they had energy and willpower.
Adolescents with motivation were 5.28 times more likely to comply than those without motivation, making motivation the third most powerful predictor of compliance.

Kyngas and Rissanen (2001) concluded that crucial predictors of compliance for adolescents include support from nurses, physicians, and friends. When patients are actively involved in their care, they may be more committed to the health regimen. It is important to adolescents that the nurse pays attention to each adolescent’s life situation. The researchers also concluded that parents need to offer motivation to adolescents through positive feedback, planning self-care with the adolescent, and offering rewards to promote compliance.

Psychosocial research on adolescents with type I diabetes has predominantly focused on the effects of family on outcomes, but more research is needed to study the mechanisms by which the family environment influences self-care, well-being, and metabolic control. The purpose of Skinner and Hampson’s (2001) study was to test the utility of illness beliefs, conceptualized as personal models of diabetes, in predicting self-care, well-being, and subsequent glycemic control in adolescents with type I diabetes. Personal models were used as the framework for the study. These models are grounded in a general Theory of Cognition that accounts for the combining of incoming information with past experiences and beliefs change in response to new experiences. The following are the five components of the personal model or representation of an illness: identity, cause, consequences, timeline, and control/cure. The authors give the following conceptual definitions for two of the components. The control/cure is conceptualized as beliefs about the effectiveness of treatment. The perceived
consequences of the personal model is conceptualized as perceived severity of the
disease, perceived susceptibility to complications, and perceived impact of diabetes.

The sample for Skinner and Hampson’s (2001) study was recruited from a population
of outpatients at four regional hospitals in southern England during a four month period.
Inclusion criteria were age between 12 and 18 years, diagnoses of type I diabetes for a
minimum of one year, and the ability to complete a questionnaire unassisted. The sample
consisted of 74 participants (32 girls, 42 boys) with type I diabetes, between the age of 12
and 18 years.

A questionnaire booklet was used in Skinner and Hampson’s (2001) study that
included four instruments. The booklets were completed by the adolescents unassisted
and mailed to the researchers at baseline and at 12 month follow-up. Hemoglobin A1C
levels were also collected via blood draw at baseline and 12 month follow-up to measure
metabolic control. The first of the four instruments in the booklet was to gather
demographic information and included gender, age, duration of illness, and parental
occupation. The second instrument was the Well-Being Questionnaire, a 22 item
instrument with four subscales that assess depression, anxiety, positive well-being, and
perceived energy over the previous seven days. Testing of the instrument revealed that
positive well-being and perceived energy were not reliable therefore only the depression
and anxiety scales were used in this study. The internal consistency assessed by
Cronbach’s alpha coefficient was adequate for depression (0.63) and anxiety (0.78). The
third instrument in the booklet was the Summary of Diabetes Self-Care Schedule. This
had 12 items to assess self-management of diet, exercise, blood glucose monitoring, and
injecting over the previous 7 days. Cronbach alpha coefficient indicated internal consistency was adequate for diet (0.64), exercise (0.83), and blood glucose testing (0.80), but poor for insulin injecting (0.41). The final instrument was the eight item Personal Models of Diabetes Questionnaire. It measures the effectiveness of treatment to control diabetes, effectiveness of treatment to prevent complications, perceived seriousness of diabetes, and perceived impact of diabetes. Each item is scored on a 5-point Likert scale ranging from 1-not at all serious/important/likely to help to 5-extremely serious/important/likely to help. Internal consistency was reported as good using Spearman’s p (r=0.68).

Skinner and Hampson (2001) found girls reported higher levels of depression (F=7.69; df=1; p<0.01) and anxiety (F=15.73; df=1; p<0.0001) than boys. Girls also reported their diabetes as more serious (F7.13; df=1; p<0.01) and as having a greater impact on their lives (F=4.95; df=1; p<0.05) than boys’ reports. Poorer glycemic control was correlated with lower socioeconomic groups, female gender, anxiety, and poor diets. Age, duration of diabetes, and socioeconomic status were not associated with depression, anxiety, exercise, blood glucose monitoring, injection behavior, or any of the personal model constructs. Skinner and Hampson (2001) also found that a change in the perceived effectiveness of treatment to control diabetes was correlated significantly with change in dietary self-care (r=0.42, p<0.005) but not with any other self-care measure.

Skinner and Hampson (2001) concluded the more adolescents believe their self-care regimen will control their diabetes, the better will be their dietary adherence. Improved dietary self-care and male gender were associated with better glycemic control.
Adolescents’ beliefs about their diabetes and its treatment influence their self-care, emotional well-being, and glycemic control, therefore personal models can be used in determining outcomes of diabetes care with this age group.

It is essential that patients with diabetes adhere to self-care to maintain optimal glycemic control to prevent complications associated with diabetes. The purpose of Toljamo and Hentinen’s (2001) study was to answer the following questions:

1. How do adult people with insulin-requiring diabetes accomplish their self-care?

2. What is adherence to self-care among people with diabetes like?

3. What factors are associated with neglect of rather than adherence to self-care?

The researchers based the study on Hentinen’s (1987) concept of adherence to self-care, defined as “an active, responsible and flexible process of self-care, in which the person work to maintain his or her health in close collaboration with health care staff, instead of simply following the rules that are prescribed” (Toljamo & Hentinen, 2001, p. 781).

Toljamo and Hentinen’s (2001) study population consisted of insulin-treated adults who visited the Oulu Health Center and the Central Hospital of Lapland in Northern Finland. Criteria for inclusion in the study were age between 17 and 65 years, diagnosis of insulin-treated diabetes, and had to have had diabetes for over one year. The sample was 213 insulin-treated diabetic adults between the ages of 17 and 65 years.

Tolijamo and Hentinen (2001) used a self-report questionnaire with a 5 point Likert scale (daily-never) on self-care behaviors. The specific self-care behaviors measured included: insulin injections, eating and exercise habits, blood glucose and urine testing,
and mode of self-care (flexibility, activity, and responsibility). The questionnaire also gathered the following background variables: age, gender, duration of disease, complications caused by diabetes, other diseases, smoking, living status, and education. Hemoglobin A1C, was used to measure glycemic control. Validity and reliability of the questionnaire was assessed using interitem correlations and determined to be good, according to the authors. The questionnaires were mailed and returned by the participants. Statistical analysis was done with SPSS/PC version 7.5.

Toljamo and Hentinen (2001) found that participants living alone had a higher hemoglobin A1C level (8.7%) than those that lived with family or a partner (8.0%). Adherence to insulin treatment was the highest self-care behavior among participants (84% accomplished scheduled daily injections and 15% almost daily). Dietary was the second self-care regimen most closely adhered to with 67% of the participants eating regular main meals and 48% assessing the content of meals daily. The majority of subjects (46%) reported using a flexible mode of self-care rather than rigid adherence. Toljamo and Hentinen (2001) also found that poor glycemic control, smoking, and living alone significantly increased the likelihood of neglecting self-care. Gender, age, other diseases, duration of disease, and education had no significant relationship to adherence or neglect of self-care.

Toljamo and Hentinen (2001) concluded that their study supported previous findings of insulin injections being the most adhered to self-care behavior. However, other self-care behaviors are regularly neglected, especially monitoring blood glucose levels. The authors suggest that self-care needs should be assessed individually without labeling the
patient as having overall good or poor compliance. It is also suggested that those living alone may need special support and attention to manage their disease to achieve optimal glycemic control.

Adolescents with type I diabetes have increased knowledge compared to younger children, but have often been found to have decreased adherence to self-care. The purpose of Hains et al. (2006) study was to examine the relationship among negative attributions of friend reactions within a social context, anticipated adherence difficulties, diabetes stress, and metabolic control of adolescents with type I diabetes. The role of cognitive processes that were part of the problem behavior choices of the adolescents were studied using a Social Information-Processing Model of Adjustment. According to the researchers, “the model suggests that adolescents with type I diabetes may perceive adherence behavior as difficult in social situations due to a fear of negative friend evaluations” (Hains et al., 2006, p. 818).

Hains et al. (2006) study population consisted of adolescents between the ages of 11 and 18 who were receiving treatment for type I diabetes at Children’s Hospital of Wisconsin. The sample consisted of 104 participants between the ages of 11 and 18 with type I diabetes. Participants could complete the questionnaires in the clinic or take them home and return them by mail. Each participant received a gift certificate for a local shopping mall for their participation. Inclusion criteria were not specifically stated other than age between 11 and 18 years and diagnoses of type I diabetes.

Hains et al. (2006) used a variety of instruments to measure variables. Demographic information was collected via a questionnaire that included questions about sex, race,
age, grade, duration of diabetes, and how many friends they told about their diabetes using a 5-point scale (1-only one or two, 3-some of them, 5-most of them). Another questionnaire was used to measure attribution of friend reactions. The questionnaire described seven social situations an adolescent would be involved in with friends where the adolescent is faced with an adherence situation. The situation is then followed by nine questions. Six questions asked about the adolescents’ expected thoughts about the friends’ reactions, responding on a 5-point scale (1-“I’m sure I would not think this”, 5-“I’m sure I’d think this”). Positively worded attributions were reverse scored. The items were summed to form the Negative Friend Attribution Score. Two additional questions following each scenario asked about the ease and likelihood of adherence in these situations and were combined to form the Anticipated Adherence Difficulties score. The researchers reported there was strong evidence for both content and construct validity of the Negative Attributions of Friend and Anticipated Adherence Difficulties scales of the questionnaire.

Hains et al. (2006) also measured diabetes stress via a 65-item questionnaire that assessed daily stressors associated with diabetes. Higher scores indicated a higher level of stress. Internal consistency was reported as excellent (Cronbach Alpha=0.97) with the measure having good concurrent validity. Metabolic control was measured by hemoglobin A1C levels obtained at the clinic visit.

Hains et al. (2006) found that negative attributions of friend reactions had a significant positive relationship with diabetes stress ($r=0.28$, $p<0.01$). Negative attributions of friend reactions also had a positive relationship with anticipated adherence difficulty ($r=0.52$,
p<0.0001), but did not have a direct relationship with metabolic control (r=0.01, p<0.90). Anticipated adherence difficulty was positively correlated with diabetes stress (r=0.40, p<0.0001) but not related directly to metabolic control (r=0.096, p<0.39). Negative attributions of friend reactions and anticipated adherence difficulties did have an indirect effect on metabolic control through the variable diabetes-related stress.

Hains et al. (2006) concluded that adolescents with type I diabetes who make negative attributions about expected friend reactions to their self-care are more likely to anticipate adherence difficulties and have increased diabetes stress, which in turn will lead to poor metabolic control. The researchers point out that most participants had told many of their friends about their disease, but were still apprehensive about friend reactions to their adherence behaviors. It is also noted that this study did not address whether participants had experienced negative reactions in the past, and the researchers felt that further research needed to be done to address how past experiences effect present adherence behaviors. The final conclusion drawn was that negative attributions of friend reactions are primarily the own thoughts of the adolescent and do impact anticipated adherence. Therefore, it is imperative that adolescent’s attributions about self-care in social situations are assessed, misconceptions are corrected, and the adolescent is prepared with specific strategies to use when with friends to gain consistency in self-management.

Summary

Diabetes is a chronic illness that requires major life changes. The disease presents unique challenges for health care providers when helping adolescents comply with self-care during transition from parental control of the disease to independence in health
management. The literature supports that improved knowledge and compliance with a self-care regimen results in lower hemoglobin A1C levels. The literature revealed self-care interventions that supported improved compliance and the adolescent’s perception of factors that impact compliance. These factors supported the Theoretical Model of Compliance of Adolescents with Diabetes (Kyngas, 1999).

Improved self-care and glycemic control through increased diabetes knowledge was supported by Berikai et al. (2007), Hernandez and Williamson (2004), and Stallwood (2006). Berikai et al. (2007) and Stallwood (2006) noted that higher knowledge scores were significantly related to lower hemoglobin A1C levels. The study by Hernandez and Williamson (2004) found that an education session increased the number of cues an adolescent can detect for differing glucose levels. The finding that typical signs for hypoglycemia and hyperglycemia were not experienced was significant for planning self-care. These studies supported that self-care could be improved through increased knowledge and that an increase in self-care did improve glycemic control.

Various self-care regulation interventions were reported in the literature review and support the impact health care providers can have on compliance with self-care among adolescents. The studies of Nansel et al. (2007) and Wysocki et al. (2003) identified self-care regulation interventions and their impact on hemoglobin A1C levels. Self-regulation interventions lowered hemoglobin A1C levels and self-care behaviors were well correlated with hemoglobin A1C levels. Jones et al.’s (2003) Pathways to Change intervention also showed a correlation between self-care behavior interventions and
improved compliance. The findings support self-care behavior interventions as an integral part of diabetes care to improve compliance and lower hemoglobin A1C levels.

The literature review also included adolescents’ perceptions of self-care. Self-care behaviors that had the highest compliance were found to be insulin regimen and diet. The self-care behavior with the lowest compliance was glucose monitoring. These findings were supported by Kyngas (2000) and also by Tolijamo and Hentinen (2001). Both studies also found that smoking was correlated with poor compliance. Adolescents reported social factors that influenced their compliance. Kyngas and Rissanen (2001), McGuinness and Cain (2007), and Kyngas (2000) all found that support from providers improved compliance. Kyngas (2000) and Kyngas and Rissanen (2001) also found that support from parents, friends, good motivation, strong sense of normality, energy and willpower, and no threat to social-well being increased compliance. These studies provide various variables that impact adolescents’ compliance with self-care but do not predict compliance.

The literature review included type I diabetics and their families. Data was gathered through interviews, questionnaires, surveys, and the biochemical indicator hemoglobin A1C levels. Various tools were used to collect and analyze the data. Different frameworks were utilized in the various studies. The findings offered important information about factors that are significantly related to self-care compliance in adolescents. However, further research is needed regarding variables that predict compliance in adolescents for health care providers to properly plan and implement
transition interventions during the crucial years when youth are gaining independence in managing chronic illness.
Chapter III

Methods and Procedures

Introduction

Adolescents with type I diabetes have to face the challenges of a chronic illness that require various behavior adjustments and long-term dependency on treatment. Rigorous compliance to self-care regimens is needed to ensure that microvascular complications will be minimal or avoided to maintain a high level of quality of life. Although compliance and factors associated with it have been studied, little is known about what factors predict compliance in adolescents with type I diabetes. The purpose of this study is to identify predictors of good compliance among adolescents with type I diabetes. This is a modified replication of Kyngas and Rissanen’s (2001) study. This chapter will discuss the methodology and procedures for the study.

Research Question

1. What factors predict the compliance of adolescents with type I diabetes?

Population, Sample and Setting

The study will take place at Peyton Manning Children’s Hospital at St. Vincent Outpatient Diabetes and Endocrinology Center in Indianapolis, Indiana. Adolescents with type I diabetes who visit the clinic for scheduled appointments over a 3 month
period of time will be invited to participate in the study. The population approached for the study will be approximately 900 adolescents. The anticipated sample will be 300 adolescents with type I diabetes. Inclusion criteria are: duration of diabetes for more than one year, age between 13 and 18 years, and ability to speak and understand English.

Protection of Human Subjects

This study will be submitted to the Ball State Institutional Review Board and to Peyton Manning Children’s Hospital at St. Vincent for approval. The participants and their guardian will be included in the study on a voluntary basis only. A cover letter explaining the purpose of the questionnaire, and a statement that their identity would not be revealed at any time would be included and explained. The information would be treated as confidential for all purposes as data will be grouped for analysis. Pre-addressed envelopes would be available for completed questionnaires to be placed in, sealed, and mailed to ensure confidentiality of the adolescent. Informed consent would be indicated by the guardian allowing the adolescent to acquire the questionnaire during the clinic visit. No risks have been identified. Benefits from participation in the study include an increased awareness of factors that affect compliance.

Procedure

Upon receiving permission from Ball State Institutional Review Board and Peyton Manning Children’s Hospital Review Board, three pediatric endocrinologists and one certified pediatric nurse practitioner will be contacted at Peyton Manning Children’s Hospital. A letter of introduction will be sent that includes the purpose of the study, anticipated sample, inclusion criteria, and instrument. A meeting will be set with the
medical director, who also is one of the practicing endocrinologists, to further explain the study and answer any questions. Participants will be contacted during scheduled clinic visits by a researcher. The guardian and adolescent can consent or decline inclusion in the study. The questionnaire will be explained in full with a cover letter attached detailing confidentiality, purpose of study, along with a pre-addressed stamped envelope. The questionnaire is then to be completed by the adolescent and mailed to the researcher in the envelope provided.

*Instrumentation, Reliability and Validity*

Data will be collected using a questionnaire that is based on the Theoretical Model of Compliance of Adolescents with Diabetes (Kyngas, 1999). This questionnaire consists of 58 items on the following: compliance, sense of normality, support from nurses; physicians; friends; and parents, energy and willpower, motivation, subjective results, impact of disease, attitude, fear of complications and fear of hypoglycemia, and 12 questions concerning background variables. The questions are formatted using five-point Likert scales ranging from 1-definite agreement to 3-indecision to 5-definite disagreement.

In Kyngas’s (2000) study the tool was reported to be pretested with three sets of data using factor analyses, LISREL analyses, correlation and covariance coefficients, face validity, and Cronbach alpha values, which showed the construct and content validity and reliability to be good. The Cronbach alpha value for the Kyngas (2000) study was reported as 0.94 for the questionnaire. Kyngas and Rissanen (2001), the study of replication, reported the Cronbach alpha value as 0.93 for the questionnaire and reported
the reliability of the instrument as good. The values of the logistic regression also show
the model to be good and to match the data well (Kyngas & Rissanen, 2001).

*Research Design*

This study will use a predictive correlational design. “Predictive designs are used to
predict the value of one variable on the basis of values obtained from another variable or
variables” (Burns & Grove, 2005, p. 240). In this design, the researcher wants to predict
the level of the dependent variable from the independent variables (Burns & Grove,
2005). The dependent variable is compliance in this study. According to Burns & Grove
(2005), regression analysis can be used to examine data.

*Data Analysis*

Data analysis will done using logistic regression, which is a procedure that
approximates the likelihood of an outcome to be present given certain conditions (Kyngas
& Rissanen, 2001). Logistic regression uses a maximal likelihood estimation approach
(Burns & Grove, 2005). It requires that the distribution of variables have dichotomous
codes. Therefore, the scores for the questions that belong to each category of
independent variables (i.e. motivation, sense of normality, attitude towards disease, etc.)
will be summed and the sum will be divided by the number of variables. The scores for
the items 1-3 will be assigned a value of 0, and the scores for the items 4-5 will be
assigned a value of 1. The dependent variable will be coded as 1, compliance and 0, no
compliance. Backward elimination will then be used for selecting the variables into the
model. Each variable with a P-value of less than 0.05 will be rejected. Each variable will
be tested to see how much variance would be explained in compliance if it were the last entered into the equation.

Summary

This chapter described the methods and procedures to be used to conduct the study at Peyton Manning Children’s Hospital in Indianapolis, Indiana. A predictive correlational design will be used with data analysis being done through logistic regression to identify factors that predict good compliance in adolescents with type I diabetes. An anticipated sample of 300 adolescents will be recruited and asked to complete a 58 item questionnaire that is based on the Theoretical Model of Compliance of Adolescents with Diabetes (Kyngas, 1999). This study is a modified replication of Kyngas and Ressinan’s (2001) study and will further support previous findings of crucial predictors of good compliance.
References


<table>
<thead>
<tr>
<th>Source</th>
<th>Problem</th>
<th>Purpose Research Questions</th>
<th>Framework or Concepts</th>
<th>Sample</th>
<th>Design</th>
<th>Instruments</th>
<th>Results and Implications</th>
</tr>
</thead>
</table>
| 1. Hernandez, C. A., & Williamson, K. M. (2004) | Youth need to be aware of body cues in addition to fingerstick glucose monitoring to estimate blood glucose levels to promote maintenance of glycemic control to prevent complications associated with diabetes. | 1. What is the effect of the educational session on the number of glucose cues detected for high, low and normal blood glucose?  
2. What is the impact of the educational session on the number of severe episodes of hypoglycemia?  
3. What is the relationship between perceived | Hernandez’ (1991) theory of integration  
1. Integration: an ongoing three phase process by which the two selves, diabetic (new entity that emerges upon dx) and personal (person before dx), more fully merge to create an individual who is healthy, both mentally and physically. This unification is manifested in the person’s thinking, being, acting, and verbalization. Phase one=having diabetes=dx of | 29 adolescents and young adults with type 1 diabetes from a retreat center in Ontario, Canada | Descriptive Correlational | Demographics Questionnaire, The Quality of Life Visual Analogue Scale Questionnaire with items about personal experiences and understandings r/t BG | 8 males/21 females, mean age 22.21, mean diabetes duration in years 12.63, occupation of participants 8 students, 7 blue collar workers, 6 professionals, 4 not stated, 2 unemployed, 2 other. Baseline measurements revealed participants were able to identify 82 cues for hypoglycemia, |
<table>
<thead>
<tr>
<th>Quality of life and number of glucose cues?</th>
<th>Disease, little knowledge, denial Phase two=turning point=life event upsets complacency, interest in diabetes starts, involvement in diabetes regimen Phase three=science of one, knows own diabetes and its impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. What is the relationship between perceived quality of life and number of severe episodes of hypoglycemia?</td>
<td>34 cues for hyperglycemia, and 11 cues for euglycemia. The education session resulted in a significant increase in the number of cues detected for low (93), high (53), and normal (26) blood glucose at one year post intervention. Insufficient number of questionnaires were returned post one year to determine the impact of the education session on the number of</td>
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</table>
severe hypoglycemic episodes. No significant relationship was found between perceived quality of life and number of glucose cues identified. No significant relationship was found between perceived quality of life and frequency of severe episodes of hypoglycemia. Additional findings included cues experienced by participants for high and low BG.
change or are lost over time and many classic signs of hypoglycemia were not experienced by the participants. Implications: Education sessions should be provided to youth with type I diabetes to improve self-awareness regarding glycemic control. Providers need to be aware that atypical cues exist for varying blood glucose levels.
Caregivers need an accurate diabetes knowledge base to protect children with diabetes  

Describe the relationship between caregiver socioeconomi c factors and knowledge about diabetes on glycemic control of children with type 1 diabetes  

“What is the relationship between caregiver’s diabetes knowledge and socioeconomi c factors on the glycemic outcomes of young children with type 1 diabetes”  

<table>
<thead>
<tr>
<th>The Double ABCX Model of Family Adaptation (McCubbin &amp; Patterson, 1983a, b)</th>
<th>73 caregivers (one caregiver per child)</th>
<th>Cross-sectional, correlational</th>
<th>Demographic Information Questionnaire</th>
<th>Participants were as follows: 42.5% were single, 84.9% were female, 50.7% were white, 49.3% were non-white, 59% had an annual income below $50,000, 19% had an annual income between $50,000-$200,000, 8.2% had less than a high-school level of education and 61.6% had attained some college education.</th>
</tr>
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<tbody>
<tr>
<td>aA=stressor</td>
<td>bB=resources</td>
<td>cC=interpretation of the stressor event</td>
<td>xX=Adaptation</td>
<td></td>
</tr>
<tr>
<td>Caregivers need an accurate diabetes knowledge base to protect children with diabetes</td>
<td>The Double ABCX Model of Family Adaptation (McCubbin &amp; Patterson, 1983a, b)</td>
<td>73 caregivers (one caregiver per child)</td>
<td>Cross-sectional, correlational</td>
<td>Demographic Information Questionnaire</td>
</tr>
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<td>type 1 diabetes?</td>
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</table>
higher income did lead to lower hemoglobin A1C levels. Implications: Diabetes education is needed for caregivers to be able to manage the disease of an affected child to achieve better glycemic control. Lower income families are at higher risk for knowledge deficits and should be closely assessed.

| 3. Berikai, P. (2007) | Patients with type I diabetes lack knowledge | Investigate whether the gain in | Key concepts: knowledge gain (measured in relation | 155 adults in the Diabetes | Retrospective predictive | 5-item questionnaire on glycemic | A higher percentage of knowledge |
regarding target hemoglobin A1C levels or how to interpret hemoglobin A1C levels in relation to glycemic control.

Knowledge after receiving diabetes self-management education (DSME) predicts the achievement of target hemoglobin A1C levels of < 7% at 6 months.

To baseline scores:
- Low baseline knowledge group: pretest score ≤ 40%
- High baseline knowledge group: pretest score > 40%
- Knowledge gainers: posttest score of ≥80% and 100% for low and high baseline respectively
- Non-gainers: scores below the gainer scores
- Target hemoglobin A1C level: < 7%

Center of John H. Stroger, Jr. Hospital in Chicago, Illinois between 2001 -2004 who received DSME

Control, blood pressure, and LDL cholesterol targets.

Biochemical indicator: Hemoglobin A1C level was used to measure glycemic control.

SPSS version 12.0 was used for logistic regression.

gainers achieved target hemoglobin A1C levels versus non-gainers (46% vs. 29%, p=0.032). The low baseline knowledge group attained a higher target hemoglobin A1C rate than non-gainers.

Implications: Patients with low baseline knowledge should receive special attention in Diabetes Self-management programs to improve glycemic control.
### Treatment Intervention Effects on Self-Care Practices

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<tr>
<td><strong>Compare</strong> [\text{diabetes treatment as usual (TAU) with Pathways to Change (PTC)}] to determine whether the PTC intervention would result in greater readiness to change, greater increase in self-care, and improved glycemic control. [\text{Hypothesis: Compared to TAU, patients receiving the PTC intervention}]</td>
<td><strong>Transtheoretical Model of Change (TTM).</strong> Consists of 5 stages. [\text{Pre-action-individual not planning on changing}] [\text{Contemplation-individual in planning on changing in next 6 months but is not prepared}] [\text{Preparation-individual in planning on changing in the immediate future}] [\text{Action-individual has made a change but the behavior is not well established}] [\text{Maintenance-individual is}]</td>
</tr>
<tr>
<td><strong>1,029 individuals participating in less than optimal self-care practices with type I or type II diabetes</strong></td>
<td><strong>Height and weight were assessed to measure BMI</strong></td>
</tr>
</tbody>
</table>
will demonstrate more forward movement in stage of readiness for self monitoring blood glucose (SMBG), healthy eating, smoking cessation, and increased frequency of SMBG.

Working on sustaining the change after the first 6 months

Collect data regarding visits with family physician, medications used, and diabetes education received.

Group who had 11.6% move to action and 0% move to maintenance. The PTC group also had better eating habits, participated in diabetes education, and had increased frequency in SMBG than the TAU group. No differences in visits to physician or medications between groups.

Implications: Self-care behavior interventions need to be an
Maintenance of glycemic control is needed to delay the onset and slow the progression of long-term complications of type 1 diabetes in youth. This can be done through intensive therapy (IT) but is very costly in comparison to usual care (UC).

Evaluate the effects of IT versus UC on hemoglobin A1C levels of youth with type 1 diabetes.

**Hypothesis:**
Patients with moderate self management competence (SCM) will benefit more from intensive therapy than those with either high or low self management competence.

**Self Management Competence** defined as skills needed for effective family management of type 1 diabetes including: diabetes knowledge, treatment adherence, quality of health care interactions.

**Intensive Therapy (IT)** defined as:
- Hemoglobin A1C < 6.5%
- Preprandial BG 70-120 mg/dl
- Postprandial BG < 150 mg/dl
- Three or more daily insulin injections or

142 youth between the ages of 6 and 15 years with type 1 diabetes.

**Predictive design**

**Biochemical indicator** hemoglobin A1C lab levels

**Hollingshead Four-Factor Index of Social Status** used for demographic information and medical history.

**The Diabetes Information Survey for Children (DISC)** used for diabetes knowledge (used to assess SCM).

**The Diabetes Family T scores for** diabetes knowledge (DISC), treatment adherence (DSMP), and quality of health care interactions (PSQ) were summed and averaged, yielding an SCM composite score. Based on a tertile split of resultant SMC scores, families were categorized as integral part of diabetes care to improve glycemic control.
| pump therapy | 4 to 6 daily glucose tests | Weekly 3am glucose tests | Weekly telephone contact with the diabetes nurse | Access to dietician and psychologist without charge | Monthly clinic visits with diabetes nurse | Quarterly visits with endocrinologist | Advanced diabetes education | Access to support group | Usual Care  
(UC)=hemoglobin A1C<8.0%  
Preprandial BG 70-140mg/dl  
Postprandial BG <180mg/dl  
Two or three daily insulin injections | Self-Management Profile to assess five domains of type 1 diabetes selfmanagement (DSMP). (used to assess SMC)  
The Physician Satisfaction Questionnaire to rate the quality of the patient-provider relationship, adequacy of collection of clinical information, and efficiency of the visit (PSQ) (used to assess SMC)  
Daily blood low, moderate, or high SMC. The demographics of the IT and UC groups were similar the only significant differences were as follows: there were 65 males in the IT group compared to 47 in the UC group. Children in the low SMC group were older, more likely to be members of a racial minority, and in families that were
3 to 4 daily glucose tests
Annual visits with dietician and psychologist
Quarterly clinic visits with the diabetes nurse and endocrinologist.
Participation in systematic diabetes education.

Hypoglycemia Diary

4% to 5% glucose levels record.

Hemoglobin A1C was 7.8±0.9% for IT and 8.6±1.1% for UC. All three SMC groups receiving IT had lower hemoglobin A1C levels than those receiving UC. The low SMC group showed the most improvement in hemoglobin A1C levels during IT compared to the moderate SMC groups.
or high SMC groups compared to the UC counterparts. Hemoglobin A1C levels increased with UC among the low SMC group however there was no change in levels among the moderate or high SMC groups receiving UC. Implications: Youth with type I diabetes and low self-management competence should not be denied access to intensive therapy since
| 6. McGuinness, C. & Cain, M. (2007) | Glycemic control has been inconsistent in children and adolescents | Determine if participation in research can have a positive effect on the education and management of disease of children and young people with diabetes. | Key concepts: self-management | 44 participants aged 6-17 years with type I diabetes among pediatric clinics | Correlational | 23 item questionnaire that evaluated the impact of the patient’s own involvement on the management of their own diabetes and their view of clinical trial participation | Pre-trial findings showed one third of the subjects had 4 or more injections per day and 64% tested blood glucose levels at least four times per day. Older children had significantly higher number of injections per day. 83% | they may derive the most glycemic benefit. Self-management behaviors are well correlated with hemoglobin A1C levels. |
of subjects did not express any concerns about the increase in injection regimen for the trial and 97% stated they would continue the regimen post trial. 56% indicated an increase in diabetes knowledge from involvement in the trial and 86% indicated a positive response to more frequent clinic visits. Implications: Increased contact with providers that
<table>
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<tr>
<th>Reference</th>
<th>Summary</th>
<th>Methods</th>
<th>Sample Size</th>
<th>Design</th>
<th>Tools</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Nansel, T. et al. (2007)</td>
<td>Adolescence is a time during growth and development that has poor glycemic control.</td>
<td>Assess the cognitive, behavioral, and physiological outcomes of a self-regulation intervention for youth with type I diabetes. Examine differing intervention</td>
<td>81 youth between the ages of 11 to 16 years with type I diabetes and their parents</td>
<td>Correlational</td>
<td>29 item Diabetes Self-Management Profile was used to measure adherence to insulin administration, self-care adjustment, dietary practices, blood glucose</td>
<td>Youth that received the self-regulation intervention had lower hemoglobin A1C levels than those in the control group. (control group showed a 4.15 increase from baseline in...</td>
</tr>
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</table>
effects between pre- and middle adolescents.

<table>
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<tr>
<th>monitoring, and exercise</th>
<th>hemoglobin A1C percent over normal</th>
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<tr>
<td>Self-Efficacy for Diabetes Self-Management scale</td>
<td>and the intervention group had a 4.76 decrease from baseline in hemoglobin A1C percent</td>
</tr>
<tr>
<td>measured the confidence in one’s ability to carry out diabetes regimen</td>
<td>The intervention had a greater effect on lowering hemoglobin A1C levels in older youth (14-16 years) than younger youth (11-13 years)</td>
</tr>
<tr>
<td>Outcome Expectations of Diabetes Self-Management Positive and Negative scales</td>
<td>Youth in the intervention group reported lower positive outcome expectations and higher</td>
</tr>
</tbody>
</table>
Diabetes Quality of Life scale measured impact, worry, and satisfaction.

Hemoglobin A1C levels measured glycemic control.

Intervention satisfaction questionnaire measured youth and parent satisfaction with the program and trainer on a 1-6 scale (strongly agree-strongly disagree).

Diabetes impact. No significance was found on adherence, worry, or satisfaction in any age group.

Implications: Self-management skills can be mediated by trained non-professionals as an effective approach to preventing decline in glycemic control during middle adolescence.
### Adolescents’ Perceptions of Self-Care Practices

| 8. Kyngas, H. (2000). | Adolescents need to comply with long-term care recommendations for diabetes management to prevent diabetes complications. | To what extent do adolescents with diabetes comply with the health regimens? What kind of factors are connected with the compliance of adolescents with diabetes? | **Theoretical model of compliance of adolescents with diabetes (Kyngas, 1999).** Concept of Compliance = an active, intentional, and responsible process whereby young persons with diabetes aim to maintain their health in collaboration with the health care staff. The following improve compliance according to Kyngas’s theory: Motivation, the results of care, a sense of normality, adequate energy and willpower for care, and some fear. Support of parents and results of care improve motivation, | 300 adolescents (aged 13 to 17) with diabetes | **Exploratory/Descriptive** | 58 item Questionnaire formatted with a 5-point Likert Scale that contained items on compliance, sense of normality, support from nurses; physicians; friends; and parents, energy and will power, motivation, subjective experience of results, impact of care and treatment, attitude, fear of complications, and fear of hypoglycemia, self care behaviors, collaboration | Adolescents most fully complied with insulin treatment (81%). Dietary regimen was the second item adolescents were most compliant to follow (25% in good compliance and 38% in satisfactory compliance). Home monitoring had the least compliance with 51% of the adolescents reporting poor compliance. |
and energy and willpower. This study expanded on the theory using the additional factors of attitude and impact of care.

There was a significant relationship between increased compliance in adolescents and the following background variables: having the disease for no more than 1 to 3 years, regular exercise, no smoking, no drinking of alcohol, and hemoglobin A1C levels less than 7%. Compliance and support from friends had a statistically significant
connection.
Good motivation, a strong sense of normality, energy and willpower, support from parents; physicians; and nurses, a positive attitude toward the disease and its treatment, no threat to one’s social well-being, and fears of complications improved compliance.
Implications: Adolescents need to be involved in the planning and decision
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<tr>
<td>Identify predictors of good compliance among adolescents with a chronic disease such as asthma, epilepsy, JRA, and IDDM. Research Question: What factors</td>
<td>Modified the Theoretical Model of Compliance of Adolescents with Diabetes (Kyngas, 1999) to apply to other chronic illnesses by studying the concept compliance in relationship to the other concepts of the theory including sense of normality, support from nurses; 1200 adolescents between the ages of 13 and 17 years with asthma, epilepsy, JRA, or IDDM.</td>
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</table>
However, very little is known about the factors that predict compliance in adolescents with a chronic disease. predict the compliance of adolescents with chronic disease? physicians; friends and parents, energy and willpower; motivation; subjective experience of results; impact of disease; attitude; fear of complications; hypoglycaemia; seizures. Also included fear of asthma attacks and uncontrollable pain. **Concept of compliance defined as** = an active, intentional and responsible process of care, in which the individual works to maintain his or her health in close collaboration with the health care personnel (Kyngas, 1999).

support from nurses; physicians; friends and parents, energy and willpower, motivation, subjective experience of results, impact of disease, attitude, fear of complications, and fear of hypoglycaemia, fear of asthma attack, seizures, and uncontrollable pain. 12 Questions pertained to background variables

Implications:

- The second most powerful predictor is energy and willpower (6.69 times more likely to comply than those without energy and willpower). Adolescents with motivation are 5.28 times more likely to comply than those without motivation. Other predictors include support of parents, friends, and physicians.
| 10. Skinner, T. & Hampson, S. (2001) | The family environment influences the self-care, well-being, and | Test the utility of illness beliefs, conceptualized as personal | **Personal Model** (grounded in a general theory of cognition) Five components: | 74 adolescents between the age 12-18 years with | Predictive correlational | Demographic information questionnaire (gender, age, duration of) | Girls have poorer glycemic control and report higher |  
Nurses need to individualize care for each adolescent and involve them in the planning to improve compliance. Providers need to encourage parents and other support people to offer positive feedback, motivation, and inclusion of the adolescent in planning to improve compliance. |
| models of diabetes, in predicting self-care, well-being, and subsequent glycemic control in adolescents with type I diabetes. | 1) Identity 2) Cause 3) Consequences - perceived severity of diabetes, perceived susceptibility to complications, perceived impact of diabetes 4) Timeline 5) Control/cure - beliefs about the effectiveness of treatment | type I diabetes | disease, parental occupation) The Well-Being Questionnaire (depression and anxiety) The Summary of Diabetes Self-Care Schedule (diet, exercise, blood glucose monitoring, injecting insulin) The Personal Models of Diabetes Questionnaire (effectiveness of treatment to control diabetes, effectiveness of | levels of anxiety, depression, greater impact of diabetes in their lives, and that their diabetes is more serious than boys. Lower socioeconomic groups had poorer diets and poorer glycemic control. Anxiety was predictive of poor glycemic control. Improved dietary self care was predictive of better glycemic control. Change in the |
| Hemoglobin A1C Levels | treatment to prevent complications, perceived seriousness of diabetes, and perceived impact of diabetes | perceived effectiveness of treatment to control diabetes was correlated significantly with change in dietary self-care but not with any other self-care measure. Implications: Health care providers need to understand adolescents’ beliefs about their diabetes to offer information and support their decisions about diabetes self-care because their beliefs about their disease |
It is essential that patients with diabetes adhere to self-care to maintain optimal glycemic control to prevent complications associated with diabetes.

**Hentinen (1987)** adherence to self-care is an active, responsible and flexible process of self-care, in which the person works to maintain his or her health in close collaboration with health care staff, instead of simply following the rules that are prescribed.

213 adults between the ages 17 and 65 years with type 1 diabetes descriptive study design

Biochemical Adherence to insulin treatment was highest among the subjects (84% daily, 15% almost daily). Dietary was the second self-care regimen most closely adhered to with 67% of the subjects eating regular main meals. 48% of the subjects assessed the...
self-care?

indic
hemoglobin A1C Lab Levels

content of the meals daily and 30% almost daily. The majority of subjects (46%) used a flexible mode of self-care rather than a rigid adherence. Poor metabolic control (hemoglobin A1C), smoking, and living alone increased neglect to self-care. Gender, age, other diseases, education, or duration of disease had no significant relationship to
adherence of self-care. Implications: Health care providers should assess self-care behaviors individually and not label individuals with diabetes as good or poor compliers. Individuals living alone may need specialized support and attention to manage their care to achieve optimal glycemic control.
| 12. Hains, A. et al (2006) | Adolescents with type I diabetes have increased knowledge compared to younger children, but have often been found to have decreased adherence to self-care. | Examine the relationship among negative attributions of friend reactions within a social context, anticipated adherence difficulties, diabetes stress, and metabolic control of adolescents with type I diabetes. | **Social information-Processing Model:**  
1) filtering only specific aspects of the situation  
2) incorrectly appraising others’ intentions  
3) assessing the situation as threatening in terms of potential consequences  
Adolescents with type I diabetes may perceive adherence behavior as difficult in social situations due to a fear of negative friend evaluations. | 104 adolescents age 11 to 18 with type I diabetes | **Predictive correlational** | **Demographic questionnaire** with items about sex, age, race, grade, duration of diabetes, and how many friends has the participant told about their disease. **Attribution of Friend Reactions questionnaire-7 social scenarios where adolescent is faced with adherence situation followed by 6 questions pertaining to adolescent expected thoughts about** | **Negative attribution of friend reactions had a significant positive relationship with diabetes stress and a positive relationship with anticipated adherence difficulties. Anticipated adherence difficulties was positively correlated with diabetes stress, but not directly related to metabolic control. Negative attribution of friend** |
friends’ reactions and 2 questions about likelihood of adherence.

Diabetes Stress questionnaire - 65 item questionnaire to assess stressors related to diabetes.

Hemoglobin A1C - measure metabolic control.

Reactions had no direct relationship with metabolic control. Both negative attribution of friend reactions and anticipated adherence difficulty had an indirect relationship to metabolic control through the variable diabetes stress.

Implications: Adolescents with type I diabetes need to be assessed for negative attributions toward self-
| care in social situations since this can lead to anticipated adherence difficulty and increased diabetes stress and ultimately poor metabolic control. |