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The relationship between perceived self-efficacy, regimen adherence, and glycemic control in adolescents with Type 1 diabetes mellitus: A pilot study

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THE RELATIONSHIP BETWEEN PERCEIVED SELF-EFFICACY, REGIMEN ADHERENCE, AND GLYCEMIC CONTROL IN ADOLESCENTS WITH TYPE 1 DIABETES MELLITUS: A PILOT STUDY

A Thesis

by

ANTONIETA P. ALTEZA

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ABSTRACT

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This pilot study examined the relationship between perceived self-efficacy and regimen adherence on glycemic control among adolescents, aged 11 to 18 years, with Type 1 Diabetes Mellitus. Thirty-six adolescent-parent dyads participated in this study. Bivariate analysis using Pearson product moment-correlations identified no significant relationships among the variables. Regarding treatment regimen, adolescents on insulin pumps had a mean glycosylated hemoglobin level of 8.09% whereas adolescents on daily insulin injections had a mean glycosylated hemoglobin level of 9.26%. Bandura's theory of self-efficacy provided the theoretical framework for this study. The Self-Efficacy for Diabetes scale and Questionnaire of Self-Care Behaviors scale were used to assess self-efficacy beliefs and adherence behaviors. Nurses are encouraged to continue to incorporate the self-efficacy concept in assisting adolescents to develop their own strategies for long-term disease self-management.

DEDICATION

Gabriella,

this is for you.

ACKNOWLEDGMENT

Many people have provided the encouragement and support that helped me complete this thesis. First, I would like to thank all the families for participating in this study. I learned so much from them!

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CHAPTER 1

INTRODUCTION

Type 1 diabetes mellitus (DM) is one of the most common chronic metabolic disorders in children. There are 13,000 new cases diagnosed annually. Long-term complications include retinopathy, nephropathy, and cardiovascular disease (American Diabetes Association [ADA], 2001b). Type 1 DM also leads to significantly reduced life expectancy in adulthood compared to persons of similar age in the population. Furthermore, the economic costs of diabetes are extremely high, with an estimated $98 billion spent on disease care in 1997 (Center for Disease Control, 1999).

The primary objective of treatment for persons with Type 1 DM is glycemic control. Achieving near-normal blood glucose levels requires comprehensive education in self-management (Mensing et al., 2001). Intensive treatment programs include the following components according to individual patient need: appropriate frequency of self-monitoring of blood glucose, medical nutrition therapy, regular exercise, physiologically based insulin regimens, periodic assessment of treatment goals, and continuing education and reinforcement (ADA, 2001b). The Diabetes Control and Complications Trial (Diabetes Control and Complications Trial Research Group [DCCT], 1994) conclusively demonstrated that euglycemia delayed and reduced the occurrence of the chronic debilitating complications of the disease. These research findings underscore the need to

increase the emphasis upon intensive self-management skills by persons with Type 1 DM and their families.

Statement of the Problem

There is increasing interest in the interrelationships between psychosocial factors and health behaviors among children and adolescents. For young individuals coping with a chronic disease these variables may make a critical difference between adequate and dysfunctional health maintenance. Diabetes education has long been a cornerstone of the treatment regimen. Knowledge alone however, is an insufficient predictor of individuals' capabilities to incorporate the necessary self-care behaviors into their activities of daily living (Hurley & Shea, 1992). In a meta-analysis of 26 diabetes studies that examined patient compliance with prescribed medications, the relationship between knowledge and compliance varied greatly (Nagasawa, Smith, Barnes & Fincham, 1990). Managing Type 1 DM is a difficult task at any age, but particularly during adolescence, when these young people are experiencing a whirlwind of physical, social, and psychological changes (Weissberg-Benchell & Antisdel, 2000). The challenge for nursing focuses on helping adolescents develop their own strategies for long-term disease management. It is crucial for the health care provider to know the issues that are of greatest importance in achieving and maintaining adequate metabolic control during adolescence.

Diabetes is unique among chronic illnesses in the degree that patient behavior influences both the application and outcomes of therapy (Marrero, Peyrot & Garfield, 2001). Indeed, there is emerging evidence suggesting that in order to effectively implement intensive regimens designed to achieve optimal glycemic control, it is necessary to address a variety of behavioral issues among diabetic patients (Grey,

Boland, Davidson, Yu, & Tamborlane, 1999; Hampson et al., 2000; Mendez & Belendez, 1997). The literature provides some guidance in the management of Type 1 DM in adolescents, but many important questions remain. The purpose of this pilot study therefore, is to investigate if a relationship exists between perceived self-efficacy and regimen adherence on glycemic control in adolescents with Type 1 DM.

Research Questions

Because psychosocial factors are relevant to nearly every aspect of diabetes management, the primary aim of this pilot study is to examine the role of two factors: perceived self-efficacy and regimen adherence. The research questions are two-fold:

1. Is there a relationship between perceived self-efficacy and glycemic control in adolescents with Type1 DM?
2. Is there a relationship between regimen adherence and glycemic control in adolescents with Type 1 DM?

Significance of the Problem

About 151,000 individuals less than 20 years of age have diabetes. Approximately one in every 400-500 children and adolescents have Type 1 DM. The highest incidence is among youths aged 10 to 14 years (Karvonen et al., 2000). There are no gender differences in the prevalence rates; however, Caucasian children seem to be more at risk for diabetes than African-American children (Harris, 1998; Sperling, 1996).

Diabetes was the seventh leading cause of death listed on U.S. death certificates in 1996, according to the Center for Disease Control's National Center for Health Statistics (CDC, 1999). Poor disease control leads to significant morbidity and mortality because

of its short-term and long-term complications. The most frequent acute complications include hypoglycemia, hyperglycemia, and diabetic ketoacidosis (DKA). The basic underlying mechanism for DKA is a combination of insulin deficiency and increased counterregulatory hormones, leading to the release of free fatty acids into the circulation from adipose tissue and to unrestrained hepatic fatty acid oxidation to ketone bodies, with resulting ketonemia and metabolic acidosis (ADA, 2001d). The annual incidence rate for DKA from population-based studies ranges from 4.6 to 8 episodes per 1,000 patients with diabetes, with a trend towards increased hospitalization rate in the past two decades (ADA, 2001d). DKA is the main cause of death in Type 1 DM patients under 20 years of age, with the overall mortality rate around 7% (CDC, 1999). The life expectancy of a child with diabetes at the age of 10 is 44 years, whereas his or her age mates without diabetes have a life expectancy of 72 years (CDC, 1999).

An eight-year longitudinal cohort study involving 76 individuals traced the clinical course of diabetes from adolescence to young adulthood. Mean glycosylated hemoglobin levels peaked in late adolescence and were worse in female patients (an average of 11.1% at 18 to 19 years of age). The proportion of participants who were overweight increased during the study period from 21% to 54% in female patients and from 2% to 28% in male patients. Serious diabetes-related events included death in one patient due to diabetic ketoacidosis and cognitive impairment in two patients. The researchers concluded that behavioral problems in adolescence were important in influencing later glycemic control (Bryden et al., 2001).

The brain and other neural structures are critically dependent upon glucose for normal neuronal functioning (Holmes, O'Brien & Greer, 1995). Large imbalances in glucose can

have adverse physiological and neurological effects. Evidence of disrupted central nervous system functioning has been found in youths with Type 1 DM in electrophysiological studies. Decrements in attention and mental efficiency occur at higher blood glucose levels. Repeated episodes of hypoglycemia may lead to cumulative or enduring cognitive deficits (Northam et al., 2001).

Youth with Type 1 DM with early or late onset may be at differential risk for deficits in Performance IQ and Verbal IQ. The occurrence of these cognitive deficits, coupled with school absences, may place youth with Type 1 DM at an increased risk for scholastic problems. Although the academic achievement of youth with Type 1 DM is generally in the average range, there is evidence that significantly more of these youth experience more school difficulties (Holmes et al., 1995).

The Diabetes Control and Complications Trial (DCCT, 1994) was a multicenter, randomized research study involving 1441 patients, from 13 to 39 years of age, in the United States and Canada. From this total sample, the effects of intensive therapy were investigated in a subset of adolescents aged 13 to 17 years. One hundred and twenty five adolescents with Type 1 DM but with no retinopathy at baseline (primary prevention cohort) and 70 adolescent subjects with mild retinopathy (secondary intervention cohort) were randomly assigned to receive either (a) intensive therapy with an external insulin pump, together with frequent daily blood glucose monitoring, or (b) conventional therapy with one or two daily insulin injections and once-daily monitoring. Subjects were followed for a mean of 7.4 years. In the primary prevention cohort, intensive therapy decreased the risk of having retinopathy by 53% in comparison with conventional therapy. In the secondary intervention cohort, intensive therapy decreased the risk of retinopathy

progression by 70% and the occurrence of microalbuminuria by 55%. In addition, motor and sensory nerve conduction velocities were faster in intensively treated subjects.

The role of chronic hyperglycemia in the development of complications has been demonstrated empirically and conclusively. The magnitude of morbidity and mortality related to childhood diabetes, the difficulty that many adolescents and their families face in implementing their daily regimen tasks, and the importance of optimal glycemic control to prevent complications make management of this disease a priority for nursing (Brink, 1997; DiLiberti & Lorenz, 2001).

Assumptions and Limitations

Two assumptions were identified within this pilot study. First, it was assumed that the participants were able to understand the items on the questionnaires and would answer truthfully. Second, glycosylated hemoglobin (HbA1c) was considered the best predictor of glycemic control.

There were a number of limitations that should be considered when interpreting the descriptive results of the study. One limitation was that the purposive, nonprobability sampling technique allowed self-selection to introduce bias into the study as those who volunteered as participants represented a unique group of individuals. Additionally, the cross-sectional design of the study limited the measurement of the variables of interest to a single point in time which prevented obtaining a description of how self-efficacy or regimen adherence changes over time. Finally, glycemic control may be influenced by several factors other than those being studied, such as daily stress variability, learned resourcefulness, coping styles, illness, hormonal changes, and social support (Aikens, Wallander, Bell, & Cole, 1992; Grey et al., 1999; Peyrot, McMurray & Kruger, 1999).

The composition of the sample was limited to established insulin-dependent young diabetics and generalizability of the results should be viewed with caution. Among this adolescent diabetic group, there may be extraneous variables that confound the results. Sociodemographic variables such as age and gender, and disease-related variables such as duration, severity, and number of complications may influence the findings (Burns, Green, & Chase, 1986; Burroughs, Pontius, & Santiago, 1993; Wysocki, Hough, Ward, & Green, 1992).

Another limitation of the study was the exclusive reliance on self-report measures. Self-report measures overestimate adherence when compared with other measures because self-report measures rely on memory and willingness to report. Given the difficulties in remembering recurring behaviors, the tendency is to rely on recent events as indicators of longer term events (Dunbar-Jacob & Schlenk, 2001). Steps were taken by the researcher to reduce possible response biases. The youth were asked to report on their typical adherence behaviors rather than on correct behaviors. This method decreases the potential for socially desirable responses (Johnson, 1992). In an effort to check the validity of the adolescents' self-reports, the adolescents' adherence scores were compared with their parents' scores. Previous research on adolescents' reports of risky health behaviors also yielded valid reports (Gerrard, Gibbons, Benthin & Hessling, 1996). Other data-gathering methods such as interviews and direct observation may also be beneficial to obtain corroboration of the adolescents' perceptions; however, implementation of these other methods was not possible given the design of the study.

Finally, reliability of the Questionnaire of Self-Care Behaviors (QSCB) is only moderately adequate since it is a relatively new instrument (Rempala, 1999). Whenever

new instruments are used, the reliability and validity of the instrument are not firmly established. The interpretation of results is always considered tentative until others have reported their experience with the measure based on other samples and settings (Bradley, 1994).

Definition of Terms

Perceived self-efficacy – **conceptual**: judgements of one's own capability to monitor, plan, and implement activities of daily living related to diabetes

operational: score on the Self-Efficacy for Diabetes (SED) scale completed by the adolescent

Adherence – **conceptual**: extent to which behavior coincides with the diabetes regimen prescription provided by the health care team

operational: score on the Questionnaire of Self-Care Behaviors (QSCB) scale completed by both the adolescent and a participating parent

Adolescents – male and female subjects aged 11 to 18 years

Established Type 1 diabetes mellitus – diagnosed with the disease for at least 1 year

Glycemic control – HbA1c value within the last 6 months

CHAPTER II

REVIEW OF LITERATURE

The review of literature is organized around the primary variables of interest: the theoretical framework of self-efficacy, regimen adherence, and glycemic control. Furthermore, the nature of Type 1 diabetes mellitus, the adolescent developmental stage, and parental influence on regimen adherence are also discussed.

Theoretical Framework – Bandura's Theory of Self-Efficacy

Perceived self-efficacy has been shown empirically to be an influential mechanism in health behavior change. The theory of self-efficacy has produced a considerable amount of research and has been applied to understanding, predicting, and modifying a broad range of behavior related to health and illness. Since its promulgation in the 1970's, self-efficacy has become progressively more visible in the health literature (DeVellis & DeVellis, 2001). From a combined database search into Medline and PsychINFO, entering the text word "self-efficacy" reveals no citations between 1965 and 1975, 534 citations between 1976 and 1985, and 8,703 citations between 1986 and 2001. It is clear therefore, that self-efficacy is an influential concept in contemporary health literature.

The theory of self-efficacy originated from social learning theory, which in turn emanated from the principles of operant conditioning (DeVellis & DeVellis, 2001).

These principles explained that behavior is determined by the consequences it produces. Rotter's (1954) social learning theory conveyed the ideas underlying these principles into the realm of more complex, cognitively influenced, social behavior. Two critical determinants of behavior, according to social learning theory, are the value individuals place on a specific outcome and the expectancy that the behavior in question will produce that outcome (DeVellis & DeVellis, 2001). "The occurrence of a behavior in a person is determined not only by the nature or importance of goals or reinforcements but also by the person's anticipation or expectancy that these goals will occur" (Rotter, 1954, p. 102). In other words, people will behave in a certain manner if they believe their behavior will produce a desired effect.

Bandura developed a separate social learning theory largely independent from Rotter (Woodward, 1982). Distinct additions in Bandura's theory were imitation as a process through which behavior could be acquired and later, the concept of self-efficacy. Bandura changed the name of his theory from social learning theory to social cognitive theory. This change reflected the broader scope of his theory and the central contribution of thought processes to motivation, action, and affect (Bandura, 1986).

Social cognitive theory provides the theoretical basis for the use of the self-efficacy concept to understand diabetes self-management in adolescents. The degree to which adolescents follow their diabetic regimen may be influenced by self-efficacy, that is, their level of confidence in their ability to monitor, plan, and implement activities of daily living related to their diabetes (Bandura, 1977b). This theory proposes that behavior is the result of cognitive processes that people develop through the social acquisition of

knowledge. Self-efficacy, "a judgement of one's capability to accomplish a certain level of performance," is the central concept of the theory (Bandura, 1986, p. 391).

In this social learning analysis, perceived self-efficacy asserts that individuals' confidence in their ability to perform a task determines which behavior they will engage in, how long they will persist in the face of obstacles and aversive experiences, and how much effort they will expend to achieve their goals. Expectations of personal efficacy are derived from four sources of information. **Enactive attainment** provides the most influential efficacy information because it is based on personal mastery experiences. The other sources include the **vicarious experiences** of observing others succeed through their efforts, **verbal persuasion** that one has the ability to cope successfully, and the **physiological state** from which people judge their level of anxiety and vulnerability to stress (Bandura, 1977a). The consequences of self-efficacy are the behaviors that people undertake and the outcomes that follow the behavior.

In the self-efficacy model, **knowledge**, **outcome expectations**, and **incentive to action** collectively determine the behavior that follows and leads to the outcome. Knowledge is necessary, but alone is an insufficient predictor of behavior. The expectation that behavior will or will not be related to the outcome and the value of the outcome to the individual constitute an outcome expectation. Finally, no matter how capable one is of performing the behavior, motivation or action incentive is required to invoke self-efficacy (Bandura, 1977b; Bandura & Adams, 1977).

A substantial amount of research in the area of self-efficacy and health exists in the literature. Early empirical tests of this theory were implemented in clinical trials investigating phobias and systematic desensitization (Bandura & Adams, 1977; Telch,

Bandura, Vinciguerra, Agras, & Stout, 1982). Results from these studies revealed that self-efficacy predicted behavior and verified that interventions could enhance self-efficacy beliefs. In his book, Bandura (1997) summarized health functioning in relation to the biological effects of self-efficacy, including pain tolerance and biological markers of distress, the role of self-efficacy in health promoting behavior, and the role of self-efficacy beliefs in recovery from heart attacks. Other researchers also studied self-efficacy in relation to health behavior (Maddux, 1995), physiological stress responses (O'Leary & Brown, 1995), addictive behaviors (DiClemente, Fairhurst & Piotrowski, 1995), anxiety disorders (Williams, 1995), and depression (Maddux & Meier, 1995). The overall conclusion emerging from these studies is that self-efficacy is an important variable for health research and interventions.

Self-efficacy theory has significant implications for diabetes self-care. Because the regimen required to control diabetes requires various situation-specific self-management tasks such as monitoring blood glucose or treating a hypoglycemic reaction, there is a pragmatic interconnection between perceived self-efficacy and self-care of diabetes. (Hurley, 1988). Possession of skills alone, however, does not guarantee successful execution of the act because competent functioning requires the ability to use those skills in appropriate combinations under diverse sets of circumstances (Bandura, 1986). For example, an insulin-requiring diabetic individual may know the technique of fingerstick testing and the parameters of normal blood glucose levels. This person may also have seen a self-monitoring diary to document the results. Someone lacking the ability to apply skills in the appropriate combinations and contexts, however, may not recognize that a means of accomplishing the goal of understanding the effect of insulin on blood

glucose levels is to discern glucose patterns over several days. A more efficacious person, according to Bandura's definition, would be able to make the connection between his or her basic skill of testing blood and the availability of a logbook for pattern recognition to achieve a system that facilitates understanding of the relationship among the components of the diabetic regimen. This example illustrates that mere possession of the requisite skills and the presence of external resources does not guarantee successful performance. The individuals' belief that they can coordinate the skills into an orchestrated behavioral sequence is also an important part of the equation.

Measuring Self-Efficacy

A few research studies made self-efficacy operational for individuals with diabetes. According to Maibach and Murphy (1995), self-efficacy scales must be tailored to specific domains of functioning. Efficacy judgements are a function of both the specific behaviors and situational contexts in which they occur. Previous research related to self-efficacy suggests that for self-efficacy scores to have a strong predictive value related to particular behaviors, the items must be very specific (Anderson, Funnell, Fitzgerald, & Marrero, 2000). Crabtree (1986) developed a scale to measure self-efficacy of adults who self-managed their treatment regimen either by diet alone, oral agents, or insulin. Although the researcher hypothesized that the interaction of self-efficacy and social support would predict diabetes self-care, the findings revealed that neither social support alone nor the interaction between social support and self-efficacy predicted self-care. The diabetes self-efficacy scales that represented the specific behavior of general management, diet, and exercise, however, were successful predictors of related self-care activities. Grossman, Brink, and Hauser (1987) developed the Self-Efficacy for Diabetes

scale to measure the self-efficacy of adolescents. The results indicated that boys and girls had similar diabetes self-efficacy beliefs; however, a significant positive correlation was found only with adolescent girls.

The Insulin Management Diabetes Self-Efficacy Scale (Hurley, 1988) is a measure of individuals' beliefs in their ability to organize and implement their care related to insulin administration, monitoring, and management. The Diabetes Empowerment Scale (Anderson et al., 2000) is a measure of diabetes-related psychosocial self-efficacy with three subscales: managing the psychosocial aspects of diabetes, assessing dissatisfaction and readiness to change, and setting and achieving diabetes goals.

Research studies in diabetes have demonstrated the effect of perceived self-efficacy on the adherence behavior of adolescents (Griva, Myers & Newman, 2000; Grossman et al., 1987; Littlefield et al., 1992) and diabetes-specific conflict among parents and children (Steinberg, 1998). Changes in diabetes self-efficacy as a result of psychosocial interventions were also studied (Grey et al., 1999; Rubin, Young-Hyman & Peyrot, 1989). Findings from these clusters of studies support the application of self-efficacy to diabetes self-care.

Type 1 Diabetes Mellitus

Diabetes mellitus is a clinical syndrome characterized by elevated blood glucose levels due to deficiency or diminished effectiveness of insulin (ADA, 2001a). The revised classification scheme identifies two major classes of diabetes: Type 1 and Type 2. These designations replace the historic nomenclature of insulin-dependent diabetes mellitus (IDDM) and non-insulin-dependent diabetes mellitus (NIDDM). Type 1 involves pancreatic beta-cell destruction, usually by an autoimmune process, subsequently leading

to absolute insulin deficiency. This classification represents approximately 5 to 10% of cases. Type 2, which affects mostly adults, is characterized by an impaired physiological effectiveness of insulin (ADA, 2001a; Frongia, Pascutto & Sechi, Soro, & Angioi, 2001). Abnormalities in carbohydrate, fat, and protein metabolism occur due to the deficient action of insulin on target tissues.

Classes of Type 1 Diabetes Mellitus

Immune-mediated diabetes, previously encompassed by the terms insulin-dependent diabetes, Type 1 diabetes, or juvenile-onset diabetes, results from a cellular-mediated autoimmune destruction of the beta-cells of the pancreas . Markers of the immune destruction of the beta-cell include islet cell autoantibodies, autoantibodies to insulin, autoantibodies to glutamic acid decarboxylase and autoantibodies to the tyrosine phosphatases 1A-2 and 1A-2β. One and usually more of these autoantibodies are present in 85-90% of individuals when fasting hyperglycemia is initially detected (Decochez et al., 2000). These distinctive markers differentiate children with Type 1 versus Type 2 DM and dictate the treatment modality.

Idiopathic diabetes has no known etiologies. Some of these patients have permanent insulinopenia and are prone to ketoacidosis. A minority of patients with Type 1 diabetes falls into this category, primarily those who are of African or Asian origin. Individuals with this form of diabetes suffer from episodic ketoacidosis and exhibit varying degrees of insulin deficiency between episodes. This form of diabetes is strongly inherited and lacks immunological evidence for beta-cell autoimmunity. An absolute requirement for insulin replacement therapy in affected patients may come and go (Pinero-Pilona, Litonjua, Aviles-Santa, & Raskin, 2001).

The goal of disease management is to achieve and maintain blood glucose levels as normal as possible, while allowing for normal growth and development (ADA, 2001c). Daily self-care is complex and demanding. The recommendations for optimal management include: several daily insulin injections or the use of an insulin pump, self-monitoring of blood glucose, a prescribed meal plan, and adjustment of food, insulin, and exercise according to blood glucose patterns (Grey, 2000).

Measuring Glycemic Control

Glycosylated hemoglobin (HbA1c) is the joining of hemoglobin and glucose. Specifically, hemoglobin becomes glycosylated in red blood cells in proportion to an individual's average serum blood glucose level. This glycosylation is nonreversible and therefore lasts as long as the life of the red blood cell, which is about 120 days. Thus glycosylated hemoglobin level reflects a time-averaged blood glucose concentration over the previous two to three months (Hamera, 1992). This method permits better monitoring of treatment outcome over longer time segments than does occasional fasting or random glucose determinations. As such, the HbA1c has become the most widely accepted index of metabolic control in both clinical and research settings. HbA1c values less than 7% (150 mg/dl) indicate good control of diabetes (ADA, 2001b). For the purposes of this pilot study, the most recent HbA1c of the participating adolescent was retrieved from that subject's medical record.

Regimen Adherence

Self-care in diabetes is crucial. As much as 98% of diabetes management is self-care (Anderson, 1995; Jacobson, 1996). Diabetes regimens have multiple components. Rodin & Salovey (1989) noted that lowest adherence rates occur when patients who have

chronic disorders require lifestyle changes; when treatment is complex, intrusive and inconvenient; when behaviors are not directly supervised; and when symptom reduction instead of cure is the goal. Regimen adherence has a large effect on metabolic control, yet non-adherence prevents the realization of potential benefits from therapy and produces inestimable costs in both human and economic terms (Clark, 1998).

A review of the adherence literature suggests that as a group, patients with diabetes are largely nonadherent, with studies showing between 23% and 93% nonadherence rates (Kurtz, 1990). Previous findings concerning adherence to diabetes self-care vary widely. Some researchers demonstrated that diabetic patients control their blood glucose regularly (Peveler, Davies, Mayou, Fairburn, & Mann, 1993), while others presented results to contradict these findings (Richmond, 1993; Evans et al., 1999). In a confidential survey of 144 adolescents, 25% admitted to missing insulin injections and 29% falsified blood glucose readings because the true values were elevated (Weissberg-Benchell et al., 1995). Many teens reported deliberately missing insulin injections because they did not think the evening dose was necessary. The teens also fabricated blood test values because of perceived pressure from family and physicians to produce good results. Musey et al. (1995) indicated that readmissions for DKA were primarily due to major deviations from recommended therapy, such as insulin omission. For young women in particular, psychological problems complicated by eating disorders may be a contributing factor in 20% of recurrent ketoacidosis. Factors that may lead to deliberate insulin cessation include fear of weight gain with improved metabolic control, fear of hypoglycemia, rebellion from authority, and stress of chronic disease (Polonsky et al, 1994).

Sackett and Haynes (1976) defined the term "compliance" as the extent to which the patient's behavior coincides with the clinical prescription. The authors did acknowledge that this term might be troublesome to those who view the development of a clinical prescription "as an essentially dictatorial process in which a clinician... issues an edict to be obeyed" (Sackett & Haynes, 1976, p.1). Some researchers have suggested that "adherence" might imply a more holistic view about self-care than compliance, because adherence places the patient in a central position and minimizes the authoritative practitioner-submissive patient model of health care (Lutfey & Wishner, 1999; McNabb, 1997). Others have argued against the conceptual contention between compliance and adherence and have suggested the terms "collaborative diabetes management" or "self-management" instead of the previously used terms (Glasgow & Anderson, 1999). The concept of self-management epitomizes patient empowerment philosophy. "Adherence to self-care" implies 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 (Toljamo & Hentinen, 2001). In addition, Hernandez (1997) has suggested an "integration" paradigm in which collaborative alliance relationships are developed with patients who are viewed as co-experts.

Research Studies on Adherence and Glycemic Control

Because poor adherence to treatment regimen has a significant impact on the outcomes of care and subsequently on health care costs, increasing attention has been given to exploring the various predictors of adherence (Dunbar-Jacob & Schlenk, 2001). In recent years, a number of studies have investigated the relationship between different

psychosocial variables, adherence, and metabolic control in adolescents with Type 1 DM. Several patient cross-sectional studies have suggested that adherence is associated with characteristics. Statistically significant relationships have been identified between adherence and health attitudes (Palardy, Greening, Ott, Holderby, & Atchison, 1998); rapport with health professionals and personal competence for disease self-management (Lo, 1999); coping and adjustment (Jacobson et al., 1990; Murphy, Thompson & Morris, 1998), and self-efficacy (Kavanagh, Gooley, & Wilson, 1993). Of note, one particular research study proposed that psychosocial variables do not directly affect metabolic control, but rather, psychosocial variables affect health care adherence, which in turn, affects metabolic control (Hanson, Henggeler, & Burghen, 1987).

Longitudinal studies offer several advantages over cross-sectional studies, including the examination of predictive relationships and the use of repeated measures to identify trends in adherence over time. Since diabetes is a long-term illness, it would be valuable to understand the underpinnings of persistent differences in adherence; however, strong associations between adherence behaviors and glycemic control have been difficult to obtain in longitudinal studies.

Results of an 18-month longitudinal study of 192 youths indicated that 29% of the variance in glycemic control was predicted by eating frequency and insulin dosage (Johnson et al., 1992). A significant finding of this study was that predictive power was improved when age-homogeneous samples of youth were used. Preadolescents were grouped separately from adolescents in the analysis. The investigators suggested that physiologic changes and the potential to become insulin-resistant during puberty might

be important mechanisms for explaining the type of associations among adherence behaviors and glycemic control outcomes during that age period.

An onset cohort of 61 adolescents and children aged 9 to 16 years with Type 1 DM was studied over a 4-year period (Jacobson et al., 1990). Psychosocial and demographic factors were assessed at study inception and used to examine aspects of adherence in the follow-up. Preadolescents (aged 9 to 12) at study entry were more adherent than patients who were already adolescent (aged 13 to 16) when diagnosed. Using multiple regression analysis, three factors (age, adjustment, ego defense level) accounted for 47% of the variance in adherence. The investigators explained that this finding likely reflected the social transformations of adolescence, including a greater interest in peer relations and increased desire for independence from parents. The results also suggested that individual patient coping and adjustment predicted medically relevant outcomes.

Another research study investigated the relationships between self-care behaviors and illness-specific outcomes in 270 youth with Type 1 DM at three points in time (Hanson et al., 1996). Glycemic control was most strongly related to the semi-structured Self-Care Adherence Interview [SCAI], and second, to the overall quality of the youth's dietary intake. The SCAI also predicted glycemic control over time. Physical activity levels and specific nutritional components from the logs and recalls were generally unrelated to glycemic control.

Measuring Adherence

Measuring adherence behaviors of diabetics can be difficult because there is no known standard of regimen. There is considerable ongoing research and debate regarding methods for assessing adherence in diabetes (Johnson, 1992; Lutfey &

Wishner, 1999; McNabb, 1997). Although regimen adherence is considered important in maintaining stable blood glucose levels, the relation between adherence and metabolic control is not as strong as might be expected. In fact, some researchers have found weak associations between adherence behaviors and metabolic control (Glasgow, McCaul & Schafer, 1987; Johnson, Freund, Silverstein, Hansen & Malone, 1990; Kavanagh, Gooley & Wilson, 1993). Physiologic, developmental, and familial factors have been implicated as some of the reasons for deteriorating glycemic control in adolescents (Delamater et al., 1999; Mortensen & Hougaard, 1997). Disease management is multifaceted. Clinicians and researchers must recognize the independence of the different components of the diabetes regimen. Adherence to one aspect of the regimen may not be highly correlated with other aspects of the regimen (Johnson et al., 1990). According to some studies (Glasgow, 1997; Ruggiero et al., 1997), adult patients with diabetes have more difficulties in adhering to a diet and exercise prescription than to insulin self-injection.

Diabetes researchers typically measure disease adherence through self-report data. It is possible that social desirability may bias the responses, as adolescents may not be truthful when reflecting on their diabetes management. Measures of adherence vary considerably in the literature as there are no universally accepted measures of adherence behaviors. There are disease-specific adherence scales developed for adolescents and their parents. Both the Self-Care Inventory (LaGreca et al, 1995) and the Questionnaire of Self-Care Behaviors (Rempala, 1999) attempted to provide researchers with a standardized, internally consistent measure of adherence. These instruments rely on the report of both the adolescent and the parent on the different self-care activities.

Finally, most diabetes studies employ general measures of psychological functioning. Skyler (1987) noted that "conventional standardized instruments may be irrelevant" and called for measures "designed to assess parameters of specific interest in diabetes" (p. 742). Limited findings indicate that diabetes-specific scales are more predictive of adherence and metabolic control (McKelvey et al., 1993).

Adolescence and Diabetes Self-Management

Research consistently demonstrates that there is a decline in glycemic control during adolescence. The adolescent subgroup of the DCCT study (1994) had higher glycosylated hemoglobin levels when compared to the adult participants (8.06% versus 7.12%), even though the adolescents received more staff support and counseling. Although the reduction in glycemic control is partly attributable to physiologic changes, the decline in self-care behavior in this developmental stage should also be considered.

Ambivalence, upheaval, and re-evaluation characterize the period of adolescence (Kyngas & Barlow, 1995). In psychosocial development, the main conflict in this age group is ego identity versus role diffusion (Erikson, 1959). The adolescent constantly strives to build and confirm a stable identity. The young individual must adjust to a new physical self, cognitive self, and social self (Chigier, 1992). An adolescent without chronic illness often moves through this phase with no physiological repercussions. Adolescents with Type 1 DM are faced with the added challenge of being reminded that they are different from their peers every time they monitor their blood glucose, inject insulin, or eat a snack. Using a grounded theory approach, Kyngas and Barlow (1995) explored the personal meaning and perceived impact of Type 1 DM among 51 Finnish adolescents between 13 and 17 years of age. The adolescents described the disease as: a

nightmare, devil, prison, hell, and death. The adolescents also expressed that the illness controlled and limited their independence. These same themes emerged in other studies (Hentinen & Kyngas, 1992; Kyngas & Hentinen, 1995; Thomas, Peterson, & Goldstein, 1997). The adolescents felt that the demands of intensive treatment intruded into various areas of life, such as school, sports, friendships, and dating. Teens who perceived their diabetes as having a significant impact on their lives were less satisfied, felt that management was more difficult, and felt that diabetes was more upsetting. Teenagers may be particularly sensitive to the impact of diabetes on their social lives. In a study that asked teens to respond to hypothetical social situations, the adolescents indicated they would be less adherent to their diabetes treatment regimen in social situations than they would be at home (Thomas et al., 1997).

Within the context of an adolescent's developmentally appropriate push for independence, teens with diabetes often seek increased freedom in managing their therapeutic regimen. This increased independence may lead to increased nonadherence. Several researchers, in fact, suggest that parental involvement in disease management significantly decreases in adolescence and that poor adherence to the regimen is a common consequence of that decreased supervision (Miller-Johnson et al., 1994; Weissberg-Benchall & Glasgow, 1997; Wysocki et al., 1996).

Wysocki and colleagues (1996) assessed diabetes self-care autonomy among 100 children and adolescents with diabetes. Determinations regarding developmentally appropriate levels of self-care were based on relationships between level of self-care and psychological maturity (cognitive function, social-cognitive development, and academic achievement). Results indicated that excessive self-care autonomy of diabetes

management was associated with decreased treatment adherence, greater diabetes-related hospitalizations and poorer glycemic control.

Disease knowledge and skill in implementing various self-care tasks correlate positively with chronological age (Reid, Dubow, Carey, & Dura, 1994; Steinberg, 1998). As children grow older, they become more able to complete a wider range of regimen tasks for themselves. Few studies, however, have specified the particular ages at which adolescents master specific self-care tasks. Some researchers reported that by the age of 14 years, most children are expected by diabetes professionals to have mastered all aspects of the disease regimen (Giordano, Petrila, Banion, & Neuenkirchen, 1992; Reid, Ellis, Owens, & Jones, 1992). Despite some agreement on general age range at which children learn aspects of self-care such as monitoring hypoglycemia and hyperglycemia, it is not completely clear when children are prepared to manage each of the tasks independently. Moreover, parents and professionals appear to disagree about what ages prior to adolescence that children should master specific regimen tasks (Wysocki et al., 1992).

In addition to diabetes-related tasks, children and adolescents at every age confront normal psychosocial developmental tasks that may facilitate or complicate disease management. An adolescent's developmental status (that is, cognitive, motor, social, and emotional functioning) contributes to the level of self-care competence, the amount of responsibility the adolescent assumes for treatment, and the types of obstacles that complicate management of the disease (Reid et al., 1994). Until the advent of formal operational thinking and abstract thought, however, children and young adolescents lack the cognitive maturity to understand and manage the disease in an operational day-to-day

sense. From a Piagetian framework, as mode of conceptualizing matures, the adolescent's view of the world changes from concrete and egocentric to more abstract and decentered. The development of formal operational thought may help adolescents learn complex relationships between aspects of the treatment regimen, thereby allowing them to assume an increasing amount of responsibility for self-care (Inhelder & Piaget, 1958). Achievement of advanced thinking facilitates the ability to project into the future and makes the avoidance of long-term sequelae relevant as a possible motivating factor for achieving optimal metabolic control (Ingersoll, Orr, Herrold, & Golden, 1986). Similarly, Thomas et al. (1997) found that problem-solving ability increased across age. The authors suggested that adolescents, compared to children and preadolescents, have more complex thought processes and the ability to see more alternatives when presented with a dilemma. Social developments however, such as the increasing focus on peer relationships at this age often compete with many aspects of the diabetes regimen. The decrease in regimen adherence and increase in peer conformity however, may indicate psychosocial vulnerability in adolescents.

One study found that metabolic control and psychological adjustment not only worsened with movement into adolescence, but that age was associated with the manner in which youths coped with their illness (Grey, Cameron & Thurber, 1991). Adolescents used avoidance (smoking, drinking, and staying away from home) and relaxation behaviors more than their younger counterparts. The difference is noteworthy since avoidance behaviors were significantly associated with poorer adaptation and metabolic control. In addition, investing in close friends was associated with poorer control, while seeking professional support and the use of humor was associated with better metabolic

control. Other researchers found similar results. Children used higher levels of approach-coping strategies such as problem-solving and seeking social support more frequently than adolescents and suggested that adolescents may deny their illness in an effort to emulate their peers when faced with diabetes-related problems, increasing the use of avoidance coping strategies such as internalizing and distancing (Reid, Dubow, & Carey, 1995).

Parental Involvement

Diabetes management must also be viewed within the context of the family system. Increased levels of family support and organization (Gowers, Jones, Kiana, North & Price, 1995), parental involvement (Anderson, Ho, Brackett, Finkelstein & Laffel, 1997; LaGreca et al., 1995; Weist, Finney, Barnard, Davis, & Ollendick, 1993), parental warmth (Davis et al., 2001) and effective communication (Anderson, Auslander, Jung, Miller & Santiago, 1990; Wysocki, 1993) are associated with better adherence and control of the disease. Other studies show that nontraditional family structure (Harris, Greco, Wysocki, Elder-Danda & White, 1999; Thompson, Auslander & White, 2001) and family conflict (Miller-Johnson et al., 1994) negatively affect both adherence to the diabetic regimen and metabolic control in children and adolescents.

Although parents may believe that their teens are adhering to their regimen, the teens' and parents' views about what constitutes sufficient adherence may differ. Anderson et al. (1990) examined family sharing of diabetes management responsibilities among 121 adolescents and their mothers. Results indicated substantial differences between adolescent and parental perceptions of responsibilities for diabetes management tasks, with 70% of families acknowledging "no one taking responsibility" for one or more daily

regimen tasks, such as rotating injection sites or carrying a sugar source for hypoglycemic reactions. The researchers explained that a number of tasks were not accomplished because no one claimed responsibility for ensuring their completion. These results indicate the need for increased communication between parents and teens at a time in the family cycle when communication between teens and parents is often difficult.

Inappropriate transfer of self-care responsibility can precipitate poor glycemic control and increase conflict between parents and children. The transfer of self-care responsibility from parents to adolescents needs to occur gradually, with a key focus on how and when. Negotiating this transfer must include consideration of such factors as the child's level of diabetes knowledge, degree of cognitive and emotional development, ability to perform self-care tasks, locus of control, and family environment (Wysocki et al., 1996). While children at certain chronological ages may have the necessary mechanical skills or knowledge to perform these tasks, there is wide variability in development and not all children of a given age can emotionally handle these responsibilities.

Anderson et al. (1997) found that greater parental involvement in blood glucose monitoring was significantly related to improved adherence for this task. Furthermore, increased frequency of blood glucose monitoring predicted improvement in glycosylated hemoglobin level. Maintaining parental involvement in diabetes management tasks may help to prevent the deterioration in glycemic control often seen in puberty. La Greca et al. (1995) interviewed 74 adolescents about their perceptions of the diabetes-related support they received from family and friends. Teens reported that family members

provided tangible support around insulin administration and blood glucose monitoring, while friends provided more emotional support. Higher levels of family support were significantly related to better adherence.

Miller-Johnson et al. (1994) theorized that diabetes management worsens during adolescence because of the heightened parent-child conflict typically seen during this developmental period. In another longitudinal study, three maternally reported family dimensions, including cohesion, conflict, and expressiveness were strongly related to glycemic control. Those adolescents from the least expressive families had the greatest deterioration in glycemic control. Family cohesiveness and conflict were linked to deterioration in glycemic control in boys, with those boys from the least cohesive and most conflicted families having the most rapid deterioration in glycemic control. The pattern for girls suggested that low family cohesiveness and high family conflict were associated with the worst glycemic control initially, but this did not persist over time (Hauser et al., 1990).

In sum, results from this cluster of studies demonstrate that adherence with a complex treatment regimen cannot be considered as a unitary concept because of the multifaceted nature of diabetes management. Behavioral, developmental, and family factors are embedded in the concept of adherence. It is, therefore, not surprising that there have been considerable methodological difficulties in measuring adherence and in linking adherence behaviors to indices of metabolic control.

CHAPTER III

METHODOLOGY

This pilot study utilized a quantitative, nonexperimental approach. A cross-sectional design using diabetes-specific psychometric scales was employed to collect data. Multiple correlational, descriptive methods were used to identify the relationships among perceived self-efficacy, regimen adherence, and glycemic control.

The sample was selected from two locations: (a) the inpatient/outpatient registry of Type 1 DM patients from a local hospital, and (b) outpatient adolescents from a pediatric endocrinology clinic in the community. Through purposive sampling technique, certain individuals with pre-specified characteristics were selected (Polit & Hungler, 1999). Adolescents were eligible for inclusion if they met the following criteria: (a) age between 11 to 18 years, (b) no other existing health problems, (c) diagnosis made at least one year, (d) no recent severe hypoglycemic events or DKA within past 3 months, (e) in a school-grade that is appropriate to their age within 1 year, (f) not pregnant, and (g) able to read, write, and speak English.

Adolescents who had any other illnesses or recent acute diabetic complications were excluded to avoid any potential unwanted effects in the overall glycemic control. The diagnosis must have been present for at least one year to ensure that the initial stage of the adolescent's metabolic readjustment and/or "honeymoon stage" was over and that his/her treatment parameters were established (ADA, 2001b). Appropriate school grade

to age ensured absence of cognitive deficits. The ability to read, speak, and write English was necessary to self-administer the questionnaires.

A list of 80 potential subjects in the specified age range (11 to 18 years old) was obtained from the hospital and the clinic. Permission to recruit subjects was obtained from the Chief Nurse Executive of the hospital and the pediatric endocrinologist of the clinic. Data collection started from October 2001 to May 2002. Recruitment methods included telephone or mail contact with eligible participants. Multiple methods of publicity about the study were also utilized, such as advertising in a local radio show, conducting small group presentations in the schools, and attending monthly community support group meetings of the Juvenile Diabetes Research Foundation.

The University of Texas-Pan American Institutional Review Board (UTPA IRB) was responsible for the review of measures to protect the rights of human research subjects in this study. Families were contacted initially through a letter describing the basic purpose of the study and the criteria for participation. After an intent-to-participate response was received, the researcher sent the questionnaires by mail. The subjects received a written description of the purpose of the study, the possible future benefits to individuals who care for diabetics and the adolescent diabetics themselves, and potential risks associated with participation in the study. The subject's participation was described including the amount of time required to complete the questionnaires. Parents and adolescents were assigned corresponding participation numbers, which were used to identify the participants' measures. To ensure confidentiality of the responses, only the numbers appeared on the questionnaires. The subjects were assured that their decision regarding participation in the study would not affect their relationship with the hospital, the diabetes

education center, and their health care provider's practice. The participants were given opportunities to ask questions which were answered by the investigator. In addition, the subjects were informed that the study met the approval of the UTPA IRB. A copy of the Informed Consent Form indicating the rights of the subjects is included in Appendix A.

The Informed Consent Form, together with the questionnaires such as the Demographic Sheet, SED, and the QSCB-child and parent versions were sent to subjects and their parents with explicit instructions on how to respond to the questions. The parent was asked to complete the parent version of the QSCB. The questionnaires were to be completed independently.

Of the 40 packets of questionnaires mailed, 3 questionnaires were completed and returned within a month. Telephone calls were made to families who had not completed the questionnaires by one to two months after the packets had been mailed. Many of these families indicated that they had forgotten or had been busy and agreed to return them, but only 3 eventually complied. Three packets were returned to the investigator due to wrong addresses. The rest of the families never returned the packets or could not be contacted.

Because of the low response rate with the mailed questionnaires, the investigator attempted home visits for data collection. Another 40 families were contacted. After ascertaining participation through telephone contact, the investigator made arrangements with families regarding mutually convenient times for data collection. A majority of the families (85%) were met in their homes. Prior to the administration of the questionnaires, the researcher repeated a verbal description of the research study and offered the consent form for both the adolescent subject and parent to sign.

Of the 80 families contacted, 40 pairs of adolescent-parent questionnaires were obtained for a response rate of 50%. Three youths within the specified age range and duration of diabetes were excluded for the following reasons. One female subject was experiencing anorexia and depression. Another female subject was diagnosed as being pregnant. A male participant was actually a Type 2 diabetic on a combination therapy of insulin and oral agent. Another female subject's HbA1c result could not be located. A final sample of 36 adolescent-parent dyads was considered for data analysis for this pilot study.

Instrumentation

The instruments used to collect data about the variables being studied are discussed in this section. These diabetes-specific questionnaires are tools designed to produce quantitative, numerical results.

Measuring Glycemic Control

Glycemic control was assessed by the participants' glycosylated hemoglobin level. The HbA1c provided a reliable estimate of the average blood glucose during the previous 2- to 3-month period. The normal range is 4.0 to 6.3% (ADA, 2001). This result was retrieved from the participant's medical record. For the purposes of this pilot study, only those HbA1c tests done within the previous six months were considered. The HbA1c of this sample ranged from 5.4% to 13.0%.

Measuring Perceived Self-Efficacy

The Self-Efficacy for Diabetes Scale measures the expectations held by individuals with diabetes about their personal competence, power, and resourcefulness for

successfully managing their diabetes (Grossman et al, 1987; Appendix B). From a research perspective, to be consistent with the behavior specificity of self-efficacy, items in scales that operationalize the concept must contain both a specific behavior and circumstance (Bandura, 1986). Furthermore, the theorist consistently emphasized that self-efficacy items should assess people's judgements about their operative capabilities at the present time rather than potential or hypothetical capabilities at some unspecified time in the future (Bandura, 1986). Instructions for completing the SED scale encouraged respondents to rate what they believe they could actually do given current conditions in their lives. Permission to use this measurement scale was obtained from the instrument developer (Appendix C).

The scale consists of 35 items in three subscales: diabetes-specific self-efficacy (24 items), medical situations self-efficacy (5 items), and general situations (6 items). Each item consists of a statement of a diabetes activity and circumstance. A sample item is: "Figure out how much insulin I give myself when I am sick in bed." Respondents rate their degree of capability for being able to carry out the activity. Degree of capability is recorded on a five-point Likert scale: **1**, very sure I cannot do it; **2**, somewhat sure I cannot do it; **3**, not sure I cannot do it; **4**, somewhat sure I can do it; and **5**, very sure I can do it. This five-point fully semantically anchored scale is appropriate for individuals with lower literacy skills, including children. The benefit of using a five-point scale to assess strength of self-efficacy includes ease of administration, especially in community settings (Maibach & Murphy, 1995). Higher scores indicate greater self-efficacy. Kuder-Richardson reliability coefficient alpha ranged from 0.90 to 0.92 for the total scale. For the diabetes-specific subscale, alpha was 0.90. For the general situations subscale, alpha

was 0.60 (Grossman et al, 1987). This instrument has been used in research studies involving children and adolescents with Type 1 DM (Grey et al, 1999; Palardy et al., 1998).

Measuring Regimen Adherence

The Questionnaire of Self-Care Behaviors (QSCB) is a tool that measures the participant's self-report of adherence to the treatment regimen (Rempala, 1999; Appendix B). The content areas include items on diet, exercise, and blood and urine testing. The scale has a child and parent version. Rempala (1999) modified the terminology for applicability to a pediatric population. The scale included three items on diet, two items on exercise, and six items on blood and urine testing. A sample item on the children's version of the QSCB is: "I change the time of my insulin injection because of the sugar test results." The parent's version of the QSCB contains the same items but is worded from the caregiver's perspective: "My child changes the time of his/her insulin injection because of the sugar test results." Permission to use this measurement scale was obtained from the instrument developer (Appendix C).

With respect to the format of the QSCB, the children were asked to select the best description of how often they follow the treatment plan prescribed for them. The respondents were asked to indicate their answers by circling a number on a five-point scale: 1.) Rarely, 2.) Sometimes, 3.) Usually, 4.) Very Often, and 5.) Always. Higher numbers reflect greater compliance.

The instrument developer's preliminary work on the scale's psychometric properties, using a sample of 21 diabetic children aged 7 to 17 years and their mothers, suggested that the scale had adequate internal reliability despite its brevity. Cronbach's coefficient

alpha for the child version was 0.69 and for the parent version was 0.55 (Rempala, 1999). Evidence of construct validity was provided by the correlation of QSCB scores with measures of medical adjustment ($r = .46$ for children and $r = .55$ for mothers) suggesting that the more adherent the children were, the better was their metabolic control, and that the more the mothers saw their children as adherent the better was their children's metabolic control (Rempala, 1999). For this pilot study, the totals for each adherence domain were obtained and then summed for a global measure of adherence. Statistical analysis was performed on both the global and separate scores for parents and youths.

CHAPTER IV

ANALYSIS OF DATA

The results of this pilot study are presented in this chapter. This study utilized correlational analyses to determine if there was a relationship between perceived self-efficacy and regimen adherence on glycemic control among a sample of 36 adolescents with Type 1 DM. The first section presents the descriptive statistics for the participants on the sociodemographic and disease-related information (age, gender, ethnicity, duration of diabetes, and treatment regimen). Bivariate analysis with Pearson's product-moment correlation was utilized to investigate possible relationships between the independent variables and the dependent variable. In addition, the internal consistency of the measurement instruments was ascertained by obtaining their reliability coefficients. The second section addresses the research questions. The third section provides a summary of the results.

Subjects

The participants ranged in age from 11 years to 18 years (mean=14.8; sd=1.93). There were 15 males (42%) and 21 females (58%). Seventy-five percent of the sample was Mexican-American (n=27), 16.7% was non-Hispanic Caucasian (n=6), and 8.3% was of mixed ethnicity (n=3). These families live along the Texas-Mexico border, in which 82% of the population is of Hispanic origin (Villas, Garza, Lopez, Gonzales, & Salazar, 1998). Duration of diabetes ranged from 1 year to 15 years

(mean=6.48; sd=3.98). Regarding treatment regimen, one-half of the participants were using daily insulin injections (n=18) and the other one-half were using the insulin pump (n=18). Mean HbA1c level for the sample was 8.67%. By ADA standards (2001), only 13.9% (n=5) of the sample demonstrated good glycemic control with HbA1c values under 7%.

Table 1

Demographic Characteristics

Subjects	Number	Percent
Gender		
Male	15	41.7%
Female	21	58.3%
Ethnicity		
Mexican-American	27	75%
Non-Hispanic Caucasian	6	16.7%
Mixed Ethnicity	3	8.3%
Treatment Regimen		
Daily insulin injections	18	50%
Insulin Pump	18	50%

Table 2

Descriptive Statistics

	Minimum	Maximum	Mean	Standard Deviation
Age	11	18	14.80	1.93
Age at Diagnosis	1	15	8.19	3.39
Duration of Diabetes	1	15	6.48	3.98
HbA1c	5.4	13.0	8.67	1.89

Table 3

Frequencies and Percentages of 36 Subjects by Glycemic Control According to Glycosylated Hemoglobin by ADA Standards (2001)

Glycosylated Hemoglobin	Number	Percent
Under 7%	5	13.9%
Over 7%	31	86.1%

As an initial step in data analysis, Cronbach's alpha, a reliability estimate, was derived for each measurement scale. Because urine glucose testing is no longer a recommended practice, these questions were deleted from both scales. These questions were: Item 5 on the SED scale ("Watch my own sugar levels in my urine"), Item 6 on the QSCB-child scale ("I test my urine sugar as often as my doctor told me to"), and the corresponding Item 6 on the QSCB-parent scale ("Your child tests his/her urine sugar as often as his/her doctor recommended"). On all instruments, there was evidence of moderate to strong internal consistency with reliabilities of .70 or greater. Specifically, the alpha reliability coefficients were .88 for the 34-item SED, .75 for the 11-item QSCB-child scale, and .73 for the 11-item QSCB-parent scale. The SED, in particular, is a psychometrically and conceptually sound measurement scale. In other words, 88% of the total variance on the SED scale is in fact, true or reliable and only 12% is due to content sampling error.

Research Question One

Research question one was stated as follows: Is there a relationship between perceived self-efficacy and glycemic control in adolescents with Type 1 DM? Pearson

product moment correlation was used to explore the relationship between Self-Efficacy for Diabetes and glycosylated hemoglobin. As shown in Table 4, the statistical analysis yielded no correlation between total scores on the SED and glycosylated hemoglobin level ($r = .139$; $p \geq .05$). In addition, the correlations between the SED subscale scores and HbA1c were also not significant.

Table 4

Pearson Product Moment Correlation Coefficient Between SED and HbA1c

Variables	R	p
SED-Total and HbA1c	.139	.473
SED-Diabetes Situations and HbA1c	.157	.416
SED-Medical Situations and HbA1c	.081	.646
SED-General Situations and HbA1c	.170	.321

Research Question Two

Research question two was stated as follows: Is there a relationship between regimen adherence and glycemic control in adolescents with Type 1 DM? The result of Pearson product moment correlation analysis showed no relationship between either the subscale or total scores on the QSCB and glycosylated hemoglobin level, for both the child and parent questionnaires ($p \geq .05$).

Table 5

Pearson Product Moment Correlation Coefficient Between QSCB-Child and HbA1c

Variables	r	p
QSCB-Total and HbA1c	-.185	.319
QSCB-Diet and HbA1c	-.075	.667
QSCB-Exercise and HbA1c	.081	.646
QSCB-Testing and HbA1c	-.238	.182

Table 6

Pearson Product Moment Correlation Coefficient Between QSCB-Parent and HbA1c

Variables	r	p
QSCB-Total and HbA1c	-.177	.331
QSCB-Diet and HbA1c	-.276	.103
QSCB-Exercise and HbA1c	.152	.376
QSCB-Testing and HbA1c	-.130	.478

Diabetes-Related variables, Demographic Variables, and Glycemic Control

Previous studies of diabetes had found that age, disease duration, and gender were associated with metabolic control. The relatively small sample size did not allow the use of more sophisticated statistical analysis tools such as regression analysis. For the number of predictor variables being examined, a minimum of 100 subjects is required. If regression analysis was conducted with fewer individuals than optimal, the results may be erroneous. When simply comparing glycemic control based on treatment regimen, however, adolescents on daily injections had a mean HbA1c level of 9.26% versus 8.09% for those

subjects on insulin pumps. Subjects on daily injections used a combination of intermediate- and rapid-acting insulins whereas subjects on insulin pumps used rapid-acting insulins only.

Table 7

Subject Characteristics and Mean HbA1c Levels

Gender	Mean HbA1c (%)	Standard Deviation
Male	8.37	1.57
Female	8.89	2.11
Ethnicity		
Mexican-American	8.75	2.02
Non-Hispanic Caucasian	8.45	1.78
Mixed Ethnicity	8.47	1.10
Treatment Regimen		
Daily insulin injections	9.26	2.07
Insulin pump	8.09	1.54

Summary of Findings

The findings of this pilot study yielded no significant correlations between the scales of Self-Efficacy for Diabetes and Questionnaire of Self-Care Behaviors and glycemic control. Additionally, the limited sample size did not permit regression analysis of the diabetes-related and demographic variables such as age, ethnicity, gender, disease duration, and treatment regimen.

CHAPTER V

DISCUSSION

A summary of this pilot study is presented in this chapter. The findings are discussed in relation to previous empirical data found in the literature. Conclusions derived from the findings, in light of the limitations, and the implications based on the findings are also presented. Finally, recommendations for future research are offered.

Type 1 DM involves a complex treatment regimen of diet, exercise, monitoring of blood glucose levels, and insulin injections, as well as adjustment of the regimen with respect to physical activity, stress, and illness. Implementing these components of the regimen on a daily basis is crucial for obtaining glycemic control. The results of the DCCT study indicated that adolescents with Type 1 DM should receive intensive diabetes management because of the long-term benefits of reducing complications. Nurses, clinicians, and researchers have been interested in finding a link between behavioral factors and glycemic control.

The purpose of this descriptive, correlational study was to determine if a relationship existed between perceived self-efficacy and regimen adherence on glycemic control among a sample of 36 adolescents with Type 1 DM. Based on the findings of this study, the following conclusions were drawn:

1. There was no identified significant relationship between perceived self-efficacy and glycemic control.
2. There was no identified significant relationship between regimen adherence and glycemic control.

Limitations

Given the preliminary nature of this study, cautious interpretation of the findings is warranted. A primary concern relates to the homogeneity and limited size of the convenience sample. The participants were predominantly Mexican-American and rural in character. Because of this lack of heterogeneity in terms of socioeconomic status and racial background of the subjects, further investigation with a larger, more diverse sample in different settings should be performed. Furthermore, both instruments utilized in this study have never been used in Mexican-American adolescents. A culturally sensitive tool may have tapped the participants' social values, beliefs, and perspectives as they relate to diabetes self-management. There may also be differences between the study population and the general population of adolescents with Type 1 DM based upon self-selection, motivation, or other psychosocial factors.

A second concern relates to the cross-sectional rather than longitudinal design of the study. Evidence of the persistence of suboptimal glycemic control in adolescence could be accomplished by prospective evaluation of self-efficacy and adherence over a period of years by following the same cohort of adolescents longitudinally. Retrospective evaluation of glycemic control by glycosylated hemoglobin levels may be particularly

prone to bias by recency effects (Wysocki, 1992). Furthermore, the cross-sectional design of this study could not identify the direction of predictive relationships, if any, among the variables of interest. Another benefit of longitudinal analysis would be to expose the effect of age on HbA1c, that is, if glycemic control changes as the adolescent matures.

A third concern relates to using the HbA1c as the sole measure of glycemic control. HbA1c results only reflect the average levels of blood glucose over a two- to three-month period. Fructosamine assays may have been useful in capturing metabolic control within the previous two weeks prior to sampling (ADA, 2001c). Lipid metabolism is also disrupted in Type 1 DM and has rarely been used as an outcome variable, despite the incidence of atherosclerosis in this population (ADA, 2001c). Future research should include quality of life measures, such as number of emergency room visits, academic performance, participation in extracurricular activities, episodes of DKA, in addition to laboratory assays. It may also be helpful to assess for adverse effects of intensive disease management. In the DCCT study (1994), strict glycemic control was associated with a three-fold increase in the incidence of severe hypoglycemia and clinically significant weight gain. Given these methodological and research limitations, the findings are generalizable only to this sample.

Discussion of Results

This section presents an explanation of the findings based upon the statistical analysis of the data. The results are also discussed in relation to findings from past research studies.

Self-Efficacy and Glycemic Control

In this pilot study, there was no correlation found between perceived self-efficacy and glycemic control. These findings were in contrast with those of previous studies that indicated a positive relationship between these variables (Grey et al., 1999; Griva et al., 2000; Hurley & Shea, 1992; Littlefield et al., 1992). One explanation for this contradictory result may be that the diabetes tasks such as self-monitoring of glucose and self-administration of insulin had become daily routine activities that these adolescents became complacent regarding their ability to perform these tasks. The mean duration of diabetes in this sample was 6.48 years. These adolescents have developed self-efficacy and proficiency regarding the daily tasks of disease management. Bandura (1986) explained that self-appraisal may not be necessary when performing routine behaviors because of past experiences with these familiar tasks. Performance of routine behaviors may be better explained by incentives to perform rather than levels of self-efficacy (Bandura, 1986). Assessing self-efficacy may be more appropriate in the initial stages of the disease, that is, in newly diagnosed adolescent diabetics. Evaluating self-efficacy beliefs may also be useful when assessing competency during the transfer of diabetes tasks from parent to child or during acquisition of new skills related to changes in treatment regimen, such as switching from daily insulin injections to insulin pump.

It may also be useful to obtain parental or caregiver perception of adolescent efficacy, to assess whether parent and child perceptions differ. The beliefs and dynamics underlying perceptions of competence in the performance of daily diabetes tasks are complex and warrant further research. Clearly, how efficacious adolescents are in their self-care will have implications for parental involvement. In this study, only the

adolescent perception of self-efficacy was assessed. Steinberg (1998) found that adolescents and their parents showed concordance on their perceptions of diabetes responsibility and that more positive parent-child relations surrounding diabetes care predicted better diabetes self-efficacy and decreasing involvement of parents in the treatment regimen.

Despite the high reliability coefficient of the SED scale, some modifications need to be considered. Some participants in this study found the 34-item SED scale to be lengthy. The 24-item diabetes-specific subscale may be sufficient to measure disease-related self-efficacy beliefs. The SED scale was developed approximately 15 years ago (Grossman et al., 1987). Current diabetic regimen practices, such as carbohydrate counting and adjusting insulin rates for insulin pump users, should be incorporated in this measurement instrument. Some subjects reported that they no longer record their glucose results in a logbook. These adolescents downloaded their results from their glucose meter into the computer when analyzing trends or patterns.

Adherence and Glycemic Control

In both parent and child groups, reports of adherence were not significantly related to glycemic control. The resulting negative correlation between HbA1c and adherence scores, however, indicated an expected inverse relationship between the variables. In other words, high adherence scores were related to low HbA1c levels. Although these findings did not support the major results of the DCCT study (1994), in which low adherence level was related to chronic complications, they are by no means unique. Other researchers have also found an absence of relationships between adherence and HbA1c in adolescents (Miller-Johnson et al., 1994; Glasgow et al., 1987). Other research

studies found correlations to be significant yet small, in the .20's and .30's (Brownlee-Duffeck et al., 1994; Hanson et al., 1987). These clusters of findings suggest that a careful examination of the relationship between adherence and glycemic control is needed.

The lack of significant correlation between these variables in the present study could have resulted from the following difficulties. The QSCB did not require participants to recall adherence behavior over a specific period of time and its reliability may have been compromised by difficulty remembering. There is increasing evidence however, that self-reports can provide valid and reliable data on condition that certain behaviors are recalled over a recent, specified temporal interval (Gorin & Stone, 2001). A 24-hour recall interview about dietary intake or frequency of blood glucose testing would have been a useful adjunct when assessing adherence. Patient recall over the previous 24 hours has been found to be more accurate than recall over an extended, retrospective time period (Gorin & Stone, 2001). Statistically correlating the child and parent responses on the QSCB revealed that the scores were congruent ($r = .58$; $p = .001$). The agreement of scores between the adolescents and parents suggested that the adolescents' reports were valid.

The reliability coefficient by Cronbach's alpha of the QSCB has been reported as .69 for the child scale and .55 for the parent scale (Rempala, 1999). For the purposes of this study, the reliability of the modified child scale was .75 and the parent scale was.73. According to the instrument developer, this measurement scale has never been used elsewhere (H. Rempala, personal communication, April 8, 2002). Future studies should

continue to modify the current scale or use adherence instruments with higher reliability and validity scores.

In addition, it is difficult to compare adherence levels across individuals when the treatment regimen differs (daily insulin injections versus insulin pump). Continuous insulin infusion via pump involves more complex tasks such as carbohydrate counting and adjusting basal and bolus insulin rates. Adolescents using insulin pumps may be more motivated, and therefore, more adherent. Interestingly enough, there has been recent concern about intentional or intelligent non-adherence. This situation occurs when an individual chooses not to follow some or all of the prescribed recommendations or when an individual has learned to manipulate and deviate from treatment regimens in a manner that suits his or her individual lifestyle (Weistaub, 1976). For example, one mother of a boy on an insulin pump reported that he sometimes "uses" the regimen to his advantage. The mother further explained that if her son wanted another slice of pizza, he would merely increase the bolus units of insulin to cover the extra serving of carbohydrates. Future studies should address the impact of intentional non-adherence on glycemic control.

Finally, the QSCB was originally developed exclusively within a population of adolescents attending a diabetic summer camp (Rempala, 1999). As such, it may have limitations when applied to a general population of adolescents with Type 1 DM. As with other diabetes adherence scales, the QSCB assessed perceptions of adherence and, consequently, the participants' responses may not be valid indicators of actual behavioral compliance to the prescribed regimen. This problem has been an ongoing methodological concern in diabetes research.

Diabetes-Related Variables, Demographic Variables, and Glycemic Control

In the DCCT study (1994), subjects on insulin pumps achieved 0.2 % to 0.4% lower HbA1c levels than subjects on multiple daily injections. Similarly in the present study, adolescents on insulin pumps had better mean HbA1c values compared to those on daily injections. Continuous subcutaneous insulin infusion using rapid-acting insulin provides the greatest day-to-day reproducibility in insulin availability and the least unexpected fluctuation in glycemic control. In addition to its pharmacokinetic advantages, the insulin pump uses only one body region for insulin delivery, thus avoiding interregional variation of insulin absorption (Farkas-Hirsch & Hirsch, 1994).

Redefining Glycemic Control

The current recommendation for strict glycemic control in adolescents with Type 1 DM may be particularly difficult to achieve in this age group. The adolescents in this pilot study, as a whole, had a mean HbA1c level of 8.67%. Although this result fell beyond the desired range established by the ADA (2001a), it closely paralleled the mean HbA1c level of the DCCT adolescent subgroup. The adolescents in the DCCT study required intensive management from the research team, in the form of counseling and support. These adolescents nonetheless, had a mean HbA1c level of 8.06%, compared with 7.12% for the adult participants. Other studies reported mean HbA1c levels of their adolescent sample from 8.59% to as high as 13.1% (Aikens et al., 1992; Burroughs et al., 1993; Griva et al., 2000; Hanson et al., 1996; Johnson et al., 1992; Wysocki et al., 1992).

These previous studies on adolescent diabetes utilized subjects who were primarily middle-class in socioeconomic status and Caucasian in racial background. The present study consisted of 75% (n=27) Mexican-American adolescents living along the rural

Texas-Mexico border. Despite their unique characteristics, the sample in the present study demonstrated glycemic control similar to subjects in past research. The primary over-arching similarity of all these subjects is their adolescent developmental stage.

Perhaps the most important component of an intensive diabetes therapy program is individualized target blood glucose and glycosylated hemoglobin levels. Patients with hypoglycemia unawareness, advanced microvascular disease, and learning disabilities should have higher glycemic goals than patients without such conditions (Farkas-Hirsch & Hirsch, 1994). Intensive therapy was associated with hypoglycemia-related seizures and increased body mass index among the adolescent participants in the DCCT (1994). In the present study, some adolescents and/or parents may have been fearful of hypoglycemia and therefore, may have decided to maintain higher blood glucose levels. One mother of a 14-year old girl diagnosed a year ago, admitted to having a full candy dish in every room of her home for easy access to a rapid-acting carbohydrate source. Another mother of an 11-year old boy reported being afraid of nocturnal hypoglycemia that she prefers the bedtime glucose reading near 200 mg/dl. Polonsky et al. (1994) found that fear of hypoglycemia is one of the reasons for insulin omission in women with Type 1 DM. Further research on other indices of glycemic control is necessary. Some researchers recommended an HbA1c level of 8% as a target that best balances the benefits against the risks of intensive treatment (Krowelski, Laffel, Krowelski, Quinn, & Warram, 1995; Warram, Manson, & Krowelski , 1995). In the present study, five adolescents had an HbA1c level of less than 7%. It would be beneficial to carefully examine the characteristics and traits of these adolescents and their families to gain an understanding about factors that influence optimal glycemic control. Because the study

failed to demonstrate a correlation between SED and QSCB on HbA1c values, nurse clinicians and researchers must attempt to identify other potent predictors that may influence the patient's behavior in diabetes self-management.

Implications and Directions for Future Research

This pilot study can contribute to nursing practice, particularly in the realm of diabetes education. From the perspective of being able to measure outcomes, the instruments used in this study are conceptually and psychometrically sound. The SED scale may be used as an aid in determining if there have been any changes in adolescents' beliefs about self-managing their diabetes. The adherence scale may be used in clinical practice settings to obtain pretreatment information and evaluate outcomes. Both these scales tap the perceptions of participants on the variables being measured. Future research should include semi-structured interviews and direct observation involving family members and caregivers in order to provide further insight into these behaviors. An observational study of parents and children with Type 1 DM on a variety of individual and relationship traits found support for the association of traits such as emotional support, conflict resolution, affective expression, and acceptance of the diagnosis with measures of adherence and glycemic control (Martin, Miller-Johnson, Kitzman, & Emery, 1998). Future research should continue to include multi-method and multi-trait designs.

This pilot study failed to demonstrate a correlation between self-efficacy and regimen adherence on glycemic control. This lack of correlation, however, does not mean that the relationships among the variables do not exist in reality. Nurses must continue to acknowledge the importance of self-efficacy and regimen adherence as empirical data support their utility in clinical practice. Further studies evaluating similar relationships

among these variables should be undertaken using a large, randomized population of adolescents who are representative of the general diabetic population, in order to obtain enhanced statistical power.

The age group targeted for this pilot study deserves particular attention. Health care professionals must recognize that the stage of adolescence represents a high-risk period. There is deterioration of blood glucose associated with hormonal changes in puberty and a decrease in insulin sensitivity (Johnson et al., 1992). In addition to these physiological changes, adolescence is marked by behavioral and emotional issues related to establishing independence, increasing experimentation, and conforming with peers (Kyngas & Barlow, 1995). These developmental tasks may interfere with adherence to the treatment regimen. The transition of responsibility for disease self-management often occurs during this stage. Gowers and his colleagues (1995) suggested that when parents prematurely pass on the responsibility to the adolescent for the diabetic regimen, poor control may result. Intervening at the family level may be advantageous.

Diabetes education is concerned with promoting independence in self-management of the disease. A combination of educational strategies and behavioral interventions to enhance self-efficacy can be directed to any of the four sources of information used by individuals to develop their self-efficacy beliefs. Enactive attainment is the most influential source of efficacy information because it is based on the individuals' past behaviors. More importantly, performance of self-care may be a function of the value placed on the outcome, as well as the perceived ability to perform the behavior necessary to attain the outcome.

For adolescents to engage in effective diabetes self-management, an understanding of its value must be emphasized. Perhaps because many of the activities associated with diabetes self-care do not produce clear and immediate positive consequences, nurses must focus on finding immediate rewards for adherence. Identifying factors that affect adherence behavior and glycemic control in adolescence offers the opportunity to improve their health across the lifespan.

Conclusion

Optimal glycemic control in adolescents with Type 1 DM is necessary to avert the development of chronic complications. The results of this pilot study of 36 adolescent participants with Type 1 DM yielded no significant correlations between perceived self-efficacy and regimen adherence on glycemic control. Bandura's theory of self-efficacy provided the theoretical framework for the study. The normative developmental tasks of adolescence, the complexity of the treatment regimen, and the physiological changes associated with puberty contribute to the challenging task of promoting glycemic control in this high-risk age group. Nurses, clinicians, and researchers should continue to explore more potent predictors of positive disease outcomes so that specific interventions may be implemented.

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APPENDIX A
INFORMED CONSENT DOCUMENTS

Subject Code # _____

INFORMED CONSENT DOCUMENT
FOR PARTICIPATION OF A SUBJECT IN A RESEARCH STUDY

1. **Title of research project:** Self-efficacy and regimen adherence as predictors of glycemic control in adolescents with Type 1 diabetes mellitus

2. **Name of the investigator:** Nannette Alteza, MSN graduate student

A. Information on the research study

1. Purpose of the research study

You are being asked to join in a research project. The purpose of this study is to find out if self-efficacy and regimen adherence influence the control of your diabetes.

2. Eligibility to participate in the study as a research subject

Young people between the ages of 11 to 18 with Type 1 diabetes mellitus, who received diabetes instruction at McAllen Medical Center, will be asked to join the study. About 40 patients will be in this study.

3. Power of free choice to join or to terminate participation in the study

Your participation in this project is voluntary. You do not have to join, and you can leave the study at any time. There will be no penalty to you.

4. Study protocol, and experimental procedures to take place in the study

If you decide to join, you will be asked to complete 2 surveys. These surveys will also have questions about your level of education and diabetes regimen. Answering these questions will take about 30 minutes of your time. Also, information will be collected from your medical chart on your demographic characteristics (your age, sex and race) and your glycosylated hemoglobin value (your "average" blood sugar level within the last 2-3 months). Taking part in this study will not change the care you get for your condition.

5. Risks, discomforts and inconveniences of the research, and measures to be taken to minimize them

There are no risks to you by being in this study.

6. Measures to preserve confidentiality of the information collected, and privacy of the subject

Your study record will be kept in a confidential file at the University of Texas - Pan American. Only those persons who work on the study will have access to your records and your data. These include the Graduate Research Committee and the Institutional Review Board monitoring the study. All of the information will be combined with data collected from other participants for a final review. All information obtained will be held strictly confidential.

7. Expected direct benefits to the research subjects

There are no direct benefits from being in this study.

8. Expected indirect benefits to others

Information from this study could help other young people with Type 1 diabetes and health care providers better understand factors, which determine control of this disease.

9. Management of any physical injury

You should not get any physical injury from being in this study.

10. Payments to the subject for participating in the study

You will not be paid or get any other form of compensation for being in this study.

11. Costs to the subject or subjects health insurance carrier resulting from participation in the study

There will be no extra costs to you or your health care insurer from being in this study.

12. How to learn more about the study, or raise concerns

This study has been reviewed by the Institutional Review Board – Human Subjects in Research. To find out more about any aspect of this study, including your rights as a subject, you may contact:

Dr. Juan Gonzalez – Chair, University of Texas Pan-American – Institutional Review Board
(956) 381-2880
Dr. Barbara Tucker – Chair, Graduate Research Committee – Masters of Science in Nursing
University of Texas Pan-American
(956) 316-7082
Nannette Alteza – Principal Investigator, MSN graduate student
(956) 496-5678

13. Alternatives to not participating in the study

Should you choose not to participate in this study, you will receive the usual care for your condition.

The study was explained to me by _____
I agree to take part in this study. I also give permission to access my medical record.
Signature of Subject_____
Print Name_____
Signature of Parent/Legally Authorized
Representative_____Date____/____/___
Print Name_____

Signature of Witness_____ Date____/____/___

APPENDIX B
MEASUREMENT INSTRUMENTS

Subject Code # _____

PLEASE ANSWER THE FOLLOWING QUESTIONS

BACKGROUND:

1. Sex: Male ☐ Female ☐
2. How old are you? _____ years old
3. How long ago were you told by a doctor that you had diabetes? _____ years
4. Have you ever attended a diabetes patient education program (a series of classes)?

   ☐ No ☐ Yes (If "Yes", how may years ago? _____)
5. What school-grade are you in now? _____

Self-efficacy for diabetes scale (SED) Subject Code # _____

Instruction: Please read the following questions. After each question, please make a circle on the number to show how much you believe you can or cannot do what is asked now. Use the following scale:

1 = very sure I cannot do it
2 = somewhat sure I cannot do it
3 = not sure I cannot do it
4 = somewhat sure I can do it
5 = very sure I can do it

1. Be the one in charge of giving my insulin injection to myself
   1 2 3 4 5
2. Figure out my own meals and snacks at home
   1 2 3 4 5
3. Figure out what foods to eat when I am away from home
   1 2 3 4 5
4. Keep track of my own blood sugar levels
   1 2 3 4 5
5. Watch my own sugar levels in my urine
   1 2 3 5
6. Change the amount of time I get insulin when I get a lot of extra exercise
   1 2 3 4 5
7. Judge the amount of food I should eat before activities
   1 2 3 4 5
8. Figure out how much insulin I give myself 'when I am sick in bed
   1 2 3 4 5
9. Prevent having reactions
   1 2 3 4 5
10. Avoid or get rid of dents, swelling, or redness of my skin where I get my shot
    1 2 3 4 5
11. Talk to my doctor myself and ask for the things I need
    1 2 3 4 5
12. Suggest to my parents changes in my insulin dose
    1 2 3 4 5
13. Sleep away from home on a class trip or at a friend's house where no knows about my diabetes.
    1 2 3 4 5
14. Keep myself free of high blood sugar levels
    1 2 3 4 5
15. Know how to make my urine tests look better or worse than they are
    1 2 3 4 5
16. Avoid having acetones
    1 2 3 4 5

17. Change my doctor if I don't like him/her
    1 2 3 4 5
18. Feel able to stop reactions when I am having one
    1 2 3 4 5
19. Ask for help I need from other people when I feel sick
    1 2 3 4 5
20. Tell a friend I have diabetes
    1 2 3 4 5
21. Play baseball or other sports that take a lot of energy
    1 2 3 4 5
22. Argue with my doctor if I felt he/she were not being fair
    1 2 3 4 5
23. Prevent blindness and other complications from my diabetes
    1 2 3 4 5
24. Tell my boyfriend or girlfriend I am diabetic
    1 2 3 4 5
25. Do things I have been told not to when I really want to do them
    1 2 3 4 5
26. Get as much attention from others when my diabetes is under control as when it isn't
    1 2 3 4 5
27. Easily talk to a group of people at a party when I don't know them
    1 2 3 4 5
28. Make a teacher see my point of view
    1 2 3 4 5
29. Show my anger to a friend when he/she has done something to upset me
    1 2 3 4 5
30. Take responsibility for getting my homework and chores done
    1 2 3 4 5
31. Regularly wear a medical alert tag or bracelet which says I have diabetes
    1 2 3 4 5
32. Sneak food not on my diet without getting caught
    1 2 3 4 5
33. Believe that I have the ability to have control over my diabetes
    1 2 3
34. Follow my doctor's orders for taking care of my diabetes
    1 2 3 4 5
35. Run my life the same as I would if I didn't have diabetes
    1 2 3 4 5

Subject Code # _____

Questionnaire of Self-Care Behaviors

Children with diabetes are usually asked by the doctors and nurses to do as many things such as eating right, exercise, test the blood and urine sugar level, and many other tasks that will help them control their diabetes. But it is often hard to follow doctor's orders. We would like to know how it is for you to follow doctor's orders.

Please complete each of the following sentences by circling the number that best describes you. Your answers will be known only to the experimenter and will not be given to anybody else.

	What is your answer? 1- Rarely 2- Sometimes 3- Usually 4- Very Often 5- Almost always
1. I follow a meal plan or a diet as often as my doctor told me to	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
2. I eat regularly meals and snacks	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
3. I weigh or measure food before eating	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
4. I check my feet for signs of problems as often as my doctor told me to	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
5. I exercise as often as my doctor told me to	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
6. I test my urine sugar as often as my doctor told me to	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
7. I test my blood sugar as often as my doctor told me to	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
8. I keep record of my sugar tests results	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
9. I change my diet because of the sugar tests results	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
10. I test my urine for ketones as often as my doctor told me to	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
11. I change my way of exercising (exercise less or more) because of the sugar tests results	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
12. I change the time of my insulin injection because of the sugar tests results	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5

Subject Code # (P) _____

Questionnaire of Self-Care Behaviors

Children with diabetes are usually asked by their doctors and nurses to do many things such as eating right, exercise, test the blood and urine sugar level, and many other tasks that will help them control their diabetes. You as a parent are often involved in helping your child to adhere to various requirements in diabetes management. We believe that parents' observations of their child's behavior is very important in understanding children's attempts to follow treatment.

Please complete each of the following statements indicating your **OWN OPINION** about your child's adherence to treatment requirements. Please complete the statements by circling the number that best describes your opinion.

In this table indicate <u>what is your own opinion</u> about your child's adherence to the treatment.	What would be your child's answer? 1- Rarely 2- Sometimes 3- Usually 4- Very Often 5- Almost always
1. Your child follows a meal plan or a diet as often as his/her doctor recommended	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
2. Your child eats meals and snacks regularly	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
3. Your child weighs and measures his/her food before eating	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
4. Your child checks his feet for signs of problems as often as his doctor recommended	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
5. Your child exercises as often as his/her doctor recommended	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
6. Your child tests his/her urine sugar as often as his/her doctor recommended	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
7. Your child checks his/her blood sugar as often as his/her doctor recommended	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
8. Your child keeps records of his/her sugar test results	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
9. Your child changes his/her diet because of his/her sugar test results	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
10. Your child tests his/her urine for ketones as often as his/her doctor recommended	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
11. Your child changes his/her way of exercising (exercises less or more) because of sugar test results	1 - - - - - - 2 - - - - - - - 3 - - - - - - - 4 - - - - - - 5
12. Your child changes the time of his/her insulin injection because of the sugar test results	1 - - - - - - 2 - - - - - - - 3 - - - - - - -

APPENDIX C
PERMISSION LETTERS TO USE MEASUREMENT INSTRUMENTS

Read Mail

From: Stubrink@aol.com **[Save Address]** **[Block Sender]**

To: nalteza@email.com

Cc:

Subject: Re: Self-Efficacy for Diabetes Scale (SED)

Date: Tue, 2 Apr 2002 22:31:50 EST

Reply | **Reply All** | **Forward** As Attachment **Previous** | **Nex**

Move To Trash Delete Close

Glad to have you use the SED. Good luck with your research.

Stu Brink

Read Mail

From: "Helena Rempala" <helenarempala@hotmail.com> [Save Address] [Block Sender]

To: Nalteza@email.com

Cc:

Subject:

Date: Tue, 05 Feb 2002 14:01:55 -0500

REPLY | REPLY ALL | FORWARD [As Attachment] Previous | Nex

[redacted] Drafts [redacted]

Helena Rempala, Ph.D.
Clinical Psychologist, Research Coordinator
The Morton Center
NIAAA Grant phone: 502-456-1025
1028 Barret Ave., Louisville, KY, 40204

Dear Nannette (I am sure I am misspelling your name, sorry),

I give you permission to use and/or adapt Questionnaire of Self-Care Behaviors developed for my prelim and dissertation. Please, take into consideration the specific recommendations that your medical center may be giving to the children that may not be reflected in my scale (created for a rural northern Ohio population). Also, consider the moderate reliability of the measure. You may want to run a reliability check on it (internal consistency or test-re-test in a short period of time).

Good luck,

Helena

Helena Rempala, Ph.D.
Clinical Psychologist, Research Coordinator
The Morton Center
NIAAA Grant phone: 502-456-1025
1028 Barret Ave., Louisville, KY, 40204

VITA

Antonieta P. Alteza

Experience	1996 – present	McAllen Medical Center
		Diabetes Educator
		• Counsel diabetic patients on disease self-management
Education	2002	University of Texas Pan American Edinburg, Texas
		• Master of Science in Nursing – presently enrolled
	1988	University of Toronto Toronto, Ontario
		• Bachelor of Science in Nursing
Certification	Certified Diabetes Educator	