A Behavioral Family Intervention to Improve Adherence and Metabolic Control in Children with IDDM

by

Melanie Jean Bonner

Department of Psychology

Thesis submitted to the Faculty of the Department of Psychology,

Virginia Polytechnic Institute and State University

in partial fulfillment of the requirements for the degree of

in

MASTER OF SCIENCE

Psychology

APPROVED:

ack W. Finney, Chairperson

Thomas H. Ollendick, Ph.D.

Robin Panneton Cooper, Ph.D.

May, 1992

Blacksburg, Virginia

S.

LD 5655 V855 1992 B666 c.2

-

,

A BEHAVIORAL FAMILY INTERVENTION TO IMPROVE ADHERENCE AND METABOLIC CONTROL IN CHILDREN WITH IDDM

by

Melanie Jean Bonner

Committee Chairperson: Jack W. Finney, Ph.D.

Department of Psychology

(ABSTRACT)

The present study evaluated the effectiveness of a behavioral family intervention on adherence and metabolic control in insulin dependent diabetic children (IDDM). Specifically, assumption of regimen responsibilities between the parent and child were manipulated to facilitate regimen adherence. The intervention delivered was a target-specific behavioral contract extended sequentially across four target behaviors (i.e., blood glucose testing, insulin injections, diet, and exercise). Regimen components were targeted in a withinsubjects, multiple baseline design across behaviors to assess the relationship between adherence and metabolic control. Metabolic control was assessed with a measure of glycosylated hemoglobin (e.g., HbA1c.) Five IDDM children (3 female, 2 male), who met study criteria (i.e., nonadherence to blood glucose testing defined as ≤ 2 tests daily and metabolic status outside the optimal range using standard laboratory reference values) were recruited from physician referrals and media announcements. Subjects were between the ages of 10 and 15 years (M = 12.6); four were Caucasian and one was African-American. Mean duration of diabetes upon entry into the study was 4.3 years. Results revealed that four subjects responded to the intervention and three of those four evidenced clinically significant improvements in metabolic control at midand/or post-study. One subject demonstrated only moderate intervention effects and no improvement in metabolic control while another increased adherence, but decrements in metabolic control were noted. These results suggest that adherence may mediate the relationship between family variables and metabolic status. Two additional subjects demonstrating consistently good metabolic were employed to assess the validity of target behaviors. The results were related to various family and diabetes-specific psychosocial indices.

Acknowledgements

While the title page indicates a single author, I would be remiss if I failed to point out that this thesis was a collaborative effort by many competent and inspiring persons. First and foremost, I wish to express my sincere gratitude to my advisor, Jack Finney, without whose support, patience, availability, and valuable feedback, this project would not have been possible nor as rewarding as it proved to be. I am extremely proud to have him as my mentor and I look forward to working on future projects under his guidance.

I would like to thank my committee members, Tom Ollendick and Robin Cooper, for challenging me and providing new insights throughout this process. I feel honored to have had the opportunity to learn from them.

I would also like to extend warm thanks to Dana Putnam and David Jaquess who listened patiently at our research meetings and provided thoughtful feedback and a great deal of encouragement. Special thanks go to Thomas Berry for his sincere interest in my intellectual growth. I feel fortunate to have such a caring friend who is most generous in giving of his time to discuss the past, present, and especially the future — over coffee!

I would like to extend a very special thanks to Mike Gilmore, without whose support, respect, and unbelievable patience (that I tested the limits of several times when preparing the final draft of this project) helped me succeed in pulling this all together. I feel privileged to have such a wonderful partner.

Finally, and importantly, I wish to thank my family, especially my mother who has inspired me and has served as an extremely valuable role model.

Additionally, I am most fortunate to have a caring step-father and a wonderful sister in my life. I love you all.

Table of Contents

ABSTRACT	ii
ACKNOWLEDGEMENTS	iv
Introduction	1
METHOD	34
RESULTS	45
Discussion	60
References	88
TABLES	
Table 1 Demographics	97
Table 2 Ghb Results	98
Table 3 Glucose Regimen Results	99
Table 4 Insulin Regimen Results	100
Table 5 Insulin Adjustment Results	101
Table 6 FACES III Results	102
Table 7 DFBC Results	103
Table 8 MHLC Results	104
Table 9 BAS Results	105
Table 10 DKT Results	106
Table 11 FRI Results	107
APPENDICES	
Appendix A - Diabetes Family Behavior Checklist	108
Appendix B - Interview	109
Appendix C - Barriers to Adherence Scale	111
Appendix D - Sample Behavioral Contract	113
Appendix E - Diabetes Knowledge Test	114

Appendix F - FACES III	120
Appendix G - Family Routines Inventory	123
Appendix H - Multidimensional Health Locus of Control	126
Appendix I - Consent and Assent Forms	128
FIGURES	
Figure Captions	130
Figure 1 - Adherence Defined	131
Figures 2-8 - Baseline and Intervention Data for All Subjects	132
Figure 9 - Adherence Re-Defined	139
VITA	140

A Behavioral Family Intervention to Improve Adherence and Metabolic Control in Children with IDDM

BRIEF OVERVIEW OF CHRONIC ILLNESS

Epidemiological data indicate that approximately one in ten children in the United States will be diagnosed with one or more chronic medical conditions by 18 years of age (Gortmaker, 1985; La Greca & Stone, 1985). Furthermore, it has been estimated that these children comprise approximately 50% of pediatric practice (Magrab & Calcagno, 1978). As a result of increasingly sophisticated medical advances, the prognosis for pediatric populations afflicted with chronic illnesses has improved dramatically. Consequently, pediatric care has shifted from the management of acute and infectious diseases to chronic disease management with the focus shifting from death issues to those of coping (Spinetta, 1983). Additionally, those diagnosed with diseases that have traditionally had a more favorable prognosis (e.g., diabetes and asthma) now have the potential to live relatively symptom free and near "normal" lives through daily management of the disease.

Some maintain that research on chronically ill children is inadequate and intervention services are lacking (Gaudet & Powers, 1989). This is particularly important when considering that despite medical advances, a certain percentage of chronically ill children remain vulnerable in terms of psychosocial problems (Eiser, 1990). However, research regarding the psychological sequela of chronically ill children and their families has been characterized by discrepancies and contradictions. Currently, some researchers maintain that while considerable improvements in prognosis are encouraging, living with a chronic illness has resulted in previously unforeseen problems including disruptive

behavior, nonadherence with treatment regimens, anxiety or depression, poor socialization with peers, cognitive deficits, and family dysfunction (Drotar, 1981).

According to Epstein and Cluss (1982), the effectiveness of treatment for chronic illness is dependent on at least two factors: the efficacy of treatment and the rate of adherence. Differential rates of nonadherence to prescribed medical regimens have been reported, with estimates ranging from 20-30% for shortterm medical regimens, 30-40% for preventative or curative regimens, and as high as 50% for adult and pediatric populations for both acute and chronic conditions (DiMatteo & DiNicola, 1982; La Greca, 1988a; Litt & Cuskey, 1980). Adherence has been defined differentially by researchers but the majority of definitions include the extent of concordance between patient behavior and medical recommendations or fulfillment of a clinical prescription (DiMatteo & DiNicola, 1982; Haynes, 1979). However, divergent definitions remain, even with regard to the components of the same illness or medical regimen (La Greca, 1988a). The semantics of adherence also differ including terms such as compliance, obedience, and therapeutic alliance being used interchangeably (DiMatteo & DiNicola, 1982). Some have argued that adherence is the most appropriate term because it implies the necessity of active participation of the patient in treatment and has less authoritative connotations (Meichenbaum & Turk, 1987).

The assessment and measurement of adherence can include a variety of direct and indirect methods for evaluating medication use including: (a) self-report, (b) therapeutic outcome, (c) pill/bottle counts, (d) physician estimates, (e) mechanical methods, (f) blood/serum assays, (g) urine assays, and (h) tracer or marker methods (Epstein & Cluss, 1982). Each method has advantages and

disadvantages and therefore, the use of multiple measures is recommended in order to obtain a reliable assessment of adherence.

There are a variety of procedures currently used to increase adherence to medical regimens including: instruction/information, reduction of barriers to adherence, behavior modification, patient supervision, reminders/cues, and pharmacy intervention (Epstein & Cluss, 1982; La Greca, 1988a). In a review of the various approaches, Epstein and Cluss (1982) concluded that behavioral techniques were among the most effective for improving medication adherence to chronic regimens. In fact, Varni and Wallander (1984) imply that nonadherence to long-term regimens is likely in the absence of systematic behavioral intervention. Such interventions include stimulus-control approaches (pill salience), self-control approaches (self-monitoring), and reinforcement approaches (behavioral contracts). However, many chronic illnesses require adherence to complex regimens that not only include frequent ingestion of medication, but alterations in other aspects of the individuals' lives (e.g., diet, exercise, daily monitoring of symptoms, or frequent blood or urine testing in the case of diabetes). With advances in medical technology and treatment procedures, previously life-threatening illnesses can now be successfully controlled but require an active role by the patient and his/her family (La Greca & Stone, 1985). With these advances, it is crucial that the problem of nonadherence be addressed in order to enhance the therapeutic benefits of these treatment methods. Pediatric psychologists have recently become increasingly involved in the identification and evaluation of variables that mediate adherence behaviors in chronic illness populations.

DIABETES MELLITUS

Characteristics

Diabetes mellitus is a chronic metabolic disorder characterized by insufficient insulin production by the pancreas. Two types exist that can be classified as either Type I or insulin-dependent (IDDM) and Type II or non-insulin-dependent (NIDDM). Together, both disorders represent the third greatest cause of death in the United States (Jacobson & Leibovich, 1984). NIDDM accounts for 90% of the diabetic population and is most frequently diagnosed after age thirty and can generally be regulated through alterations in diet as well as weight reduction. Although the pancreas maintains some functioning, exogenous insulin may be needed.

IDDM, however, is typically diagnosed during childhood between the ages of 5-6 or 11-13 (Johnson, 1988) and is associated with ketoacidosis, a condition characterized by high blood glucose and the presence of large amounts of ketone bodies in the blood and urine. It is one of the most prevalent endocrine disorders diagnosed in children, affecting approximately 1 in 800 children under the age of 18 (Johnson, 1988). Currently 120,000 children in United States have been diagnosed with IDDM with comparable frequency between males and females.

Metabolic homeostasis is compromised by fluctuating hormonal levels of glucagon and subsequent deficiencies in insulin. These deficiencies result in the beta cells becoming inactive with insufficient production or a complete lack of production of endogenous insulin leading to dependence on exogenous insulin replacement. The disease process results when glucose is ingested by the diabetic and there is insufficient insulin available for anabolic cell activity,

resulting in blood sugar increases and subsequent spillage of glucose into the urine. A primary diagnostic indicator is fasting blood glucose levels above 140 mg/dl. accompanied by acute thirst (polydipsia), frequent urination (polyuria), and progressive weight loss despite increased caloric intake (polyphasia) (Hendrick, 1985).

Etiology and Prognosis

The most widely proposed explanation for the etiology of diabetes implicates the human leukocyte antigen (HLA) which has been associated with autoimmune disease. In diabetes, it is suspected that the body erroneously identifies the pancreatic beta cell (insulin producers) as foreign agents and consequently produces islet cell antibodies (ICA) which destroy the beta cells (see LaPorte & Cruickshanks, 1985 for a review).

Presently there is no cure for diabetes mellitus, but it can be diagnosed and treated successfully by insulin replacement through daily injections. Exogenous insulin is derived from the pancreas of pigs (porcine insulin) or cows (bovine insulin) or by synthetic production. IDDM is an example of a chronic disease that, with recent sophisticated medical advances, can now be controlled with a fairly good prognosis. However, the prognosis is less optimistic for those nonadherent to the prescribed medical regimen. This poor prognosis is further complicated by the fact that diabetes is largely asymptomatic except in cases of hypo- or hyperglycemia and ketoacidosis. Therefore, it is unlikely that children and teenagers can adequately appreciate the severity and chronicity of the disease, which results in little incentive to participate in the requisite daily

management behaviors. This elevates the risk of both short- and long-term complications.

Implications for Nonadherence

Short-term problems may result from hypoglycemia which is characterized by insufficient levels of glucose in the blood (e.g., 45 mg/dl and below). Hypoglycemia most frequently results from erroneous insulin doses, strenuous exercise, or insufficient levels of carbohydrates. Hyperglycemia occurs when blood glucose levels are too high and is characterized by fasting levels of 140 mg/dl or higher. If the insulin levels are severely low and blood sugar levels are abnormally high, ketoacidosis can result. The long-term complications that could result include: macroangiopathy, a disease which results in a thickening of the walls of the arteries of the heart, brain, or periphery (particularly the feet); microangiopathy, resulting in disease of the kidneys (nephropathy), the peripheral nervous system and/or the autonomic nervous system (neuropathy) and; diseases of the tiny blood vessels in the retina of the eye (retinopathy) which currently is the leading cause of new blindness (Hendrick, 1985; Wing, Epstein, Nowalk, & Lamparski, 1986). Importantly however, the consequences can be prevented or minimized through proper disease management.

Given that complexity of the treatment regimen is a predictor of adherence, it is not surprising that adherence to the diabetic regimen is generally quite poor (Haynes, Taylor, & Sackett, 1979). In fact, some regard it as the most complex and challenging regimen of all common disease (Fisher, Delamater, Bertelson, & Kirkley, 1982). However, differences have emerged with increased chronological age. For example, it has been reported that pre-school and

elementary school children are more adherent than teenagers and that metabolic control deteriorates as the duration of diabetes increases (Hanson, Henggeler, Harris, Burghen, & Moore, 1989; Johnson, Silverstein, Rosenbloom, Carter, & Cunningham, 1986). This is a paradoxical finding considering assessment of teenaged diabetics generally shows increased knowledge and skills regarding daily management behaviors. Undoubtedly, the increased role of the parents with younger children facilitates adherence. Similarly, metabolic control in teenagers may be mediated by hormonal changes at puberty. However, the role of psychosocial factors and adherence behaviors cannot be dismissed as inconsequential for any age group. This suggests that it is necessary to assess barriers to adherence for individuals at different ages and design interventions that consider these differences (Johnson, 1988).

Diabetes mellitus is a disease particularly amenable to this type of psychological intervention, primarily with regard to the factors implicated in adherence to the daily management behaviors (La Greca & Stone, 1985) and therefore, serves as a particularly useful model disease for chronic illness interventions (Hanson, 1990).

Components of the Diabetic Regimen

The diabetic regimen is complex and involves daily management of a number of behaviors. The prescribed regimen typically involves the following:

1. Blood Glucose Monitoring: Blood glucose testing plays a critical role in the management of insulin-dependent diabetes mellitus. The tests serve as the primary and most objective means of feedback to a diabetic regarding glucose levels in the blood. Because glucose levels fluctuate daily, the diabetic must test

his/her blood so that appropriate behavior changes can be made. It is typically recommended that the diabetic test the blood and record the results at least four times daily coinciding with insulin injections, meals, and exercise. Tests are performed by pricking the finger with a lancet device to obtain a blood sample that is subsequently dropped onto a reagent strip. Blood glucose concentration can be determined by either visual comparison of the strip with a chart or by inserting the strip into a reflectance photometer to obtain an automated reading. Wysocki (1989) reported the main advantages to monitoring blood glucose levels as recommended by the American Diabetes Association:

- Monitoring permits the development of an individualized blood glucose profile which could guide the physician in treatment planning and decisions making;
- b. the technique could possibly facilitate appropriate day-to-day treatment choices by patients and their families;
- it should improve the recognition and prompt response to emergency situations such as hypoglycemia and incipient diabetic ketoacidosis; and
- d. it could enhance patient education by providing real-life
 demonstrations of principles learned in the classroom (p. 184).

While blood glucose monitoring does not have a direct effect on blood glucose concentrations, it is a technique that when used consistently, can enhance therapeutic outcome (Wysocki, 1989). Unfortunately, adherence to blood glucose monitoring is poor, and frequently diabetics across all age ranges fabricate the results. The unreliability of recorded tests (due to falsification of results) has been demonstrated in several studies that have used reflectance meters equipped

with a memory function in which stored data was compared to logbook data (Langer & Mazze, 1986; Mazze et al., 1984; Phillips, Sanchez, Pedromingo, & Fernandez-Cruz, 1987; Wilson & Endres, 1986). Until recently, however, adherence to blood glucose monitoring was assessed by self-report. This suggests an area where interventions are needed that are designed to assess the frequency, timing, and recording of blood glucose values, using objective and reliable methods (Wysocki, 1989).

2. *Insulin Injections*: Exogenous insulin is typically injected one to three times daily, and may vary depending upon the physician's prescription, insulin type and potency, and results of blood glucose tests. The diabetic must routinely alter the site of injections in order to prevent lipohypertrophy (an increase in subcutaneous fat) or lipoatrophy (a loss of subcutaneous fat), both of which can compromise the therapeutic effectiveness of the insulin. Knowledge of the absorption rates of each injection site is also necessary, particularly in the case where rapid absorption is desired because of very low insulin levels.

Recently, continuous subcutaneous insulin infusion pumps (CSII) have been used in place of conventional insulin therapy. The CSII delivers insulin via indwelling catheters typically placed in a region close to the stomach. Careful hygiene is crucial to prevent inflammation or infection at the catheter cite which could adversely affect insulin absorption. Consistent with prescriptions for careful preprandial (e.g., pre-meal) timing of conventional insulin therapy, diabetics using the CSII are expected to increase the basal rate of insulin delivery (i.e., pre-meal bolus that overides the single control over basal infusion) 15-30 minutes prior to meals for maximal effectiveness.

- 3. *Diet:* It is generally recommended that the diabetic obtain 50-60% of calories from carbohydrates, 30-35% from fat, and 15% from protein. Diabetics are typically placed on an exchange-system that divides foods into six categories that can be used interchangeably, allowing for variety without compromising the nutritional value of the meal. It is suggested that diabetics eat at the same time each day and ingest a similar amount of food at each meal so that intake will coincide with the temporal course of insulin. Because it is unrealistic to assume that the family will eat at the same time everyday, it is incumbent upon the diabetic to adjust insulin injections accordingly to maximize the treatment effects.
- 4. Exercise: Exercise recommendations vary according to the individual. Typically, however, diabetics are encouraged to participate in activities at least three to four times weekly. Exercise can function in an insulin-like manner (e.g., by lowering blood sugar), however the effects of exercise are dependent on the metabolic state at the onset of exercise. Therefore, it is important to test blood glucose levels prior to increasing activity levels. The diabetic is also encouraged to have available, 15 gms of fast-acting carbohydrates in case blood glucose levels are low at the onset or in the event of a hypoglycemic reaction during the period of exercise.

While adherence to each of the above components of the prescribed regimen is important, only a few interventions have been designed to impact such behaviors. Furthermore, many studies erroneously use health outcome as an indicant of adherence without directly and independently assessing whether adherence has actually occurred (Epstein & Cluss, 1982). The current study operationalized adherence using dimensions of each of the above-described regimen components (see Figure 1). Specifically, dimensions of frequency and

timing were targeted for blood glucose testing where the diabetic was expected to perform a minimum of four tests daily prior to meals, insulin injections, and bedtime. Insulin injection adherence was defined by performance of all prescribed injections within the appropriate temporal window as indicated by insulin type. Deviations in nutritional content of meals (e.g., fats, carbohydrates, and protein) comprised the dietary adherence measure and exercise adherence was defined as aerobic activity lasting in duration of at least 30 minutes. These target behaviors were selected on the basis of current conceptualizations of the diabetic treatment regimen.

Current Conceptualizations

Wing et al. (1986) proposed a self-regulation model to explain how the diabetic regimen is designed to control blood sugar levels. The authors' conceptualize the diabetic regimen as a series of behaviors that lead to the regulation of blood sugar, thereby accomplishing through external behavior change, what the non-diabetic body does automatically. Behavior change can be summarized in an algorithm that includes the following components: (a) error detection whereby the body detects a discrepancy between actual and normal blood sugar levels following a disturbance in the system. This is accomplished by frequent blood sugar and urine monitoring; (b) controlling responses consisting of frequency and accuracy of insulin administrations and subsequent adjustments based on glucose serum levels once an error has been detected; (c) reducing disturbances (particularly environmental stimuli) by regulating diet, exercise, and stress; and (d) self-reinforcement in which reinforcement

contingencies are provided to facilitate both short and long-term self-regulatory responses.

While this model addresses the diabetic treatment using a unique approach (e.g., negative feedback control system), the conceptualization is simplistic and primarily offers a reiteration of the components involved in the diabetic regimen. Noteworthy, however, the model stipulates specific behaviors to be targeted by interventions and suggests several methods by which this could be achieved. Furthermore, the model accounts for the importance of reinforcement when targeting treatment adherence. In this regard, the behavioral self-regulation model presents a useful framework for developing interventions by highlighting the importance of the multiple behaviors involved in the diabetic treatment. The validity of this model needs to be subjected to empirical investigation with direct assessment of self-regulatory behaviors and employment of a valid index of metabolic control.

Currently, however, health outcome or metabolic control is consistently and erroneously used as the primary global index of adherence without consideration of the variables that influence adherence behaviors. Metabolic control is assessed using measures of glycosylated hemoglobin (Ghb), which reflects the degree of glucose bound to the hemoglobin in the blood and represents metabolic control over a 6-8-week period (i.e., the half-life of hemoglobin is approximately 8 weeks). Currently Ghb represents the most stable and valid index of metabolic control. Several studies, however, have operationalized adherence to daily regimen behaviors using this alone or by using a global adherence index that is inclusive of a variety of different behaviors (Carney, Schachter, & Davis, 1983; Johnson, et al., 1986). Alternatively,

adherence should be studied directly to more accurately assess the relationship between adherence behaviors and metabolic control (Goodall & Halford, 1991).

Using multiple regression analyses Hanson, Henggeler, and Burghen (1987) developed a multidimensional model that demonstrated how adherence to the medical regimen was directly related to metabolic control, but is influenced by mediating variables such as knowledge about diabetes, adolescent age, and family relations. Appropriately, this model suggests the influence of other variables that are related to metabolic control and does not rely solely on measures of Ghb as an index of the level of self-management. While this is an improvement over previous conceptualizations, this model employed a global index of adherence by summing the scores of self-report and observational items across five different adherence behaviors that accounted for only 18.5% of the variance in predicting adherence. Aggregate scores of adherence may mask the contributions of each adherence behavior and its relative effects on metabolic control. This preliminary model, however, provides another useful framework from which to design interventions.

La Greca (1988b) proposed a framework for IDDM that outlines various components that could be targeted hierarchically for intervention. Specifically, if the diabetic possesses the requisite knowledge and skills for diabetes management (Level I), then treatment adherence or "level of self-care" would represent the next target behavior (Level II). Behaviors at this level would be targeted to assess the relationship between adherence and metabolic control. Once adherence is noted, stress and psychological functioning (Level III) would be targeted if improvements in metabolic control were not yet noted. This

model also makes provisions for individual difference variables such as physiological functioning and disease pathogenesis.

This framework has utility for integrating important psychosocial variables with disease variables for the design of interventions. Specifically, various psychosocial variables could potentially influence one or more of the levels of the model. The current study was designed to address Level II variables (e.g., adherence) whereby treatment adherence was targeted using a behavioral intervention. Behaviors targeted were those identified in the self-regulatory model proposed by Wing et al. (1986) including blood glucose testing, insulin injections, diet, and exercise. Furthermore, the relationship between adherence and metabolic control was evaluated. The emergence of a direct relationship between these variables would lend support for the negative feedback control system described by Wing et al. (1986) and would demonstrate the efficacy of designing Level II interventions. Furthermore, to evaluate the hypothesized influence of psychosocial variables, family involvement (e.g., family responsibilities) in the treatment regimen was addressed by the current intervention. While La Greca's model proposed that psychosocial factors may influence metabolic control directly and/or indirectly, the current study was designed to experimentally explore whether or not adherence could mediate this relationship, thereby demonstrating an indirect relationship. Data in support of this hypothesis would be consistent with the conceptualization proposed by Hanson et al. (1987) described earlier.

The few interventions that have been designed for diabetic populations vary according to behaviors targeted and measurement procedures employed.

Typically intervention approaches fall into one of four categories including: education, skills training, behavioral, and self-monitoring.

Previous Interventions

Education

Educational interventions typically include teaching diabetics about the characteristics of the disease and its course of treatment. Although knowledge is decidedly a prerequisite for acquiring the necessary adherence behaviors and related skills, there is limited evidence of its effectiveness in improving adherence (Fisher et al., 1982; Johnson, 1988; Watts, 1980). In a review of several recent educational studies, Goodall and Halford (1991) concluded that increases in knowledge rarely resulted in improved metabolic control. Educational interventions frequently demonstrate differences in pre- and post-test measures of knowledge, but too often studies focus only on knowledge improvements and do not evaluate the specific effects on adherence to regimen components. Because all diabetics do not respond to the disease in similar ways, standardized educational programs that do not account for individual differences may be limited (Johnson, 1988). As implied in the models described earlier (Hanson et al., 1987; Wing et al., 1986), knowledge may directly affect adherence, while only indirectly affecting metabolic control, thereby necessitating alternate interventions and closer evaluation of the actual adherence behaviors.

Skills Training

There have been a number of skills training and feedback programs developed that, when added to educational programs, result in improved

metabolic control. For example, Mazzuca et al. (1986) used a competency-based computer program. The program, however, placed considerable time demands on each patient including 14 hours of education as well as a lengthy assessment period and consequently, the attrition rate was high. Gross, Heimann, Shapiro, & Schulz (1983) designed an intervention that targeted social skills in juvenile diabetics based on the premise that this would facilitate coping with environmental stress (e.g., peer pressure to deviate from prescribed diet). Ratings of selected target behaviors based on role playing using the Diabetes Assertiveness Test (Gross & Johnson, 1981) were recorded, including eye contact, duration of speech, and appropriateness of verbalizations, as well as an index of overall affect for the experimental (social skills training) and control groups (no training). Both groups demonstrated similar levels of metabolic control prior to the study. Results showed a substantial improvement in the ability to cope effectively with stressful social situations related to diabetes for the experimental group. However, no improvements in metabolic control were found using hemoglobin measures. While it is likely that improved social skills can influence metabolic control by reducing the effects of stressful situations, the current study did not evaluate other factors including adherence behaviors. The non-significant effect on metabolic control could have been masked by deviations in insulin requirements, dietary intake, lack of exercise, or any number of related variables.

Follansbee, La Greca, & Citrin (1983) randomly assigned juvenile diabetics to either a coping skill training (CST) group or a discussion-control group during a summer camp. Whereas the CST group improved with respect to assertiveness in diabetes-related social situations as demonstrated by role-playing and self-

report assessments, both groups improved with respect to adherence. The authors suggested that the positive experience of the diabetes camp may explain the similar improvements for both groups. La Greca (1988a) suggested that while the results were encouraging, replication in a more natural setting is needed.

Self-Monitoring Interventions

Interventions that do not incorporate behavioral contingencies have been less successful. For example, self-monitoring of blood glucose levels is a critical component in the diabetic regimen, and several studies have designed interventions to target this behavior. Using questionnaire responses from a large sample of unselected diabetic children, Wing et al. (1985) reported that there were no differences in metabolic control as a function of the frequency and accuracy of glucose testing for diabetics using both blood and urine tests. However, as cited above, fabrication of test results is common and could have affected the validity of the results. Additionally, adherence to other components of the regimen such as insulin injections and dietary consumption were not reported. Evaluation of the temporal congruence with other regimen behaviors is needed (e.g., insulin, meals, exercise) before inferences can be extrapolated to conclusions about metabolic control.

In another study that targeted blood glucose monitoring, subjects in a self-monitoring group were compared to a group that received an education intervention only (Mann, Noronha, & Hohnstgon, 1984). Results showed no significant differences between baseline mean glucose levels and those recorded at 18 months. Additionally no differences were reported in glycosylated

hemoglobin levels between the two groups, suggesting minimal therapeutic benefit.

The above studies suggest that self-monitoring alone is not sufficient to produce significant changes, particularly in the absence of a behavioral manipulation. Studies that have incorporated behavioral principles, however, have been more successful. For example, Carney et al. (1983) designed a behavior modification program to increase blood glucose monitoring using contingent praise and a point system for the completion, appropriate timing, and recording of blood glucose levels in a log book. During baseline, three subjects were employed, two of which refused to test their blood glucose and one who required considerable nagging by the parents to complete even 20% of the recommended urine tests (blood glucose monitoring was still a relatively new concept). Results showed dramatic increases in the percentage of time the children monitored their blood glucose as well as improvement in glycosylated hemoglobin measures. These rates were maintained at a 4-month follow-up. While these data are encouraging, adherence to other aspects of the regimen was not monitored and behavior change was not reported based upon the result of the glucose tests (e.g., insulin adjustments). Although parental reports indicated an improvement in dietary intake, it cannot be determined whether the improvements in metabolic control resulted from the percentage increase in blood glucose monitoring, dietary improvements, or to some other variables potentially related to the regimen.

Wysocki, Green, & Huxtable (1989) also evaluated the effects of a behavioral contract on adherence to the prescribed frequency of blood glucose monitoring and metabolic control. Using reflectance meters with memory capabilities,

diabetics were randomly assigned to a meter only or a meter plus contract group. Results revealed that the contract group maintained adherence levels over the 16-week period of data collection, whereas the meter alone group evidenced a significant decline in adherence at the 8th week. While these group differences corroborate the utility of a behavioral contract as an intervention strategy, neither group showed improvements in metabolic control which is consistent with the findings of previous studies (Glasgow, McCaul & Schafer, 1987; Wing et al., 1985).

However, according to Wysocki (1989) such interventions should not be prematurely abandoned, and efforts are needed to clarify the inconsistencies and contradictory findings regarding the impact of glucose monitoring on metabolic control. Wysocki suggests that variables that potentially mediate the utility of monitoring need to be addressed further and evaluations of more than a single dimension of blood glucose monitoring behavior is warranted. This may necessitate combining several behavioral dimensions, including the precision of testing techniques, reliability of patient reported data, frequency of testing, and the timing of testing before an accurate assessment of the benefits of blood glucose monitoring can emerge. With the development of sophisticated glucose meters that have a memory capacity, the potential for reliable behavioral assessment is enhanced. Additionally, as more components of the diabetic regimen are evaluated concurrently, better predictors of adherence and perhaps metabolic control may emerge. Support for this contention comes from Schafer, Glasgow, McCaul, and Dreher (1983) where results from a multiple regression analysis demonstrated that the combination of blood glucose monitoring, careful insulin measurement, and dietary adherence predicted metabolic control well.

Similarly, in a recent study of metabolic control, extensive statistical analyses suggested that a single dimension of diabetic adherence is limited (Glasgow et al., 1987). However, given that behavior modification procedures have been successful in at least increasing the frequency of blood glucose monitoring, the procedures should now to be extended to other behavioral dimensions in an effort to use this information effectively to yield improvements in metabolic control. Further replications of earlier behavioral studies that were successful in increasing the percentage of negative urine tests (Epstein et al., 1981) should be conducted using blood glucose monitoring as the dependent variable in an effort to yield improvements in metabolic control (Wysocki, 1989).

While self-monitoring of blood glucose levels is a requisite skill, alone it is of limited value if the diabetic does not use the information for effective behavior change (e.g., insulin adjustments) (Wysocki, 1989). This dimension of blood glucose monitoring has received little attention and the results that have been reported are discouraging. In a recent study, Delamater, Davis, Bubb, and Smith (1987) found that while 72% of the adolescents sampled tested their blood glucose levels two times daily only 50% recorded the results and 47% reported rarely or never altering insulin dosage based on the results. This highlights the importance of not only monitoring glucose levels frequently, but also recording the results so that if the diabetic is not making the necessary alterations in insulin units, the physician can intervene after reviewing the recorded values. Blood glucose testing and relevant dimensions of this behavior represents a vastly understudied area and necessitates the development of methods to evaluate and improve the use of the test results (Wing et al., 1985).

As a variant to the self-monitoring interventions, several studies have been designed to train patients to discriminate blood sugar levels by using subjective appraisals. For example, subjects have been taught to discriminate between normal and high blood sugar levels (hyperglycemia) by receiving feedback regarding the accuracy of discriminations (Cameron & Curtis, 1980; Gross et al., 1983). However, there are a wide variety of symptoms that can be experienced prior to and during a hypo- or hyperglycemic reaction that underscores the need for blood glucose testing. For example, hypoglycemia may be preceded by symptoms ranging from light headedness and hunger to lack of coordination and delirium, depending on the intensity of the reaction. While it is possible for diabetics to be trained to recognize their own idiosyncratic symptoms, a blood glucose test should not be negated. The blood glucose test provides more accurate data and allows for appropriate behavior change decisions (e.g., increased insulin, consumption of carbohydrates). This will also help the diabetic avoid the impending reaction and will guard against overcompensation for the reaction. Consistent testing and the resulting feedback may also help the diabetic predict the metabolic effects of particular stressful events, thereby increasing the likelihood of avoiding or counteracting those effects (Watts, 1980).

Behavioral Interventions

The diabetes literature is characterized by a paucity of comprehensive and effective behavioral intervention studies, although a few have been successful. While the majority of behavioral interventions have focused on Type II Diabetes using weight reduction methods, several studies with IDDM report promising

and useful results for both improvements in adherence behaviors and metabolic control (Goodall & Halford, 1991).

Epstein et al. (1981) used a multiple baseline design across groups to evaluate the effects of a comprehensive treatment program for a sample of 19 diabetic children and their families. The intervention targeted several aspects of the diabetic regimen, including insulin adjustment, diet, exercise, as well as parent training. Specifically, parents were instructed to use a point economy system by providing positive contingencies for improved outcome in the form of symptom reduction (e.g., negative urine test results). While significant increases in negative urine glucose results were reported, improvements in metabolic control were not found. However, this study relied on the results of urine glucose tests which detect the presence of excess blood sugar that has spilled into the urine. This represents only a variable relationship to actual blood glucose levels. While in the past this method has been the primary means of daily feedback regarding glucose levels, negative results do not provide feedback regarding the level of blood sugar and therefore, do not account for the differential renal thresholds for blood glucose across individuals (Fisher et al., 1982). In other words, urine tests simply tell the diabetic that too much glucose has spilled, but do not provide crucial data regarding how much. More accurate and sophisticated assessments of serum glucose levels have been developed in the last decade and have improved the quantification of daily self-management behaviors (Goodall & Halford, 1991). Home blood glucose monitoring provides continuous data and therefore is more sensitive to the varying levels of serum glucose. Although the procedure is more invasive than urine testing, such advances allow the

diabetic to determine if insulin or dietary adjustments are warranted which may help prevent the occurrence of hypo- or hyperglycemia. (Carney et al., 1983).

In a single-case study, Lowe & Lutzker (1979) used a multiple baseline design across behaviors to evaluate the effects of written instructions ("memo") and a point system on three targeted behaviors. The point system resulted in increased adherence during the intervention for urine testing and foot care and was maintained at a 10-week follow-up assessment. The "memo" condition was successful for dietary adherence in the absence of a point system, however, the authors noted the inherent reinforcing properties of eating and suggested that the results be interpreted cautiously. Additionally, the subject's mothers assumed the responsibility for following the dietary guidelines proposed by the American Diabetes Association.

Using a multiple baseline across behaviors design, Schafer, Glasgow, & McCaul (1982) targeted several regimen components identified by diabetics and family members as barriers to adherence. Behaviors were targeted by sequentially presenting three behavioral procedures including: self-monitoring, behavioral contracting, and a graduated goal setting phase that was based upon baseline data. Results showed increased adherence and metabolic control for two of the three subjects following the goal-setting method for exercise behavior. However, contingent reinforcement was necessary to improve adherence to the timing of insulin injections for one subject. The third subject did not demonstrate an increase in adherence behaviors nor metabolic control, a finding attributed to the subject's dysfunctional family environment. Although the sample size was small, these results point to the relationship between adherence and metabolic

control and attest to the efficacy of behavioral treatments as well as the significance of the family environment.

Another study involved training of both diabetics and their families in the principles of behavior modification. Gross, Magalnick, & Richardson (1985) found that families receiving this training reported declines in family conflict as well as an increase in adherence to the medical regimen. Training involved providing information and role-playing exercises related to reinforcement, punishment, extinction, shaping, self-management, modifying the behavior of others, negotiation, and contracting. While this was a nicely controlled behavioral investigation, the results suggested that both the experimental and control groups demonstrated significant improvements in metabolic control. This finding might be attributed to the fact that behavior modification sessions were conducted separately between the parent and child. Perhaps if the focus of the intervention had been more integrative and family-oriented, the controlling effects of the program would have been demonstrated by significant differences in metabolic control between the experimental and control groups.

While behavioral interventions have demonstrated some success in improving adherence, the literature has been characterized by a general lack of acknowledgement of the role of family members in the management of the disease. Much of the early research conducted with chronic illness populations focused primarily on the medical characteristics of the child only, consistent with the medical or disease model of medicine. However, this model does not sufficiently account for other important variables that potentially mediate the illness condition (Russo & Tarbell, 1984) including psychosocial variables such as family discord or family involvement. Furthermore, empirically based family

approaches are quite rare (see Finney & Bonner, under review, for a review; Friedrich & Copeland, 1983).

In an innovative study of diabetics and their families, Satin, La Greca, Zigo, & Skyler (1989) reported the significant effects of a multifamily group intervention on metabolic control. Diabetics and their families were assigned to one of three groups: multifamily plus parent simulation of diabetes (MF-S); multifamily without simulation (MF), and control. The family intervention consisted of discussions of diabetes management and attitudes among parents and children, discussion of ways the family could work harmoniously regarding diabetes management, and "brainstorming" on how things could be improved. Emphasis was also placed on enhancing family communication and problem solving. The parents assigned to the MF-S group were asked to simulate having a diagnosis of diabetes for 1 week in addition to attending family counseling. The results showed that families in both intervention groups evidenced clinically significant improvements in total Ghb from pre- to post-intervention. The control group did not change. Although no differences were found on subscales of the Family Environment Scale (FES), this study was the first to demonstrate the effectiveness of a family based group intervention and confirmed it with health outcome data. The authors suggested the the FES may not have been sensitive enough to detect daily changes in how families cope with diabetes issues. Importantly, at posttreatment, mothers in the MF and MF-S groups rated their children as higher in diabetes self-management activities. This suggests that improved adherence may have influenced the metabolic status of the subjects as a result of the family intervention and suggests that the behavior of family members represents another potentially useful treatment target.

Parental Responsibility and Disease Management

While family behavior is clearly implicated in the adherence behaviors of diabetics, this influence warrants further investigation. Specifically, in order to examine adherence behaviors adequately, it may be necessary to first delineate who assumes responsibility for various aspects of the prescribed regimen (La Greca, 1988a). Maddux et al. (1986) suggests that increasing a child's responsibility for health-related behaviors is an important goal given the increased prevalence of single-parent families and families with two working parents. Moreover, the authors' suggest that the "greatest challenge and potential for advancement in child health psychology will come from efforts to increase childrens' responsibility for their own health and safety" (pp. 32). They suggest that interventions designed to meet this challenge can be effective if consideration is given to developmental parameters. Therefore, it is necessary to first determine the degree of independence possible, expected, and tolerated by family members. This is important when considering the results of several studies that suggest that increased responsibility is associated with poor metabolic control (La Greca 1982; La Greca, Follansbee, & Skyler, 1990). Moreover, Skyler (1980) suggests that the diabetic should not assume complete responsibility for the regimen, unless he/she feels comfortable with independent self-management.

Ingersoll, Orr, Herrold, and Golden (1986) reported that older and more cognitively mature adolescents adjusted their insulin more frequently based upon blood glucose levels. The authors attributed the behavior of those that did not make adjustments when clearly mandated by the test results to the fact that the parents relinquished responsibility for that part of the regimen prematurely.

Other studies report that good metabolic control is found in families that are involved in the treatment regimen by sharing responsibilities while those in poor control were embedded in a family environment that required the child to assume full responsibility for all aspects of the regimen (Anderson et al., 1981; Hanson & Henggeler, 1984; La Greca, 1982; Newbrough et al., 1985).

Alternatively, poor control is also evidenced in families where parents are too involved and assume too much responsibility (e.g., by being overprotective) (LaHood, 1970). Furthermore, Wertlieb et al. (1986) found that negative behavioral symptoms in IDDM children were correlated with family environments that did not support independence and self-sufficiency.

Certainly, parents of young children would be expected to be involved in the treatment process much more extensively than parents of adolescents who themselves are presumably mature enough to handle the additional responsibilities. Therefore, it follows that problems with adherence behaviors can be expected when the respective roles of the family and diabetic are equivocal (Newbrough et al., 1985).

While family involvement reportedly has a positive affect, albeit indirect, on metabolic control, it is critically important for a child to learn how to manage his/her medical regimen such that the behaviors become habitual before the child gets older and parental involvement may no longer be feasible (Lowe & Lutzker, 1979). This would facilitate the acquisition of health behaviors that can subsequently be integrated into an individual's existing daily routine.

Recently, Anderson et al. (1990) highlighted the importance of sharing and transfer of responsibility for diabetes management tasks. They found that in addition to adherence, disagreements between parents and diabetic children

regarding their perceptions of the assumption of responsibility for diabetes management was predictive of metabolic control. The importance of patterns of agreement and disagreements was underscored when these researchers found that 70% of the families reported that "no one takes responsibility" for one or more regimen tasks. These results suggest that equivocally defined responsibilities need to be identified and clarified before conclusions about the relationship between adherence and metabolic control can be drawn. This is particularly important for preadolescents and adolescents who are seeking more independence in many aspects of their lives. Unfortunately, it is at this crucial time that communication about the transfer and assumption of responsibilities seems to be the most ill-defined (Anderson et al., 1990). Therefore, interventions that facilitate the delineation and negotiation of diabetes management tasks are warranted. When tasks are specifically defined and targeted in an adherence intervention, more informed conclusions can be made about the influence of the family environment on adherence and consequently, metabolic control. A behavioral or contingency contract is a method particularly amenable to this type of responsibility/adherence intervention and involves an agreement for behavior change.

Behavioral Contracts

Behavioral contracts involve several components including: (a) a clear and detailed description of the behavior to be performed; (b) specification of positive rewards if behavior is appropriate; (c) provisions for failure to perform specified behavior; (d) outline of the methods by which the behavior is to be

observed, measured, and recorded; and (e) arrangement so that rewards are proximal to the appropriately performed behavior (Shelton & Levy, 1981).

Behavioral contracting may involve the manipulation of commitment whereby the client agrees verbally, in writing, or a combination of the two to perform the specified behavior (Shelton & Levy, 1981; Wurtele, Galanos, & Roberts, 1980). There have been a number of studies that have used commitment strategies to improve short-term adherence behaviors such as adherence to 10-day antibiotic regimens (Putnam, Finney, Barkley, & Bonner, 1991) or combined strategies that include both behavioral and educational techniques (Finney, Friman, Rapoff, & Christophersen, 1985) that have proven successful in improving adherence. However, there have been few studies that have investigated the impact of commitment to regimens that require multiple adherence behaviors. One recent study reported that a verbal commitment increased the adherence behaviors prescribed for treatment of otitis media (Kulik & Carlino, 1987). Additional research is needed to determine if this method can be extended to long-term multi-component regimens.

In a review of intervention studies classified as behavioral, educational, or combined, Haynes (1979) rated the effectiveness of each type and concluded that behavioral interventions were as good as those that combined strategies (85% and 88%, respectively), whereas educational interventions alone were the least successful in increasing adherence (64%). This is consistent with the findings in the diabetes intervention literature. Three studies reported earlier (Carney et al., 1983; Schafer et al., 1982; Wysocki et al., 1989) have demonstrated the virtues of behavioral contracts with regard to improved frequency of blood glucose

monitoring. This method now requires extension to other components of the regimen to determine the effects on adherence behaviors.

Too often, however, studies employ an approach that combines a number of adherence variables into one measure of adherence, thereby masking the potential significance of individual adherence behaviors (Goodall, & Halford, 1991). Using a principal-component factor analysis of 13 adherence behaviors, Johnson et al. (1986) reported a five-factor solution that accounted for 70.6% of the variance. The factors included: (1) exercise measures; (2) injection measures (3) diet type; (4) eating frequency and glucose testing frequency; and (5) total calories consumed and amount of concentrated sweets ingested. These results are consistent with the findings of Schafer et al. (1983) and suggest that adherence to the diabetic regimen is not a unitary construct and diabetics are not characteristically good or bad adherers. However, the components of the regimen could be viewed as interdependent and functionally related since the therapeutic effectiveness of one component of the regimen is necessarily dependent upon other components. Therefore, a global measure of adherence that combines some or all of these components into one index of adherence may not be appropriate and may lead to erroneous findings. Additionally, it does not reveal to the patient or physician why metabolic control is not maintained within the expected range which may seriously circumvent proper health care delivery. Therefore, even subjects who are non-adherent to only one component, particularly blood glucose testing, are likely compromising the therapeutic benefits of adherence to other components. For example, even if a child administers all prescribed insulin injections, if he/she does not test the blood glucose levels first, an incorrect amount may be injected which may lead to problems (e.g., hypoglycemia). Since adherence to one aspect of the regimen does not predict adherence to others (Johnson et al., 1986), an evaluation of each adherence behavior is critical in order to determine avenues that require behavior change. Interventions can then be developed to target adherence to each component while establishing the functional relationship between each behavior. The behavioral contingency contract then that can more specifically address issues of responsibility and barriers to adherence for parents and children, thus structuring the activities of diabetics and others that indirectly affect and are affected by the disease.

While behavioral contracts have been used in nomothetic studies, the specificity, preciseness, and individualistic nature that characterizes this approach may be compromised in group designs. Instead, the effectiveness of this type of intervention might be better demonstrated using an idiographic approach. Clarity and precision are particularly important when assessing a complex construct such as adherence.

Single Case Designs

Studies that employ within-subjects, single-case designs that allow for the comprehensive evaluation of individual behaviors are needed to more accurately assess the relationship between adherence and metabolic control. Such designs may alleviate the problems inherent in using aggregate definitions of adherence or problems associated with making comparisons across diabetics who are heterogeneous with respect to developmental levels, family environments, regimen prescriptions, or level of metabolic control. A closer examination of daily self-management behaviors using an individuals' own behavior as a

baseline from which to make comparisons may help clarify the relationship between adherence and metabolic control as well as facilitate our understanding of the directionality and temporal ordering of this relationship (Glasgow, Wilson, & McCaul, 1985).

Single-case designs are more flexible and allow for the adjustment of treatment strategies in accordance with the response of the patient. This is particularly important when attempting to isolate effective strategies in populations where methods of behavior change have yielded equivocal results (Rapoff & Christophersen, 1982). It is particularly crucial to design such interventions for pediatric populations who may not have an adequate understanding and appreciation for the potential long-term complications that could result from maintaining poor metabolic control. If adherence behaviors can be improved and maintained through behavioral methods and can be demonstrated to influence metabolic control, the prognosis for juvenile diabetics could be more favorable.

Rationale for Current Study

Because behavioral methods have demonstrated the most promising results for adherence to long-term regimens, the current proposal was designed to evaluate the effects of a behavioral family intervention on adherence to four target behaviors including: blood glucose testing, insulin injections, exercise, and dietary recommendations. The proposed study evaluated the effects of a target-specific written behavioral contract on adherence to the prescribed regimen.

Although the target behaviors chosen were topographically distinct, blood glucose testing is integrally involved in other regimen components. Therefore, by initially placing contingencies on dimensions of blood glucose testing, an assessment of potential of the target behaviors was possible. It could also indicate how future interventions could be designed and where contingencies could best be placed to maximize the therapeutic effects of the regimen.

A behavioral contract was chosen because of its potential applicability for altering the behaviors of both the parent and child with regard to the prescribed regimen. It allows for target-specific barriers to adherence to be addressed with specifications of how those barriers can be attenuated. Importantly, provisions negotiated by both the parent and child can be outlined such that performance of the adherence behaviors is enhanced. This necessitates active participation by both the parent and child and therefore, allows for an evaluation of the diabetic in the context of the family system. Because adherence to the behaviors of the prescribed regimen generally does not have inherent positive properties, target-specific proximal rewards were outlined in the contract for each intervention and delivered by the parent. An emphasis was also placed on distal rewards associated with improved metabolic control. The controlling effects of the behavioral contract were inferred by evaluating rate changes in treated targets while rates remain unchanged in untreated targets (Barlow & Hersen, 1984).

Hypotheses

- 1) Behavioral contracting between the parent and child will result in increased adherence to blood glucose testing, insulin injections, diet, and exercise.
- 2) Target-specific, proximal rewards contingent on performance of the behaviors outlined in the contract will improve the adherence to each target behavior, but

only when the intervention specifically targets that behavior. Untreated behaviors will not be affected until the contingency is placed on that behavior.

- 3) Behaviors that have already been targeted and rewarded will remain high since the contract is extended and cumulative.
- 4) An emphasis on distal rewards contingent on improved metabolic control will serve to maintain target adherence behaviors following the removal of proximal rewards during the follow-up period.
- 5) Improved adherence will result in enhanced metabolic control as measured by a glycosylated hemoglobin test (HbA_{1c}) at post-study.

METHOD

Subjects

Five children with IDDM, (3 female, 2 male) who met study criteria (i.e., nonadherence to blood glucose testing defined as \leq 2 tests daily and metabolic status outside the optimal range according to normal laboratory reference values) were recruited from physician referrals and media announcements. Subjects were between the ages of 10 and 15 (M = 12.6); four were Caucasian and one was African-American. Three subjects were from intact families, one from a family where the father was deceased, and one from a home in which the parents were separated at the time of the study. The duration of IDDM at study entry ranged from 1 year, 11 months to 6 years, 1 month (M =4.3) (see Table 1). All subjects were under the care of a pediatrician or endocrinologist. Four subjects injected insulin (Regular and Lente) one to two times daily and one subject used an insulin pump. Subjects were paid \$30.00 for participation. To

assess metabolic control, all subjects had a glycosylated hemoglobin test (Hb_{alc}) within two weeks prior to the beginning of the study (see Table 2).

A sample of two additional children with IDDM who demonstrated consistently good metabolic control were included to provide a comparison of target behaviors. Subjects included two Caucasian females, ages 10 and 11 whose duration of IDDM was 7 years, 7 months and 2 years, 0 months respectively.

Design and Procedure

A within-subject multiple baseline design across behaviors was employed (Barlow & Hersen, 1984). Following an initial baseline of a minimum of two weeks, a series of four interventions were implemented sequentially, across time, to evaluate adherence to four target behaviors of the prescribed diabetic regimen. Targets included: blood glucose testing, insulin injections, dietary intake, and exercise. Baseline periods for each target behavior consisted of daily monitoring of selected dimensions of each behavior by the diabetic and continued through all phases of the study. To assess nonadherence, subjects were instructed to record daily regimen behaviors for a minimum of two weeks. During the baseline phase, parents were instructed to record these behaviors periodically as a reliability check.

The intervention consisted of developing a target-specific behavioral contract that over time, included additional target behaviors. Each intervention included the following:

1. Delineation of the regimen responsibilities assumed by the diabetic and his/her parent(s) as well as those that are equivocally defined for the specified target behaviors. This was assessed using the Diabetes Family

Behavior Checklist (Schafer et al., 1986) and responses to an interview (see Appendixes A and B).

- 2. Identification of the problems or concerns associated with the current division of responsibilities and potential reasons for nonadherence using the Barriers to Adherence Scale (Glasgow et al., 1986) (see Appendix C).
- 3. Development of a behavioral contract with target-specific contingent rewards designed to address the barriers specific to the target behavior. The contract was negotiated between the parent(s) and the diabetic for each target behavior and implemented sequentially and was facilitated by the researcher (see Appendix D). Included in each contract were the following objectives:
 - a. an outline of the adherence behaviors expected for the target behavior;
 - specification of the responsibilities to be assumed by the diabetic and the parent(s);
 - c. daily and/or weekly rewards contingent on completing target-specific adherence behaviors;
 - d. designation of rewards available for improved health outcome as defined by improved glycosylated hemoglobin results at the threemonth follow-up period; and
 - e. signature from both the parent and child indicating that they agree to adhere to the stated objectives.

Before the intervention, each child was administered a knowledge test developed by the Michigan Diabetes Research and Training Center (1988; see Appendix E) and was evaluated on the skills requisite for adhering to the target behavior (by a physician or diabetes educator when necessary) to determine if

assumption of the negotiated responsibilities was legitimate. This was necessary to eliminate lack of knowledge or a skills deficit as a contributing factor to nonadherence.

Two additional family measures were administered, The Family Adaptability and Cohesion Evaluation Scales (FACES III; Olson, Portner, & Lavee, 1985) and the Family Routines Inventory (FRI; Jensen, James, Boyce, & Hartnett, 1983). These instruments were used to assess family functioning and to facilitate the development of the behavioral contract (see Appendixes F and G).

The Multidimensional Health Locus of Control (MHLC; Thompson et al., 1987) was also administered to evaluate the extent to which subjects believed they controlled their health outcome.

Target/Measures

Blood Glucose Testing: Adherence was defined by an absence of deviations on the dimensions of frequency, timing, and recording of blood glucose levels.

- Frequency: Blood glucose levels should be monitored a minimum frequency of four times daily.
- Timing: At a minimum, blood glucose levels should be monitored prior to dinner or a large meal, exercising, insulin injections, and bedtime.
- Recording: All test results must be recorded in the logbook provided by the experimenter.

Each diabetic was provided with a Lifescan One Touch II glucometer (Johnson & Johnson Company) for blood glucose testing. These meters were equipped with a memory function (250 test capacity) that recorded the date,

time, and level of blood glucose. This provided objective data to validate the self-report logbook data.

Behavior change as a result of blood glucose testing was also recorded and evaluated as a secondary dependent variable that was not specifically targeted. Daily glucose results and subsequent behavior change (if any) was reviewed to determine if the appropriate action was taken. Percentages were calculated by dividing the number of results that were followed by appropriate adjustments by the number of blood glucose test results recorded. Adjustments were defined as appropriate when no change was made when the glucose level was in the normal range and when compensatory changes were made for glucose levels that fell within the hyperglycemic (>180) or hypoglycemic (<75) range.

Insulin Injections: Adherence was defined by an absence of deviations on the dimensions of appropriate frequency and timing.

- Frequency: Insulin frequency must correspond to that prescribed by the physician or endocrinologist (typically 1-2 injections daily).
- Timing: Insulin must be administered in appropriate temporal congruity with meals and insulin peaks and must not deviate by more than 15-30 minutes of that prescribed by the physician.

The site of the insulin injection was evaluated to determine if regularity of rotation was accomplished and served as a secondary dependent variable that was not specifically targeted.

Dietary Intake: Adherence was defined by an absence of deviations on the dimensions of caloric intake.

• Two unscheduled 24-hour recall interviews were conducted each week by the researcher to assess the caloric composition of daily meals. Deviations were recorded if caloric intake violated the recommendations of the American Diabetes Association. Current recommendations include 60% of calories from carbohydrates, 25% from fat, and 15% from protein. If physician recommendations differ from those listed above, adherence definitions were altered accordingly. Deviations were recorded by subtracting the ideal consumption from the actual consumption for each category. A score above zero indicates over-consumption of calories from a particular category; a score of zero indicates ideal consumption; and a score below zero indicates underconsumption (Johnson et al., 1986).

Exercise: Adherence was defined by an absence of deviations on the dimensions of activity frequency and availability of a fast acting simple-sugar.

- Frequency: Subjects were required to exercise at least three times per week. Duration was determined from physician recommendations. Although this was assessed primarily by self-report, the subjects were observed on several occasions if the selected exercise behavior was one that was public. Otherwise, the subjects were asked to verify their exercising behavior (e.g., note from soccer coach) when feasible.
- Carbohydrate Availability: Subjects were asked to record if a fast-acting carbohydrate was easily accessible during periods of exercise in case of a hypoglycemic episode. The criteria for adherence was a minimum of 15 grams of the carbohydrate.

• A secondary dependent variable included the recording of the site of the daily insulin injections to determine if it was conducive to the chosen exercise.

Glycosylated hemoglobin tests were completed before and after the study and served as an index of health outcome. Decreases of 1-2% are considered clinically significant improvements (Goldstein et al., 1982; Jovanovic & Peterson, 1981).

Family Targets

On the basis of interview and assessment data, problematic regimen behaviors were identified by the researcher. During the interventions family members were asked to negotiate which person was to assume responsibility for particular behaviors and to identify means by which this could be achieved by problem solving. Assessment and intervention profiles are given for each subject in Appendix I. Except where noted, all families accepted the division of responsibility described below.

Glucose Intervention. The glucose intervention fostered independence in children by allowing the children to set occasions where at least two blood glucose test could be performed in the absence of parental guidance (e.g., at school, before exercise, at bedtime) while still allowing a supervisory role for preprandial tests. This supervisory role was maintained given that it is on the basis of the preprandial tests that insulin dose adjustments are typically made for hyperglycemia. Additionally, when hypoglycemia occurs, incipient central nervous system dysfunction can occur quickly leaving the child unable to respond to the emergency alone. The children and the family members in the current study all agreed that assistance was still required for these important decisions. Instead of dictating the appropriate adjustment however, the parents

were encouraged to problem solve with the diabetic. Secondly, the child was expected to keep his/her glucometer available at all times (e.g., at school, friend's house, etc.). In addition to contributing to independence, this was considered important so that the child could not cite unavailability of the glucometer as a reason for not testing. Thirdly, the child was given the responsibility for keeping an inventory of glucose testing supplies (e.g., test strips, lancets) and to alert a parent when supply depletion reached a specified level (e.g., 8 test strips left). Again the purpose was to increase responsibility and to reduce the potential for using a lack of supplies as a reason for not testing. Finally, children were expected to record all blood test results. The purpose of this behavior was to provide feedback such that a glucose profile could emerge and provide standards by which the child could interpret results over time. For example, if glucose levels are generally low in the evening before bedtime this should provide a marker to judge an unusually high result. Secondly, the test records could be used by the childs' physician to make informed decisions about the regimen prescription. Finally, the records could be used by the parents to judge performance and provide rewards accordingly. One important caveat to the above guidelines for increased independence was that diabetics were expected to immediately report any instances of extreme hypo- or hyperglycemia in case assistance was needed. The parental response to such reports comprised the first responsibility delineated.

Specifically, the parent was expected to be supportive and helpful in the event of an extreme score instead of demanding an explanation for the result or punishing the child. Subjects in the current study cited this as perhaps their biggest complaint about their parents' behavior. Secondly, the parents were

expected to provide assistance in interpreting and making adjustments for preprandial blood glucose tests. In response to the supply inventory kept by the subject, the parent was expected to maintain supplies. Finally, and importantly, the parent was to reward <u>performance</u>, not results, of daily blood glucose tests. This behavior could be supplemented by providing verbal praise for good results and constructive feedback/suggestions for poor results but the reward was not to be contingent on this. Feedback about poor results was to be given in a manner that was encouraging, not accusatory or punishing.

<u>Insulin Regimen.</u> Because all children with the exception of one (W) were delivering their own insulin, the insulin intervention primarily focused on structuring family routines in order to accommodate the necessary temporal interval between insulin peaks and meal timing. In general, the diabetic children assumed responsibility for altering morning and/or evening routines sufficiently to ensure that ample time was allotted to the insulin regimen. During baseline, all subjects ignored the temporal relationship and instead insulin was injected simultaneously with meals and in many cases after the meal, which likely compromised the therapeutic effects. Therefore, children were expected to set alarms in order to wake up at a time to accommodate the time interval in the mornings or they were expected to alter the order of morning behaviors (e.g., injection, shower, then meal). Secondly, the diabetics were expected to inquire about meal timing instead of relying on the parent to prompt or "nag" them about the injection. Thirdly, diabetics were also expected to keep a supply inventory. Subject W who was not injecting his insulin independently yet (only 1 injection daily), was instead required to prepare the injection site, have the

supplies ready, and practice injections on scheduled mornings as his responsibilities.

Parental responsibilities for the insulin intervention included consistent meal timing in order to increase routinization and predictability in the family environment and maintenance of supplies.

Dietary Regimen. In the dietary intervention, diabetics assumed responsibility for contributing to meal planning and in some cases meal preparation. For example, the diabetic was expected to select foods that were appropriate for the regimen for the family meals and to provide input on shopping lists. Independence was also fostered by giving the child the primary responsibility for lunch meals. This meant that it was the child's responsibility to pack his/her lunch on days when the school lunch was not appropriate for the dietary regimen or to take supplements for the school lunch (e.g., take an apple instead of eating the school dessert). Additionally, the children were expected to select the appropriate milk product at lunch (e.g., low fat instead of whole or chocolate). Finally, the diabetics were expected to eat all meals (frequently they skipped breakfast) and to eat snacks at prescribed times only. Related to this, in the event of parental absence at meal time, diabetics were expected to prepare their own meals in order to maintain the dietary routine.

Parental responsibilities included providing a variety of foods for meal preparation and snacks (frequently the children reported that they were "sick of eating the same thing every day"). It was expected that the greater the variety in the diet regimen, the less likely the children would be to deviate from their diets. Instrumental support was provided when the parents structured their own routines so that meals could be eaten together at a time that accommodated

insulin peaks of the diabetic. When this was not possible or when the parent was absent, they were also responsible for providing foods that were reasonably simple to prepare and appropriate for the diabetic diet.

Exercise Regimen. Diabetics were given the responsibility for initiating regular exercise routines (other than school physical education); choosing indoor activities in the event of inclement weather (this was identified as a barrier to adherence for all subjects), and ensuring that fast-acting carbohydrates were available in several places in the event of a hypoglycemic response (e.g., in locker at school, book bag, purse). Finally, children were expected to exercise at times when blood sugar results indicated it would be appropriate, with consideration of insulin peaks.

Parental responsibilities included maintaining supplies of fast-acting carbohydrates that were designated as diabetes specific snacks (e.g., other family members were not to deplete the supply). Secondly, parents were to be tolerant of indoor physical activity (e.g., aerobics). Instrumental support was provided when the parents agreed to participate in exercise routines periodically (e.g., walked or rode bikes together).

Follow-Up

Follow-up data were collected one-month post-study. Subjects were asked to monitor their adherence behaviors for a one week period and two diet interviews were conducted.

Data Analysis

The results were analyzed by visual inspection of a graphic display of the data (Baer, 1977; Barlow & Hersen, 1984) across baseline and intervention phases and computation of phase means and adherence index percentages for glucose and insulin target behaviors. The adherence index (AI) represents a composite of frequency and timing dimensions relative to the level of adherence prescribed for each phase (e.g., AI = total number of tests or injections performed at the appropriate time/level of adherence prescribed). Dietary data were analyzed with Nutritionist III (1985) computer software.

RESULTS

Subject B: (Figure 2)

Glucose Regimen

Figure 2 shows that subject B tested her blood glucose an average of 1.9 times daily during baseline with all tests performed at the appropriate time. When the glucose intervention was implemented B initially demonstrated a sharp increase in daily tests, but over time, responding leveled off to a mean of 2.8 tests daily, revealing moderate intervention effects. Of those 2.8 daily tests, 95% were performed at the appropriate time. Figure 2 illustrates the effects of the intervention by revealing an increase in responding when blood glucose testing was specifically targeted, with no concomitant increase in non-targeted behaviors. Testing frequency and timing remained relatively stable across subsequent interventions although responding to both variables decreased during the final phase (e.g., exercise) with 2.6 tests performed at the appropriate

time on 92% of occasions. Table 3 summarizes frequency means, timing percentages, and adherence indices across conditions.

Therefore, adherence to glucose timing was demonstrated initially following intervention, but was limited to a mean of 2.8 tests across all phases. In fact, this subject only achieved 100% adherence on 5 of 118 days. Furthermore, it should be noted that B was the only subject who fabricated data for blood glucose testing during the baseline phase of the experiment. Data collected from the memory function of her blood glucose testing meter revealed that there were several errors of commission. Although reliability data were collected from the mother, this subject's father cautioned the experimenter about the accuracy of this data as well. Therefore, the accuracy of the self-report data that could not be independently verified is questionable.

Insulin Regimen

Baseline responding for insulin behaviors revealed a mean performance of 2 tests daily indicating 100% adherence to insulin injection frequency. Of the 66 injections given during the baseline phase, however, only 2 were performed at the appropriate time yielding an adherence index of only 3%. When the insulin intervention was delivered, injection frequency remained high and 77% of the injections were given within the appropriate temporal interval with meals. Frequency remained stable across subsequent phases of the study but decrements in timing behavior were noted. This suggests moderate maintenance of intervention effects (see Table 4).

Dietary Regimen

Dietary intake evidenced substantial variability across all phases of the study. However, there was marked under-consumption of carbohydrates during the baseline phase and over-consumption of fat. Figure 2 shows a substantial decrease in fat consumption after the intervention and this decrease was maintained. Carbohydrate consumption showed an initial increase close to ideal consumption during the first week of intervention (week 11) but subsequently returned to near baseline levels. During the first week of the exercise intervention (week 15), carbohydrate intake returned to the ideal level, but the effects were not maintained. Protein intake was relatively stable across all phases. According to medical records, this subject gained approximately 8-10 pounds over the course of the study, which suggests that errors of omission may have occurred with this subject's self-report data. In other words, this subject may have failed to report all food consumed (overtly or covertly) during recall interviews.

Exercise Regimen

Baseline responding to exercise behaviors (frequency and availability of a carbohydrate) was characterized by nonadherence with the exception of week 5. When exercise was specifically targeted, weekly exercise frequency increased to three times for week 15 (adherence reached) and two times for week 16. Carbohydrates were available on all occasions. While intervention effects for adherence for both variables were noted, exercise responding demonstrated an initial increase during the dietary intervention (see weeks 11-14) although adherence (e.g., three times weekly) levels were not achieved. This suggests, however, that diet and exercise may not be independent target behaviors, particularly with regard to fat consumption. Ideally, baseline for exercise behaviors would have been extended for another week to determine if responding continued to increase or returned to previously levels. However,

due to the problems mentioned above with this subject, the experimenter proceeded to introduce the final phase of the study.

Health Outcome

The health outcome measure for subject B revealed a post-study increase in glycosylated hemoglobin by 1% (see Table 2). Although considerable increases in responding over baseline were exhibited with the implementation of glucose testing and insulin timing interventions, these increases suggested only moderate adherence overall. Additionally, maintenance of responding decreased for all dependent measures. This is important given that the hemoglobin assay yields a mean glycosylated hemoglobin level over the previous 6-8 weeks which would have predominantly reflected the subject's responding during the latter phases of the study. Finally, as mentioned earlier, the questionable veracity of the self-report data may also help explain the health outcome results.

One Month Follow-Up

Data collected at the one month follow-up period revealed a return to baseline levels of responding for glucose behaviors. While insulin responding evidenced a progressive regression toward baseline across the intervention phases, responding was moderately higher at the follow-up period when compared to baseline levels. Minimal improvements were noted in carbohydrate intake and protein intake reached the ideal level.

Subject W: (Figure 3)

Glucose Regimen

Baseline responding for blood glucose testing revealed that W tested his blood a mean of 2.3 times daily with only 28% of those tests performed at the

appropriate time. When glucose testing was specifically targeted, frequency increased considerably to a mean of 3.8 tests daily with 74% performed at the correct time with no concomitant increases in non-targeted behaviors.

Maintenance of responding to this target was evidenced during subsequent conditions with an improvement noted in timing during the final phase of the study (see Table 3).

<u>Insulin Regimen</u>

Baseline insulin responding yielded a mean frequency of one injection daily yielding 100% adherence, however, only 25% of those injections were given at the appropriate time. When the insulin intervention was delivered, frequency remained stable and appropriate timing increased considerably to 85% which demonstrated the effectiveness of the intervention. These results are particularly important given that this subject only received one injection daily. Insulin frequency responding was maintained during subsequent conditions although a slight decrease was noted in timing during the exercise condition (see Table 4).

Dietary Regimen

Dietary analyses indicated that during baseline, calorie consumption initially demonstrated levels that were close to ideal (e.g., weeks 1 and 3). However, decrements were noted prior to the introduction of the glucose intervention. Over the course of the baseline period fat was typically over-consumed but decreased closer to the ideal line during the diet intervention. Underconsumption characterized baseline intake of carbohydrates and levels close to the ideal were achieved during the intervention. Less remarkable changes were evidenced for protein which remained fairly stable across all phases.

Exercise Regimen

Exercise responding revealed very little activity during baseline with only one week where adherence was achieved. However, 100% adherence was exhibited during the exercise intervention. For this subject, diet and exercise appeared to be independent behaviors.

Health Outcome

A mid-study glycosylated hemoglobin test was performed which reflected behavioral responding following both glucose and insulin interventions. At this time, glucose adherence was 71% and insulin adherence was 85%. The test revealed a clinically notable 3.8% decrease over pre-study levels. Additionally, this result was the lowest ever achieved for this subject with previous levels never falling below 12% and reaching as high as 17.3% on one occasion. The post-study health outcome index revealed glycosylated hemoglobin percentage of 9.5% which suggests that metabolic status remained stable (see Table 2).

One Month Follow-Up

Data collected at the one month follow-up period revealed maintenance of responding to all target behaviors.

Subject T: (Figure 4)

Glucose Regimen

Baseline responding for blood glucose testing revealed a mean of 2.1 tests daily with 97% of those tests performed at the appropriate time. During the glucose intervention phase, frequency increased to a mean of 3.9 tests daily with 92% performed at the appropriate time. Frequency increased to perfect adherence during the insulin intervention (e.g., 4 tests daily) and remained high

across subsequent condition. Timing, however decreased in the final phase. (see Table 3).

Insulin Regimen

During baseline for insulin behaviors, T injected insulin a mean of two times daily equalling 100% adherence. However, injections were given during the appropriate time interval only 11% of the time. When timing was specifically targeted during the insulin intervention, frequency remained stable while timing showed a marked increase to 84%. Frequency remained stable throughout all subsequent phases but maintenance of timing behaviors deteriorated somewhat during the final condition of the study (see Table 4).

Dietary Regimen

Dietary intake during baseline revealed that, consistent with the previous two subjects, carbohydrate intake was low and fat intake was initially low but increased considerably prior to the intervention. During the intervention, fat consumption reached near ideal levels but carbohydrate intake remained low (although higher than baseline levels). Protein levels remained stable across all phases.

Exercise Regimen

While the exercise intervention demonstrated an increase in responding, this subject was already exercising fairly regularly throughout the study. Because she was concerned with weight gain, she purchased an aerobics videotape and began exercising during baseline and increased responding over the course of the study. While it might be argued that this responding was in response to participation in the study, the fact that the behavior was maintained over all phases suggests that other factors were involved. Given that adherence was

initially reached during the glucose intervention and maintained for 10 of the subsequent weeks, it is plausible that increased attention to other areas of the diabetic regimen generalized to exercise behavior, thereby suggesting that exercise covaries with other target behaviors. An intervention was introduced anyway since a slight decrease in responding was noted during the latter part of the diet phase.

Health Outcome

The health outcome index result of 8.3% is a clinically significant 1.8% decrease over the pre-study glycosylated hemoglobin level (see Table 2).

One Month Follow-Up

Data collected at the one month follow-up period revealed an average testing frequency of three tests daily but a return to baseline levels of responding for glucose timing (AI = 67%). Insulin timing was consistent with responding during the final phase of the study, although considerably higher when compared to baseline. Dietary intake was close to ideal for fat and protein and carbohydrate intake was consistent with that during the intervention. Exercising decreased substantially.

Subject H. (Figure 5)

Glucose Regimen

Baseline data for blood glucose testing frequency and timing revealed marked nonadherence (e.g., only one test performed during the 28 day baseline period). When the glucose behaviors were specifically targeted, testing frequency increased sharply to an average of 3.7 tests daily with 98% performed at the appropriate time. No changes were observed in non-targeted behaviors.

Testing frequency declined across subsequent conditions to an average of two tests daily during the final phase of the study although timing remained high (see Table 3).

Insulin Regimen

During baseline, insulin frequency data indicated that two injections were performed daily, however, only 15% of the injections were administered at the appropriate time. When the insulin intervention was implemented, frequency remained adherent and appropriate timing index yielded 61% which represents a substantial increase over baseline behavior. Insulin frequency and timing remained stable for the remainder of the study although two injections were erroneously omitted during the final phase of the study (see Table 4).

Dietary Regimen

Dietary intake during baseline revealed that, consistent with other subjects, carbohydrate intake was low and fat intake was high prior to the intervention. During the intervention, fat and carbohydrate consumption reached near ideal levels but carbohydrate intake decreased progressively and approached baseline levels during the final week of the study. Protein levels remained stable across all phases.

Exercise Regimen

Because of the already high adherence to the exercise regimen, a formal exercise intervention was not implemented.

Health Outcome

A mid-study glycosylated hemoglobin test was performed which reflected behavioral responding following both glucose and insulin interventions. It should be noted that this subject exercised regularly throughout all phases of the

study. Specifically, he reached or exceeded the adherence index specified in the study for 7 out of the 9 weeks prior to the hemoglobin test. Therefore, the hemoglobin test included this data as well as glucose adherence of 70% and insulin adherence at 61%. The test revealed a clinically significant 4% decrease over pre-study levels, which placed him in the normal range. Additionally, this result was the lowest ever achieved for this subject. The post-study health outcome index revealed a glycosylated hemoglobin percentage of 8.8%. This represents .8% decrease over pre-study results and approached clinical significance (see Table 2). This was in spite of the fact that this subject continued to exercise regularly and insulin adherence was maintained at the level achieved for the mid-study hemoglobin test. However, maintenance of glucose regimen behaviors decreased considerably. Additionally, it should be noted that following the insulin intervention, this subject's physician changed the timing of insulin injections (e.g., injections were to be given at 5:30 everyday, regardless of meal timing). Given the increase in glycosylated hemoglobin levels following this alteration, it appears as though this subject would benefit from returning to the temporal parameters suggested by the insulin intervention (e.g., 15-30 minutes prior to meals). Consistent with other subjects, it appears as though glucose testing and insulin behaviors contribute the most to the glycosylated hemoglobin results.

One Month Follow-Up

Data collected at the one month follow-up period revealed moderate maintenance of responding to all target behaviors. Although glucose responding was characterized by a progressive decline across the intervention phases, follow-up data suggests considerable improvement over baseline.

Subject S (Figure 6)

Glucose Regimen

Figure 6 shows that Subject S tested her blood glucose an average of 1.3 times daily during baseline with 63% of those tests performed at the appropriate time. When the glucose intervention was implemented S initially demonstrated a increase to 2.9 daily tests (71% performed at the appropriate time), and continued to increase during the insulin phase. However, during the diet phase, S failed to complete the daily monitoring forms and in the final phase, responding (particularly appropriate timing) decreased considerably (see Table 3). Figure 6 illustrates the initial effects of the intervention by revealing an increase in responding when blood glucose testing was specifically targeted.

Additionally, it appears as though glucose and insulin regimen behaviors are functionally related for this subject. Figure 6 reveals that when glucose testing was targeted, changes in insulin behaviors were also noted. An insulin intervention was delivered anyway given that there was additional room for improvement.

Insulin Regimen

Subject S used a continuous subcutaneous insulin infusion pump (CSII) instead of insulin delivery by injection. Baseline responding for insulin behaviors revealed a mean performance of two basal rate increases daily indicating 100% adherence for frequency. Of the 138 meal-boluses during the baseline phase, however, only 31 were performed at the appropriate time yielding an adherence index of only 22%. All 31 occurred when glucose testing was targeted. When the insulin intervention was delivered, frequency remained high and basal rate increases were performed within the appropriate temporal

interval on 75% of the occasions. Frequency remained stable across subsequent phases of the study but timing decrements were noted in the final phase, suggesting moderate maintenance of intervention effects (see Table 4).

Dietary Regimen

Dietary intake during baseline evidenced substantial variability. However, with the exception of week 4, there was marked under-consumption of carbohydrates. Fat intake was close to ideal levels for the majority of the baseline period (with the exception of weeks 6,8,10). Figure 6 shows the improvements in carbohydrate intake and near ideal levels of fat consumption after intervention. According to medical records, this subject gained approximately 18 pounds across the three weeks prior to and including the study period, which suggests that errors of omission may have occurred with this subject's self-report data. Additionally, the nutritional content of between meal snacks was not assessed. Protein intake for this subject was somewhat higher than other subjects and this may also have contributed to weight gain. Notably, this subject's mother reported that S frequently coped with "stress" periods by eating. Given that at the time of the study, this subject's life was characterized by a considerable degree of stress the weight gain could have been expected. Finally, this subject's father participated during the diet intervention for one session only. While he and the subject appeared to appropriately negotiate treatment goals for meals at his house, the effectiveness of the diet contract could not be evaluated. S reported that the father did not follow through on his designated responsibilities, however.

Exercise Regimen

Baseline responding to exercise behaviors (frequency and availability of a carbohydrate) was characterized by moderate adherence (with the exception of week 7), the adherence criterion was not met. When exercise was specifically targeted, weekly exercise frequency increased to 3 times for week 15 and 5 times for the final week.

Health Outcome

The health outcome measure for subject S revealed a disappointing poststudy increase in glycosylated hemoglobin by 3.3% (see Table 2).

One Month Follow-Up

Data collected at the one-month follow-up period suggested poor maintenance of responding to blood glucose testing and adequate maintenance of insulin behaviors. Near ideal levels of carbohydrates and fats were consumed and adherence to the exercise regimen was maintained.

Comparison Subjects

Subject J (Figure 7)

During the three week monitoring period, Figure 8 reveals that subject J tested her blood a mean of 2.7 times daily with 95% of those tests performed at the appropriate time. All insulin injections were given and 81% were given in the appropriate time interval. Dietary analyses revealed under-consumption of carbohydrates but only minimal over-consumption of fat. The adherence criterion was met for exercise frequency for two of the three weeks and carbohydrates were available during all occasions.

Subject A (Figure 8)

During the three week monitoring period, Figure 7 illustrates that subject K tested her blood an average of 3.8 times daily and 91% of these tests were performed at the appropriate time. Insulin injection frequency was stable (e.g., 2 injections daily) and injections were given at the appropriate time on 81% of the occasions. Consistent with the treatment subjects, this subject's diet was characterized by over-consumption of fat and under-consumption of carbohydrates. Exercise data indicated adherence across the three week period with carbohydrates available on all occasions.

Regimen Alterations

Table 5 summarizes the percentage of appropriate action taken following blood glucose testing. While this behavior was not specifically targeted, the data is informative for interpreting intervention effects. Appropriate change was defined in the current study as the administration of supplemental insulin when preprandial blood glucose levels reached the hyperglycemic range (>180) or compensatory responses when blood glucose levels fell within the hypoglycemic range (<75). The most appropriate response in the latter case would be the ingestion of a fast-acting carbohydrate. Judgments about insulin supplements were based upon specific recommendations for subjects if provided by his/her physician/endocrinologist. If specific guidelines were not provided, algorithms proposed by Skyler, Skyler, Seigler, & O'Sulllivan (1981) were used. These algorithms were developed on the basis of insulin type, weight of the diabetic, and blood glucose ranges. For example, a person greater than 40kg in weight

on regular insulin should administer 1-2 units of insulin (supplements) for every 30-50 mg/dl that the preprandial blood glucose result exceeded 140 mg/dl.

In general treatment subjects made appropriate alterations on greater than half of the possible occasions during baseline. Following the glucose intervention, improvements in alterations were noted. One subject (B), however, made the appropriate change on only 37% of the possible occasions. This is noteworthy given that this subject had fewer opportunities to make changes given her relative nonadherence to blood glucose testing across treatment phases. In effect, she not only failed to take advantage of feedback, but when the feedback was available, it was responded to inappropriately. Noteworthy is subject H who tested his blood only one time during baseline and in the treatment phase, made appropriate adjustments 61% of the time which likely contributed to the clinically significant change in metabolic control at mid-study. Comparison subjects demonstrated the greatest percentage of appropriate changes (e.g., 87% and 80% percent). With the exception of one subject (T), changes made in response to hypoglycemic test results were considerably better than those for hyperglycemic test results.

Data regarding other secondary dependent variables (e.g., rotation of injection site and appropriateness of injection site for chosen exercise) suggested adequate adherence.

Psychosocial Measures

Psychosocial data are summarized in Tables 12 through 17. In general subjects' ratings on the FACES III (Table 6) indicated that their families were functioning in the mid- or extreme ranges of the circumplex model. Interestingly,

discrepancies were noted between child and parental ratings for all subjects, with most parents' rating their families as balanced.

All treatment subjects except one (subject B) evidenced increases in positive family behaviors at post-study as measured by the DFBC (Table 7). The data for negative family behaviors were variable.

All children except one comparison subject (subject J) believed health-related behaviors were controlled internally as measured by the MDHL (Table 8).

The frequency of barriers to adherence was higher for treatment subjects (with the exception of subject S) at pre- and post-study on the BAS (Table 9). However, the frequency of barriers endorsed for treatment subjects decreased to the level of comparison subjects at post-study (with the exception of subject B).

Diabetes knowledge as measured by DKT (Table 10) scores were low (below 70% for all subjects except S and A) and endorsement of pre-study family routines on the FRI (Table 11) did not distinguish treatment from comparison subjects.

DISCUSSION

The current study was designed to assess the effectiveness of a behavioral family intervention for improving diabetes management in children with IDDM and to evaluate the nature of the relationship between adherence and metabolic control. The results showed that adherence could be improved using a family intervention and that in general, improved adherence directly affected metabolic control. Specifically, four of the five children demonstrated substantial improvements in adherence across all target behaviors. One subject evidenced improvements initially, but adherence levels were not maintained. Of the four

subjects that increased adherence, three showed clinically significant improvements in metabolic control as indexed by Ghb levels at mid- and/or post study. The data suggested moderate support for the independence of target behaviors; however, there was some evidence to suggest that diet and exercise may covary with other regimen behaviors for some individuals. Furthermore, for one subject, glucose testing and insulin behaviors appeared to be functionally related.

Temporal generalization of treatment effects was attempted by using delayed rewards (for improved health outcome) and through the inclusion of family members as active agents who could continue the intervention upon completion of the study. In general, however, data collected at the one-month follow-up period revealed only moderate maintenance of responding to target behaviors.

While the delineation of family responsibilities has been identified as one important variable for diabetes management (Anderson et al., 1990; Ruggiero, Mindell, & Kairys, 1991), this has never been manipulated and tested empirically. The current study suggests that by instructing diabetics and their parent(s) to identify important regimen behaviors and then negotiating which person is to assume responsibility for each behavior, an environment conducive to adherence can be constructed. Behavioral contracting was particularly useful for this strategy. In the current study, instead of the contract being proposed between the therapist and subject as in the more traditional approach, the contract was placed between the diabetic and relevant family members who agreed to participate. The utility of this approach is highlighted when considering that with chronic illness, the family is partially, and in some cases, fully responsible

for the medical care (La Greca & Stone, 1985). Therefore, contracting between family members is a viable strategy that might facilitate maintenance of treatment gains once removed from the treatment setting. These contracts were based on individual psychosocial profiles using both global family measures and more proximal diabetes specific assessment tools. Additionally, interview data facilitated their development.

The contracts in the current study fostered independence in the diabetic children by allowing them to assume more responsibility for their regimen while allowing the parents to remain peripherally involved. Parent behaviors were expected to become more encouraging and supportive. Responsibility for behaviors specified in the contract was assumed by a family member only when agreement was reached that such responsibility assumption was appropriate. The importance of family negotiation of the regimen responsibilities is underscored when considering that some have found that increased responsibility is associated with poorer metabolic control (La Greca, 1982; Satin, La Greca, Zigo, & Skyler, 1990). Indeed this appeared to be the case with subject S who assumed more responsibilities, demonstrated improved adherence, and yet showed poorer metabolic control. In general, however, increased responsibility was associated with improvements in metabolic control. These results are not necessarily inconsistent with previous findings since responsibility in the current study was transferred to diabetics in a mutually agreed upon manner while also allowing parents to remain involved. Therefore, consistent with Anderson et al. (1990), it is the family sharing of responsibility that is associated with well-controlled children. This suggests that it may not be

the amount of responsibility per se, but how it is delineated and transferred to the diabetic that is most important.

Another important component of the intervention employed in the current study was the provision of rewards for adherence behaviors. Rewarding healthy behavior is important when one considers that with diabetes, there are relatively few immediate consequences for noncompliance. It is well established that some children may not be cognitively prepared to understand the potential long-term impact of poor management of a disease, and therefore, contingencies need to be altered so that the likelihood of disease management is enhanced. Furthermore, rewarding disease related healthy behaviors may reduce the need for a child to use the disease as a means of eliciting attention or using the diabetes as a "crutch." Although setting definable treatment goals is an integral component of many behavioral programs, long-term goal setting may not always be feasible with chronically ill children given the uncertainty of the course of their disease. However, when combined with short-range goals, a focus on distal goals may be appropriate. In the current study, the provision of a larger reward for improved metabolic control at post-study served as a long-term goal.

The incremental nature of the contract (e.g., 1 target behavior at a time) was useful in that it allowed the diabetic and family members to make behavioral changes progressively. Given the complexity of the regimen, this strategy is preferable to advising major alterations that might be overwhelming to families already experiencing difficulties with disease management. Rosenstock (1985) suggests that this type of approach allows for successes at each stage of the

intervention and consequently increases self-efficacy, thereby facilitating the introduction of subsequent target behaviors.

The results of the current study are contrary to those of other studies that have failed to find a relationship between adherence and metabolic control (see Johnson et al., 1990 for a review). Consistent with Anderson et al. (1990), however, three families where responsibilities were clearly defined demonstrated improved adherence and better metabolic control. However, the current data suggest that the influence of each dependent variable may not be comparable in its influence on Ghb results (see Figure 9). While the precise effects of each variable could not be determined from the design employed in the present study, it appears as though behavior change on the dimensions of the glucose and insulin regimens, particularly timing, comprises the primary influence on metabolic status. This was suggested by mid-study hemoglobin tests performed for two subjects and the adherence indices for the final phases of the study that comprised post-study Ghb levels. Furthermore, because all subjects in the current study demonstrated adherence to insulin injection frequency during baseline, this variable alone was not sufficient to improve metabolic control. Therefore, it appears as though the timing dimension combined with improvements in the glucose regimen were the most important while diet and exercise adherence as defined in the current study, did not appear to add much to the therapeutic effectiveness of the intervention. This study, however, does not show the independent effects of the target dimensions of glucose and insulin behaviors. For example, it is not known how much of an effect would have been produced following improvements in each of the glucose regimen dimensions combined only with insulin frequency adherence versus the effects of insulin

frequency and timing in the absence of glucose regimen adherence. Therefore, it is not clear whether it is the interaction between the glucose and insulin regimens or specific effects of each regimen that related most to metabolic status. Because the best available index of metabolic control is the Ghb test which represents control over the previous 6-8 weeks, the effects of each dependent variable alone could not be determined.

Although exercise does not appear to add anything unique to the index of metabolic control, the importance of this regimen component should not be dismissed prematurely given that exercise facilitates insulin absorption and utilization. Perhaps the effects are more cumulative and since it was the last behavior targeted, its influence may not have been apparent following only two weeks of improved adherence (particularly when this is contrasted with the relative absence of energy expenditure prior to exercise intervention). The remarkable improvement in metabolic control at mid-study for subject H (after the glucose and insulin interventions) may have been facilitated by the fact that he was already adherent to the exercise regimen, although this would not explain subject W's mid-study improvement.

Similarly, adherence to the dietary regimen should remain as a target for future interventions given the hypothesized effects of dietary adherence on long-term consequences (e.g., atherosclerosis). Again, levels of adherence may not have been sustained long enough to result in notable effects on metabolic control. Interestingly, however, the comparison subjects were not particularly adherent to these behaviors and yet consistently maintained good metabolic control. Additional factors that may have compromised the effectiveness of the dietary intervention are discussed later.

The results of the current study helped clarify the relationship between adherence and health outcome and addressed some of the inconsistencies in the literature. The target behaviors chosen for the intervention were consistent with those that have been identified in the literature as important for positive health outcome (see Wing et al., 1986) as assessed using a valid index of metabolic control. Because the data from previous studies have yielded equivocal results regarding the relationship between these target behaviors and metabolic control, an attempt was also made to empirically validate these targets. This was accomplished post-hoc by employing diabetic "exemplars" who evidenced consistently good metabolic control and comparing them to the intervention subjects on the adherence dimensions (see Weist, Ollendick, & Finney, 1991; Weist et al., in press). According to Weist et al. (1991) the process for empirical validation should progress from an evaluation of potentially important variables as gleaned from the literature using a between-groups design. Following this, the target behaviors that emerge as significant would then be subjected to an idiographic intervention. Recently, using a nomothetic approach Weist et al. (in press) identified several important target variables that distinguished diabetic children and adolescence in optimal metabolic control from those characterized by non-optimal metabolic status. Specifically, family environment variables (family rules and routines), health locus of control, and coping style emerged as relevant variables to investigate in an idiographic design. Based on these findings, the current study was designed to further investigate family variables, specifically issues of family responsibility for diabetes management. Additionally, health locus of control was assessed but not specifically targeted.

Interestingly, adherence did not emerge as a valid target behavior in the Weist et al. (1991) study. Although this is consistent with the equivocal findings in the literature regarding the nature of the relationship between adherence and metabolic control, adequate assessment of this relationship has been precluded by at least two factors in many investigations: 1) indirect or lack of an independent assessment of adherence with adherence being erroneously inferred from health outcome measures and 2) the lack of a comprehensive assessment of adherence (e.g., typically only one behavior has been assessed or targeted in testing hypotheses about adherence). Therefore, given the limitations inherent in the literature, to determine the validity of adherence as a relevant target, it was necessary to first devise a way to effectively increase adherence to the levels thought to be important for metabolic control. Only then could the effects of adherence on health outcome be assessed.

The comparison subjects employed in the current study differed from treatment subjects in baseline in that they were more adherent to the blood glucose testing and insulin injection regimens, had families that were characterized by a relative absence of diabetes management and responsibility problems as assessed by a structured interview and psychosocial measures, and were in good metabolic control. When adherence was manipulated in the treatment subjects, the differences were less marked between treatment and comparison subjects, most notably with regard to glucose and insulin adherence, thereby supporting the validity of these target behaviors. Moreover, subject B, who did not evidence substantial improvements in these variables, consequently did not show improvements in metabolic control. The behaviors targeted for the dietary and exercise regimens did not distinguish the experimental from the

comparison subjects which suggests that the validation of other dependent measures related to these targets is warranted. Importantly, while metabolic status improved for subjects that attained high levels of adherence, the resulting health outcome index only approached that of comparison subjects. This suggests that other variables might have been operating that were not targeted or controlled in the current intervention.

Based on the current data one important factor that distinguished the intervention subjects from the control subjects appears to be the frequency with which a therapeutic "action" or "controlling responses" (see Wing et al., 1986) is exercised following a blood glucose tests. Specifically, diabetes must be considered a process in which adjustments are made in an effort to prevent the adverse effects of hyper- and hypoglycemia (Weist et al., in press). Selfmonitoring of blood glucose alone is not expected to improve metabolic control if appropriate decisions are not made based on the results. In other words, informed decisions about regimen alterations can be made most effectively when given feedback about blood glucose levels which is best accomplished through frequent blood testing. In this regard, adherence to blood glucose testing can be considered a necessary prerequisite for regimen alterations.

During baseline, appropriate adjustments were made by treatment subjects 1% to 72% of the time (M = 48%). Following the glucose intervention, improvements were noted in all subjects except one (range 37% - 82%, M= 62%). Comparison subjects made appropriate adjustments more consistently (e.g., greater than 80% of the time) which may explain why, even with substantial improvements in adherence, treatment subjects did not attain glycosylated hemoglobin levels as low as the comparison subjects at post-study. Notably, all

subjects (except subject T) including the comparison subjects evidenced poor decision making following hyperglycemic results which suggests problems in utilizing insulin adjustment algorithms. Interventions are needed to test methods by which hyperglycemic excursions can better be controlled given the long-term implications of hyperglycemia.

Anticipatory insulin supplements are also important for the prevention of hyperglycemia (e.g., if the diabetic anticipates ingesting a large meal or unusual exercise activity is planned) but this was not assessed in the current study. Several devices based on computerized algorithms have been developed (e.g., Beyer et al., 1988; Chanoch, Jovanovic, & Peterson, 1985; Peters et al., 1991; Peterson, Jovanovic, & Chanoch, 1985; Schiffrin, Mihic, Leibel, & Albisser, 1985) to facilitate appropriate anticipatory responses where actual blood glucose, planned carbohydrate intake, and planned physical exercise for the next 4-6 hours is estimated prospectively and entered in the computer. The computer then evaluates the information and recommends an insulin dose alteration. A recent study (Peters et al., 1991) found that computer assisted patients were as effective as a group who received guidelines from a diabetes educator in making appropriate adjustments. Prospective combined with appropriate compensatory responses may help the diabetic maintain near-normal glucose results. While promising, computer assisted units will not be available to all diabetics and therefore, research that investigates the most effective method for teaching diabetics to make appropriate regimen changes is an important area for future studies.

Although this paper has thus far attempted to demonstrate the potency of the <u>family</u> as a primary unit of investigation, at times family intervention may be contraindicated (see Finney & Bonner, under review). When the necessary resources, competencies, and requisite skills do not exist, family interventions may prove ineffective. For example, parental psychopathology may preclude a family intervention and in such cases it is perhaps prudent to first treat the parent(s) before expecting him/her to serve as an agent of behavior change for others in the family system. Financial burden of the illness and lack of time may also impede interventions and may represent an added insult by labelling the family even further by their disease (Drotar, 1981). Given that the two subjects characterized by poor metabolic status at post-study did evidence moderate behavioral change following the intervention and yet had hemoglobin levels higher than pre-study levels suggests that other uncontrolled deleterious factors may be functional in the relationship between adherence and metabolic control. Therefore, the hypothesized direct relationship between adherence and metabolic control may be attenuated by other factors including family functioning.

Family Functioning

Why was the intervention effective for some families but not others? Kazak (1989) suggested that although diagnosable psychological problems may not be apparent, typically there is evidence of at least mild or moderate psychopathology somewhere within the family system. Perhaps the same variables responsible for the ineffectiveness of the family intervention itself contributed to decrements in metabolic status. If the family is considered the child's principal source of social support with the most significant role-models by which young children learn how to cope with life stressors, it is imperative to

evaluate both positive and negative contributions of family members to a child's disease adjustment (Blotcky, Raczynski, Gurwitch, & Smith, 1985; Spinetta, 1983).

For example, the impact of paternal characteristics in the chronic illness literature has been scant, however, a few studies have demonstrated the importance of including the father when evaluating adjustment to chronic illnesses (Blotcky et al., 1985; Shapiro & Shumaker, 1987). In a recent study, Chaney and Peterson (1989) found that fathers' satisfaction scores on the Family Satisfaction Questionnaire (Olson & Wilson, 1985) were positively associated with medication compliance in juvenile rheumatoid arthritis patients. This and other studies (Hanson et al., 1988) suggest that fathers would likely play an integral role in the design and implementation of psychological interventions. In the current study, only one subject's father consistently participated (subject T) despite requests by the researcher for their involvement. Therefore, the nonparticipation of the fathers in the current study may have compromised some of the existing resources and support within the family context that could have facilitated the effectiveness of the intervention (Anderson & Auslander, 1980; Sourkes, 1977). Conversely, their nonparticipation limited evaluation of problem behaviors that may have represented barriers to adherence for the diabetics.

Some families may require a renegotiation of roles and routines for a family intervention to be effective. For example, traditional husband-wife roles may need to be modified in order to accommodate the needs of a chronically ill child. Similarly, typical family routines may need to be re-established to integrate the ill child. This inevitably will require communication and cooperation among all family members which has been associated with better long-term adjustment

(Koocher, 1984). In the current study, behavioral observations of subject B's parents suggested that they were a likely candidate for role renegotiation and perhaps had this process been addressed before delivering the family intervention, the effects would have been more favorable.

These data provide support for the proposed direct relationship between psychosocial variables and metabolic control as outlined in the La Greca et al. (1990) model. Specifically, this relationship was hypothesized by La Greca et al. (1990) to be a function of environmental stress which has received some empirical support in diabetic studies.

<u>Stress</u>

Stressors were informally assessed in the current study by asking the diabetics to describe in a space provided on their daily monitoring sheets, any factors that prevented the performance of diabetes management routines that they perceived had an impact on their blood sugar levels. With the exception of a couple of factors (e.g., final exams, death of a pet, and illness), there was a relative absence of recorded stressors. However, it is possible that the acrimonious marital relationships and the allegations of child abuse evident in two families (e.g., B and S, respectively) could have been perceived as stressful to the subjects and may in part explain the non-adherence and poor health outcome results. That some level of adherence was reached by both subjects suggests that the effects of this stress may have been more direct.

Currently, the relationship between stress and metabolic control is unclear. It has been hypothesized that stress can have an indirect effect on health outcome by influencing adherence. However, other studies maintain that stress has a direct effect on metabolic control via the effects of stress on the autonomic

nervous system as well as its hormonal impact on the pancreas (Goetsch, 1989). Specifically, stimulation of the parasympathetic nervous system is thought to release "stress hormones" (e.g, epinephrine and cortisol) as well as growth hormones and endogenous opiates that have been implicated in increased blood glucose levels and impairment of glucose metabolism (Goetsch, 1989, p. 103). In nondiabetics, these hormones enter the blood stream from the pancreas and are activated when a stressful event is encountered which may have an inhibitory effect on insulin release.

Early evidence provided by Minuchin et al. (1975) demonstrates the possible direct effect of psychosocial stressors (e.g., family conflict) on the biological systems of diabetic children. They showed that laboratory induced stress within the context of a family interview resulted in an increase in arousal and free fatty acid production. Such physiological changes, if induced and sustained by the home environment may subsequently compromise metabolic control and the long-term health status of the diabetic.

The direct effects of stress on metabolic control has been explored by Goetsch (1989), who reviewed and critiqued the literature on laboratory studies. Additionally, Cox et al. (1984) investigated the effects of daily hassles as measured by the Hassles Scale (Kanner et al, 1981) on with metabolic control (Hemoglobin A1) in a sample of adult IDDM patients. In general these studies provide compelling evidence for the direct deleterious effects of stress on metabolic control and this represents an area that warrants additional investigation.

Other factors that may be interpreted as stressful include events that occur during the period of adolesence for some persons. Such events as peer pressure and body changes may have deleterious effects on metabolic control.

Adverse Effects of Adolescence on Metabolic Control

Skyler (1980) describes the period of adolescence as the "forgotten years" (p. 463). He further describes this period as characterized by instability and suggests that the diagnosis of diabetes represents an additional stressor that adds to the "turbulence". In addition to potential psychosocial stressors prevalent during adolescence, two others may compromise intervention effectiveness.

Hormonal Changes at the Onset of Puberty. The onset of puberty has been associated with declines in insulin sensitivity in both diabetic and nondiabetic children. In nondiabetics, the body can compensate for this increased resistance to insulin. In diabetics, however, this requires an increase in insulin by approximately 30% to compensate for increased hyperglycemic episodes (Amiel et al., 1986; Bloch, Clemons, & Sperling, 1986). These changes are compounded by the fact that just prior to puberty, growth hormone secretion increases which has also been associated with insulin resistance (Rizza, Mandarino, & Gerich, 1981). Two subjects in the current study (B and S) may have been particularly susceptible to these influences which may have contributed to their reduced metabolic control.

Weight Gain. Although primarily characteristic of NIDDM, obesity has also been linked to decrements in metabolic control of IDDM. While subjects B and S gained a considerable amount of weight over the course of the study, they were

not considered obese. However, the weight gain may have compromised the effectiveness of the insulin therapy given that insulin dosages are determined in part by dietary intake. While intake increased, insulin dosages remained the same and, therefore, may not have been sufficient to compensate for the increased calories. Additionally, given that both subjects were nonadherent to their exercise regimen until it was specifically targeted, the increased caloric intake combined with this low energy expenditure likely further exacerbated the problem. This argues for targeting diet and exercise simultaneously for pubertal children. Additionally, a revision of nutritional guidelines may be necessary for subjects at risk for gaining weight. However, currently there is a great deal of debate about nutrition recommendations.

Nutrition Guideline Controversy

The current study used dietary guidelines consistent with the American Heart Association, the National Cancer Institute, the Nutritional Committee for Recommendations for Children With Diabetes of the American Academy of Pediatrics, and national/international diabetes associations. These guidelines have been used in other studies of diabetic adherence (Johnson et al., 1986). Only one of the subjects in the current study was prescribed a specific diet that included adherence to dietary exchanges while the rest were simply encouraged to follow the guidelines of the American Diabetes Association. While these guidelines have been widely adopted, recently there has been some controversy in the literature regarding the adequacy of the guidelines for effecting improvements in metabolic control (Grundy, 1991; Hollenbeck & Coulston, 1991; Howard, Abbot, & Swinburn, 1991; Riccardi & Rivellese, 1991). Although most of

the dietary research has been conducted with NIDDM, there is evidence to suggest that the guidelines for IDDM need to be revised.

In general the guidelines for diabetics typically include a high complex carbohydrate/low fat diet. The major rationale for this diet is to reduce potential long-term consequences of diabetes (e.g., coronary heart disease), to promote weight control, and to aid blood glucose metabolism. However, some studies have demonstrated that the effectiveness of this diet may instead be dependent upon the type of carbohydrates ingested (e.g., starch vs. fiber), the type of fat (saturated vs. unsaturated vs polyunsaturated vs. monounsaturated), and importantly, the amount of dietary fiber in the diet (Anderson & Akanji, 1991). Interestingly, fiber-rich diets have also be found to increase peripheral insulin sensitivity in non-diabetics, which may have significant implications for the exogenous replacement of insulin in IDDM patients. Additionally, the physical form of fiber has been found to be important for metabolic control (O'Dea, Nestal, & Antonoff, 1980; Riccardi & Rivellese, 1991; Wolver, 1990). Therefore, the simple carbohydrate-fat dimension may not be as useful as once thought.

In summary, recent studies suggest that foods with a slow rate of digestion and slow rate of absorption due to the physical form should comprise the carbohydrate portion of the diabetic meals. This micro-analytic level of analysis was not employed in the current study. However, inspection of the food sources obtained in the recall interviews reveals that subjects infrequently ingested foods that met the above criteria. This may explain in part, why the implementation of the dietary intervention appeared to add very little to the metabolic status of the subjects at post-study. Very few clinical trials testing the

fiber-rich diets have been performed and the long-term effects are currently unknown. Therefore, fiber was not targeted in the current study, although this represents an area where additional research may prove useful for both diabetic and nondiabetic populations.

Cognitive and Developmental Status

A consistent problem in health-related interventions is the subject's lack of appreciation for the long-term consequences of behavior (La Greca, 1988a; Maddux et al., 1986). The importance of cognitive development is underscored when assessing a child's understanding of the relationship between his/her health behavior and illness. Moreover, some level of cognitive development is necessary if children are expected to make independent decisions about their health behaviors and to assume responsibility for such behaviors (Maddux et al., 1986). Furthermore, the maintenance of intervention effects can be expected to be influenced by such variables. Because cognitive developmental differences are possible even within narrow age ranges, the interventions in the current study were carefully designed such that assumption of responsibilities were transferred in a manner that was judged acceptable by both the parents and children. Furthermore, the intervention used could be expected to differ for older or younger children than those employed in the current study given that the level of parental involvement would likely be different for these age groups. Specifically, the nature of the intervention might change as a result of properties of both the parent and the child that vary as the child's chronological age and cognitive maturity evidence changes. Therefore, caution must be taken regarding the external validity of the results.

The extent to which subjects in the current study had an understanding of their disease and its consequences may have impacted their ability to accept responsibility and appreciate the importance of the prescribed regimen. A related construct, health locus of control, was assessed using a revised version of the Multidimensional Health Locus of Control Scales (MHLC; Thompson et al., 1987). Perceptions of control have been associated with acceptance of responsibility for medical problems (Strickland, 1978) and thus, this was likely an important subject variable in the current study. The MHLC is designed to assess childrens' beliefs about sources of health and how much control they perceive they have over health-related factors. A positive relationship between internal locus of control and physical health has been reported in numerous studies although the opposite relationship has been found with chronic illness populations (see Wallston & Wallston, 1981 for a review of the research; Evans & Hughes, 1987). Weist et al. (in press) found a main effect for age and metabolic control in that younger children (between the ages of 8 and 12) scored higher on the Powerful Others subscale as did those in optimal metabolic control. These results suggest the diabetics in good metabolic control believed that their health was determined by their parents and health-care professionals (Thompson et. al., 1987). Interestingly, the optimally controlled children in the Weist et al. study were not significantly more adherent than the nonoptimally controlled children which suggests that the children in that study may not have been prepared cognitively and developmentally to accept more responsibility and independence for their regimen. Conversely, the results of the current study found that all intervention subjects and one comparison subject endorsed items that loaded highest on the Internal scale which suggests that they may have been more prepared for an intervention that delineated more responsibility to the diabetic.

One way to reconcile the differences obtained in this study and previous studies that assessed locus of control is by suggesting that effective diabetes management may best be achieved when children take personal responsibility for their health and are willing to comply with the prescriptions of his/her health care provider (Ferraro, Price, Desmond, & Roberts, 1987). Changing one's health-related beliefs and attitudes may represent one of the most difficult tasks in adherence research with chronically ill children (Rosenstock, 1985), particularly when disease symptoms are minimal as with diabetes.

Some researchers (La Greca, 1988b; Rosenstock, 1985) have suggested that one proposal of health-related perceptions that may prove useful as a model of medical adherence is the Health Belief Model (Becker, Drachman, & Kirscht., 1972). La Greca & Hanna (1983) proposed that those children most likely to be adherent score high on the dimensions of perceived vulnerability to disease, hold strong beliefs that the disease is serious, perceive adherence to the regimen as beneficial for health outcome, and have fewer barriers to adherence. Weaker perceptions of the influence of these variables could be expected to attenuate the effectiveness of an adherence intervention, particularly if family members also score low. Furthermore, self-efficacy (akin to locus of control and beliefs about health) has been implicated in several studies (McCaul, Glasgow, & Schafer, 1987; Rosenstock, 1985) as an important construct for diabetes management. This Social Learning Theory perspective represents an interesting area for further research and suggests other variables that may have attenuated the effects of the current intervention for some families.

A host of psychosocial variables have been identified in the diabetes literature as reliably distinguishing diabetics in poor versus good metabolic control. However, currently there is an absence of a conceptual framework to guide the selection of psychosocial targets (Rosenstock, 1985) and consequently it is unclear which variables predict adherence and/or metabolic control. Furthermore, while some studies have proposed that adherence mediates the relationship between psychosocial variables and metabolic control (Hanson et al., 1987; Anderson et al., 1981; Schafer et al., 1983) others have speculated that, in some cases, the relationship may be direct (see La Greca & Skyler, 1991).

Predictive Utility of Current Psychosocial Variables

Current family-based instruments (e.g., FACES III) are a cost and time efficient method of assessing family functioning, however, equivocal results have been obtained, particularly with regard to the "cohesion" dimension (Hanson et al., 1989; Kazak, 1989). Although these family-oriented instruments have been used to assess family functioning in chronic illness samples, it is unclear whether the results simply represent an artifact of the instruments since such measures have not been validated on chronic illness populations (Beck & Smith, 1988). Furthermore, these instruments may mask the competencies that such families possess in the face on unique stressors and an uncertain future, particularly those that rely on clinical scales (e.g., symptom checklists, behavior problem checklists).

A related problem is suggested by the fact that different results emerge regarding such constructs as "cohesion", "conflict", and "rigidity" depending upon the instrument employed. For example, using the Family Environment Scale Anderson et al. (1981) and Klemp and La Greca (1987) found that low

cohesion (enmeshment) and low organization were linked to poor metabolic control in diabetics, whereas Cederblad, Helgesson, Larsson, & Ludvigsson (1982) supported the hypothesis that high cohesion and rigidity (high organization) were associated with poor control.

The Diabetes Family Behavior Checklist (DFBC; Schafer et al., 1986) used in the current study holds promise as a relevant instrument to assess family functioning. Interestingly, in a comparison of pre- and post-study scores on the DFBC, subjects who evidenced the greatest improvements in adherence and metabolic control also evidenced increases in positive family behaviors following the intervention. While the results of negative behavior endorsement were less clear, this and other diabetes specific measure that include an assessment of both positive and negative family behaviors may be useful for structuring interventions where the identification of both strengths and deficits is important.

In general, it appears as though one's standing on measures of relevant psychosocial variables may represent a necessary but not a sufficient condition for subsequent improvements in health outcome (La Greca & Skyler, 1991). However, a better understanding of the contribution of these variables may help resolve the equivocal findings surrounding the relationship between adherence and metabolic control. It may be that the level of adherence necessary may be dictated in part by one's psychosocial profile. Therefore, when attempting to understand the association between a particular psychosocial variable in nomothetic studies, it will be necessary for other potential influential variables, their interactions, and bidirectional influences to be controlled for the effects to be observed (La Greca & Skyler, 1991).

Furthermore, the effects of an intervention on other non-diabetes specific behaviors needs to be considered, given that changes in such behaviors may serve to change the family environment in a way that makes it more conducive to improvements in adherence. Clearly a multivariate approach will be necessary to consider all relevant dimensions of the diabetic treatment regimen as well as numerous other variables that have been implicated. Studies that assess adherence using global composite measures or those that are time limited (e.g., as in the case of data collected at diabetes camps) may fail to achieve a representative sample of behavior and will likely mask relevant variables.

The current study has provided evidence for the importance of one more variable, specifically the clear delineation of regimen responsibilities among family members. The results suggest that a family intervention that targets regimen responsibilities of both the parent and diabetic can indeed effect changes in adherence for some families, although several limitations should be noted.

Limitations

Self Report Data

Effective measurement of a multivariate construct such as adherence is a difficult task (Cluss & Epstein, 1985; Epstein & Cluss, 1982; Glasgow, Wilson, & McCaul, 1985; Johnson et al., 1990), and consequently, the design of interventions poses a particular challenge. The self-report nature of the current study highlights this difficulty. With the exception of blood glucose testing, accuracy of the data could not be verified. Although parents were asked to monitor regimen behaviors periodically to provide an estimate of reliability, the

nature of the intervention limited this as an effective tool (e.g., the diabetics were encouraged to be more independent and parents were expected to be only peripherally involved). The development of blood glucose meters with a memory capacity has led to improvements in the accuracy of research data, however, until more objective instruments are developed for other regimen components, a reliance on self-report seems inevitable. In the current study accuracy of self-report data of blood glucose monitoring was used as a proxy to predict the likelihood of accurate reporting for subsequent target behaviors. Using this criterion, the accuracy of only one subject's data (B) was questionable.

Intervention Length

The virtues of an incremental intervention have been discussed previously. However, future interventions might combine target behaviors that are intuitively related (e.g., glucose testing + insulin and diet + exercise) to reduce the length of study participation. While the self-monitoring in the current study was not particularly difficult or time consuming, the relatively long study period may have compromised the subjects' interest and willingness to participate.

Sample-Selection

Subjects in the current study were those who voluntarily participated. It is possible that these subjects differed in their motivation to make improvements when compared to those who did not participate and therefore, the effects of current intervention may not have been robust for such families.

Temporal Generalization

With the exception of subject W, data collected at the one-month follow-up period revealed moderate to poor maintenance of responding to target behaviors. Historically, maintenance following behavioral interventions has been limited, thereby requiring active efforts to program generalization (Stokes & Baer, 1977). The designation of a distal reward for improved metabolic control at the three-month follow-up period was expected to foster maintenance, however, this did not prove to be powerful enough. Adherence for subject B during the intervention was only moderate at best, therefore, poor maintenance was expected. Additionally, she may have been discouraged by her poor post-study Ghb result and therefore, decided that rigorous adherence to the prescribed regimen was not worthwhile. Conversely, considerable improvements in metabolic control at mid- and post-study may have been reinforcing enough to maintain adherence in subject W. However, this explanation does not hold for subject H who reached normal metabolic status and yet evidenced decrements in responding, primarily to glucose testing targets. It is possible that the subjects lack an appreciation for the importance of their current behavior on future health status and once removed from the stimuli associated with the study that were potentially controlling their behavior (e.g., daily monitoring, contact with the researcher), the importance of adherence was minimized. This suggests that other methods to enhance generalization are warranted. Perhaps the use of intermittent rewards during the intervention period combined with the promise of a distal reward for improved outcome would have been more effective.

Multisystemic Approach

The interventions in the current study focused primarily on the family environment. However, because effective diabetes management relies upon the occurrence of specific behaviors at specified times during the day (Hanson, 1990) behaviors that occur outside of the family system may comprise other potentially valid target behaviors including: coping with perceptions of being different from peers, peer pressure to drink alcohol or deviate from dietary guidelines, and body image problems (Weist et al., 1991). To address these and other potential targets would necessitate a multisystemic approach to treatment (Hanson, 1990). Specifically, interventions may need to be extended to the school environment. In this regard, interventions that foster a better understanding and appreciation of the disease process by school officials and peers may help reduce the stigma commonly associated with having a chronic disease (La Greca, 1990).

Additionally, to maximize the treatment effects, characteristics of medical personnel may need to be targeted. One study has demonstrated the relationship between family satisfaction with health care and health outcome (Hanson et al., 1988). The results suggested that adherence to the regimen was marginally correlated with subjects' satisfaction with the personal attributes of the physician (e.g., a caring attitude) and mothers' perception of the professional competence of the physician. It is interesting to note that three of the subjects in the current study changed physicians at least once and in one case three times in the previous two-year period due to their dissatisfaction with the "mannerism", "style" and "attitude" of the initial physician and beliefs of inadequate medical management. Other studies have shown a physician may have different

attributions for nonadherence that might impact the physician-patient relationship. For example, House, Pendleton, & Parker (1986) found that physicians typically endorse motivation as the primary contributor to nonadherence whereas the patients implicated environmental factors more often.

Consideration of these variables not only expands the range of potential treatment targets, but a focus on other environments and agents may facilitate maintenance and generalization of the intervention effects. This is particularly important in light of the fact that two subjects in the current study (T and H) obtained jobs after school. Decreases in maintenance of targeted variables were concomitant with the onset of these jobs.

The current study employed a multidimensional definition of the construct of adherence. The results suggested that an intervention that focused on aspects of the family system (i.e., regimen responsibilities of family members) was important when targeting this complex construct. Furthermore, measurable increases in adherence resulted in improved metabolic status of three subjects. These results contribute to the validation of the La Greca et al. (1990) psychosocial model in which adherence, a Level II variable, can be influenced by various psychosocial variables. The psyhosocial variables targeted in the current study focused primarily on family responsibility. However, the intervention was not effective for all subjects which suggests that the direct relationship between psychosocial variables and metabolic control proposed in La Greca's model, may also be tenable. Therefore, a more thorough behavioral analysis may be necessary in order to identify other functional variables (stress, family dysfunction, other systems) that are controlling the behaviors (e.g.,

nonadherence) of the subjects more directly. Success in this regard will depend on the development of valid instruments to assess important psychosocial variables potentially involved in adherence; the design of interventions that involve other relevant persons including family members (e.g., fathers, siblings), peers, medical staff, and school/work personnel; the development of objective and verifiable measures of adherence and use of multidimensional instead of univariate definitions of adherence; continued improvement of the medical intervention (e.g., revised nutritional guidelines, appropriate compensation for insulin resistance during puberty); more long-term and prospective (from diagnosis) studies that employ valid health outcome measures to chart interaction patterns across time and status of the medical condition; and validation of treatment targets. These and other factors underscore the fact that psychological intervention should be considered an adjunct to medical treatment for chronic illness populations.

It should be noted, however, that it cannot be determined from the current design whether it was changes in the behavior of family members, the behavioral contract alone, or the interaction between these variables that contributed to the results. This is an important area for future investigation. In particular, if the behavioral contract alone could improve adherence, this would represent a more cost efficient intervention as opposed to attempting to involve multiple family members.

References

- American Diabetes Association, & The American Dietetic Association. (1989). Exchange lists for meal planning. Alexandria, VA: American Diabetes Association/American Dietetic Association.
- Amiel, S.A., Sherwin, R.S., Simonson, D.C., Lauritano, A.A., & Tamborlane, W.V. (1986). Impaired insulin action in puberty: A contributing factor to poor glycemic control in adolescents with diabetes. *The New England Journal of Medicine*, 315, 215-219.
- Anderson, J.W., & Akanji, A.O. (1991). Dietary fiber an overview. *Diabetes Care*, 14, 1126-1131.
- Anderson, B., & Auslander, W. (1980). Research on diabetes management and the family: A critique. *Diabetes Care*, 3, 696-702.
- Anderson, B., Auslander, W., Jung, K.C., Miller, P., & Santiago, J.V. (1990). Assessing family sharing of diabetes responsibilities. *Journal of Pediatric Psychology*, 15, (477-492).
- Anderson, B., Miller, J.P., Auslander, W., & Santiago, J. (1981). Family characteristics of diabetic adolescents: Relationship to insulin control. *Diabetes Care*, 4, 586-594.
- Baer, D. M. (1977). Perhaps it would be better not to know everything. *Journal of Applied Behavior Analysis*, 10, 117-119.
- Barlow, D.H., & Hersen, M. (1984). Single case experimental designs: Strategies for studying behavior change. New York: Pergamon.
- Beck, S., & Smith, L.K. (1988). Personality and social skills assessment of children with special reference to somatic disorders. In P. Karoly (Ed.), *Handbook of child health assessment: Biopsychosocial perspectives* (pp. 149-172). New York: John Wiley and Sons.
- Becker, M.H., Drachman, R.H., & Kirscht, J.P. (1972). Predicting mothers' compliance with pediatric medical regimens. *Journal of Pediatrics*, 81, 843-854.
- Beyer, J., Justner, L., Schrezenmeir, J., Walther, U., Schultz, G., Cordes, U., Kohlmann, C.W., Krohne, H. (1988). Effects of the computer-assisted, meal-dependent intensified insulin therapy on metabolic control, diabetes knowledge, and computer acceptance. [Abstract]. *Diabetologia*, 31, 470.
- Bibace, R., & Walsh, M.E. (1980). Development of children's concepts of illness. *Pediatrics*, 66, 912-917.
- Bloch, C.A., Clemons, P., & Sperling, M.A. (1986). Puberty decreases insulin sensitivity. *Journal of Pediatrics*, 110, 481-487.
- Blotcky, A.D., Raczynski, J.M., Gurwitch, R., & Smith, K. (1985). Family influences on hopelessness among children early in the cancer experience. *Journal of Pediatric Psychology*, 10, 479-493.
- Brewster, A. (1982). Chronically ill hospitalized children's concepts of their illness. *Pediatrics*, 69, 355-362.
- Cameron, O.G., & Curtis, M.D. (1980). Discrimination of intravenously-administered glucose by nondiabetic humans. *Psychosomatic Medicine*, 42, 73.
- Campbell, J.D. (1975). Illness is a point of view: The development of children's concepts of illness. *Child Development*, 46, 92-100.

- Carney, R.M., Schachter, K., & Davis, T. (1983). Improving adherence to blood glucose testing in insulin-dependent diabetic children. *Behavior Therapy*, 24, 247-254.
- Cederblad, M., Helgesson, M., Larsson, Y., & Ludvigsson, J. (1982). Family structure and diabetes in children. *Pediatric and Adolescent Endocrinology*, 10, 94-98.
- Chaney, J.M., & Peterson, L. (1989). Family variables and disease management in juvenile rheumatoid arthritis. *Journal of Pediatric Psychology*, 14, 389-403.
- Chanoch, L.H., Jovanovic, L., & Peterson, C.M. (1985). The evaluation of a pocket computer as an aid to insulin dose determination by patients. *Diabetes Care*, 8, 172-176.
- Cluss, P.A., & Epstein, L.H. (1985). The measurement of medical compliance in the treatment of disease. In P. Karoly (Ed.), Measurement strategies in health psychology (pp. 403-432). New York: Wiley.
- Cox, D.J., Taylor, A.G., Nowacek, G., Holley-Wilcox, P., Pohl, S.L., & Guthrow, E. (1984). The relationship between psychological stress and insulin-dependent diabetic blood glucose control: Preliminary investigations. *Health Psychology*, 3, 63-75.
- Delamater, A.M., Davis, S.G., Bubb, J., & Smith, J. (1987). Utilization of self blood glucose monitoring (SBGM) data by adolescents with Type I diabetes. *Diabetes*, 36 (Supplement 1): 17A.
- DiMatteo, R.M., & DiNicola, D.D. (1982). Achieving patient compliance. New York: Pergamon.
- Drotar, D. (1981). Psychological perspectives in chronic childhood illness. *Journal of Pediatric Psychology*, 6, 211-228.
- Eiser, C. (1990). Psychological effects of chronic disease. *Journal of Child Psychology and Psychiatry*, 31, 85-98. Epstein, L.H., Beck, S., Figueroa, J., Farkas, G., Kazdin, A.E., Daneman, D., &
- Epstein, L.H., Beck, S., Figueroa, J., Farkas, G., Kazdin, A.E., Daneman, D., & Becker, D. (1981). The effects of targeting improvements in urine glucose on metabolic control in children with insulin dependent diabetes. *Journal of Applied Behavior Analysis*, 14, 365-375.
- Epstein, L.H., & Cluss, P.A. (1982). A behavioral medicine perspective on adherence to long-term medical regimens. *Journal of Consulting and Clinical Psychology*, 50, 950-971.
- Evans, C.L., & Hughes, I.M. (1987). The relationship between diabetic control and individual and family characteristics. *Journal of Psychosomatic Research*, 31, 367-374.
- Ferraro, L.A., Price, J.H., Desmond, S.M., & Roberts, S.M. (1987). Development of a diabetes locus of control scale. *Psychological Reports*, 61, 763-770.
- Fiese, B.H., & Sameroff, A.J. (1989). Family contest in pediatric psychology: A transactional perspective. *Journal of Pediatric Psychology*, 14, 293-314.
- Finney, J.W., & Bonner, M.J. (under review). The influence of behavioral family intervention on children's health and health care use. Invited Paper, Behavior Change.
- Finney, J.W., Friman, P.C., Rapoff, M.A., & Christophersen, E.R. (1985). Improving compliance with antibiotic regimens for otitis media. *American Journal of Diseases of Children*, 139, 89-95.
- Fisher, E.B., Delamater, A.M., Bertelson, A.D., & Kirkley, B.G. (1982).
 Psychological factors in diabetes and its treatment. *Journal of Consulting and Clinical Psychology*, 50, 993-1003.

- Follansbee, D.J., La Greca, A.M., & Citrin, W.C. (1983). Coping skills training for adolescents with diabetes. *Diabetes*, 32 (Supplement 1), 147.
- Friedrich, W.N., & Copeland, D.R. (1983). Brief family-focused intervention on the pediatric cancer unit. *Journal of Marital and Family Therapy*, 9, 293-298.
- Gaudet, L.M., & Powers, G.M. (1989). Systems treatment in pediatric chronic illness: A parent group program. Family Systems Medicine, 7, 90-99.
- Glasgow, R.E., McCaul, K.D., & Schafer, L.C. (1986). Barriers to regimen adherence among persons with insulin-dependent diabetes. *Journal of Behavioral Medicine*, 9, 65-77.
- Glasgow, R.E., McCaul, K.D., & Schafer, L.C. (1987). Self-care behaviors and glycemic control in Type I diabetes. *Journal of Chronic Disease*, 40, 399-412.
- Glasgow, R.E., Wilson, W., & McCaul, K.D. (1985). Regimen adherence: A problematic construct in diabetes research. *Diabetes Care*, 8, 300-301.
- Goetsch, V.L. (1989). Stress and blood glucose in diabetes mellitus: A review and methodological commentary. *Annals of Behavioral Medicine*, 11, 102-105.
- Goldstein, D.E., Parker, K.M., England, J.D., England, J.D., Jr., Wiedmeyer, H.M., Rawlings, S.S., Hell, R., Little, R.R., Simonds, J.F., & Breyfogle, R.P. (1982). Clinical applications of glycosylated hemoglobin measurements. *Diabetes*, 31, (Suppl. 3), 70-78.
- Goodall, T.A., & Halford, W.K. (1991). Self-management of diabetes mellitus: A critical review. *Health Psychology*, 10, 1-8.
- Gortmaker, S.L. (1985). Demography of chronic childhood diseases. In N. Hobbs & j.M. Perin (Eds.), Issues in the care of children with chronic illness: A sourcebook on problems, services, and policies (pp. 135-154). San Francisco: Josey Bass.
- Gross, A.M., Heimann, L., Shapiro, R., & Schulz, R.M. (1983). Children with diabetes: Social skills training and hemoglobin Alc levels. *Behavior Modification*, 7, 151-164.
- Gross, A.M., & Johnson, W.G. (1981). The diabetes assertiveness test: A measure of social coping skills in adolescent diabetes. *The Diabetes Educator*, 7, 26-27.
- Gross, A.M., Magalnick, L.J., & Richardson, P. (1985). Self-management training with families of insulin-dependent diabetic children: A controlled long-term investigation. *Child and Family Behavior Therapy*, 7, 35-50.
- Grundy, S.M. (1991). Dietary therapy in diabetes mellitus: Is there a single best diet? *Diabetes Care*, 14, 796-801,
- Hanson, C. (1990). Understanding insulin-dependent diabetes mellitus (IDDM) and treating children with IDDM and their families. In S.W. Henggeler, & C.M. Borduin (Eds.), Family therapy and beyond: A multisystemic approach to treating the behavior problems of children and adolescents (pp. 278-323). Pacific Grove, CA: Brooks/Cole.
- Hanson, C., & Henggeler, S.W. (1984). Metabolic control in adolescents with diabetes: An examination of systemic variables. *Family Systems Medicine*, 2, 5-17.
- Hanson, C., Henggeler, S.W., & Burghen, G.A. (1987). Model of associations between psychosocial variables and health outcome measures of adolescents with IDDM. *Diabetes Care*, 10, 752-758.
- Hanson, C., Henggeler, S.W., Harris, M.A., Burghen, G.A., & Moore, M. (1989). Family system variables and the health status of adolescents with insulindependent diabetes mellitus. *Health Psychology*, *8*, 239-253.

Hanson, C.L., Henggeler, S.W, Harris, M.A., Mitchell, K.A., Carle, D.L., & Burghen, G.A. (1988). Associations between family members' perceptions of the health care system and the health of youths with insulin-dependent diabetes mellitus. Journal of Pediatric Psychology, 13, 543-554.

Haynes, R.B. (1979). Strategies to improve compliance with referrals, appointments, and prescribed medical regimens. In R.B. Haynes, D.W. Taylor, & D.L. Sackett (Eds.), Compliance in health care. Baltimore, MD:

Johns Hopkins Press.

Haynes, R.B., Taylor, D.W., & Sackett, D.L. (1979). Compliance in health care.

Baltimore, MD: Johns Hopkins Press.

Hendrick, S.S. (1985). Behavioral medicine approaches to diabetes mellitus. In N. Schneiderman, & J.T. Tapp (Eds.), Behavioral medicine: The biopsychosocial approach. Hillsdale, NJ: Erlbaum.

Hollenbeck, C.B., & Coulston, A.M. (1991). Effects of dietary carbohydrate and fat intake on glucose and lipoprotein metabolism in individuals with diabetes

mellitus. Diabetes Care, 14, 774-785.

House, W.E., Pendleton, L., & Parker, L. (1986). Patients' versus physicians' attributions of reasons for diabetic patients' noncompliance with diet. Diabetes Care, 9, 434.

Howard, B.V., Abbot, W.G.H., & Swinburn, B.A. (1991). Evaluation of metabolic effects of substitution of complex carbohydrates for saturated fat in individuals with obesity and NIDDM. Diabetes Care, 14, 786-795.

Ingersoll, G., Orr, D., Herrold, A., & Golden, M. (1986). Cognitive maturity and self management among adolescents with insulin-dependent diabetes mellitus. Journal of Pediatrics, 108, 620-623.

Jacobson, A.M., & Leibovich, J.B. (1984). Psychological issues in diabetes mellitus.

Psychosomatic Illness Review, 25, 7-13.

- Jensen, E.W., James, S.A., Boyce, W.T., & Hartnett, S.A. (1983). The family routines inventory: Development and validation. Social Science and Medicine, 17, 201-211.
- Johnson, S.B. (1988). Diabetes mellitus in childhood. In D.K. Routh (Ed.),
- Handbook of Pédiatric Psychology. New York: Guilford. Johnson, S.B., Freund, A., Silverstein, J., Hansen, C.A., & Malone, H. (1990). Adherence-health status relationships in childhood diabetes. *Health* Psychology, 9, 606-631.

Johnson, S.B., Silverstein, J., Rosenbloom, A., Carter, R., & Cunningham, W. (1986). Assessing daily management in childhood diabetes. *Health*

Psychology, 5, 545-564.

Jovanovic, L., & Peterson, C.M. (1981). The clinical utility of glycosylated hemoglobin. American Journal of Medicine, 70, 331-338.

Kanner, A.D., Coyne, J.C., Schaefer, C.A., & Lazarus, R.S. (1981). Comparison of two modes of stress measurement: Daily hassles and uplifts versus major life events. Journal of Behavioral Medicine, 4, 1-39.

Kazak, A.E. (1989). Families of chronically ill children: A systems and socialecological model of adaptation and challenge. Journal of Consulting and

Clinical Psychology, 57, 25-30. Klemp, S.B., & La Greca, A.M. (1987). Adolescents with IDDM: The role of family cohesion and conflict [Abstract]. Diabetes, 36, 18A.

Koocher, G.P. (1984). Terminal care and survivorship of pediatric chronic illness. Clinical Psychology Review, 4, 571-583.

Kronenberger, W.G., & Thompson, R.J., Jr. (1990). Dimensions of family functioning in families with chronically ill children: A higher-order factor analysis of the family environment scale. Journal of Clinical Child Psychology, 380-388.

Kulik, J.A., & Carlino, P. (1987). The effect of verbal commitment and treatment choice on medication compliance in a pediatric setting. Journal of Behavioral

Medicine, 10, 367-376.

La Greca, A.M. (1982). Behavioral aspects of diabetes management in children and adolescents. [Abstract]. Diabetes Care, 31, (Suppl. 2), 47.

La Greca, A.M. (1988a). Adherence to prescribed medical regimens. In D.K. Routh (Ed.), Handbook of Pediatric Psychology. New York: Guilford.

- La Greca, A.M. (1988b). Children with diabetes and their families: Coping and disease management. In T.M. Field, P.M. McCabe, & N. Schneiderman (Eds.), Stress and coping across development (pp. 139-159). Hillsdale, NJ: Erlbaum.
- La Greca, A.M. (1990). Social consequences of pediatric conditions: Fertile area for future investigation and intervention? Journal of Pediatric Psychology, 3, 285-307.
- La Greca, A.M., Follansbee, D., & Skyler, J.S. (1990). Developmental and behavioral aspects of diabetes management in youngsters. Children's Health Care, 19, 132-139.
- La Greca, A.M., & Hanna, N. (1983). Diabetes related health beliefs in children and their mothers: Implications for treatment, Diabetes, 32, (Suppl. 1), 66.
- La Greca, A.M., & Skyler, J.S. (1991). Psychosocial issues in IDDM: A multivariate framework. In P.M. McCabe, N. Schneiderman, T.M., Field, & J.S. Skyler (Eds.), Stress, coping, and disease (pp. 169-190). New Jersey: Lawrence Erlbaum Associates.
- La Greca, A.M., & Stone, W.L. (1985). Behavioral pediatrics. In N. Schneiderman & J. Tapp (Eds.), Behavioral medicine: The biopsychosocial approach. Hillsdale, NJ: Erlbaum.
- LaHood, B.J. (1970). Parental attitudes and their influence on the medical management of diabetic adolescents. Clinical Pediatrics, 468-471.
- Langer, O., & Mazze, R.S. (1986). Diabetes in pregnancy: Evaluating selfmonitoring performance and glycemic control with memory-based reflectance meters. American Journal of Obstetric Gynecology, 155, 635-637.
- LaPorte, R.E., & Cruickshanks, K.H. (1985). Incidence and risk factors for noninsulin-dependent diabetes. In Diabetes in America (pp. 1-12). (NIH Publication No. 85-1468, August). Washington, DC: U.S. Government Printing Office.

Litt, I.F., & Cuskey, W.R. (1980). Compliance with medical regimens during adolescence. Pediatric Clinics of North America, 27, 3-15.

Lowe, K., & Lutzker, J.R. (1979). Increasing compliance to a medical regimen

with a juvenile diabetic. *Behavior Therapy*, 10, 57-64. Maddux, J.E., Roberts, M.C., Sledden, E.A., & Wright, L. (1986). Developmental issues in child health psychology. American Psychologist, 41, 25-34.

Magrab, P., & Calcagno, P. (1978). Psychological impact of chronic pediatric conditions. In P.R. Magrab (Éd.), Psychological management of pediatric problems. Baltimore: University Park.

Mann, N.P., Noronha, J.L., & Johnson, D.I. (1984). A prospective study to evaluate the benefits of long-term self-monitoring of blood glucose in diabetic children. *Diabetes Care*, 7, 322-326.

Marteau, T.M., Bloch, S., & Baum, J.D. (1987). Family life and diabetic control.

Journal of Child Psychology and Psychiatry, 28, 823-833.

Mazze, R.S., Shamoon, H., Pasmantier, R., Lucido, D., Murphy, J., Hartmann, K., Kuykendall, V., & Lopatin, W. (1984). Reliability of blood glucose monitoring by patients with diabetes mellitus. American Journal of Medicine. *77,* 211-21**7**.

- Mazzuca, S.A., Moorman, N.H., Wheeler, M.L., Norton, J.A., Fineburg, N.S., Vincour, F., Cohen, S.J., & Clark, C.M. (1986). The diabetes education study: A controlled trial of the effects of diabetes patient education. Diabetes Care, *9*, 1-10.
- McCaul, K.D., Glasgow, R.E., & Schafer, L.C. (1987). Diabetes regimen behaviors: Predicting adherence. Medical Care, 25, 868-881.

Meichenbaum, D., & Turk, D.C. (1987). Facilitating treatment adherence: Practitioner's guidebook. New York: Plenum Press.

Minuchin, S., & Baker, L., Rosman, B.L., Liebman, R., Milman, L., & Todd, T.C. (1975). A conceptual model of psychosomatic illness in children. Archives of General Psychiatry, 32, 1031-1038.

Moos, R.H., & Moos, B.S. (1981). Family environment scale manual. Palo Alto,

CA: Consulting Psychologists Press.

- Newbrough, J.R., Simpkins, C.G., & Maurer, H. (1985). A family development approach to studying factors in the management and control of childhood diabetes. Diabetes Care, 8, 83-92.
- O'Dea, K., Nestel, P.J., & Antonoff, L. (1980). Physical factors influencing postprandial glucose and insulin responses to starch. American Journal of Clinical Nutrition, 33, 760-765.
- Olson, D.H., Portner, J., & Lavee, Y. (1985). FACES III. St. Paul, MN: Family Social Science.
- Olson, D.H., & Wilson, M. (1985). Family satisfaction. In D.H. Olson, H.I., McCubbin, H. Barnes, A. Larsen, M. Muxen, & M. Wilson (Eds.), Family inventories: Inventories used in a national survey of families across the life cycle (pp. 43-50). St. Paul: Family Social Science, University of Minnesota.

Perrin, E.C., & Gerrity, P.S. (1981). There's a demon in your belly: Children's

understanding of illness. *Pediatrics*, 67, 841-849.

- Peters, A., Rubsamen, M., Jacob, U., Look, D., & Scriba, P.C. (1991). Clinical evaluation of decision support system for insulin-dose adjustment in IDDM. Diabetes Care, 14, 875-880.
- Peterson, C.M., Jovanovic, L, & Chanoch, L.H. (1986). Randomized trial of computer-assisted insulin delivery in patients with type I diabetes beginning pump therapy. American Journal of Medicine, 81, 69-72.
- Phillips, R., Sanchez, J., Pedromingo, A., & Fernandez-Cruz, A. (1987). An evaluation of the credibility of blood glucose results reported by diabetic patients through the use of a reflectance meter with memory. Diabetes, 36 (Supplement 1): 63A.

Potter, P.C., & Roberts, M.C. (1984). Children's perceptions of chronic illness: The roles of disease symptoms, cognitive development, and information.

Journal of Pediatric Psychology, 9, 13-27.

Putnam, D.E., Finney, J.W., Barkley, P.L., & Bonner, M.J. (1991). Enhancing commitment increases adherence with medical regimen. Poster presentation at the annual meeting of the Society of Behavioral Medicine, Washington, D.C.

- Rapoff, M.A., & Christophersen, E.R. (1982). Compliance of pediatric patients with medical regimens: A review and evaluation. In R.B. Stuart (Ed.), *Adherence, compliance and generalization in behavioral medicine*. New York: Brunner/Mazel.
- Redpath, C.C., & Rodgers, C.S. (1984). Healthy young children's concepts of hospitals, medical personnel, operations, and illness. *Journal of Pediatric Psychology*, *9*, 29-40.
- Riccardi, G., & Rivellese, A.A. (1991). Effects of dietary fiber and carbohydrate on glucose and lipoprotein metabolism in diabetic patients. *Diabetes Care*, 14, 1115-1125.
- Rizza, R.A., Mandarino, L.J., & Gerich, J.E. (1981). Dose-response characteristics for effects of insulin on production and utilization of glucose in man. *American Journal of Physiology*, 240, 630-639.
- Rosenstock, I.W. (1985). Understanding and enhancing patient compliance with diabetic regimens. *Diabetes Care*, 8, 610-616.
- Ruggiero, L., Mindell, J.A., & Kairys, S. (1991). A new measure for assessing diabetes self-management responsibility in pediatric populations: The Diabetes Regimen Responsibility Scale. *The Behavior Therapist*, 9, 233-234.
- Russo, D.C., & Tarbell, S.E. (1984). Child health psychology: Emerging responsibilities of the pediatric health psychologist. *Clinical Psychology Review*, 4, 495-502.
- Russo, D.C., & Varni, J. (1982). Behavioral pediatrics. In D. Russo & J. Varni (Eds.), *Behavioral pediatrics: Research and practice* (pp.13-24). New York: Plenum.
- Satin, W., La Greca, A.M., Zigo, M.A., & Skyler, J.S. (1989). Diabetes in adolescence: Effects of multifamily group intervention and parent simulation of diabetes. *Journal of Pediatric Psychology*, 14, 259-275.
- Schafer, L.C., Glasgow, R.E., & McCaul, K.D. (1982). Increasing adherence on diabetic adolescents. *Journal of Behavioral Medicine*, 5, 353-363.
- Schafer, L.C., Glasgow, R.E., McCaul, K.D., & Dreher, M. (1983). Adherence to IDDM regimens: Relationship to psychosocial variables and metabolic control. *Diabetes Care*, 6, 493-498.
- Schafer, L.C., McCaul, K.D., & Glasgow, R.E. (1986). Supportive and nonsupportive family behaviors: Relationships to adherence and metabolic control in persons with Type I diabetes. *Diabetes Care*, *9*, 179-185.
- Schiffrin, A., Mihic, M., Leibel, B.S., & Albissser, A.M. (1985). Computer-assisted insulin dosage adjustment. *Diabetes Care*, 8, 545-552.
- Shapiro, J., & Shumaker, S. (1987). Differences in emotional well-being and communication styles between mother and fathers of pediatric cancer patients. *Journal of Psychosocial Oncology*, 5, 121-131.
- Shelton, J.L., & Levy, R.L. (1981). Behavioral assignments and treatment compliance: A handbook of clinical strategies. Champaign, IL: Research Press.
- Simeonsson, R.J., Buckley, L., & Monson, L. (1979). Conceptions of illness causality in hospitalized children. *Journal of Pediatric Psychology*, 4, 77-84.
- Skyler, J.S. (1980). Diabetes in adolescence: The forgotten years. In S. Podolsky (Ed.), Clinical diabetes: Modern Management (pp. 463-479). New York: Appleton-Century-Crofts.
- Skyler, J.S., Skyler, D.L., Siegler, D.E., & O'Sullivan, M.J. (1981). Algorithms for adjustment of insulin dosage by patients who monitor blood glucose. *Diabetes Care*, 4, 311-318.

Sourkes, B. (1977). Facilitating family coping with childhood cancer. Journal of

Pediatric Psychology, 2, 65-67.

Spinetta, J. (1983). Family response to childhood and adolescent cancer. In D.R. Copeland, B. Pfefferbaum, & A.J. Stovall (Eds.), The mind of the child who is said to be sick. Springfield, IL: Charles C. Thomas.

Stokes, T.F., & Baer, D.M. (1977). An implicit technology of generalization.

Journal of Applied Behavior Analysis, 10, 349-367.

Strickland, B.R. (1978). Internal-external expectancies and health-related behaviors. Journal of Consulting and Clinical Psychology, 46, 1192-1211.

- Tapp, J.L. (1985). Multisystems interventions in disease. In N. Schneiderman & J.T. Tapp (Eds.), Behavioral medicine: The biopsychosocial approach, (pp. 219-254). New Jersey: Lawrence Erlbaum Associates.
- Thompson, B., Butcher, A., & Berenson, G. (1987). Children's beliefs about sources of health: A reliability and validity study. Measurement and Evaluation in Counseling and Development, 80-88. Varni, J.W. (1983). Clinical behavioral pediatrics: An interdisciplinary

approach. New York: Pergamon Press.

Varni, J.W., & Jay S.M. (1984). Behavioral factors in juvenile rheumatoid arthritis. Clinical Psychology Review, 4, 543-560.

Varni, J.W., & Wallander, J.L. (1984). Adherence to health-related regimens in pediatric chronic disorders. Clinical Psychology Review, 4, 585-596.

- Wallston, K.A., & Wallston, B.S. (1981). Health locus of control scales. In H. Lefcourt Ed.), Research with the locus of control construct, Vol. 1, (pp. 189-243). Orlando, FL: Academic Press.
- Watts, F.N. (1980). Behavioral aspects of the management of diabetes mellitus: Education, self-care, and metabolic control. Behavior Research and Therapy, *18*, 171-180.
- Weist, M.D., Ollendick, T.H., & Finney, J.W. (1991). Toward the empirical validation of treatment targets in children. Clinical Psychology Review, 11, 515-538.
- Weist, M.D., Finney, J.W., Barnard, M.V., Davis, C.D., & Ollendick, T.H. (in press). Empirical validation of treatment targets for the management of diabetes in children. Journal of Pediatric Psychology.

Wertlieb, D., Hauser, S.T., & Jacobson, A. (1986). Adaptation to diabetes: Behavior symptoms and family context. *Journal of Pediatric Psychology*, 11,

463-479.

Wilson, D.P., & Endres, R.K. (1986). Compliance with blood glucose monitoring in children with Type I diabetes mellitus. Journal of Pediatrics, 108, 1022-1024.

Wing, R.R., Epstein, L.H., Nowalk, M.P., & Lamparski, D.M. (1986). Behavioral self-regulation in the treatment of patients with diabetes mellitus. Psychological Bulletin, 99, 78-89.

Wing, R.R., Lamparski, D., Zaslow, S., Betschart, J., Siminerio, L., & Becker, D. (1985). Accuracy and compliance to blood sugar monitoring among children

with Type I diabetes. *Diabetes Care, 8*, 214-218.

Wolver, T.M.S., Jenkins, D.J.A., Vuksan, V., Josse, R.G., Wong, G.S., & Jenkins, A.L. (1990). Glycemic index of foods in individual subjects. *Diabetes Care*, 13, 126-132.

Wurtele, S.K., Galanos, A.N., & Roberts, M.C. (1980). Increasing return compliance in a tuberculosis detection drive. Journal of Behavior Medicine, 3, 311-318.

Wysocki, T. (1989). Impact of blood glucose monitoring on diabetic control: Obstacles and interventions. *Journal of Behavioral Medicine*, 12, 183-205. Wysocki, T., Green, L., & Huxtable, K. (1989). Behavioral application of reflectance meters with memory in juvenile diabetes. *Diabetes*, 37(Supplement 1): 18A.

Table 1

<u>Demographic Information for All Subjects</u>

Subject	Gender	Age	Disease Duration at Study Entry	
Experimental	Ss			
В	F	12	1 year, 11 months	
W	M	10	5 years, 11 months	
T	F	15	6 years, 1 month	
Н	M	15	3 years, 3 months	
S	F	11	4 years, 4 months	
	Mean	N Disease	Duration 4 years, 3 months	
Comparison	Ss			
J	F	11	2 years, 0 months	
Α	F	10	7 years, 7 months	
	Mean	N Disease	Duration 4 years, 8 months	

Table 2

Glycosylated Hemoglobin Results for All Subjects

Subject	Pre- Study	Mid- Study	Post- Study	Ghb Change*
Experimental	Ss			
В	7.6	_	8.6	+1.0
W	13.5	9.7	9.5	-4.0
T	10.1		8.3	-1.8
Н	9.6	5.6	8.8	-0.8
S	8.3		11.9	+3.6
Control Ss				
J	7.2		_	
Α	7.3		_	

^{*} Negative scores indicate improvement. A change of 1–2% is considered clinically significant.

Table 3
Glucose Regimen: Frequency Means, Timing Percentages, and Adherence Index

PHASE

Subject	Baseline	Glucose Intervention	Insulin	Diet	Exercise	One Month_F/U
SUBJECT "B"						
Frequency Means Timing Percentage Adherence Index	1.9 100 48	2.8 95 66	2.8 99 70	2.7 90 61	2.6 92 61	2.0 92 50
SUBJECT "W"						
Frequency Means Timing Percentage Adherence Index	2.3 28 1 6	3.8 74 69	3.9 73 71	3.8 73 65	3.9 88 88	4.0 96 96
SUBJECT "T"						
Frequency Means Timing Percentage Adherence Index	2.1 97 52	3.9 92 90	4.0 80 80	3.8 85 81	3.8 76 73	3.0 67 50
SUBJECT "H"						
Frequency Means Timing Percentage Adherence Index	0 0 0	3.7 98 90	2.9 96 70	2.0 92 46		2.0 100 50
SUBJECT "S"						
Frequency Means Timing Percentage Adherence Index	1.3 62 21	2.9 71 52	3.4 80 69	Insufficient Data	2.5 59 30	1.8 80 40
SUBJECT "J"						
Frequency Means Timing Percentage Adherence Index	2.7 95 63					
SUBJECT "A"						
Frequency Means Timing Percentage Adherence Index	3.8 91 87					

Frequency Means: Mean number of daily glucose tests per condition.

Timing Percentage: Percent of daily glucose tests which were performed at the correct time.

Adherence Index: Composite of frequency and timing dimensions, relative to total adherence prescribed.

99

Table 4 Insulin regimen: Frequency Means and Adherence Index

PHASE

FIRSE					
Subject	Baseline	Insulin Intervention		Exercise	One Month F/U
SUBJECT "B"					
Frequency Means Adherence Index	2.0 3	2.0 77	2.0 74	2.0 68	2.0 36
SUBJECT "W"					
Frequency Means Adherence Index	1.0 25	1.0 85	1.0 92	1.0 71	1.0 71
SUBJECT "T"					
Frequency Means Adherence Index	2.0 11	2.0 84	2.0 95	2.0 67	2.0 67
SUBJECT "H"					
Frequency Means Adherence Index	2 15	2 61	1.9 60	=	2.0 67
SUBJECT "S"					
Frequency Means Adherence Index	2.0 22	2.0 75	Insufficient Data	2.0 63	2.0 70
SUBJECT "J"					
Frequency Means Adherence Index	2.0 81				
SUBJECT "A"					
Frequency Means Adherence Index	2.0 81				

LegendFrequency Means: Mean number of daily glucose tests per condition.
Adherence Index: Composite of frequency and timing dimensions, relative to total adherence prescribed.

Table 5

Percent Appropriate Adjustments According to Blood Glucose Levels

Subject	Baseline	Treatment	Hyperglycemia	Hypoglycemia
В	61	37	16	25
w	59	67	38	73
т	72	82	68	27
н	1	61	36	79
J	87		67	100
A	80		38	95

Percentages were calculated using the following formula:

Appropriate Adjustments # of Blood Glucose Tests

= no change when glucose level in normal range

Compensatory changes when glucose level fell within hyperglycemic (>180) or hypoglycemic (<75) range.

Note: Subject S was excluded from this analysis because adjustments were made automatically with her insulin pump.

Table 6
FACES III

1110	Circumplex Distance						
Sub	jects	Cohesion	Adapt	Range	from Center		
В	M F C	27 31 35	21 21 25	M: St/D M: St/D B: F/S	7.2 (M)		
W	M C	36 39	27 16	B: F/S M: R/C	2.7 (B)		
Т	M+F C	41 27	27 18	B: F/C E: R/D	4.2 (B)		
Н	M C	35 32	25 17	B: F/C M: R/S	5.4 (M)		
S	M C	39 34	25 30	B: F/C M: C/S	3.5 (B)		
J	M C	46 39	36 33	E: Ch/E M: Ch/C	11.2 (E)		
A	M C	40 29	20 18	B: St/C E: R/D	6.2 (M)		

Cohesion: X = 37.1, SD = 6.1 Adaptability: X = 24.3, SD = 4.8

COHESION

D: Disengaged S: Separated C: Connected E: Enmeshed

ADAPTABILITY

R: Rigid
St: Structured
F: Flexible
Ch: Chaotic

Table 7

<u>Diabetes Family Behavior Checklist</u>

Subject	Pos Pre	itive Post	Nega Pre	ative Post	
В	30	26	30	17	
W	28	36	26	16	
Т	9	26	16	16	
н	20	24	17	24	
S	21	24	19	17	
J		26		1	
A	2	28	1	9	
Checklist Ranges:	9-	-45	7–	35	

Table 8

Multidimensional Health Locus of Control (Form A-revised)

Subjects	Factor I (Powerful Others)	Factor II (Chance)	Factor III (Internal)
В	2.5	2.4	3.3
W	2.3	1.7	2.4
Т	1.8	1.3	3.2
Н	2.7	1.4	4.0
S	2.8	2.7	3.2
J	2.2	2.0	2.0
Α	1.8	2.1	3.4

Powerful Others = Belief that one's health is determined by parents and healthcare providers.

Chance = Belief that one's health is determined by luck or chance.

Internal = Belief that one's health is controlled by internal means.

Table 9 Barriers to Adherence

Subject	Total	Glucose	Insulin	Diet	Exercise
B pre	48	3.5	3.0	3.5	3.6
post	50	4.0	2.6	4.3	3.0
W pre	46	5.0	1.0	5.0	1.0
post	43	3.8	1.0	5.0	1.6
T pre	57	4.8	3.0	4.5	4.7
post	26	2.3	1.3	2.3	1.3
H pre	50	4.3	3.7	4.3	1.7
post	42	2.5	4.0	1.3	4.0
S pre post	40	5.0	N/A	4.3	3.7
	40	4.5	N/A	3.0	3.0
J	38	3.5	3.0	2.5	3.3
A	43	4.0	1.0	3.8	3.0

Range: Total Barriers: 15-105; Subscores 1.0-7.0 Norms: Mean = 35.9 SD = 9.5 for males 41.1 SD = 10.6 for females

Table 10

<u>Diabetes Knowledge Test</u>

Subject	Percent Correct
В	55
w	58
Т	67
н	61
s	75
J	44
A	75

Table 11

Family Routines Inventory

Subjects	Frequency Score*
В	46
W	56
Т	52
Н	33
S	52
J	61
A	57

RANGE: 0 - 84

^{*} This score represents an index of routine endorsement (does the family participate in this routine) and adherence (how frequently does the family engage in this routine).

Appendix A

The Diabetes Family Behavior Checklist

The Diabetes Family Behavior Checklist (DFBC; Schafer, McCaul, & Glasgow, 1986) is a 16-item questionnaire that was designed to assess supportive and non-supportive behaviors specific to the diabetes self-care regimen. Subjects are instructed to rate the frequency of behaviors performed by family members using a scale ranging from 1 (never) to 5 (at least once a day) for the areas of glucose testing, insulin injections, diet, and exercise. The checklist consists of nine supportive items and seven nonsupportive items and approximately equal numbers of items for each regimen component. The same items are then rated in terms of how helpful or unhelpful they are

In a sample of 18 adolescent diabetics measures of internal consistency revealed a mean Chronbach's alpha of 0.63 for supportive behaviors and 0.60 for nonsupportive behaviors (Schafer, McCaul, & Glasgow, 1986). Pearson product-moment correlations were computed to evaluate the stability of the DFBC over a 6-month test-retest interval. Correlations for adolescents and their family members yielded r = 0.60 and r = 0.75 (p < .05), respectively for supportive behaviors and r = 0.60 and r = 0.28, respectively for nonsupportive behaviors. Although poor test-retest reliability values were obtained, the sample size was small and the time interval was long. Using a larger adult sample and a shorter time interval (2 months), test-retest values were considerably stronger, ranging from .84 to .69 for the supportive and nonsupportive behaviors.

The DFBC was useful in identifying potential areas of conflict between the parent and the child and facilitated the development of the behavioral contract. The DFBC was administered pre-and post-treatment to both the diabetic and parent(s).

Appendix A cont.

Diabetes Family Behavior Checklist (Form P)

(Schafer, McCaul, & Glasgow, 1986)

We want to know how often family members do each of the following things. Just put down what usually happens at home - there are no right or wrong answers. Write down one number from the scale below that best shows how often the person being rated does each of the following things.

1 = never 2 = twice a month 3 = once a week 4 = several times a week 5 = at least once a day

Next, please rate the same behaviors as to how helpful or unhelpful they are (or how helpful the behavior would be if it did occur) using the following scale.

			neither			
			helpful			
extremely		or				extremely
unheipful			unhelpfu	ıŧ		helpful
-3	-2	-1	0	∔1	+2	+3

Family Member you are rating:

How often does he/she:	frequency ratings	helpful ratings
Praise you for following your diet.		
Nag you about testing your glucose level.		
Suggest things that might help you take insulin on time.		
Criticize you for not exercising regularly.		
5. Help you decide if changes should be made based on glucose test results.		
Nag you about following your diet.		
7. Argue with you about your diabetes.		
8. Encourage you to participate in sports activities.		
9. Plan family activities so that they will fit in with your diabetes self care schedule	9	
Congratulate you for sticking to your diabetes self-care schedule.		
Criticize you for not recording the results of glucose tests.		
12. Eat at the same time that you do.		
13. Exercise with you.		
14. Let you sleep late rather than getting up to take your insulin.		
15. Buy you things containing sugar to carry with you in case of an insulin reaction	n	
16. Fat foods that are not part of your diabetic diet.		

Appendix B

<u>Interview</u>

1) Who is responsible for monitoring your blood glucose levels?

If the diabetic indicates that he/she is responsible for this behavior, ask the following questions:

a) How often do you perform these tests?

b) Do your parents think this is often enough? Why or why not?
c) Do you think it is important to perform these tests?

d) Do you feel like you are capable of performing these tests without the aid of a family member? Does someone need to remind you to perform the tests?

To what extent is your family involved in your glucose testing?

Would you like for your parents to be more or less involved in this part of your regimen? If less, why? If more, how?

Does your family encourage you to perform these tests?

- h) Do you know how to adjust your insulin dosage based on the test results without the aid of a family member?
- Do you know how to adjust your diet on the basis of these tests? Do you alter your level of physical activity as a result of your tests?
- k) What causes you the most difficulty with this part of your regimen?

If the diabetic indicates that a family member is responsible for this behavior, ask the following questions:

a) Which family member does your glucose testing for you?

_ perform these tests? b) How often does

c) To what extent are you involved in the daily glucose testing procedure?

d) Do you feel like you are capable of performing the tests yourself? Why or why not?

2) Do you inject your own insulin?

If the diabetic indicates that he/she is responsible for this behavior, ask the following questions:

a) How often do you inject insulin?

b) Do you feel like you are capable of doing the injections alone without the aid of a family member?

To what extent is your family involved in your daily injections?

d) Does your family remind you to take your insulin at the appropriate times daily? e) Would you like for your family to be more or less involved in this part of your regimen? If less, why? If more, how?

What causes you the most difficulty with this part of the regimen?

If the diabetic indicates that a family member assumes the responsibility for this behavior, ask the following questions:

a) Who is responsible for injecting your insulin daily?

b) To what extent are you involved in the daily insulin injections?

c) Do you feel like you are capable of injecting your insulin on your own? Why or why

Appendix B (cont.)

3) Are you responsible for choosing foods that are part of your diabetic diet or do you depend on others to shop or prepare you food?

If the diabetic indicates that he/she is responsible for this behavior, ask the following questions:

a) Is it difficult sticking to your diet? Why or why not?

- b) Can you determine the approximate amount of carbohydrates, protein, and fat of
- your meals?
 c) Do you feel like you are capable of choosing the right foods for your diabetic regimen without the aid of a family member?

d) To what extent is your family involved in your diet planning?

e) Would you like for your family to be more or less involved in this part of your regimen? If less, why? If more, how?

f) What causes you the most difficulty with this part of the regimen?

If the diabetic indicates that a family member assumes the responsibility for this behavior, ask the following questions:
a) Who takes care of your dietary needs?

b) To what extent are you involved in planning your diet?

c) Would you like to be more active in choosing foods for your meals?

4) Are you responsible for deciding the type and duration of exercising and

physical activities?
If the diabetic indicates that he/she is responsible for this behavior, ask the following questions:

a) How often do you exercise?b) What types of activities do you like to do to get exercise?

c) Do you feel like you are capable of choosing these activities without the aid of another family member?

d) To what extent is your family involved in these activities?
e) Would you like for your family to be more or less involved in this part of your regimen? If less, why? If more, how?

f) What causes you the most difficulty with this part of the regimen?

If the diabetic indicates that a family member assumes the responsibility for this behavior, ask the following questions:

a) Who is responsible for determining when and how you will exercise?

b) Do you like the activities that are chosen for you? Why or why not?

c) To what extent are you involved in choosing when and how to exercise?

- d) Do you feel like you are capable of choosing these activities yourself without the aid of a family member?
- Do your parent(s) ever "nag" you about your diabetic regimen. If yes, what do you do?
- 6) Do you wish you were more independent (allowed to make more decisions about your regimen)?
- 7) Overall, do you feel like your family has given you too much responsibility, just enough, or too little responsibility for your regimen? Explain.

Appendix C

Barriers to Adherence

The Barriers to Adherence Scale (BAS; Glasgow, McCaul, & Schafer, 1986) was constructed to assess the frequency of environmental and cognitive barriers to adherence among persons with insulin-dependent diabetes mellitus between the ages of 12 and 65. The scale includes 15 items that sample behaviors related to the appropriate conduct or timing of the following regimen components: glucose testing, insulin injections, diet, and exercising. The scale can be scored by summing frequency ratings over the 15 items or subscores for barriers can be obtained by summing the frequency ratings for items in that area and dividing by the number of items contributing to that subscale.

Using a combined sample of children and adults (n = 65), test-retest subscore reliabilities for diet, exercise, glucose, and insulin barriers were r = 0.67, 0.64, 0.56, and 0.36 (p < .01), respectively. Test-retest reliability for the total barriers score yielded a coefficient of r = 0.71. The subscores were not significantly intercorrelated with a mean r = .23. Females reported more barriers than males (particularly in the areas of diet) and age was not associated with barrier scores.

The frequency of reported barriers was found to be significantly related to self-report measures of adherence for each regimen component, although the scale was not strongly predictive of future adherence levels when other specific dependent measures of adherence were employed (e.g., self-monitoring). The authors suggest, however, that the BAS may be useful in designing interventions to reduce barriers and to improve health outcome, however to date no such studies have been done. The BAS was administered pre-study to identify potential barriers that were subsequently addressed in the behavioral contract.

Barriers to Adherence Questionnaire

(Glasgow, McCaul, & Schafer, 1986)

Read through the following situations and, using the scale below, indicate how often each problem situation occurs for you. It is important that you rate every situation.

How frequently is this situation a problem for you? (Choose one number)

(1) Very Rarely	(2) Once per Month	(3) Twice per Month	(4) Once per Week	(5) Twice per Week	(6) More than twice per week	(7) Daily
1. It is emi	barrassing to eat wh	en the people aroun	d me are not eating			
2. It is inc	onvenient to inject m	ny insulin when I am	not at home.			_
3. Bad we	ather interferes with	ı my regular exercise	routine.			_
	my (urine or blood) g to know why.	lucose tests are high	my mother (or othe	r family member)		
	the middle of an act on snack.	tivity with friends wh	en I realize it is time	e to have my		_
6. On a w	eekend, it is difficul	t to get up at the reg	ular time to take m	shot.		
7. It is too	much trouble to wri	te down the results	of my urine or bloo	d tests.		_
8. I don't l	have my urine or blo	ood testing materials	when it is time to d	o the testing.	-	
9. I just d	on't like to exercise					
10. It is eas	sy to make a mistak	e on the number of fo	ood exchanges in a	meal.	-	
11. Some	times I don't draw the	e proper amount of in	nsulin into the syring	ge.		_
12. I feel o	out of place testing r	ny urine or blood at s	school or work duri	ng the day.		
13. After e	eating what I am allo	wed at a meal, I still	feel hungry.			
		e my exercise, beca I exercise a lot on t				
	ch or a clock with a ne or blood test.	second hand is not	available to time			

Appendix D BLOOD GLUCOSE TESTING CONTRACT

I ADHERENCE BEHAVIORS:

- 1. Test blood glucose levels a minimum of 4 times daily using glucometer
- 2. Test blood glucose levels at appropriate times
 - prior to each insulin injections
 - prior to large meal (dinner)
 - prior to any form of strenuous exercise
 - · prior to bedtime
 - immediately when you experience symptoms of hypoglycemia or hyperglycemia
- 3. Record all test results in log book

Diabetic		Parent	_
III DESIGNATION OF DAILY/W I understand that my logboo Examples of potential reward	k will be reviewed daily and it	f 80% adherence is achieved, a reward wil	l be giver
I understand that if 80% adherotential rewards include:	erence is achieved over a 7-d	ay period, a larger reward will be given. Ex	kamples o
IV DESIGNATION OF FUTURE	REWARD FOR IMPROVED MET	ABOLIC CONTROL:	
I understand that if my meta given. Examples of potential		s following the study, an even larger rewa	ard will b
	_		
We agree to follow the guide throughout the duration of the		ct as closely as possible and to uphold thi	is contrac
Diabetic	Parent	Witness	_
	114		

Appendix E

Diabetes Knowledge Test

The Diabetes Knowledge Test (DKT; Michigan Diabetes Research and Training Center, 1988) is a 36-item test that assesses the following: (a) knowledge of diabetes as a disease; (b) management of diabetes in the areas of glucose monitoring, insulin injections, diet, and exercise; (c) physiological aspects of the disease and metabolic control; and (d) treatment of hypo- or hyperglycemia. It has been found to have adequate psychometric properties for both children and adults. The DKT was used as a pre-test prior to the intervention phase of the study to eliminate a deficit in knowledge as a contributing factor to nonadherence. Any questions answered incorrectly were discussed with the experimenter or a diabetes educator until the diabetic thoroughly understood the answer.

Appendix E (cont.)

A DIABETES KNOWLEDGE TEST

Circle the one best answer to each question. Try to answer every question. If you aren't sure, choose the answer you think may be right.

- 1. Diabetes is a disease in which:
 - a. the pancreas makes too much glucose
 - b. the pancreas makes little or no insulin
 - c. there are not enough red blood cells to carry the glucose
 - d. there are not enough red blood cells to carry the insulin
- 2. Normal fasting blood glucose level is about:
 - a. 40-70 mg/dl
 - b. 70-115 mg/dl
 - c. 115-160 mg/dl
 - d. 160-240 mg/dl
- 3. The diet for a person with diabetes usually:
 - a. is made up of special dietetic foods
 - b. is low in starch
 - c. is high in carbohydrate
 - d. cannot include alcohol
- 4. For persons who do not have diabetes, the diabetes diet would be:
 - a. too low in fat
 - b. to high in carbohydrate
 - c. too low in protein
 - d. well-balanced
- 5. Which of the following is highest in carbohydrate?
 - a. baked chicken
 - b. swiss cheese
 - c. baked potato
 - d. peanut butter
- 6. Which of the following is highest in fat?
 - a. whole milk
 - b. orange juice
 - c. com
 - d. honey
- 7. Which of the following is a "free food"?
 - a. any unsweetened food
 - b. any dietetic food
 - c. any food that says "sugar free" on the label
 - d. Any food that has less than 20 calories per serving

15.	If you have taken intermediate-acting insulin (NPH or Lente), you are most likely to have an insulin reaction in: a. 1-3 hours b. 6-12 hours c. 12-15 hours
14.	One reason for changing the site of your insulin shot is to prevent: a. infection b. muscle damage c. tissue damage d. nerve damage
13.	Testing blood glucose: a. can done accurately at home b. should only be done by a doctor or nurse c. is only useful when you are ill d. is very painful to do
12	Which is the best method for testing blood glucose? a. urine testing b. blood testing c. both are equally good
11.	Hyperglycemia means: a. low blood glucose b. high blood glucose c. low blood ketones d. high blood ketones
10.	Glycosylated hemoglobin (hemoglobin A1) is a test that is a measure of your average blood glucose level for the past: a. day b. week c. 6-10 weeks d. 6 months
9.	Which is true about alcohol? a. It has no calories b. it has no effect on blood glucose c. it can be part of a diabetes diet d. it words against insulin in the body
Append 8.	dix E (cont.) People with diabetes should eat a diet that is: a. low in fat b. high in protein c. low in carbohydrate d. equal in protein, carbohydrate, and fat

Appendix E (cont.)

- 16. Today your blood glucose is 300 mg/dl and you have been going to the bathroom often. You should:
 - a. test more often and drink extra fluids
 - b. exercise more than you would normally
 - c. take twice as much insulin as you usually take at breakfast
 - d. check your blood glucose level to decide how much insulin to take
- 17. You realize just before lunch time that you forgot to take your insulin before breakfast. What should you do now?
 - a. skip lunch to lower your blood sugar
 - b. take the insulin that you usually take at breakfast
 - c. take twice as much insulin as you usually take at breakfast
 - d. check your blood glucose levels to decide how much insulin to take
- 18. If you are beginning to have an insulin reaction, you should:
 - a. exercise
 - b. lie down and rest
 - c. drink some juice
 - d. take regular insulin
- 19. What effect does unsweetened fruit juice have on blood glucose?
 - a. lowers it
 - b. raises it
 - c. has no effect
- 20. Which should not be used to treat low blood glucose?
 - a. 3 hard candies
 - b. 1/2 cup of orange juice
 - c. 1 cup of diet soft drink
 - d. 1 cup skim milk
- 21. Low blood glucose may be caused by:
 - a. too much insulin
 - b. too little insulin
 - c. too much food
 - d. to little exercise
- 22. If you take your morning insulin but skip breakfast, your blood glucose level will usually:
 - a. increase
 - b. decrease
 - c. remain the same
- 23. Which is the best exercise program for your heart?
 - a. riding a bike for 1 hour once a week
 - b. bowling for 1 hour twice a week
 - c. doing push-ups every day
 - d. brisk walking for 30-minutes for days a week

A .		_		\
Appe	งทดเจ	- 1	i COI	11
	шик	_		и.

- 24. For a person in good control, what effect does exercise have on blood glucose?
 - a. lowers it
 - b. raises it
 - c. has no effect
- 25. After heavy exercise, your blood glucose levels may be affected for as long as:
 - a. 1 hour
 - b. 6 hours
 - c. 12 hours
 - d. 24 hours
- 26. People with diabetes who have nerve disease may:
 - a. have numb feet
 - b. get dizzy when they stand up quickly
 - c. injure their feet and not know it right away
 - d. all the above
- 27. High blood glucose may be caused by:
 - a. not enough insulin
 - b. skipping meals
 - c. delaying your snack
 - d. large ketones in your insulin
- 28. Ketones in the urine may be the result of:
 - a. not enough insulin
 - b. not enough food
 - c. illness
 - d. all of the above
- 29. Which of the following will most likely cause an insulin reaction:
 - a. heavy exercise
 - b. infection
 - c. overeating
 - d. not taking your insulin
- Signs of ketoacidosis include:
 - a. shakiness
 - b. sweating
 - c. vomiting
 - d. low blood glucose
- 31. Infection is likely to cause:
 - a. an increase in blood glucose
 - b. a decrease in blood glucose
 - c. no change in blood glucose

Appendix E (cont.)

- 32. If you are sick with the flu, which of the following changes should you make?
 - a. take less insulin
 - b. drink less liquids
 - c. eat more proteins
 - d. test for glucose and ketones more often
- 33. The best way to take care of your feet is to:
 - a. look at and wash them each day
 - b. massage them with alcohol each day
 - c. soak them for one hour each day
 - d. buy shoes a size large than usual
- 34. Eating less fat you can decrease your risk for:
 - a. nerve disease
 - b. kidney disease
 - c. heart disease
 - d. eye disease
- 35. Numbness and tingling may be symptoms of:
 - a. kidney disease
 - b. nerve disease
 - c. eye disease
 - d. liver disease
- 36. Which of the following is usually not associated with diabetes?
 - a. vision problems
 - b. kidney problems
 - c. nerve problems
 - d. lung problems

Michigan Diabetes Research and Training Center. Ann Arbor, MI 48109-0200 The University of Michigan, 1988

Appendix F

FACES III

The Family Adaptability and Cohesion Evaluation Scales III (FACES III; Olson, Portner, & Lavee, 1985) is the third version of an instrument designed to assess the two major dimensions of the Circumplex Model (Olson, Russell, Sprenkle, 1979, 1980, 1982, & 1983) which include Family Cohesion and Family Adaptability. The Circumplex Model is rooted in family systems theory and allows for the classification of families into one of 16 specific family types using a 20-item scale. Family Cohesion is defined in terms of emotional bonding between family members and assess the degree to which family members are separated or connected. Families are classified into one of four levels including: disengaged, separated, connected, or enmeshed. Ten items were developed to assess the level of Family Cohesion and include the concepts of emotional bonding, supportiveness, family boundaries, time and friends, and interest in recreation. Family Adaptability is defined in terms of the ability of the family system to alter the power structure, role relationships, and rules in response to situational and developmental stress. Families are classified into one of four levels of functioning including: rigid, structured, flexible, or chaotic. Ten items were developed to asses the level of Family Adaptability and include the concepts of leadership, control, discipline, roles, and rules.

Olson et. al (1985) hypothesize that families in the extreme ranges of of Adaptability or Cohesion will evidence more difficulty in coping with situational and developmental stress. While the original FACES and FACES II have demonstrated adequate psychometric properties, only a few empirical studies

Appendix F (cont.)

have used the FACES III. Initial studies, however, have been encouraging. In particular, two factor analytic studies resulted in identical factor structures and the correlation between the Cohesion and Adaptability scales has been reduced to near zero (r = 0.03) suggesting that the two dimensions are independent. Additional evidence of construct validity comes from evidence that the items within each scale are highly correlated with the total scales. Further, the correlation between the Adaptability and Cohesion scales and a measure of social desirability is minimal, ranging from 0.35 to 0.00.

Using two samples (n=1206 for each) to evaluate internal consistency,
Chronbach Alpha values yielded means of 0.75 for the Cohesion Scale, 0.61 for
the Adaptability Scale and .67 for the Total Scale.

Norms and cutting scores are provided for three samples including adults, families with adolescents, and young couples. Although FACES III has not been normed on families with chronically ill children, it was used as an index of family functioning to further explore the impact of family variables on adherence and metabolic control. It was administered to both the parent(s) and child prior to baseline.

Appendix	F
cont.	

FACES III

(Olsen, Portner, & Lavee, 1985)

1 ALMOST NEVER 2 ONCE IN AWHILE

3 SOMETIMES FREQUENTLY

5 ALMOST ALWAYS

DESCRIBE YOUR FAMILY NOW

 1. Family members ask each other for help.
 2. In solving problems, the children's suggestions are followed.
 3. We approve of each other's friends.
 4. Children have a say in their discipline.
 5. We like to do things with just our immediate family.
 6. Different persons act as leaders in our family.
 $7. \ \ \text{Family members feel closer to other family members than to people outside the family}$
 8. Our family changes its way of handling tasks.
 9. Family members like to spend free time with each other.
 10. Parent(s) and children discuss punishment together.
 11. Family members feel very close to each other.
 12. The children make the decisions in our family.
 13. When our family gets tegether for activites, everybody is present.
 14. Rules change in our family.
 15. We can easily think of things to do together as a family.
16. We shift household responsibilities from person to person.
 17. Family members consult other family members on their decisions.
 18. It is hard to identify the leader(s) in our family.
 19. Family togetherness is very important.
 20. It is hard to tell who does which household chores.

FAMILY SOCIAL SCIENCE, 290 McNeal Hall, University of Minnesota, St. Paul, MN 55108 D.H. Olson, 1985

Appendix G

Family Routines Inventory

The Family Routines Inventory (FRI; Jensen, James, & Boyce, 1983) is an instrument designed to measure the extent of predictability or routinization of daily family life. The FRI consists of 28 items that assess positive family routines in terms of *routine endorsement* (the extent to which the family subscribes to a set of behavioral routines) and *routine adherence* (the degree to which a family rigorously executes the routines to which it subscribes). The frequency score provides a measure of family cohesion, solidarity, order, and overall satisfaction. The family routines are defined by observable, repetitive behaviors involving two or more family members which occur with predictable regularity in daily family life. The items comprise ten conceptual domains including: work day routines, weekend/leisure, children's routines, parents routines, bedtime, meals, the extended family, leaving/homecoming, disciplinary routines, and chores.

Test-retest reliability assessments, using a 25-day time interval, yielded a coefficient of 0.79, which demonstrates acceptable temporal stability. The construct validity of the instrument was assessed by evaluating the degree to which the scores correlated positively with other validated measures of positive aspects of family life including the Cohesion and Organization subscales of the Moos Family Environment Scale (FES) and a family-life satisfaction questionnaire and negative correlations with FES subscales of Control and Conflict. All validity coefficients were in the predicted direction.

The FRI was administered to the parent pre- and post-study and was used as an additional measure to further explore the family system and its potential impact on regimen adherence.

Family Routines Questionnaire

All families do certain things regularly from day to day. These are the common routine events which are done over and over again and give a pattern to daily living. We call these Family Routines. We would like to learn about some of your family's routines and how important they are to you

Instructions: Please answer both the Frequency and the Importance questions for each statement listed. There are no "right" or "wrong" answers to any of the questions. Please answer the questions by putting a check ($\sqrt{}$) in the box of your choice. Do not skip any questions about these routines unless they do not apply to your family. Remember that the questions are about your family significant routines. There are some additional questions on the back of this questionnaire.

Frequency: How often does this currently happen in your family?		Frequency			Importance			
Importance: How important is this routine for keeping your family strong	Everyda,	3-5 times per week	1-2 times per week	Almost never	Very important	Somewhat important	Not at all important	
Parent(s) have certain things they do every morning while getting ready to start the day.								
2. Whole family eats dinner together almost every might								
3. Children do regular household chores.								
4. Children do the same things each morning as soon as they wake up.		_		_				
Children do their homework at the same time each day or night during the week.								
6. Parent(s) have some time each day for just talking with the children.								
7. Parent(s) and children play together sometime each day.								
8. Children go to bed at the same time almost every night.								
 Family checks in or out with each other when someone leaves or comes home. 								
10, Working perent(s) comes home from work at the same time each day.								
Non-working parent and children do something together outside the home almost every day (for example, shopping, walking, etc.).								
 Family has certain things they almost always do to greet the working parent at the end of the day. 								
13. Children take part in regular activities after school.								
14. Parent(s) read or tell stories to the children almost every day.								
 Working parent has a regular play time with the children after coming home from work. 								
16. Children have special things they do or ask for each night at bedtime (for example: a story, a good-night kiss, a drink of water).								
17. At least some of the family eats breakfast together almost every morning.								
18. Family eats at the same time each night.							ı	
19. Family has a "quiet time" each evening when everyone talks or plays quietly,								
20. Young children go to play-school the same days each week.								
21. Each child has some time each day for playing alone.					,			
22. Working parent takes care of the children sometime almost every day.								
1				6	<u></u>			
	7	7						
10 11 12 13 14 15 16	17	18		_ _	20	21	22	

Family Routines Questionnaire (Continued)

Instructions: Please answer both the Erequency and Importance questions for each of the additional activities. Please notice that the choices under Erequency are different from those on the first page of this questionnaire.

Frequency: How often does this corrently topped in your family?	Frequency			Importance			
Importance: How important is this routing for Leeping your family strong	Always every vers			Less than		Somev.tut important	
 Family has a certain "family time" each week in two they do things towether at home. 							
24. Family regularly visits with the relatives							
25. Family goes some place special together one boxest							
26. At least one parent talks to his or her pair ats regularly							
27. Farguts have a certain highly, or sport the , do regetter regularly,							

	Always every day	Most of	Sametimes	Almost	Very	Somewhat	filot at att Important	1
28. Parent(s) have certain through they almost also, side each time the children get out of line.								1



Appendix H <u>Multidimensional Health Locus of Control</u>

The Multidimensional Health Locus of Control (MHLC) is a scale designed to assess the extent to which one believes that his/her health is controlled internally, by chance, or by powerful others. The MHLC was originally designed by Wallston and Wallston (1978) to assess the locus of control construct in adults. The scale was subsequently modified for children by Thompson, Butcher, & Berenson (1987) and emerged as a reliable and valid instrument. Testretest reliability coefficients for Internal, Chance, Powerful Others, and total scores are, .62, .80, .69, .77, respectively. The three factor structure initially proposed by Wallston and Wallston was retained and provided evidence of the construct validity of the scale, although three items loaded significantly on unexpected factors.

Appendix H cont.

Multidimensional Health Locus of Control

	Disagree Very Muc	h		gree y Much
1) I am in control of my own health.	1	2	3	4
2) My own actions mostly determine how soon I will recover from an illness.	1	2	3	4
3) No matter what I do, if I am going to get sick, I will get sick.	1	2	3	4
 The best way to keep from getting sick is to have regular medical checkups. 	1	2	3	4
5) My family has alot to do with my becoming sick or staying healthy.	1	2	3	4
6) If I take the right actions I can stay healthy.	1	2	3	4
7) The main thing that effects my health is what I do.	1	2	3	4
8) My good health is mostly a matter of good luck.	1	2	3	4
9) If I take care of myself, I can avoid illness.	1	2	3	4
10) Most things that affect my health happen to me by accident.	1	2	3	4
11) Whenever I don't feel well I should see a doctor or nurse.	1	2	3	4
12) When I get sick, I am to blame.	1	2	3	4
13) Luck is mostly what determines how soon I will recover from an illness.	1	2	3	4
14) Doctors and nurses control my health.	1	2	3	4
15) When I get well, its usually because other people (like family, friends, doctors) have been taking care of me.	1	2	3	4
16) I am likely to get sick no matter what I do.	1	2	3	4
17) If it's meant to be, I will stay healthy.	1	2	3	4
18) I can only do what my doctor tells me to do about my health.	1	2	3	4

Appendix I

Parent Consent Form

I understand this study involves no treatment for diabetes beyond that prescribed by my child's physician.

I understand that I am being asked to participate in a research study designed to assess factors related to adherence to the prescribed diabetic regimen and metabolic control. Additionally, I understand that methods will be designed to help both me and my child manage the components of the diabetic regimen. This will include having me or my child monitor daily blood glucose levels, inject prescribed insulin dosages, and use the American Diabetes Association dietary exchange list. I also understand that my child will be requested to engage in exercise on a regular basis according to that recommended by his/her physician.

I understand that as a parent, I and my child will be asked to complete several questionnaires about daily diabetes management behaviors, barriers to adhering to those behaviors, and family adaptation to diabetes, Both my child and I will also be asked to complete a knowledge test about diabetes. I also understand that a glycosylated hemoglobin test (AIC) will be requested from my child's physician and that my child will be required to use a glucometer provided by the experimenter for daily blood glucose monitoring (the glucometer will be provided at no cost to the participants).

I understand that there are no special risks associated with participation in this study and that all information obtained from me and my child will be kept strictly confidential. All information will be available to the researchers only. Numbers, rather than your names, will be used for summaries of information. No information that could be used to identify you will be reported with the results of the study.

I understand that participation will require a minimum of 5 and a maximum of 10 weekly visits to the Child Study Center and that my child will receive \$30.00 upon completion of the study.

I understand that it is my responsibility to ensure that my child will continue to receive regular medical care as needed while participating in the study and that I should contact the physician if I have questions about my child's metabolic status.

I understand that my participation is completely voluntary and free of charge (with the exception of 4 requested glycosylated hemoglobin tests (A1C) for which I will incur the costs) and that I or my child may discontinue participation at any time without prejudice or penalty.

I understand that a summary of the results will be discussed with me by one of the researchers upon request.

I give permission to have my physician contacted to release information about my child regarding the following issues: glycosylated hemoglobin tests results over the previous year, insulin dosage alterations, and current prescribed treatement regimen. My physician's name is

This research project has been approved by the Human Subjects Research Committee and the Institutional Review Board of Virginia Polytechnic Institute and State University. Questions about the project should be directed to the principle investigator: Melanie J. Bonner, 231-6914; or Dr. Jack W. Finney, 231-6670; Dr. Richard M. Eisler, chair of the Human Subjects Research Committee, 231-6914; or Dr. Ernest Stout, chair of the Institutional Review Board, 231-5284.

I hereby agree to voluntarily particip conditions described above.	ate in the research	project	described	above	and	under	the
Date:	Signature of Paren	t or Gua	ardian:				

Appendix I

Subject Assent Form

I understand this study will not cure my diabetes and gives no treatment beyond that provided by my doctor.

I understand that I am being asked to participate in a research study about diabetes. I also understand that I will learn things to help both me and my family handle my diabetes the way my doctor has asked me to . I also understand that I or my parent(s) will be doing blood glucose tests, insulin injections, and using exchange lists for my meals each day and that I will have to exercise each week.

I understand that I will be asked to complete surveys about diabetes and the problems me and my family have had while dealing with my diabetes. I will also be asked to take a knowledge test about diabetes. I also understand that a I will be learn how to use a "glucometer" for daily blood glucose tests.

I understand that all survey answers will be kept in locked files and will be seen by the researcher only.

I understand I will have to visit the Child Study Center as many as 10 times during the study and that I child will receive \$30.00 when I finish the study.

I understand that my doctor will be told about the study and that I or my parents should call my doctor at any time during the study if I have questions about my diabetes.

I understand that my participation is voluntary and that I may stop participating at any time without punishment.

I understand that if I have questions about the study when it is over, the researcher will talk with me about them.

This research study has been approved by the Human Subjects Research Committee and the Institutional Review Board of Virginia Polytechnic Institute and State University. If I have questions about the study I can call the researchers: Melanie J. Bonner, 231-6914; or Dr. Jack W. Finney, 231-6670; Dr. Richard M. Eisler, chair of the Human Subjects Research Committee, 231-6914; or Dr. Ernest Stout, chair of the Institutional Review Board, 231-5284.

conditions described above.	, ,	
Date:	Signature of Participant:	

I hereby agree to voluntarily participate in the research project described above and under the

Figure Captions

- Figure 1. Operationalization of adherence.
- Figure 2. Baseline and intervention data for treatment subject B across all four target behaviors.
- Figure 3. Baseline and intervention data for treatment subject W across all four target behaviors.
- Figure 4. Baseline and intervention data for treatment subject T across all four target behaviors.
- Figure 5. Baseline and intervention data for treatment subject H across all four target behaviors.
- Figure 6. Baseline and intervention data for treatment subject S across all four target behaviors.
- Figure 7. Adherence levels for comparison subject J across all four regimen components.
- Figure 8. Adherence levels for comparison subject K across all four regimen components.
- Figure 9. Adherence re-defined on the basis of the results of the current study.

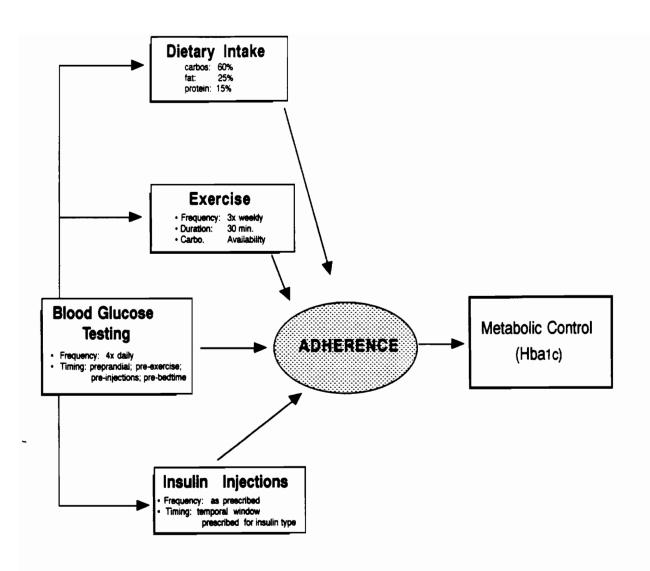
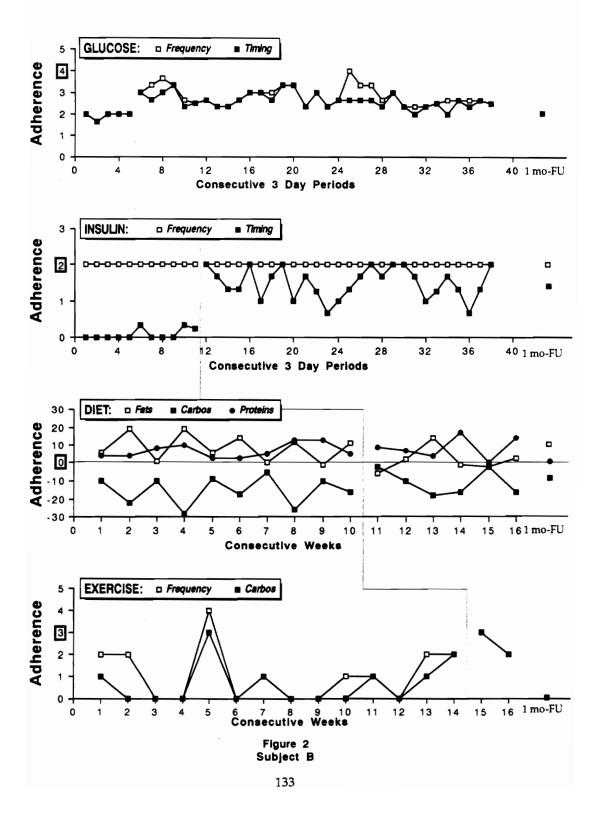
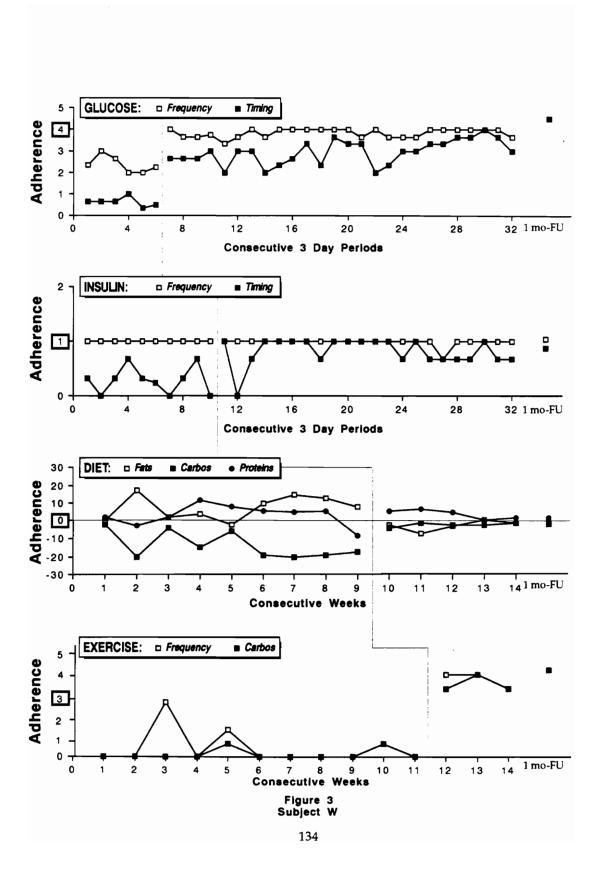
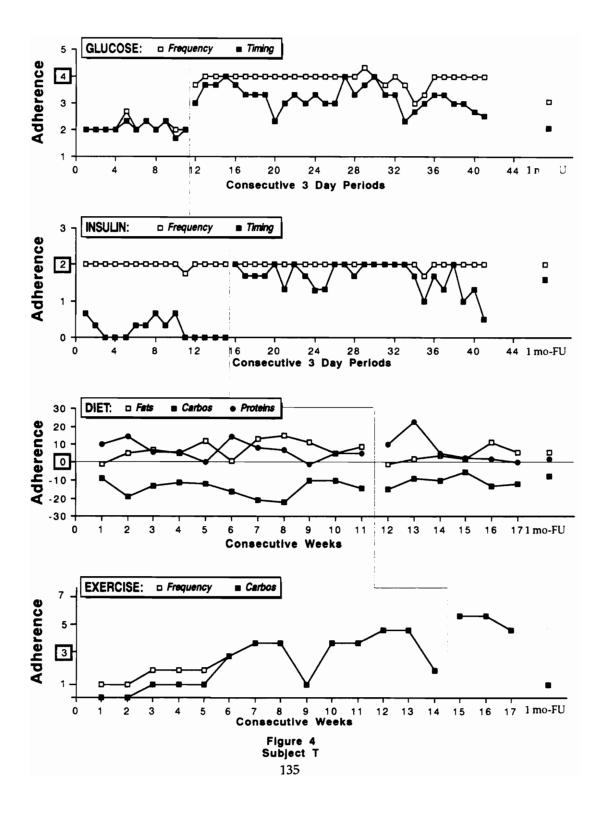
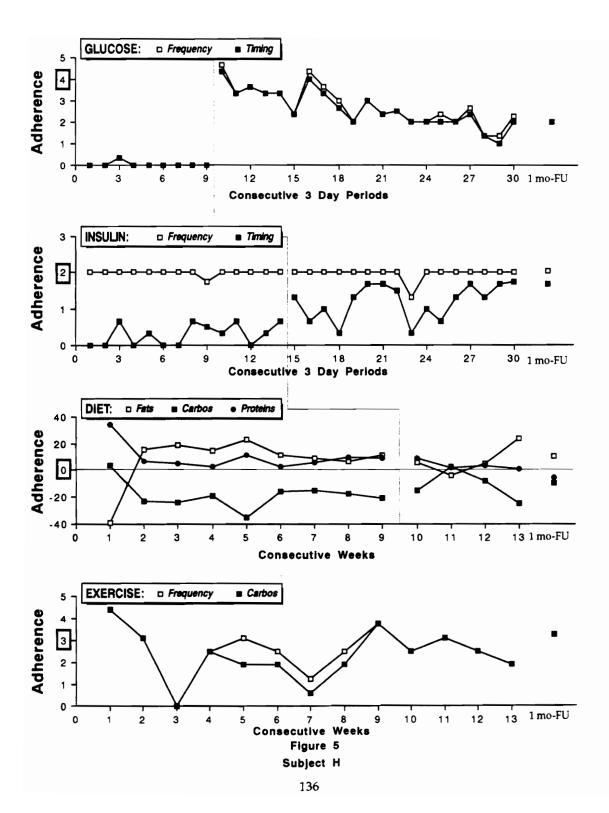


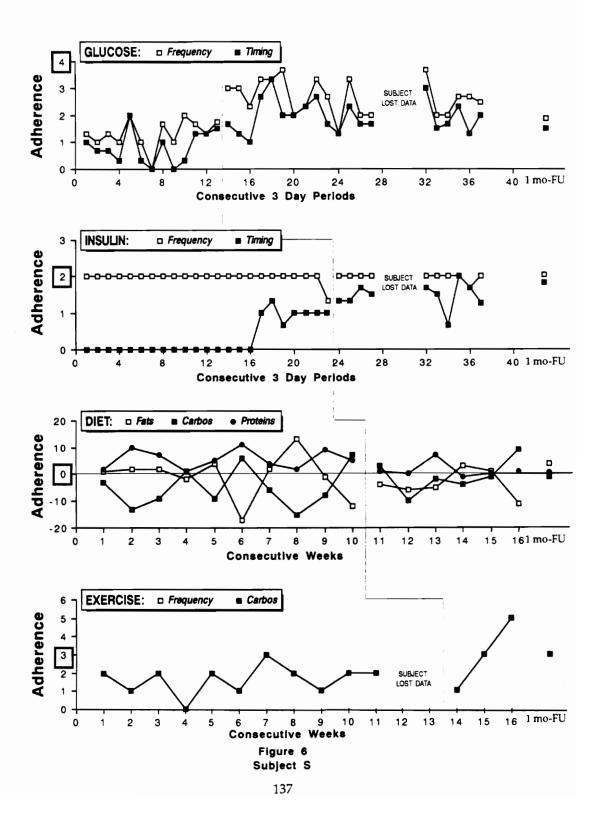
Figure 1
Adherence Defined

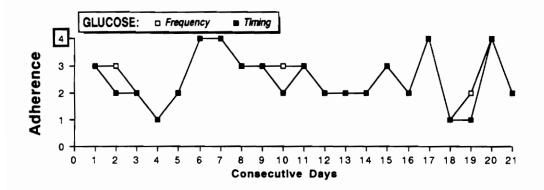


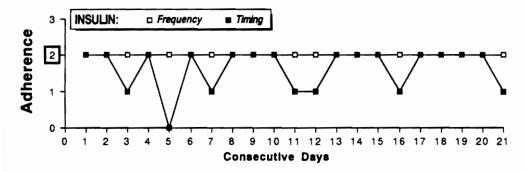


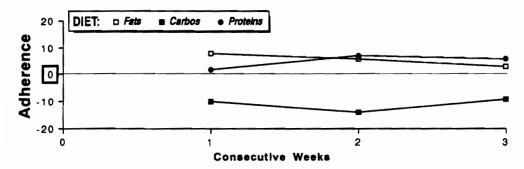












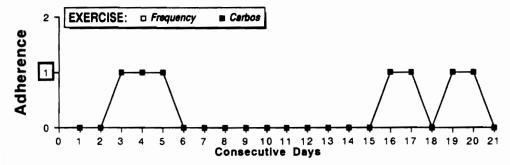
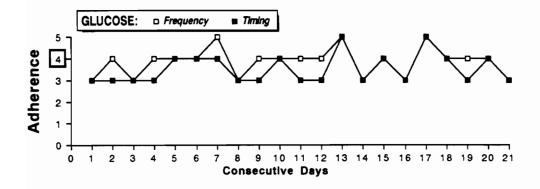
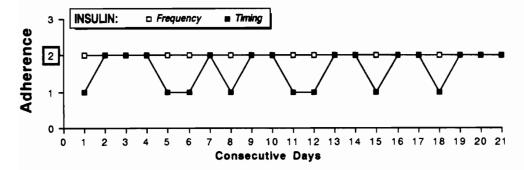
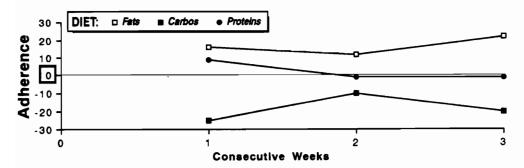


Figure 7 Subject J







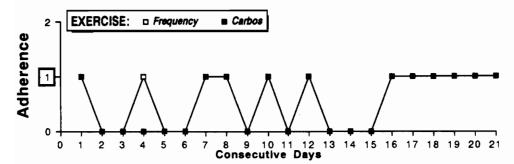


Figure 8 Subject A

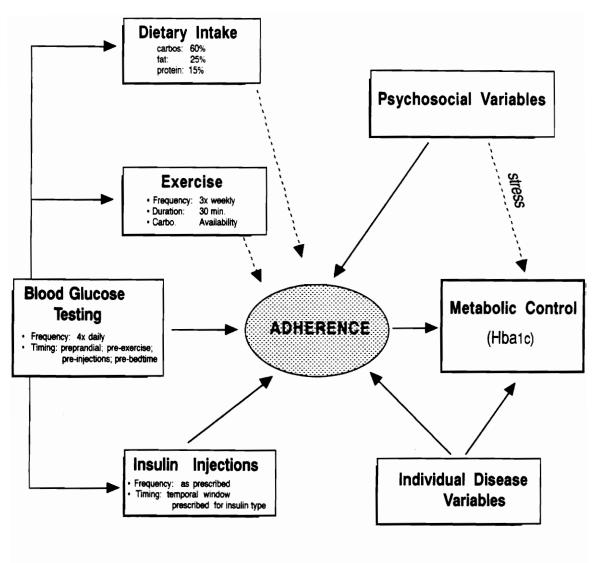


Figure 9
Adherence Re-Defined

CURRICULUM VITA

Melanie Jean Bonner

PERSONAL INFORMATION:

924 Rocky Acres Lane Blacksburg, VA 24060 Home: (703) 951-9057

Department of Psychology 5088 Derring Hall Virginia Polytechnic Institute and State University Blacksburg, VA 24061-0436 Office: (703) 231-6914

Date of Birth: June 12, 1967

Marital Status: Single

EDUCATION

Virginia Polytechnic Institute and State University, Blacksburg, VA.

• B.S., Psychology, 1989

Currently enrolled in the Clinical Psychology Doctorate program

CLINICAL & RESEARCH EXPERIENCE

Masters Thesis: The Use of a Behavioral Family Intervention to Assess the Relationship Between Adherence and Metabolic Control in Insulin-Dependent Diabetics (in progress).

1/92-present: *National Institute of Mental Health Training Fellowship* Supervisor: Thomas H. Ollendick, Ph.D.

 Duties include assessment and treatment services for emotionally disturbed children in the public school system.

 Research assistant on a project designed to explore the comorbidity of depressive disorders and disruptive behavior disorders in hospitalized adolescents.

5/91-8/91: Graduate Clinician, Psychological Services Center & Child Study Center. Supervisor: Richard M. Eisler, Ph.D.

Maintained an outpatient caseload of 10-12 clients.

 Services included behavioral assessment and treatment for adult, child and family clientele.

4/88 - 8/91: Clinical Research Assistant

Research study involving the assessment and treatment of 17 children with recurrent abdominal pain. Supervisor: Jack W. Finney, Ph.D.

Conducted child interviews to assess stomachache history.

- Monitored children throughout baseline, treatment, and followup.
- Administered relaxation therapy and evaluated performance.

Conducted weekly home visits to evaluate progress.

 Assisted in the analysis of data and interpretation of results for professional presentation.

8/89 - 6/90: Laboratory Administrator & Research Assistant

Administrative and Research Assistant for research grants and projects in the Applied Behavioral Systems Laboratory, Va. Tech. Supervisor: E. Scott Geller, Ph.D.

Manuscript processing for the Editorial Office of Journal of

Applied Behavior Analysis.

- Maintenance of financial records for research grants and contracts of funded projects (i.e., Department of Motor Vehicles; Centers for Disease Control; National Institute of Health).
- Data collection and analysis for several projects in the areas of health and safety.

1/89 - 1/90: Research Assistant and Project Manager

Research study designed to investigate muscle discrimination ability in tension headache sufferers and controls. Supervisor: Jack W. Finney, Ph.D.

Conducted 26 psychophysiological assessments.

Operated Grass equipment for EMG data.

 Administered stress inducing tasks and evaluated performance on a magnitude estimation procedure.

 Interpreted EMG graphs and assisted in the analysis of data and writing of paper for professional presentation.

12/87 - 5 /89: Clinical Research Assistant.

Research study involving the assessment and treatment of 25 chronic tension headache patients. Supervisor: Debra F. Neff, Ph.D.

Administered structured interviews and psychological tests to

subjects and their family members.

Scréened patients to diagnose headache type and qualification for study.

Performed 90 psychophysiological assessments to measure EMG

patterns in frontalis and trapezius muscles.

Evaluated muscle discrimination ability following a magnitude production procedure.

Operated Coulbourn equipment and trained other technicians.

PUBLICATIONS

- Edwards, M.C., Finney, J.W., & Bonner, M.J. (1991). Matching treatment with recurrent abdominal pain symptoms: An evaluation of dietary fiber and relaxation treatments. *Behavior Therapy*, 22, 257-267.
- Finney, J.W., & Bonner, M.J. (1992). The influence of behavioral family intervention on children's health and health care use. Invited Paper, *Behavior Change*.
- Putnam, D. E., Finney, J.W., Barkley, P.L., Bonner, M.J. (1992). Enhancing commitment improves adherence to a medical regimen. *Journal of Consulting and Clinical Psychology*. Under review.

PUBLISHED ABSTRACTS

- Bonner, M.J., Kalsher, M.J., & Burnette, L.C. (1988, May). Behavioral intentions and alcohol consumption: A field study. *Virginia Journal of Science*, 39, 191.
- Paper presented at the 1988 meeting of the Virginia Academy of Science, Charlottesville.
- Clarke, S.W., Kalsher, M.J., Burnette, L.C., & Bonner, M.J. (1988, May). Does handwriting predict drunkenness: Observations from university parties. *Virginia Journal of Science*, 39, 191. Paper presented at the 1988 meeting of the Virginia Academy of Science, Charlottesville.

PROFESSIONAL PRESENTATIONS

- Putnam, D.E., Finney, J.W., Barkley, P.L., & Bonner, M.J. (1991, March). Enhancing commitment increases adherence to medical regimen. Society of Behavioral Medicine, Washington, D.C.
- Glindemann, K.E., Geller, E.S., Bonner, M.J., & Lugo, M.C. (1990, April). Use of an intoxication detection aid to assess BAC levels at university fraternity parties. Southeastern Psychological Association, Atlanta.
- Glindemann, K.E., Bonner, M.J., Clarke, S.W., & Brooks, A. (1990, May). Developing a behavioral checklist for estimating partiers' blood alcohol concentration. Association for Behavior Analysis, Nashville.
- Gilmore, M.R., & Bonner, M.J. (1990, August). Community-based interventions for children: Rewards, Prompts, Education, and Policy. American Psychological Association, Boston.
- Kalsher, M.J., Clarke, S.W., & Bonner, M.J. (1989, March). A behavior analysis of party drinking: Self-service vs. bartenders. Southeastern Psychological Association, Washington D.C.

- Neff, D.F., Broyles, S., Edwards, M.C., Sikemma, I., Crowe, H., Gould, R., Jasie, D., Kudlas, J., Bonner, M.J., & Keister, L.M. (1989, April). *The influence of success experiences on chronic tension headache treatment outcome*. Society of Behavioral Medicine, San Francisco.
- Edwards, M.C., Bonner, M.J., & Finney, J.W. (1989, November). Recurrent abdominal pain: Matching treatment with symptom presentation. Association for the Advancement of Behavior Therapy, Washington, D.C.
- Edwards, M.C., Bonner, M.J., Keister, L.M., & Finney, J.W. (1989, November). A comparison of muscle discrimination ability in tension headache sufferers and controls. Association for the Advancement of Behavior Therapy, Washington, D.C.

TRAINING MANUAL

Geller, E.S., Kello, J.E., Bonner, M.J., & Gilmore, M.R. (1989, December). Achieving occupational health and safety: Safety motivation and presentation skills. Detroit, MI: UAW Chrysler Corporation.

TECHNICAL REPORT

Final report for the Virginia Department of Motor Vehicles, Project no.: 230-11-110c-053-402293-1 -- Establishing corporate-based programs to increase the use of safety belts..

HONORS

Graduated Cum Laude
Psi Chi National Honor Society in Psychology
Phi Kappa Phi National Honor Society
Gamma Beta Phi National Honor Society
Golden Key National Honor Society
President's List for Notable Academic Achievement, 1988
Va. Tech Union Up and Coming Leadership Award, 1988
Deans List 1986-89

PROFESSIONAL AFFILIATIONS

American Psychological Association, Student Affiliate APA, Division 12: Sections I, III, and V Association for Behavior Analysis Association for the Advancement of Behavior Therapy Society for Behavioral Medicine Virginia Academy of Science

REFERENCES

Jack W. Finney, Ph.D.
Director, Child Study Center
Department of Psychology
Virginia Polytechnic Institute and State University
Blacksburg, VA 24061-0436
(703) 231-6670

Thomas H. Ollendick, Ph.D. Director of Clinical Training Department of Psychology Virginia Polytechnic Institute and State University Blacksburg, VA 24061-0436 (703) 231-6581

E. Scott Geller, Ph.D. Director, Applied Behavioral Systems Laboratory Department of Psychology Virginia Polytechnic Institute and State University Blacksburg, VA 24061-0436 (703) 231-6223

Melani & Bonner