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The Effects of Psychosocial Factors on Control and Compliance with Diabetes Treatment Regimens in a Sample of Children with Insulin-Dependent Diabetes Mellitus

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THE EFFECTS OF PSYCHOSOCIAL FACTORS ON CONTROL AND
COMPLIANCE WITH DIABETES TREATMENT REGIMENS IN A SAMPLE
OF CHILDREN WITH INSULIN-DEPENDENT DIABETES MELLITUS

by

Denise Verones

A Dissertation Submitted to the Faculty of the Graduate School
of Loyola University of Chicago in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy

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VITA

The author, Denise Verones, is the daughter of Joseph and Dorothy (Snack) Verones. She was born February 17, 1951 in Passaic, New Jersey.

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CHAPTER ONE

INTRODUCTION

Despite medical advances, many people with health-threatening disorders fail to derive the full benefits of a treatment regimen due to failure to comply with prescribed recommendations. Historically however, physicians did not have to worry about whether or not a patient complied because most treatments were administered rather than prescribed. As such, the emphasis was on treatment procedures rather than processes that affect compliance. The patient played a passive role in treatment. Therefore, cure and the efficacy of the treatment regimen received the primary focus. The increased use of drugs in medical treatment and the recognition of the rights of the individual shifted some of the responsibility for treatment efficacy to the individual and the extent to which he/she adhered to prescribed recommendations. The now familiar procedure of physician prescribing and patient adhering gradually changed the focus of medical practice.

For many illnesses, such as diabetes, hypertension, peptic ulcers, and colitis, a multifaceted treatment regimen (diet, exercise, medication) is required to ensure both survival and optimal functioning throughout the life span. Not only are these treatment regimens long-term, but they also require that substantial behavioral changes be made in an individual's daily routine. The particular interest of this proposal is the treatment regimen for the person with insulin dependent diabetes mellitus.

Insulin-dependent diabetes mellitus (IDDM) is a life-long chronic illness characterized by complete pancreatic failure. From a behavioral perspective, the demands of the illness (e.g., daily insulin injections at regular intervals in the proper amount, careful regulation and timing of food intake, testing of blood glucose levels several times daily, and physical activity on a regular basis) supply numerous occasions for noncompliance. The consequences of not adhering to this treatment regimen, however, can be and often are fatal.

Compliance with this regimen is understandably difficult and demands substantial maturity and capacity for self-regulation. Furthermore, compliance with the diabetes treatment regimen is complicated by psychosocial factors which weaken the individual's capacity to perform the necessary management tasks. Johnson (1984) points out that inadvertent noncompliance also occurs when a person through errors in knowledge or skill, fails to comply with recommended treatment tasks as a result of errors. Noncompliance in children is linked to a certain extent, to the parents' belief in the efficacy of the child's treatment regimen, their perception of the seriousness of the child's illness, and their own knowledge and skill at performing or assisting the child to perform the necessary management tasks.

Insulin dependent diabetes mellitus is a particularly difficult disease for children. Besides the very demanding and complicated treatment regimen, which must be managed on a daily basis, the child with IDDM is faced with age appropriate developmental crises and conflicts that all children experience. Hence, it is difficult at times for parents to know whether their child is experiencing problems because

of their disease, or if he/she is working through normal developmental crisis. The treatment of the disease and the disruption evident in adherence to dietary, injection, and testing routines threaten the child's self-esteem, potentiate embarrassment with peers, test the tolerance/acceptance of parents, and can exacerbate conflict within the family. Hence, it is not surprising that the burden of the research conducted to date reveals that the incidence of nonadherence with all or part of the treatment regimen is approximately thirty-three percent (Cerkoney & Hart, 1980).

Research shows that there are numerous factors that interfere with a child's efforts to be compliant. Conflictual family relations, the child's developmental/maturity level, anxiety level, and acceptance of the disease by the child and the parent, psychological adjustment, knowledge of the treatment regimen and skill at performing the required tasks, and parental health beliefs have all been implicated as having an impact on the child's ability/willingness to conform to prescribed recommendations.

The rationale that has guided previous research in this area is that maturity, positive acceptance of the disease and the treatment regimen by the child and the parents, adequate understanding of disease and its management, and high cohesion and minimal conflict in the family should predict compliance with the diabetes treatment regimen. However, previous studies have been flawed by conceptual limitations, construct measurement problems, and methodological weaknesses (see Johnson, 1980 for a review of these).

Most research efforts have attempted to correlate various psychosocial factors with measures of compliance and/or control. Although few studies in the diabetes compliance literature have distinguished between compliance and control, these are two separate and distinct constructs. Compliance, as conceptualized in the literature, is the degree to which behavioral changes are made to conform with prescribed recommendations. Control, on the other hand, is a measure of a metabolic state. In diabetes, although compliance may have an effect on control, other factors, such as stress, changes in metabolic needs, and illness, are also implicated in the deterioration of metabolic control.

It can be fairly concluded from the literature that an adequate instrument that measures compliance has yet to be constructed and tested. Since investigators use different scales and inventories to measure compliance, it is not surprising therefore, that research findings are often contradictory. Also, most investigators conceptualize compliance as a singular entity when it clearly involves numerous behaviors associated with at least four categories (insulin injection, glucose/urinary testing, diet management, and exercise). Although measures of metabolic control are available, there is no consistency in the literature as to which measure is used. While some investigators use hemoglobin tests, others use urine and blood glucose tests.

Certain methodological improvements are also needed. Studies have shown that variables such as knowledge, family functioning, psychological adjustment, and compliance are interrelated. However,

most studies employ univariate statistical designs which are inadequate for analyzing complex relationships among variables. No study to date has adequately examined the combination of psychosocial factors that are considered to influence compliance with the numerous behaviors that comprise the entire diabetes treatment regimen. Multivariate statistical designs would provide a more rigorous empirical test of the relationship between the aforementioned psychosocial variables and compliance.

The overall purpose of this study is to examine the impact of seven psychosocial variables (family functioning, psychological adjustment, anxiety level, adjustment to diabetes, knowledge of and skill at diabetes-related tasks, parental acceptance of the disease, maturity/developmental level) on four general aspects of compliance to the diabetes treatment regimen (insulin injection, blood glucose/urine testing, diet, physical activity). In this study an attempt will be made to differentiate between compliance and control and to look at the relative impact of each of the psychosocial variables under study on both constructs. Glycosylated hemoglobin A1C (Hb A1C) tests will be used as a measure of metabolic control. The literature suggests that it is the most sophisticated, long-term measure of diabetes control. Specifically, the study will strive to answer the following questions:

- 1) What is the relationship between psychosocial variables and demographic factors (e.g., subjects' age, sex, race, socio-economic status of the subjects' parents, number of siblings, birth order of subjects, parental marital status, onset and duration of the disease) and compliance variables?
- 2) What is the relationship between compliance measures, metabolic

control and the psychosocial variables under study?

- 3) What are the most potent predictors of compliance with diet, exercise, blood glucose testing, and insulin injection recommendations?
- 4) Which of the psychosocial variables best discriminates subjects on the basis of levels of metabolic control?
- 5) What psychosocial variables are the most potent predictors of metabolic control?
- 6) What compliance variables are the most potent predictors of metabolic control?

Multivariate statistical procedures will be used to analyze the data (canonical correlation, multiple regression, discriminant analysis). By using a multivariate design, this study will significantly add to the knowledge in the field by estimating the relative impact that psychosocial variables have on compliance to multiple aspects of the diabetes treatment regimen and on metabolic control. A clear understanding of noncompliance will assist in the development of intervention strategies that would aid children and parents in fostering compliance.

CHAPTER II

REVIEW OF THE LITERATURE

Overview

In this chapter a review of the pertinent literature will be outlined and discussed. Due to the massive volume of literature on patient compliance, this chapter will focus on only those studies that specifically relate to compliance with the diabetes treatment regimen in children and adolescents. Studies with adult subjects will be discussed only as they relate to methodological issues. Key studies and issues in three broad areas of research will be examined: 1) a description of diabetes and the diabetes treatment regimen, 2) psychosocial variables which impact upon the child's ability to manage the disease, and 3) methodological problems in measuring compliance. The most important studies will be discussed in detail delineating the variables under study and the methodology used to examine them. Other relevant studies will be briefly outlined.

Definition of Diabetes Mellitus

Diabetes mellitus is a chronic disorder of carbohydrate metabolism, that results from inadequate production or utilization of insulin. Normally, during digestion, the body changes sugar, starches, and other foods into a form of sugar called glucose. Some glucose is used immediately for heat or energy, and some is stored for future use in the liver and in the muscles in the form of glycogen. Glycogen (stored glucose) is converted into glucose when needed for performing muscular work or for liberating heat.

The basic cause of diabetes is unknown, but the direct cause is a failure of the beta cells of the pancreas to secrete an adequate amount of insulin. The pancreas, a large gland located behind the stomach produces a numbers of substances that are important in body processes. Two of these substances, glucagon and insulin, are essential to energy production. Glucagon is produced in the alpha cells of the pancreas. It helps to raise the blood glucose level by taking glycogen out of the body reserves. Insulin, produced by the beta cells of the pancreas, acts to lower blood sugar by transporting glucose from the blood to the cells, a process that is essential for normal metabolism. When glucose cannot enter the cells it accumulates in the blood and is passed through the kidneys and overflows into the urine. Because the cells cannot metabolize glucose, they instead metabolize fats and protein for the energy the body needs. As this occurs the body literally begins to fed upon itself, causing extreme weakness, weight loss, and dehydration.

There are two major types of diabetes, Type I, or insulin-dependent diabetes, (IDDM) and Type II, or non-insulin-dependent diabetes (NIDDM). Insulin-dependent diabetes is often referred to as juvenile diabetes because its onset usually occurs prior to the age of fifteen. In this form of diabetes, the pancreas stops making insulin or makes an inadequate amount. Those who contract IDDM are dependent on daily injections of insulin for survival. It is the more severe form of diabetes and its onset can be sudden and in some cases, life threatening. Production of insulin stops abruptly, leaving large amounts of glucose trapped in the bloodstream. When this happened prior to the discovery of insulin in 1921, patients usually went into diabetic comas and died within a few weeks. A diabetic coma is a state of

unconsciousness which can occur if ketoacidosis is untreated. Ketoacidosis is a build-up of sugar and ketones (fatty acids that collect in the blood and urine when the body cells burn fat for energy) in the body which occurs when there is not enough insulin. Symptoms include dry mouth, great thirst, loss of appetite, excessive urination, dry and flushed skin, labored breathing, fruity-smelling breath, and possibly vomiting, abdominal pain, and unconsciousness. Type II diabetes is more common, less abrupt, and less severe than Type I diabetes. In Type II diabetes the pancreas produces some insulin, but it is not used efficiently. People who contract Type II diabetes can often be treated through diet alone, or a combination of diet and oral medication. Type II diabetes usually occurs in people who are overweight and over the age of forty. Heredity is a strong factor for both types of diabetes.

Although there is no cure for diabetes, it can be controlled in most people. Good control is evidenced by the following: the person feels well, he/she maintains normal weight on a well-balanced diet, urine tests are usually negative (see below), and blood tests are usually normal (the normal level of blood sugar is 70-110 milligrams of sugar per 100 milliliters of blood). If diabetes is not properly controlled, two types of reactions that can develop, hypoglycemia (low blood sugar) or hyperglycemia (high blood sugar). Hypoglycemia is a reaction to too much insulin. Because insulin lowers blood glucose level and food consumption raises it, hyperglycemia can occur if a person takes insulin, but skips a meal. Hyperglycemia occurs when there is too much glucose in the blood and not enough insulin, thus causing the body to use its proteins and fats for energy. This then results in the

appearance of large amounts of ketones in the urine and can lead to the development of ketoacidosis.

According to the American Diabetes Association (ADA, 1984), approximately ten million American now have diabetes. Although only five million cases have been diagnosed, it is estimated that there are another five million people who are unaware that they have the disease. Approximately one and one half million people have IDDM and take daily injections of insulin. Because people with diabetes often lead active lives and are often gainfully employed, diabetes is usually not perceived by the general public to be a major health problem. However, the numerous complications that are related to diabetes make it the third leading cause of death and indirectly responsible for three hundred thousand deaths in the United States each year (ADA, 1984). Some of the complications include blindness, kidney diseases, gangrene and amputation, heart disease, unsuccessful pregnancies and birth defects, retinopathy (hemorrhage of the eye), and neuropathy (nerve damage). Good control of the disease can delay or prevent complications or make them less severe if they do occur. Also, advanced treatment methods increase the likelihood that people with diabetes will live near normal life spans.

TREATMENT REGIMENS

The goal of the treatment regimen for people with IDDM is to provide sufficient food for growth and energy, to keep blood glucose levels as normal as possible, to maintain ideal body weight, and to prevent complications (ADA, 1984). This is accomplished by monitoring diet, exercise, insulin, and blood glucose levels.

Diet. Because diabetes affects the way the body uses food, diet is frequently referred to as the cornerstone of the diabetes treatment regimen. Eating and digesting food raises blood glucose level, while physical activity and insulin lower it. Therefore, if a person with insulin-dependent diabetes takes his/her insulin but forgets to eat, the blood glucose level will fall below normal and he/she will have an insulin reaction. On the other hand, if the person eats, but fail to take insulin, the blood glucose level will be above normal. Therefore, special precautions with regard to amount, distribution, and timing of food intake are essential (ADA, 1984).

According to the American Diabetes Association (ADA, 1979), dietary recommendaticns for people with IDDM should be as flexible as possible provided that the diet is consistent with the fundamentals of good nutrition. Nuttall (1983) reiterated the same philosophy, stating that no one diet has been proven to be superior to another with regards to either life expectancy or glucose control. While it is desirable to adapt dietary plans to individual preferences, there are some recommendations that deserve consideration.

1) Diet Compositon

Simple sugars are carbohydrates which are quickly absorbed into the blood stream. Their use by people with diabetes should be restricted. Approximately 50-60% of total daily calories should come from carbohydrates, chiefly complex carbohydrates, 12-20% from protein, and the remainder from fat. Daily consistency in amounts of carbohydrates, proteins, and fats is recommended.

2) Regularity of meals (American Diabetes Association, 1979)

For people with insulin-dependent diabetes the regularity of food intake is an important element in maintaining good metabolic control. The plan typically consists of three meals and two to three snacks at certain times during the day, and should be designed to coincide with peak times in insulin action. When insulin peaks, its action, which includes lowering blood glucose levels, is strongest. If a person does not eat something when the insulin is peaking, he/she risks having an insulin reaction.

Insulin. When insulin was first developed people with diabetes had no choice but to take multiple injections per day. Today there are three types of insulin- short, intermediate, and long-acting, each with its own onset, peak, and duration. It is important to know what type of insulin is being taken and how it works. Information concerning onset, peak, and duration are important in the timing of meals and snacks, as well as the amount of food needed at any given time. Insulins are typed according to the duration of their action. Some people will use only one type, while others will mix types. This is usually done when one type is not enough to control the diabetes.

Rapid or short-acting insulins start to work quickly (within one-half hour) and last for approximately five to twelve hours. Their peak action time is two to five hours after injection. Intermediate-acting insulins take effect within two hours of injection and can last up to twenty-four hours. Their peak is sometime within eight to twelve hours after injection. Short/intermediate-acting insulin is a combination of insulins. It starts to act quickly like short-acting insulins but lasts

for twenty-four hours like the intermediate-acting insulins. Their peak action is in four to eight hours. Mixing insulins does not change the onset, peak time or duration of each. However, when both are working at the same time, blood sugar will be lower than if only one insulin is active. Long-acting insulins can work for as long as thirty-six hours or more. Onset varies from four to ten hours depending on the brand, with peak action times varying from ten to thirty hours. When long-acting was first developed in 1936, it was welcomed enthusiastically. However, in the past ten years, the definition of good control was changed. Today good control means keeping blood sugar levels as close to normal as possible. A normal pancreas does not deliver insulin only once a day, therefore in order to achieve levels of good control, insulin therapy needs to resemble a normal pancreas as much as possible (Narins, 1984).

When determining the number of injections to prescribe, a physician must consider the individual needs of the patient. Other than insulin, diet, activity level, general health, level of emotional stress, among other factors, also affect blood glucose levels. Danowski, Ohlsen, Fisher, and Sunder (1980) found that the prevalent method of one to two injections of a mixture of intermediate and rapid-acting insulin does not in many cases provide adequate control. Some subjects in their study needed as much as four injections per day to maintain good control. This illustrates the fact that there is no simple relationship between insulin dosage and blood glucose.

Insulin Pumps. Insulin pumps are a new method for delivering insulin to people with IDDM. The pump is about the size of a small

camera and is worn around the waist. A portable syringe, which can be manually operated or connected to a microcomputer is used to regulate insulin flow. The syringe is connected to a catheter with a needle at its end, which is inserted in the abdomen. Placement of the needle is changed every 2 to 5 days to avoid irritation. Similar in action to a real pancreas, the pump steadily delivers insulin at a low rate between meals. The person can then increase the dosage of insulin by a simple flick of a switch, which pumps additional insulin into the body to accommodate the increase of blood glucose provided as a meal is digested. The pump can then be reset to continue a slow, measured, constant dose. Since insulin needs vary, dosages must be tailored to an individual's needs. The physician determines the proper level of dosage and gives the person instructions for making adjustments for meals, exercise, and the results of blood glucose tests. The results of the tests determine the rate of insulin given.

Not all people with IDDM will find insulin pump therapy to be the best option for them. First of all, there may be medical reasons why a person's physician might not suggest pump therapy. Pump therapy is as demanding as taking multiple injections daily, and requires regular blood glucose testing (Weinrauch & Tomky, 1985). Therefore, it is only recommended for people who are willing to test blood glucose levels at least four times a day. The pump is worn externally and must stay attached twenty-four hours a day, removing it only for vigorous exercise, bathing, sexual activity, or similar activities. The pumps are also fairly expensive, ranging in price from \$995 to \$2,595. Because it is a recent development, research on the effectiveness of insulin pumps in achieving normal glucose levels and in preventing or

delaying complications, is still in progress.

Exercise. Metabolic control can be improved by a daily regimen of physical exercise. Exercise is particularly good for diabetics because it lowers blood glucose levels by speeding the absorption of glucose in the cells. Cantu (1980) maintains that diabetic children should be taught the value of exercise early in life. He believes that exercise is mandatory for maximum control as well as a means of retarding the development of vascular complications. However, exercise must be planned in accordance with diet and the action of insulin. Exercise enhances the action of injected insulin. As blood glucose is lowered, the body uses food more efficiently and little or no sugar is lost in the urine. Therefore, exercise should not be done during peak insulin action since insulin also acts to lower blood glucose levels. Extremities that are to be exercised should not be used as injection sites (Zinman & Vranic, 1985). When insulin is injected in a muscle it is absorbed more rapidly when that muscle is used during exercise (ADA, 1982). To avoid having too much insulin and too little glucose, unplanned physical exercise should be preceded by a snack. Eating protein before exercise will prevent low blood sugar.

Blood Glucose Testing. One of the ways a person with IDDM controls blood glucose levels is through careful monitoring. There are two methods of testing glucose levels that can be done at home, blood tests and urine tests.

Blood tests. Blood tests yield the exact amount of glucose at the time of testing and as such are useful for people who need to maintain tight control. Tight control is important because it can help to delay

or prevent complications. Tight control is defined as blood sugar levels that are consistently in or near the normal range (70-110 mg/dl (milligrams of glucose per deciliter of blood) before meals and 160 mg/dl after meals). It is particularly important for people with hard to control diabetes to maintain tight control. The reasons for this are several: 1) they need to make frequent adjustments in their treatment routines; 2) they sometimes feel they are having a reaction even when they are not; and 3) they tend to have quick changes in blood sugar levels.

The blood test requires the person to prick his/her finger and place a drop of blood on a glucose sensitive strip. The strip is then read by either matching it to color shades displayed on a scale or by placing it in a color sensitive meter. Blood tests are usually done four or more times per day (Orzeck, 1984).

Urine Tests. Urine tests yield the percentage of glucose in the urine. Glycosuria (the presence of glucose in the urine) is related to the level of glucose in the blood during the time urine is collecting in the bladder. When the blood glucose exceeds the normal renal threshold (the level at which sugar usually passes from the blood to the urine) of approximately 150-200 milligrams, glucose appears in the urine.

There are several types of urine tests. As with the blood glucose tests, test results are compared to color charts. However, unlike blood glucose test results which give an exact measure of glucose in the blood, urine test results provide an indication of the percentage of sugar in the urine. Clinitest is one test in which urine reacts with a chemical in a boiling process. Two drops of urine, ten drops of water,

and a Clinitest tablet are placed in a test tube. The mixture will then start to boil. Fifteen seconds after the boiling stops, the color of the mixture in the test tube is compared to colors on a chart provided by the manufacturer. The colors represent the percent of glucose in the urine. Tes-Tape and Diastix are other types of urine tests that use chemically treated paper and sticks. The tape or stick is dipped in the urine for one to two seconds and the color is then compared with the chart on the package. These two methods are more sensitive than Clinitest to smaller amounts of glucose and are therefore recommended for people with high renal thresholds.

Urine tests can also be misleading if the person's renal threshold is not the same as it is for the average person. Some people have a high renal threshold and don't spill sugar into the urine until the level in the blood is higher than 200. Others have a low renal threshold and spill sugar even though their blood sugar level is within normal ranges.

Urine tests are usually performed before each meal and at bedtime (ADA, 1984). The physician will inform the patient as to whether the first or second morning urine sample is to be tested. The first will reveal blood glucose levels over a period of a few hours, whereas the second sample will show what is present at the time of testing.

Guthrie, Guthrie, and Hinnen (1985) report that although blood tests are more accurate in that they give a precise measure of blood sugar level at the moment of the test, they say nothing about what the blood sugar level was like an hour ago. Urine tests, on the other hand, carry a "memory" of increases in blood sugar over a period of hours. Therefore, if a person's blood sugar was high enough to spill into the

urine a few hours earlier, the urine test will still show a high reading, even if the blood sugar level is back to normal. As such, urine tests can provide a person with information about what their blood sugar control was like between tests.

Urine tests are the only simple way to test for ketones, which are a sign of impending ketoacidosis. Even those people who rely solely on blood glucose tests will need to test their urine for ketones. Ketoacidosis often occurs during times of illness or stress when blood sugar levels are likely to be high. Some urine-testing products test for ketones alone and others measure both ketones and glucose at the same time. Acetest is specific for ketones and comes in tablet form. A drop of urine is placed on a tablet. After thirty seconds the tablet is read by comparing it to the color chart. Ketodiastix tests for both ketones and glucose. A stick is dipped in urine for one to two seconds. After fifteen seconds the stick is read for ketones, and after an additional fifteen seconds, the stick is read for glucose. Ketostix uses the same procedure, but tests for ketones only.

Glycosylated Hemoglobin A1C Test. Glycosylated Hemoglobin A1C is a test that yields an overview of a person's blood glucose control for the past three to four months. It is a test that must be done in a laboratory, rather than at home. Hemoglobin is the substance inside the red blood cells that carries oxygen from the lungs to all the cells and tissues of the body. When blood glucose is elevated it attaches (glycosylates) to molecules of hemoglobin and is carried in the red blood cells as they circulate in the blood. This attachment is permanent and lasts for the life of the cell, which is approximately 120

days. When the amount of glucose that is bound to hemoglobin is measured, the pattern of control for the past three or four months will be evidenced. The more glucose there is in the blood, the more hemoglobin will become glycosylated (Goldstein, Valuck, & Hazelwood, 1985). (ADA, 1984). This test is not meant to replace home urine or blood tests, which are much more useful in day to day management, but is useful in determining the overall effectiveness of a particular treatment regimen.

Foot Care. People with diabetes often experience foot problems related to the lack of blood circulation to the extremities. Problems that ensue can be more severe and involved more complications than in non-diabetic people. This is especially true when the circulation or nerves are impaired. When circulation is poor, the tissue in the foot becomes less able to fight infection. Damage to the nerves can affect a person's ability to feel pain or temperature. Consequently, problems may go untreated and become aggravated. Special vigilance to and early treatment of foot injuries can prevent further complications (Helfand, 1979).

COMPLIANCE WITH THE DIABETES TREATMENT REGIMEN

Intuitively, it is evident that unless a person complies with therapeutic recommendations, treatment will be ineffective. However, despite extensive documentation of this theory, compliance is one of the most poorly understood health behaviors (Becker & Mainman, 1975). While most studies tend to view subjects as compliant or noncompliant, this dichotomy is far too simple. Compliance with the treatment regimen for IDDM illustrates this point well. For example, an individual may comply

with insulin injections, intermittently comply with urine testing, and ignore diet recommendations. As such, a composite score of compliance is of limited utility.

Managing a disease such as IDDM involves adhering to a daily, life-long, multifaceted treatment program to ensure both survival and optimal functioning. Any measure of compliance, therefore, must take into account these multiple dimensions, as well as both qualitative issues (which components of the regimen are being followed and which are not) and quantitative concerns (the extent of compliance with each of the components, from total adherence to total rejection) (Blum, 1984). Because the person with diabetes must assume a major role in his/her own care, adherence to the many facets of the regimen presents numerous occasions for varying degrees of noncompliance.

The general literature suggests that one-quarter to one-half of people who seek medical treatment fail to comply in some way with their prescribed regimen (Haynes, Taylor, and Sackett, 1979). Studies of noncompliance in children and adolescents indicate the average rate to be above 50% (Jay, Litt, and Durant, 1985). The rate of noncompliance among diabetics is particularly poor (Gillum and Barsky, 1974). Studies suggest that 75% of people with diabetes fail to comply with prescribed dietary plans (Watkins, Williams, Martin, Hogan, & Anderson, 1967), while 80% make errors in insulin administration (Hulka, Cassel, Kupper, & Burdette, 1976), and 45% perform urine tests incorrectly (Watkins et al, 1967).

Noncompliance has been implicated as a cause of disturbance in metabolic control in diabetes. However, control and compliance may not

be as closely related as one might suspect. One issue that is generally overlooked in many studies is a need to differentiate between compliance and control. Compliance has been defined as "the extent to which a person's behavior...coincides with medical or health advise." (Haynes, Taylor, & Sackett, 1979) It is usually defined and measured as an outcome and generally conceptualized as a singular entity. However, it clearly involves numerous behaviors associated with at least four categories: (injection, glucose/urinary testing, diet management, and exercise). For the person with diabetes mellitus, control is the extent to which blood glucose levels are as near to normal as possible (ADA, 1982). As such, compliance is a measure of behavior, whereas control is a measure of carbohydrate metabolism. Failure to comply with prescribed recommendations can affect metabolic control. However, stress, changes in metabolic needs, and in exercise routines, among other things, can also alter control. As such, it is important to differentiate between compliance and control, and not to conceptualize them as solely cause and effect constructs (i.e, compliance produces control).

Problems in Measuring Compliance and Control

Previous research on patient compliance with diabetes treatment regimens has been flawed by conceptual limitations, construct measurement problems, and methodological weaknesses. Most of the research conducted thus far has attempted to correlate psychosocial variables with measures of metabolic control, rather than with behavioral measures of compliance. In order to evaluate compliance to the diabetes treatment regimen, it is necessary to assess multiple behaviors. This line of research is still in the early stages of

development.

Patient interviews or self-reports and clinician's ratings are the most frequently used methods of measuring compliance. Generally, these methods have problems with validity and reliability, although there are conflicting points of view on this. Self-reports are generally considered to be the least accurate method of assessment (Rickels and Briscoe, 1970). Haynes (1982) reports, however, that when done in a nonthreatening, nonjudgmental manner, patients will admit to missing some of their doses. The general compliance literature suggest that physician's ratings of patient compliance is not significantly better than chance alone, and that compliance tends to be overestimated (Charney, Bynum, and Eldredge, 1967, Blackwell, 1973). However, Witenberg, Blachard, McCoy, Suls, and McGoldrick (1983) report that physician's subjective ratings of patient compliance were significantly higher than ratings based on objective laboratory data (e.g., Hb A1C).

A number of investigators have looked at compliance or adherence to diabetes treatment regimens and their correlation with various psychosocial variables. Haynes et al. (1979) contend that the term adherence can be used interchangeably with compliance.) A lack of an adequate instrument to measure compliance, however, has caused investigators to use a variety of methods.

Galatzer et al. (1982) measured compliance with a two level scale of adjustment and maladjustment. A positive rating was assigned if the patient kept to his/her diet, injected him/herself, tested urine daily and knew what to do when there were changes in blood sugar, attended follow-up visits and brought urine samples to clinic appointments. A

negative rating was assigned if the patient failed to engage in the above behaviors. Ratings were done by two members of the medical staff team, uninformed as to the purpose of the study, on the basis of medical record reports.

Some studies with adult subjects (Cerkoney & Hart, 1980; Schlenk & Hart, 1984) have used a combination of self-reports and direct observations to measure compliance. In these studies, a twenty-three item compliance measurement tool was used to assess activities with regards to diet, hypoglycemia, and exercise. Interviews were conducted where insulin administration, blood glucose testing, and foot care techniques were observed and rated.

Bobrow et al. (1985) measured adherence to treatment plans by interviewing mothers and their adolescent daughters. The questionnaire focused on the adolescent's behaviors with regards to: 1) eating well-balanced meals, 2) limiting sweets, 3) adhering to recommendations regarding starches, 4) eating the appropriate number of calories on a consistent basis, 5) skipping meals, 6) eating on a regular schedule, 7) injecting insulin and scheduling, 8) testing blood and urine, 9) recording blood and urine test results, 10) exercising, 11) carrying sweets in case of a reaction. Responses were independently rated by the interviewers and a nurse. Interrater reliability ranged from .84 to .97. Mother and daughter ratings were combined to yield an overall adherence rating on each adolescent subject.

Moffatt and Pless (1983) used subjective rating from physicians, nurses, dieticians, and camp staff as an overall assessment of adjustment to diabetes and camp life. Two physicians rated diabetes

control and disease knowledge, two nurses rated self-help technical skills, two dieticians rated diet knowledge and adherence, and two senior camp staff members rated adjustment to camp life. Each independently rated the campers using a five point Likert-type scale. The scores of all the raters were combined for each subject to arrive at a total assesement of diabetes management skills.

This lack of uniformity in measurements makes it difficult to compare results. Unfortunately, this criticism also applies to measures of metabolic control, where some investigators used the hemoglobin A1C test, others have used blood glucose tests or urine tests. Measures of metabolic control appear to be better than compliance measures, since they are more objective and obtainable. Despite its appeal, this method is only of limited value. As discussed earlier, many factors aside from following the prescribed treatment plan, can effect metabolic control. As such, the research findings may be misleading. For example, if an investigator determines that negative attitudes toward the treatment regimen correlate with poor metabolic control, it would be important to also look at what the person was doing to control his/her disease. Perhaps, despite strict adherence to the treatment regimen, other factors were affecting control. The negative attitude could possibly be a consequence of frustration with a prescribed regimen that was ineffective. Therefore, metabolic control may be an effective method of measurement, but it may not be a precise one. Watkins, Williams, Martin, Hogan, and Anderson (1967) contend that although we now think that there are factors other than what patients know about their disease and what they do that are important in controlling it, it is also important to look at the relationship between these variables.

Some investigators (Barglow, Edidin, Budlong-Springer, Berndt, Phillips, & Dubow, 1983; Ahlfield, Soler, & Marcus, 1983; Orr, Golden, Myers, & Marrero 1983; Simonds, Goldstein, Walker, & Rawling 1981; Carney, Schechter, & Davis 1983) have used the hemoglobin A1C test as a measure of metabolic control. Christophersen (1982) contends that the Hb A1C test is one of the most sophisticated since it assesses a patient's level of metabolic control for the past three months. Ahlfield, Soler, and Marcus (1983) used the mean of Hb A1C determinations obtained over a twelve month period prior to the start of the study. Barglow et al. (1983) took three measures of Hb A1C approximately six to eight weeks apart to measure the magnitude of improved control. Orr et al. (1983) used Hb A1C and the number of hospitalizations in the subsequent twelve to eighteen month period as an outcome measure of a psychosocial intervention. Anderson et al. (1981) used Hb A1C measures to differentiate subjects into groups of good, fair, and poor control, so as to evaluate the relationship between family characteristics and levels of metabolic control.

Readings from blood glucose and urine tests can often be misleading since they provide only a short-term measure of a patient's compliance. Grey, Genel, and Tamborlane (1980) measured diabetic control with 24 hour urinary glucose excretion one month prior to conducting patient interviews. Rose, Firestone, Heick, and Faught (1983) assessed the effectiveness of an anxiety management training program by looking at daily diastix readings and weekly 24 hour quantitative glucose measures for a six month period. Hamburg and Inoff (1982) used counselor monitored urine tests four times daily for a two week period as their measure of diabetic control with children attending a summer camp

program. Tests were assessed using a four point scale reflecting frequency and degree of sugar in the urine.

Urine and blood glucose tests, however, can be accurately used in experimental studies where the outcome measure is the number of tests performed. For example, Daneman et. al (1982) used urine tests as a measure of adherence to testing regimens. The authors were interested in the efficacy of a behavior modification program targeted toward a sample of children with IDDM who demonstrated a problematic percentage of negative urine tests. Adherence was measured by means of a marked item technique using placebo Clinitest tablets of an unknown number each week. At the end of the week children reported the number of placebos they found. Carney, Scheckter, and Davis (1983) measured adherence to blood glucose testing by asking parents and children to save the child's Chemstrips and staple them to a recording sheet with the date, the time the test was performed, and the test results. In addition, Hb A1C measures were taken at baseline and follow-up and were used to assess long term degree of metabolic control.

Few investigators have attempted to differentiate between compliance and control. One study that attempted to do this, as well as account for the multitude of behaviors inherent in the diabetes treatment regimen with an adolescent population, was done by Waller and North (1981). They used Hb A1C readings to measure degree of diabetic control and interview material obtained from patients to measure overall level of compliance. Typewritten copies of these interviews, which included questions about diet, insulin, testing, and exercise, were rated by two independent raters. To validate these ratings, material from each

patient's medical record was rated by two additional independent raters who were blind to the interview material. These ratings were compared to the interview-based ratings and were found to be highly correlated. Metabolic control, as measured by hemoglobin A1C did not correlate significantly with interview-based ($r=.38$) or chart-based ($r=.38$) ratings of overall compliance. In addition, the study took into account the severity of each patient's illness. This was done by dividing the amount of intermediate-acting insulin required in a 24 hour period by the patient's weight in kg. Disease severity did not correlate significantly with either interview-based ($r=.38$) or chart-based ($r=.47$) ratings of compliance. Craig (1981) contends, however, that the amount of insulin needed does not necessarily reflect difficulty in control.

One possible criticism of this study is the use of self reports. Waller and North (1981) pointed out, however that when patient interviews were conducted, emphasis was placed on ensuring that the interview was "nonjudgmental in tone." Nonetheless, Haynes (1982) reports that patients will still overestimate their compliance rate by about twenty percent.

Schafer, Glasgow, McCaul and Dreher (1983) examined the relationship between psychosocial variables, adherence to the treatment regimen and metabolic control with 34 adolescents (age 12 -14 years) with IDDM who were attending a summer camp for children with diabetes. Regimen adherence was measured using a self report questionnaire of the frequency of completing different regimen activities over the preceding seven days. The scale consisted of seven questions related to diet, insulin, exercise and glucose testing. HbA1 values were used the

metabolic control measure. The authors reported that three of the seven adherence measures were significantly associated with metabolic control. These measures were the extent to which the diet was followed, reported care in measuring insulin doses and the number of daily glucose tests.

There are, however, some methodological considerations that were not addressed in this study. First, the authors did not report validity and reliability data for their adherence measure. This is particularly problematic for self report measures which are subject to problems of response bias on overreporting (Dunbar & Stunkard, 1979). The metabolic control measure used in this study was a home blood test rather than a laboratory test (e.g., Hb A1C) which yields an overview of blood glucose control for the past three to four months. Procedures were performed, however, that have previously demonstrated a correlation between HbA1 and the more definitive determinants of Hb A1C (Schafer et al., 1983).

In a more recent study, Schafer, McCaul and Glasgow (1986) examined the relationship between supportive and nonsupportive family behaviors and regimen adherence and metabolic control with a group of adults and older adolescents (< 19 years of age). The self-report measure used in the previous study (Schafer et al., 1983) was once again used to assess adherence. In addition to that, however, more specific measures of adherence were also collected. For one week, subjects recorded the timing and frequency of their insulin injections and glucose testing. To assess dietary adherence, nutritionists conducted 24 hour dietary recall interviews. Data for each measure was collected at an initial interview and at a six month follow-up. For the adolescents in the study, no significant relationship was found between adherence and

metabolic control. For adults, adherence to glucose testing as measured by both self-monitoring and self-report at the initial interview was predictive of HbA1c levels at the six month follow-up ($r=.34$ and $.31$).

Another recent attempt to differentiate between compliance and control was Harris and Linn's (1985) study with adult males. In this study, compliance was measured behaviorally, using a combination of patient self-reports and a nurse's evaluation. The nurse reviewed the patient's medical charts to compare the patient's reports and the physician's recommendations, and then rated each of the following on a four point scale: medication, diet, exercise, foot care, urine testing. The total of these five areas comprised the compliance score. Control was measured by 24 hour urine test, fasting blood glucose, and Hb A1C summed together to provide a control score. One problem with this study, is that there was only one rater. Rater biases, which are almost impossible to completely control, and rater unreliability operate to lower validity. If more than one rater is used, inter-rater reliability can be established, which will improve the overall reliability of the instrument. Thorndike and Hagen (1969) ascertain that the use of ratings generally means that no better measure of the question is available.

A moderate, but statistically significant correlation ($r=.21$; $p<.05$) was found between compliance and metabolic control. In a regression analysis, however, when compliance was combined with health beliefs, the health beliefs were found to be better predictors of control than compliance. Compliance did not enter into the best set of individual predictors.

A study by Allen et. al (1983) also differentiated between compliance and control, although the main focus of the study was on parent and child perspectives on performing the various management tasks inherent in the diabetes treatment regimen. Parents and children were interviewed regarding responsibility for insulin injections, drawing up insulin, urine testing, deciding what to eat, timing of meals, eating regular snacks, carrying emergency sweets, and choosing food away from home. Responses were rated on a four point scale and were then compared to 1) medical staff evaluations of regimen compliance, 2) medical staff evaluation of parent and child coping with diabetes, 3) a weighted index of metabolic control based on clinical observations and biochemical measures, and 4) parental estimates of the child's metabolic control. Clinical measures of metabolic control included gross symptoms of diabetes and the adequacy of linear growth and weight gain. Biochemical measures were a quantitative 24 hour urinary glucose test and a Hb A1C test. A measure was weighted according to physicians' judgments of it's relative reliability as an indicator of metabolic control. An overall index of metabolic control was derived as the total of these scores.

Metabolic control was found to be only marginally related ($r=.28$; $p=.056$) to regimen compliance. The authors point out that this finding is consistent with previous reports (Molar, 1978) that other factors (maturation, psychosocial, disease severity) have an effect on control.

Another study that incorporated both compliance and control measures was done by Schaefer, Glasgow, and McCaul (1982). For each of three subjects, a multiple baseline across behaviors design was used to study urine testing, insulin injections, exercise, wearing diabetic

identification and blood glucose testing. Self-monitoring of behavior was used as an adherence measure and blood glucose and 24 hour urine tests were used as measures of metabolic control. The blood glucose and 24 hour urine tests were collected before and after an eight week treatment and at a two month follow-up. Urine tests were also used to provide a daily measure of metabolic control. Reliability checks were conducted by having the subject's mother periodically perform the urine tests.

The results of this study indicated that two of the three subjects increased their adherence and showed improvements in metabolic control levels. The third subject did not increase her compliance and her metabolic control did not improve. The authors contend that this demonstrates a strong relationship between compliance and control. This was not proven statistically because of the small sample size and is inconsistent with other research findings (Waller & North, 1981, Harris & Linn, 1985, Allen et al., 1983). Further investigation is warranted before such a conclusion can be drawn.

The studies by Waller and North (1981), Harris and Linn (1985), Allen et al. (1983), Schafer et al. (1983) and Schafer et al. (1986) provide some evidence that compliance and control are two separate concepts that should be measured independently of one another. However, several methodological problems still persist. A review of the literature clearly indicates that there is a lack of adequate measures to assess compliance with diabetes treatment regimens. Investigators must often resort to developing their own measures, although few attempt to establish reliability and validity for them. When raters are used, they

are often aware of either the study's hypotheses or the status of the subject, thereby risking the possibility of rater bias. The need for the development of such instruments is unquestionable. Presently, however, investigators who are interested in examining this construct can improve their empirical work by differentiating between compliance and control, and by establishing reliability and validity for the instruments they devise.

Factors that Influence Compliance and Control

A vast volume of literature has been generated to explain compliant behavior. A thorough review of this literature is beyond the purview of this chapter. Sackett and Haynes (1976) reviewed the general literature and found complexity, duration, and degree of behavioral change as specific factors associated with noncompliance. They also found that continuity of care, increased supervision, and patient satisfaction lead to greater compliance. A patient who believes in the efficacy of the treatment regimen is more likely to comply with prescribed recommendations. Compliance was not found to be associated with the type of illness except in cases involving psychiatric diagnosis. In terms of patients characteristics, Sackett and Haynes (1976) report few studies that found any association between demographic factors and compliance and noncompliance. Specific patient characteristics associated with noncompliance were inappropriate health beliefs, previous or present noncompliance with other regimens, and family instability.

The diagnosis of IDDM in children and adolescents potentiate problems in psychosocial development. Initially, however, it was believed that

there were correlations between personality traits (dependence/independence conflicts, poor sexual adjustment, anxiety, depression, and paranoid suspicion) and a predisposition to the disease (Dunbar, 1954). Attempts to define a relationship between physiological and psychological factors peaked in the 1950's and a good deal of effort had gone into a search for the "diabetic personality". The research, however was unable to distinguish a diabetic personality that was uniquely and directly associated with the disease from any other chronic illness. Large scale epidemiologic surveys failed to find significant correlations between onset and emotional factors. However, emotional stressors have been implicated as having an effect on the course of the disease (Kimball, 1971).

Stress and Anxiety. Considerable evidence supports the hypothesis that stress can influence diabetic control. Stress hormones raise the levels of glucose and ketones and provide the brain and muscles with important sources of energy. In a healthy person insulin prevents glucose levels from rising too high and prevents the excessive buildup of ketones. In people with diabetes, the effect of the stress hormones can cause glucose and ketones in the blood to rise to above normal levels. As such, diabetes can be in poor control regardless of how well the patient complied with treatment recommendations.

Stress in children is often measured with the Coddington (1972) Social Readjustment Scale. The Coddington Scale provides a measure of the amount of social readjustment required of a child or adolescent in a given year. The method involves asking the subject to check from a list of age-relevant items, events that occurred during the previous twelve

month period. Readjustment is quantified in terms of Life Change Units (LCU's) with different LCU's assigned to each event to account for differences in adaptional demands. Both positive and negative events are summed to provide a measure of the adaptional demands that impinged upon the subject in a given year. Coddington notes that the scale may be flawed in that it does not ask a subject to report how many times an event occurred in the course of the year.

Barglow, Edidin, Budlong-Springer, Berndt, Phillips, and Dubow (1983) studied latency and adolescent age children with IDDM and found the number of life event changes on the Coddington Social Readjustment Rating Scale to be the most important predictor of initial diabetic control. Chase and Jackson (1981) also report findings that support the hypothesis that diabetic control is affected by how one adapts to stressful changes in the environment.

Simonds (1979) reviewed the literature on the effects of emotions on metabolic control and raised the question whether ordinary emotional states (e.g., anger, sadness, anxiety) can affect metabolic control. Hinkle and Wolfe (1952) pioneered the work in this area and found that anxiety producing stimuli lowered blood glucose levels in non-diabetics and that this effect had an even greater magnitude with subjects with diabetes. Fear or anger induced a rise in blood sugar. Vandenberg, Sassman, and Titus (1966) found similar results with subjects under hypnosis, although Weller, Linder, and Nuland (1961) had earlier obtained results that suggested just the opposite. Hinkle and Wolf (1952) maintained that persons exposed to stress over long periods of time had higher blood ketones and could tolerate higher levels of blood

glucose.

In an experimental study, Rose, Firestone, Heich, and Faught (1983) used anxiety management training to determine whether metabolic control could be improved in adolescents with IDDM. Although their sample size was small (n=5), the authors report the technique was effective in improving control of stress and anxiety and this in turn had a positive effect on diabetic regulation. However, subjects' perception of stress and anxiety were not changed. The authors advise caution in drawing conclusions from the results they obtained. An increase in attention to the treatment regimen, may have contributed to improved control, rather than a correlation between control levels and anxiety reduction.

Psychological Factors. Some investigators have attempted to study psychological factors in children with diabetes by developing psychological profiles of children who comply with the treatment regimen and children who do not comply. For example, Simonds (1977) compared children with diabetes in good control and poor control with a matched non-diabetic control group. The results showed no significant differences between children with diabetes and the control group. Interestingly, however, children in good control were found to be in better mental health than the control group. On the other hand, children in poor control had significantly more dependency conflicts and more anxiety and depression than the control group.

Simonds, Golstein, Walker and Rawlings (1981) studied psychological and personality variables of insulin-dependent diabetic adolescents and attempted to differentiate the group into high versus low hemoglobin A1C levels. No significant differences were found between the two groups.

However there were some significant differences between boys and girls. The girls had higher Hb A1C levels, were more independent, and had higher anxiety scores. The authors suggest that the sexes differ in degree of metabolic control perhaps due to differences in their reasons for maintaining or not maintaining adequate metabolic regulation. Due to the homogeneity of the sample (white, rural, middle class) these findings are not widely generalizable, but certainly warrant further investigation with other populations.

The general literature, however, suggests that sex is a weak distinguisher between compliers and noncompliers (Blum, 1984). For the most part, characteristics such as sex, age, race, and education have been only weakly associated with compliance behavior. There is some evidence, however, that adaptation to an illness and the treatment regimen is related to early coping responses (Mattsson, 1972).

Reactions to Diabetes Onset and Subsequent Adjustment. For some illnesses (e.g., cancer), denial serves as an effective coping mechanism in the early stages of the illness (Hackett and Weisman, 1964). However, the onset of IDDM is often sudden and severe, and requires immediate medical intervention for survival. The initial diagnosis is a difficult time for both parents and child. Parents will often feel a sense of loss, that is, the loss of a healthy child. They can also experience fear for their child's life. Mattsson (1972) points out that although diabetic children can adapt well to their illness, a successful resolution of the initial crisis is necessary. This requires that the family accepts the diagnosis and feel confident about the treatment regimen. Tietz and Vidmar (1972) found that the initial reaction to the

diagnosis and onset of the disease influenced the style of coping with it. Denial and overconcern often result in poor coping strategies (LaHood, 1970, Swift et al., 1970).

Kovacs et al. (1985) conducted a longitudinal study of children with newly diagnosed IDDM in order to examine their initial coping responses and psychosocial characteristics. The authors contend that there is no empirical evidence on what type of responses are normal or atypical at various points in the course of a disease, whether preexisting psychological health affects the child's ability to cope, and how to distinguish coping behaviors from psychopathologic behavior. The children in the study were found to be within normative ranges for life stresses and psychiatric disorders that predated the onset of the disease. Two general modes of coping characterized this sample. The majority (64%) of the children responded to the initial stress of living with IDDM with mild sadness, anxiety, feelings of friendlessness, and social withdrawal. A more extreme reaction was seen in 36% of the children, with depressive syndromes being the most common response. This response was found to be more prevalent among children whose parents were of low SES and had marital distress. However, initial responses were not maintained over time. Even those children who manifested more serious adjustment problems recovered with seven to nine months of the initial diagnosis.

Galatzer, Amir, Gil, Karp, and Laron (1982) investigated the effect of the initial therapeutic approach to the diabetic child and his/her family on subsequent development. The authors compared two groups of children: those who were treated in a clinic that provided a crisis

intervention program to every family upon referral of a newly diagnosed patient and those who were initially treated at a clinic that had no such program. Each subject was rated separately by a psychologist and a social worker. Ratings were based on the subject's condition during the previous six months. Significant differences were found between the two groups with respect to compliance, familial relationships, and sociability. There were no significant differences on school achievement and work performance. The authors contend that special preventive services could reduce future psychosocial maladjustment and improve compliance.

There are, however, several methodological problems with this study. While the purpose of the study was to examine the effect of a crisis intervention program, subjects' exposure to the program varied from three years to fifteen years prior to the study. As such, the effects of history and maturation could have biased the results. Also, lack of control for duration and onset of the disease, age of the subjects, and psychosocial variables leaves the study open to questions of external validity. As such, the hypothesis being tested here is worthy, but the methodology is weak.

Greydanus and Hofmann (1979) report that there is disagreement as to whether age of onset of diabetes is related to behavioral problems in adolescents. They cite early studies from the 1940's and 1950's which found that the earlier the onset, the more readily the child accepts the disease and others where earlier onset was found to be a risk factor.

Ahnsjo, Humble, Larsson, Settergren-Carlsson, and Sterky (1981) studied personality changes and social adjustment in diabetic children

for the first three years after onset. Sixty-four diabetic children were compared to a control group of thirty non-diabetic children. Four variables were identified: 1) psychiatric assesement of the child's mental state, 2) evaluation of the child's social situation assessed by the social worker, 3) intelligence quotient measured according to a the Terman-Merrill method (a standardized Swedish test), and 4) a Rorschach test with standard presentation and scoring techniques, evaluated according to variables constructed by the authors. Measures were obtained at baseline (within 5 months after onset) and at a three year follow-up. The authors found no significant differences between the two groups with regards to mental state, although the diabetic children showed an increase from baseline to follow-up with regards to symptoms of aggression. This was not found, however, when controlling for high or low glucose levels. At baseline, the Rorschach showed diabetic children with higher degrees of anxiety concerning their health, but this decreased by follow-up. No differences were found between the two groups with regards to social problems or intelligence. The authors speculate that the few differences they found between the two groups may in fact be due to the traumatic experience of the seriousness of a chronic illness.

Developmental Stages. The diagnosis of a chronic disease such as diabetes necessarily influences or threatens a child's accomplishment of developmental tasks. Carreto and Travis (1984) note that a chronic illness can disrupt the maturational process and can have an effect both on the achievement of developmental tasks and the ability of the child to cope with the demands of a treatment regimen. There are, however, few infancy and early childhood studies that examine the effects of

diabetes on the child's development. For school-aged children, most of the research has focused on the emotional adjustment of the child and family patterns that negatively affect the child's ability to manage the disease.

Adolescence can be a trying time for children and their parents. It is generally agreed that these years are especially difficult for children with diabetes mellitus (Tatersall & Lowe, 1981). It is a time when the child is least motivated to adhere to a treatment regimen that sets him/her apart from peers (Gerreto & Travis, 1984). Identity, independence, body integrity, privacy, and a desire to be similar to peers are some of the major concerns for adolescents (Sullivan, 1979). The public nature of the health care behaviors specific to the diabetic regimen interfere with these concerns and contribute an increase in normal life stress.

Greydanus and Hofmann (1979) suggest that a key factor in the quality of the diabetic adolescent's self-care is his/her self-image or self-esteem. They contend that low self-esteem may be a catalyst for poor adjustment difficulties and rebellion. This might be associated with conflicts with parents over control issues and might be complicated further by issues of secondary gain or denial of the illness. Sullivan (1979) reports that most adolescents with diabetes handle these stresses fairly well. However, some reports (Khurana and White, 1970) suggest that adolescents may be denying the seriousness of the disease as evidenced in reports of beliefs that diabetes will not affect their futures or cause health complications. Bobrow et al. (1985) found that adolescent girls who had difficulty adhering to their treatment regimens

did not believe that adherence would delay or prevent complications. Many of the adolescents in this study did not report concern about their future health.

Ego development, as conceptualized by Loevinger (1976), is the attainment of increasingly more mature levels of functioning in the realm of impulse control, moral development, and quality of interpersonal relations. It is the framework of meaning one subjectively imposes on experience. It encompasses the individual's self-esteem, knowledge by experience, character and moral attitudes, and interpersonal development (Hoette, 1983). As with Piaget's system, Loevinger's stages of ego development comprise a hierarchical order, although it is not strictly dependent on age. Each stage is more complex than the preceding one, and none can be skipped in the course of development. It is possible, however, that an individual may not develop beyond a certain stage.

In an investigation of the interaction between personality factors and metabolic control, Barglow et al. (1983) found that ego development significantly predicted the magnitude of improved diabetic control in a group of latency and adolescent age insulin-dependent diabetic children. Hauser, Pollets, and Turner (1979) found that diabetic adolescents had lower levels of ego development than a control group. Generally, boys were lower than girls, and self-esteem was found to be impaired in subjects with lower ego development.

Knowledge. Knowledge and beliefs about health and illness develop gradually during childhood. Leventhal (1973) argued that compliance entails a rather sophisticated set of beliefs and knowledge about

health. For children, this is much more difficult due to limitations in their cognitive development (Brown, 1985). In order to avoid a health threat, an individual must possess both the knowledge to identify the danger, as well as the belief that it is in fact a threat.

Using Piaget's model of cognitive development, Bibace and Walsh (1979) addressed themselves to the following question: How do children's conceptions of health and illness change as a function of changes in their developmental status? They discovered that children's beliefs and knowledge about health and illness interacted with age, with the sophistication of the child's concepts increasing with age.

Johnson et al. (1982) studied childrens' and parents' knowledge about IDDM. They found that older children were more knowledgeable than younger children and were more skilled at diabetes-related tasks (e.g., urine testing, insulin injections). The authors assessed knowledge across three areas: 1) general information, 2) problem solving, and 3) skill at urine testing and self-injections. The first two areas were assessed with multiple choice questionnaires modeled after the work of previous authors (see Etzwiler & Sines, 1962, Etzwiler & Robb, 1972, and Travis, 1978) and were statistically validated. Skill was measured with an observational procedure by two independent raters and showed good interrater reliability. The children completed all three components of the assessment battery and their parents completed only the two questionnaires. In addition to age differences, the study indicated that girls are more accurate than boys in performing urine tests and self-injections, and that mothers were more knowledgeable than fathers and children about diabetes. Duration of the disease was not found to

be related to any of the knowledge measures. Knowledge in one content area was not predictive of knowledge in another content area. Overall, the study indicated that childrens' and parents' knowledge was insufficient to make accurate diabetes management decisions.

Summer camps are a means of providing diabetic youth with the opportunity to learn more about their disease and how to control it, while at the same time providing them with recreational activities and a chance to make new friends. Studies have been conducted to measure the degree to which the camp experience was successful in increasing the children's knowledge and improving their skills at managing their disease. Harkavy et al. (1983) conducted a study with a group of IDDM children at a diabetes summer camp, using the same assessment battery as the Johnson et al. (1982) study. As in the previous study, Harkavy et al. found age and sex to be important predictors of how much the children knew at the beginning and the end of the camp experience. In terms of improved test scores, 12 to 15 year-olds showed significant improvements in four knowledge areas, whereas 10 to 11 year-olds showed no changes. The authors conclude that cognitive development is an important determinant of who will benefit from the educational information available during the camp experience.

Moffatt and Pless (1983) studied changes in locus of control in a group of diabetic children attending a summer camp. Locus of control is a psychological construct that is often used to study degree of success. It is intended to measure the degree to which a person believes his/her action influences events in his/her life. A control group of non-campers was also included in the analysis. Significant changes toward

internal locus of control on the Nowicki Strickland Children's Locus of Control Scale was found for campers, but not for the control group. On the Parcel Health Locus of Control Scale, although campers' scores changed significantly from the pre-camp experience, these changes were not significantly different from those of the control group. Subjective assessment of diabetes management skills were also obtained from camp staff. A moderate correlation was found between initial locus of control scales and the camp staff's rating of diabetes management skills. Although the study examines a possible important variable for predicting compliance, the authors failed to take into account a number of other significant variables that could have an effect on both compliance and locus of control, such as family environment, level of ego development, duration of illness, and age of onset, among others.

Hamburg and Inoff (1982) also studied insulin-dependent diabetic children (ages 5-19) at a summer camp for a two week period. The focus of their study was to examine the relationship between degree of diabetic control and knowledge of diabetes and locus of control. Daily counselor -monitored urine tests four times per day were used as measures of control. A special questionnaire designed for the purpose of this study was developed to measure knowledge of diabetes and the Norwicki-Strickland Children's Test of Locus of Control was used as the measure of the independent variable. The authors reported that although knowledge of diabetes increased with age, it was found to be negatively related to level of control. Locus of control was significantly related to level of control, but for boys, the more external locus of control, the better the metabolic control, whereas for girls, the more internal locus of control, the better the metabolic control. For girls it was

also found that the older they were at onset, the better the metabolic control. Metabolic control was found to improve with age, yet it worsened for girls in the 15-19 year old age group.

The finding that knowledge is negatively correlated with metabolic control is not only counterintuitive, but is also contradicts the findings of previous studies. However, the lack of a standardized instrument to measure knowledge and the variety of ways used to measure compliance makes comparisons between studies difficult. Measures of control over time need to be investigated. However, Watkins, Williams, Martin, Hogan, and Anderson (1967) contend that there are factors other than what a person knows about his/her disease and what they do that are important in controlling it.

Health Beliefs. Children's health beliefs is a recent topic of interest in child health psychology. The idea that an individual's behavior can be predicted from his/her beliefs was first introduced by Kurt Lewin in the 1930's. Hochbaum (1956) extended this concept to health behaviors. He suggested that health behaviors are a function of the perception of illness as a threat and the expected value of preventive action for reducing that threat. First developed by Rosenstock (1966), the formalization of the relationship between health beliefs and behavior grew mainly out of the work of Becker (1974). According to the model, an individual's health beliefs determine his/her readiness to engage in health-related behaviors.

The Health Beliefs Model requires that distinctions be made among various types of health behaviors (Jordan and O'Grady, 1982). Preventive health behaviors are activities pursued by asymptomatic

individuals for the purpose of preventing or detecting disease. Illness behaviors are activities undertaken by symptomatic individuals for the purpose of defining and treating illness. Sick role behaviors are actions engaged in by individuals with diagnosed illnesses for the purpose of getting well. (Kasl and Cobb, 1966). It is conceivable, then that a person with diabetes will engage in all three types of behaviors. Preventive health behaviors are undertaken to delay or prevent complications, illness behaviors are engaged in daily in the individual's attempt to maintain metabolic control, and sick role behaviors are undertaken during times of illness (e.g., ketoacidosis, hypoglycemia).

Most of the research on children's concepts of health and illness has focused on healthy children. Blos (1978) suggested that chronic illness will influence a child's conceptions. Two opposing theoretical predictions have been postulated. The Piagetian perspective posits that knowledge will be gained by the experience of illness and as such chronically ill children will be more knowledgeable on matters related to health and illness. An alternative position is that the experience of illness is emotionally overwhelming resulting in regressed or inhibited levels of conceptualizing with respect to health and illness (Bibace & Walsh, 1981).

Eiser, Patterson, and Tripp (1984) compared the health beliefs of a group of children with diabetes with a matched group of healthy children. The children were interviewed and asked general questions about various diseases. No significant differences were found between the two groups, except with regards to knowledge about diabetes.

Children with diabetes were more knowledgeable than healthy children about the specifics of their own disease. Eisner et al. concluded that the study demonstrates that illness does not significantly affect children's knowledge of health and illness, but that attitudes and beliefs would be a fruitful area for further research. However, the data was rated by two of the authors, and as such may have been affected by experimenter bias.

Parent's health beliefs are frequently used to predict health behaviors in children. Several health beliefs were found to be related to compliant behavior (Becker, 1974). In the case of chronic illness, Radius, Becker, Rosenstock, Drachman, Schubert, and Teets (1978) found that compliance was best among mothers who believed that their child was more vulnerable than other children and would require medication for a lifetime. There was also a strong relationship between compliance and the mother's belief in the seriousness of the illness (Becker, 1974). Mothers who believed in the efficacy of the treatment regimen, agreed with the diagnosis, and were satisfied with the quality of care were also more likely to comply with recommendations for their child's treatment (Becker, Drachman, and Kirscht, 1972). Mothers who found the treatment regimen to be disruptive were poor compliers with treatment regimens (Radius, Becker, Rosenstock, Drachman, Schuberth, and Teets, 1978). Although parental attitudes have also been found to have an effect on the child's ability to comply.

Attitudes Toward the Disease and the Treatment Regimen. Early research on diabetes management and the family addressed the influence of parental attitudes on the child's adjustment to the disease and

his/her level of metabolic control. Pond (1979) found that parental attitudes toward a child with a chronic illness can have an affect on the course of the treatment and the child's ability to follow the prescribed treatment regimen. She suggested that parental attitudes can be categorized in the following areas: attitudes toward 1) etiology and hereditary factors, 2) the child, 3) treatment, 4) the physican and the medical team, and 5) to each other. Some parents will feel resentful when their child is diagnosed, while others will feel guilty and may search for a scapegoat. Some will blame each other. Overprotectiveness of the child is common in very anxious parents. In such instances, the anxiety can be so severe that the child and his/her illness is rejected, thus allowing the parents to deny it. However, the child's illness usually only accentuates existing neurotic traits in the parents. Parental attitudes toward the treatment regimen may change over time. Initially, parents are grateful that treatment is effective, but may later tire of the daily drugery of the regimen. Parental attitudes toward treatment can influence their relationship with the child's physican which in turn can affect the child's attitude and how well the disease is managed.

Khurana and White (1970) interviewed 140 diabetic girls, ages 10-15 regarding their attitudes toward their illness. Forty-eight responded that the disease did not bother them. Fifty of this group of 140 were questioned about complications, 34% were unaware of any, and others stated that they feared blindness and amputation.

Ahlfield, Soler, and Marcus (1983) looked at the effects of diabetes on family and social interactions from the adolescent's and parent's

perspectives. Using a special questionnaire designed for the purpose of this study, the authors found that agreement between the adolescent's and the parent's responses varied from a high of 86% to a low of 30%. Questions referring to the effect of diabetes on scholastic performance, concentration, and social life were associated with poor agreement. No correlation was found between the extent to which parents and children agreed on various responses and hemoglobin A1C tests.

Other studies examined specific behaviors in the treatment regimen. Ludvigsson and Svensson (1979), for example, found a positive correlation between attitudes toward urinalysis and number of urine tests performed. Both patients and their parents indicated that the test was an effective way to manage the disease. Ludvigsson, Larsson, and Svensson (1980) found that although most adolescents in their study believe that physical exercise is a positive thing to do and know that it is an important part of the treatment regimen, but reported that they did not exercise regularly.

Diabetic adolescents' attitude toward themselves and responsibility for their illness was studied by Patridge, Garner, Thompson, and Cherry (1972). Specifically, the study addressed the following issues: 1) how diabetic adolescents see themselves in terms of independence and responsibility as compared with their non-diabetic peers, 2) whether their views on diabetes management responsibility were consonant with their views in other areas of their lives, 3) their understanding of their condition, and 4) self-appraisal of diabetic control. In order to obtain information about these four issues, the authors devised four instruments: a questionnaire on Adolescent Responsibility, a

questionnaire on Responsibility for Diabetes Management, a 25 item Diabetes Information Test, and a five point self-rating scale for the General Diabetic Condition. The result obtained indicated that the subjects accepted responsibility for their diabetes, had viewpoints similar to non-diabetic youth regarding responsibility in other important life areas, were ready to accept responsibility for their diabetes management at about age 12, and had a "realistic" view of their level of control. Self-ratings of general diabetic condition were compared to a global ratings of diabetic condition based upon laboratory and clinical data taken from the subjects' charts and the physicians' subjective ratings of subjects' condition. Both were found to be significant beyond the .05 level. However, no attempt was made to validate the other three instruments used in this study, and as such results must be interpreted with caution.

Family Factors. The focus on the relationship between the child and his/her disease does not adequately account for findings relative to the child's ability to cope with the disease. Carreto and Travis (1984) point out that the child does not function in a vacuum but rather within a network of social environments, the most influential of which is the family.

The first studies conducted on diabetes management and family factors were done in the 1940's and 1950's. Anderson and Auslander (1980) reviewed the literature on this topic and cited four types of maternal attitudes that were correlated with poor metabolic control: 1) overprotective, overanxious, 2) overindulgent, overpermissive, 3) perfectionist, controlling, and 4) indifferent or rejecting. Swift,

Seidman, and Stein (1967) reported that children with high levels of metabolic control had families with the following characteristics: 1) few conflicts, 2) low levels of stress in the parent-child relationship, 3) adequate home adjustment of the child, and 4) no financial problems. Koski (1969) found that maternal competence and adjustment to the disease correlated positively with metabolic control. In follow-up studies Koski, Ahlas, & Kumento (1976) and Koski & Kumento (1977) found that those families whose child's metabolic control had improved had the following characteristics: 1) family composition was stable, 2) there were clear, distinct boundaries between generations and they were recognized by family members, 3) family members were realistic and cooperative in helping to implement the treatment regimen, 4) low marital conflict, and 5) both parents were in the house or a competent single parent was present.

Quint (1970) identified two basic patterns of family adaptation to the diabetic treatment regimen. In one, the family incorporates the regimen into their daily routine, whereas in the other, the regimen creates reoccurring crises and results in poor metabolic control. Quint also identified four styles of parental functioning with respect to the treatment regimen: protective, manipulative, abdicative, and adaptive. She found that parental treatment styles influenced the child's ability to adhere to the diabetes treatment regimen. In families where the parents had different styles, there were more problems with management. (Benoliel and Quint, 1975) Anderson, Miller, Auslander, and Santiago (1981) compared the family environments of diabetic adolescents in good (Hb A1C < 10), fair (10 > Hb A1C < 14), and poor (Hb A1C > 14) control. Both parents and adolescents were independently assessed with structured

interviews and the Moos Family Environment Scale (1974). The adolescents also completed the Piers-Harris Children's Self Concept Scale (1967). Adolescents in good control reported fewer diabetes-related symptoms, less anxiety, and had a more positive self-concept. More cohesion, less conflict among family members, and parental encouragement for independent behavior were also characteristic of this group. Baker, Minuchin, Milman, Liebman, & Todd (1975) studied family interaction patterns in a group of "psychosomatic" diabetic children, who experienced recurrent ketoacidosis, despite adherence to insulin requirements. They discovered several family patterns: 1) psychological overinvolvement or enmeshment between family members, 2) overprotective concerns, 3) rigid family interaction patterns, and 4) lack of effective methods for resolving family conflict.

Schafer et al. (1983) examined the relationship between both global measures of family functioning using the Family Environment Scale (Moos, 1981) and more specific measures of diabetes-related family behaviors using the Diabetes Family Behavior Checklist, which they designed for use in this study and adherence and metabolic control in a group of adolescents with IDDM. No significant correlations were found between either of the measures and metabolic control. The more specific measures were found to be better predictors of adherence than the global measures. Negative correlations were found between negative interactions with mother and the extent to which the child follows the diet and the number of daily glucose tests, and negative interactions with father and care in measuring insulin. On the Family Environment Scale, conflict correlated negatively with number of daily glucose tests.

In a subsequent study with adults and adolescents using the Diabetes Family Behavior Checklist, Schaefer et al. (1986) found no consistent pattern for adolescents between Diabetes Family Behavior Checklist scores and adherence measure or HbA1c.

The mother's perception of the difficulty of the treatment regimen and the effect of her perception on the child's ability to manage the disease was examined by Banion, Miles, and Carter (1983). Through a review of the literature and personal experiences with diabetic children, the authors were able to identify eleven aspects of diabetes management: dietary management, urine testing, insulin injections, diabetic control, future concerns, hypoglycemia, finances, regularity of daily activities/time demands, availability of help and social support, and psychological stigma. Based on these aspects, the authors developed the Diabetic Management Concern Questionnaire to measure which aspects of diabetic management were most problematic for mothers of children with diabetes. The mothers studied reported concerns about their child's future, hypoglycemia and diabetic control as the most problematic aspects of having a child with diabetes. The younger the child, the more the mother was concerned about insulin injection. Lower SES mothers reported finances, the availability of help and support and the psychological stigma of the disease to be most problematic. Single mothers were also concerned about finances.

Studies have shown that it the mother rather than the father who assumes the prominent role in the child's diabetes-related tasks (Fallstrom, 1974) and who is most knowledgeable about diabetes (Johnson et al., 1982). Much of the research conducted thus far has focused on

the mother-child relationship and how it impacts upon compliance with treatment recommendations. Bobrow, AvRuskin, and Siller (1985) explored the relationship of mother-daughter interactions to adherence to treatment regimens among a group of diabetic adolescents. Structured interviews were conducted with both mothers and daughters to assess adherence to diabetes regimens. Mother-daughter discussions, analyzed according to the Hill Interaction Matrix and a modified version of the Beaver-Timberlawn Family Evaluation Scale, yielded information on feelings, problems, concerns, parental supervision, adjustment, and family life. Subjects who were assessed to be poor adherers were found to have more difficulty than good adherers in discussing feelings, problems, and concerns with their mothers. Poor adherers also demonstrated more emotionally charged interactions with their mothers and were less efficient at negotiating conflict issues.

Pless, Roghman, and Haggerty (1972) proposed that chronic illness has an effect on a child's self-esteem, behavior, and mental health, which in turn are influenced by factors such as family functioning and social environment. Grey, Genel, and Tamborlane (1980) tested this hypothesis on a group of latency-aged diabetic children. They examined the relationship between psychosocial adjustment, family functioning, and self-esteem (both the child's and the parent's) on diabetic control. Of the twenty children they studied, 55% were found to have moderate to severe adjustment problems. The well-adjusted group was discovered to be significantly higher on all measures of the independent variables (e.g., optimal family functioning, higher parental and child self esteem) and lower (indicating good metabolic control) on the dependent variable. The Grey et al study thus lends support to Pless et al's

hypothesis and adds another variable to the equation, parental self-esteem. The results of this study should be interpreted with caution, however, due to the small, convenient sample size, which may have biased the results.

Orr, Golden, Myers, and Marrero (1983) studied fifteen adolescents with poorly controlled diabetes who were referred to a tertiary care center. The authors hypothesized that since all fifteen adolescents had been treated by conventional treatment regimens, psychosocial factors were contributing to the development and persistence of poor metabolic control. The purpose of the study was to explore the child's current social milieu in order to discover commonalities among these fifteen adolescents. The most common problems were reported to be excessive school absences (53%), depressive episodes (33%), and social isolation (33%). The authors further contend that "8 of the 15 families demonstrated dynamics that directly appear to contribute to poor metabolic control of the child." Ten of the fifteen patients were later recommended for counseling interventions consisting of family, individual and/or group counseling. Of the eight who accepted treatment, the authors found all of them in the subsequent 12 to 18 month period to have improved metabolic control and improved psychological functioning with no incidents of hospitalization for ketoacidosis.

White, Kolman, Wexler, Polin, and Winter (1984) reviewed the medical records of thirty children and adolescents with recurrent diabetic ketacidosis. Psychosocial data was obtained from summaries found in the medical records that were written by a social worker and/or psychologist

as part of either a routine intake interview or an evaluation for suspected psychosocial problems. The information obtained was categorized into eight areas: caretaker, home environment, parental functioning, family problems, family involvement in diabetes, subject's reaction to diabetes, subject's behavior problems, and subject's personality and affect. White et al. interpreted their results to mean that only a small percentage of the patients experienced ketoacidotic episodes as a result of intercurrent illness or poor compliance. They suggest that stressful family situations, including poor problem solving skills, interpersonal conflict, financial difficulties, and lack of family involvement with the diabetes were the major reasons for repeated diabetic ketoacidosis. These findings provide a very promising area for empirical investigation in the future.

Waller and North (1981) used a semi-structured interview and a brief questionnaire to measure compliance with medical regimen and to assess family support, perceived difficulty of the treatment program, and attitude toward the clinic. Diabetic control, as measured by Hemoglobin A1C, did not correlate significantly with compliance. However, interview based ratings of the subject's family support system, perceived difficulty of the program and attitude toward the clinic, correlated significantly with both chart-based and interview-based ratings of overall compliance.

Waller and North maintain that family support is an extremely important factor in compliance, particularly the degree to which the family "shares the burden" of the illness. Subjects experienced parental monitoring of the treatment program in different ways. Some

saw it as nagging, but necessary, while others viewed it a overprotective. Family support was also found to be negatively correlated with perceived difficulty of the diabetic program.

Thus far, the majority of the research on diabetic children and their families has focused on the effects of family dynamics on the child's ability to manage the disease. However, as Carreto and Travis (1984) point out, the impact is not unidirectional, rather both child and family functioning are affected by each other. As such, researchers should be looking at two questions: 1) How is family functioning affected by the presence of a diabetic child? and 2) How is the child's ability to cope with diabetes affected by family factors?.

Experimental Studies. Besides the camp studies, few investigators have conducted studies with the goal of actively intervening to produce changes in diabetes management behaviors. Schaefer, Glasgow, and McCaul (1982) investigated the effectiveness of social learning techniques of goal setting and behavioral contracting for increasing the adherence to urine testing, insulin injections, exercise, wearing diabetic identification, and blood glucose testing in three diabetic adolescents. The results indicated that adherence was increased and maintained and metabolic control improved at desired levels for two of the three subjects. If this study was replicated with a larger population, it might be possible to make some determinations as to when this treatment would be effective and under what circumstances and with what kind of patients. The small sample prevents one from drawing any conclusions beyond these two subjects.

Daneman, Epstein, Siminerio, Beck, Farkas, Figueroa, Becker, and Drash (1982) implemented a behavior modification program to improve diet, exercise, urine testing, and insulin adjustment in twenty (8-12 year old) diabetic children. The study was divided into three phases and took place over the course of 32 weeks. The program was found to be successful in improving the children's self-care skills, but the acquisition of these skills did not produce the desired changes in metabolic control. Frequent parent checks and the use of Clinitest placebos were used in this study to improve reliability and compliance. Placebo Clinitest tablets (clinkers) are similar in appearance to regular Clinitest tablets, but are inert when added to the urine/water solution. Subjects in this study were provided with an unknown number of clinkers throughout the course of the study and were asked to record the number they found each week. Agreement between the number reported and the actual number of clinkers was used as a measure of compliance since the only way a subject could know the number of clinkers was to do the urine tests. The authors suggest that these controls may not have been sufficient and that other methods will need to be tested. However, the study does represent one of the few where an attempt was made to control for reliability and compliance.

Summary

The studies reviewed here suggest that psychosocial factors may have an impact on diabetic control and compliance with treatment regimens, although the direction of the impact is not clear. Specifically, family functioning, attitudes toward the treatment regimen, health beliefs, level of ego development, parental attitudes, locus of control, and

knowledge of the treatment recommendations, have all been implicated as being related to the child's metabolic control and his/her ability to comply with prescribed recommendations. However, the studies are fraught with methodological weaknesses. Some rely on either patient self-reports, medical staff ratings, or special questionnaires designed for the purpose of the study without making an effort to establish reliability and validity. Others lack external validity due to small sample sizes or homogeneous populations. Comparisons between studies are difficult because even if standardized instruments are used, different measures are used by different researchers to measure the same construct. The difficulty and the numerous ways used to measure compliance further complicates the issue.

CHAPTER THREE

METHODOLOGY

Overview

This chapter presents the methodology used to address the research questions under study. Information pertaining to sample characteristics, procedure and instruments are discussed in detail. The hypotheses that were tested in this study are presented and the statistical analyses used are described.

Subjects

The sample for this study consisted of 47 children with insulin-dependent diabetes mellitus and their parent or guardian. Children of both sexes, between the ages of 7 and 17 were asked to participate in the study. Subjects were not excluded from the study on the basis of race or socioeconomic status. Excluded from the study were children who are mentally retarded or emotionally disturbed because the focus of the study is on normal children with a chronic illness. Subjects were obtained from a private pediatric practice in a large Midwestern city.

Sixty children and their parents were asked to participate in the study. Seventy-eight percent (47) of those surveyed completed the questionnaires. The most common reason given for not participating in the study was a busy schedule and the amount of time required to complete the questionnaires. The physician reported that one family declined to participate because the child was being hospitalized for recurrent episodes of ketoacidosis. Of the children there were 17 males and 30 females respondents. The mean age was 12.72 (SD=2.21). Eighty-

nine percent of the adult subjects were the mothers of the children, with 76.6 percent reporting to be married to their child's father. This was expected since research (e.g., Fallstrom, 1974) has shown that it is the mother rather than the father who assumes the major responsibility for management of the child's diabetes. The average household consisted of four people with the average annual income ranging from \$40,000 to \$50,000. Forty percent of the children were first borns. The age at which the children were diagnosed as having insulin dependent diabetes mellitus ranged from less than a year to age fourteen ($X=6.884$; $SD=3.246$). In 47% of the subjects' families there were no other family members with diabetes. Fifty-three percent of the children inject their insulin themselves, 28% do so themselves some of the time, and the remainder do not inject their insulin themselves. The most recent hemoglobin test ranged from a low of 4.8 to a high of 14.4 ($X=8.49$; $SD=1.87$).

Procedure

The study was conducted in two phases. The first phase was a pilot study. Four subjects, selected by the pediatrician who provided the subjects for the study, were asked to complete the instruments that were proposed to be used in the study. They were interviewed about the length of time it took them to complete each inventory, how well they understood the inventories, and any reactions they had about the instruments. On the basis of the information they provided, it was decided that because of the length of the Diabetes Opinion Survey and the Parents Diabetes Opinion Survey, only those items that are used to compute the scales would be used on the surveys. It was further decided

that only the General Information component of the Test of Diabetes Knowledge would be used.

The second phase of the study entailed the recruitment of subjects. The pediatrician called prospective subjects or spoke to them in person at his office and asked them to participate in the study. The investigator provided the pediatrician with packets of test instruments, consent forms and letters. The letter explained that the purpose of the study was to investigate factors that interfere with a child's ability to comply with his/her treatment regimen. The child was asked to complete five instruments and the parent was asked to complete four instruments. Interested subjects were either given the questionnaires at the pediatrician's office or received them in the mail. The parent was also asked to sign research waiver forms that permitted the pediatrician to give the investigator the child's most recent hemoglobin A1C test. Stamped self-addressed envelopes were provided for both the child and the parent. This was to ensure confidentiality and to reassure the child that his/her responses would not be shared with the parent, unless he/she chose to do so.

The following procedures were used to insure confidentiality of the participant's responses. Subjects were assigned code numbers for use on all questionnaires; names were not used on any of the instruments. All of the raw data were number coded and entered into a computer data file at Loyola University. A master list of subjects' names and code numbers was kept in a private file by the investigator to allow for individual feedback of the results. Subjects and their parents were informed of the procedures for insuring confidentiality in the letter that explained

the purpose of the study. Appendix A contains a copy of the letter and the consent forms.

After the data was collected and analyzed, subjects will be debriefed. Subjects will receive a written report of the findings of the study. Separate reports will be provided for parents and children. Feedback sessions will be made available to those subjects who wish to talk about their individual test results.

Instruments

The children were administered five instruments, and parents were administered four instruments. Appendix A contains copies of the instruments. Two instruments (Diabetes Behavior Checklist and the Demographic Questionnaire) were designed specifically for the purpose of this study.

The parents were asked to complete the following instruments.

Demographic Information Questionnaire. This questionnaire was used to obtain such demographic information as the child's age, sex, race, age at diabetes onset, parent's socioeconomic status, parent's marital status, number of siblings, child's birth order, number of people in the household, and number of other people in the family who have diabetes.

Parents Diabetes Opinion Survey. (PDOS) (Johnson, 1985). This instrument was used to measure a parent's attitude toward his/her child's diabetes. The author developed the items for the scale based on the clinical literature and interviews she conducted with clinicians and patients concerning parent attitudes toward diabetes.

The PDOS consists of items pertaining to how a parent feels and what he/she thinks about his/her child's diabetes and the medical treatment the child receives. Responses are on a Likert-scale ranging from one (strongly agree) to five (strongly disagree). The instrument was normed on a sample of 228 mothers. The author reported that an eight factor solution was derived from an item factor analysis based on the responses of this sample. (See Table 1 for a description of the contents of each of the subscales). Using the factor solutions derived from the mothers' data analysis, the author calculated coefficient alpha's with the data from 116 fathers. The fathers' data yielded reliability estimates equivalent to those obtained from the mothers' data on all but one factor. Alpha coefficients for mothers' data ranged from .70 to .84 and for fathers from .60 to .85. The author contends that the fathers' data provided an independent replication of the reliability of the factor analytically derived scales based on mothers' data, thereby offering some support for their validity.

Intercorrelations between the factors using the mothers' data were reported to be nonsignificant with a few exceptions. The Family Interruption subscale is reported to be significantly correlated with Manipulativeness ($r=.25$), Rule Orientation ($r=.27$), Stigma ($r=.51$) and Sweet Consumption ($r=.25$). Other reported significant correlations include Manipulativeness with Stigma ($r=.32$) and Rule Orientation with Sweet Consumption ($r=.39$).

Johnson also included items from the lie scale of the Personality Inventory for Children (PIC) (Wirt, Seat, Broen, and Luchar, 1981). The PIC uses a true-false format which is different than the 1 to 5 ratings

used on the PDOS. For comparison purposes, she rescored the PDOS lie scale to make it more similar to the PIC format (e.g., ratings of 4 or 5 were rescored as "true" and given a value of "1", ratings of 1 to 3 were rescored as "false" and given a value of "0"). The correlations of this scale with PDOS factors were reported to be nonsignificant, with the exception of Manipulativeness ($r=.48$) and Family Interruption ($r=.16$).

Table 1

Parents Diabetes Opinion Survey

Subscale Name	Content
Manipulativeness	The extent to which the parent perceives the child as using diabetes to manipulate others around him.
Rule Orientation/ High Supervision	Adherence to rules about managing the diabetes that have righteous overtones, how cautious or protective the parent is and how much the parent feels that others can better manage the diabetes.
Stigma	The extent to which the parent feels the child and/or family is treated differently because of the diabetes.
Divine Intervention	Beliefs that the diabetes is a religious test or that God can take it away.
Attitudes toward the Medical Staff	How positively the parent feels toward the child's physicians, nurses, hospital, etc.
Reactions: Observa- tion/Detection	How carefully the parent observes the child's symptoms.
Sweet Consumption	Adherence to rules concerning the eating of sweets.
Family Interruption	How disruptive diabetes has been on the child's parents and family.

Personality Inventory for Children. (PIC) (Wirt, Seat, Broen, & Luchar, 1981). This instrument was used to provide information on the child's behavior, affect, and cognitive status. The entire inventory consists of 600 true-false items and includes four factor scales, four validity and screening scales, twelve clinical scales, and seventeen experimental scales. For the purpose of this study, subjects were asked to complete only the first 131 items. Completion of these 131 items provides a measure of defensiveness (the Lie scale) and four broad-band factor derived scales that reflect the major content dimensions of the PIC item pool (Undisciplined/Poor Self Control, Social Incompetence, Internalization/Somatic Symptoms, Cognitive Development (see Table 2 for a description of each of these scales). The measures obtained from these scales were thought to provide sufficient information as to the child's current level of psychological functioning and identify general patterns of behavioral disturbance.

The authors conducted iterative principle axis factor analyses using the 313 items that appear on the twelve clinical scales. A series of factor analyses were conducted until a six factor solution was derived. The authors decided to retain only the first four factors. They excluded Factor V since it contained only 13 items with factor weights of .30 or higher and appeared to reflect only differences between disturbed children and disturbed adolescents. Factor VI was excluded since 24 out of the 26 items loadings at .25 or higher also appeared on one of the clinical scales.

Table 2

Personality Inventory for Children

Factor Scales	Major Content Dimension
Undisciplined/ Poor Self Control	Ineffective discipline
Social Incompetence	Sad affect
Internalization/ Somatic Symptoms:	Worry and a poor self concept
Cognitive Development	Adaptive behavior
Validity Scale	Content
Lie	Identifies a defensive response set manifested by a tendency to ascribe the most virtuous of behaviors and to deny minor, commonly occurring behavior problems.

Alpha coefficients for the four factor scales ranged from .81 to .92 (Wirt, Seat, Broen, & Luchar, 1981). According to the authors, three validity studies have been completed to date. Two studies were conducted to investigate construct validity and another assessed the predictive validity of each scale.

The following instrument will be completed by both the mother and the child.

Family Environment Scale. (Moos, 1974). This instrument was used to measure the social-environmental characteristics of the family, specifically the child's perception of his/her conjugal or nuclear family environment. The scale consists of 90 true-false items which are divided into ten subscales. For this study only the following subscales were used: Cohesion, Expressiveness, Conflict, Independence, Organization and Control (see Table 3 for a description of each subscale).

Moos constructed the items for this scale from information he gathered in structured interviews with members of different types of families. He adapted additional items from other Social Climate Scales (Moos, 1974) developed by him. An overall item split between normal and distressed families was derived from means and standard deviations to avoid items characteristic only of distressed families. Cronbach's alpha coefficient was calculated for each of the ten subscales. Internal consistencies were reported to range from .61 to .78. Test-retest reliability coefficients were reported to be in an acceptable range, varying from .68 to .86 (Moos, 1974).

Table 3

Family Environment Scale

Subscale	Content
Cohesion	The degree of commitment, help, and support family members provide for one another.
Expressiveness	The extent to which family members are encouraged to act openly and to express their feelings directly.
Conflict	The amount of openly expressed anger, aggression and conflict among family.
Independence	The extent to which family members are assertive, self-sufficient, and make their own decisions.
Organization	The degree of importance of clear organization and structure in planning family activities and responsibilities.
Control	The extent to which set rules and procedures are used to run family life.

The children were asked to complete the following instruments:

State-Trait Anxiety Inventory for Children. (STAIC) (Spielberger, Edwards, Lushene, Montuori, & Platzek, 1973). This inventory was used for children age twelve and younger. It measures two distinct anxiety concepts: state anxiety and trait anxiety. The A-state scale consists of 20 statements that ask children how they feel at a particular moment in time. It was designed to measure transitory anxiety states, that is, subjective, consciously perceived feelings of apprehension, tension, and worry that vary in intensity and fluctuate over time. The A-trait scale also consists of 20 items, but subjects respond to these items by indicating how they generally feel. This scale measures relatively stable individual differences in anxiety proneness, that is, differences between children in the tendency to experience anxiety states. As such, high A-trait children are more prone to respond to situations perceived as threatening with elevations in A-state intensity than low A-trait children.

Subjects respond to the STAIC by selecting one of three alternative choices for each item. Values of 1, 2, and 3 are assigned for each of the three alternatives. The stem for all the A-state items is "I feel" and is followed by key adjective terms. "Very" and "not" are assigned values of 3 and 1 respectively (e.g., I feel very nervous (3), nervous (2) and not nervous (1)). The A-trait items require the subject to indicate the frequency of occurrence of the behavior described by the item. The choices are "hardly ever", "sometimes", and "often", scored 1, 2, and 3 respectively.

The test was normed on two large samples ($n=913$ and $n=638$) of fourth, fifth, and sixth grade boys and girls. Test-retest reliability coefficients for the A-trait scale ranged from .65 for males to .71 for females, and for the A-state scale, ranged from .31 for males to .41 for females. The authors note the difference in the reliability coefficients for the two scales. They contend that a valid measure of A-state would reflect the influence of unique situational factors existing at the time of testing and as such, low test-retest correlations for the A-state scale were anticipated. They further contend that given the transitory nature of anxiety states, measures of internal consistency such as the alpha coefficient would provide a more meaningful index of reliability than test-retest correlations. Alpha reliability coefficients were also calculated using the Kuder Richardson formula 20 as modified by Cronbach. For the A-trait scale, the alpha coefficients were .78 for males and .81 for females, and for the A-state scale, they were .82 for males and .87 for females. Item-remainder correlations were also computed as further evidence of internal consistency. The median correlation for A-state scale items was .38 for males and .48 for females. For the A-trait scale, the median correlation was .35 for males and .40 for females (Spielberger et al., 1973).

Evidence of concurrent validity of the A-trait scale is demonstrated by its correlation ($r=.75$) with the Children's Manifest Anxiety Scale (Castaneda, McCandless, & Palermo, 1956), ($r=.63$) with the General Anxiety Scale for Children (Sarason, Davidson, Lighthall, Waite, & Ruebash, 1960). Evidence bearing on construct validity of the A-state scale was calculated by comparing subjects responses to the scale under

normal conditions and under experimental conditions (subjects were asked to respond according to how they believed they would feel just before a final exam in an important subject). Critical ratios for the differences between the means and point biserial correlations for scores on each item were computed. Mean scores were higher under experimental conditions than normal conditions.

State-Trait Anxiety Inventory. (STAI) Form Y. (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983). This inventory was used for children age twelve or older. Like the STAIC, this inventory measures state and trait anxiety and consists of 20 items for each scale. Each item on this inventory, however, is given a weighted score of 1 to 4. A rating of 4 indicates the presence of a high level of anxiety for the ten S-Anxiety items and the eleven T-Anxiety items. A high rating indicates the absence of anxiety for the remaining ten S-Anxiety items and nine T-Anxiety items.

Form Y represents a major revision of the scale that the authors began in 1979. In Form Y, thirty percent of the Form X items were replaced. This is reported to have resulted in improved psychometric properties for the the S-Anxiety and the T-Anxiety scales. However, the authors contend that research based on Form X can be readily generalized to Form Y. The two forms are reported to be highly correlated ($r=.96$ to $.97$), so that the two forms are considered essentially equivalent (Spielberger et al., 1983).

The following normative information is based on Form Y. The high school normative sample the authors used consisted of 424 tenth grade students. Test-retest correlations for the T-Anxiety scale ranged from

.65 to .75. Alpha coefficients computed by Formula KR-20 as modified by Cronbach (1951) are reported to range from .86 for males to .94 for females for the S-Anxiety scale, and .90 for both males and females for the T-Anxiety scale. Further evidence of internal consistency of the STAI scales was provided by item-remainder correlations. The median S-Anxiety item-remainder correlation was reported to be .55 and the median T-Anxiety item remainder correlation was reported to be .54 for the high school normative group (Spielberger et al., 1983).

Evidence of the construct validity of the T-Anxiety scale was demonstrated by comparing the mean scores of neuropsychiatric groups (NP) with normal subjects. All but one of the NP groups had substantially higher T-Anxiety scores than the normal subjects. The authors contend that this indicates that the STAI discriminates between normals and psychiatric patients for whom anxiety is a major symptom. Evidence of the construct validity of the S-Anxiety scale was shown by comparing the scores of military recruits, tested shortly after they began highly stressful training programs and normal subjects, tested under nonstressful conditions. The mean S-Anxiety score for the recruits was reported to be much higher than those of the high school students, as well as much higher than their own T-Anxiety scores. The authors contend that this suggests that the recruits were experiencing a high state of emotional turmoil when they were tested. (Spielberger et al., 1983).

Diabetes Opinion Survey. (DOS) (Johnson, 1985). This instrument was used to measure children's attitudes about their diabetes and the medical treatment they receive. The author developed the items for this

scale from the clinical literature and interviews she conducted with clinicians and patients as to patients' attitudes toward diabetes. The survey used the lie scale from the Manifest Anxiety Scale (Castaneda, McCandless, and Palermo, 1956) to identify defensive response sets. Table 4 contains a description of the subscales.

The inventory consists of 73 items requiring responses on a five point Likert scale ranging from one (strongly agree) to five (strongly disagree). Johnson used a principal component factor analysis using a varimax procedure based on data from a sample of 281 children with diabetes ranging in age from 6 to 19 years to derive the scales. Up to ten factors were rotated using this procedure and the resulting solutions were explored for goodness of fit and conceptual clarity. A five factor solution was selected. For each factor, an item was retained if the item/factor correlation was $>.40$ (absolute value) and the item correlated $<.30$ (absolute value) with any other factor.

Table 4

Diabetes Opinion Survey

Subscales	Content
Stigma	The extent to which the child feels different from peers, whether or not he/she feels other people treat him/her differently because of diabetes.
Rule Orientation	How rigidly the child adheres to "rules" about managing diabetes the "right" way.
Sick Role	The extent to which the child admits to using diabetes to get things he/she likes or to get out of things he/she doesn't like.
Family Interruption	How disruptive diabetes has been on the child's parents and family.
Divine Intervention	Whether the child feels he "deserves" diabetes as a punishment for sins and whether he believes God can take away the diabetes.

The intercorrelations for the five factors were reported. Stigma, Rule Orientation, and Divine Intervention were reported to show the greatest independence with intercorrelations ranging from .16 to .25. Intercorrelation with the Sick Role and Family Interruption subscales, however ranged from .20 to .52. This is reportedly due to the retention of items on the Family Interruption subscale that loaded $>.30$ but $<.40$ on another factor. Alpha coefficients for the five subscales are reported to range from .69 to .77 (Johnson, 1985). Because of the content and the psychometric properties of this scale, it appeared to be appropriate for use in this study.

Test of Diabetes Knowledge. (Johnson, 1985). This instrument is divided into two sections: the General Information and the Problem Solving components. For the purpose of this study only the General Information component was used. This measures the child's general knowledge about diabetes. It consists of 39 multiple choice questions concerning the cause of diabetes, the meaning of common terminology and facts about treatment components.

Split-half reliability estimates are reported to range from .84 to .90 (Johnson et al., 1982). Content validity was addressed by developing items based on previous work by Etzwiler (Collier and Etzwiler, 1971; Etzwiler, 1962; Etzwiler and Sines, 1962) and Travis (1978), as well as instructional materials used in the University of Florida's Regional Diabetes Program. Once the instruments were developed, two physicians and a nurse answered each question independently. Items were retained only if all three respondents provided the same answer.

Diabetes Behavior Checklist. This 55 item instrument was designed specifically for the purpose of this study. Items 1 through 49 are intended to provide measures of typical and atypical behaviors associated with the diabetes treatment regimen. The instrument consists of ten statements, each of which is paired with every other statement, yielding 45 pairs, with each pair constituting an item. The order of presentation of statements for each pair is random. An additional four items were repeated in reverse order to provide a measure of response consistency. For each of these 49 items, the subject is asked to choose the statement of the pair which describes the behavior engaged in more often. For example,

a) I follow a regular schedule of times that I eat.

OR

b) I take the number of insulin injections my doctor recommended every day.

Items 50 through 59 comprise a zero point scale. The items ask the subject to decide if the statement describes something that he/she usually does, or if the statement describes something that the respondent does not usually do, using yes and no as the response alternatives. "Yes" responses are scored "1" and "no" responses are scored "0". The zero point scale makes it possible to treat scale scores as distances from a well-defined point (e.g., zero) on the scale, i.e., the scale scores acquire interval scale properties. Thus, for the first 49 items, a subject is asked to make comparison judgments, but for the last ten items, he/she is asked to make absolute judgments.

There are eleven raw scores generated by the scoring of the instrument. Scores for the diabetes behaviors constitute ten of these,

the eleventh is the zero point scale. The raw score for each of the diabetes behaviors is the number of times the statement representing that behavior was chosen as the one that is done more often. Chosen statements are scored "1" and statements not chosen are scored "0". The zero point scale raw score is obtained by counting the number of "no" responses to the ten statements (items 50 to 59). Raw scores, therefore, range from 0 to 10. Table 5 shows the conversion of raw scores to scale values.

Scale values indicate how far in standard deviations a given raw score deviates from a subject's own mean raw score, which is arbitrarily defined as 0.0. This procedure yields a set of scale values which are equally distributed around zero, with half the scale values positive and half negative. However, different individuals will have different scale values for each of the ten diabetes behaviors. To obtain more meaningful comparisons among individuals, scale values must be adjusted.

Once the scale value for the zero point is determined, scale values for the other ten scales can be adjusted with respect to it, by subtracting the zero point scale value from the other scale values and from itself. This will yield a group of eleven adjusted scale values with a subject's zero point scale value adjusted to zero and the diabetes behaviors adjusted with respect to the subject's zero point.

Table 5

Conversion of Raw Scores to Scale Values

Raw Score	Scale Value
0	-1.0
1	- .8
2	- .6
3	- .4
4	- .2
5	0.0
6	.2
7	.4
8	.6
9	.8
10	1.0

Because of the adjustment procedure the sign of each adjusted scale value indicates whether the behavior is typical (positive signs) or atypical (negative signs) of the subject. The magnitude of the adjusted scale value indicates how typical a particular behavior is.

The ten statements and the variable labels used to identify them are as follows:

- 1) I follow a regular schedule of times that I eat. (Schedule)
- 2) I eat three meals a day and the number of snacks my doctor recommended. (Meals)
- 3) I eat only the foods that are part of my meal plan prescribed by my doctor. (Foods)
- 4) I exercise four or more times per week. (Exercise)
- 5) I eat extra food or take less insulin on the days that I exercise. (Extra)
- 6) I take my insulin injections at the same time every day. (Inject)
- 7) I take the number of insulin injections my doctor recommended every day. (Number)
- 8) I do all the urine and blood glucose tests my doctor recommended every day. (Tests)
- 9) I record the results of all my urine and/or blood glucose tests every day. (Record)
- 10) I follow a regular schedule of times that I do my urine and blood glucose tests. (Testing)

Alpha reliability coefficients were calculated using the Kuder Richardson formula 20 as modified by Cronbach. The alpha coefficients ranged from a low of .36 for the Testing scale to a high of .76 for the Inject scale. Moderate alpha coefficients may be reflective of the forced choice nature of the inventory. Table 6 contains a listing of the coefficients for each of the ten scales.

Table 6

Alpha Coefficients for the Diabetes Behavior Checklist

Scale	Alpha
Schedule	.65
Foods	.73
Meals	.46
Exercise	.71
Injection	.76
Number	.79
Extra	.71
Tests	.67
Record	.71
Testing	.36

Content validity for the Diabetes Behavior Checklist was established by developing a rationale for the construction of each of the ten scales. The scales were constructed based on recommendations published by the American Diabetes Association (1982) for people with diabetes concerning the diabetes treatment regimen.

The first three scales (Schedule, Meals, and Food) have to do with the timing and regularity of meals and the amount and kind of foods eaten. ADA (1982) recommends that people with diabetes always eat meals

and snacks at regularly scheduled times. The regularity of food intake is important for maintaining metabolic control. This generally consists of three meals a day and two to three snacks at certain times during the day (ADA,1979). Timing of meals is important because the food intake is designed to coincide with times when insulin peaks. ADA (1982) also recommends that the meal plan be prescribed by a physician. In this way, and individual will be provided with a diet that provides all the calories needed to meet his/her individual energy needs according to that person's age, sex, and size. Insulin is prescribed to match the foods in an individual's meal plan.

The next two scales (Exercise and Extra) are related to exercising and modifying the regimen to accomodate increased activity levels. ADA (1982) recommends that a person with diabetes exercise on a regular basis, daily if possible. ADA further advises that exercise should be planned to avoid having too much insulin or too little glucose circulating in the blood. To avoid this, an individual should eat a snack before exercising or take less insulin in the injection taken prior to exercising.

The timing and the number of insulin injections comprise the next two scales (Injection and Number). ADA (1982) reports that insulin should be taken approximately thirty minutes prior to meals to offset the effects of food on blood glucose level. If timing of meals and physical activity is also fairly constant, the action of insulin will have the same effect after each injection. In addition there are three different types of types of insulin - short, intermediate, and long-acting. Each type differs in terms of time of onset, peak, and duration. As such,

both timing and number of injections are important. The physician determines the number of injection based on the patient's individual needs, such as diet, activity level, general health, level of stress.

The last three scales (Tests, Record and Testing) are related to doing all of the recommended blood/urine tests, recording the results of all testing, and following a schedule for testing. According to the ADA (1982) a person's physician will make recommendations about the time of the day the person should test his/her blood and/or urine. The timing and completion of each test is important because each test gives information about the action of insulin during a different period of food intake and activity. Recording the results of the tests is important for future reference in order to maintain good metabolic control.

Metabolic Control. The hemoglobin A1C test was used to assess the child's level of metabolic control. This test gives an overview of a person's blood glucose control for the past three to four months. Masek and Jankel (1982) contend that such bioassay techniques are the standards by which other methods of assessing adherence are compared.

Hypotheses and Statistical Procedures

This section will outline the major hypotheses that were tested in this study the statistical procedures that were used. Table 7 defines each of the variables used to test the hypotheses under investigation.

Table 7

Variable Definitions Used in Hypothesis Testing

Variable	Measure
Metabolic Control Variable	Hb A1C
Compliance Variables	Diabetes Behavior Checklist
Psychosocial Variables	Personality Inventory for Children
	Family Environment Scale
	Diabetes Opinion Survey
	Parents Diabetes Opinion Survey
	Diabetes Knowledge Test
	State-Trait Anxiety Inventory
	State-Trait Anxiety Inventory for Children
Demographic Variables	Age, race, sex, SES, age of onset, birth order, size of family, number of siblings, duration of disease, parents' marital status, who gives insulin injections, family members with diabetes.

Hypothesis 1. There are no significant intercorrelations among the individual subscale scores of the psychosocial variables.

Hypothesis 2 There are no significant correlations between the demographic and psychosocial variables.

Hypothesis 3. There are no significant correlations between the demographic and compliance and control variables.

Hypothesis 4. There are no significant correlations between the psychosocial and the compliance and control variables.

Pearson product-moment correlation coefficients were computed to test hypotheses 1, 2, 3, and 4 when the independent variable was continuous. A statistically significant correlation between any two variables indicates that there is an association between the two variables, and that it is possible to predict one value from the other. Eta squared was used as a measure of association for independent variables that were nominal. The nominal variables were sex, who gives the insulin injections, family members with diabetes, age group, and birth order.

Hypothesis 5. There are no significant differences in psychosocial variables' mean scores between subjects grouped according to demographic characteristics.

Hypothesis 6. There are no significant differences in compliance and control variables mean scores between subjects grouped according to demographic characteristics.

Analysis of variance was used to test hypotheses 5 and 6. ANOVA was used to determine whether there was any overall difference between the

groups.

Hypothesis 7. There is no significant correlation between a set of compliance variables and a set of psychosocial variables.

Canonical correlation analysis was used to test this hypothesis. The aim of the canonical correlation technique was to account for the maximum amount of variance between the two sets of variables. The technique consists of finding several linear combinations of the independent variables and the same number of linear combinations of the dependent variables in such a way that these linear combinations best express the correlations between the two sets.

Hypothesis 8. The multiple correlation coefficient formed between each of the ten compliance variable and a set of psychosocial and demographic variables is equal to zero. (Each compliance variable will be analyzed separately, so that there will be ten hypotheses to test in all).

Hypothesis 9. The multiple correlation coefficient formed between the control variable and a set of compliance variables is equal to zero.

Hypothesis 10. The multiple correlation coefficient formed between the control variable and a set of psychosocial and demographic variables is equal to zero.

Multiple regression analysis was used to test hypotheses 8, 9, and 10. The objective of this technique was to find the best prediction equation for predicting the dependent variable from the independent variables. The independent variables are differentially weighted so

that the correlation between the composite scores thus obtained and the dependent variable can be maximized.

Hypothesis 11. There is no significant difference between subjects in good, moderate and poor control, as measured by the psychosocial and demographic variables.

Discriminant analyses were used to test this hypothesis. Subjects were split into groups as follows: Subjects with Hb A1C levels under 8% comprised the good control group, subjects with Hb A1C levels between 8 and 10% were assigned to the moderate control group, and subjects with HbA1C levels over 10% were assigned to the poor control group. The most recent Hb A1C test on the subject's medical record was used. This breakdown is in accordance with the guidelines provided by the pediatrician who provided the subjects for this study. Although figures of HbA1C may vary slightly with the method used, Craig (1981) reports that levels under 10% indicate good control. Goldstein, Valuck, and Hazelwood (1985) report that at the University of Missouri clinic, HbA1C levels less than 9% is considered good diabetes control.

CHAPTER FOUR

RESULTS

Overview

This chapter presents the results of the data analyses. It will be organized into three sections. The first section describes the procedures used for the treatment of missing data. The statistical tests of the hypotheses are presented in the second section. They are presented in the following order: intercorrelations, analyses of variance, multiple regressions for the compliance variables, canonical correlation, multiple regressions for the control variable and discriminant analysis for the control variable. Data are summarized in tabular form where appropriate. For all correlations, .40 was taken as a significant result even though there were others that fell below .40 and were statistically significant. This level represents what might be termed practical significance. The final section is a summary of the major findings of the study.

The definition of each variable can be found in Chapter 3. Table 8 gives the label used in the remaining tables to describe each variable.

Table 8

Variable Names and Labels used in Tables

 Parents Diabetes Opinion Survey

Manipulativeness	Manipulative
Rule Orientation/Supervision	Rule-p
Stigma	Stigma-p
Divine Intervention	Divine-p
Attitude toward Medical Staff	Attitude
Sweet Consumption	Sweet
Family Interruption	Family-p

 Diabetes Opinion Survey

Stigma	Stigma-c
Rule Orientation	Rule-c
Sick Role	Sick Role
Family Interruption	Family-c
Divine Intervention	Divine-c

 Family Environment Scale

(c=child, p=parent after each variable)

Cohesion	Cohesion
Expressiveness	Express
Conflict	Conflict
Independence	Independence
Organization	Organization
Control	Control

Table 8 (cont'd)

 Demographic Variables

Family members with diabetes	Diabetic
Does child give own insulin injection	Insulin
Income level	Income
Birth order	Birth
Number of people in the household	Household
Number of brothers	Brothers
Number of sisters	Sisters
Number of children in the home	Home
Age at diagnosis	Diagnose
Number of years child's had diabetes	Years

 State-Trait Anxiety Inventory for Children

State anxiety	C-state
Trait anxiety	C-trait

 State-Trait Anxiety Inventory

State Anxiety	State
Trait Anxiety	Trait

Table 8 (cont'd)

 Diabetes Knowledge Test

 General Information Component DKT

 Diabetes Behavior Checklist:

Following a regular schedule of times to eat	Schedule
Eating three meals a day and snacks	Meals
Eating only prescribed foods	Foods
Exercising four or more times per week	Exercise
Eating extra food or taking less insulin to adjust for exercise	Extra
Taking the prescribed number of injections	Number
Doing all the required injections at the same time every day	Injection
Recording the results of all testing	Record
Doing all the required blood/urine tests	Tests
Following a regular schedule of times for blood/urine testing	Testing

TREATMENT OF MISSING DATA

In order to accurately analyze the data, the manner in which missing data were treated was determined prior to performing the statistical procedures. For the Parents' Diabetes Opinion Survey (PDOS) and the Diabetes Opinion Survey (DOS) missing items were replaced by the mean score of all of the other items on the appropriate scale. For all other inventories and for the demographic variables, cases with missing values were deleted on an analysis-by-analysis basis. That is, analyses were performed using only cases with non-missing values on all variables named in any given statistical procedure. The only exceptions to this rule occur on the multiple regression analyses where missing values were replaced with the variable mean. As such, all cases were used in the analyses with the substitutions treated as valid observations.

TESTS OF THE HYPOTHESES

Hypothesis 1

Hypothesis 1 stated that there were no significant intercorrelations among the individual subscale scores of the psychosocial measures. Tables containing the subscale intercorrelations and means can be found in Appendix B. Tables containing subscale intercorrelation between the inventories can be found in Appendix C. The decimals have been omitted in these tables.

Intercorrelations with individual inventories. There was only one intercorrelation that was statistically significant and at the .40 level or above on the Parents Diabetes Opinion Survey (PDOS). Stigma was

significantly related to Family Interruption ($r=.50$). This is close to the .51 correlation Johnson (1985) reported for the norm sample. For the most part, scale intercorrelations agreed moderately with those reported for the norm sample (Johnson, 1985).

There were five significant intercorrelations on the Diabetes Opinion Survey (DOS). They were Stigma and Family Interruption ($r=.68$), Stigma and Sick Role ($r=.50$), Stigma and Divine Intervention ($r=.53$), Sick Role and Rule Orientation ($r=.42$) and Sick Role and Family Interruption ($r=.40$). An inspection of the Table in Appendix B shows that for the most part, these correlations are moderately higher than the norm sample (Johnson, 1985).

The subscales of the Personality Inventory for Children (PIC) were highly intercorrelated, ranging from a low of .17 to a high of .88. The subscale intercorrelations for the norm sample however, ranged from a low of .17 to a high of only .38.

The subscales of the State-Trait Anxiety Inventory for Children were also highly intercorrelated ($r=.63$). However, the authors (Spielberger et al., 1973) did not provide scale intercorrelations from the norm sample. Subscale intercorrelations on the State-Trait Anxiety Inventory given to children age 13 and older were statistically significant ($r=.89$ for boys and $r=.71$ for girls). These correlations were moderately higher than the norm sample, although this could be a function of the size of the sample ($n=26$) on which the correlations in the present investigation were based.

The children's responses on the Family Environment Scale had eleven

significant intercorrelations. The parents' responses to this scale, however, had only five significant intercorrelations. For the children, Cohesion correlated with Expressiveness ($r=.62$), Independence ($r=.74$), Organization ($r=.83$), and Control ($r=.43$). Control also correlated with Conflict ($r=.54$), and Organization ($r=.55$). Expressiveness correlated with Conflict ($r=.45$), Independence ($r=.58$) and Organization ($r=.46$). The parents' scale showed significant intercorrelations between Cohesion and Expressiveness ($r=.56$), Cohesion and Independence ($r=.46$), Cohesion and Organization ($r=.44$), Independence and Expressiveness ($r=.47$) and Conflict and Control ($r=.50$). Generally, the intercorrelations on the parents' scale were lower than those on the children's scale.

The Family Environment Scale and the Personality Inventory for Children subscale intercorrelations deviated considerably from those reported in the norm sample. This may be due to the small size of the sample used in this study as well as to differences between this sample and that used to develop norms for the Family Environment Scale and the Personality Inventory for Children.

The subscale means for all the inventories fell within the norm sample ranges. The only exception was that the Cognitive Development subscale of the Personality Inventory for Children was moderately elevated. This may be reflective of the nature of some of the questions on this subscale. For example, 15% of the parents responded true to the statement "My child needs protection from every day dangers", and 15% responded true to the statement "My child can be left home alone without danger." Parents of children with insulin-dependent diabetes may be more inclined than parents of non-diabetic children to be concerned

about their children in their absence. Holmes (1986) contends that some parents of children with IDDM are particularly vulnerable to medical emergencies to the extent that they fear that their children may die if left alone.

Interrcorrelations between the inventories. Pearson product-moment correlations were computed on the Family Environment Scale to determine if there were any relationships between the parents' and the children's responses on the same scales. Only three of the six scales were significantly correlated: Conflict ($r=.42$), Independence ($r=.41$) and Organization ($r=.47$). Correlations were also computed for the Parents Diabetes Opinion Survey and the Diabetes Opinion Survey. Significant correlations were found for Rule Orientation ($r=.53$) and for Divine Intervention ($r=.62$).

There were no significant correlations between any of the scales on the Family Environment Scale (parents) and the Parents Diabetes Opinion Survey, the Diabetes Opinion Survey or the Personality Inventory for Children. The only significant correlation between other inventories and the Family Environment Scale was Conflict and Rule Orientation (DOS) ($r=.47$). Thirteen significant correlations were found between the State-Trait Anxiety Inventory and some of the scales on the DOS, PDOS, FES (parents) and the PIC. Nineteen significant correlations were found between the State-Trait Anxiety Scale for Children and some of the scales on the DOS, PDOS, FES (parents and children) and the PIC. (See Appendix B for tables).

Of the 453 possible intercorrelations between the inventories, 39 were statistically significant and were at the .40 level or above,

although the significance of some of these could be due to chance. The most interesting of these appeared to be those which examined the relationship between childrens' and parents' responses on the same or similar subscales. For example, on the Family Environment Scale, childrens' and parents' responses correlated significantly on each of the subscales except for Control, or the extent to which rules and procedures are used to run family life. However, in a seemingly contrary result, their responses were significantly related on the Diabetes Opinion Survey and the Parents Diabetes Survey on the subscale that measures how rigidly they adhere to rules about managing the diabetes the "right" way. Despite the lack of agreement between children and parents concerning general rules and procedures in the family, they agree on management of the diabetes. One possible explanation of this is that the children's health beliefs are influenced by their parents' beliefs. Their responses were also significantly correlated on the extent to which they believe that diabetes is a religious test. However, it should be noted that their responses fell within the normal range, indicating that neither the children nor the parents believe the diabetes to be a religious test or a punishment from God.

The results of the analyses indicate that there were some significant relationships among the psychosocial variables. As such, the null hypothesis was partially rejected.

Hypothesis 2

Hypothesis 2 stated that there were no significant correlations between the demographic and the psychosocial variables used in this study. This hypothesis was tested using Eta squared for the nominal demographic variables and Pearson product-moment correlation coefficients for the interval demographic variables and the psychosocial variables. Table 9 contains the breakdown for the nominal demographic variables.

Table 9

Demographic Nominal Variables

Variable	Categories	
Diabetic	Yes	No
Insulin	Yes	No or sometimes
Income	Under \$50,000	\$50,000 or over
Birth	First born	Other
Age group	12 or under	13 or older.
Sex	Male	Female

A large proportion of the adult subjects were the mothers of the child subjects (89%) and were married to the child's father (77%). A majority (87%) of all subjects were white. Therefore, correlations

between race and marital status and the psychosocial and demographic variables were not computed. The results of the analyses can be found in Tables 10 and 11.

The results of the Eta squared analyses indicated that there was no association between any of the psychosocial variables and having other family members with diabetes. There were significant relationships between the sex of the child and Family Interruption(c), Undisciplined, Independence(p), Manipulativeness, and Attitude. These results are difficult to interpret except in light of sociocultural expectations for the sexes. Significant relationships were also found between whether or not the child injects his/her insulin and Expression(c), Rule Orientation (c) and Conflict (c) and between age group and Reaction. An inspection of Table 10 indicates that the strength of these measures of association for most of the variables was fairly weak. Therefore, although they were statistically significant, the strength of the association suggests that little is actually contributed to the ability to predict the score of one variable from the score of another.

Table 10

*Eta Squared Analyses for Demographic (Nominal)
and Psychosocial Variables*

Demographic Variable	Psychosocial Variable	Eta Squared	F	p
Insulin	Express-c	.1143	5.29	.027
Insulin	Rule-c	.1089	4.89	.033
Insulin	Conflict-c	.0981	4.46	.041
Sex	Undisciplined	.1650	8.89	.005
Sex	Independence-c	.1141	5.80	.020
Sex	Family-c	.1015	4.86	.033
Sex	Manipulative	.0994	4.96	.031
Sex	Attitude	.0928	4.60	.037
Age Group	Reaction	.0933	4.63	.037
Birth Order	Sick Role	.0991	4.29	.045

Moderate associations were found between the sex of the subject and how undisciplined the parent perceives his/her child to be and the parent's perception of the self-sufficiency and assertiveness of family members. The mean scores of the parents of boys were higher on both of these dimensions, indicating that boys are seen by their parents as more undisciplined, more self-sufficient and assertive than girls. A moderate association was also found between whether or not the child injects his/her insulin and the parents' perception of the degree to which family members are encouraged to express their feelings directly. The parents of children who do not inject their insulin themselves or do so only some of the time scored relatively higher on the degree of expressiveness in the family than the parents of children who inject their insulin themselves.

The results of the Pearson product-moment correlations indicated significant relationships between rule orientation and age at diagnosis. This suggests that diagnosis at an early age is positively related to rigidly adhering to rules concerning diabetes management. Organization(p) was negatively related to the number of people in the household, indicating the more people in the household the less structure and organization the parents report in the family. An inspection of Table 11 also reveals significant correlations between state and trait anxiety and several psychosocial variables. While statistically significant, these correlations have little meaning relative to the purposes of this study.

In short, some of the psychosocial variables are intercorrelated, and as such, the null hypothesis was partially rejected.

Table 11

*Pearson Product-Moment Correlations between
Demographic and Psychosocial Variables*

Demographic Variable	Psychosocial Variable	r	p
Diagnose	Rule-c	.44	.002
Home	Organization-p	-.52	.000
Home	C-State	.46	.023
Home	C-Trait	.64	.002
Age Group	State	.45	.010
Household	C-State	.40	.039
Household	C-Trait	.61	.003
Brothers	C-State	.40	.040
Sisters	C-State	.45	.024
Sisters	C-Trait	.46	.024

Hypothesis 3

Hypothesis 3 stated that there was no significant correlation between the demographic variables and the compliance and control (HbA1C) variables. This hypothesis was tested using Eta squared for the nominal variables and and Pearson product-moment correlations for the interval variables. The results of the Eta squared analyses for the compliance variables can be found in Tables 12.

The results of the Eta squared analyses indicated significant relationships between birth order and taking insulin injections at the same time every day, and recording the results of urine/blood glucose tests. Level of income was significantly related to taking insulin injections at the same time every day. Sex was significantly correlated with exercise. Age group was significantly related to taking insulin injections at the same time every day, and eating extra food or taking less insulin on days of exercise. An inspection of Table 12 reveals that the strength of the association for most of these variables was fairly weak, although statistically significant. As such, little is actually contributed to the ability to predict the score of one variable from another.

Table 12

*Eta Squared Analyses for Demographic (Nominal)
and Compliance Variables*

Demographic Variable	Compliance Variable	Eta Squared	F	p
Birth	Injection	.1147	4.79	.035
Birth	Record	.1029	4.24	.047
Income	Inject	.1840	6.99	.013
Insulin	Extra	.1503	3.31	.014
Sex	Exercise	.1101	5.19	.028
Age Group	Injection	.1034	4.84	.033
Age Group	Extra	.0906	4.18	.047

Moderate associations were found between income and injection. This suggests a positive relationship between high income and a tendency to follow a regular schedule of times for insulin injections, regardless of who gives the injection. The meaning of this result is difficult to ascertain in that the mean income (range=\$40,000 to \$50,000) for this population was high and there were 11 cases with missing data on the income question. However, this result supports Antonovsky's (1979) claim that material wealth enhances health care and coping with chronic disease.

A moderate association was also found between making dietary and insulin adjustments for physical activity and children who inject their insulin themselves. This suggests that children who take responsibility for their insulin injections also monitor their activity level in relation to the amount of insulin they inject.

The results of the Eta squared analyses for compliance variables showed some significant relations between the nominal demographic variables and the compliance variables, and as such the compliance portion of the null hypothesis is partially supported.

The results of the Pearson product-moment correlations showed only one significant relationship between the demographic and compliance variables, and as such the results will not be reported in a table. Age at diagnosis was negatively related ($r = -.44$) to following a regular schedule of time for blood glucose and urine testing. This indicates an relationship between children diagnosed at an early age and a tendency to adhere to a regular schedule of times for doing blood glucose and/or urine testing. This could be interpreted to mean that the younger child is at diagnosis the less likely he/she is to have established patterns of behavior that might interfere with adherence to prescribed treatment regimen.

The results of the Pearson product-moment correlation analyses for the compliance variable indicated one significant relationship between the interval demographic variables and the compliance variables, and as such the null hypothesis was partially supported.

The results of the Eta squared analyses for the control variable (Hb

A1C) indicated that there were no significant correlations between the nominal demographic variables and the control variable (HbA1C). Therefore, the null hypothesis cannot be rejected. The results of these nonsignificant statistical tests will not be reported.

The results of the Pearson product-moment correlation analyses for the control variable (Hb A1c) indicated that there were no significant correlations between any of the demographic variables and the control variable (Hb A1C). Therefore, the null hypothesis cannot be rejected. The results of these nonsignificant correlations will not be reported.

Hypothesis 4

Hypothesis 4 stated there was no significant correlation between the psychosocial variables and the compliance and control variables. The results of this hypothesis were obtained by using Pearson product-moment correlations. The results of the analyses for the compliance variables can be found in Table 13.

Table 13

*Pearson Product-Moment Correlations between
Psychosocial and Compliance Variables*

Psychosocial Variable	Compliance Variable	r	p
Rule-p	Foods	-.41	.003
Attitude	Exercise	.44	.001
Reaction	Record	.40	.003
State	Injection	.43	.019
State	Number	.39	.029
C-Trait	Tests	.41	.026
Family-c	Number	-.39	.004
Rule-c	Exercise	.39	.004

A significant correlation was found between eating only foods that are part of a prescribed meal plan and how rigid the parent feels about managing the child's diabetes and how cautious and protective the parent is. This association makes intuitive sense, especially for parents who take responsibility for their child's diabetes management. A parents' positive attitude toward the child's physician and other medical staff is associated with a child's tendency to exercise less than four times a week. This suggests that a parent's positive attitude may facilitate some compliance behaviors in children, but not exercise. Careful observation by the parent of the child's symptoms is related to a tendency for the child to not typically record the results of all urine and blood glucose testing. This suggests that the child may not feel a need to carefully monitor his/her symptoms in the face of high parental vigilance to symptoms.

High state anxiety in adolescents significantly correlated with taking insulin injections on a regular schedule. High Trait anxiety in children, however is associated with following a regular schedule of times for urine and blood glucose testing. Out of a possible 40 correlations between measures of state and trait anxiety for children and adolescents and the ten compliance variable, only two were statistically significant at or above the .40 level. These correlations could be significant by chance alone, especially in view of the small sample size used to compute them (n=20).

The results of the Pearson product-moment correlation analyses for the compliance variables indicated significant relationships between some of the psychosocial and some of the compliance variables. As such,

the null hypothesis was partially rejected.

Because few studies have measured compliance as discrete behaviors, it is difficult to compare the results of this study with others. Schafer et al. (1983) examined the relationship between four aspects of the IDDM regimen (insulin injection, glucose testing, dietary patterns and exercise) and diabetes-specific family behaviors and more global measures of family interaction. They found the diabetes-specific measures to be more predictive of compliance than the more global measures. The findings of this study indicated that there were significant relationships between parents' and children's attitudes toward diabetes and some compliance behaviors. However, there were no significant correlations between global measures of family functioning and any of the compliance behaviors. These findings lend support to the contention of Schafer et al. (1983) that it is preferable to construct psychosocial measures directly related to the behaviors of interest.

The results of the Pearson product-moment correlation analyses for the control variable (Hb A1c) indicated that there were no significant correlations between any of the psychosocial variables and the control variable. Therefore, the null hypothesis cannot be rejected and these nonsignificant correlations will not be reported.

Most investigators who have examined the relationship between metabolic control and psychosocial variables have reported significant findings, particularly in relation to various aspects of family functioning (Anderson et al., 1981, Koski et al., 1976, Orr et al., 1983, Pless et al., 1972, White et al., 1984). The findings of this study supports those of Schafer et al. (1983) who found that psychosocial

measures were unrelated to metabolic control. A lack of uniformity in measurement may account for the different results. Where some investigators use the hemoglobin A1C test, others have used blood glucose tests or urine tests as the measure of control.

The relationship between compliance and control. Additionally, Pearson product-moment correlations were performed to assess the relationship between the compliance variables and the control measure. Only one significant correlation was found ($r=-.43$; $p<.002$), although this could be due to chance. Taking the insulin injections at the same time every day negatively correlated with the hemoglobin test. (Note: A low hemoglobin test indicates good control). Therefore, subjects in good control tend to take their insulin injections at the same time every day.

These results partially support the findings of other studies (Allen et al., 1983, Harris & Linn, 1985, Schafer et al., 1986, Waller & North, 1981) that there is no relationship between compliance and control. It should be noted, however that with the exception of the study by Schafer et al. (1986) compliance was measured as a unitary construct. In an earlier study Schafer et al. (1983) reported significant relationships between some adherence measures (the extent to which the diet is followed, care in measuring insulin and number of daily glucose tests) and metabolic control. However, Schafer et al. (1983) used frequency counts for the adherence measures and Hb A1 for the metabolic control measure. As such, a lack of uniformity in measurement makes it difficult to compare the results of this study with those reported by Schafer et al. (1983) or other investigators.

The compliance variables were also correlated with one another. Three significant negative correlations above the .40 level were found. Following a regular schedule of times to eat correlated with not doing all the urine and blood glucose tests recommended by the physician ($r=-.41$) and not recording the results of all urine and blood glucose testing ever day ($r=-.39$). Taking the insulin injections at the same time every day was related to not recording the results of all urine and blood glucose testing every day ($r=-.41$).

The findings of these analyses indicate that there is a trend toward negative relationships between the compliance variables. This suggests that a child who complies with one aspect of the regimen, may not comply with another. One possible explanation for this is that the regimen is so demanding that it may be unrealistic to expect a child to adhere to all recommendations on a daily basis.

Hypothesis 5

Hypothesis 5 stated that there were no significant differences in mean scores on the psychosocial variables between subjects grouped according to demographic characteristics. One way analyses of variance (ANOVA's) were used to test this hypothesis. Subjects were grouped according to the responses on the Demographic Questionnaire. Table 14 contains the significant findings.

Significant differences were found between first born and later born children for Sick Role. Later born children admitted to using their diabetes to manipulate others more often than first born children. The parents of boys however, perceived them to be significantly more

manipulative than girls relative to diabetes symptoms (e.g., sick role behavior). Taken together, these results suggest that the later born males tend to use their diabetes in a manipulative manner to get what they want. Interestingly, boys more often than girls believed that their diabetes causes more work and worry on the part of their parents than might be necessary.

Table 14

One Way Analyses of Variance Involving the Demographic Variables and the Psychosocial Variables:

Demographic Variable	Psychological Variable	F	p
Birth Order	Sick Role	4.29	.045
Sex	Family-c	4.86	.033
Sex	Manipulativeness	4.96	.031
Sex	Attitude	4.60	.037
Sex	Independence-c	5.80	.020
Sex	Undisciplined	8.89	.005
Age Group	Reaction	4.63	.037
Insulin	Express-c	5.29	.027
Insulin	Rule-c	4.89	.033
Insulin	Conflict-c	4.46	.041

While it is difficult to be certain, there seems to be more emphasis in the parents of boys toward independence and self-sufficiency than in the parents of girls. However, the parents of boys also report a tendency on the part of their child to act out more and to have problematic peer relations. The parents of girls, however, felt more positive than the parents of boys about their children's physicians. Differences between the sexes may be reflective of cultural expectations.

Significant differences were also found between the parents of subjects age 12 and younger and parents of subjects age 13 and older. Parents of the younger children reported greater sensitivity to symptoms related to adverse diabetic reactions. This makes intuitive sense in that parents may be more protective of younger children, particularly when a child has a chronic illness.

Children who do not inject their insulin themselves or do so only some of the time more often than children who do inject their insulin themselves believed that family members are encouraged to express their feelings. However, they also believed that there were set rules and procedures in their families and that they themselves were more rigid about adhering to rules concerning diabetes management. This suggests that although the child may feel free to express his/her feelings, there are certain rules in the family, one of which is that the child cannot manage the diabetes the "right" way on his/her own.

The results of the analyses indicated some significant differences between the groups, and as such the null hypothesis was partially rejected.

Hypothesis 6

Hypothesis 6 stated that there were no significant differences in mean scores on the compliance and control variables between subjects grouped according to demographic characteristics. In order to test this hypothesis, one way analysis of variance tests were performed.

An inspection of Table 15 indicates that regardless of who administers the insulin injections, first born children more often than later born children take their insulin injections at the same time every day. However, later born children have a greater tendency to record the results of all blood glucose and urine testing. Because the mean age of the first born and later born children were not significantly different these results are not easy to interpret. However, they have no direct impact on the major findings of the study.

Children who administer their insulin injections themselves more typically make dietary or insulin adjustments for physical activity than children who do not inject their insulin themselves or do so only some of the time. Older children are also more likely than younger children to follow a regular schedule for insulin injections and make the necessary adjustments for physical activity level. Additional analyses revealed significant differences in age between children who inject their insulin themselves and those who do not or do so only sometimes ($F(1, 41) = 7.10, p < .01$). This finding supports the American Diabetes Association's (1984) contention that by the age of 12 children generally begin to administer their insulin injections themselves. As such, older children are more likely than younger children to administer their own insulin injections, follow a regular schedule of times for injections

and make the necessary dietary and insulin adjustments for physical activity. This suggests that children who administer their own insulin also have a tendency to take responsibility for other tasks related to insulin administration.

Table 15

One Way Analyses of Variance Involving the Demographic Variables and the Compliance Variables

Demographic Variable	Compliance Variable	F	p
Birth Order	Injection	4.79	.035
Birth Order	Record	4.24	.047
Sex	Exercise	5.19	.028
Age Group	Injection	4.84	.033
Age Group	Extra	4.18	.047
Income	Injection	6.99	.013
Insulin	Extra	3.31	.048

Children from families from a higher income bracket have a greater tendency to take their insulin injections at the same time every day than children of lower income families. As was pointed out in hypothesis 3, differences between the groups for income level are difficult to interpret given that the mean income for the families in this study was high. Boys differed from girls in that boys more often reported exercising four or more times a week. This difference might be interpreted in terms of differences in cultural expectations for the sexes.

The results of the analyses indicated some significant differences between the groups, and as such the null hypothesis was partially rejected.

The results of the analyses indicated there were no significant differences between subjects for the control variable (Hb A1C). As such, the null hypothesis cannot be rejected and the nonsignificant results will not be reported.

Hypothesis 7

Hypothesis 7 stated there was no significant correlation between a set of compliance variables and a set of psychosocial variables. A canonical correlation analysis was used to test this hypothesis. The results of this analysis can be found in Table 16.

Table 16

*Canonical Correlation Analysis Between
the Compliance and Psychosocial Variables*

Roots	Eigenvalue	Canonical	Wilks	F	p
1	564969.68	1.00	.000	2.95	.000
2	249.51	.99	.000	.97	.577

Standardized Canonical Coefficients

Dependent Variable	Independent Variable
Extra	Express-p -1.12
Record	Rule-c -.75
Testing	Express-c -.55
Exercise	Organize-p .54
	Independence-c .52
	Organize-c -.49
	Conflict-c .46
	Cohesion-c .46
	Social Incompetence -.45
	Cohesion-p .42
	Rule-p .40

The results of the analysis yielded one significant eigenvalue. For the dependent (compliance) variables, eating extra food or taking less insulin on exercise days was the most important variable. It is negatively related to the function. Recording the results of all urine/blood glucose testing was the next most important variable. Following a regular schedule of times for blood/urine testing and exercising four or more times a week were the next two most important variables, carrying approximately equal weight. Parents' perception of family expressiveness was the most important variable in the set of independent variables. It is inversely related to the function. Other relatively important variables were: how rigidly the child adheres to rules concerning the management of the diabetes, the childrens' perception of family expressiveness, parents' perception of family organization, childrens' perception of family organization, conflict and cohesiveness, social incompetence of the children, parents' perception of family cohesiveness and how rigidly parents adhere to rules concerning the management of the diabetes. One possible explanation for these results is that the less expressive the family is the more likely the child is to follow through with these four aspects of the treatment regimen.

The results of the analysis indicated that there was a significant correlation between a set of compliance variables and a set of psychosocial variables. As such, the null hypothesis was rejected.

Hypothesis 8

Hypothesis 8 stated that the multiple correlation coefficient formed between each of the ten compliance variables and a set of psychosocial and demographic variables was equal to zero. Multiple regression equations were used to test this hypothesis. The backward elimination method was used in computing the multiple regression analyses because there was no theoretical reason for individually entering the variables as is done in the stepwise method. The backward elimination method initially enters all the variables into the equation and then removes them step by step on the basis of the F ratio. Separate analyses were computed for each of the ten compliance variables. Four demographic variables were included in the equation as dichotomous dummy variables. They were birth order, sex, who gives the child's insulin injections, and family members with diabetes.

The first analysis performed used the dependent variable, following a regular schedule of times to eat (Schedule). Schedule was best predicted by high cognitive development, a poor self-concept and an attachment of fear to interpersonal situations and relations. While these three predictors are psychosocial, no compelling interpretation of the equation is apparent because for the most part when a child eats is usually dictated by others and is not a function of his/her personality. These three variables accounted for 24% of the variance on the dependent variable. However, 76% of the variance remained unaccounted for. Results of the analysis can be found in Table 17.

Table 17

*Backward Elimination Multiple Regression Analysis:
Psychosocial and Demographic Predictors of Schedule*

Step	R squared	F	df	p
1	.73	.487	6, 33	.91
63	.24	3.711	3, 36	.02

<i>Variables in the equation</i>	<i>Beta</i>	<i>Sig T</i>
Cognitive Development	-.71	.006
Internalization	.54	.016
Social Incompetence	.41	.036

The most significant predictor of eating three meals a day and snacks (Meals) at the final step in the regression analysis was the child's perception of low levels of family conflict. An inspection of Table 18 reveals that the other variables that were included in the equation in order of importance were: the child feeling stigmatized because of the diabetes, the parents' positive attitude toward the child's physician, and the child's perception that family members are not particularly assertive and self-sufficient. These variables account for 45% of the variance on the dependent variable. All of the independent variables, with the exception of child's perception of family independence, had statistically significant beta weights. Nonetheless, independence does

account for a significant amount of the variance in the prediction equation.

Table 18

*Backward Elimination Regression Analysis:
Psychosocial and Demographic Predictors of Meals*

Step	R squared	F	df	p
1	.69	.401	6, 33	.958
62	.45	7.091	4, 35	.000

Variables in the equation	Beta	Sig T
Conflict-c	-.51	.001
Stigma-c	-.36	.015
Attitude	-.32	.015
Independence-c	-.23	.091

Eating only foods prescribed by the physician (Foods) was best predicted by parents' perception that family members are not very independent, combined with parents' perception that there are set rules and procedures in their families, good self-control on the part of the child, the child subject being male and the child's perception that

family members are not encouraged to express their feelings. Other variables that were included in the equation in the order of their importance were: a positive attitude toward the child's physician, the child's perception of low levels of conflict in the family, a tendency for the parents not to believe that the diabetes is a religious test, the parents' perception that family members help and support one another, and the child subject being the first born in his/her family. These variables accounted for 78% for the variance on the dependent variable. Table 19 reveals that all of the independent variables, with the exception of birth order had statistically significant beta weights.

The most significant predictor of exercising four or more times a week (Exercise) at the final step in the regression analysis was poor self-control. Other significant predictors in the order of their importance were the parents' perception of conflict in the family, the child's perception that family members are encouraged to express their feelings openly, the parents' perception that family members are assertive and self-sufficient, a tendency for the parents to perceive the child as not using the disease to get what he/she wants, the parents' perception of a lack of rules and procedures in the family, the child's perception that there is little conflict among family members, a tendency on the part of the parent to believe that the diabetes is a religious test, the parents' perception that family members do not openly express their feelings and having other family members with diabetes. An inspection of Table 20 reveals 13 other less important variables that entered into the equation at the final step in the analysis. Together, these variables accounted for 91% of the variance on the dependent variable.

Table 19

*Backward Elimination Regression Analysis:
Psychosocial and Demographic Predictors of Foods*

Step	R squared	F	df	p
1	.93	2.442	6, 33	.133
56	.78	10.424	10, 29	.000

Variables in the equation	Beta	Sig T
Independence-p	-.80	.000
Control-p	.55	.000
Undisciplined	-.51	.000
Sex	-.48	.000
Express-c	.47	.000
Attitude	-.32	.005
Conflict-c	-.29	.008
Divine-p	.28	.006
Cohesion-p	.27	.027
Birth Order	-.18	.083

Table 20

*Backward Elimination Regression Analysis:
Psychosocial and Demographic Predictors of Exercise*

Step	R squared	F	df	p
1	.95	3.69	6, 33	.053
43	.91	7.00	23, 16	.000

Variables in the equation	Beta	Sig T
Undisciplined	.90	.000
Conflict-p	.74	.000
Express-c	.65	.001
Independence-p	.60	.001
Manipulative	.59	.004
Control-p	-.58	.002
Conflict-c	-.57	.003
Divine-p	-.53	.000
Express-p	-.51	.001
Diabetic	-.50	.000
Control-c	.43	.020
Organize-c	-.43	.019
Social Incompetence	-.40	.005
Rule-c	.38	.001
Independence-c	-.37	.022
Cohesion-p	.37	.015

Table 20 (cont'd)

Organize-p	-.36	.029
Internalization	.29	.067
Sweet	.28	.012
DKT	.28	.014
Reaction	.27	.087
Birth Order	.26	.021
Stigma-p	.22	.095

Eating extra food or taking less insulin on exercise days (Extra) was best predicted by a tendency for parents to be rigid about adhering to rules concerning diabetes management, combined with: the parent's perception that the child has a poor self-concept, a tendency for the child not to be rigid about diabetes management, parents' perception of aggression and conflict among family members, the child's perception that family members do not help and support one another, parents' perception that there are a few rules and procedures for running family life, a tendency for parents not to overreact to their child's symptoms, a child who injects his/her insulin, the child's perception that family members are assertive and self-sufficient, and the child not feeling stigmatized by the disease. Combined with 13 other statistically significant but relatively less important variables, these variables accounted for 97% of the variance on the dependent variable. The results of the analysis can be found in Table 21.

Table 21

*Backward Elimination Regression Analysis:
Psychosocial and Demographic Predictors of Extra*

Step	R squared	F	df	p
1	.98	7.841	6, 33	.008
42	.97	20.276	24, 15	.000

Variables in the equation	Beta	Sig T
Rule-p	-.84	.000
Internalization	.81	.000
Rule-c	.68	.000
Conflict-p	.60	.000
Cohesion-c	-.60	.000
Control-p	-.59	.000
Reaction	.58	.000
Insulin	-.53	.000
Independence	.52	.000
Stigma-c	.52	.000
Express-p	.44	.000
Express-c	.35	.000
Organize-c	.32	.019
Divine-p	-.29	.001
DKT	-.25	.001
Organize-p	-.25	.013

Table 21 (cont'd)

Attitude	-.24	.004
Control-c	.23	.009
Sex	-.23	.002
Manipulative	.20	.044
Undisciplined	.18	.070
Cohesion-p	.17	.053
Age	-.16	.048
Diabetic	-.16	.023

The best predictor of taking insulin injections at the same time every day (Injection) was a tendency for the child to feel stigmatized by the diabetes. Other relatively important predictors were a tendency for the child not to be rigid about managing the disease, children who have had the disease for a longer period of time, a tendency for parents not to adhere to rules concerning sweet consumption, and not having other family members with diabetes. An inspection of Table 22 indicates that there are 10 other statistically significant but relatively less important variables that entered into the prediction equation at the final step in the analysis. These variables accounted for 77% of the variance on the dependent variable.

Table 22

*Backward Elimination Regression Analysis:
Psychosocial and Demographic Predictors of Injection*

Step	R squared	F	df	p
1	.90	1.633	6, 33	.281
51	.77	5.399	15, 24	.000

Variables in the equation	Beta	Sig T
Stigma-c	-.95	.000
Rule-c	.65	.000
Years	.62	.000
Sweet	.56	.000
Diabetic	.51	.000
Conflict-p	-.48	.001
Family-p	.47	.003
Independence-p	.46	.013
Independence-c	-.45	.003
Insulin	.44	.002
Reaction	-.39	.003
Sex	.38	.008
Cognitive Development	-.36	.009
Manipulative	-.35	.014
Cohesion-p	-.25	.090

Taking the number of insulin injections (Number) was best predicted by the parents' perception that family members are not encouraged to openly express their feelings, combined with: a tendency for parents to perceive the child as using the diabetes to manipulate others, the child's perception that family members help and support one another, having the disease for a short period of time, a tendency for parents to overreact to the child's symptoms, the child's perception that family members are not encouraged to openly express their feelings, a tendency for the parents not to believe that the diabetes is a religious test, and the parents' perception that there is structure and organization in the family. Table 23 reveals that there also are 10 other statistically significant but relatively less important variables that account for the 86% variance on the dependent variable.

Table 23

*Backward Elimination Regression Analysis:
Psychosocial and Demographic Predictors of Number*

Step	R squared	F	df	p
1	.90	1.606	6, 33	.289
47	.86	6.555	19, 20	.000

Variables in the equation	Beta	Sig T
Express-p	-1.31	.000
Manipulative	-.92	.000
Cohesion-c	.84	.001
Years	-.80	.000
Reaction	-.77	.000
Express-c	-.77	.000
Internalization	-.72	.000
Divine-p	.72	.000
Organize-p	.71	.000
Organize-c	-.64	.006
Attitude	.57	.000
Rule-c	-.55	.000
Birth	-.52	.000
Conflict-c	.51	.007
Control-c	-.43	.019
Independence-c	.39	.000

Table 23 (cont'd)

Control-p	.35	.040
Conflict-p	-.34	.035
DKT	.24	.032

Performing all the recommended blood/urine tests every day (Tests) was best predicted by the child's perception that organization and structure was not important in the family, combined with a tendency for the child to be rigid about the management of the disease and a high level of knowledge about diabetes. These three variables accounted for 30% of the variance on the dependent variable. The results of the analysis are found in Table 24.

Recording the results of blood/urine tests every day (Record) was best predicted by the child's perception that family members do not help and support one another, combined with the child's perception that family members are not encouraged to openly express their feelings, but are assertive and self sufficient, a good self-concept on the part of the child, the parents' perception that family life is structured and organized, a tendency for the child to be rigid about managing the disease, the parents' perception that family members are not particularly independent, and having the disease for a short period of time. An inspection of Table 25 reveals that there are 12 other statistically significant but relatively less important variables that entered into the prediction equation. Together, these variables

accounted for 84% of the variance on the dependent variable.

Table 24

*Backward Elimination Regression Analysis:
Psychosocial and Demographic Predictors of Tests*

Step	R squared	F	df	p
1	.81	.770	6, 33	.715
63	.30	5.083	3, 36	.005

Variables in the equation	Beta	Sig T
Organize-c	-.45	.003
Rule-c	-.34	.025
DKT	.30	.045

Table 25

*Backward Elimination Regression Analysis:
Psychosocial and Demographic Predictors of Record*

Step	R squared	F	df	p
1	.90	1.702	6, 33	.262
46	.84	4.895	20, 19	.001

Variables in the equation	Beta	Sig T
Cohesion-c	1.16	.000
Express-c	-1.15	.000
Independence-c	.98	.000
Internalization	-.95	.000
Organize-p	.90	.000
Rule-c	-.85	.000
Independence-p	-.76	.003
Years	-.65	.001
Stigma-p	-.61	.000
Sweet	-.61	.000
Cognitive Development	.61	.003
Conflict-c	.60	.009
Manipulative	-.59	.001
Stigma-c	.56	.012
Age	.55	.004
Control-c	-.49	.008

Table 25 (cont'd)

Organize-c	-.49	.033
Divine-p	.42	.004
Insulin	-.35	.012
Sex	.24	.060

The best predictor of following a regular schedule of time for blood/urine testing (Testing) was a tendency for the child not to feel stigmatized by the disease, combined with the child's perception of conflict and anger among family members and a lack of encouragement to openly express feelings in the family, the parents' perception that there are rules and procedures used to run family life, the child's perception that there is little structure and organization in the family, a tendency for the parents not to perceive the child as using the diabetes to manipulate others and the child's perception that family members are assertive and self-sufficient. Combined with six other relatively less important variables, these variables accounted for 67% of the variance on the dependent variable. Results of the analysis can be found in Table 26.

Table 26

*Backward Elimination Regression Analysis:
Psychosocial and Demographic Predictors of Testing*

Step	R squared	F	df	p
1	.79	.682	6, 33	.780
54	.67	4.658	12, 27	.000

Variables in the equation	Beta	Sig T
Stigma-c	.82	.000
Conflict-c	.76	.000
Express-c	-.68	.001
Control-p	-.59	.000
Organization-c	-.55	.007
Manipulative	.54	.001
Independence-c	.54	.004
Undisciplined	.51	.003
Rule-c	-.43	.002
Control-c	.33	.087
DKT	-.30	.027
Internalization	.25	.085

Overall, the results of the regression analyses indicated that children's and parents' perception of how the family functions and their attitudes about diabetes can be used to predict almost all of the compliance behaviors. However, there was no consistent pattern of predictors. Different psychosocial variables predicted different aspects of the treatment regimen.

The results of the regression analyses indicated that the multiple correlation coefficient formed between each of the ten compliance variables and a set of psychosocial and demographic variables was not equal to zero. As such, the null hypothesis was rejected.

Hypothesis 9

Hypothesis 9 stated that the multiple correlation coefficient formed between the control variable (Hb A1c) and a set of compliance variables was equal to zero. This hypothesis was tested using the backward elimination method of multiple regression analysis.

The results of this analysis showed that only one of the compliance variables was a statistically significant predictor of the control variable (Hb A1c). A tendency to take all the required insulin injections at the same time every day predicted low hemoglobin levels (good control). An inspection of Table 27 reveals that this variable accounted for only 18% of the variance on the dependent variable and had a statistically significant beta weight. This suggests that there are other factors besides the ten compliance behaviors that have an effect on metabolic control.

Table 27

*Backward Elimination Regression Analysis:
Compliance Predictors of Control (Hb A1c)*

Step	R squared	F	df	p
1	.35	1.94	10, 36	.072
19	.18	9.77	1, 45	.003

Variables in the equation	Beta	Sig T
Injection	-.42	.003

The results of the analysis indicated that the multiple correlation coefficient formed between the control variable and a set of compliance variables was not equal to zero. As such, the null hypothesis was rejected.

Hypothesis 10

Hypothesis 10 stated that the multiple correlation coefficient formed between the control variable (Hb A1C) and a set of psychosocial and demographic variables was equal to zero. The backward elimination method of multiple regression analysis was used to test this hypothesis. This analysis also included the dummy variables listed under Hypothesis 8.

The results of this analysis indicated that the best predictor of low hemoglobin levels was the child's perception that there was structure and organization in the family. Other relatively important predictors were the child's perception that family members have a tendency not to help and to support one another, a tendency for the child to feel stigmatized by the disease, the child's perception that there was little openly expressed anger and conflict in the family, good self-control on the part of the child, not having other family members with diabetes and high cognitive development. An inspection of Table 28 reveals 13 other statistically significant but relatively less important variables in the prediction equation at the final step in the analysis. Combined, these variables accounted for 86% of the variance on the dependent variable.

Table 28

*Backward Elimination Regression Analysis:
Psychosocial and Demographic Predictors of Control (Hb A1C)*

Step	R squared	F	df	p
1	.92	2.612	8, 33	.078
46	.86	6.702	20, 21	.000

Variables in the equation	Beta	Sig T
Organize-c	-1.41	.000
Cohesion-c	1.11	.000
Stigma-c	1.10	.000
Conflict-c	1.09	.000
Undisciplined	.81	.000
Diabetic	-.63	.000
Cognitive Development	.62	.001
Rule-c	-.59	.000
Control-c	.58	.001
Manipulative	.58	.001
Stigma-p	.58	.000
Organize-p	-.58	.001
Insulin	-.54	.000
Cohesion-p	.54	.001
Control-p	-.52	.002

Table 28 (cont'd)

Social Incompetence	-.50	.004
Express-c	-.46	.002
Attitude	-.43	.001
Divine-p	-.39	.001
Sweet	-.22	.041

The results of the analysis indicated that the children's perception of how the family functions and their attitude toward the diabetes were the best predictors of metabolic control. The findings of this study suggest that both negative and positive family interactions can be used to predict control. One possible explanation for this is that a child with diabetes is affected by and has an effect on how the family functions. It would be expected that low conflict, high cohesiveness, etc., would enhance compliance, however, the stress of a daily multifaceted treatment regimen can have a negative impact on family interactions.

The results of the analysis indicated that the multiple correlation coefficient formed between the control variable and a set of psychosocial and demographic variables was not equal to zero. As such, the null hypothesis was rejected.

Hypothesis 11

Hypothesis 11 stated there is no significant difference between subjects in good, moderate and poor control, as measured by the psychosocial and the demographic (sex, age, number of years with diabetes, whether or not the child gives his/her own insulin and other family members with diabetes) variables. This hypothesis was tested by using a discriminant analysis using Rao's V as the criterion for maximizing group differences. The criteria for the classification of subjects into each of the three groups is described in Chapter 3. The results of the analysis can be found in Table 29.

The discriminant analysis yielded two significant functions, indicating that there are significant differences between the groups or among the group centroids. Using the stepwise method, twenty-two of the original thirty-five variables were selected before RAO became nonsignificant. Approximately 95.5% of grouped cases were correctly classified on the basis of these variables. The eigenvalue associated with the first function indicated the relative importance of this function to be 79.35%. The corresponding canonical correlation showed that 91% of the variance between the groups can be explained by the function. The Wilks' Lambda indicated that a considerable amount of discriminating power existed in the variables that were used.

Table 29

*Discriminant Analysis**Good, Moderate and Poor Metabolic Control*

Function	Eigenvalue	Canonical	Wilks'	Chi Squared	d.f.	p
1	10.38	.96	.02	106.62	44	.000
2	2.70	.85	.27	37.30	21	.016

Standardized Canonical Discriminant Function Coefficients

	Function 1	Function 2
Stigma-p	-0.06	-0.95
Divine-p	-0.22	0.79
Attitude	1.10	0.30
Family-p	-1.55	0.66
Reaction	1.64	0.29
Stigma-c	0.06	-1.33
Rule-c	1.94	0.46
Sick Role	-0.64	-0.61
Family-c	-0.94	1.01
Cohesion-c	-1.93	-1.57
Conflict-c	1.50	0.59
Conflict-p	-1.51	-1.15
Independence-p	-1.06	-0.31
Organization-c	3.51	1.41
Organization-p	1.79	0.79

Table 29 (cont'd)

Control-c	-1.33	-0.09
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	Function 1	Function 2
Undisciplined	-1.13	-0.14
Social Incompetence	0.74	0.31
DKT	0.76	-0.20
Age	-1.10	-0.03
Insulin	0.97	0.22
Diabetic	1.73	0.25

Classification Results

Actual Group	n	Predicted Group Membership		
		1	2	3
Group 1	17	17 (100%)	0 (0%)	0 (0%)
Group 2	19	1 (5.3%)	18 (94.7%)	0 (0%)
Group 3	9	0 (0%)	1 (11.1%)	8 (88.9%)

Percent of Grouped Cases Correctly Classified: 95.56%

The first function served to discriminate subjects in good control from subjects in moderate and poor control. The child's perception of the family's level of organization was the most important variable for this function. Other significant variables were: how rigidly the child adheres to rule concerning diabetes management, the child's perception of family cohesiveness, the parents' perception of family organization, other family members with diabetes, how carefully the parent observes the child's symptoms, how disruptive the parent feels the diabetes has been on the family, the parent's perception of the amount of conflict in the family, the child's perception of the amount of conflict and the level of control in the family, poor self control, how positively the parent feels toward the medical staff, the child's age, the child's perception of family independence, whether or not the child gives his/her own insulin injections, how disruptive the child feels the diabetes has been on the family, the child's level of knowledge about diabetes, social incompetence, and the extent to which the child uses the diabetes to get his/her own way.

The eigenvalue associated with the second function indicated the relative importance of this function to be 20.65%. The corresponding correlation showed that 73% of the variance between the groups can be explained by the function. The Wilks' Lambda indicated that a considerable amount of discriminating power existed in the variables that were used.

The second function served to discriminate between subjects in moderate and poor control. The child's perception of family cohesiveness was the most important variable in this function. Other

significant variables were: the child's perception of family organization, how stigmatized the child feels by the diabetes, the parent's perception of the level of family conflict, how disruptive the child feels the diabetes has been on the family, the degree to which the parent feels the family has been stigmatized by the child's diabetes, the parent's perception of family organization, the degree to which the parent believes that the diabetes is a religious test, how disruptive the parent feels the diabetes has been on the family, the extent to which the child admits to using diabetes to get his/her own way, and the child's perception of family conflict.

The results of this analysis indicated that family functioning and attitude about diabetes were the most important variables for classifying cases into groups. More specifically, subjects in good control were characterized by the child's perception that there was clear organization and structure in planning family activities and responsibilities, a tendency for the child not to be rigid about managing the disease, and a perception that family members have a tendency not to help and support one another. Subjects in moderate control were characterized by the child's perception that family members have a tendency not to help and support one another, that there was clear organization and structure in planning family activities and responsibilities, and a tendency for the child to feel stigmatized by the disease. As such, organization and structure in the family and low levels of cohesiveness were the two most important characteristics of subjects in good and moderate control. This finding does not support that reported by Anderson et al. (1981). In their study the families of subjects in good control were more cohesive than the families of

subjects in moderate and poor control. It is difficult to compare results however, since Anderson et al. (1981) used an analysis of variance.

The results of the analysis indicated that there was a significant differences between subjects in good, moderate and poor metabolic control, as measured by the psychosocial and demographic variables. As such, the null hypothesis was rejected.

Summary.

Several important findings emerged from this study. This study was based on the premise that compliance is not a unitary construct, but is comprised of multiple behaviors. The results of the statistical analyses indicated that these behaviors are discrete and independent. There were further indications that factors that predicted compliance with one behavior were unrelated to factors that predicted compliance with other behaviors. The findings of this study partially support those reported in the literature that measures of family functioning are the most important predictors of measures of both compliance and control. This study also supports a growing body of evidence that suggests there is no relationship between compliance and control. Further discussion on the implications of these findings is presented in the next chapter.

CHAPTER FIVE

DISCUSSION

Overview

This chapter is organized into five sections. The first section is a discussion of the results of the data analyses. The results are evaluated in relation to the specific hypothesis addressed in this study as well as to the findings of previous research. In the second section the clinical implications for pediatricians, pediatric psychologists and anyone who intervenes psychologically with children with insulin-dependent diabetes and their families are discussed. The third section is a discussion of the theoretical implications. The fourth section addresses the methodological implications of the study. This is followed by a discussion of the limitations of this study. Directions for future research are presented in the final section.

Interpretation of Results

This section is organized into four subsections. The first will be a description of the psychosocial and demographic characteristics of the sample. The second and third subsections, respectively, contain discussions of the most important finds pertaining to compliance and control. A summary highlighting the relevant findings can be found in the final subsection.

Psychosocial and Demographic Characteristics. The first hypothesis tested in this research project pertained to subscale intercorrelations. The inventory intercorrelations between the scales used in this study were compared to those of the normative samples of the Diabetes Opinion

Survey (Johnson, 1985), the Parents Diabetes Opinion Survey (Johnson, 1985), the Family Environment Scale (Moos, 1974), the State-Trait Anxiety Inventory (Spielberger et al., 1983), the State-Trait Anxiety Inventory for Children (Spielberger et al., 1973) and the Personality Inventory for Children (Wirt, Seat, Broen, & Luchar, 1981). Overall, the subscale intercorrelations for the present sample were moderately higher than those of the normative samples. This was expected because of the small sample size and the homogeneity (e.g., white, upper middle class) of the sample under study.

The subscale means for the normative sample fell within the normative sample range. This indicates that the sample was comprised of psychologically healthy children living in normal family environments, possessing the age appropriate level of knowledge about their illness and experiencing a normal level of stress. Both the children's and the parents' opinions about diabetes can be considered appropriate. These findings were anticipated since the target population for this study was psychologically healthy children with a chronic illness such as insulin-dependent diabetes mellitus.

The intercorrelations between the inventories indicated some disagreement between the children's and the parents' responses on the same or similar subscales. For example, on the Family Environment Scale (Moos, 1974), significant intercorrelations between the parents' and the children's responses were found for three of the six subscales. As such, there was no relationship between children's and parents' responses on Cohesion, Expressiveness and Control. Given that the sample consisted mostly of adolescents (the average age was 13), this

result was expected. Adolescence is a time when individuals attempt to assert themselves and become less dependent on their parents. They typically find themselves questioning the values of their parents and trying out new ones. Therefore, not only it is likely that disagreements with respect to family will occur, they were expected.

Other analyses in this study examined the relationship between demographic and psychosocial variables. The Eta squared statistic used to compute the degree of association between the nominal demographic variables and the psychosocial variables is based on the F statistic. Therefore, Eta squared analyses and the analyses of variance are discussed simultaneously.

Diagnosis at an early age was negatively related to rigidly adhering to rules concerning the diabetes management. This suggests that the more experienced the child is with the treatment regimen, the more likely he/she is to believe that there is a "right" way to manage the disease.

Significant differences were found between the degree to which the parents of younger and older children respond to their child's symptoms. Parents of younger children reported greater sensitivity to diabetic symptoms. This finding is consistent with Holmes (1986) contention that when children become diabetic before the age of five, parents are particularly sensitized to medical emergencies and respond with increased intensity to even minor fluctuations in the child's health.

Not all children administer their insulin injections themselves. When they begin to take on this responsibility generally depends on the

cognitive maturity of the child (Ingersoll, Orr, Herold & Golden, 1986). Allen et al. (1983) found that parents and children attach particular significance to responsibility for insulin injection as an indication of the child's independence. Patridge, Garner, Thompson and Cherry (1972) found that the adolescents in their study took responsibility for diabetes management at about age 12. Ingersoll et al. (1986) found that parental involvement ceased at about age 15. In the present study there were significant differences in age between children who injected their insulin themselves and children who did not or did so only some of the time ($F(1, 41) = 7.10, p < .01$). The children who injected their insulin themselves were significantly older than the other group. Ingersoll et al. (1986) contend that parents presume that older, physically mature children are cognitively mature. However, their study did not support this assumption.

The present investigation indicates that children who do not self administer their insulin injections or do so only some of the time tend to be rigid about adhering to rules about managing the diabetes the "right" way, believe that they can openly express their feelings in their families and that there are set rules and procedures in their families for running family life. Because these children are younger than the group of children who self inject their insulin, they may be perceived by their parents as unable to assume responsibility for the management of the diabetes.

Differences were also found between the sexes. The boys were more likely than the girls to believe that their diabetes caused more work and worry for their parents than was necessary. The parents of boys

also perceived their family members as more self sufficient and assertive than the parents of girls. The boys were perceived by their parents to be more undisciplined and more manipulative in relation to the diabetes than the girls. These results are difficult to interpret except in light of sociocultural expectations for the sexes. Blum (1984) contends that sex only weakly distinguishes between people who comply with their treatment regimens and those who do not.

The results of these analyses revealed that the children who served as subjects for this study for the most part came from white, upper middle class, two parent families with only one sibling in the home. On the average, the children have had diabetes for six years. Their responses to the various inventories fell within the norm sample range, although the intercorrelations were higher than those reported for the norm sample. As was pointed out earlier this was most likely due to homogeneity and a small sample. Some significant differences were found for age, sex and between subjects who gave their own insulin injections and those who did not. Generally, these differences were similar to those found in other studies.

Compliance. Most of the research conducted on compliance with diabetes treatment regimens has used metabolic control as the measure of compliance. It may be more accurate to state that compliance is a measure of behavior, whereas control is a measure of carbohydrate metabolism. The few studies (Allen et al., 1983, Harris & Linn, 1985, Schafer et al., 1983, Schafer et al., 1986, Waller & North, 1981) that have differentiated between compliance and control have found little or no relationship between them. In addition, Schafer et al. (1983) have

demonstrated that adherence to one aspect of the regimen (e.g., insulin injections) may not be related to adherence to others (e.g., diet). The findings of the present investigation supports this finding and the hypothesis of Schafer et al. (1983) that factors that influence compliance with some aspects of the regimen may be unrelated to factors that influence compliance with another aspect. The diabetes treatment regimen is a multifaceted program that encompasses multiple independent behaviors. As such, compliance is not a unitary dimension.

The Diabetes Behavior Checklist was designed specifically for the purpose of this study to measure multiple compliance behaviors that comprise the diabetes treatment regimen. Although generally there are some concerns about the validity of self report measures (Rickel & Briscoe, 1970) they are frequently used if only for a lack of a better method for measuring compliance. The Diabetes Behavior Checklist attempted to overcome some of the pitfalls of using a self report measure by pairing socially desirable items and asking subjects to choose between them. In this way, error due to social desirability is decreased.

What follows is a discussion of the analyses of the ten compliance behaviors measured by the Diabetes Behavior Checklist. Each of the ten behaviors will be discussed separately followed by a summary. The results of the analyses for the control variable is then presented.

Following a regular schedule of times to eat was best predicted by variables related to the parents' perception of the child's overall psychological functioning. It is unclear at present as to why high cognitive development, social incompetence and internalization could

predict compliance to eating on a regular schedule. This result was not anticipated as it was expected that environmental factors would play a role in when a child eats.

Eating three meals and snacks was predicted by the child's perception of low levels of family conflict, the child feeling stigmatized by the disease and that members of his/her family were not particularly self sufficient, and the parents having a positive attitude toward the child's physician. These findings seem to lend support to Schaefer et al.'s (1986) contention that the behaviors of family members may interfere with or facilitate compliance. Ary, Toobert, Wilson and Glasgow (1986) have pointed out that there has been relatively little research done on social learning factors such as situations, behaviors of persons with diabetes, actions of family members and friends or consequences of one's behavior that may be related to compliance. The data seem to indicate that eating three meals a day is influenced by the child's perception of aspects of family life and the child's perception of self in relation to others. As will be discussed later, the child's self-perception and his/her perception of family life tend to predict some compliance behaviors but are unrelated to others.

A significant relationship was found between following a prescribed meal plan and parents who are rigid about diabetes management. It is important to note that the physician of the children who served as subjects for this study is particularly strict about dietary adherence. One way to interpret this is that the physician's attitude toward diet may have had an impact on how cautious the parent and the child are with regards to diet.

Eating only prescribed foods was best predicted by parents' perception of the level of independence and control in the family. That is, children who had a tendency to eat only prescribed foods had families in which the parents perceived family members as not particularly self-sufficient or assertive, believed that there were set rules and procedures used to run family life and the perception that the child had the ability to exercise good self control. Ary et al. (1986) found that one reasons for noncompliance to dietary recommendations in adults was inappropriate offers of food from others. Shenkel, Rogers, Perfetto and Levin (1986) contend that how important following the treatment regimen was to "significant others" in a person's life was a stronger predictor of behavioral intention than were the person's own beliefs. In this study, eating only prescribed foods was best predicted by the parents' perception of the family and of the child. The parents' perception that the child had good self control combined with a view of family members as dependent and that family functioning is enhanced by rules and procedures does not necessarily suggest a supportive environment. However, it seems likely that the way in which the family functions makes it easier or more difficult for the child to adhere to his/her diet.

Some studies (Glasgow et al., in press, Williams, Martin, Hogan, Watkins & Ellis, 1967) have suggested that for people with diabetes the highest rates of noncompliance to treatment recommendations centered around dietary and exercise behaviors. Exercise is particularly problematic because few people who are told to exercise regularly are given a written regimen of what to do (Ary et al., 1986). This was also a problem with the Diabetes Behavior Checklist in that the items

concerning exercise were not explicit in terms of defining what constituted exercise. As such, it is unclear as to what the children responding to the questionnaire understood to be exercise.

A significant correlation was found between parents' positive attitude toward the child's physician and medical staff and the child's tendency not to exercise four times or more a week. The parents of girls were more positive than the parents of boys about their child's physician. Yet boys more often than girls exercised four or more times a week. Pond (1979) found that parental attitudes toward treatment can have an affect on the child's attitude and how well the disease is managed. However, these findings suggest that parental attitude may be a poor predictor of compliance in relation to exercise. Other findings indicated that children who were rigid about diabetes management had a tendency not to exercise four or more times per week. This is another instance of seemingly contradictory findings in the prediction of compliance. One would expect that rigid adherence would predict exercise.

The best predictor of exercising four or more times per week were the child being perceived by the parents as undisciplined, the parents' perception that anger was openly expressed in the family and the child's perception that family members are encouraged to express their feeling openly and directly. The child's perception of exercise could be anything from an organized sport to simply running around with friends in the neighborhood. Going out to exercise may be a means of getting out of the house and is most likely not reflective of a disciplined attempt to adhere to treatment recommendations.

Ary et al. (1986) contend that dietary and exercise self care behaviors are similar in that they are time consuming and require alterations in life style. The Diabetes Behavior Checklist item, "I eat extra food or take less insulin on days that I exercise" encompasses three diabetes-specific tasks related to diet, insulin and exercise that require alterations in one's daily routine. This item was best predicted by parents who have a tendency to be cautious and protective (i.e., rigid about the diabetes management), who perceived their child as being insecure, fearful and worried, combined with the child's tendency not to be particularly rigid about the diabetes management. This seems to support the theory of Shenkel et al. (1985) concerning compliance with a regimen because it is important to significant others. In this case the child complies without being particularly rigid because he/she may sense the parent's anxiety, which may get projected onto the child (thus the perception of the child as insecure and fearful).

In a study of people with both Type I and Type II diabetes, Ary et al. (1986) found that adherence was highest for medication compliance whether it was insulin injections or oral medication. Two items on the Diabetes Behavior Checklist related to insulin injections, one on the timing of the injections and the other on the number of injections. Findings of the present investigation indicated that older children who administer their own insulin injections are more likely to follow a regular schedule of time for insulin injections and make the necessary dietary and insulin adjustments for physical activity than younger children who do not or do so some of the time. Intuitively, these findings make sense in that the older child is assuming more responsibility for diabetes management. Although it is clear that age

does not always predict compliance, the age at which a child begins to assume responsibility for tasks related to insulin injections is an important issue for children and parents (Allen et al., 1983).

Compliance with taking the insulin injections at the same time every day was predicted by the child feeling different from others because of the diabetes, a tendency to be not particularly rigid about adhering to rules concerning diabetes management, combined with a tendency to have some experience with the regimen as a function of having the disease for some time. A child who must take insulin every day to survive is reminded at least once a day that he/she is different from other people. However, after a few years, the child becomes more experienced with the regimen and the extent to which he/she can deviate without adverse reactions, and as such effective consistency in disease management does not have to be accompanied by anxiety and rigid rules management.

Radius et al. (1979) found that mothers who felt that the treatment regimen was disruptive poorly complied with recommendations for their child's treatment. However, this study found that a tendency for children to believe that their diabetes was disruptive on their families was associated with taking the required number of insulin injections every day. This suggests that the children may be taking responsibility for the management of the disease in an effort to minimize the disruption they believe it causes in their families.

Compliance with taking the required number of insulin injections every day was best predicted by the parents perception that family members have a tendency to keep their feelings to themselves, that the child uses the diabetes to manipulate others, the child's perception

that family members help and support one another, a tendency to have less experience with the treatment regimen, a tendency for parents to overreact to the child's symptoms, as well as the child's perception of family expressiveness being in agreement with the parents' perception. The dynamics of these predictor variables seem to indicate a situation in which the child has had the disease for a relatively brief period of time, the parents see the child as manipulative, but nonetheless observe his symptoms very carefully without expressing how they feel. The child in turn feels that he/she is being helped and supported and thus complies with the treatment recommendation. It appears that the attention the child is receiving from family members offsets any negative feelings the parents may be experiencing about his/her child's behavior.

Ary et al. (1986) reported that subjects adhered to tasks related to blood/urine testing about 55-67% of the time. Schaefer et al. (1982) content that adherence rates can be increased through behavior modification techniques. A positive attitude toward urinalysis and the number of urine tests performed has also been demonstrated (Ludvigsson & Svensson, 1979). However, there is some evidence to suggest that adolescents find the testing and recording part of their regimens to be problematic (Waller & North, 1981). Three items on the Diabetes Behavior Checklist are related to blood/urine testing: performing the recommended number of tests on a daily basis, recording the results and following a regular schedule of times for testing.

The best predictors of performing the recommended number of tests each day were the child's perception that family life lacked structure

and organization, a tendency on the part of the child to be rigid about diabetes management and the child being knowledgeable about the disease. The child's rigidity about management may be a reaction to what he/she perceives as a lack of structure in the family. Structure refers to the manner in which family activities are planned and expectations for responsibilities are determined. Although knowledge alone does not predict compliance it is one factor that may influence compliance behavior (Watkins et al., 1967, Kersell & Milsum, 1985).

Parents overreacting to the child's symptoms was associated with a tendency for the child not to record the results of blood glucose and urine tests. It may be that the child may not feel a need to monitor his/her blood glucose levels because the parent is so vigilant. This study also found that parents of younger children tended to overreact more than the parents of older children. This bears on the issue of responsibility for management of the disease and how that changes over time.

Recording the results of all blood/urine tests was best predicted by the child's perception that family members help and support one another, keep their feelings to themselves and are self-sufficient, assertive and make their own decisions. For this behavior, the primary predictors appear to be the child's perception of environmental factors related to the family rather than factors internal to the child. This finding is somewhat counterintuitive in that it was anticipated that cognitive maturity would be one of the more important predictor variables. Failing to record test results is probably a task that a child could not do and not suffer immediate adverse reactions. One possible

explanation for this is that only relatively mature children would have a tendency to comply with this recommendation.

Following a regular schedule of times for testing blood glucose levels was best predicted by a tendency for the child not to feel different from others, to perceive that there is conflict among family members, but that family members keep their feelings to themselves. One interpretation of these data is that it may be difficult for the child to say what he/she feels without upsetting someone in the family and consequently may in fact be suppressing or denying thoughts about feeling different from other people. He/she may feel that it is unacceptable to complain about things in the family and as such complies with treatment recommendations to avoid conflict in the family.

Separate analyses of each of the ten compliance behaviors was preceded by a canonical correlation analysis, which was used to derive an optimal set of compliance and psychosocial variables. The results of this analysis indicated that a tendency not to make dietary and insulin adjustments for physical activity, to record the results of all urine/blood testing, to follow a regular schedule of times for testing and to exercise four or more times a week was best predicted by parents' perception that family members keep their feelings to themselves, a tendency for the child to be rigid about adhering to rules concerning diabetes management, the child's perception that family members keep their feelings to themselves, the parents' perception that there is structure and organization in the family and the child's perception that family members are assertive and self-sufficient, but that there is a lack of structure and organization in the family. One possible

explanation for these results is that low expressive emotionality in the family may foster compliance with some aspects of the treatment regimen. Overall, it appears that the results of the canonical correlation are similar to those of the regression analysis in that there is no consistent pattern as to which psychosocial variables can be used to predict different aspects of the treatment regimen.

Overall, the results of the analyses related to compliance behaviors suggest several interpretations. There were significant intercorrelations between parents' and childrens' attitudes about diabetes and some behavioral measures of compliance. However, there were no significant intercorrelations between measures of family functioning and any of the compliance behaviors. Measures of family functioning and to a lesser extent, attitudes about diabetes can be used to predict compliance behaviors. However, different psychosocial variables predicted compliance to different aspects of the treatment regimen.

Most studies have found significant relationship between individual measures of family functioning and various aspects of compliance behaviors (Schafer et al., 1983, Schafer et al., 1986, Waller & North, 1981). It should be noted, however that Schafer et al. (1983, 1986) found that diabetes-specific family behaviors were more related to compliance behaviors than were global measures of family functioning. What this study found was that individual measures of attitudes correlated with specific compliance behaviors, whereas a set of psychosocial variables (global measures of family functioning and attitude) could be used to predict compliance behaviors. By using both

simple correlational techniques and multivariate statistical procedures this study was able to make a distinction between a set of variables that can be used to predict compliance and individual variables that correlate with compliance.

There was no consistent pattern as to which psychosocial variables predicted the different compliance behaviors. To some extent this was anticipated since one of the goals of the study was to measure compliance as discrete, independent behaviors, rather than as a unitary dimension. This study was successful in pointing out how different the behaviors are from one another and that compliance to one aspect of the regimen was unrelated to compliance with another aspect. There were only two significant intercorrelations that were at or above .40 between the compliance variables, indicating that compliance behaviors are not highly correlated. However, the majority of the intercorrelations (significant or nonsignificant) were negative. This suggests that a child who complies with one aspect of the regimen does not necessarily comply with another aspect of the regimen.

Control. As was discussed earlier in this chapter, the relationship between compliance and control is tenuous at best. Most studies have found no significant relationship between the two variables (Allen et al., 1983, Harris & Linn, 1985, Schafer et al., 1986, Waller & North, 1981). This study supports such findings. However, a regression analysis found that taking insulin injections at the same time every day predicted good control. This equation accounted for only 18% of the variance on control, which suggests that there are other factors besides the ten compliance behaviors that influence control.

A variety of methods have been used to identify factors that have an impact on metabolic control. Some investigators (Anderson et al, 1981, Simonds et al., 1981) have attempted to compare children in good and poor control. Others (Baker et al., 1975, Orr et al., 1983) studied children who were in poor control or were experiencing recurrent ketoacidosis. Although most authors have found little psychological disturbance in their sample of children with diabetes (Simonds et al., 1981, Simonds, 1977), a high incidence of disruption in the families of children in poor control have been reported (Anderson et al., 1981, Baker et al., 1975, Waller & North, 1981).

In the present investigation, no significant relationship was found between psychosocial variables and metabolic control. This supports the findings reported by Schafer et al. (1983). However, this investigation found that it is possible to identify a set of psychosocial variables that be used to predict metabolic control.

This study found that 86% of the variance on metabolic control could be accounted for by psychosocial variables. Poor metabolic control was best predicted by the child's perception that there was a lack of structure and organization in the family, that family members helped and supported one another, but that there was conflict among family members, a tendency for the child to feel that he/she is not treated differently because of his/her diabetes and the parents' perception that the child is undisciplined (e.g., has poor self-control).

These findings are inconsistent to some extent with those of previous studies. For the most part, other studies (Anderson et al., 1981, Baker et al., 1975, Schafer et al., 1983) found only negative family

interactional patterns to be related to poor control. However, the present investigation, using multivariate statistical techniques, indicates that, taken as a set of predictors, both negative (lack of organization, conflict) and positive (cohesiveness) family interactional patterns influence metabolic control. Intuitively, this makes more sense in that it is unlikely that family interactions would be either all positive or all negative. It is more likely that families interact in ways that are both positive and negative. This finding supports the use of multivariate statistical techniques for health psychology research.

Thus far, there has been no study that has used discriminant analysis to differentiate between subjects in good, moderate and poor metabolic control. Most investigators dichotomize control into good and bad and employ analysis of variance techniques to identify differences between the groups.

The results of the discriminant analysis yielded two significant functions. The first function discriminated between subjects in good control from subjects in moderate and poor control. The variables that were most important to the first function were the child's perception of structure and organization in the family, a tendency for the child not to be rigid about managing the disease, the child's perception that family members do not really help and support one another, and the parents' perception that there is organization and structure in the family.

The second function discriminates between subjects in moderate control from subjects in poor control. The most important variables for

this function were the child's perception that family members do not really help and support one another, but that there was structure and organization in the family, a tendency for the child to feel stigmatized by the disease and parents' perception that family members try to work out conflicts without getting angry.

In both of these functions, and in the regression analysis as well, family organization and cohesiveness were the most important variables. More specifically, organization and structure in the family and a lack of cohesiveness were the most important discriminating variables. This finding does not support those reported by Anderson et al. (1981) who also compared subjects in good, moderate and poor control using an analysis of variance. They found that families of adolescents in good control were more cohesive than the other two groups. Again, the different findings could be a result of the use of different statistical procedures. The unreliability of the analyses of the present study due to the small sample size in relation to the number of variables may also account for these differences. Overall, this study found that control could be predicted by measures of family functioning, although attitudes about diabetes were often among the more important discriminating variables.

The findings of this study support previous research (Allen et al., 1983, Harris & Linn, 1985, Schafer et al., 1986, Waller & North, 1981) that there is no significant relationship between behavioral measures of compliance and metabolic control. This finding, although seemingly counterintuitive, suggests that there are other factors that impact upon metabolic control. There is some evidence (Hinkle & Wolfe, 1952, Chase

& Johnson, 1981, Barglow et al., 1983) that supports the hypothesis that stress has an influence on metabolic control. However, stress may be the mediating variable in the link between psychological factors and metabolic control. For example, conflict in the family was one of the variables in this study that predicted poor metabolic control. One might hypothesize that conflict in the family produces stress, which in turn has an effect on metabolic control. However, strained family relationships may be a function of the burden of a daily regimen that entails numerous time consuming tasks. Although stress is a part of daily life, it has an even greater impact on people with diabetes (Hinkle & Wolfe, 1952). Thus, future studies might examine the relationship between stress and family functioning and how they impact upon metabolic control.

Clinical Implications

The findings of this study have implications for both theory and clinical practice. "Clinical" refers to interventions whose goals are to enhance compliance behaviors and to foster behavioral change associated with compliance. As such, the target of these interventions could include the child, the family, school officials, etc. Several theories related to family systems, illness behavior, behavior modification and self-control will be discussed.

Family Systems Theory. Children do not come for treatment at their own initiative, nor do they typically live independently from their families. As such, anyone who attempts to intervene psychologically with children with insulin-dependent diabetes will inevitably also work with the family. The findings of this study support a growing body of

evidence that the family plays an important role in how well the child manages the disease. Unlike the child with an acute illness, who is usually hospitalized, the chronically ill child lives at home and the primary responsibility for his/her care and treatment rests with the family rather than medical personnel. Patterson and McCubbin (1983) contend that the child's health status impacts on the whole family in that it affects interpersonal relationships, where the family lives, family finances, the amount of free time for both the parents and the child, parental careers, etc.

From a theoretical perspective it makes sense to conceptualize a child with diabetes as a part of an ongoing family system. This study has indicated that the extent to which the child complies with treatment recommendations is in part influenced by the child's and the parent's perceptions of how the family functions and their attitudes toward diabetes. However, the direction of the impact is unclear. Most investigators study the impact of the family upon the diabetic child. Cerreto and Travis (1984) suggest that a more parsimonious way to conceptualize the problem is to integrate it into a family systems model that focuses on the reciprocity and interdependence of parts (i.e., children, parents, etc.) in a social context.

Weeks (1986) contends that the key to understanding any theory of therapy is how it views symptomatic behavior and change. A systems approach holds that symptomatic behaviors develop in the context of a system, which is defined by the interaction between and among the participants. In order for individual change to occur, the interpersonal system must change (Stanton, 1981). How the family

functions has implications for helping the child become compliant if he/she is having difficulty complying with certain aspects of the regimen and for organizing family life in such a way that help to prevent noncompliance from occurring in the first place. For example, the family could help the child who is having difficulty adhering to the prescribed diet by not having foods that the child should not eat in the home. If the family eats on a regular schedule, the child would probably not have difficulty complying with that aspect of the treatment regimen.

The results of this study indicate that some compliance behaviors are best predicted by positive aspects of family functioning, whereas others are predicted by negative family interactions. For example, compliance with eating only prescribed foods and exercising four or more times a week was predicted by parental perceptions that family members helped and supported one another. However, compliance with taking insulin injections on a regular schedule was predicted by parents' perception that family members have a tendency not to help and support one another. One possible explanation for these contradictory findings is that perhaps one parent is taking the burden of the responsibility for either giving or making sure the child takes his/her insulin injections on a regular schedule. This parent may resent this obligation and may feel that he/she is not being helped or supported by other members of the family.

Another example of negative family interactions that influence adherence was testing on a regular schedule. This behavior was predicted by the child's perception that in his/her family, family members openly

express angry feelings (e.g., conflict in the family). The child's compliance with testing on a regular schedule may in some way interfere with family routines, which in turn may cause conflict.

The examples cited above illustrate several important points that have implications for clinical interventions. The first point is that although negative family interactions predict some compliance behaviors, they also predict noncompliance with other behaviors. As such, interventions designed to enhance some behaviors might decrease the occurrence of other behaviors. Therefore, it is important for the therapist to know the contingencies that predict compliance to all of the diabetes-related behaviors.

Another important point is that the stereotyped image of patients as compliant or noncompliant is no longer a valid distinction. It is more accurate to view compliance along a continuum of multiple behaviors that are rooted in a variety of contexts (family, school, peer group, etc.) in which the child will find him/herself. As pointed out earlier, individual change is contingent upon change in the system (Stanton, 1981). The findings of this study suggest that there may be a reciprocal relationship between how the family functions and the extent to which a child's complies with treatment recommendations. By attempting to understand the whole family while at the same time remaining aware of the system's interrelated components, a systems approach allows the therapist to look at both how the child impacts upon the family and how the family impacts upon the child's ability to comply with treatment recommendations.

Illness Behavior. The theory that the family is both affected by and has an affect on a child with a chronic illness such as diabetes has implications for how the child copes with the illness. An individual's personal meaning (the meaning that a child attaches to the diabetes) and attitude toward his/her illness is related to how he/she copes with it (Lipowski, 1970). Some people view illness as a punishment for sins (although this was not the case with this sample). Some people see it as an opportunity to relieve themselves of unwanted responsibilities, whereas others use their illness as a way to get attention from others. Illness behavior is a term conceptualized by Mechanic (1962) to describe behaviors that pertain to the perception of bodily symptoms, an evaluation of the significance of the symptoms and the extent to which help is sought, life routines altered, etc. as a consequence. One possible consequence of the perception of symptoms is that the person views him/herself as sick and behaves accordingly (e.g., seeks treatment, stays at home, etc.).

Through the use of the Diabetes Opinion Survey and the Parents Diabetes Opinion Survey (Johnson, 1985), this study was able to identify child and parental attitudes about diabetes and their influence on compliance behaviors. Two subscales from these inventories that seem to have implications for illness behavior were manipulateness and stigma. The parent's perception that the child uses the diabetes to manipulate others was an important predictor of taking the required number of insulin injections every day. This implies that the child uses the illness to get out of doing things he/she does not want to do or to get things he/she wants. Illness behavior is intentional in the sense that the behavior or set of behaviors is performed for the purpose of the

obtaining specific consequences. In the case of manipulative behavior, the behaviors are physical complaints about symptoms for the purpose of getting something or getting out of doing something (e.g., going to school, household chores, etc.). One possible explanation of the results cited above is that the child manipulates the parent into taking responsibility for giving him/her the insulin injections.

Injecting on a regular schedule and eating three meals and snacks were predicted by a tendency for the child to feel stigmatized by the disease. That is the child feels different from peers and feels that he/she is treated differently because of the diabetes. Being different refers to being sick or not as healthy as other people. To some extent this perception may function as a motivator to comply with treatment recommendations because other people do not inject themselves with insulin every day or have to monitor when and what they eat. However, it could also interfere with compliance behaviors particularly during adolescence when children are least motivated to do things that are different from what their peers are doing.

Clinically, it is important to understand both how the child perceives him/herself in relation to the illness and how that affects behavior. The example cited earlier of a person perceiving him/herself as sick and behaving accordingly is probably too simplistic in that it does not take into account the person's evaluation of the consequences of his/her behavior. A child who feels stigmatized and complies with treatment recommendations may also believe that his/her compliant behavior leads to a desirable consequence (e.g., no adverse symptoms). However, a person behaves in a specific way, in part because he/she

believes that the behavior will lead to specific consequences that are desirable (Fishbein & Ajzen, 1976). In the example of the child who feels stigmatized and does not comply, one of the consequences of the noncompliant behavior is that the child does not behave differently from the peer group and this consequence may be desirable. One approach to helping children who have difficulty turning down inappropriate offers of foods from their peers is to reframe the child's thoughts so that he/she no longer associates food with being one of the group.

Behavioral Interventions. A more direct approach to changing the behavior of children who have difficulty adhering to some aspects of their treatment regimen is through the use of behavioral interventions. Rather than looking at the underlying causes of the behavior (e.g., unconscious motivation) as is done in the more traditional approaches, the therapist who employs a behavioral approach is less inferential in postulating underlying causes to account for overt behavior (Ciminero, 1977). Behavioral change entails either the alteration of a (noncompliant) response to a specific stimulus and/or a change in the environment that elicits inappropriate (noncompliant) behaviors. The behavioral approach looks for functional relationships between behavior and specific environmental factors.

Behavioral interventions can be effective when a particular behavior may be threatening to the child and must be brought under control quickly and efficiently. For example, a child who refuses to follow dietary recommendations and is experiencing recurrent episodes of ketoacidosis might benefit from an immediate, direct approach to behavioral change. One approach used to help obese patients identify

difficult times, places or people that stimulate their inappropriate eating behavior might also be effective with more mature children. The child keeps a log of everything he/she eats, when, where and with whom, as well as how he/she was feeling. The therapist can use the log to help the child identify problematic persons or situations that may be contributing to the noncompliant behavior. Changes in the child's environment (e.g., not eating with people who make inappropriate food offers) can then be arranged in an effort to foster compliant behavior.

For the most part, standard procedures such as the one described above can be applied. However, each case is unique and therefore usually require innovative interventions or a combination of interventions (Roberts, Maddux, Wurtele, & Wright, 1982). For example, Schafer et al. (1982) conducted a study that employed self-monitoring, goal setting and behavioral contracting techniques to increase the adherence of adolescents with insulin-dependent diabetes. The findings of this study suggest that behavioral interventions may be effective for increasing compliance behaviors. Mahoney (1974) contends that the operant conditioning paradigm is increasingly being used for self-management, as opposed to various types of external behavioral controls. These self-management approaches include self-monitoring of target behaviors (recording of time, place, situation, etc.), environmental planning (control of stimulus conditions which might affect the behavior, such as putting up posters with messages of encouragement) and behavioral programming (contingency contracts, token economies, self-rewards and self-punishments) strategies.

The dietary noncompliance example cited above could also include

contingency contracts negotiated between the child and the therapist to get the child to record the behavior and to increase compliance with dietary recommendations. The child leaves an object of some personal value to him/her with the therapist. The contract is negotiated whereby at the end of a designated period of time the object is returned if the child recorded his/her behavior for a predetermined amount of time (e.g., 5 out of 7 days). Another contract that focuses more specifically on the eating behavior is negotiated between the parent and the child with the help of the therapist. Thus, for example if the child does not deviate from the prescribed diet for a predetermined period of time, he/she will receive a reward (e.g., object, activity, etc.).

Shafer et al. (1983) used self-monitoring as a baseline measure for one week and replaced it with goal setting when there was no consistent improvement in compliance. Goals could be set based on the results of the baseline measure. Schafer et al. (1982) also included behavioral contracting with subjects who had not achieved a 90% rate of compliance by the end of a goal setting phase. Contracts were negotiated between the child and the parents with suggestions from the therapist. Reinforcers such as activities, objects and foods were administered by the parent. One of the advantages of this approach over the direct observation method, where the child's behavior is monitored by some independent observer, is that self-monitoring can be continued while the treatment program is in operation and as such provides an ongoing evaluation of the effects of treatment (Ciminero, 1977).

Self-Control. Compliance behaviors can be construed as a form of self-control. Thoresen and Mahoney (1974) contend that the traditional

"willpower" conception of the term is inadequate, in that it dictomizes it as either something a person has (willpower) or does not have. More recent research has suggested that a person's ability to control his/her own actions is a function of knowledge and control of current situational factors. One is said to have self-control if some behavior is given up (e.g., smoking, overeating) or performed in the face in alternative distractions (e.g., writing a dissertation rather than going out with friends). Thoresen and Mahoney (1974) suggest that there are several possible reasons for the high value placed on a person's ability to control his/her own behavior. One reason is that many self-control patterns possess survival value of one kind or another. For example, a diabetic person's ability to control his/her diet can have a considerable influence on his/her health. The behavioral viewpoint on self-control states that in order for a person to exercise self-control he/she must understand what factors influence his/her behavior and how he/she can alter those factors to bring about a desired change (Thoresen & Mahoney, 1974). The act of manipulating environmental variables in order to change behavior requires self-control. The behavioral approach to self-control emphasizes the relationship between behavior and environment.

There are three important features of classical self-control phenomena that have implications for psychological interventions with diabetic children. The first feature is that the child always has two or more alternative behaviors (Thoresen & Mahoney, 1974). For example, he/she can take the prescribed number of insulin injections on a regular schedule, or he/she can take the prescribed number of injections at any convenient time, or he/she can take only less than the prescribed number

of injections on a regular schedule. The option not to take any insulin injections at all does exist, but the consequences would be immediate and severe. Thus, it is unlikely that a child would consistently choose this option. It is important to note that the above example concerns only two compliance behaviors as described on the Diabetes Behavior Checklist: injecting on a regular schedule and taking the prescribed number of injections. Thus, it is apparent that the child who complies with his/her entire regimen is doing so in the face of numerous alternative choices because the regimen involves multiple behaviors.

The second important feature of classical self-control phenomena is that the consequences of each of the behaviors are usually conflicting (Thoresen & Mahoney, 1974). For the child with diabetes, this is only true to a certain extent because the regimen is composed of numerous behaviors that affect blood glucose level. Blood glucose level provides an indication of the extent to which the child is complying with various aspects of the treatment regimen. For example, if a child with insulin-dependent diabetes takes the insulin but forgets to eat, the blood glucose level will fall below normal and the child will have an insulin reaction. On the other hand, if the child eats, but forgets to take insulin, the blood glucose level will be above normal. However, it is not simply a matter of eating or not eating or taking the insulin or not taking it that determines whether or not the person with diabetes has an adverse reaction. Other behavioral choices also affect blood glucose level. A child with diabetes will also have an insulin reaction if the timing of food intake does not coincide with the time the insulin is peaking. Thus, timing of food intake is another behavioral alternative that has an effect on blood glucose level. Clinically, this implies

that any intervention with a child with diabetes should include an analysis of all the behaviors that comprise the child's treatment regimen and not just one or two that appear to be most problematic.

The final important feature is that the self-regulatory patterns are usually prompted and/or maintained by external factors such as long-term consequences (Thoresen & Mahoney, 1974). In theory this is true for children with diabetes in that one of the goals of the diabetes treatment regimen is to prevent complications at some point in the future. However, in practice, the threat of future complications does not seem to be a motivating factor for children and adolescents. There is some evidence to suggest that adolescents do not believe that the diabetes could affect their future or cause complications (Khurana & White, 1970, Greydanus & Hofmann, 1979). Bobrow et al. (1985) found that adolescent girls who had difficulty adhering to their treatment regimens did not believe that adherence would delay or prevent complications.

Other external factors besides long-term consequences also affect behavior. Thoresen and Mahoney (1974) contend that a person's attempt to regulate his/her behavior is influenced by things as family and friends, doctor's orders, changes in health status, etc. Thus, for the child with diabetes, the parents' attitude toward the diabetes may play a role in what the child believes and how he/she feels about the disease. For example, the findings of this study indicated that there is a relationship between parents' and children's attitudes concerning the management of the diabetes.

The child's current health status could also be an important factor. A child who suddenly begins to experience vision problems may be more likely to think of long-term consequences, than the child who has not experienced any complications. Thus, clinicians who intervene with diabetic children should attempt to understand what the child believes about the consequences of noncompliance. Misunderstanding could be a function of misinformation or an incapacity to cognitively understand the information. However, in adolescents, it is also possible that misunderstanding is in actuality denial. Khurana and White (1970) reported that adolescents who do not believe that their diabetes can have affect their future health are denying the seriousness of their illness. The distinction between misunderstanding and denial has important implications for how the clinician would intervene. An accurate perception of the consequences of noncompliance may foster more appropriate self-regulated (i.e., compliant) behavior. Self-control theory has implications for interventions with children with insulin-dependent diabetes, despite the fact that the regimen goes beyond what Thoresen and Mahoney (1974) say constitutes self-control.

Theoretical Implications

The findings of this study have implications for several theories related to health behavior change and prevention.

A Systems Model of Health Behavior Change. Several findings of this study have implications for a systems model of health behavior change developed by Kersell & Milsum (1985). First, the model is based on the assumption that health behaviors are influenced by multiple factors rather than caused by a single factor. The findings of this

study support this assumption in that multiple factors were found to be predictors for compliance behaviors. Second, the model was designed to apply to specific health-related behaviors. The results of this study support the idea that compliance is not a unitary concept, but is comprised of multiple behaviors. The systems model could be used to assess the influence of multiple factors on individual compliance behaviors.

The model below describes how health behaviors are developed, changed and maintained. Four levels or categories are represented within the model. The first level is the external antecedent variables, which includes parental and hereditary processes and socio-cultural environmental milieu. The next level is the personal antecedent variables. It contains three sets of processes: personal demographic dynamics, personal socialization process and personal health dynamics. The socio-psychological variables make up the third level and include four processes: perception of self, perception of social influences, perception of health status and perception of environmental factors. The final level is the behavioral variable, which is comprised mainly of intention formation. Each of the processes serve as inputs for processes at the next level.

The model does not end at behavior change. Behavior change mediates the behavioral repertoire, directly influences personal health dynamics and can have an affect on the socio-cultural/environmental milieu. As such, behavior change can modify the entire behavior change process (Kersell & Milsum, 1985). The authors believe that this rich feedback system and incorporation of social, environmental, psychological and

physiological factors to describe the health behavior change process make their model an improvement over most other models. As was stated earlier in this chapter, the impact of psychosocial variables on compliance behaviors is not unidirectional. As such, this model is particularly useful for describing how psychosocial variables, such as the family are affected by and have an affect on a child's ability to comply with treatment recommendations.

The model is intended to be descriptive rather than predictive. However, hereditary and environmental processes are viewed as less influential than intention formation. Intention formation is a theory developed by Fishbein and Ajzen (1976). A basic assumption of the theory is that behavior is under the voluntary control of the individual. A single behavior is determined by the individual's intention to perform the behavior. The behavioral intention is influenced by an individual's attitude toward performance of the behavior and the perception of the degree to which significant others think such performance is important. The attitude component entails the belief that performing a specific behavior will lead to a certain consequence and the individual's evaluation of that consequence. The influence of a significant other also includes the individual's motivation to comply with that person's expectations.

The theory takes into account the individual's attitude toward the behavior and the influence of the social environment on the behavior (Shenkel et al., 1985). The findings of this study suggest that factors related to the child's and the parent's perception of how the family functions (i.e., the social environment) and their attitudes toward

diabetes and the diabetes treatment regimen were more important predictors of compliance behaviors than other psychosocial factors or demographic variables. However, Kersell and Milsum (1985) contend that intention does not lead to behavior change unless the individual has the requisite skills. For example, a child who believes that deviating from dietary recommendations is harmful, value his/her health, believe that parents do not want him/her to eat inappropriate foods, and want to please parents, is likely to form an intention to adhere to dietary recommendations. However, if the child who does not have the skill to recognize and resist peer pressure to eat inappropriate foods, he/she may eat them, even though the intention was to not eat them. This suggests then is that it may be important to identify possible barriers to adherence. Schafer et al. (1983) developed the Barriers to Adherence and Problem Solving Scale to measure the extent to which environmental barriers interfere with compliance as well as a person's ability to solve the problems created by the barriers. The findings of their study suggested that there was a relationship between the barriers measure and the extent to which a child follows his/her diet and how careful he/she is at measuring insulin. The concept of barriers to adherence suggests that it is just as important to identify factors that interfere with compliance as it is to identify those that predict compliance. Most programs designed to foster compliance focus on enhancing knowledge and understanding of the disease. Knowledge alone has not been proven to be a sufficient predictor of compliance (Johnson, 1984). A more effective approach may be to combine education with methods of enhancing adherence and learning problem solving skills to deal with the many barriers the child will encounter.

Prevention. The systems model of health behavior change was designed for use as a guide for developing health education programs. It can also be used for primary, secondary and tertiary prevention. As pointed out in chapter two, a person with diabetes will need to engage in primary preventive behaviors to delay or prevent complications, secondary preventive behaviors to maintain metabolic control, and tertiary preventive behaviors to recover from episodes of ketoacidosis or hypoglycemia.

The findings of this study indicated that there are psychosocial factors that enhance compliance behaviors. This has implications for both primary and secondary prevention programs. Although most primary prevention programs are educationally-oriented, knowledge has not been demonstrated to be an important predictor of noncompliance. Psychoosocial factors, particularly the family environment have been implicated as influential in predicting behavior. As such, primary prevention programs could be developed for newly diagnosed children and their families that focus on both educating the child and the family about the disease and teaching them problem solving skills to cope with problematic situations (i.e., meal schedules) that might interfere with compliance behaviors.

Although demographic characteristics are generally unrelated to compliance behavior, there is some evidence (Drash, 1981) that suggests that adolescence is a time when children have the most difficulty adhering to treatment recommendations. It is a time when the child is least motivated to engage in behaviors that set him/her apart from peers. The findings of this study indicated that feeling stigmatized by

the diabetes predicted both compliant and noncompliant behavior. Secondary prevention could take the form of a group approach, that emphasizes self-help as a means of improving one's health. Peer influence could be effective with this age group both as a means of enhancing compliance and providing social support.

Orr et al. (1983) reported positive results with tertiary prevention interventions designed for adolescents with poorly controlled diabetes. The intervention was based on an assessment of the etiology of the problem and the individual needs of the child and the family and included either individual, family or group treatment. The findings of the Orr et al. (1983) study indicated an improvement in psychosocial functioning (e.g., better socialization, less withdrawal and isolation, satisfactory school attendance, and better family functioning). Despite improvements in psychosocial functioning, hemoglobin levels remained elevated, although not to the extent that required hospitalization.

The findings of the present investigation have indicated that there is no relationship between psychosocial factors and metabolic control. However, Orr et al. (1983) based their intervention on the assumption that improvement in psychosocial functioning would result in improved metabolic control. At this time there is no conclusive evidence as to what factors impact upon metabolic control, although it is clear that some kind of tertiary intervention is needed for children in poor metabolic control. The findings of this study also support a growing body of evidence that suggests that there is no relationship between compliance and control. As such, it is conceivable that a the child could be complying with treatment recommendations, but still be in poor

control. Poor control may be a function of an ineffective treatment regimen or stress. An ineffective treatment regimen calls for medical, rather than psychological interventions. On the other hand, emotional upset may lead to an increase in stress hormones which can result in an increase in glucose, thus placing the child in poor metabolic control (Tarnow & Silverman, 1981-1982). Stress could be caused by any number of problems (e.g., the stress of a daily, multifaceted treatment regimen, family conflict, etc.) that might best be addressed through behavioral interventions designed to regulate the physiological stress response.

The findings of this study suggest that compliance behaviors are not positively interrelated. Different psychosocial factors predicted different compliance behaviors. No one theory that was reviewed here can account for this pattern of results. This suggests that the study should be replicated with a different measure of compliance as a means of testing the various theoretical positions.

Methodological Implications.

The overall purpose of this study was to examine the impact of several psychosocial variables on ten behaviors related to the diabetes treatment regimen. Most investigators measure compliance as a unitary construct. However, it is clear that the diabetes treatment regimen is a multifaceted program that involves numerous behaviors associated with at least four categories: injection, glucose/urinary testing, diet management and exercise. An instrument was designed for the purpose of this study to measure compliance as discrete behaviors. The use of such an instrument raised several methodological issues.

The findings of this study support the contention that compliance is not a unitary construct, but is comprised of several, independent behaviors. Thus, individuals may adhere to some aspects of their regimen, but may not adhere to other aspects. Also, psychosocial factors that predicted some adherence behaviors are different from factors that predicted other adherence behaviors. Therefore, one methodological implication is that future research should focus on behavioral rather than personality variables. Methodologically and clinically, it would be more beneficial to identify factors that affect individual compliance behaviors. In this way behavioral interventions could be developed and implemented to assist individuals increase compliance behaviors that are particularly problematic.

Other methodological issues are related to the way in which the the Diabetes Behavior Checklist was designed. In an effort to overcome the pitfalls of using self-report measures the Diabetes Behavior Checklist asked subjects to choose between pairs of items that represented ten compliance behaviors. Each of the ten behaviors was paired with every other one, yielding 45 pairs, each constituting an item. An additional four items were repeated in reverse order to provide a measure of consistency. However, there was no significant relationship between the reversed items and the original items. One obvious problem with this instrument was that it had the potential to be very tedious, particularly for children.

While the Diabetes Behavior Checklist attempted to correct for response set, it was unable to tap the frequency of which all the behaviors were performed. As such, the findings of this study cannot

make inferences about possible problematic behaviors.

Another problem with the Diabetes Behavior Checklist was that it provided only a single measure for each of the behaviors. Repeated measures obtained over a period of time might provide a more accurate assessment of the child's level of compliance. It might have been better to obtain repeated measures of both compliance behaviors and measures of metabolic control. However, this could require a carefully controlled study in order to rule out the effects of history and maturation.

The findings of this study lend support to the theoretical model of health behavior change developed by Kersell and Milsum (1985), which is based on the assumption that health behaviors are influenced by multiple factors rather than caused by a single factor. The results indicated that multiple factors can be identified to predict compliance behaviors. This finding has implications for statistical analysis. Most investigators correlate single measures of compliance with single measures of various psychosocial factors. This is clearly an inadequate method for assessing the impact that psychosocial variables have on compliance. The current body of knowledge about compliance with diabetes treatment regimen has reached a point where the questions being posed can only be answered through multivariate statistical procedures.

Limitations of the Study.

There are several limitations to the present study that should be recognized. First, caution should be exercised in generalizing from the results given the relatively small sample size and the homogeneity of

the sample. The selection of subjects from upper middle class backgrounds may have had an effect on the outcomes of the study. There is some evidence (Antonovsky, 1979) that suggests that membership in a high socioeconomic class provides an individual with financial and educational resources that can help him/her and the family cope with the stresses of disease. The same financial and educational resources may not be available to individuals of lower socioeconomic groups. Additionally, the results of the statistical analyses may be unreliable due to the small sample size and the large number of variables. This may also account for some of the counterintuitive findings.

Because the study was designed to assess the impact of several psychosocial factors on compliance and control, subjects were asked to complete a number of inventories. The length of time it took to complete these inventories could have created a fatigue effect. The Diabetes Behavior Checklist appeared to be a particularly tedious instrument to complete. A problem that is inherent to survey research of this sort was a lack of control for the mental set of the subjects and for the environmental conditions under which they completed the inventories.

It was anticipated that because of the way in which compliance was measured, the findings of this study might not easily be compared to the reports of other compliance studies. Also, some of the regression analyses for compliance accounted for only a small percentage of the variance on the dependent variable. For example, the psychosocial and demographic variables accounted for only 24% of the variance on eating on a regular schedule and only 30% of the variance on performing all

blood/urine testing. This suggests that this study did not measure all the factors that bear on these ten compliance behaviors. As such, it would not suffice to predict these compliance behaviors on the basis of only the measures used in this study. However, it may be unreasonable to expect that one study could include all factors that have an influence on compliance.

Some of the instruments used in this study, particularly, the Diabetes Opinion Survey (DOS), the Parents Diabetes Opinion Survey (PDOS) (Johnson, 1985) and the Diabetes Behavior Checklist raised some concerns about internal validity. Internal validity data were not reported for the DOS, although the content of the scale appeared to be appropriate for this study. Johnson (1985) reported that norms established for the PDOS were based on data obtained from both mothers and fathers. The fathers data was used by Johnson as the criterion measure for the mothers' data. Content validity was established for the Diabetes Behavior Checklist. The construction of each of the ten scales was based on recommendations provided by the American Diabetes Association (1982). However, the present investigation measured compliance differently from that reported in other research studies, and as such, no criterion measure was available for comparison.

The findings of this study indicated that there is no relationship between compliance and control. However, a multiple regression analysis indicated that the only predictor of control was injecting on a regular schedule. This predictor accounted for only 18% of the variance. There is some evidence (Tarnow & Silverman, 1981-1982) that implicates stress as a factor in metabolic control. The burden of a daily, multifaceted

treatment regimen alone can be a stressor. Also, adolescence is a particularly difficult developmental stage with puberty adding new stresses to the adolescent's life. Parents expect that their adolescent will become more self-reliant and assume more responsibility for their treatment regimen possibly before he/she is ready to do so. This suggests that a stress measure should be included in the analyses in order to assess the role stress plays in metabolic control.

Directions for Future Research.

There are several directions future research can take. Because of the limitations of a small sample, this study should be repeated with a larger sample size and a more heterogeneous group to estimate external validity. It would also be useful to replicate the study to see if the same results are obtained.

Although the results of this study and others have suggested that the family environment is influential in predicting compliance, other social contexts (e.g., the school, peer interactions) should be examined to determine what affect they may have on compliance behaviors. This raises the question, what is the best way to measure compliance? Different measures have yielded different results. Future research may include two or more measures of compliance to see if the various measures correlate and if they yield different results.

The findings of this study have implications for a systems model of health behavior change (Kersell & Milsum, 1985). The validity of this model should be tested empirically, particularly as it may pertain to compliance behaviors.

The findings of this study that multiple factors have impact upon compliance behaviors suggest the need for a path analytic study. While most investigators have attempted to assess either how the family impacts upon the child or how the presence of a diabetic child impacts upon the family, the answers to these questions should not be sought separately. A path analytic study with a large sample size would allow an investigator to examine the reciprocal relationship among a number of psychosocial variables and their relationship to compliance behaviors.

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APPENDIX A

LOYOLA UNIVERSITY OF CHICAGO



SCHOOL OF EDUCATION

Water Tower Campus • 820 North Michigan Avenue, Chicago, Illinois 60611 • (312) 670-3030

Dear Parent,

My name is Denise Verones. I am a doctoral student in the Counseling Psychology program at Loyola University of Chicago. I am doing a dissertation on factors that affect compliance with diabetes treatment regimens. I have been interested in this topic for some time. Part of the reason for my interest in this topic is that my father has diabetes.

Because you have a child with insulin-dependent diabetes, you are well aware of the seriousness of this illness and how difficult it is to maintain good control. Proper control of the disease usually requires adjusting one's daily habits, which can cause a certain amount of emotional strain. Maintaining good control is especially difficult for children. Therefore, it is important to have a better understanding of factors that affect whether or not a child will comply with the diabetes regimen. A better knowledge of these factors will help health care providers to assist parents who have children who do not comply as well as they might.

Research is one of the ways in which we can learn about how to increase a child's level of compliance with treatment recommendations. I am interested in studying the impact that psychological, social, and environmental factors have on a child's degree of compliance. I am asking for your help in my study.

This project will involve having your child complete five test instruments that will require approximately 1½ hours of his/her time. You will be asked to complete four test instruments that will take approximately one hour. All of your responses will be kept in strictest confidence and the information obtained will be coded so as to ensure that your and your child's identities are completely concealed. You may leave questions unanswered if you choose to and you may withdraw from this study at any time.

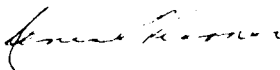
After you have completed the test instruments, please return them in the enclosed stamped self-addressed envelopes. If you have any questions about the research project or the test instruments, please call me or my chairman, Dr. Kevin Hartigan at 670-3274.

At the end of the project I will prepare a statement of the results and send them to each parent and child who participates. I will also provide individual feedback to those parents and children who wish it.

I am grateful to Drs. Howard and Edward Traisman for their support and interest in this project.

I appreciate your spending the time on this project.

Sincerely,



Denise Verones, M.A.
Doctoral Candidate
Counseling Psychology Program



Kevin J. Hartigan, Ph.D.
Assistant Professor
Department of Counseling Psychology
& Higher Education
Dissertation Committee Chairman

Code # _____

CONSENT TO PARTICIPATE IN A RESEARCH PROJECT AND PARENTAL CONSENT
FOR A MINOR TO PARTICIPATE IN A RESEARCH PROJECT

IN ORDER FOR YOU AND YOUR CHILD TO PARTICIPATE IN THIS RESEARCH PROJECT,
IT IS NECESSARY THAT YOU SIGN YOUR NAME UNDER THE RESEARCH CONSENT STATEMENT.
PLEASE SIGN YOUR NAME IN THE APPROPRIATE SPACE ONLY IF YOU AND YOUR CHILD
WISH TO PARTICIPATE IN THIS RESEARCH PROJECT AND AGREE WITH THE STATEMENT
BELOW. THANK YOU.

The purpose of this research project has been explained to me and I
understand what the project is about. I agree to participate in the project
and understand that I have the right to withhold information or to withdraw
from the project at any time. Also, I freely and voluntarily consent to the
participation of my minor child _____.

(Child's name)

I understand that the data collected by Ms. Denise Verones may be used
in research reports, but that I and my child will not be identified by name.
Included in my consent to participate in this research project is my permission
for Drs. Howard and Edward Traisman to provide Ms. Verones with the results of
my child's most recent Hemoglobin A₁C test. Finally, I understand that I will
not be required to perform any tasks other than those which have been explained
to me as pertinent to this research project.

Signature _____

Name (Please Print) _____

Date _____

Code # _____

CONSENT TO PARTICIPATE IN A DIABETES RESEARCH PROJECT

I, _____, state that I am not over eighteen (18) years of age and that I agree to participate in a research project being conducted by Denise Verones.

I understand that the primary purpose of the project is to learn more about things that children do that affect their diabetes treatment program.

The project involves completing five test instruments.

I understand that all information I provide will be kept private, and that Ms. Verones will be the only person who will see my information. I also understand that I will be given a code number to conceal my identity. A code list which matches names and code numbers will be kept in a locked file which is available only to Ms. Verones.

I understand that I am free to withdraw my consent and to discontinue my participation in the study at any time without any negative consequences to me or to my parents by Ms. Verones.

I have had the study described to me to my satisfaction and I have had the opportunity to ask questions.

THE PROJECT HAS BEEN FULLY EXPLAINED TO ME AND I HAVE CAREFULLY READ AND UNDERSTAND THE AGREEMENT, THEREFORE I FREELY AND VOLUNTARILY AGREE TO PARTICIPATE IN THE STUDY.

Name (please print) _____

Signature _____

Parent (or Guardian) Signature _____

Date _____

Code # _____

DEMOGRAPHIC QUESTIONNAIRE

Please answer each question by either circling the appropriate response or writing the information in the space provided.

All information will be strictly confidential.

- 1) What is your relationship to your child?
 - a) mother
 - b) grandmother
 - c) stepmother
 - d) legal guardian
 - e) other - please specify _____

- 2) What is your child's age? _____

- 3) What is your child sex? _____

- 4) What is your race?
 - a) White
 - b) Black
 - c) Hispanic
 - d) American Indian
 - e) Asian
 - f) Other

- 5) What is your current marital status?
 - a) married to my child's father
 - b) married to someone other than my child's father
 - c) separated
 - d) divorced
 - e) single

- 6) How many people currently live in your household? _____

- 7) How many siblings does your child have?
_____ brothers
_____ sisters

(OVER)

- 8) What is your child's birth order in the family? _____
- 9) How many children currently live at home? _____
- 10) At what age was your child diagnosed as having insulin-dependent diabetes? _____
- 11) Does anyone else in your family have diabetes?
a) Yes If so, please specify _____
b) No
- 12) Does your child give his/her own insulin injections?
a) Yes
b) No
c) Sometimes
- 13) What is your current annual income level (include spouse if married)
a) under \$5,000
b) \$5,000 to \$9,999
c) \$10,000 to \$14,999
d) \$15,000 to \$19,999
e) \$20,000 to \$24,999
f) \$25,000 to \$29,999
g) \$30,000 to \$34,999
h) \$35,000 to \$39,999
i) \$40,000 to \$44,999
j) \$45,000 to \$49,999
k) \$50,000 to \$54,999
l) \$55,000 to \$59,999
m) \$60,000 or over

Code # _____

PARENT'S DIABETES OPINION SURVEY

Directions: We are interested in how you feel about your child's diabetes and the medical treatment you receive for it.

Read each statement carefully. Then indicate how much you agree or disagree with each item by putting a circle around:

the number 1 if you STRONGLY AGREE
 the number 2 if you MILDLY AGREE
 the number 3 if you are NEUTRAL
 the number 4 if you MILDLY DISAGREE
 the number 5 if you STRONGLY DISAGREE

	STRONGLY AGREE	MILDLY AGREE	NEUTRAL	MILDLY DISAGREE	STRONGLY DISAGREE
1. A child with diabetes should see a doctor at least once a month.	1	2	3	4	5
2. My child sometimes gets angry.	1	2	3	4	5
3. If God plans for you to get better, you will.	1	2	3	4	5
4. I know there are times when my child tries to use diabetes to get his/her way.	1	2	3	4	5
5. I always know when my child is about to have an insulin reaction by the way he/she looks and acts.	1	2	3	4	5
6. It's up to the doctors to find out how to control my child's illness.	1	2	3	4	5
7. My child almost never argues.	1	2	3	4	5
8. Children with diabetes must go to bed early in order to stay healthy.	1	2	3	4	5
9. Some of our relatives don't agree with how we handle our child's diabetes.	1	2	3	4	5

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page 2

	STRONGLY AGREE	MILDLY AGREE	NEUTRAL	MILDLY DISAGREE	STRONGLY DISAGREE
10. My child would never take advantage of others.	1	2	3	4	5
11. Our child's diabetes puts real limits on how we budget our family's time and money	1	2	3	4	5
12. My child sometimes tells me one thing and tells the doctors something quite different.	1	2	3	4	5
13. My child's doctors and nurses really know what it's like for a child to live with diabetes.	1	2	3	4	5
14. Doctors are so busy they never have enough time for their patients.	1	2	3	4	5
15. If I have enough faith God will take away my child's diabetes.	1	2	3	4	5
16. I can tell when my child is beginning to have an insulin reaction.	1	2	3	4	5
17. Hospital nurses are usually there when patients need them.	1	2	3	4	5
18. My child sometimes disobeys his parents.	1	2	3	4	5
19. I usually can tell how my child feels inside.	1	2	3	4	5
20. When people learn you have a child with diabetes they feel sorry for you.	1	2	3	4	5
21. We have had trouble deciding on babysitting services because of our child's diabetes.	1	2	3	4	5
22. Either my parents or my spouse's parents are always trying to tell us what to do about our child's diabetes.	1	2	3	4	5

GO ON TO THE NEXT PAGE

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	STRONGLY AGREE	MILDLY AGREE	NEUTRAL	MILDLY DISAGREE	STRONGLY DISAGREE
23. My child's brothers and sisters are jealous of the extra attention that he/she gets.	1	2	3	4	5
24. When my child complains of feeling ill, I sometimes wonder if he/she is really as sick as he/she says.	1	2	3	4	5
25. My child sometimes eats too many sweets.	1	2	3	4	5
26. People who know my child has diabetes, treat us differently.	1	2	3	4	5
27. The diabetes clinic doctors and nurses really help only a few of their patients.	1	2	3	4	5
28. Sometimes my child tries to convince us hard work is bad for people who have diabetes.	1	2	3	4	5
29. The diabetes will be cured if my child has enough faith.	1	2	3	4	5
30. I can usually tell before testing whether my child's sugar is going to come out high or low.	1	2	3	4	5
31. A person with diabetes must never eat sweets.	1	2	3	4	5
32. Sometimes my child's room is messy.	1	2	3	4	5
33. Having a child with diabetes puts a lot of extra stress on a parent.	1	2	3	4	5
34. Most people think that kids with diabetes are handicapped.	1	2	3	4	5
35. Our child's diabetes limits what the family can do with our time and money.	1	2	3	4	5
36. My spouse and I sometimes argue about our child's future.	1	2	3	4	5

OVER

page 4

	STRONGLY AGREE	MILDLY AGREE	NEUTRAL	MILDLY DISAGREE	STRONGLY DISAGREE
37. My child always does his/her homework on time.	1	2	3	4	5
38. I watch everything my child eats.	1	2	3	4	5
39. I can tell the difference between a low blood sugar reaction and high sugar or acidosis in my child.	1	2	3	4	5
40. My child gets fewer invitations to go places because people think that he/she is going to get sick.	1	2	3	4	5
41. Doctors and nurses really understand what it is like to live with diabetes.	1	2	3	4	5
42. Diabetes is God's test of my personal strength and faith.	1	2	3	4	5
43. Sometimes my child lies to avoid embarrassment or punishment.	1	2	3	4	5
44. I always double-check my child's urine or blood tests.	1	2	3	4	5
45. Parents should tell their children with diabetes exactly what they can eat.	1	2	3	4	5
46. Buying special foods for diabetes puts a strain on the family's finances.	1	2	3	4	5
47. There are certain foods that a person with diabetes should never be allowed to eat.	1	2	3	4	5
48. Most employers don't like to hire people with diabetes.	1	2	3	4	5
49. To take good care of diabetes a child <u>must</u> test 4 times daily.	1	2	3	4	5
50. At times I am unsure if my child's physical complaints are real or exaggerated.	1	2	3	4	5

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	STRONGLY AGREE	MILDLY AGREE	NEUTRAL	MILDLY DISAGREE	STRONGLY DISAGREE
51. There is seldom a need to correct or criticize my child.	1	2	3	4	5
52. My spouse and I argue about how to make decisions about our child's diabetes.	1	2	3	4	5
53. A parent can't be too careful when a child has diabetes.	1	2	3	4	5
54. God can take away my child's diabetes.	1	2	3	4	5
55. Most people wouldn't marry someone who has diabetes.	1	2	3	4	5
56. My child often says he/she is ill to get out of doing chores.	1	2	3	4	5
57. Doctors really understand what it is like to have a child with diabetes.	1	2	3	4	5
58. A child with diabetes must never eat candy or drink Coke.	1	2	3	4	5
59. After my child grows up most people will tell him/her not to have children.	1	2	3	4	5
60. The doctors should tell me exactly what foods my child with diabetes can have.	1	2	3	4	5
61. Sometimes my child says he/she is too sick to go to school, but I'm not sure that I should let him/her stay home.	1	2	3	4	5
62. Sometimes my child will put off doing a chore.	1	2	3	4	5
63. I suspect that my child eats candy, cake, or Cokes without telling me.	1	2	3	4	5
64. Sometimes I know my child uses his/her illness to get what he/she wants.	1	2	3	4	5

OVER

page 6

	STRONGLY AGREE	MILDLY AGREE	NEUTRAL	MILDLY DISAGREE	STRONGLY DISAGREE
65. My child's doctor has spent too little time teaching my child about diabetes.	1	2	3	4	5
66. I can tell whether my child's sugar is high or low just by the way he/she behaves.	1	2	3	4	5

Code # _____

DIABETES OPINION SURVEY

Directions: We are interested in how you feel about your diabetes and the medical treatment you get for it.

Read each statement carefully. Then indicate how much you truly agree or disagree by putting a circle around:

the number 1 if you STRONGLY AGREE
 the number 2 if you MILDLY AGREE
 the number 3 if you are NEUTRAL
 the number 4 if you MILDLY DISAGREE
 the number 5 if you STRONGLY DISAGREE

	STRONGLY AGREE	MILDLY AGREE	NEUTRAL	MILDLY DISAGREE	STRONGLY DISAGREE
1. I think my diabetes could be completely cured by the right medicine.	1	2	3	4	5
2. If God plans for you to get better, you will.	1	2	3	4	5
3. I like everyone I know.	1	2	3	4	5
4. All patients should learn the one right way to live with diabetes.	1	2	3	4	5
5. To get well again, the only things a patient needs are good food and a chance to rest.	1	2	3	4	5
6. A person with diabetes should see a doctor at least once a month.	1	2	3	4	5
7. Having diabetes makes other people feel sorry for me.	1	2	3	4	5
8. I am always kind.	1	2	3	4	5
9. I can only do a few chores around the house because working too hard can cause a reaction.	1	2	3	4	5
10. People should be nice to me, because I get sick when I get upset.	1	2	3	4	5

OVER

page 2

	STRONGLY AGREE	MILDLY AGREE	NEUTRAL	MILDLY DISAGREE	STRONGLY DISAGREE
11. I believe God can take away my diabetes.	1	2	3	4	5
12. I am always good.	1	2	3	4	5
13. I think my parents worry about me more than they do about anyone else in the family.	1	2	3	4	5
14. People really like you better when you are well.	1	2	3	4	5
15. My family has been forced to make a lot of changes because of my illness.	1	2	3	4	5
16. I am always nice to everyone.	1	2	3	4	5
17. My diabetes gives me no problems as long as I just eat right and keep calm.	1	2	3	4	5
18. I tell the truth every single time.	1	2	3	4	5
19. My family doesn't have enough money because of my diabetes.	1	2	3	4	5
20. If I have enough faith my diabetes will be cured.	1	2	3	4	5
21. A person with diabetes must never eat sweets.	1	2	3	4	5
22. When people ask me, "How are you?" they are really asking about my diabetes.	1	2	3	4	5
23. My diabetes is as tough on my family as it is on me.	1	2	3	4	5
24. I never get angry.	1	2	3	4	5
25. Most people think that kids with diabetes are handicapped.	1	2	3	4	5
26. To take good care of my diabetes, I must test four times every day.	1	2	3	4	5

GO ON TO THE NEXT PAGE

page 3

	STRONGLY AGREE	MILDLY AGREE	NEUTRAL	MILDLY DISAGREE	STRONGLY DISAGREE
27. Doctors should be the only ones to change my daily dose of insulin.	1	2	3	4	5
28. I never lie.	1	2	3	4	5
29. Parents should make their kids test their urine or blood each day.	1	2	3	4	5
30. Kids really make fun of you when they know you take a shot everyday and test your urine or blood.	1	2	3	4	5
31. When I keep my testing records my parents get after me about what's on them.	1	2	3	4	5
32. People are afraid to invite me anywhere because they think I will get sick.	1	2	3	4	5
33. My parents always bother me about my eating.	1	2	3	4	5
34. People are nicest to me when I'm sick.	1	2	3	4	5
35. My diabetes makes extra work for my mom because she has to worry about what I eat.	1	2	3	4	5
36. I never say things I shouldn't.	1	2	3	4	5
37. Parents should tell their children with diabetes exactly what they can eat.	1	2	3	4	5
38. My parents don't think I know enough to take care of my diabetes, so they decide everything for me.	1	2	3	4	5
39. I suppose that in spite of anything I do, my diabetes will get worse and worse.	1	2	3	4	5
40. People feel sorry for me when they find out I have diabetes	1	2	3	4	5

OVER

page 4

	STRONGLY AGREE	MILDLY AGREE	NEUTRAL	MILDLY DISAGREE	STRONGLY DISAGREE
41. God can take away my diabetes.	1	2	3	4	5
42. Whenever I have high sugar, my parents get upset.	1	2	3	4	5
43. Kids with diabetes should not work too hard or they might get sick.	1	2	3	4	5

Code # _____

TEST OF DIABETES KNOWLEDGE

Directions: We are interested in how much you know about diabetes and how you take care of it.

Read each question carefully and decide which choice best completes the statement or answers the question. Circle the letter of your choice.

Note: Some of the following questions give both urine and blood sugar test results. Use either the urine or chemstrip results, or both, whichever you are familiar with.

1. When giving insulin injections you should:

- a) inject into the same area
- b) inject into a different area every time
- c) inject only in the leg
- d) I don't know

2. A person with diabetes should eat:

- a) only when hungry
- b) only lunch and dinner
- c) regular meals
- d) I don't know

3. Routine urine tests or blood tests for sugar should be done:

- a) just before meals
- b) one hour after meals
- c) anytime during the day
- d) I don't know

4. Diabetes is:

- a) curable
- b) goes away with age
- c) controllable
- d) I don't know

Test of Diabetes Knowledge
Page 2

5. It is important for the person with diabetes to take insulin:
- a) about the same time every day
 - b) whenever he remembers to
 - c) before every meal
 - d) I don't know
6. When a person with diabetes begins to have a reaction he should immediately:
- a) take some insulin
 - b) lie down and rest
 - c) eat some form of sugar
 - d) I don't know
7. Insulin dosage is measured by:
- a) ounces
 - b) drops
 - c) units
 - d) I don't know
8. If you have a large amount of sugar in your urine and blood, the color of the results would be:
- | Clinitest | Chemstrip |
|-----------------|------------------------|
| a) purple..... | purple & orange |
| b) orange..... | dark green & dark blue |
| c) green..... | light tan & light blue |
| d) I don't know | |
9. When your urine test or chemstrip comes out high for sugar, you should:
- a) lie down and rest
 - b) test for ketones
 - c) eat something soon
 - d) I don't know
10. A person with diabetes should be able to exercise:
- a) only a little
 - b) as much as a person without diabetes
 - c) only if they take insulin before exercising
 - d) I don't know
11. Test for ketones (Acetest tablets) turn the following color when ketones are present:
- a) green
 - b) orange
 - c) purple
 - d) I don't know
12. Insulin is normally produced in the:
- a) kidneys
 - b) pancreas
 - c) liver
 - d) I don't know

Test of Diabetes Knowledge
Page 3

13. Diabetes is caused by:
- a) eating too much sugar and other sweet foods
 - b) not enough insulin in the body
 - c) sugar in the urine
 - d) I don't know
14. Exercise:
- a) lowers the blood sugar level
 - b) raises the blood sugar level
 - c) increases sugar in the urine
 - d) I don't know
15. Regular insulin is:
- a) cloudy
 - b) clear
 - c) bluish
 - d) I don't know
16. The action of Lente insulin is the same as:
- a) regular
 - b) quick acting
 - c) NPH
 - d) I don't know
17. When a person with diabetes has an insulin reaction the amount of sugar in his blood is:
- a) usually normal
 - b) usually high
 - c) usually low
 - d) I don't know
18. Insulin:
- a) lowers the blood sugar level
 - b) raises the blood sugar level
 - c) increases sugar in the urine
 - d) I don't know
19. Which of the following complications is usually not associated with diabetes:
- a) changes in the lungs
 - b) changes in the kidney
 - c) changes in vision
 - d) I don't know
20. In untreated diabetes the blood sugar is usually:
- a) normal (not too high but not too low)
 - b) decreased (too low)
 - c) increased (too high)
 - d) I don't know

Test of Diabetes Knowledge
Page 4

21. Which one of the following may cause an insulin reaction:
- a) infection
 - b) forgetting to take your insulin
 - c) playing hard or exercising a lot
 - d) I don't know
22. Regular insulin:
- a) works fast
 - b) works a long time
 - c) takes a long time to start working
 - d) I don't know
23. You use additional regular insulin when you:
- a) feel shaky, sweaty and hungry
 - b) are spilling large amounts of glucose and ketones in your urine
 - c) are about to play tennis
 - d) I don't know
24. When the urine contains ketones, it means:
- a) you took too much insulin
 - b) your body is using fat for energy
 - c) you played too hard
 - d) I don't know
25. In which parts of the body can diabetes complications appear:
- a) ears and skin
 - b) eyes and kidneys
 - c) stomach and lungs
 - d) I don't know
26. When a person with diabetes plays or exercises a lot, he needs:
- a) less insulin
 - b) more insulin
 - c) to eat less
 - d) I don't know
27. People with diabetes:
- a) may have complications later in life
 - b) will never have complications
 - c) only have complications if they don't take their insulin
 - d) I don't know
28. People with diabetes should:
- a) eat only dietetic foods
 - b) never eat any sweets
 - c) eat a well-balanced diet the whole family can eat
 - d) I don't know

Test of Diabetes Knowledge
Page 5

29. Which of the following symptoms might suggest to the person with diabetes that too little insulin is being taken:
- a) decrease in thirst
 - b) cold sweat, shaking
 - c) increase in urination
 - d) I don't know
30. Ketones in the urine of a person with diabetes is:
- a) a warning sign of an insulin reaction
 - b) a warning sign of acidosis
 - c) a warning sign of hypoglycemia
 - d) I don't know
31. An insulin reaction or insulin shock is caused by:
- a) too much insulin in the body
 - b) too little insulin in the body
 - c) too little exercise
 - d) I don't know
32. Lente and NPH insulins last for:
- a) 8 hours
 - b) 24 hours
 - c) 36 hours
 - d) I don't know
33. When a person with diabetes who routinely uses insulin becomes ill with an infection, he frequently requires:
- a) more insulin
 - b) less insulin
 - c) no insulin
 - d) I don't know
34. Which of the following things that can happen to you will most probably change in the amount of insulin that you need:
- a) you get the flu
 - b) you are just starting piano lessons
 - c) your report card was much worse than you thought it would be
 - d) I don't know
35. Sugar, starch and fruit are all:
- a) carbohydrates
 - b) proteins
 - c) fats
 - d) I don't know
36. The food groups that have carbohydrates in them are:
- a) fat, protein
 - b) fruit, starch, milk
 - c) free foods, fats, protein
 - d) I don't know

Test of Diabetes Knowledge
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37. A low blood sugar level is called:
- a) Glycosuria
 - b) Hyperglycemia
 - c) Hypoglycemia
 - d) I don't know
38. If you took regular insulin at 7:00 a.m., an insulin reaction is most likely to happen at around:
- a) 10:00 - 11:00 in the morning
 - b) 9:00 - 10:00 in the evening
 - c) 3:00 - 5:00 in the afternoon
 - d) I don't know
39. If you took NPH or Lente insulin at 7:00 a.m., an insulin reaction is most likely to happen at around:
- a) 12:00 noon
 - b) 3:00 - 5:00 in the afternoon
 - c) 9:00 - 10:00 in the evening
 - d) I don't know

Code # _____

DIABETES BEHAVIOR CHECKLIST

INSTRUCTIONS: ON THE FOLLOWING PAGES YOU WILL FIND PAIRS OF STATEMENTS ABOUT THINGS YOU MIGHT DO TO CONTROL YOUR DIABETES. MANY OF THE STATEMENTS WILL BE REPEATED.

READ EACH PAIR OF STATEMENTS CAREFULLY.

DECIDE WHICH STATEMENT BEST DESCRIBES WHAT YOU DO MORE OFTEN.

FOR EACH PAIR, CIRCLE YOUR CHOICE (A OR B).

- 1) a) I follow a regular schedule of times that I eat.
OR
b) I eat three meals a day and the number of snacks that my doctor recommended.
- 2) a) I follow a regular schedule of times that I do my urine and blood glucose tests.
OR
b) I record the results of all my urine and blood glucose tests every day.
- 3) a) I eat extra food or take less insulin on days that I exercise.
OR
b) I take my insulin injections at the same time every day.
- 4) a) I eat three meals a day and the number of snacks that my doctor recommended.
OR
b) I only eat the foods that are part of the meal plan prescribed by my doctor.
- 5) a) I only eat the foods that are part of the meal plan prescribed by my doctor.
OR
b) I exercise four or more times per week.
- 6) a) I take my insulin injections at the same time every day.
OR
b) I take the number of insulin injections my doctor recommended every day.
- 7) a) I do all the urine and blood glucose tests my doctor recommended every day.
OR
b) I record the results of all my urine and blood glucose tests every day.
- 8) a) I eat three meals a day and the number of snacks that my doctor recommended.
OR
b) I follow a regular schedule of times that I do my urine and blood glucose tests.
- 9) a) I only eat the foods that are part of the meal plan prescribed by my doctor.
OR
b) I follow a regular schedule of times that I eat.

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- 10) a) I exercise four or more times per week.
OR
b) I eat three meals a day and the number of snacks my doctor recommended.
- 11) a) I follow a regular schedule of times that I do my urine and blood glucose tests.
OR
b) I take the number of insulin injections my doctor recommended every day.
- 12) a) I exercise four or more times per week.
OR
b) I eat extra food or take less insulin on the days that I exercise.
- 13) a) I only eat the foods that are part of the meal plan prescribed by my doctor.
OR
b) I eat extra food or take less insulin on the days that I exercise.
- 14) a) I follow a regular schedule of times that I do my urine and blood glucose tests.
OR
b) I only eat the foods that are part of the meal plan prescribed by my doctor.
- 15) a) I exercise four or more times per week.
OR
b) I take my insulin injections at the same time every day.
- 16) a) I eat extra food or take less insulin on the days that I exercise.
OR
b) I take the number of insulin injections my doctor recommended every day.
- 17) a) I take the number of insulin injections my doctor recommended every day.
OR
b) I do all the urine and blood glucose tests my doctor recommended every day.
- 18) a) I follow a regular schedule of times that I eat.
OR
b) I exercise four or more times per week.
- 19) a) I eat three meals a day and the number of snacks my doctor recommended.
OR
b) I eat extra food or take less insulin on the days that I exercise.
- 20) a) I only eat the foods that are part of the meal plan prescribed by my doctor.
OR
b) I take my insulin injections at the same time every day.
- 21) a) I only eat the foods that are part of the meal plan prescribed by my doctor.
OR
b) I eat three meals a day and the number of snacks my doctor recommended.

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- 22) a) I follow a regular schedule of times that I eat.
OR
b) I follow a regular schedule of times that I do my urine and blood glucose tests.
- 23) a) I exercise four or more times per week.
OR
b) I take the number of insulin injections my doctor recommended every day.
- 24) a) I take my insulin injections at the same time every day.
OR
b) I do all the urine and blood glucose tests my doctor recommended every day.
- 25) a) I take the number of insulin injections my doctor recommended every day.
OR
b) I record the results of all my urine and blood glucose tests every day.
- 26) a) I take the number of insulin injections my doctor recommended every day.
OR
b) I follow a regular schedule of times that I do my urine and blood glucose tests.
- 27) a) I follow a regular schedule of times that I eat.
OR
b) I eat extra food or take less insulin on the days that I exercise.
- 28) a) I exercise four or more times per week.
OR
b) I do all the urine and blood glucose tests my doctor recommended every day.
- 29) a) I eat three meals a day and the number of snacks my doctor recommended.
OR
b) I take the number of insulin injections my doctor recommended every day.
- 30) a) I follow a regular schedule of times that I eat.
OR
b) I take the number of insulin injections my doctor recommended every day.
- 31) a) I eat extra food or take less insulin on the days that I exercise.
OR
b) I exercise four or more times per week.
- 32) a) I follow a regular schedule of times that I do my urine and blood glucose tests.
OR
b) I eat extra food or take less insulin on the days that I exercise.
- 33) a) I only eat the foods that are part of the meal plan prescribed by my doctor.
OR
b) I take the number of insulin injections my doctor recommended every day.

OVER

- 34) a) I take my insulin injections at the same time every day.
OR
b) I record the results of all my urine and blood glucose tests every day.
- 35) a) I eat three meals a day and the number of snacks that my doctor recommended.
OR
b) I record the results of all my urine and blood glucose tests every day.
- 36) a) I eat extra food or take less insulin on the days that I exercise.
OR
b) I record the results of all my urine and blood glucose tests every day.
- 37) a) I follow a regular schedule of times that I eat.
OR
b) I do all the urine and blood glucose tests my doctor recommended every day.
- 38) a) I take my insulin injections at the same time every day.
OR
b) I follow a regular schedule of times that I do my urine and blood glucose tests.
- 39) a) I only eat the foods that are part of the meal plan prescribed by my doctor.
OR
b) I record the results of all my urine and blood glucose tests every day.
- 40) a) I follow a regular schedule of times that I eat.
OR
b) I record the results of all my urine and blood glucose tests every day.
- 41) a) I eat three meals a day and the number of snacks my doctor recommended.
OR
b) I take my insulin injections at the same time every day.
- 42) a) I follow a regular schedule of times that I do my urine and blood glucose tests.
OR
b) I do all the urine and blood glucose tests my doctor recommended every day.
- 43) a) I take the number of insulin injections my doctor recommended every day.
OR
b) I take my insulin injections at the same time every day.
- 44) a) I eat three meals a day and the number of snacks my doctor recommended.
OR
b) I do all the urine and blood glucose tests my doctor recommended every day.
- 45) a) I only eat the foods that are part of the meal plan prescribed by my doctor.
OR
b) I do all the urine and blood glucose tests my doctor recommended every day.

OVER

- 46) a) I exercise four or more times per week.
OR
b) I follow a regular schedule of times that I do my urine and blood glucose tests.
- 47) a) I exercise four or more times per week.
OR
b) I record the results of all my urine and blood glucose tests every day.
- 48) a) I eat extra food or take less insulin on the days that I exercise.
OR
b) I do all the urine and blood glucose tests my doctor recommended every day.
- 49) a) I follow a regular schedule of times that I eat.
OR
b) I take my insulin injections at the same time every day.

FOR ITEMS 50 to 59, CIRCLE "A" FOR YES, IF THE STATEMENT DESCRIBES SOMETHING YOU USUALLY DO, OR "B" FOR NO, IF THE STATEMENT DOES NOT DESCRIBE SOMETHING YOU USUALLY DO.

- 50) I follow a regular schedule of times that I eat.
a) Yes
b) No
- 51) I eat three meals a day and the number of snacks my doctor recommended.
a) Yes
b) No
- 52) I only eat the foods that are part of the meal plan prescribed by my doctor.
a) Yes
b) No
- 53) I exercise four or more times per week.
a) Yes
b) No
- 54) I eat extra food or take less insulin on the days that I exercise.
a) Yes
b) No
- 55) I take my insulin injections at the same time every day.
a) Yes
b) No
- 56) I take the number of insulin injections my doctor recommended every day.
a) Yes
b) No

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- 57) I do all the urine and blood glucose tests my doctor recommended every day.
a) Yes
b) No
- 58) I record the results of all my urine and blood glucose tests every day.
a) Yes
b) No
- 59) I follow a regular schedule of times that I do my urine and blood glucose tests.
a) Yes
b) No

APPENDIX B

*Parents Diabetes Opinion Survey**Subscale Intercorrelations*

	Manipult	Rule	Stigma	Divine	Attit	React	Sweet
Manipult							
Rule	-12						
Stigma	27*	08					
Divine	06	31*	17				
Attitude	-27*	38**	-22	12			
Reaction	-38**	27*	-10	20	33**		
Sweet	01	25*	-10	15	18	15	
Family	30*	22	50**	19	-07	01	-10

* $p < .04$ ** $p < .01$

Normative Sample

	Manipult	Rule	Stigma	Divine	Attit	React	Sweet
Manipult							
Rule	13						
Stigma	32	14					
Divine	03	22	-00				
Attitude	-16	11	-24	24			
Reaction	05	08	07	01	06		
Sweet	13	39	09	15	02	03	
Family	55	27	51	-03	-13	05	25

*Diabetes Opinion Survey**Subscale Intercorrelations vs. Normative Sample (In Parentheses)*

	Stigma	Rule	Sick Role	Family
Stigma				
Rule	25* (25)			
Sick Role	50** (41)	42* (38)		
Family	68** (52)	10 (40)	40* (43)	
Divine	53** (16)	23 (18)	14 (20)	33*(25)

* $p < .05$ ** $p < .001$

*State-Trait Anxiety Inventory**Subscale Intercorrelations vs. Normative Sample (In Parentheses)*

	Boys	Girls
	89* (72)	71** (64)

* $p < .002$ ** $p < .000$

Personality Inventory for Children

Subscale Intercorrelations vs. Normative Sample (In Parentheses)

Males				
	1	2	3	4
Factor 1				
Factor 2	60* (27)			
Factor 3	59* (38)	74** (29)		
Factor 4	39 (24)	71** (30)	88** (17)	

Females				
	1	2	3	4
Factor 1				
Factor 2	61** (25)			
Factor 3	21 (38)	17 (36)		
Factor 4	39* (32)	56** (32)	58** (18)	

* $p < .05$ ** $p < .001$

*Family Environment Scale**Subscale Intercorrelations vs. Normative Sample (In Parentheses)*

Children

	Cohesion	Express	Conflict	Independ	Organize
Cohesion					
Express	62** (32)				
Conflict	04 (-53)	45** (-07)			
Independ	74** (30)	58** (32)	22 (-13)		
Organize	83** (38)	46** (-05)	05 (-33)	67** (04)	
Control	43** (-20)	32* (-42)	54** (22)	39* (-36)	55** (27)

Parents

	Cohesion	Express	Conflict	Independ	Organize
Cohesion					
Express	55** (40)				
Conflict	-08 (-44)	-10 (-05)			
Independ	46* (28)	47** (24)	11 (-19)		
Organize	44* (41)	27* (-01)	-13 (-33)	38* (09)	
Control	07 (-17)	-05 (-30)	50** (31)	21 (-24)	33* (20)

* p<.05 ** p<.001

*Parents Diabetes Opinion Survey**Subscale Means vs. Normative Sample (in Parentheses)*

Manipulative	33.66 (20-38)
P-Rule	28.66 (23-37)
P-Stigma	24.70 (20-30)
P-Divine	19.83 (11-23)
P-Family	34.17 (28-44)
Attitude	17.21 (11-23)
Reaction	13.83 (11-19)
Sweet	9.38 (8-14)
Lie	27.09 (16-30)

*Diabetes Opinion Survey**Subscale Means vs. Normative Sample (in Parentheses)*

Stigma	31.04 (21-35)
Rule	21.53 (16-30)
Sick Role	21.76 (16-24)
Family	29.58 (22-36)
Divine	14.96 (9-19)
Lie	27.31 (23-37)

*Personality Inventory for Children**Subscale Means vs. Normative Sample**Age 10 and Older (In Parentheses)*

	Males	Females
Factor 1	6.41 (-.05-9.53)	2.50 (-.35-7.41)
Factor 2	5.71 (1.22-9.84)	5.82 (.94-9.68)
Factor 3	5.59 (.23-5.73)	4.89 (.41-6.73)
Factor 4	5.59 (.80-4.66)	4.21 (.21-3.65)
		6.00 (1.15-6.49) (age 7)
		6.00 (.26-4.80) (age 9)
Lie Scale	53.83 (37.0-57.2)	

*State-Trait Anxiety Inventory**Subscale Means vs. Normative Sample (In Parentheses)*

	Trait	State
Males	35.75 (29.64-50.70)	31.38 (26.71-49.19)
Females	41.50 (30.34-51.60)	38.83 (27.68-53.40)

*State-Trait Anxiety Inventory for Children**Subscale Means vs. Normative Sample (In Parentheses)*

	Trait	State
Males	31.14 (30.38-43.02)	29.75 (25.29-36.71)
Females	31.67 (31.32-44.68)	28.75 (24.69-36.71)

Family Environment Scale

Subscale Means vs. Normative Sample (in Parentheses)

	Parents	Children
Cohesion	7.36 (4.78-8.82)	5.70 (3.98-8.20)
Expressive	5.53 (3.90-7.46)	3.68 (2.73-6.25)
Conflict	3.53 (1.44-6.08)	3.13 (2.03-6.57)
Independence	6.32 (5.53-8.15)	5.28 (4.88-7.86)
Organization	6.15 (3.35-7.73)	4.96 (3.35-7.51)
Control	5.09 (3.08-6.86)	4.23 (2.77-6.97)

Diabetes Knowledge Test

Mean Scores vs. Normative Sample (in Parentheses)

Age	Score
6-9 yr olds	67.9 (41.0-84.8)
10-11 yr olds	76.1 (48.6-80.6)
12-13 yr old	83.6 (55.6-89.0)
14 yrs and older	84.2 (68.5-95.9)
Total Sample	81.2 (54.2-91.2)

APPENDIX C

*Family Environment Scale Subscale Intercorrelations
Between Children and Parents*

	Conflict	Independence	Organize	Cohesion
Conflict	42			
Independence		49		43
Organize			47	
Cohesion			42	

*Parents Diabetes Opinion Survey and Diabetes Opinion Survey
Subscale Intercorrelations*

PDOS	DOS		
	Rule	Divine	Family
Rule	53		
Divine		62	
Manipulative			40

*State-Trait Anxiety Inventory Subscale Intercorrelations
with Other Inventory Subscales*

Subscale	State	Trait
Stigma	-55	-63
Sweet	-44	
Independence-p	-40	
Express-p	-50	
Undisciplined	42	
Social Incompet	53	46
Family		-55
Cohesion-p		-49
Conflict-p		-54
Internalization		40

*State-Trait Anxiety Inventory for Children**Subscale Intercorrelations with Other Inventory Subscales*

Subscale	CState	CTrait
Manipulative	-42	-51
Reaction	-43	
Cohesion-p	-45	-46
Organization-p	-44	-44
Express-p	-40	-47
Cognitive Develop	40	59
Sick Role		-43
Family		-45
Cohesion-c		-68
Independence-c		-39
Organization-c		-54
Independence-p		-47
Social Incompet		62
Internalization		44

APPROVAL SHEET

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The final copies have been examined by the director of the dissertation and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the dissertation is now given final approval by the Committee with reference to content and form.

The dissertation is therefore accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

2/25/87

Kevin J. Hartigan

Date

Director's Signature