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THE ROLE OF MARITAL DISTRESS, PARENTAL AND CHILD DEPRESSION, FAMILY FUNCTIONING AND HEALTH CARE BEHAVIORS IN TREATMENT ADHERENCE AND METABOLIC CONTROL AMONG ADOLESCENTS WITH DIABETES

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ABSTRACT

Fifty-five adolescents with Type 1 diabetes, who were receiving secondary care services from diabetes clinics and pediatricians, were followed for three months in this exploratory community study. Measures of parental depression, marital distress, general family functioning, and diabetes-specific family functioning were obtained during an assessment of both parents and adolescent. The 24-hour recall adherence interviews were conducted separately with both the parent and adolescent on six occasions over the three months, and metabolic control was measured by HbA1c levels at the onset and end of the study. Multiple regression analyses showed that adherence was not associated with control. Adolescents who had been diagnosed longer were in worse metabolic control. Family relations were not linked with glycemic control and their influence varied on the five dimensions of adherence. The family relations variables, as a model, was significant in predicting diet amount adherence, accounting for 32.8% of the variance, with parental depression and general family conflict accounting for most of it. The family relations model was significant in predicting exercise adherence, with diabetes-specific guidance-control, accounting for 37.2% of the variance. Controlling for chronological age and gender, adolescent depression, as a measure of child adaptation, was not a significant predictor of glycemic control or adherence. However, both gender and chronological age accounted for 39.2% of exercise adherence. Glycemic control was consistent, with 75% of the adolescents displaying stable controlled and non-controlled metabolic control throughout the study. Metabolic control, treatment adherence and frequency of insulin omissions were similar for those receiving treatment from a diabetes clinic versus a pediatrician. Using an insulin sliding scale improved metabolic control, whereas adherence was similar for the groups. Males and females omitted insulin injections equally across the three adolescent age groupings and metabolic control was worse for those who missed insulin injections. Neither adherence nor family relations differentiated between the adolescents who missed or did not miss insulin injections. Parental involvement in the diabetes regime differed by gender,

with parents remaining involved with females for longer. Results were discussed in the context of adolescent development and the systems social/ecological model of adaptation and coping developed by Kazak (1989).

CHAPTER 1: INTRODUCTION TO THE PROBLEM

The most common chronic endocrine childhood disorder is insulin-dependent diabetes mellitus (IDDM). Treatment involves using a complex and varied lifelong self-management regimen which must be learned by both the parent and child and integrated into the daily routine. The developmental task of achieving independence and autonomy during adolescence creates an added challenge to the adolescent with diabetes and his or her family as responsibility for self-care increases with developmental maturation. While there is a natural process of transferring and sharing responsibility for aspects of the diabetes management regimen, the giving up and sharing of responsibilities can be difficult for the parent (La Greca, 1982). Parents and adolescents have the added responsibility of adjusting the regimen treatment to take into consideration the marked changes in physical, cognitive, emotional, and social development which accompany fluctuations in metabolic control. Such adjustments during adolescence make adhering to a complicated diabetes treatment regime more challenging (Satin, La Greca, Zigo, & Skyler, 1992) and contributed to the adolescent period being characterized by consistent findings of reduced adherence (Bennett Johnson, 1988; Tattersall & Lowe, 1987) and difficulties maintaining blood glucose levels within the optimal range (Tamborlane & Ahern, 1997).

Although diabetes is not life threatening, there is always the possibility of complications which are life threatening or debilitating (Catellier et al., 1992). There is a higher risk for physiological complications in children and adolescents who are chronically out of metabolic control because they are undergoing physical and cognitive maturation. In the long term, diabetes can lead to damage in various tissues and organs, such as the kidney, nerve cells, and the retina. Other complications can be coma, growth delay, and altered cognitive functioning (Ryan, Vega, & Drash, 1985; Wise, Kolb, & Sauder, 1992). Long-term morbidity and death result from acute episodes of hypoglycemia and micro vascular, macro vascular and neurologic complications (Allen, Duck, Sufit, Swick, & D'Alessio, 1992). Consequently, optimizing

diabetes adherence and improving metabolic control could significantly reduce health care costs, improve quality of life, and reduce morbidity and mortality in the long term.

Research indicates that both aspects of the management of childhood diabetes, adherence to treatment and metabolic control, are influenced by family relationships because diabetes management depends a great deal upon parental and family support (Patterson & McCubbin, 1983). The relevance of studying the parent-child relationship within the family context in families with a chronically ill child is of foremost importance because the literature has clearly shown that it is the mothers of these ill children who assume the majority of the care-taking functions. Although there is a large empirical body of evidence supporting the impact of maternal psychological adjustment on child adjustment in general (Burbach & Borduin, 1986; Weissman & Paykel, 1974), and in the pediatric illness population (Cadman, Rosenbaum, Boyle, & Offord, 1991), fathers have not generally been the focus of research (Phares, 1992). It has been suggested by some researchers (Bennett Johnson, 1980; Kazak, 1989; Kazak & Nachman, 1991) that the adaptation of children with a chronic illness be studied in various life contexts. Researchers have begun to take a family systems approach to studying the adaptation of adolescents with IDDM (Hanson, Henggeler, Harris, Burghen, & Moore, 1989; Hanson, DeGuire, Schinkel, & Henggeler, 1992). This approach is supported by both developmentalists (Bronfenbrenner, 1979) and family systems theorists (Minuchin, 1974) because children's needs are met through the family, the primary unit of our society. A well-functioning family will attend to the needs of the children by providing guidance, nurturance, discipline and support. Psychologically healthy parents and a good marital relationship allow for the resources of the family to be drawn upon to parent the children. Family problems, marital distress and parental depression could have deleterious effects on adherence and glycemic control in diabetes by interfering with self-care behaviors and by causing physiological dysregulation because of the stress (Peyrot and McMurry, 1984). Conversely, the stressors of parenting a child with a chronic illness may be a risk factor that impinges upon individual parental functioning and family relationships. The family systems/social-ecological model of

adaptation and coping developed by Kazak (1989) provides a framework from which we can understand the various influences on adaptation in childhood diabetes. Following a discussion of this model, research findings at each level of this model (the parental and the family subsystems, the adolescent, and the larger systems) are presented.

Family Systems/Social-Ecological Model of Adaptation and Coping in Childhood Chronic Illness

Kazak's (1989) family systems/social-ecological model of adaptation and coping in childhood chronic illness, which is based on a social ecological model developed by developmentalist Bronfenbrenner (1979), provides a model for understanding diabetes adjustment. In this systems/social ecological model, the child is at the center of a series of concentric rings that affect the child and that the child in turn influences. According to Bronfenbrenner's (1979) model, developmental processes can be understood as multidirectional. The family is one of the subsystems and adults in the family may belong to multiple subsystems, such as the parenting and spousal subsystems. Thus, the adjustment of the child can be understood in terms of its subsystems and the ways in which they interact. In consideration of the family subsystem, there is influence of the siblings, the parents, and the individual ill child. The social support network and the educational and health care systems are broader systems that can also affect the family system.

In contrast to linear causality, which supposes that event A causes event B, a basic principle in a systems framework is circular causality. It implies that there is no cause and effect but rather there is a repeating cycle of complementary behavior. That is, there is interdependency among family members and that change in one aspect of the family system can lead to change in the other parts of the system (Von Bertalanffy, 1968). In other words, all family members are dependent upon the behavior of the other family members and any change in one member will have consequences for the other members. Thus, in family systems theory, it is important to understand that when one individual alters his/her behavior, all of

the other family members are forced to a new level of adjustment. In applying circular causality from a systems perspective, it is perceived that a problem in one individual of the family will have an effect on all other family members and their reaction will in turn affect the family member with the problem. In other words, dysfunctional behavior in a family member is the product of their relationship with their family members, and it is the interrelationships that are producing and maintaining the problem. Consequently, the problem of living with a childhood chronic illness will not remain enclosed within the child, but rather the illness will have ramifications for all family members.

From a family systems theory perspective, the adjustment and physical health of adolescents with IDDM will be associated with the quality of their family relations during this family life cycle stage. Because the diabetic treatment regimen is complicated and adherence is time consuming, diabetes management may affect the family's life style and daily routines, which in turn may influence the management of diabetes (Bennett Johnson, 1988). A reciprocal relationship may exist. Thus, family relationship variables may be additional risk factors vis-à-vis the management of a diabetic regime and metabolic control.

According to developmentalist Duvall (1977), the family passes through eight stages in the normal cycle of its development and each family life cycle stage is characterized by specific tasks and challenges. The stages of the family are: beginning, infant, preschool, school-age, adolescent, launching, postparental and aging family. The way in which the critical tasks of communication and boundary negotiation have been resolved in past stages will affect the resolution of the challenges of the adolescent stage. Not only is it characteristic of the adolescent family stage for the adolescent to challenge and test the family's rules and regulations concerning privacy, control and responsibility, the parents are coping with their own mid-life transitions during this adolescent period. Thus, developmental stages are characterized by both adolescent and parental challenges. At this point it is important to highlight some central tasks and issues which are characteristic of the adolescent developmental stage and relative to diabetes.

Adolescent Development

Developmental theorist Erik Erikson views adolescence, the transition period between childhood and adulthood, as the most critical period in development because of the important social and personal transitions and the search for personal identity that occurs (Erikson, 1968). Erikson provides a theoretical framework for understanding identity formation in which it is recognized that part of establishing a personal identity is gaining some degree of independence from parents. This emancipation, which accelerates during adolescence, is accompanied by decreasing parental influence and an increase in the influence of peers (Brown, Clasen, & Eicher, 1986).

While some theorists of the psychoanalytic tradition view adolescence as a period of emotional turmoil, empirical researchers have not unanimously confirmed this view. The majority of adolescents do not fit the storm and stress model proposed (Freud, 1969; Hall, 1904). There are inconsistent opinions about whether parent-child conflict is the norm during adolescence. A much cited finding from a review of observational studies of parent-child interactions in families of adolescents in the United States by Montemayor (1983) found that there was an inverted U-shaped function between age and conflict. Parent-adolescent conflict increased during the early years following puberty and abated during adolescence. Montemayor summarized that the worsening of the parent-child relationship was associated with an increase in parent-child conflict and the mother's loss of power and influence over her adolescent. Generally, conflict was over everyday chores and responsibilities. Rather than an inverted U-shape, Fuhrman and Buhrmester (1992) found that the parent-child conflicts that do develop tended to normally peak during the early pubertal change of grades 7 through 10, and then decline.

More recently, a series of meta-analyses, that examined studies of parent-child conflict in terms of whether conflict was a function of adolescent age or pubertal maturation, found little support for the commonly held view that parent-child conflict rises and abates across adolescence (Laursen, Coy, & Collins, 1998). In these meta-analyses, three types of parent-child conflict were examined: conflict rate,

conflict affect, and total conflict (conflict rate and conflict affect were combined). They found linear effects, with a decline in conflict rate and total conflict with age, and an increase in conflict affect with both age and pubertal maturation. In the age meta-analyses, conflict rate and total conflict declined from early adolescence to mid-adolescence and mid-adolescence to late adolescence, whereas conflict affect increased from early adolescence to mid-adolescence. A positive linear relationship between conflict affect and pubertal maturation was found in the puberty meta-analyses as well.

In contrast to Erikson (1968), who views the central tasks of adolescent development to be separation, differentiation and autonomy, McGoldrick (1989) argues that theorists such as Erikson have not recognized the importance of continued connection and relational issues and have focused uniquely on individual developmental issues. The role of values such as attachment, caring, interdependence, and relationships in adolescent development are encompassed in contemporary theories of female development (Gilligan, 1982; Miller, 1976).

Laursen and Collins (1994) take a social relational perspective on conflict in social relationships and discuss its implications for adolescent development. In this social relational model, "adolescent behavior will vary more as a function of the relationship in which the conflict arises and the setting in which it takes place than as a function of the age or maturation of the participants" (p. 200). This social relational view of development is grounded in equity theory (Kelley et al., 1983). According to equity theory, increasing closeness and interdependence develop as participants invest in a relationship and its rewards. Laursen and Collins (1994) hypothesize that conflict is generated in the process of developing closeness because there is an integration of goals and behaviors. The impact of conflict will be minimized in relationships in which there is greater investment, such as with family members, so as to continue the rewards of the relationship. Thus, variation in conflict will exist among family members because there are varying levels of interdependency and closeness. According to this model, there will be greater conflict between adolescents and mothers because of the greater closeness and interdependency compared to

relationships with fathers or siblings. Lauren and Collins argue for consistency and gradual transformation in behaviors, especially within close relationships, rather than age-related changes in conflict behavior. Instead of an age related rise and fall in parent-child conflict, they see that life-transition issues need to be taken into account in understanding conflict and adolescent adjustment. They also recognize both biological and environmental variables which influence developmental adjustment. For example, they advance that there is an interaction effect in which the changes associated with puberty coincide with the stressors associated with changing from an elementary school to a junior high school at age 12 and to a high school at age 14 (Simmons & Blyth, 1987; Simmons, Burgeson, & Reef, 1988). Moreover, parents may also be facing their own concerns about relationships, work, biological changes and occupational achievement that may influence family adjustment.

Baumrind (1991), in her review of effective parenting, and Hill and Holmbeck (1986) in their article on attachment and autonomy in adolescence, also stress the importance of balancing separation and connectedness. These contemporary theorists emphasize connectedness (Chodorow, 1978; Gilligan, 1982; Josselson, 1973) and stress that adolescent individuation should take place in the context of continued attachment to the family rather than emphasizing autonomy which would leave individuals vulnerable to alienation according to Baumrind (1991). In her opinion, early separation from family attachments is a greater threat to mature identify formation than delayed separation from family attachments, as it leaves adolescents vulnerable to peer group influence and loneliness.

Research has found that there are also gender-related differences in expectations for autonomy. Developmental norms suggest that parents have higher behavioral expectations for their female children, particularly because they mature physically more rapidly (Brooks-Gunn & Zahaykevich, 1989). The literature provides some support for the view that both parents and adolescents agree that autonomy should be granted to males at a younger age compared to females, but also that parents expect autonomy in certain areas at younger ages than the adolescents themselves expect it (Farnill, 1987). Adolescents' and parents'

opinions differ in regard to chores and responsibilities around the house.

The additional shared parental and child responsibilities associated with adhering to a diabetes regime suggests that there would be more areas in which parent-child conflict could potentially develop. While adolescent tasks and issues for the chronically ill child are probably not unlike those of physically healthy adolescents, the adolescent developmental task of achieving independence from the family could create further risk for metabolic instability as he or she assumes more responsibility for self-care. Parents must decide on how much responsibility to give and how to remain involved.

While most individuals pass through adolescence without excessive difficulties, some do experience stressful periods. This stress is frequently associated with the issues of control and autonomy within the family which are re-negotiated during this period. Eccles et al. (1993) advanced the hypothesis that some of the negative changes that can occur during adolescence result from a mismatch between the needs of developing adolescents and the opportunities afforded them by their social environments. They draw on person-environment fit theory, as developed by Hunt (1975), which stipulates that individuals are not likely to do well or be motivated if their social environment does not meet their psychological needs. During the control/autonomy re-negotiation process during adolescence, it may not be easy for parents to determine the optimal level of autonomy versus control. This developmental stage-environment fit perspective on adult control draws on research which shows that there is a decrease in self-esteem and intrinsic motivation in adolescents who reported decreasing opportunities to participate in family decisions. Eccles et al. (1993) also highlight that a mismatch between authority relationships in the home precipitates increased conflict which may also be detrimental to self-esteem and school-related motivation. This environment fit perspective integrates the findings on parenting styles which shows that parents who reinforce and stimulate the process of growing autonomy, self-determination, and independence will do best (Baumrind, 1991). It is recognized that the re-negotiation process of control/autonomy during adolescence may not be easy as it may be difficult for parents to determine optimal levels of autonomy versus control. This will be especially

difficult because adolescence is a period of development which is characterized by excessive risk taking (Arnett & Balle-Jensen, 1993; Moore & Gullone, 1996) and parents and adolescents may not always evaluate the desirability of consequences in similar ways. Recent research is indicating that, contrary to a commonly held opinion that adolescents are poor decision makers, they make decisions much the same way that adults do but that they differ in terms of their evaluation of consequences (Beyth-Marom, Austin, Fischoff, Palmgren, & Jacobs-Quadrel, 1993).

In the pediatric chronically ill population, this re-negotiation process of control/autonomy may be more difficult for parents, as their child's health is at stake. While there is a transfer of responsibility from the physician and various diabetes specialists who may be involved, it is the parent and adolescent who must manage the disease on a day to day basis (Bennett Johnson, 1985). Consequently, it is the parent who must decide on how much independence to give the child. It is not surprising then that research has shown that there are more difficulties in adolescence related to adherence to a treatment regime, and control of the disease is less stable. Moreover, there are consistent findings indicating reduced diabetes adherence during the adolescent period (Bennett Johnson, 1992; Tattersall & Lowe, 1987) and the number of children with diabetes in poor control increases during adolescence (Fallstrom, 1974; Koski & Kumento, 1975; Ludvigsson, 1977). This finding is common in other diseases and is not unique to diabetes (Daltroy et al., 1992). Moreover, the mothers and fathers of these children with chronic health problems reported receiving two to three times more mental health treatment than parents of well children (Cadman et al., 1991). These findings certainly imply an increased risk for difficulties for all members of families caring for a chronically ill child. Although it is not clear what type of mental health treatment was received, it could be assumed that the stressors of parenting a child with a chronic illness may be a stress-related risk factor that impinge upon both individual parental functioning and family relationships.

The evidence is considerable that metabolic control and treatment adherence, among adolescents with IDDM, are related to a variety of biological, familial, psychological and health care system variables.

Yet, treating health care professionals have focused mainly on teaching health behaviors such as testing blood glucose levels, injecting insulin, adjusting insulin dosages, following a diet regime, engaging in regular exercise and learning symptom recognition. For some adolescents such direction and intervention are all that is required, while for others the importance of the potential influence and interaction of these systemic variables need to be considered. Identifying health-compromising behaviors during adolescence is crucial as patterns in the general population of smoking, diet, and exercise established during adolescence persist into adulthood. The systems/social-ecological conceptual framework (ill child, family subsystems, larger systems) provides a basis for understanding the links between diabetes-specific support and general family support and conflict, marital functioning, adolescent and parental depression and health care behaviors and adherence to treatment on the one hand, and metabolic control in a population of adolescents with diabetes on the other hand.

At this point it is important to have a clear understanding of the nature of insulin dependent diabetes mellitus (IDDM) and the treatment demands that this condition imposes on the child and the family. An overview of the disease and the constructs of adherence to treatment and metabolic control will first be presented. The discussion will then focus on: (1) the role of marital distress, parental depression and family functioning in relation to pediatric chronic illness; (2) the impact of marital distress, parental depression and family functioning on child adjustment and treatment adherence and metabolic control; and (3) a review of child depression, as a measure of child adaptation, in pediatric chronic illness.

The Nature of Insulin Dependent Diabetes Mellitus

Types of Diabetes

Insulin-dependent diabetes mellitus (IDDM, or Type 1 diabetes mellitus) is more likely to appear in children and young adults and is the most common childhood endocrine disorder. The peak age for developing IDDM is during puberty. IDDM is characterized by complete pancreatic failure, which means

that there is low or no endogenous insulin produced. The individuals always require daily insulin injections for survival to prevent a life-threatening elevation of glucose and diabetic ketoacidosis. In contrast, in non insulin-dependent diabetes (NIDDM), or the adult type of diabetes, the pancreas continues to produce some insulin and NIDDM can be controlled through weight reduction and a dietary regime (Catellier et al., 1992). Gestational diabetes is the third type of diabetes , occurring in 2 to 5% of all pregnancies. The mothers typically return to normal glucose tolerance levels following the birth of the baby. The fourth type is diabetes associated with or secondary to a health problem.

Epidemiology

The incidence rates of IDDM vary world wide, with examples of reported incidence rates ranging from 34.9 per 100,00 children in Finland, 32.4 in Sardinia, 25.7 in Sweden to less than 1 per 100,000 children in Hong Kong, Pakistan and Paraguay (Sperling, 1997). Drash (1987) reports an incidence of 10-16 cases per 100,000 population per year in the United States, a prevalence of about 1 per 600 children below 20 years of age. In Canada incidence data collected in three locations show an incidence rate in Toronto of 9.0 per 100,000 children per year, 10.1 per 100,000 per year in Montreal, and 18.9 to 25.5 per 100,000 per year in Prince Edward Island (Diabetes Epidemiology Research International Group, 1988; Ehrlich, Walsh, Falk, Middleton, & Simpson, 1982; Siemiatycki et al., 1988; Tan & Wornell, 1991). A recent study by Toth, Lee, Couch, Kwok-Choy, and Martin (1997) determined that the incidence rate of diabetes in patients under the age of 15 living in Edmonton, Alberta, Canada was 25.7 per 100,000, with the highest incidence occurring in the 10 to 14 age group. Finally, there are no sex differences in IDDM with diabetes affecting females and males equally.

Although it is believed that IDDM is partly inherited, all those at risk do not develop the disease. Because a sibling of an identical twin with diabetes has only a 30-40% chance of developing the disease (Dosch, 1993), other factors appear to influence the development of the disease. A study of the effects of psychological stress and the onset of IDDM in children revealed that negative life events occurring during

the first two years of life increased the risk of IDDM, as did premorbid child behavior and dysfunctional family patterns (Themlund et al., 1995). An example of environmental stressors that may influence diabetes onset is indicated by the incidence rates of diabetes in children in Kuwait. A study of the IDDM incidence rates in Kuwait by the World Health Organization Multinational Collaborative Study determined that there has been a fourfold increase of IDDM in the 0 to 14 year age group with the highest incidence in children less than five years of age (Shaltout et al., 1995). While the incidence rates of diabetes are reported, the mechanism by which diabetes develops is not completely understood.

It is believed that IDDM, Type 1 diabetes, is an autoimmune disease in which the body's immune or defense system attacks its own insulin-producing cells, the insulin producing β-cells of the pancreatic islets of Langerhans (Daneman, 1990). IDDM develops when the insulin producing cells have been damaged or destroyed. In general, it is now believed that IDDM in childhood is a disease which evolves over a period of months to years, the consequence of exposing a genetically predisposed individual to an environmental trigger such as cow's milk during the first three months of life (Sperling, 1997; Verge et al., 1994).

Complications of Diabetes

Although diabetes is not life threatening, there is always the possibility of complications which are life-threatening or debilitating (Catellier et al., 1992). The failure to maintain adequate diabetic control can result in either hyperglycemia, a state where there is high blood sugar, or hypoglycemia, a state of low blood sugar. Hyperglycemia occurs when there is insufficient insulin to metabolize enough glucose to meet the needs of the body. The pancreas produces insulin, which is critical for the appropriate metabolization of glucose. Without the production of insulin, the body starves because glucose cannot be metabolized. Because there are abnormally high blood glucose levels, the body reacts, as in a state of starvation, by breaking down fats. As a consequence, the liver releases its own supply of glucose to correct the imbalance. The muscles use fat as a source of energy when there is markedly insufficient insulin and,

because the body cannot use up the fats completely in the absence of insulin, a build up of ketone bodies is the result. The initial symptoms of diabetes include excessive thirst, hunger, urination, fatigue, and loss of weight. Frequent urination is an attempt to eliminate the high levels of fatty acids. Without treatment the individual will enter a coma and die. Symptoms of hyperglycemia include sleepiness, flushing, dry mouth, nausea, and headache. The person is at risk of entering a state of diabetic ketoacidosis from the accumulation of ketone bodies should hyperglycemia extend to several hours or days. Ketoacidosis may result in coma or death.

Diabetic ketoacidosis (DKA) is a special concern during childhood illnesses, for illnesses and infections can precipitate this state. DKA is a more frequent complication of children in poor metabolic control and it occurs when there is an insufficiency of insulin, hyperglycemia, an elevation of ketones, and a loss of fluids associated with hyperglycemia. In order to avoid hypoglycemic reactions, maintaining mild to moderate elevations of glucose is at times tolerated during childhood. This produces mild hyperglycemia. Although mild to moderate hyperglycemia can be tolerated in the short term, it does have complications that are not usually immediately seen, a factor which is especially important with children who are in a state of growth.

One mechanism by which damage occurs from hyperglycemia stems from a build up of by-products of glucose in certain areas such as the lens of the eye and nerve cells, causing cataracts and nerve damage. The leading cause of new cases of legal blindness from disease is diabetic retinopathy. Eighty percent of individuals with diabetes will develop retinopathy within 10 years of diabetes. Furthermore, blockage of the larger blood vessels that supply oxygen and their nutrients to the heart, brain, and legs can also occur from hyperglycemia and this may lead to heart attack, stroke, and poor circulation (Ryan, 1988). Diabetic dyslipidemias are also common with diabetes. Dyslipidemia, which is poor lipid metabolism, increases the risk for developing heart disease, the leading cause of death in the diabetic population (Tan, 1992).

The health care expenditures associated with the complications of diabetes are costly. The Ontario Diabetes Status Index (ODSI) (Ontario Government, Diabetes Advisory Committee, 1995) has provided an index of the extent of the complications associated with diabetes and of the medical interventions involved. There is an inter-relationship between diabetes and other diseases such as, retinopathy, arteriosclerosis, heart disease, and stroke. In calculating their statistics, the ODSI defined most responsible diagnosis as the most significant cause for the hospital stay, whereas, primary diagnosis was defined as another condition which affected the length of hospital stay. In 1993 and 1994, the average length of hospital stay was 10 days for those with a most responsible diagnosis of diabetes and 12.8 days for those with a primary diagnosis. While the medical interventions associated with diabetes are very costly, Tamborlane and Ahern (1997) presented an analysis which showed that a 10% decrease in Hemoglobin A1c level (i.e., HbA1c from 12.0 to 10.8%) was associated with a 40 to 50% percent lower risk for the progression of retinopathy. Of course such reductions in HbA1c level would also be associated with a decrease in the cost to the health care system.

In conclusion, there is a higher risk for physiological complications in youngsters who are chronically out of metabolic control because they are in a state of physical and cognitive maturation. In the long term, diabetes can lead to damage in various tissues and organs, such as the kidney, nerve cells, and the retina. Other complications can be coma, growth delay and altered cognitive functioning. The sources of long-term morbidity and death are acute episodes of hypoglycemia and micro vascular, macro vascular, and neurologic complications. Optimizing diabetes adherence could potentially significantly reduce health care costs, improve quality of life and reduce morbidity and mortality.

Management of Insulin-dependent Diabetes Mellitus

The two main aspects of diabetes management are adherence to a medical regime and metabolic control of the disease. Metabolic control refers to the health status of the individual or the metabolic

stability or instability of the disease. Although there are inconsistencies and lack of agreement about the definition of adherence to treatment, essentially the term signifies to what extent the person is following medical or health advice (Haynes, 1979). The construct of adherence will be discussed at greater length in a subsequent section on adherence to treatment. First, the diabetes treatment regimen will be described. The results of the Diabetes Control and Complications Trial (DCCT), a randomized clinical trial of historic importance, will then be discussed followed by measurement of metabolic control and a review of the influence of various variables on metabolic control. A review of health behaviors will then follow prior to addressing, treatment adherence, the primary factor affecting metabolic control which has been studied.

Diabetes Treatment Regimen

Although there is no cure for diabetes, the discovery of insulin in 1922 by Banting and Best provided a means for treating diabetes and prolonging life (Bliss, 1993; Santiago, 1993). Treatment involves not only the injection of both short and long acting insulin, but also daily insulin adjustments must be made in response to the results of regular urine and blood testing, activity level anticipated, the types and quantities of food eaten, and caloric input. Daily decisions must be made in terms of food choices and amount of insulin to be injected, as glucose levels can be dramatically affected by biological factors such as, physical growth, hormonal changes at puberty and during adolescence, illness, emotional states, such as stress levels, and infections (Danowski, Ohlsen, & Fisher, 1980), and by level of activity (Felig, 1982). Ideally, three meals and three snacks are to be consumed at regular intervals and certain foods, such as, those high in fat or concentrated sweets should be avoided and complex carbohydrates encouraged. Eating needs to be coordinated with the timing of insulin injections, and exercise needs to be coordinated with insulin action and food consumption to eliminate reactions. Treatment also involves caloric regulation, regular exercise, and the management of injection-site rotation.

Regular exercise is encouraged because it reduces the risk of coronary heart disease and improves cardiovascular functioning (Campaigne, Gilliam, Spencer, Lampman, & Schork, 1984). Hanson (1990)

summarized the complications that can result from exercise. The factors which influence the metabolic response to exercise include the part of the body injected, the timing of the exercise relative to the insulin action, and the peaks and level of glucose at the onset of the exercise. Exercise is encouraged only when glucose levels are within the normal range because exercise can increase blood glucose levels even further when blood glucose levels are too high at the outset. Similarly, if the blood glucose level is too low (hypoglycemic), the blood glucose level will rise because of the counter-regulatory hormones that occur to make glucose available for the muscles. Attention must be paid to when exercise is engaged in, as exercise and insulin action lower blood glucose levels. It is important to test blood glucose levels and eat before exercising because a decrease in insulin is required when exercising and there is an increase sensitivity to insulin. The risks associated with engaging in exercise include increased blood pressure, which can aggravate retinopathy increase the risk of hemorrhages and accelerate nephropathy.

The introduction of self-monitoring of blood glucose levels using glucometers and reflectance meters has provided a means to more closely monitor diabetes and take a more active role in self-management. Daily self-monitoring of blood glucose replaced urine glucose monitoring with the introduction of human insulin, which was developed within the last decade (Santiago, 1993). Although blood glucose testing provides a more accurate reading of glucose levels than urine testing (Varni & Wallander, 1984), urine testing is an efficient way to measure ketone levels as an elevation would indicate possible hyperglycemia. The individual with diabetes is ideally expected to test capillary blood sugar levels four times daily, with a minimum expectation of twice daily as the primary method of monitoring control. This self-monitoring of blood glucose levels assists the individual in making the required adjustments to insulin requirements, food intake and exercise (Catellier et al., 1992). While adherence to a prescribed treatment regime is essential, the patient must also strive for good glycemicc control.

Diabetes Control and Complications Trial (DCCT)

A longstanding controversy has existed about the optimal level of control necessary for the

prevention of complications. A study organized by the United States National Institute of Health, and which involved two Canadian centres, was designed to test the question of whether tight control delayed or prevented the development of complications. This study, which is of historic importance, is called "The Diabetes Control and Complications Trial (DCCT)" (Canadian Diabetes Association, 1993; DCCT Research Group, 1994). The results of this landmark study clearly demonstrated that intensive treatment of those between 13 and 39 years of age with IDDM delayed the onset and progression of diabetic complications in those without complications and also in those with early complications. Because the majority of the subjects in the study were more than 18 years of age at baseline, with participants ranging between 13 and 39 years, the researchers queried whether the efficacy and safety in younger children with diabetes (13 to 17 years of age) would differ because of the biological and psychosocial changes that occur during adolescence. A comparison of 125 adolescents with IDDM with no retinopathy and a secondary intervention group of 70 adolescents with IDDM and mild retinopathy was made. Two treatment conditions were involved: (1) an intensive therapy with an external insulin pump or at least three daily insulin injections and once daily monitoring, and (2) a standard conventional treatment regime (DCCT Research Group, 1994). There was concern about the effectiveness of intensive treatment during adolescence because of elevated concentrations of growth hormone and insulin-like growth factor-1 (IGF-1) which are present during puberty. The results showed that intensive therapy decreased the risk of retinopathy by 53% and decreased the risk of retinopathy progression by 70% in the secondary intervention group. Overall, intensive therapy reduced the risk of neuropathy by 60%, of micro albuminuria by 39%, and of proteinuria by 54% (Tamborlane & Ahern, 1997). In contrast with the adult results, very few adolescents were able to maintain HbA1c blood levels within the non-diabetic range throughout the duration of the study. As well, the daily insulin doses were higher for the adolescents when compared to the adults and the mean HbA1c values in intensively treated adolescents were higher than the adult values. Additionally, in the adolescents there was a twofold greater risk of becoming overweight and a threefold

risk of severe hypoglycemic reactions.

The results of the DCCT study highlight the inherent difficulties that adolescents experience in maintaining non-diabetic blood glucose levels on a consistent basis and also despite the health benefits, there are consequences that may be aversive to adolescents who try to maintain blood glucose levels closer to non-diabetic levels (Tamborlane & Ahern, 1997). Nevertheless, the DCCT study recommended intensive therapy from the onset of the diagnosis as the treatment of choice in adolescents between the ages of 13 and 17 years of age with IDDM.

Since the results of the DCCT trials were published, the evidence that maintaining blood glucose levels at normal or near normal levels can delay and reduce the severity of the complications associated with IDDM has influenced standards of care and which have just recently been adjusted to incorporate these changes. Current therapeutic goals for the treatment of diabetes now include the following (Canadian Diabetes Association, 1993; DCCT Research Group, 1994): the achievement of normal or near normal blood glucose levels; a decrease in HbA1c levels to as near the non-diabetic range as possible; the abolition of symptoms of hyperglycemia; the avoidance of severe hypoglycemia; the avoidance of ketonuria; the maintenance of normal growth and physical maturation; the promotion of physical and emotional well-being; the minimization of urine glucose losses; and, the maintenance of normal blood lipids.

The clinical practice guidelines for the treatment of diabetes, as presented by the Canadian Diabetes Advisory Board, have suggested that the following metabolic levels of plasma glucose and glycosylated hemoglobin levels presented in Table 1 be used as targets for the control of diabetes. These are general, not adolescent-specific guidelines.

TABLE 1:

Targets for Control of Diabetes (Adapted from Catellier et al., 1992, p. 9)

	Metabolic Control		
Value	Optimal	Acceptable	Compromised
Plasma glucose level (mmol/L)			
Preprandial	4 - 7	7.1 - 10.0	>10
Postprandial	5 - 10	10.1 - 12	>12
Glycated Hb level (percent of upper limit)	< 110	111 - 140	>140
Triglyceride level (mmol/L)	< 1.7	1.7 - 2.5	>2.5

Measurement of Metabolic Control

Glycosylated hemoglobin or hemoglobin A1c (HbA1c) is the gold standard by which researchers have been measuring metabolic control. HbA1c is a measure of glucose metabolism, which is an indication of stability of the disease (Daneman, Wolfson, Becker, & Drash, 1981). Glycosylation is a process by which glucose sticks to proteins, and the more glucose there is in the body, the more proteins become glycosylated. Measurement of hemoglobin A1c (HbA1c) gives a measure of average blood sugar control over the previous two to three months (Daneman et al., 1981). Quarterly testing of hemoglobin A1c levels is a minimum evaluation criterion for individuals with diabetes.

The use of HbA1c as the sole measure of control has created some methodological problems for researchers. First, since HbA1c provides an average value of blood sugar over the previous two to three months, it does not indicate variability over the period in question. Thus, the patient could have experienced extreme blood sugar levels and the HbA1c value would only indicate the average during that period. Consequently, the HbA1c assay is not sensitive to fluctuations in blood sugar levels. Daily

capillary self-monitoring of blood sugar levels provides daily fluctuations and is reflective of the variability in control. Second, each laboratory has its own assay methodology and consequent range of values that requires unique interpretation as laboratory results are not standardized. To facilitate interpretation of HbA1c assay results from different laboratories with differing reference ranges, it is standard clinical practice to commute HbA1c assay values to a percentage of the upper reference range determined by the laboratory (Catellier et al., 1992; Daneman & Ellis, 1996).

Since the Diabetes Control and Complications Trial (DCCT) demonstrated that a decrease in HbA1c resulted in significant reduction in microvascular complications associated with diabetes, the laboratories have been under increasing pressure to provide reproducible, standardized measurements of glycohemoglobin. A glycohemoglobin standardization subcommittee of the American Association of Clinical Chemistry was established in 1993 with the goal of developing a plan for standardization that would allow individual laboratories to relate their glycolated hemoglobin results to those of large scale studies such as the DCCT (Ward, 1997). The goal of the National Glycohemoglobin Standardization Program was to allow standardization of most existing and future assays. By working with the manufacturers, a network of reference laboratories calibrated to the DCCT reference value was established. To achieve comparability of sample results with the DCCT reference of method standardization, a central primary reference laboratory sets up the initial calibration and is responsible for monitoring two back-up primary reference laboratories and four secondary reference laboratories. The primary reference laboratories work directly with the manufacturers to standardize their methods and provide comparative results for method certification in order to achieve comparability of results with the DCCT reference of method standardization. Upon meeting stringent certification criteria set by the National glycohemoglobin standardization program, manufacturers receive a certificate of traceability (Ward, 1997). Such standardization of glycohemoglobin measurement was not underway in Ontario at the time of the data

collection phase of this thesis.

Nevertheless, the use of glycohemoglobin measurement (GHb) using HbA1c has several utilities and is indispensable in diabetes management. The first use is assisting in the diagnosis of diabetes mellitus as glycohemoglobin levels are elevated at the time of diagnosis. Secondly, GHb provides a way of assessing and tracking blood glucose levels in individuals with IDDM. It is of practical interest to understand whether knowledge of HbA1c assay results influence self-care behaviors.

Knowledge of HbA1c levels was found to improve metabolic control in a study by Larsen, Horder and Mogensen (1990) who followed 240 subjects which were assigned into two groups. In one group the results of HbA1c were used by both the care-givers and patients to assess and modify metabolic control and the other group results were not given. Knowledge of HbA1c levels resulted in a reduction which was equivalent to a fall in mean plasma glucose concentration of 1 mmol/L, whereas the control group values were unchanged. Sharing HbA1c assay results with patients is not uniform practice and not all patients understand the significance of the readings.

How stable is metabolic control over time? There is limited data on the stability of glycated hemoglobin over time. However, the results from Daneman et al. (1981), who studied 477 children with IDDM who were following a conventional diabetic regime and whose glycated hemoglobin was measured every 3 months over a one year period, found that 40% of the children remained within one percent of the initial value. They also found that there was a small but significant decline in glycated hemoglobin level over the next five years. A quarter increased by more than one percent and 33% decreased by more than one percent during the year.

Although the HbA1c assay has been considered the gold standard for measuring metabolic control, a group of researchers has discovered that lipid metabolism may be a more sensitive measure of control in diabetes (Bennett Johnson, Freund, Silverstein, Apperson Hansen, & Malone, 1990; Bennett Johnson et al.,

1992). Both glucose metabolism and lipid metabolism will fluctuate with level of control and will be elevated in individuals with diabetes in fair or poor control (Glasgow, August, & Hung, 1981; Lopes-Virella, Wohltmann, Loadholt, & Buse, 1981; Peterson, Koenig, Jones Saudek, & Cerami, 1977). As discussed earlier, dyslipidemia, which is the result of elevations in lipid metabolism, is a common complication of diabetes. Insulin plays several critical roles in lipid metaboiism (Felig, 1982). Insulin expedites the removal of triglycerides and inhibits the breakdown of triglycerides stored within the fat cells. An elevation of triglyceride levels occurs with insulin insufficiency because they are not stored efficiently and already stored triglycerides are broken down into free fatty acids, which are converted to triglycerides by the liver. Because of the increased risk for atherosclerotic heart disease in diabetes (Skyler, 1979), assessing the relationship between adherence and lipid metabolism is relevant.

Influences on Metabolic Control

In addition to the re-negotiation of control/autonomy during adolescence, maintaining glucose stability during adolescence is affected by developmental hormonal changes, residual β-cell function, and emotional stress, thus creating further challenges for the adolescent (Clarson, Daneman, Drash, Becker, & Ehrlich, 1987). There is a 20 to 30% increase in insulin doses during puberty because of the insulin resistance that accompanies puberty and the increased concentrations of sex hormones and growth factors (Amiel, Sherwin, Simonson, Lauritano, & Tamborlane, 1986; Blethen, Sargeant, Whitlow, & Santiago, 1981).

Additionally, adolescents with IDDM are particularly susceptible to stress because they lack insulin, an important hormone involved in reaction to stress. Stress results in the release of catecholamines through the autonomic nervous system. Catecholamines play a number of important roles in the metabolism of glucose. A catecholamine increase suppresses the release of insulin, causing hyperglycemia. It will also increase lipolysis, a process of breakdown of fat and mobilization of free fatty acids which

antagonizes the peripheral metabolic effects of insulin, and stimulates hepatic glycogenolysis and glyconeogenesis (Tarnow & Silverman, 1981-1982).

In addition to the hormonal changes which affect insulin metabolization, several studies with both adolescents and adults have suggested that poorer metabolic control is associated with high levels of stress (Bedell, Giordani, & Amour, Tavormina, & Boll, 1977; Brand et al., 1986; Chase & Jackson, 1981; Cox et al., 1984; Minuchin et al., 1975). There is evidence which demonstrates that experimentally manipulated conflict between parents or unfamiliar adults produces behavioral, cognitive, affective and psycho physiological responses in children in the absence of adult-child interaction (Gottman & Fainsilber Katz, 1989). Moreover, there is considerable individual variability in biological response which has also been noted. For example, an evaluation of 141 children and adolescents with diabetes at a summer camp indicated that negative stressful life events were (1) only correlated with diabetic control in males with an internal locus of control; (2) related most consistently with an increase in free fatty acids; and (3) associated with blood sugar levels only in certain individuals (Brand et al., 1986). Bedell et al. (1977) have suggested that chronically ill children have a tolerance for disruption which includes heightened stress tolerance; this may explain individual variability.

Although there exists great controversy as to the mechanisms by which stress can affect glycemic control, Peyrot and McMurry (1984) have proposed two mechanisms: first, stress directly affects glycemic control by triggering a physiological state of arousal characterized by increased output of counter regulatory hormones; and second, stress may indirectly affect metabolic control via its disruption of adherence to treatment behaviors. Of course, a third mechanism may be that familial relationships may also affect both treatment adherence and metabolic control directly. That is, a stressful family environment, such as would exist with marital discord, parental depression, lack of family support and family conflict, may play a role in disrupting treatment adherence and dysregulating metabolic control as

well. Achieving the adolescent developmental task of becoming independent and autonomous could also be considered a stressor which may also play a role in the ability to follow a treatment regime and ultimately in maintaining metabolic control in diabetes.

Health Behaviors

In addition to physiological measures of control such as HbA1c and triglyceride, Bennett Johnson (1992) has suggested that health behaviors, as indices of quality of life, should be introduced as measures of adjustment. First, the frequency of hospitalization for diabetes complications and, length of hospital stay can be viewed as indices of adjustment. An investigation of 2,889 hospital discharges with any mention of IDDM and of 2,270 discharges with diabetes as the principle diagnosis found gender differences in hospitalizations for IDDM (Cohn, Cirillo, Wingard, Austin, & Roffers, 1997). They found that in individuals with diabetes as the principle diagnosis, females had 40% more hospitalizations and 44% more repeated hospitalizations. Moreover, gender differences occurred primarily in adolescence, with a rate of 50 per 100,000 for females for ages 10-14 years compared to 38 per 100,000 for males. The rate increased to 68 per 100,00 for females 15-18 years compared to 29 per 100,000 for males. Because adolescent females had more diabetes-related hospitalizations than did males, these researchers suggested that diabetes management strategies be tailored to reduce hospitalizations among female adolescents. Again, these findings highlight how difficult it is for adolescents to maintain good metabolic control.

Second, since some research has indicated that metabolic control problems may be associated with individuals using insulin as a weight-control strategy, the omission of insulin injections appears to be an important health behavior which is indicative of adjustment (La Greca, Schwarz, & Satin, 1987; Wing, Nowalk, Marcus, Koeske, & Finegold, 1986). Maintaining an ideal body weight may be a challenge for an individual with diabetes, as over-treatment with insulin can result in weight gain and under-treatment with insulin can cause weight loss (Clarke, Vance, & Rogol, 1993). There was a twofold greater risk of

becoming overweight and a threefold greater risk of severe hypoglycemia reaction in those following an intensive regime (Tamborlane & Ahern, 1997). Fifteen percent of a subclinical group of adult females with IDDM were incorrectly using insulin compared to 71% of a clinical group of eating disordered individuals with IDDM (Affenito et al., 1997). Of the 124 adolescents between the ages of 10 to 17 years of age with IDDM who were being treated in a clinic, 9% had omitted insulin injections at least once during the three-week span of the study (Bennett Johnson, Silverstein & Mauras, 1995). In the La Greca et al. (1987) study of 30 females between the ages of 15 and 35 years, 85% of the women reported at least occasional binging and 50% of the women in the fair control group and 70% in the poor control group reduced or omitted insulin or avoided the use of insulin supplements as a means of coping with overeating. A comparison study of insulin withholders and non-withholders between the ages of 16 to 40 years (Biggs, Ramirez Basco, Patterson, & Raskin, 1994) found that the withholders had poorer metabolic control and a current or past history of an eating disorder. Another group of women with IDDM between the ages of 18 and 30 were contacted by mail to complete questionnaires on their eating patterns (Stancin, Link, & Reuter, 1989). Fourty percent admitted to controlling their weight by reducing insulin, with 86% of the bulimic group using this method. Bulimic episodes were related to increased hospitalizations, episodes of ketoacidosis and psychological symptoms on the Eating Disorder Inventory.

Third, further consequences of having diabetes include increased school absenteeism due to more frequent medical appointments and diabetic reactions such as hypoglycemia and hyperglycemia which may require specialized attention or at least reduced functioning for a period of time. School absenteeism has been identified as an important variable indicative of child adjustment because school attendance and academic achievement are measures of the child's ability to fulfil his or her principal developmental demand. The relationship between school absenteeism and psychosocial problems was first studied among 201 children with a wide range of chronic health impairments by Weitzman, Walker, and Gortmaker

(1986). In this child health study conducted in Massachusetts, the children with chronic conditions missed 8.7 days per year compared to 5.8 days for children without conditions. Peckham and Butler (1987) found in their study of children with asthma that half of those who had more than one attack per month had missed at least four weeks of school in that past year. These children also had higher behavior rating scores. Similarly, in a study of 81 patients, aged 5 to 10 years, there was poorer psychosocial and functional adjustment and increased school absenteeism for those children with a chronic illness (Stein & Jessop, 1984). Moreover, in this study, children from single parent families missed more school than families composed of both parents and mother with another adult. Additionally, since it has also been shown that children with milder disabilities may be more at risk for psychosocial difficulties and that children with an intellectual or physical disability may be at increased risk for the development of emotional-behavioral problems (Pless, Power & Peckham, 1993), it would be important to exclude children with an intellectual or physical disability from a study of adolescents with diabetes to not introduce confounding variables.

Diabetes Health Care Teams Versus General Practitioner Model. Fourth, since the results of the Diabetes Control and Complications Trial (DCCT) have been published establishing that more intensive treatment leads to a reduction in complications, there is interest in examining the nature of treatment received. While the clinical practice guidelines for the treatment of diabetes are clear, the medical health care providers encounter difficulties meeting the needs placed on patients and families by diabetes. There is a dearth of studies examining a comparison of the nature of treatment offered through a diabetes clinic or general practitioner model in Ontario. Nevertheless, there are common components of high quality chronic illness care. Wagner, Austin and Von Korff (1996) summarized that the common components of high-quality chronic illness care consisted of evidence-based planned care which incorporated: (1) redesigning their practice to meet the needs of the patients with follow-up, various resources and regular appointments;

(2) patient education that supports self-management, behavioral change, psychosocial support and emphasizes patient participation; (3) access to the necessary expertise to provide education, support for decision and consultation; and, (4) supportive information systems such as, using reminders, feedback, care planning and feedback. Wagner's group underscored that there is considerable variability to the nature of patient care in usual practice and that generally practitioners do not operate by protocol but rather follow an acute care model in which care is individualized. From this model, generally, there is limited capacity to consider or incorporate new approaches to care into a busy practice. On the other hand, the need for regular, thorough assessments, attention to psychosocial and behavioral issues, and access to nutritionists and social workers can be met through the diabetes-specific clinic model.

A meta-analysis of educational interventions and outcomes in diabetic adults found substantial evidence that structured self-management and behavioral change support programs, such as smoking or dietary intervention, improved outcomes in diabetes (Brown, 1990). Although not extensively studied in Canada, and least of all in pediatric populations, improved glycemic control in diabetes has been shown to be strongly associated with treatment at a centre with a special interest in diabetes (Pringle et al., 1993; Rosilio et al., 1998). That is, individuals with diabetes have done better when associated with bigger and better equipped practices, those with diabetic mini-clinics, access to dietetic advice, and availability of patient education programs.

Wagner et al. (1996) also determined that active participation in the self-care was a critical element of successful self-management. However, there is debate about how to provide services to chronic illness with evidence supporting both the generalist and the specialty care model. Wagner presents evidence for support by managed care organizations for the primary care gatekeeper model (Franks, Clancy, and Nutting, 1992) in which it is the primary care physician who is responsible for patient care. Wagner illustrates that since findings do support that specialists have greater knowledge of effective therapies than

generalists, widening the availability of expertise may also be an effective treatment option to diabetes-specialty clinics. In fact, models that distribute expertise may be more cost-effective than specialty care models of service delivery.

According to Wagner et al. (1996), there are three main barriers to high-quality chronic illness care. The first barrier relates to how care is organized. More successful chronic illness care programs rely on non-physician personnel to provide key support for self-management. Whether these support resources, such as nutritionists and social workers are located on site, will influence care. While the patient is typically responsible for initiating follow-up, research is showing that practitioner initiated follow-up can lead to better outcome. The second barrier relates to inadequate training in the area of clinical and behavioral skills and organizational and information management skills required to provide care. The third barrier is lack of financial incentives to provide comprehensive care.

Although there is minimal research on the patient-provider relationship, generally it shows that recommendations are remembered differently by the patient and the provider. For example, Page, Verstraete, Robb and Etzwiler (1981) demonstrated, through an evaluation of patient and medical provider recall of treatment recommendations, that the provider reported making more recommendations than the patient recalled and that the patient recalled recommendations that the provider had not made. In addition to difficulty with the recall of treatment recommendations, the parent or child with diabetes may not be able to carry out the provider's recommendations because of skill deficits. Skill deficits in the adult and child have been documented (Bennett Johnson et al., 1992; Delamater, Smith, Kurtz, & White, 1986; Lorenz, Christensen, & Pichert, 1985).

Finally, the relation between type of insulin regime prescribed and glycemic control also provides some insight into other indices of health status. For example, a nationwide study of 2,579 children with IDDM which involved 207 centers in France (Rosilio et al., 1998), found that 68% were prescribed two

daily injections, 27% three injections, 4% four injections, .3% one injection daily and .8% a continuous subcutaneous pump. Children with two injections did slightly better than those with three or more injections. Overall, in this study 33% had HbA1c assay levels below 8%, the optimal level for adolescents identified in the DCCT. Furthermore, in this study control was better in university-affiliated hospital and centers who followed more than 50 patients. The highest regression coefficient was between HbA1c and age ($R = 0.43$, $p < 0.0001$), daily insulin dosage per kilogram ($R = 0.28$, $p < 0.0001$), mother's age ($R = 0.26$, $p < 0.0001$), frequency of glucose measurement ($R = 0.21$, $p < 0.0001$), and diabetes duration ($R = 0.14$, $p < 0.0001$).

Adherence To Treatment in Insulin-dependent Diabetes Mellitus

The primary factor affecting metabolic control which has been studied is adherence to treatment. Haynes (1979), one of the most cited authorities on compliance to medical treatment, defines regimen adherence, a term synonymously used with compliance, as "the extent to which a person's behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice" (pp. 2-3). This definition of adherence will be used in this study. Research has used two types of approaches to the definition of adherence: one approach establishes categories of adherence and the other focuses on developing adherence rates for each health care behavior (La Greca, 1990). The categorical approach limits between-study comparison because of non-standardized classification cut-offs and the consideration of adherence as a univariate construct. The adherence rates approach places each self-care behavior on a continuum rather than using arbitrary cut-offs. The adherence rates approach seems to be most appropriate for the study of diabetes because of the complex treatment regime, the varying levels of adherence to each self-care behavior, and the multivariate nature of diabetes adherence.

There are problems associated with Haynes' definition, as the prescribed behavior is not always known, or has not been presented to the patient, or has been general and non-specific (e.g., when the

patient is told to get some exercise or watch what he or she eats), or has not been documented, or has not been clearly communicated to the patient (Glasgow, Wilson, & McCaul, 1985). Additionally, these authors reflect that the actual prescription is subject to the interpretation of the patient, as he or she is encouraged to be active in self-management. They suggest that adherence rates be used in situations where the prescribed standard is known.

Studies on diabetes adherence have been widespread and the focus of most research on diabetes. The frequency of blood glucose testing has been identified with improved glycemic control being associated with less parent-child conflict, increased knowledge about diabetes, and improved diabetes adherence (Wysocki, Hough, Ward, Allen, & Murgai, 1992). Findings on diabetes adherence during childhood show variability with age and with each aspect of the regime. In general, research has indicated that adolescents with diabetes are fairly adherent with the injection of insulin and the monitoring of blood glucose levels (Bennett Johnson, Silverstein, Rosenbloom, Carter, & Cunningham, 1986; Bennett Johnson et al., 1990; Schafer, Glasgow, McCaul & Dreher, 1983). However, adolescents experience greater difficulty adhering to the diet and exercise requirements of the regime (Bennett Johnson et al., 1986; Burroughs, Pontious, & Santiago, 1993).

Research also shows that the reporting of adherence to each self-care behavior of the regime varies with age and with the type of self-care behavior. For example, children in the 6-9 year old range were less accurate than older children in recalling adherence behaviors that involved time constructs (Reynolds, Bennett Johnson, & Silverstein, 1990). This finding again highlights the importance of taking a developmental perspective in evaluating chronically ill children. Another common finding in numerous studies is that the child's age at diagnosis did not influence adjustment, but rather the longer the duration since diagnosis the more the children appraised regimen adherence as difficult (Anderson et al., 1990; Hanson et al., 1989; Wysocki et al., 1992).

Self-reports of adherence are also typically unreliable, as demonstrated by several investigators who reported falsification or misreporting of adherence data. The study which best exemplifies this problem was conducted by Mazze, Lucio, and Shamoon (1984). Patients were asked to record results of blood glucose test values in a log book. The researchers compared the logbook values with the values stored in a glucometer with a memory function. The patients were unaware of the memory function. Findings indicated that 74% of the patients over-reported blood glucose testing and more than 30% of the logbook values were fabricated. Gonder-Frederick, Julian, Cox, Clarke, and Carter (1988) concluded, on the other hand, that discrepancies between observed and self-reported adherence were due to self-report errors rather than deliberate falsification. Bennett Johnson (1992) suggests that self-report data should not be accepted as true or false but interpreted in a social context. She suggests that as a general rule, under-reporting is more likely to be accurate than reporting high levels of adherence.

Adherence to Treatment as a Multivariate Construct

Schafer et al. (1983) were the first to affirm that adherence was a multivariate construct with differing levels of adherence to each self-care component of the regime. Recent research has supported the multivariate conceptualization of adherence (Bennett Johnson et al., 1986; Bennett Johnson et al., 1990; Bennett Johnson et al., 1992), with good adherence not always predicting good metabolic control in diabetes. Past research has confused the measurement of adherence with the measurement of metabolic control, in assuming that the two variables are similar. Unfortunately, a positive relationship has not been demonstrated in research, and, consequently, controversy has existed over the relationship between adherence and control.

Despite good adherence to treatment, control has been found to be unstable (Orr, Golden, Myers, & Marrero, 1983; Schafer et al., 1983). This is because good adherence does not necessarily improve metabolic control and unfortunately there is a belief that if the person is in poor metabolic control that they

are non-compliant to the regimen. The reasons for the inconsistent findings are numerous, with metabolic control being not only a function of adherence but a function of stress level, hormonal changes related to growth and development, illness, growth spurts in adolescence, duration of the disease, and appropriateness of the regimen. There are no studies which have examined the appropriateness of the regimen.

Unfortunately, most patients are taught that adherence to a regimen is all they need to do to achieve good metabolic control. It is hard for an adolescent to follow a regime that they do not believe is helpful. Moreover, what they perceive is helpful is related to stage of cognitive development. For example, Brotman Band and Weisz (1990) found striking differences between children at the pre-formal and formal operational stage of cognitive development and coping styles and adjustment. For instance, somatic problems were negatively associated with perceived control over diabetes among the pre-formal children. These authors suggest that somatic symptoms, such as headaches and stomachaches, would lead pre-formal children to believe that diabetes self-care behaviors are ineffective and that as a consequence they would feel less control over their diabetes. In contrast, they found that diabetes knowledge was the best predictor of diabetes adjustment in children in the formal operational group. More diabetes knowledge may be more important with increasing cognitive maturity because the adolescent can understand the importance of self-care behaviors at the abstract level. However, they advance that the more cognitively mature adolescents may be more vulnerable to feeling ineffective the more they understand their disease. Fluctuations in metabolic control can easily become associated with self-blame and guilt (Hanson, Henggeler, & Burghen, 1987b).

Further complicating the measurement of adherence is the variability in the results. In a meta-analysis of 26 studies examining the relationship between knowledge and compliance, Nagasawa, Smith, Barnes, and Fincham (1990) found inconsistencies in results were due to: (1) the measurement of adherence as a univariate construct; (2) relying on health provider ratings, which are unreliable and biased; and, (3)

typically relying on a one time assessment of perceived adherence. Health provider reports of adherence have been shown to yield unreliable and biased reports because they reflect provider beliefs about the patient's behavior, or recall of the parents reports rather than actual behavior (Bennett Johnson, 1992).

The lack of a consistent association between adherence and metabolic control also emanates from methodological weaknesses (Bennett Johnson et al., 1990): (1) the use of global measures of adherence; (2) uncorroborated self-report measures; (3) an almost total lack of prospective measurement of adherence and metabolic control measures; and (4) a failure to ensure that the temporal interval of measurement for adherence is congruent with the temporal interval for measuring metabolic control. Retrospective reports of adherence, such as was those used in the White, Kolman, Wexler, Polin, and Winter (1984) study, have also proven unreliable and have produced inconsistent results. The use of provider reports of adherence were also used in three recent major longitudinal studies of adherence and adjustment in diabetes, thus limiting the usefulness of the findings (Hauser et al., 1990; Jacobson et al., 1990; Kovacs et al., 1990).

24-Hour Recall Interview

A recently considered ideal standard for measuring adherence to treatment in diabetes is the 24-hour recall interview protocol developed by Bennett Johnson et al. (1986). The 24-hour adherence recall interview involves a 20-minute telephone call to the patient and the parent regarding the diabetic's adherence behaviors on 13 areas of adherence to treatment. Table 2 summarizes the studies of adherence to treatment in IDDM using the 24-hour recall interview.

TABLE 2.

Studies of Adherence to Treatment in IDDM Using 24-Hour Recall Interview

Study	Groups	Measures	Results
Bennett Johnson et al. (1986)	N=168 IDDM 6-19 years	24-hr recall interview	PC factor analysis found 5 factors accounting for over 70% of variance: results same as Bennett Johnson et al. (1990), except diet amount is one factor (total calories and concentrated sweets)
Bennett Johnson et al. (1990)	N=78 IDDM 6-19 years	24-hour R.I. over 3 months, HbA1c, GSP, triglyceride, cholesterol	Older adolescents less adherent than younger children; HbA1c & GSP not predicted by adherence factors; calories consumed predicted HbA1c, depended on metabolic status at entry; adherence did not predict CHOL; 5/6 adherence factors associated with TRIG
Bennett Johnson et al. (1990)	N=162 IDDM 2 groups (1982 and 1986) & parent	24-hr recall interview, 3 interviews over a 2 week period	Findings concur with exploratory factor analysis by Johnson et al. (1986); 6 factors are exercise, injection, diet type, eating /testing frequency, and total calories & concentrated sweets treat as separate factors; supports a multivariate conceptualization of adherence
Bennett Johnson et al. (1992)	N=193 IDDM longitudinal x 1.65 years	24-hr recall interview on 6 adherence constructs, HbA1c, & triglyceride	Testing/eating freq associated with HbA1c; injection associated with TRIG; older subjects were less adherent and in worse control; better adherence associated with better control
Freund, Bennett Johnson, Silverstein & Thomas (1991)	N=78 IDDM 6-19 years	24-hr recall interview; (9 interviews over 3 months)	Good parent-child concordance among 13 adherence measures ; 6-9 year olds exhibited poorer parent-child concordance on measures involving time; lower stability for exercise & injection measures; moderate stability for dietary and glucose testing
Kuttner, Delamater, & Santiago (1990)	N=50 IDDM 10-16 years	CASQ, CDI, 24-hr recall interview, HbA1, Learned Helplessness	SES, age, gender, duration, pubertal status unrelated to control; significant association between HbA1 with exercise, eating/testing frequency; adherence accounted for 24% of HbA1; learned helplessness associated with depression & HbA1 but not adherence; depression unrelated to adherence & control
Reynolds et al. (1990)	N=75 IDDM 7-12 years old	24-hr recall interview and observation of behavior	Excellent child-observer agreement on all measures of occurrence/non-occurrence of events; children under reported most dietary and some exercise behaviors

CASQ = Children's Attributional Style Questionnaire; CDI = Children's Depression Inventory; CHOL = Cholesterol; GSP = Glycosylated Serum Protein; HbA1 = Glycolated Hemoglobin assay; 24-hr R.I.; 24-hour Recall Interview; SES = Socioeconomic status, Blishen occupational code; TRIG = triglyceride.

An exploratory factor analysis of the 24-hour adherence recall interview using principal components analysis identified five components of adherence in childhood diabetes (Bennett Johnson et al., 1986): exercise, injection, diet type (percentage of total calories from carbohydrates and from fat), eating/testing frequency, and diet amount (total calories and concentrated sweets consumed). A confirmatory factor analysis was used to test the quality of this factor pattern (Bennett Johnson et al., 1990). The results of this analysis supported this multivariate conceptualization of adherence with factors one through four being confirmed (injection, diet type, diet amount and eating/testing frequency), but with factor five, total calories and concentrated sweets consumed, splitting into separate constructs. In summary, an exploratory factor analysis produced five factors and a confirmatory factor analysis produced six factors, based on the 24-hr adherence recall interview.

The results of the Reynolds et al. (1990) study comparing the accuracy of the reported self-care behaviors using the 24-hour interview with actual behavioral observations showed excellent agreement between the children's reports and observed behavior. There was 98% child-observer agreement on whether an insulin injection occurred, between 96 and 98% on the type of insulin injected, and between 89 and 94% on the units of insulin injected. The agreement on the timing of the injection was poor (32%), with observers reporting later injections than the children. Whereas, there was a respondent main effect $F(1,65) = 12.66$, $p<.001$ for the morning but not for the evening injection, the researchers report that the actual values were small. There was reasonably good agreement regarding the occurrence of exercise (80%). On the other hand, children consistently under-reported some exercise behaviors with the younger children reporting more strenuous exercise compared to the older children and girls reporting more strenuous exercise than boys. Moreover, children tended to underestimate the strenuousness of their exercise compared to the observers with concurrence being only 19%. Although children underestimated the number of snacks and meals eaten, there was good concurrence between the children and the observers on the occurrence of meals (73%) and

blood glucose testing (78%). On the other hand, children consistently under-reported their food intake, with concurrence between the children and observer being 30% for the total calories consumed, 31% for the carbohydrates consumed, 25% for the fats consumed, and 60% for the concentrated sweets consumed. A regression analysis was performed to correct this bias for the total calories consumed, and using a dependent t-test analysis, the corrected children's reports no longer differed from the observer's reports. Results based on this study and other research conducted on the adult population led the authors to suggest that underestimation of caloric consumption was a function of errors of memory and that 75-80% may be the expected upper limit of recall.

Freund et al. (1991) presented evidence for sound reliability using the 24-hour recall interview with good parent-child concordance of adherence to treatment over a three-month period. Parent-child agreement was higher for weekday (mean r = .75) versus weekend behaviors (mean r = .65) and when based on nine versus three interviews (for 8 of the 13 adherence measures). There was no improvement or deterioration in parent-child agreement across time. In this sample of 6 to 19 year old patients and their parents, parent-child agreement was higher with the older children versus the 6 to 9 year old children (Call Set x Age Group, $F(6,128) = 2.72$, $p<.02$). The lowest stability across three call sets was obtained with the exercise and injections measures. Glucose testing behaviors were most stable, followed by dietary, injection, and exercise behaviors. Dietary and glucose testing behaviors exhibited greater consistency across time and between weekends and weekdays than did exercise and injection behaviors. Because the results were consistent over time, the study suggests that this assessment technique does not induce change in parent-child agreement over a period of three months.

An association between treatment adherence and glycemic control in diabetes has been found with the 24-hour recall interview, thus providing support for the validity of the measure and for the assumption of association that both researchers and health providers have held. In a longitudinal analysis of adherence in

childhood diabetes using the 24-hr recall interview, a positive relationship was found with metabolic control, with better testing/eating frequency adherence being associated with better metabolic control (Bennett Johnson et al., 1992). The relationship between each adherence factor and glycemic control, with patient age and disease duration serving as exogenous variables in all models, was tested separately using applied structural equation modeling. The findings indicate that the older individuals in this study were less adherent, in worse glycemic control, there was a negative association between the testing-eating frequency factor and metabolic control, and the injection factor was associated with triglyceride values, a measure of lipid metabolism. The model accounted for 31% of testing frequency, 37% of eating frequency, 28% of HbA1c as a measure of metabolic control, and 13% of triglyceride. In this study it was chronological age, not duration since diagnosis that predicted metabolic control. This study also challenged the use of HbA1c as the gold standard for metabolic control, finding that a measure of lipid metabolism was a better indicator of metabolic control than was a measure of glucose metabolism. Although the link between metabolic control and adherence was weak, they suggest that age-homogeneous models improved prediction. They further suggest that biological changes associated with puberty must be underlying the relationship between age and metabolic control.

Another study by Bennett Johnson et al. (1990) found that, using hierarchical multiple regression, HbA1c and Glycosylated Serum Protein (GSP) were not predicted by adherence factors, whereas five of the six adherence factors were associated with triglyceride levels and none emerged for cholesterol. Only calories consumed predicted HbA1c ($t(54) = -2.05$, $p<.04$), but this depended upon metabolic status at the beginning of this prospective study. Poorer metabolic control at the end of the study was associated with greater caloric consumption.

These results lend support to the importance of using more than HbA1c as a measure of glucose metabolism to evaluate metabolic control in diabetes and to the construct validity of the 24-hour adherence

recall interview developed by Bennett Johnson et al. (1986). Although the 24-hour recall interview protocol appears to be an improvement in the quantification of diabetes adherence, practical problems associated with the protocol consisted of the recall interviews requiring a significant amount of patient and research time for interviews, scoring, and the interpretation of data.

Another promising approach to the quantification of adherence was developed by Hanson et al. (1996). This study of 270 subjects between the ages of 4 and 20 years examined the relationship between diabetes adherence, as measured by a semistructured adherence interview (SCAI), a 24-hour dietary recall interview, dietary logs, and glycemic control. Dietary recalls were conducted during research appointments and the dietary logs examined during clinic visits. Parents participated only if they were involved in the self-care diabetes regime. The analysis compared actual with ideal dietary intake. The physical activity levels were assessed with the seven-day Stanford Physical Activity Recall developed by Blair (1984) and a three-day daily physical activity log. The correlations between the seven-day Stanford interview and the three-day physical activity log were highly significant at each of the three time periods tested and a composite score was calculated. All of the 24-hour dietary recalls and the three-day food logs were correlated, with the exception of total calories. The variables examined were quality of the dietary intake, total calories, calories from protein, carbohydrates, added sugar, total fat and number of eating periods. There were significant relationships between SCAI, as the measure of diabetes adherence, and glycemic control, and the overall quality of the dietary intake. The physical activity levels were not significantly related to glycemic control. Because there was a significant relationship between a global measure of adherence and glycemic control ($F = 25.03$, $p \leq .001$, beta weight $= -.31$), and a lack of relationship between more specific measures of adherence, such as total calories, calories and percentages from carbohydrates, fats and sugar, the researchers suggested that the SCAI may be a sound methodology to assess the relationship between adherence and metabolic control.

In conclusion, the measurement of adherence to treatment has been varied and methodologically flawed (Bennett Johnson, 1992; La Greca, 1990; McNabb, 1997). The lack of standard means to measure adherence has been a gap in clinical practice and in the available research up until very recently. The use of the 24-hour recall interview has only recently been suggested as the method of choice for measuring adherence to medical treatment (Bennett Johnson et al., 1986). This measure also does not induce change in self-care behaviors, an important concern when considering an evaluation tool. Sound reliability and validity of the assessment of daily diabetes management using the 24-hour recall interview developed by Bennett Johnson and her colleagues is indicated. A weak association between metabolic control and adherence has been found using this measure. This discussion has highlighted that it is inappropriate to use metabolic control as a measure of adherence to treatment or to imply that poor control is similar to less than optimal diabetes adherence. Thus, both constructs should be assessed independently and at the same time. Given that the 24-hour recall interview developed by Bennett Johnson et al. (1986) is an improved measurement tool of adherence, minimal research has been conducted around important variables which influence adherence to a treatment regime using this more appropriate measurement method. Because good adherence does not necessarily improve metabolic control, the investigation of the influence of other variables, such as health care behaviors that might affect adjustment to a diabetes regime is indicated.

Family Relations Variables Associated with Metabolic Control and Adherence in Pediatric Chronic Illness

The evidence is broad that adherence and metabolic control in adolescents with diabetes are related to family and psychological systems variables. These next sections will briefly review these various areas of research that have been examined in relationship to physical status and adherence to treatment in pediatric chronic illness populations in an attempt to examine their potential influence on adjustment in pediatric

diabetes. A summary of studies examining the relationship between family relationship variables and adherence in diabetes and metabolic control is presented in Table 3. These areas are: (1) the study of family functioning and diabetes management; (2) the study of marital functioning; (3) the impact of marital distress on children; (4) the study of parental depression; (5) the impact of parental depression on children; and (6) depression in pediatric chronic illness.

Family Functioning and Diabetes Management

The initial research on chronic illness and the family, which was pioneered by Minuchin and his colleagues, largely focused upon the psychosomatic factors associated with chronic illness in relation to family interaction. A review of 75 research studies concerning the effectiveness of marital and family therapies highlighted that structural family therapy, which is based on systems theory, applied to the problems of psychosomatically ill children, was most efficacious (Gurman & Kniskern, 1981). Salvador Minuchin pioneered structural family therapy, a therapy based on systems theory. He and his colleagues pioneered innovative and successful therapeutic interventions with psychosomatic illnesses such as, diabetes, anorexia nervosa, and asthma (Minuchin et al., 1975; Minuchin, Rosman, & Baker, 1978). Minuchin and his colleagues were the first to suggest that an increase in physical symptoms in chronically ill children, despite adequate medical treatment, was related to emotional causes (Minuchin et al., 1975). They were the first to assert that conflict was not only associated with child behavior problems but also directly affected metabolic control in diabetes. A psychosomatogenic family model was developed which postulated how the dynamics of the family social environment are important factors in the management of a chronic illness. This psychosomatogenic model proposed that a combination of family characteristics and the presence of a chronically ill child in a family can create social, emotional, and medical problems for the child. They found five characteristics of family interaction to be more prevalent in families with children where illness becomes repeatedly symptomatic despite effective medical treatment and adequate adherence with the treatment

regimen: excessive cohesion (enmeshment and overprotectiveness), family structure and organization rigidity, lack of conflict resolution, and involvement of the sick child in parental conflict (Minuchin et al., 1975; Minuchin et al., 1978; Sargent, 1985).

Because Minuchin's research included a small group of children with super-labile diabetes, who were repeatedly symptomatic despite adequate care, this model has not been found to be representative of the vast majority of chronically ill or children with diabetes who are well adjusted. Nevertheless, Minuchin and his colleagues were the first to examine family interaction variables in relation to chronic illness and have since stimulated much research. The link between less adequate adherence and less positive family relations which characterized the older adolescent was also part of the systemic model of adaptation in adolescent diabetes currently being developed by Hanson (1992).

The two most fundamental dimensions of family functioning to have emanated from this research are cohesion and adaptability. Cohesion is defined as "the degree of emotional bonding that family members have with one another and the degree of individual autonomy a person experiences in the family system" (Olson, Sprenkle, & Russell, 1979, p. 5). Extremely high cohesion is characterized by enmeshment and very close, intense relations, whereas very low cohesion is typical of disengaged and distant relationships. Family adaptability is defined as "the ability of a...family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stresses" (Olson et al., 1979, p. 12). Less family cohesion would be more typical of the process of increasing independence during adolescence and the adolescent assuming greater responsibility for self-care behaviors in the diabetic treatment regime. This normative reduction in family cohesion during adolescence would seem to be related to less positive adherence to treatment and reduced metabolic control. Nonetheless, the optimal level of family cohesion needed to ensure adequate adherence to a diabetic treatment regime is unclear.

In contrast to Minuchin's findings, overall, researchers are finding that high cohesion is predictive of

better adherence to treatment. For example, Hauser et al. (1990) found that not only did high family cohesion at diagnosis predicted improved adherence in the short term and four years later, but that conflict negatively influenced adherence. Lawler, Volk, Viviani and Mengel (1990) similarly found, in their small sample (N=16), that better metabolic control was associated with higher cohesion in their 15 to 18 year old group. In another small sample of 42 newly diagnosed children with diabetes, Auslander, Anderson, Bubb, Yung and Santiago (1990) also found that high cohesion was associated with better metabolic control; This finding persisted 2 to 3 years after the diagnosis. Hanson et al. (1989) similarly found a marginal association between good metabolic control and high family cohesion using the FACES-II measure of family functioning. In this sample it was family flexibility and high marital satisfaction which were more strongly associated with metabolic control. However, this association between high marital satisfaction and good metabolic control was attenuated as the length of duration since diagnosis increased. In contrast, the findings from the six year longitudinal study conducted by Kovacs, Kass, Schnell, Goldston, and Marsh (1989) did not find an association between metabolic control and family functioning or quality of marriage.

In a review of family functioning and diabetes, Lorenz and Wysocki (1991) concluded that the following four aspects of family function are important modulators of the efficacy of IDDM treatment: conflict, communication, problem solving, and cohesion. Several researchers are finding a consistent association between poor glycemic control and higher levels of conflict in families (Anderson, Miller, Auslander & Santiago, 1981; Hauser et al., 1990; Koski & Kumento, 1977; Miller-Johnson et al., 1994; Wysocki, 1993). There is also emerging data that also shows an association between family conflict and less compliance with their diabetes regime. A number of researchers have found that the strongest predictor of long term adherence in diabetes is family conflict (Hanson et al., 1992; Hauser et al., 1990; Schafer et al., 1983; Wertlieb, Hauser, & Jacobson, 1986). Miller-Johnson et al. (1994) further determined that conflict disregulates control through the relationship to lower adherence. While the findings on the relationship

between cohesion and adherence and glycemic control are equivocal, the most consistent finding in the research on diabetes and family functioning is an association between family conflict and three outcome measures: poor metabolic control, poor adherence to treatment, and poor psychosocial adjustment.

Although longitudinal studies can provide important links among the variables examined, these studies suffered from methodological problems that have limited their usefulness in the study of diabetes. For example, the Wertlieb et al. (1986) study demonstrated the link between behavioral adjustment in both children who are diabetic and those who are healthy when specific family variables were examined. Unfortunately, the important dimensions of adherence and control in diabetes, two central notions relevant to the adjustment of children with diabetes, had not been included. This is however, the only longitudinal study to examine the relationship between family functioning and behavior in a population of children with diabetes. They compared a group of children with recent onset diabetes with acutely ill children and found family conflict was associated with an increase in behavior symptomatology and more so with the diabetic group. For the family with a child with diabetes, social and recreational family activities, clear routines and organization were linked with fewer behavior problems.

Epidemiological Studies of Family and Parental Adjustment. Because of the population parameters and findings regarding parental functioning, the Ontario Child Health Study (OCHS) is an epidemiologic study of particular interest to this study (Cadman, Boyle, Szatmari, & Offord, 1987). This study of 1869 randomly selected families (3,294 children between the ages of 4-16) compared and contrasted psychosocial characteristics of parents and family units of children with chronic health problems or physical disability with those of healthy children. An incidence of 14% of childhood chronic disease included 3.7% of the children with a physical disability. When all types of childhood chronic illness were grouped together, the results showed that children with chronic health problems resembled those of physically healthy children in demographics and psychosocial characteristics with the exception of a higher

percentage of low income families (Cadman et al., 1991). Although the magnitude of risk as reported by the OCHS for the development of social problems was minimal, the risk for psychiatric disorders in children with chronic illness was twice that for physically healthy children. Additionally, when the chronic illness was associated with a disability, the risk for the development of a psychiatric disorder was three times as high. These findings highlight the need to examine possible familial variables that may impinge upon adjustment, over and above the stress of having a chronic illness. Moreover, the mothers and fathers of these children with chronic health problems reported receiving two to three times more mental health treatment than parents of well children. These findings certainly imply an increased risk for difficulties for all members of families caring for a chronically ill child. Although it is not clear what type of mental health treatment was received it could be assumed that the stressors of parenting a child with a chronic illness may be a stress-related risk factor that impinge upon both individual parental functioning and familial relationships.

Diabetes-Specific Support. The majority of the studies of family functioning and adherence to treatment and metabolic control in IDDM listed in Table 3 have methodological weaknesses regarding the measurement of adherence. That is, the researchers used a univariate or bivariate conceptualization of adherence rather than a multivariate measurement of adherence (Auslander et al., 1990; Burroughs et al., 1993; Hanson et al. , 1987b; Hauser et al., 1990); they relied on the reports of health care providers or on self-management diaries (Miller-Johnson et al., 1994; Hauser et al., 1990); and, they measured adherence over a brief period of time (Schafer et al., 1986). The results will be equivocal until more adequate measurement of adherence is established.

Not only are there weaknesses in the measurement of adherence in diabetes, but researchers have argued that the use of general assessment measures of family functioning has been inadequate in tapping important family behaviors linked to adherence and control of diabetes. Schafer et al. (1983) were the first

to show that using a measure developed specifically for the diabetic population revealed important family behaviors that were not elucidated from general family measures. They developed the Diabetes Family Behavior Checklist (DFBC), a test which measures specific supportive and non-supportive diabetic family behaviors. They found that higher levels of diabetes-specific non-supportive family behaviors were related to reduced adherence to treatment and to poor control in a 12 to 14 year old population. They also found a relationship between poor control and higher levels of diabetes-specific non-supportive family behaviors with 54 adults and 18 adolescents. In contrast, Schafer et al. (1986) did not find a relation between HbA1c and the DFBC in a population of adolescents. Despite Schafer et al. (1983) recommending not to use the DFBC with the adolescent population, the majority of studies of family functioning in IDDM listed in Table 3 have used this measure. Another study of 95 two parent families found that both illness-specific (using DFBC) and general family relationships (using FACES-III) predicted both dietary adherence and psychosocial adjustment and that high levels of general family conflict was associated with lower adherence (Hanson et al., 1992). Not only has general family functioning predicted psychosocial adjustment, both illness-specific and general family functioning have predicted treatment adherence as well as general psychological adjustment.

The work by Schafer et al. (1983) was seminal in advancing the multivariate conceptualization of adherence and that both global and diabetes-specific family measures are important in examining relationships between adherence, metabolic control and family relations. Another diabetes-specific measure of family support has been recently developed for the adolescent developmental stage. The Diabetes Family Behavior Scale (DFBS; McKelvey et al., 1993) is a recently developed measure of diabetes-specific family support with excellent reliability and criterion validity. Significant positive relationships have been found between both the total score and the guidance-control subscale and glucose metabolism as measured by HbA1c in a population of 321 children and adolescents. Similarly, Grey, Boland, Yu, Sullivan-Bolyai, and

Tamborlane (1998) also found using the DFBS that adolescents had lower HbA1c values when their families provided more guidance and control.

Two researchers also found that diabetes-specific conflict in the form of mother-child disagreement regarding the perception of who was assuming responsibility for aspects of the diabetes regime was a significant predictor of metabolic control as measured by HbA1c values (Anderson et al., 1990; Auslander et al., 1990). Furthermore, lower diabetes adherence was associated with difficulty discussing feelings, thoughts and concerns related to diabetes with mothers in a study involving 50 mother-daughter discussions which were analyzed using the Hill Interaction Matrix and modified Beavers-Timberlawn Family Evaluation Scales (Bobrow, AvRuskin, & Siller, 1985).

TABLE 3.

Studies of Family Functioning and Adherence to Treatment and Metabolic Control in IDDM

Study	Subjects	Measures	Results
Anderson, Auslander, Jung, Miller & Santiago (1990)	N=121 IDDM 6-21 years	SES, DFRQ, demographics, HbA1c, mother and child rating adherence 3-point scale	Parent-child disagreements about responsibility and adherence level predicted HbA1c; lower adherence & poorer metabolic control with older subjects
Auslander, Anderson, Bubb, Yung & Santiago (1990)	N=42 recently diagnosed IDDM and families	Demographics, FES, Piers-Harris, 2 adherence questions	Better metabolic control associated with 2 parent families, white, better cohesion & higher SES; pattern persisted 2-3 years after diagnosis
Burroughs, Pontious & Santiago (1993)	N=21 adolescents IDDM 13-18 years	HbA1, adherence questionnaire completed by youth and parent, global measure summed, Test of Diabetes Knowledge, FACES-II, DFBC, A-FILE; SPPA MHLC	Dietary compliance best predictor of metabolic control; parents predicted control of subjects younger than 16 years and reverse for older youths; negative relationship among strong self-concept, high knowledge of IDDM, parental support and poor metabolic control
Evans & Hughes (1987)	N=38 IDDM 10-17 years	Piers Harris, locus of control, FACES-II, HbA1	Good control associated with external locus of control, with rigid family organization
Grey et al. (1998)	N=52 IDDM 13-20 years	DQLY, CDI, ICD, DFBS, FACE, Self-efficacy for diabetes, ACO, HbA1c	Lower HbA1c associated with greater guidance-control diabetes support; HbA1c not associated with any psychosocial factors
Hanson, Henggeler & Burghen (1987b)	N=104 adolescents with IDDM	DFBC, HbA1c, global index of adherence, A-FILE, PCS	Stress associated with control independent of link between adherence and control; social competence buffered negative effect of stress; parental support linked with adherence; age indirectly linked with adherence through association with parental support
Hanson, De Guire, Schinkel, Henggeler & Burghen (1992)	N=95 2 parent families and parents 11-22 years	FACES-III, MAS, DFBC, FRQ, FES, AIS, SPPC, CBCL, HbA1c, adherence	Illness-specific and general family relationships predicted dietary adherence and psychosocial adjustment; low levels of illness-specific non-support and high general family flexibility predicted dietary adherence; high levels of illness specific family non-support characterized by high levels of general family conflict; older age and longer disease duration linked to poor dietary adherence

TABLE 3.

Studies of Family Functioning and Adherence to Treatment and Metabolic Control in IDDM (Continued)

Study	Subjects	Measures	Results
Hanson, Henggeler, Harris, Burghen & Moore (1989)	N=94 intact families of adolescents with IDDM	HbA1c, FACES-II, MSS	Good control associated with high marital satisfaction, family flexibility and marginally with high family cohesion; duration of IDDM mediated effects of family relations; high marital satisfaction with short duration associated with good control but association is attenuated as duration increases
Hauser et al. (1990)	N=52 children with IDDM within one year of diagnosis	FES, global measure of adherence rated by health providers; diet exercise, insulin monitoring	Cohesion associated with short and long term adherence; conflict negatively influences adherence; only parent perception of organization associated with adherence
Kager & Holden (1992)	N=64 IDDM youth 7-15 years	HbA1c, LEC, CPCQ, CHIP, SPPC, DAS	Girls in poorer metabolic control but better disease adjusted; life stress related to diabetes adjustment; # negative life events related to HbA1c
Kovacs, Kass, Schnell, Goldston & Marsh (1989)	N=89 newly diagnosed IDDM over 6 years	Family Concept Inventory, CLES, MAQ, HbA1c	Metabolic control in short or long term did not predict quality of marriage and family functioning; initial divorce rate 26% with 2% increase over 6 years; marital distress consistently about 30% with 13% increase in conflict over 6 years
La Greca et al. (1995)	N=74 IDDM 11-18 years	DSSI, FES, DFBC, PSS-Fr, Adherence	Families provide instrumental support for: insulin injections, blood glucose monitoring, meals; Friends provided more emotional support than families; great support associated with better adherence, shorter disease duration and younger age
Lawler, Volk, Viviani & Mengel (1990)	N=16 IDDM 15-18 years & parents	FACES-II, FILE, Social Support Inventory, Kvebaek Family Sculptures, HbA1	Better metabolic control associated with higher cohesion, more mother support & social support
Miller-Johnson et al. (1994)	N=88 IDDM 8-18 years from teaching & private clinics	PCS, pubertal status, 7 days postcard ratings of 12 aspects of adherence completed by child, parents, nurse, & GHb	Conflict associated with worse adherence metabolic control; conflict dysregulates control through the relationship to lower adherence; postcard ratings not useful

TABLE 3.

Studies of Family Functioning and Adherence to Treatment and Metabolic Control in IDDM (Continued)

Study	Subjects	Measures	Results
Schafer, Glasgow, McCaul & Dreher (1983)	N=34 IDDM 12-14 years	Barriers to Adherence & Problem Solving Scale, DFBC, FES, summary of self-care activities, HbA1c	Adherence a multivariate construct; diabetes-specific behaviors related to adherence not global family measure; HbA1c predicted from diet, insulin, # blood glucose tests; conflict and psychosocial associated with poor adherence
Schafer, McCaul & Glasgow (1986)	N=54 adults and 18 adolescents with IDDM	DFBC, 1 week self-monitoring of adherence, questionnaire about previous week, 24-hr recall interview, HbA1	Positive & negative behaviors predicted adherence in adolescence; adolescents are in poorer metabolic control than adults; poor adherence related to poor control only in adults; use of DFBC not recommended with adolescents
Wertlieb, Hauser & Jacobson (1986)	N=46 recent onset IDDM N=29 recent acute illness	CBCL, FES	High family conflict associated with behavior symptomatology for both groups but more so for diabetes.
Wysocki (1993)	N=115 adolescents and families	PARQ, TADS, HbA1c from records	Responsibility compared with healthy normative groups; family communication and conflict strong predictor of HbA1c
Wysocki, Hough, Ward, Allen & Murgai (1992)	N=47 with IDDM, 9-18 years and one parent	HbA1c, fructosamine, SMBG data, self-management diaries, DK, DRCS, DCQ, DWS, DFBC and SBC	Less parent-child conflict associated with more frequent use of SMBG data, more diabetes knowledge and better overall treatment adherence; SMBG frequency unrelated to control; 74% self-regulated

Note. ACO = Adolescent Coping Orientation; A-FILE = Adolescent-Family Inventory of Life Events and Changes; AIS = Acceptance of Illness Scale; CBCL = Child Behavior Checklist; CDI = Child Depression Inventory; CPCQ = Child Perceived Coping Questionnaire; CHIP = The Coping Health Inventory for Parents; CLES = Coddington Life Events Scale; DCQ = Diabetes Compliance Questionnaire; DSSI = Diabetes Social Support Interview; DQLY= Diabetes Quality of Life for Youths; DAS = Diabetes Adjustment Scale; DFBC = Diabetes Family Behavior Checklist; DFBS = Diabetes Family Behavior Scale; DFRQ = Diabetes Family Relationship Questionnaire; DK = Diabetes Test of Knowledge; DRCS = Diabetes Responsibility & Conflict Scale; DWS = Diabetes Worry Scale; FACES-II = Family Adaptability & Cohesion Scale-II; FES = Family Environment Scale; FRQ = Family Relations Questionnaire; FILE = Family Inventory of Life Events and Changes; GhB = Glycosylated hemoglobin; HbA1c = Glycolated Hemoglobin A1c assay; ICD = Issues in Coping with Diabetes; LEC = Life Events Checklist; MAS = Marital Adjustment Scale; MAQ = Locke-Wallace Marriage Adjustment Questionnaire; MSS = Marital Satisfaction Scale; MHLC = Multidimensional Health Locus of Control; PARQ = Parent & Adolescent Responsibility Questionnaire; PCS = Perceived Confidence Scale for Children; PSS-Fr = Perceived Social Support from Friends; SBC = Symptom Belief Checklist; SES = Socioeconomic Status; SMBG = Self-monitoring of blood glucose; SPPA = Self-Perception Profile for adolescents; SPPC = Self-Perception Profile for Children; TADS = Teen adjustment to Diabetes Scale.

Social Support. Although there is increasing autonomy during adolescence, social support during this period has been found to be influential in reinforcing adherence. Diabetes-specific social support of family and friends was evaluated in a study of 74 adolescents with IDDM who ranged between 11 and 18 years (La Greca et al., 1995). Results showed that increased diabetes-specific family support predicted higher adherence among these adolescents when both chronological age and general levels of family support were accounted for. However, support from friends was not associated with adherence, a finding which highlights the importance of familial support and involvement. Parental support around the meal aspect of the diabetes regime was found most supportive by the adolescents in this study. The most important type of support from families was classified as tangible support. Examples of tangible support involved sharing a life style, helping with regimen tasks, reminding them about tasks, preparing meals, and ensuring suitable foods and insulin and technology needed for glucose monitoring, meals, and insulin injection are available. The type of emotional support perceived to be most supportive during this adolescent period was in the form of providing praise and encouragement, conveying a sense of acceptance and helping them have a positive outlook on their diabetes. In contrast, the support from friends was oriented toward companionship and emotional support. Friends provided important support outside the home environment by reminding them to test or inject insulin and by helping out with insulin reactions. The authors recommended an ideal approach to supporting adolescents with diabetes would be for parents to maintain some degree of active involvement while at the same time encouraging gradual independence in diabetes adherence. Involvement could consist of assisting in the preparation and sharing of meals and sharing in exercise activities, but they also recommended that parents needed to ensure that their involvement was perceived as supportive by their adolescent as there was a great deal of variability in what behavior was perceived as supportive.

Poor family support has also been linked to poor metabolic control as shown in a small sample of 21 adolescents with IDDM, Burroughs et al. (1993). In a larger sample of 104 adolescents with IDDM,

Hanson et al. (1987b) found that parental support was linked directly with adherence and that age was indirectly linked with adherence through its association with parental support. Whereas high stress was not associated with low adherence, it was associated with poor metabolic control but only in those with low social competence. The authors suggest that the mechanism of this direct link with metabolic control is probably physiological. They also advance that the findings are consistent with developmental transitions that occur during adolescence. Adolescents are in the process of emancipation from their parents and the development of extra-familial relations become high priority.

Responsibility. There is also evidence that parent's and children's shared responsibility in managing the treatment regime is associated with improved glycemic control and diabetes adherence. Conversely, children who assumed greater responsibility for diabetes adherence tasks have been reported to be in poorer metabolic control than those who assumed less responsibility. Generally, research has shown that by age 13 children with diabetes can carry out all the diabetes adherence self-care tasks but that continued parental supervision and support are important in decision making (Follansbee, 1989; Partridge, Garner, Thompson, & Cherry, 1972). Although parental involvement in the treatment regime has been linked with improved diabetic metabolic control, parents and health care service providers are unsure about how much parental involvement is recommended during adolescence, a period characterized by increasing independence.

Establishing a balance between parental involvement and adolescent independence is not an easy task as shown by the study by Newbrough, Lorenz, Simpkins, Walker, and Dokecki (1986). In this study of 50 children and adolescents between the ages of 8 and 18 and their parents, a relationship between shared responsibility and HbA1 was found. The four aspects of responsibility measured were: remembering management procedures, compliance with procedures, planning for changes, and presentation of information about diabetes to others. The reports of shared responsibility from mothers, fathers and the children with

diabetes were correlated with both HbA1 and the adherence measures of insulin taking, glucose testing, exercise, and diet. However, poorer glycemic control existed when mothers reported sole responsibility. The sharing of responsibility between the father and child was associated with improved HbA1. This study suggests value in the sharing of responsibility in the diabetes treatment regime, particularly the involvement of fathers.

Another researcher examined the degree of agreement between parent and child concerning the division of responsibilities in the diabetes self-care behaviors (Anderson et al., 1990). In this study of 121 children with IDDM between the ages of 6 and 21 and their mothers, they found an association between the child's age, disease duration and gender to be predictive of patterns of sharing diabetes responsibilities. Specifically, mothers and children identified higher responsibility for diabetes adherence with the increasing age of the child and that girls were given more responsibility than boys. Additionally, disagreements between the mothers and children in perception of responsibility was associated with poorer metabolic control and perception of poorer adherence to treatment. When the mother and child both rated that no one was taking responsibility for a regimen task, worse metabolic control was predicted. This emerged as an important flag for identifying possible areas for high-risk mistakes. Rather than assuming that the child is taking responsibility for the task, these authors are suggesting that families need to improve communication in identifying who has responsibility for the tasks during adolescence.

Demographics. Demographic variables have also been linked with adaptation in youth with diabetes, with such characteristics as chronological age, family structure, social class, and race mediating the relationship (Farrington, 1986). Researchers have examined both duration since diagnosis and age as mediating variables of adjustment, adherence and metabolic control. Duration since diagnosis has almost consistently been found to be the mediating variable most predictive of adjustment with children with diabetes (Hanson et al., 1989; Mullins et al., 1995). Chronological age has also been associated with worse

metabolic control and adherence (Anderson et al., 1990; Hanson et al., 1987b; Hanson et al., 1992: Rolisio et al., 1998). In a recent cross-sectional nationwide study of 2,579 children in France from 207 centers, Rosilio et al. found that metabolic control, as measured by HbA1c, was best for the 4 -5 year olds and increased gradually with age. It remained within the well controlled level of less than 8.0% before age 10-11 years but it increased after this age, with the worse metabolic control being at 17-18 years.

Although researchers have postulated that single-parent family structure was a risk for poor adherence to treatment and metabolic control, research findings are mixed. In a comparison study of 30 father-absent and 30 intact families, the single mothers of female adolescents were more involved in the daily treatment regimen than mothers of adolescent boys (Hanson, Henggeler, Rodrigue, Burghen, & Murphy, 1988). Despite adolescents receiving more maternal support in the intact families, the father-absent adolescents displayed better adherence. Results showed that psychological adjustment was better for those in two parent families in a study by Hamlett, Pellegrini, and Katz (1992) of the relationship between family functioning, maternal social support, and child life stress events to the psychological adjustment and illness events of children with asthma and diabetes. In contrast, Auslander et al. (1990) found better metabolic control in two parent families with higher socioeconomic status. The poorest metabolically controlled adolescents came from families with low socio-economic status and African-American single-parent families. These findings are consistent with the Ontario Child Health Study which found a higher percentage of low income families who were experiencing psychosocial difficulties. Similarly, another study found that Black females were in worse metabolic control than White females but that these females did not differ in knowledge about IDDM, diabetes adherence, self-concept, coping patterns, family functioning, stress, social support, or involvement in a health-care system (Hanson, Henggeler, & Burghen, 1987a).

Although the findings from the pediatric chronic illness population are inconsistent, the findings from general population studies are not. A meta-analysis examining the influence of family structure in the

general population was conducted to determine whether child adjustment was better in a two-parent household compared to a one- parent household. Findings showed that it was the children in high-conflict families who were worse off than children in low-conflict families and divorced families (Amato & Keith, 1991). The results support a family conflict perspective rather than a parental absence perspective which means that it is the conflict rather than absence of a parent that negatively affects child adjustment. These findings would likely generalize to the chronic illness pediatric population as well.

There are also differing results about the influence of gender on metabolic control and adherence to treatment. Allen et al. (1992) found glycemic control stabilized during the second year of IDDM for females but not for the males in a sample of adolescents between the ages of 10-19 years. In contrast, females were in poorer metabolic control in the Kager and Holden (1992) study of children between the ages of 7 and 15 years.

In summary, family functioning has been inconsistently linked with poor treatment adherence and metabolic control of diabetes, with family cohesion and conflict emerging as two central measurement constructs. There is equivocal evidence that family structure influences diabetes management and stronger evidence that Black adolescents and those from lower socioeconomic status homes experienced worse metabolic control. There is also equivocal evidence about gender differences in metabolic control. Chronological age has been associated with worse metabolic control and diabetes adherence. Another common finding in numerous other studies is that the child's age at diagnosis did not influence adjustment, but rather the longer the duration since diagnosis the more the children appraised the regimen adherence as difficult (Anderson et al., 1990; Hanson et al., 1989; Wysocki et al., 1992). Thus, initial level of psychological functioning and duration since diagnosis were important factors in examining adjustment in pediatric chronic illness populations. Additionally, the inadequate measurement of adherence to treatment has limited our understanding and blurred outcome results by considering adherence as a univariate

construct. Using the Bennett Johnson et al. (1986) 24-hour recall interview to determine adherence to diabetic treatment would make a significant addition to research and could make clear the association between aspects of family functioning, metabolic control and treatment adherence (Hanson, 1992). The use of a diabetes-specific measure such as the Diabetes Family Behavior Scale (KcKelvey et al., 1993), in addition to general family functioning, would aid in discerning the mediating effects of family functioning on adherence to treatment and on metabolic control.

Marital Functioning and Pediatric Chronic Illness

It has been recognized that parents are profoundly affected by the care-taking responsibilities of a pediatric chronic illness, but there is no agreement on whether these additional responsibilities place them at greater risk for distress than parents of healthy children. Although generally greater marital distress has been found in families with a chronically ill child compared with families with healthy children (Sabbeth & Leventhal, 1984), low divorce rates have been found in studies of the parents of pediatric chronic illness populations, with rates falling generally below 10% (Martin, 1975; Reynolds, Garralda, Jameson, & Postlethwaite, 1988; Silbert, Newburger, & Fyler, 1982; Tew, Paynes, & Laurence, 1974). The divorce rate of parents of children with diabetes is similar to that of parents of children with other chronic illnesses. Martin (1975) identified a divorce rate of 11.7% for the 60 couples of the children with diabetes studied. In contrast, in an examination of 85 recent onset IDDM children studied longitudinally over six years, Kovacs et al. (1989), found a divorce rate of 26% at the beginning of the study, with an increase of 2% over the six years. The divorce rates of parents of 438 children with congenital heart disease varied depending upon the status of the heart disease: 12.1% for critical congenital heart disease, 4.2% for spontaneously cured, and 11.5% for free of heart disease. These divorce rates were below the national average of 20.3% established during the course of the study (Silbert et al., 1982). The person-year divorce rate for parents of children with cancer was 1.19%, whereas, the person-year divorce rate among married couples in their population

was 2.03% (Lansky, Cairns, Hassanein, Wehr, & Lowman, 1978). These findings indicate that the use of divorce rates as a measure of marital adjustment was inappropriate due to the low divorce rate when compared to other populations and because distress would be underestimated.

A recent study of 67 parents of newly diagnosed children with cancer found that 25% of the mothers and 28% of the fathers reported significant marital distress on the Dyadic Adjustment Scale (Dahlquist et al., 1993). Similar results were found in a comparison study conducted by Crain, Sussman, and Weil (1966). They found that parents of a child with diabetes experienced lower marital integration, less agreement on how to handle their child, and greater marital conflict compared to matched non-diabetics. Another study of parents of children with cancer found that while family cohesion and marital quality were initially strengthened by their child's illness (Barbarin, Hughes, & Chesler, 1985), the perception of support from their spouse along with marital quality decreased as the child's hospitalizations increased. The husband's perception of support from his wife stemmed from her availability at home, whereas the wife's perception of support from her husband came from his involvement with the children.

Discrepant findings about the risk for marital distress in couples with a chronically ill child have been identified (Gordon Walker, Johnson, Manion, & Cloutier, 1992). These authors identified three recent studies using the Dyadic Adjustment Scale, a scale developed by Spanier (1976), that did not find greater marital distress in parents of chronically ill children (Kazak & Marvin, 1984; Kazak, Reber, & Snitzer, 1988; Spaulding & Morgan, 1986). Gordon Walker and her colleagues explained that these findings were the result of inappropriate measurement standards being used for parents of chronically ill children. Using an expressed desire for marital therapy as the criterion, a higher cut-off point on the Dyadic Adjustment Scale for couples of chronically ill children was found, and it was the recommendation of these authors to use this revised cut-off point in future research on this population. Similarly, a more recent comparison study of 36 mothers and 28 fathers of recently diagnosed infants and toddlers with cystic fibrosis (Quittner,

DiGirolamo, Michel, & Eigen, 1992) as a group, these parents were not experiencing marital distress. They obtained a mean Dyadic Adjustment Scale (DAS) score of 102.41, which is within the non-distressed range using Spanier (1976) norms, but within the distressed range using the Gordon Walker et al. (1992) cut-off point.

Despite the equivocal findings from these studies on marital distress in parents of a chronically ill child, in a recent review of the literature, Hauenstein (1990) presented three summary findings which concluded that there is a moderate amount of evidence that the experience of caring for chronically ill children results in marital distress. The three findings which suggested moderate increased risk are (1) significant emotional distress for both the fathers and the mothers, with maternal depression being common in families caring for a chronically ill child; (2) parental distress related to limited social resources; and, (3) more problems being identified by the families. The numerous methodological problems identified in a review of 34 studies on the marital adjustment in families of a chronically ill child (Sabbeth & Leventhal, 1984), account for the discrepancies in the findings. They identified the following methodological problems: (1) lack of comparison groups; (2) lack of consensus regarding the definition of marital distress; (3) varied instrumentation with questionable or unknown psychometric properties; and, (4) emphasis on cross-sectional rather than longitudinal or prospective studies.

Marital distress and diabetes management. The relationship between marital distress and health status and adherence to treatment has largely been ignored in pediatric chronic illness populations. In one study, Hanson et al. (1989) investigated the associations between both family relations and marital satisfaction and the health status of adolescents with IDDM. They found that both high marital satisfaction and family flexibility were positively correlated with good metabolic control only under conditions of short duration of the disease. That is, as the duration of the disease increased, the relationship decreased markedly. A weakness of this study was the grouping of family functioning and marital satisfaction

together as a family variable affecting metabolic control and treatment adherence. Moreover, adherence was measured as a two-factor construct rather than as a multivariate construct.

In contrast, Geiss, Hobbs, Hammersley-Maercklein, Kramer, and Henley (1992) found that higher levels of compliance in a population of children with cystic fibrosis between the ages of 6 months and 17 years was associated with less satisfactory marital relationships and with less frequent maternal social contacts. Compliance was evaluated by the physicians completing a rating scale. Overall, 28% of the mothers scored within the distressed range on the Locke Wallace Marital Adjustment Test. The group mean on the Beck Depression Inventory (BDI) was 9.5, a score which is below the clinical cut-off of mild depression, and social support was considered higher than in a community sample. These authors suggest that adequate versus high levels of compliance are more conducive to positive and normalizing family relationships, as more involvement in the treatment regime may be regarded as a substitute to marital and social interactions. However, compliance levels as reported by medical personnel are known to be an unreliable and biased evaluation method and cast doubt on the reliability of this finding (Bennett Johnson, 1980; Nagasawa et al., 1990).

A longitudinal study of adjustment in IDDM also found that the quality of the marriage as measured by a combined score from one variable from the General information sheet (GIS) and three from the Coddington life-events scales did not predict metabolic control in the short or long term (Kovacs et al., 1989). There were about 30% of these parents who identified marital distress, and a 13% increase in arguments was found over the six years.

In summary, even though there is no evidence for a higher than average divorce rate, the evidence suggests that there is marital strain and parental and marital distress in families caring for a chronically ill child. Despite inconsistent findings and the lack of studies examining adherence in diabetes and marital distress, it is nevertheless reasonable to assume that marital distress could affect the parenting functions

necessary for following a complex treatment regime. This next section discusses the impact of marital distress on child adjustment.

Impact of Marital Distress on Children

Research has consistently found that the marital relationship and family functioning are the two most important factors which contribute to an increased risk of developing emotional and behavioral difficulties in children, with the best predictors of childhood behavior problems being marital discord and family dysfunction (Cummings & Davies, 1994; Emery, 1982; Emery, Fincham & Cummings, 1992; Porter & O'Leary, 1980). An association between marital conflict and child behavioral adjustment is unequivocal within current developmental perspectives on child adaptation (Fincham, 1998; Mash & Barkley, 1989). Moreover, family functioning and the marital relationship appear to be mediators of adjustment in families with a child with a chronic illness as well (Pless, Roghmann & Haggerty, 1972).

What is the mechanism by which marital discord affects aspects of child development? Lindahl and Markman (1990) suggested that one mechanism that might contribute to the relationship between marital distress and child functioning is emotional exhaustion. Maritally distressed parents may be too tired to be responsive to their children. Another perspective for understanding the mechanisms underlying the effect of marital discord on child adjustment is the process model developed by Gottman and Fainsilber Katz (1989). This process model suggests that marital discord affects the child's social relationships and the child's susceptibility to illness. Based on an investigation of the effects of marital discord in 56 families on the peer interactions and the physical health of preschool children, they proposed that couples who were distressed displayed a parenting style that was cold, unresponsive, angry, and low in limit-setting and structure. This interactional style of the parents was found to be associated with anger, noncompliance, and high levels of stress-related hormones in their children. These children also played at a lower level with peers, had more negative peer interactions and had worse health.

Erel and Burman (1995) have proposed alternative hypotheses which may link marital and parent-child relations. A meta analysis of 68 studies examined whether a linkage between the marital and parent-child relationship existed and whether this linkage supported the spill-over or compensatory hypotheses. The spill over hypothesis suggests that positive parent-child relations are difficult to achieve in the presence of marital discord. The quality of the marriage may spillover and affect the parent-child relationship. The four spillover mechanisms are:

1. Detouring, also known as scapegoating, involves a focus on the child's problems which creates a distraction from the marital subsystem;

2. Vicarious learning of behavior modeled by parents, a concept from social learning theory, implies that children model either the warmth and caring demonstrated by harmonious relationships or the overtly hostile relationship which is characterized by a lack of warmth and caring;

3. The socialization hypothesis implies that parents experiencing marital discord provide less consistent discipline and tend to use less optimal parenting techniques than parents not experiencing marital difficulties. Inconsistencies in parenting comes from poor communication, disagreements about parenting, and different parenting practices, as parental behavior may change depending on whether the other parent is present or not.

4. Marital problems and parent-child problems are viewed as stressors that lead to further problems within the parent-child and marital relationship. There are three directions of influence in this hypothesis based on the stress and role strain literature. The first direction is within the marital relationship and the parent-child relationship. The presence of parental distress or discord will result in less emotional availability to monitor and administer to the child's needs. The second direction emanates from the parent-child to the marital relationship. Normal parenting functions during the parenting years diminish marital satisfaction and a difficult child may further disrupt

marital relations. The third direction is chronic illness or unemployment outside the parent-child or marital system, which stresses the entire family system.

The compensatory hypothesis suggests that parents may seek to meet their emotional needs through the parent-children relationship when these needs are not met within the marital relationship. Triangulation and cross-generational coalitions follow when the parent engages the child to enter into a coalition against the other parent. This meta analysis found support for the linkage between parental discord and parent-child relations and also that this disruption was supported by the spill-over hypothesis (Erel & Burman, 1995). In summary, although infrequently studied in relation to treatment adherence and metabolic control, there is strong evidence for the contribution of the marital relationship to affect related aspects of child development.

Parental Depression and Pediatric Chronic Illness

The parents of chronically ill children have shown significant levels of depression in several studies, with mothers being at significant risk for depression (Breslau, Staruch, & Mortimer, 1982; Daltroy et al., 1992; Tew & Laurence, 1973) and receiving two to three times more mental health treatment than parents of well children according to results of the Ontario Child Health Study (Cadman et al., 1991). In an intervention study using Emotionally Focused Therapy the depression rate for the parents of chronically ill children who had requested marital therapy was 44% (Gordon Walker, Johnson, Manion, & Cloutier, 1996). Not only is the mother of the chronically ill child at risk for depression, the mothers not working outside the home in this population were at increased risk. When the mothers of chronically ill, mentally retarded and physically well children were compared, the mothers not working outside the home were reported to have higher levels of depression when compared to those employed (Walker, Ortiz-Valdez, & Newbrough, 1989). A study of the distress level of the mothers of 116 children with a diagnosis of cancer, cystic fibrosis, inflammatory bowel disease or IDDM, ranging in ages 9 to 18, revealed that it was the mother's reports of burden and the functional impairment of the ill child that predicted care-giver distress as measured by the

Brief Symptom Inventory, a self-report of psychiatric symptoms (Canning, Harris, & Kelleher, 1996). In contrast, there was a lack of positive correlation between the physician's rating of care-giver burden and psychiatric symptoms, highlighting the differential results which are obtained depending upon the selected informant. Additionally, in this study lower economic resources and a female ill child were associated with more care-giver distress.

In a study of the mental health of the mothers of children with juvenile rheumatoid arthritis, Lustig, Ireys, Sills, and Walsh (1996) also found support for the variable of mother's appraisal of the child's illness on the family as the one that mediated maternal mental health. In this study, the biological severity and functional severity of the arthritis were associated with maternal mental health. A controlled study of the stress level of 49 mothers and their children with diabetes found a third of the mothers reported clinically significant parent domain stress on the Parental Stress Index (Hauenstein, Marvin, Snyder, & Clarke, 1989). This group of mothers was depressed, socially isolated, felt incompetent, was unattached to their children, and was in poor health.

Fathers have been largely ignored in the research. Gayton, Friedman, Tavormina, and Tucker (1977) were the first to examine the impact of having a child with cystic fibrosis on both family functioning and on the personality functioning of both parents. The most significant impact was on the father's adjustment with, fathers, on the whole, being less well adjusted; 50% had at least one Minnesota Multiphasic Personality Inventory scale above normal limits. A lone study of the adjustment of parents of children with newly diagnosed cancer identified scores below the cut-off for mild depression in adults as measured by the Beck Depression Inventory. Thirteen percent of the mothers and 8% of the fathers reported clinically elevated levels of depression symptomatology as identified by scores above 16 on the BDI (Dahlquist et al., 1993).

Whether parental depression is associated with physical stability of a disease or adherence to

treatment has also been largely ignored in research. Thompson, Gustafson, Hamlett, and Spock (1992) assessed the psychological adjustment of mothers of children and adolescents with cystic fibrosis in terms of illness severity. The majority of mothers were psychologically well adjusted in this study, although 34% experienced significant anxiety or depression. Parental distress was not found to be related to illness severity. Rather daily stress was the main variable which accounted for the largest increment in the variance explained for both anxiety and depression. The variables that were significant contributors for depression were more use of palliative coping methods and lower levels of family support. Higher levels of control in family functioning and low expectancy of efficacy were associated with anxiety. Similarly, role strain was identified as the crucial variable which contributed to maternal depression in a comparison study of 36 mothers and 28 fathers of recently diagnosed infants and toddlers with cystic fibrosis (Quittner, DiGirolamo, Michel, & Eigen, 1992). Contextual stressors rather than global measures of stress accounted for greater proportions of the variance in depression.

There appears to be a total absence of studies examining the association between parental depression and treatment adherence and metabolic control. However, in light of evidence indicating the existence of marital strain and parental emotional distress in families caring for a chronically ill child, the relation between these factors to adherence to treatment and metabolic control is warranted. This next section will discuss the impact of parental depression in child adjustment in general and in pediatric chronic illness populations.

Impact of Parental Depression on Children

There is a large body of empirical evidence showing that the psychological adjustment of children is affected by parental depressive symptoms and that parental depressive symptoms are associated with parent-reported child behavioral/emotional problems (Beardslee, Bemporad, Keller, & Klerman, 1983; Burbach & Borduin, 1986; Compas, Howell, Phares, Williams, & Giunta, 1989; Daniels, Moos, Billings & Miller,

1987; Downey & Coyne, 1990; Fendrich, Warner, & Weissman, 1990; Rutter, 1990; Weissman & Paykel, 1974). Reviews of the literature with respect to the psychosocial adaptation of children of depressed parents have indicated that these children may be at a higher risk than those of normal or thought-disorder parents (Beardslee et al., 1983; Downey & Coyne, 1990). Beardslee et al. (1983) summarized findings and estimated that the overall rate of significant psychiatric disturbance during childhood was 40 to 45% for the offspring of parents with affective disorders. Findings indicated that parental depression was a significant risk for children's health that continues to exist at least into the early phase of parental recovery from their depression (Billings & Moos, 1985). Considering the impact of maternal depression on children in general, maternal distress in families of chronically ill children may pose an added risk because of its influence on the psychosocial functioning of children and possibly on adherence to treatment and the health status of the disease.

A recent study suggesting such a risk is shown in a comparison study of families of children with cystic fibrosis, diabetes, and mental retardation. This study showed an association between child management problems, care taking burden, family problems, and maternal and child adjustment (Walker, Van Slyke, & Newbrough, 1992). This association between parental depression and childhood depression in chronically ill children has been found in other studies. In a study using epidemiological data, Fendrich et al. (1990) compared the relative impact of parental depression and marital discord on children and found that marital discord was linked with externalizing problems, whereas parental depression significantly increases the risk of childhood depression. Similarly, in a study of 99 children with cancer between the ages of 8 and 16 years, Mulhern, Fairclough, Smith, and Douglas (1992) found associations between maternal depression and higher levels of child depression in addition to lower social support, and between child hospitalization and child depression. Another comparison study by Mullins et al., (1995) found an association between higher maternal depression, increased illness severity and greater length of time since

diagnosis and greater child depression in a sample of 25 children with IDDM between the ages of 7 and 13 years. In contrast, this relationship was not found between the mothers of the 24 children with cystic fibrosis. Instead, they found a relationship between maternal depression and decreased trait anxiety for children in the cystic fibrosis group. Thus, there appears to be illness-specific patterns of relationships. It has also been found that the parent's emotional status influences perceptions of the child's illness severity (Frydman, 1980). Distressed mothers over-reported behavior problems in their children (Brody & Forehand, 1986). The existence of a striking link between parental depression and childhood depression was a summary finding in a review of the literature on children of depressed parents (Downey & Coyne, 1990).

What are the mechanisms that explain the association between depression and parenting? According to Downey and Coyne (1990), the link between parental depression and child adjustment can be explained by the reduced effort put forth by parents interacting with their child. In their review of the literature of children of depressed parents, these authors suggested that depressed mothers responded to other adults in the same fashion they responded to their children. First, their interactions were characterized by constricted affective expression, more negativity, less interaction, and a slower response rate to their children's efforts at engaging them. Second, depressed mothers used heightened negativity, hostility, and coercion rather than negotiation to control child behavior.

In another review, Rutter (1990) identified four other mechanisms that can explain the association between depression and the effects on parenting:

1. The mother's negative mood may lead to the expression of negative affect to the child (Field, Healy, Goldstein, & Guthertz, 1990).

2. The depressive mood may diminish the mothers' sensitivity and receptivity to children's cues and needs and may impair disciplinary functioning, or lead to the inappropriate use of their children as a source of comfort. That is, the depressive mood may reduce parental tolerance, social problem

solving and coping skills (Bettes, 1988; Radke-Yarrow, Richters, & Wilson, 1988).

3. Depression has been associated with family discord; consequently, the associated increase in conflict may negatively affect the children (Gotlib & Hooley, 1988; Rutter & Quinton, 1984).

4. Impaired parenting may be a risk factor for depression but not necessarily a function of depression. In other words, the parenting difficulties which may arise from impaired social functioning factors, such as marital discord or poor parenting, may create an increased risk for depression (Coyne, Kahn, & Gotlib, 1987; Goodman & Brumley, 1990).

The nature of the father's role in relation to the mother's emotional distress, marital distress, and family functioning seems crucial to understanding adjustment and outcome of medical treatment. Yet, the majority of studies of parental adjustment have focused upon the mother in their analyses and fathers have largely been ignored in the research (Phares, 1992). Caution must therefore be exercised in determining causal relationships in studies which have only relied upon the mother as respondents.

In light of a large empirical body of evidence supporting the negative impact of maternal psychological adjustment on child adjustment in general, it is reasonable to assume that the chronically ill child population and their parents may be at increased risk because of the increased demands of coping with a disease. Significant levels of depression in mothers of chronically ill children are not surprising considering it is the mother's of these ill children who assume the majority of the care-taking functions. The evidence shows that there is marital strain and parental emotional distress in families caring for a chronically ill child and that children are affected by marital distress and parental depression.

From a systems/social ecological perspective, it would also be erroneous to conclude that chronic childhood illness causes maternal depression or marital distress or family dysfunction. A reciprocal model would be most appropriate to describe the interrelationships between illness and family relationship

variables. Not only is it important to consider the mother's emotional status, it is crucial to evaluate the role of the father's emotional status in addition to the marital relationship in order to understand adjustment in families with a chronically ill child. A serious limitation of the extant literature on family functioning, particularly in childhood chronic illness, is the failure to take into consideration an assessment of parental emotional status as a dimension of family and marital discord (Fendrich et al., 1990), especially since it has been shown that parental psychopathology is a correlate of family discord and psychopathology in children. Since parental depression is a significant factor in the psychosocial adjustment of chronically ill children it is also reasonable to assume that parental distress may play a role in the management and health outcome of a complex and varied self-management regime for which parents are largely responsible at least until the adolescent years. In light of this evidence, the hypothesizing of a relation between marital distress and parental depression in families caring for an adolescent with diabetes in relation to adherence to treatment and metabolic control is warranted.

Adjustment and Depression in Pediatric Insulin-Dependent Diabetes Mellitus

The general adjustment of children with pediatric chronic illnesses has been widely studied in the pediatric literature. Epidemiological studies have also examined the adjustment of pediatric chronic illness populations. Several large scale epidemiological studies, which have been conducted in Great Britain, the United States, and Canada have shown that between 20 and 30% of chronically ill or physically handicapped children experience significant emotional or behavioral problems at some point during childhood and adolescence (Cadman et al., 1987; Pless & Satterwhite, 1973; Rutter, Tizard, & Whitmore, 1970; Walker, Gortmaker, & Weitzman, 1981). Within the past decade, five longitudinal studies have examined the specific adjustment to diabetes in childhood. Table 4 summarizes the results of these longitudinal studies and other studies on the adjustment of children with a chronic illness.

Among various mental disorders, it is depression which is most commonly found in adults with

IDDM (Gavard, Lustman, & Clouse, 1993). The prevalence of depression in children with IDDM and the parental risk factors for developing psychiatric disorders in children with IDDM were studied by Kovacs, Goldston, Obrosky and Bonar (1997b). This recent 10 year longitudinal and naturalistic study followed 92 children between the ages of 8 and 13 years of age from their initial diagnosis of IDDM, as well as their mothers. Psychiatric status was assessed at each contact with standardized and semi-structured interviews for both the child and the parents. In summary, there was a threefold higher risk factor of children and adolescents IDDM to develop a psychiatric disorder, and 48% were at risk of a new psychiatric disorder by the age of 20. These results suggest that the mental health of patients with IDDM should be closely monitored and that it is under-treated in the primary health care sector.

A controlled, prospective 10 year longitudinal study compared 24 youths with IDDM and major depressive disorder with a control group of depressed psychiatric subjects (Kovacs, Obrosky, Goldston, & Drash, 1997a). They identified a risk factor of 32% re-occurrence of depression by year two and, by 6.5 years, 47% were estimated to have had a reoccurrence of depression. The females with diabetes were at nine times greater risk for recurrent depression than the males with diabetes. Only 37.5% received treatment for their first episode of depression compared to 50% for the second episode, again highlighting the under-treatment in primary health care sectors.

The relationship between psychiatric diagnosis and metabolic control among children and adolescents with IDDM was also investigated as part of the longitudinal study by Kovacs, Mukerji, Iyengar, and Drash (1996). There was an association between major psychiatric disorder, duration since diagnosis, and HbA1c, while depression was not isolated as a factor which contributed to worse metabolic control.

A two year longitudinal study of psychosocial status comparing 89 children with IDDM and 53 without IDDM showed that children with diabetes were more depressed, more dependent and more withdrawn than the control group during the first 3 and 6 month evaluations (Grey, Cameron, Lipman, &

Thurber, 1995). By one year post-diagnosis, there were no differences between the groups. By two years post-diagnosis, there were significant differences between the groups on depression and withdrawal. In contrast, the results of a 10 year longitudinal study of 57 young adults who entered the study initially between the ages of 9 and 16 years of age, and were compared with 54 with moderately severe to acute illness, showed no differences in psychiatric symptoms (Jacobson et al., 1997). While there appears to be some indication of an increased risk for developing depression in children with diabetes, what is the typical rate of childhood depression in the general population?

The results from the meta-analysis of 60 studies of depressive symptoms among children and adolescents with chronic medical problems conducted by Bennett (1994) showed that overall they were slightly more at risk for depressive symptoms but that there were disease-specific differences across disorders. The rate of depressive symptoms in children with diabetes was similar to healthy controls, whereas, it was children with asthma, recurrent abdominal pain and sickle cell anemia who were more at risk for depressive symptoms. Ratings of depressive symptomatology was approximately one fourth standard deviation above the mean of control groups (the mean effect size = 0.27) (Bennett, 1994). The prevalence rate for major depressive disorder or for an unspecified depressive disorder was 9% across the 18 studies using diagnostic interviews in this meta-analysis.

Fleming and Offord (1990) also report that typical rates of depressive disorder are between 1 to 5% in community samples, slightly lower than the 9% found by Bennett (1994). In the general childhood population, the prevalence of major depressive disorder increased from about two percent in pre-adolescent children to four percent to eight percent in adolescents with equal ratios of males and females experiencing depression during childhood. The male female ratio increased to 1:2 during adolescence (Fleming & Offord, 1990; Lewinsohn, Clarke, Seeley, & Rohde, 1994).

The lifetime risk for major depressive disorder in children of depressed parents has been estimated to

range from 15 to 60% (Hammen, Burge, Burney, & Adrian, 1990; Orvachel, Walsh-Allis, & Ye, 1988; Weissman, Warner, Wickramaratne, Moreau, & Olfson, 1997). The incidence rates found in the Kovacs et al. (1997b) study of youth with IDDM are higher than community samples. For example, norms from the general population identified an overall base rate of 9.57% of children, who were classified as depressed in the general population using the Child Depression Inventory (CDI) (Kovacs, 1992). In a 10 year longitudinal study of child adjustment in the general population, Reinherz et al. (1989) investigated the relationship between early risk factors, current mediators and childhood depression. In this study of 378 children, which started in kindergarten and in which subjects ranged in age from 13.6 to 16.3 years old at the end of the study, multiple regression analysis indicated that a total of 20.6% of the adolescents studied scored within the clinical range on the CDI. Serious illness at ages 0-5 years and gender accounted for 2.6% and 2.5% respectively of CDI variance ($p<.005$), while family cohesion and social support accounted for 8.5% and 14.7% respectively of CDI score variance ($p<.005$).

Learned helplessness, a concept which was developed by Seligman (1975) and which can be part of the depressive profile, has also been studied in pediatric IDDM. Kuttner et al. (1990) found that learned helplessness was significantly correlated with depression and poor metabolic control in a clinic sample of 50 youths, 10 to 16 years of age, with IDDM. In this study, regimen adherence was measured by three telephone calls which followed the 24-hour recall interview protocol developed by Bennett Johnson et al. (1986) during a one week period. They found a significant association between learned helplessness and HbA1 ($p < .001$) but not with regimen adherence. Depression, as measured by the CDI, and regimen adherence were unrelated to metabolic control.

In conclusion there are inconsistent reports of increased risk of experiencing psychosocial and psychiatric problems during childhood when compared with healthy peers, with an indication that there is a slight increased risk among chronically ill children but that there are disease-specific differences. Moreover,

the initial level of psychological functioning and time since diagnosis have emerged as significant variables in examining adjustment in pediatric chronic illness populations.

TABLE 4.

Longitudinal Studies of Child Adjustment in Children with Diabetes

Study	Subjects	Measures	Results
Grey et al. (1995)	N = 89 with IDDM N = 53 without 8-14 years over 2 years	CDI, State-Trait AIC, CAAP, SPPC & general health	No demographic differences; initially children with diabetes more depressed, dependent & withdrawn; groups similar at year one; by year 2 depression, dependency, withdrawal higher in children with IDDM; competence similar for both groups
Jacobson et al. (1990)	N = 61 onset IDDM, 9-16 years	CBCL, DAS, LOC, SEI ego defence interview, adherence rated by health provider	Initial assessment of coping, adaptive strength, LOC and adjustment predict adherence 4 years later in 3 domains of adherence: diet, insulin adjustment, monitoring, composite adherence score; pre-adolescents more compliant than adolescents 13-16 years; 47% of adherence accounted for by age, adjustment and ego defense
Kovacs et al. (1990)	N = 95 8-13 years newly diagnosed IDDM & parents over 6 years	CDI, RCMAS, SEI, ICI-C, percent Ghb, # days in hospital	Longer duration of IDDM more treatment was difficult; girls more affected and those with more symptoms of anxiety/depression; age at diagnosis did not affect adjustment; initial psychological functioning (anxiety, depression and self-esteem) predicts later adjustment; overall adjustment below cut-off
Kovacs, Mukerji, Iyengar & Drash (1996)	N = 88 8 - 13 years for 9 years follow-up	Mothers: Hamilton Psychiatric Rating Scales for Depression /Anxiety, SCL-90, Children: ISCA	Major psychiatric disorder and non depressive disorder associated with poorer HbA1c; increased risk for psychopathology with IDDM; non compliance associated with higher HbA1c; disease duration associated with psychiatric disorder (except depression) and chronological age to a lesser but still significant extent

TABLE 4.

Longitudinal Studies of Child Adjustment in Children with Diabetes (Continued)

Study	Subjects	Measures	Results
Kovacs, Goldston, Obrosky & Bonar (1997)	N = 92 8 - 13 years at initial diagnosis for 10 years with mothers	Mothers: Hamilton Psychiatric rating Scales for depression /anxiety; SCL-90, BDI, DSM-III, SES Children: ISCA	42.4% developed at least 1 episode of psychiatric disorder, 27.6% had 2 or more psychiatric diagnoses; 26% had major depressive or dysthymic disorder, 19.6% had anxiety disorder; first year associated with highest incidence of psychiatric disorder(depression/anxiety); risk for child psychiatric disorder 2.11 higher with mothers with psychiatric disorder; risk 2.63 higher for children of depressed mothers; risk 3.5 with mothers diagnosed with premorbid anxiety & 3.21 times for premorbid depression; 4.05 times more behavior disorders with premorbid depressed child; 48% at risk of new psychiatric disorder by age 20, overall had 3 times risk to develop psychiatric disorder.
Wertlieb, Hauser & Jacobson (1986)	N = 46 Recent onset IDDM, 9-16 years vs 29 recent acute illness	CBCL, FES	No difference between internalizing & externalizing symptoms; FES associated with increase in symptoms; association bet. behavior problems and high levels of family conflict with both groups, more so for families with diabetes; social/recreational activities, clear routines, organization linked with fewer behavior problems for families with diabetes.

Note. BDI = Beck Depression Inventory; CAAP = Child & Adolescent Adjustment Profile; CBCL = Child Behavior Checklist; CDI = Children's Depression Inventory-Revised; CLES = Coddington Life-Events Scales; DAS = Dyadic Adjustment Scale; DSM-III = Diagnostic and Statistical Manual of Mental Disorders-III; FCAM = Family Concept Assessment Method; FES = Family Environment Scale; ICI-C = Issues in Coping with IDDM; ISCA = LOC = Locus of Control; MAQ = Locke Wallace Marital Adjustment Questionnaire; Ghb = percentage of glycosylated hemoglobin in whole blood; RCMAS = Children's Manifest Anxiety Scale; SCL-90 = Symptom Checklist-90; SEI = Coopersmith Self-Esteem Inventory; SES = Socioeconomic Status; SPPC = Self-Perception Profile for Children; State-Trait AIC = State-Trait Anxiety Inventory for Children.

Rationale for the Present Study

The findings from this review point to the need for the study of adaptation in age-specific groupings versus cross-sectional population studies in diabetes. Although some researchers have taken a developmental approach to studying factors in adolescents with IDDM (Hanson et al., 1989; Wysocki, 1993), most studies have combined age groups. Because most studies were cross-sectional, the combining of age groups limited finding age-specific findings from which interventions can be based. Since there is a move toward independent functioning during this developmental period and the diabetes self-care patterns established during this period are likely to continue into adulthood, determining how family relations variables influence adaptation in adolescents with diabetes is of interest. The adolescent period is of particular interest because it is a particularly difficult period in the management of diabetes, with poor adherence and a decrease in metabolic control being characteristic. There are hormonal, social and emotional changes which may contribute to increased difficulty with treatment adherence and with metabolic control during adolescence. Moreover, there is indication of poorer metabolic control and less adherence the longer the time since diagnosis and the greater the child's chronological age.

While the influence of treatment adherence on metabolic control has been the primary variable to have been examined in pediatric chronic illness, an equally important focus of this research is the influence of family factors. The families of children with diabetes face many stressors throughout the course of the illness and family relations play an important role in influencing treatment adherence and possibly metabolic control. Adhering to a complex treatment regime is time consuming and demanding and can be considered a stressor for the entire family system. Because the nature of diabetes treatment involves substantial family support, the adaptation of families with an adolescent with this chronic illness from a social/ecological adaptation perspective is ideal to study. Because IDDM involves a demanding self-regulated treatment plan, the treatment plan affects the whole family and requires their participation to ensure adherence to the regime.

Because research findings have clearly shown that good metabolic control can delay or reduce the severity of complications associated with insulin-dependent diabetes mellitus (IDDM), examination of variables that may influence metabolic control are paramount.

The primary variable that has been examined in the existing literature is the influence of treatment adherence on metabolic control in diabetes. Although treatment adherence is considered essential for good metabolic control, an inconsistent association between metabolic control and adherence to treatment has been found. The evidence regarding the direct association between adherence to treatment and glucose metabolism has been inconsistent in part because past research has assumed that adherence to treatment was a unitary concept and used univariate measures of adherence. The inconsistent findings in the literature often stemmed from methodological flaws such as the reporting of adherence by health care professionals and one time reports of adherence (Bennett Johnson, 1992; Nagasawa et al., 1990). The 24-hour recall interview of adherence to treatment in diabetes developed by Bennett Johnson et al. (1986) yields five multivariate factors and an association between adherence to treatment and metabolic control has been found with this measure of adherence. Consequently, the use of a measure which provides a multivariate conceptualization of adherence and which measures adherence by interviewing both adolescent and parent six times over three months, are significant improvements over the majority of studies in the field. Aside from the study by Kuttner et al. (1990), who employed the 24-hour recall interview to examine the association between learned helplessness and depression and metabolic control, other relations with aspects of psychological and family relations have not yet been explored using this improved measure of adherence.

The majority of studies in pediatric diabetes have relied on convenience samples from tertiary care centers such as large teaching hospitals and diabetes centers in metropolitan cities, and summer camps. There are no studies of community samples of pediatric diabetic populations receiving treatment from secondary care service providers, such as diabetes centers and pediatricians not affiliated with a large

teaching hospital. Since the adolescent period is characterized by poor adherence and metabolic control, studying a community sample who are at this developmental stage has practical ramifications.

Finally, few studies have examined the influence of parental functioning and marital relations on adherence and metabolic control in diabetes during the adolescent period. Based on a family systems/ecological model for understanding adaptation and coping in childhood chronic illness developed by Kazak (1989), it can be viewed that within the family subsystem there is influence of the parents and the individual ill child and that the broader systems, such as the health care system also impacts on adjustment. In this systems/social ecological model, there is influence by family, parents, aspects of the individual ill child, and the health care system variables that affect the child and that the child in turn influences. There is an interdependency among family members and family and broader systems. From a family systems theory perspective, the adjustment and physical health of adolescents with IDDM will be associated with the quality of their family relations during this family life cycle stage. Because the diabetic treatment regimen is complicated and adherence is time consuming, a reciprocal relationship may exist with diabetes management affecting the family's life style and daily routines, which in turn may influence the management of diabetes. Thus, family relationship variables may be additional risk factor vis-à-vis the management of a diabetic regime and metabolic control.

Family functioning and the marital relationship are the two most important factors in pediatric chronic illness populations which have contributed to an increased risk of developing emotional and behavioral difficulties (Cummings & Davies, 1984; Hamlett et al., 1992; Hanson et al., 1992; Hauenstein, 1990; Wertlieb et al., 1986). Moreover, there has been strong research support for the idea that parents with a chronically ill child are at significant risk for experiencing marital distress (Sabbeth & Leventhal, 1984). Furthermore, parents of chronically ill children showed significant levels of depression in several studies, with mothers being at significant risk for depression (Breslau et al., 1982) and mothers of

chronically ill children received two to three times more mental health treatment (Cadman et al., 1991). Although mothers have typically been the focus of study, the contribution of the fathers experience has rarely been examined. Moreover, few studies have examined the relationship between child depression as a predictor variable for metabolic control or adherence. Since, there is evidence to show that there is a higher incidence of childhood depression in children with a chronic illness (Grey et al., 1995; Kovacs et al., 1996; Kovacs et al., 1997a). Thus, within the systems social/ecological model, identifying whether the existence of depression in this population of adolescents with diabetes is a possible correlate of living with a chronic illness would have important intervention ramifications.

Moreover, since there has been an inconsistent association between general family functioning measures, diabetes-specific measures of support and adherence to treatment and to metabolic control of the disease, research using the Diabetes Family Behavior Scale (DFBS), a scale which was developed to measure diabetes-specific support during adolescence, is an improved measure to the Diabetes Behavior Checklist. Examination of the relationship between diabetes-specific support and general family support and adherence and metabolic control using both the 24-hour recall interview and the DFBS would contribute measurably to clarifying their relationship.

Thus, an adolescent living in a family with either marital discord, parent-child conflict, parental depression, or lack of family support will not only present as a greater risk of developing psychosocial problems, but there may be added negative consequence on his or her health status. The presence of family dysfunction, parental depression, and/or marital distress could be significant barriers to efficiently supporting and following an adolescent's diabetic regime. The nature of the father's role in relation to the mother's emotional distress, marital distress, and family functioning seems crucial to understanding adjustment and outcome of medical treatment. Examining the family relationship variables that may exert an influence on the self-care behaviors and metabolic control of the adolescent with diabetes is warranted in

light of the short and long term complications of poor metabolic control and the dependent role of children on their parents and families. Considering that the families of children with diabetes face many stressors throughout the course of the illness, examining these additional family relationship stressors and risk factors in a population of adolescents living in rural and small urban centers who are not receiving treatment in a metropolitan treatment hospital is of practical interest.

The first purpose of this research is to identify whether there is an association between treatment adherence using the 24-hour recall interview as a multivariate conceptualization of adherence and metabolic control. An equally important purpose is to determine whether family relations variables are significantly related to adherence to treatment, metabolic control in a community sample of adolescents with IDDM living in rural and small urban centres and receiving secondary care services from diabetes clinics and pediatricians.

The secondary purposes of this research include determining whether health care behaviors and adolescent depression may also influence diabetes management. Within a systems social/ecological model of adaptation to chronic illness, health care behaviors can be seen as measures of adaptation in the system. Considering that the 24-hour recall interviews require extensive effort and time during the data collection and the analysis phases in addition to high costs required in accumulating these data, it is reasonable to question whether health care behaviors are effective in discriminating between how well adolescents are doing in terms of adherence and metabolic control. Specifically, examining the metabolic control of those adolescents using a more intensive treatment is of interest since the Diabetes Clinical Complications Trials (DCCT) (Research group, 1994) has clearly demonstrated that intensive treatment delays the onset and progression of diabetic complications and there is a trend for the medical practitioners to increase the daily insulin injections and to teach the patient how to adjust the insulin dosage depending upon blood glucose results. Within a social/ecological model of adaptation, the individual can be seen to influence the system.

Identifying whether adolescent depression is associated with poorer treatment adherence and metabolic control can yield important prevention ramifications.

Other aspects that may influence metabolic control and adherence are also of practical clinical interest for both parents and medical health practitioners. First, how do parents and medical practitioners decide on how much parents should be involved in the treatment regimen of their adolescents? How much parental involvement in the treatment regime is advisable and at what age and for which self-care behaviors adolescents should assume responsibility for are difficult decisions to manoeuver for families and medical health practitioners. The examination of trends across the adolescent developmental period would provide practical guidance.

Also, since insulin is important in the regulation of weight, examining whether adolescents are using insulin to influence their weight is a concern. Whether an adolescent skipped insulin injections is an important variable to examine considering the psychosocial and serious physical implications of not taking insulin. The literature has focused upon female adolescents with diabetes being more susceptible to using insulin in the regulation of weight (La Greca et al., 1987). The examination of insulin omissions and variables influencing missing insulin injections has been infrequently studied.

Finally, considering this is a community sample of adolescents who are receiving treatment from secondary care service providers, it is of interest to examine whether there are any differences vis-à-vis the type of treatment, diabetes clinic versus pediatrician only. An evaluation of the dynamics associated with adolescents who miss insulin injections and an examination of the possible roles parental involvement and adolescent independence play in adherence to treatment and metabolic control may provide practical guidance for decision-making. If links between family relations, health behaviors and adherence and metabolic control can be delineated, this study can contribute to the identification of risk factors and development of interventions to improve adherence and metabolic control.

Objectives of the Present Study

The primary objectives of the study were:

1. To examine which adherence domains best predict good metabolic control using the 24-hour recall interview, as a multivariate conceptualization of adherence as developed by Bennett Johnson et al. (1986), in a community sample of adolescents living in rural and small urban centres;

2. To evaluate what family relations variables are most closely associated first, with good metabolic control, and second, to good treatment adherence.

3. To determine whether treatment adherence and metabolic control decrease as the time since diagnosis increases.

The secondary exploratory objectives of the study were:

1. To discern whether adolescent depression, as a measure of child adaptation, was associated with first, treatment adherence and second, metabolic control while controlling for gender and chronological age.

2. To examine whether there was deterioration, maintenance or improved metabolic control over the span of the study, and whether there are gender and chronological age differences in the stability of metabolic control during the study;

3. To determine whether the nature of diabetes treatment, that is whether receiving the clinical services from a clinic specializing in pediatric diabetes or from a pediatrician, resulted in improved metabolic control and adherence to treatment;

4. To address whether there was a difference in treatment adherence and metabolic control between the group prescribed an insulin dosage, which is adjusted according to a sliding scale that varies with blood glucose test results, and a fixed insulin amount. Because use of an insulin sliding scale

involves more patient and parent decision-making, as a consequence, adhering to this regimen was likely to be more sensitive to family relations and produce improved metabolic control;

5. To examine whether the adolescents who missed insulin injections differed in terms of demographics, treatment adherence, metabolic control, and nature of diabetes treatment received (diabetes clinic versus pediatrician);

6. To investigate whether there are gender and chronological age patterns of parental involvement and adolescent independence in four aspects of adherence.

Hypotheses of the Present Study

In light of the literature reviewed it was hypothesized that:

1. Greater treatment adherence to a diabetes regimen will be associated with better metabolic control. However, both metabolic control and treatment adherence will be less the more time since diagnosis increases.

2. Controlling for time since diagnosis, adolescents who are less adherent to a diabetes treatment regime and metabolically non-controlled will display family functioning characterized by lower levels of general family support, higher levels of general family conflict, lower levels of diabetes-specific family support (guidance-control and warmth-caring), higher levels of parental depression and higher levels of marital distress compared to adolescents with good adherence to treatment and good metabolic control.

Exploratory Research Questions

The following exploratory research questions will be evaluated in this study:

1. Is adolescent self-report of depressive symptoms associated with worse metabolic control and less treatment adherence to a diabetes regime? Does self-report of depressive symptoms increase with

advancing chronological age and will there be a greater proportion of females who self-report depressive symptomatology?

2. Is adherence to treatment linked to deterioration, maintenance or improved metabolic control over the span of the study? Are there gender and chronological age differences in the stability of metabolic control during the study?

3. Will adolescents receiving clinical services from a clinic specializing in pediatric diabetes display improved metabolic control and treatment adherence compared to those adolescents receiving clinical services uniquely from a pediatrician?

4. Will treatment adherence and metabolic control be better for the group of adolescents who are using an insulin sliding scale to adjust insulin dosage, with either two or more injections daily, compared to those adolescents who are prescribed two insulin injections daily and do not use a sliding scale?

5. Will the adolescents who missed insulin injections differ in terms of gender, chronological age, metabolic control, treatment adherence, family relations, and nature of diabetes treatment received (diabetes clinic versus pediatrician)?

6. Are there gender and chronological age patterns of parental involvement and adolescent independence in any of the four aspects of adherence? The four aspects of parental involvement in the diabetes regime which were measured are meal planning, exercise, blood glucose testing, and the injection of insulin.

CHAPTER 11: METHODOLOGY OF THE STUDY

Participants and General Procedure

The present study included a volunteer group of 60 families composed of both parents and their adolescent, aged 11 to 18 years with IDDM, type 1 diabetes. The adolescents were recruited from government funded diabetes clinics in Sudbury, North Bay, and Timmins and from pediatricians in the cities of Orillia, Owen Sound and Peterborough, and from a parent support group in Midland. Thus, the subjects resided in rural and small urban centers and the communities surrounding these cities in Northern and Central Ontario. These communities were not affiliated with any large teaching and research hospital with a specialty in diabetes and they received secondary care services. The study was conducted verbally in both the English and French languages, whereas the measures used are English versions. The adolescents and their families were recruited if they met the inclusion and exclusion criteria described below.

Inclusion Criteria

(1) Age: The adolescent must have been between the ages of 11 and 18 years and must have agreed to participate.

(2) Family structure: To maintain sample homogeneity, two-parent families were included. The adolescent with diabetes must have been living in a home with two parent figures, and only one adolescent per family was included.

(3) Diagnosis: IDDM must have been diagnosed more than one year prior to recruitment into the study to eliminate the confounding variable of continued insulin production and lack of adjustment to the required insulin dosage.

(4) Blood glucose monitoring: Blood glucose monitoring using a glucometer must have been used.

Exclusion Criteria

(1) Adolescents with recognized physical, intellectual or multiple handicaps, or with other chronic illnesses.

Recruitment Procedure

The data collection for this study began in March, 1996 and ended in November, 1997. The first step was to recruit the diabetes clinics in Sudbury, Timmins and North Bay to participate. All adolescents and their parents meeting the inclusion and exclusion criterion were contacted by letter, inviting their participation in the study (Appendix A). The letter was addressed by the diabetes clinic staff or pediatrician's receptionist to maintain confidentiality. The diabetes educators were free to verbally accept the name of a potential participant. The families were then contacted directly by telephone by the researcher. A follow-up telephone call by one of the diabetes center staff was made to those families who had not responded to the letter. This follow-up telephone call provided the opportunity to answer any questions, provided additional information about the study, and was used to discuss the family's willingness to participate. It was carefully explained that participation was completely voluntary and that their refusal would in no way affect quality of treatment. It was also explained that all of the information gathered, with the exception of the HbA1c and triglyceride assay values, would be kept totally confidential and that the clinic personnel would not be made aware of collected information.

An initial 27 subjects were recruited from the diabetes centers in Sudbury, Timmins and North Bay. The diabetes center in Thunder Bay was willing to participate: however, due to the distance involved, this center was not recruited for the study. The diabetes center in Sault Ste. Marie refused to participate due to limited manpower. All other diabetes centers within North and Northeastern Ontario, such as Kapuskasing, Huntsville, Bracebridge, Parry Sound, and Elliot Lake were also contacted. However, these

centers did not offer services to the pediatric population, or had few patients who also did not meet the inclusion criterion. Because there was a paucity of information on the epidemiology of the pediatric population with diabetes within Ontario, especially in northern and more rural areas, the study was expanded to include pediatricians in rural and small urban centers within approximately 600 kilometers of Sudbury. All pediatricians treating pediatric patients with diabetes were individually contacted by letter and then by telephone to enlist their participation. Pediatricians from Orillia, Owen Sound and Peterborough were recruited. The same procedure as described above was followed with the exception that those families who did not respond to the letter sent by the pediatrician did not receive a follow-up telephone call as the pediatricians were under prohibitive time constraints.

A diabetes support group was contacted in the Midland and Penetanguishene areas to enlist all possible adolescents in the area. The contact person for this group then sent the recruitment letters to the parents of the adolescents in the group and to those known to the group. Of the 10 individuals involved in the support group, five were already involved in the study, one declined to participate, two were ineligible, and two participants of a possible five agreed to participate. These two individuals were receiving medical treatment from their family physician only. It is important to note that only two of the subjects were recruited from the support group in Midland and that the support group was not the main vehicle for participant recruitment. Once these two families agreed to participate, the family physician was contacted to enlist his or her participation in the study. The same procedure as described above was followed with the exception that those families who did not respond to the letter sent by the support group did not receive a follow-up telephone call.

This study was conducted while many changes were taking place within administrative and fiscal areas: the diabetes center in Sudbury changed from one hospital administration to another hospital and more recently all of the hospitals merged under one administration in Sudbury. The Sudbury diabetes center also moved its location and at a later date a change in program co-ordinator occurred due to an

amalgamation of programs. A pediatrician from Sudbury ran the diabetes clinic in Timmins as a travelling clinic via the diabetes clinic in Sudbury with a pediatrician, nurse, nutritionist and social worker conducting diabetes clinics in the Timmins hospital every three months. In 1996, a pediatrician who resided in Timmins assumed responsibility for the pediatric population with diabetes while the clinic team from Sudbury continued to provide quarterly clinics. This necessitated enlisting the cooperation of this pediatrician in the study. There were also budgetary constraints imposed and personnel changes throughout the clinics. Thus, this clinical study faced many difficulties in recruiting participants.

From the original 60 participants, five adolescents and their parents completed the initial set of questionnaires but afterwards declined to continue with the study. The reasons for dropping out of the study were the following. An 18 year old male and a 15 year old female from the Timmins diabetes clinic were unhappy with the nurse who took one month to order the required laboratory tests. A 12 year old female from the Owen Sound area hesitantly completed the questionnaires during the interview. Her parents had assumed she would participate without seeking her consent. Afterwards, this girl's mother informed me by telephone that her daughter did not want to participate because she was too shy to talk on the telephone. The parents of a 12 year old female child from the Midland area were extremely stressed with the possibility of a business and family bankruptcy. The father of a 16 year old female in North Bay refused to complete the questionnaires after both the daughter and wife had completed the questionnaires. In summary, there were four female and one male participants who dropped out of the study after completing the initial set of questionnaires. An examination of these families showed that all of the mothers and fathers of these adolescents were working with the exception of one father who was on an extended sick leaved for psychiatric reasons. Table 5 summarizes the recruitment, participation and drop out frequencies according to areas, pediatrician and diabetes clinics. The overall participation rate ranged from 30 to 84%, with an overall rate of 49.5%. Although the recruitment strategy was similar it could not be identical because the pediatricians did not want to follow-up on non-participants. Moreover, the pediatricians could

not describe the demograhic representation of their caseload consisted of, nor of the reason for exclusion. The pediatricians verbally stated that generally families were excluded because they were single parent families or were recently diagnosed. Exclusion statistics are only available from the combined diabetes clinics in Sudbury and Timmins. The Sudbury/Timmins combined group consisted of a total of 77 patients of which 58 met inclusion criterion. Nineteen were excluded for the following reasons: 78% (n = 15) were from single parent families and 21% (n = 4) had multiple diagnoses. The pediatricians and diabetes clinics were not set up to provide demographic data. A central registry of adults with diabetes was just getting off the ground in 1995, however there were no data on the pediatric population in Ontario let alone the demographics in small urban and rural areas. The population is dispersed in North and Central Ontario and not all of these patients have access to services from small urban diabetes centers or clinical services. Patients are referred to tertiary care centers when the pediatricians and diabetes centers encounter difficulty.

This sample does not include subjects from First Nations communities. No attempt was made to directly target this population on the reserves in the areas surrounding the catchment areas as recruitment was through the pediatricians and diabetes clinics. The diabetes clinics were contacted in April, 2000 to clarify whether they indeed did provide services to this population and what the proportion of their past and present caseload consisted of First Nations pediatric patients. Services were being offered to this pediatric population through the diabetes clinics, however there were no adolescents being treated throughout the period of the study. In April, 2000 the diabetes clinic in Sudbury was serving 235 pediatric patients (child and adolescents from Sudbury and Saulte Ste. Marie combined) and only two children were Aboriginal from this group, a proportion of .008% of their pediatric population. Moreover, these two individuals were children. Since 1998, the Sudbury clinic also services the Sault Ste. Marie pediatric population due to closure of this clinic. In April, 2000, the clinic in North Bay served a total of 39 pediatric patients and there were no First nations patients being treated through the clinic at the at the time of the study nor at this

date. In April, 2000, the Timmins diabetes clinic served 35 children and adolescents and two First Nations pediatric patients received services from them. One of these patients was a 10 year old and the other was 13 year old. The latter was only recently diagnosed with Type 1 diabetes. They represent .057% of the total pediatric population in the Timmins clinic. While there was an absence of First Nations adolescents with Type 1 diabetes being treated through the diabetes clinics at the time of the study, the proportion of pediatric patients in the diabetes clinics since the study has also remained small.

While the prevalence of Type 11 diabetes is 2 to 5 times greater in the First Nations people compared to the general Canadian population, there is no indication that there is a higher incidence of Type 1 diabetes mellitus among the First Nations pediatric population (Statistics Canada, 1991 Aboriginal Peoples Survey). Only one percent of the 15 to 19 year olds in the Aboriginal Peoples Survey (APS) had diabetes and this included Type 1 and 11 diabetes. A gradual increase in diabetes with advancing age was found in these populations with the proportion of individuals with diabetes (both Type 1 and 11 combined) increasing to 2% in the 20 to 24 age group, to 3% in the 25 to 29 age group, 5% in the 30 to 39 age group, 10% in the 40 to 49 age group, 18% in the 50 to 64 age group, and 23% in the over 65 age group. The vast majority of Aboriginals are developing Type 11 diabetes. The non-inclusion of adolescents Aboriginals with Type 1 diabetes in the study does not indicate a non random sample, but rather reflects the infrequency of this type of diabetes in this population.

TABLE 5.

Recruitment Data

Area	Number of recruitment letters mailed	Number of pediatricians	Number of participants	Participation rate %	Number of drop outs
Sudbury Diabetes Clinic	38	3	15	40	0
Timmins Diabetes Clinic	20	1	6	30	2
North Bay Diabetes Clinic	12	2	7	58	0
Peterborough Pediatric Clinic	11	2	4	36	0
Owen Sound Area	19	4	16	84	2
Orillia Area	15	3	5	33	1
Midland Support Group	5	2*	2	40	0

Note. * Physicians

Subjects

Participants in the study were 55 adolescents with insulin-dependent diabetes and their parents: 26 females (47.3%) and 29 males (52.7%) ranging in age from 11.17 to 18.17 years (M = 15.13; SD = 2.07). The length of time since the onset of diabetes ranged from 1 to 16 years (M = 6.66; SD =3.53). The age at diagnosis ranged from 1.08 to 16.83 years (M = 8.67; SD = 3.56). Since the study objective was to include only couples, all of the parents were currently either married (89.1%), living common-law (3.6%) or re-married (7.3%). The range of the number of years married was .42 to 30 years (M = 18.01; SD = 6.26), and 92.7% of the families reported having three or fewer children. The majority of the families consisted of two children (49.1%), 30.9% consisted of three children, 7.3% consisted of four children, and

12.7% consisted of only one child. The average yearly family income was $60,137.04 (SD = 34, 395.74), with individual families ranging from less than $13,000 to $190,000. According to Statistics Canada 1996 census data, the average total family income of married and common-law families in each of the cities and towns involved in this study were as follows: Sudbury, $62, 092, North Bay, $57,963, Timmins, $61, 064, Peterborough, $56,222, Orillia, $53, 332, and Owen Sound, $54,285. The average total family income of married and common-law families from all of these towns and cities involved in this study was calculated to be $57,493. This averaged total is lower than both the Ontario average of $64,434 and slightly lower than the average of this study. The majority of fathers were employed (92.6%; n = 50), with the remaining five fathers receiving employment insurance, compensation benefits, disability pension, and welfare benefits. According to Statistics Canada, 1996 census data, 72.9% of women and 88.9% of men in the 25 to 44 age range in Ontario were married and employed. In this study, the majority of mothers were employed (72.7%, n = 40), a quarter (25.5%, n = 14) were stay-at-home mothers, and one mother received welfare benefits. With the exception of slightly higher total family income, the demographics of this sample are fairly comparable to Statistics Canada (1996) census data for the communities involved. The descriptive statistics for the familial demographic variables are shown in Appendix B and the adolescent demographic variables are shown in Appendix C.

Data Collection

Upon agreement to participate, both parental figures and the adolescent with diabetes were met either at the Diabetes Clinics in Timmins or North Bay, or in their home. During this meeting, the parent and adolescent were asked to sign an informed consent (Appendix D). The parents completed a demographic questionnaire together (Appendix E) and the following measures were completed independently: a marital distress measure (Dyadic Adjustment Scale; DAS), a depression measure (Beck Depression Inventory; BDI), and a family functioning measure (Family Environment Scale; FES)

(Appendix I). The adolescent completed a depression measure (Children's Depression Inventory; CDI), a family functioning measure (Family Environment Scale; FES), and a diabetes-specific measure of familial support (Diabetes Family Behavior Scale; DFBS). The adult required at least one hour and the adolescents required at least 30 minutes to complete the questionnaires. Two of the adults and three of the adolescents preferred that the questionnaires be administered orally by the researcher. The researcher was present and provided assistance when required during the completion of measures. The verbal presentation of the study and any discussions with the families occurred in both the English and French languages, whereas all measures were English versions of the measures.

Blood was drawn at the beginning and end of the study to analyze glucose metabolism by obtaining fasting HbA1c assay levels and lipid metabolism by obtaining fasting triglyceride assay levels. Because the subjects were recruited from various geographical areas it was impossible to select a single laboratory to analyze the blood assays. To maximize comparability of results the pediatricians placed orders to insure that the HbA1c and triglyceride assays were analyzed at the same laboratory at time one and time two. The subjects' HbA1c and triglyceride blood assays were analyzed by the laboratories listed in Table 6.

Although HbA1c assay reference ranges were fairly similar, the triglyceride assay reference ranges varied markedly for each laboratory. Moreover, there were differing opinions about the triglyceride reference ranges, with some laboratories utilizing sex and age reference norms and others using one cut-off range. Numerous discussions with the laboratory authorities were not successful in clarifying the issue. The Laboratory Proficiency Testing Program (LPTP), a subsidiary of the Ontario Medical Association, is responsible for setting appropriate laboratory parameters. The LPTP personnel firmly stated that triglyceride assays should not be compared to age or sex norm references and provided a reference from the National Cholesterol Education Program Working Group on Lipoprotein Measurement to this effect (Stein & Myers, 1995).

To determine whether triglyceride should be retained as a metabolic control variable, various

analyses were conducted and issues considered. First, weak correlations of (r =.372, p =.01, 2-tailed) between HbA1c and triglyceride at time one and (r = .332, p = .05, 2-tailed) at time two indicated some reliability between the measures. Since there was no standard way of interpreting the results various comparisons were conducted. When the Canadian Diabetes Association cut-off of >2.5 mmol/L was used, only one subject fell outside this limit. Obviously this recommended range was extremely high as it takes into consideration the upper most range of all possible methods of measurement. A categorical analysis of the data showed that 85.7% of the subjects at time one and 82% at time two had triglyceride values within the reference range identified by the laboratory. Categorical analyses was obviously not a sensitive enough measure. A combined measure of diabetes control such as developed by Sando, Hagen and Beck-Nielson (1994) was also considered. They calculated a metabolic score by weighting and combing the results of HbA1c, diastolic blood pressure counts, cholesterol, triglyceride, and body weight. Unfortunately there was a lack of reasoning behind the weighted values of the metabolic score which failed to provide sufficient guidelines for its use in this study. Moreover, diastolic blood pressure counts, cholesterol and body weight were not collected in this study. Because of the conflicting opinions about whether triglyceride should be compared to gender and age norms, this measure of metabolic control was eliminated from the analyses due to unreliability of the measure which resulted from laboratory inconsistencies in result interpretation.

The assessment of adherence following the 24-hour recall interview, as developed by Bennett Johnson et al. (1986), occurred over a 12-week period. It was explained to the parents and adolescent that they would be interviewed by telephone separately about the self-care behaviors of the adolescent with diabetes. Although the families knew that they would be called, they did not know in advance on which days the calls would occur. The 24-hour recall interviews assessing self-care behaviors occurred six times over the 12 weeks, with four calls occurring during weekdays and two on the weekend. The parent and child interviews together lasted between 20 and 30 minutes. The option was left to the parents to decide who would be the most knowledgeable or willing person to report on their child's self-care behaviors during

the previous day. Only one parent was required to answer the 24-hour recall interviews. Although this study was not designed to be a qualitative study, discussions, comments, reactions, concerns were documented during each of the interview sessions and 24-hour recall interviews.

Cooperation with the study was encouraged by offering each participant a gift as appreciation for their participation in the study. These gifts of appreciation were provided by local businesses, companies producing diabetic products and the Northern Diabetes Health Network. All interviews were conducted to accommodate the adolescents' eating schedule and glucose testing requirements. Snacks were provided during the interviews at the clinic.

Measures

Copies of all the measures may be found in Appendix I. A brief description of the two measures of health status, which are Hemoglobin A1c (HbA1c) laboratory assay and a selected group of health behaviors, and treatment adherence and the family relations variables, is presented in the following section.

Dependent Variables (Criterion)

Health Status

Assessment of the health status of the adolescent with diabetes involved measuring one indice of metabolic control and health behaviors. As an index of health status, metabolic control was a fasting Hemoglobin A1c or glycated hemoglobin test which measures glucose metabolism. A second health outcome measure was health behaviors. The health behaviors were included in the measures following Bennett Johnson's (1994) recommendation that health behaviors be evaluated as the central outcome in health care and not just health status as measured by HbA1c and other medical tests.

Glycemic control. Hemoglobin A1c or glycosylated hemoglobin test (HbA1c) measures the binding of blood glucose to hemoglobin and is a firmly established method of providing a reliable correlation of glycemic control over a period of two to four months. The HbA1c assay has become the

standard by which clinicians assess long-term glycemic control and is the most commonly used measure of glycemic control. The meaning of an hemoglobin A1c assay result depends on the values used by the laboratory doing the test. Typically, the normal range for non-diabetics is between 4 to 8 percent and higher values are indicative of compromised metabolic control. Ideally, the HbA1c values for children with diabetes should be as close as possible to those for healthy children.

HbA1c assay values were obtained from fasting samples of hemoglobin. Because of the different laboratories involved in the analysis of HbA1c values, both time one and time two assays for each participant were analyzed by the same laboratory site. Each laboratory used its own technique to measure glycalated hemoglobin (HbA1c). Glycolated or glycosylated refers to the mean blood glucose concentrations as obtained by the separation of hemoglobin from HbA1c by various techniques and HPLC refers to high performance liquid chromatography. Glycohemoglobin (Ghb), a measure of the amount of hemoglobin that undergoes a nonenzymatic condensation with any sugar, rises in direct proportion to the serum glucose concentration and time of exposure. Different glycohemoglobin methods are available and according to Ward (1997, July) they can be divided into three major categories: (1) those based on charge differences between glycohemoglobin, (cation-exchange chromatography, electrophoresis and isoelectric focusing); (2) those based on structural chracteristics of glycogroups on hemoglobin (affinity chromatography); and, (3) those based on an antibody of the epitope of the terminal end of the B-chain of the HbA (immunoassay). Each method is subject to its own unique set of assay limitations and interferences. Although each of the methodologies correlate well (Daneman & Ellis 1996), the absolute value obtained from the different methods will vary. "Studies comparing Ghb measurement by different techniques underline that, although most methods can be performed with acceptable precision and that there is good correlation between them, it remains impossible to compare levels measured by different assays and also between the same type of assay performed in different laboratories. Each method will have a different glycation unless they have been calibrated to match HPLC methods" (Daneman & Ellis, 1996, p. 2).

The MDS laboratory was the only one to use the HPLC method. Since the majority of laboratories did not calibrate to match high performance liquid chromatography (HPLC) methods, a method deemed to be the "gold standard" for reference methodology, the HbA1c assay values were commuted into a percentage (Catellier et al., 1992; Daneman & Ellis, 1996). A commuted HbA1c value involves taking the percentage of the obtained HbA1c assay value divided by the upper reference range set by the laboratory. The use of proportions analysis to interpret HbA1c is supported by the Canadian Diabetes Advisory Board. (Catellier et al., 1992) and is standard clinical practice. Table 6 summarizes the various laboratories who conducted the assays and the type of assay completed. The mean upper reference range for HbA1c from all of the laboratories which was computed to be .065 mmol/L is similar to the upper range of of .061 of the high performance liquid chromatography (HPLC) method used by MDS. The confidence limits of the estimates of HbA1c are as follows. At the 90% level, the confidence interval is between 134.24 and 147.58 at time one and between 134.00 and 146.94 at time two.

Lipid Metabolism. Triglyceride assays, which measure lipid metabolism, were analyzed from 12 hour fasting blood samples at the onset of the stady and again after 132 weeks. Higher triglyceride values are indicative of poor metabolic control. The acceptable CDA recommended triglcyeride level is less than 2.5 mmol/L with optimal levels being less than 1.7 mmol/L. Table 6 presents the reference ranges for the triglyceride as defined by each of the laboratories used in the study. The reference ranges vary among the laboratories and there are both age and norm references. As already discussed, because of the difficulty with appropriate interpretation of the triglyceride assays, they were not included in further analyses.

Health Behaviors. Following Bennett Johnson's (1992) recommendations, the following health behaviors were obtained from both the parents and the adolescent with diabetes during the six 24-hour recall interviews: type of diabetes service provided (diabetes clinic versus pediatrician), frequency of times injection regime was adjusted, the number of daily insulin injections, use of an insulin sliding scale versus a fixed insulin injection, frequency of diabetes related hospital admissions, emergency room visits,

pediatrician visits, diabetes clinic visits and emergency room visits, duration of hospital stay, administration of extra insulin, missing insulin injections, prescription of a meal plan, and degree of adolescent independence and parental involvement in following the diabetes treatment regime.

This study was to be an investigation of adolescents receiving services from a diabetes clinic. However, the change in recruitment strategies resulted in participants being followed either by a diabetes clinic or receiving services from their pediatrician only. This variable was included in the study for further analysis to determine whether there was a difference in adherence or metabolic control between the participants receiving care from a diabetes clinic versus those treated by a pediatrician. Since only one individual was being treated by a family physician, the term pediatrician will be used throughout.

During each interview the adolescent's injection schedules, which included frequency of type, dose and amount of insulin injected were recorded: From this data, the frequency of changes to the insulin injection prescribed regime was determined. The number of changes to the injection regime is considered a change in health status. More frequent changes in the regime would be more expected with a population of adolescents who were experiencing continued growth and hormonal changes. Frequency of changes to the insulin regime during adolescence has not been documented in the extant literature and this studies findings cannot be compared to findings from other studies. However, it seems reasonable to conjecture that there will be more frequent changes to the insulin regime and that more frequent changes will reflect instability of the disease. It would be expected that changes to the injection regime will occur more frequently than during other developmental stages because frequent and close monitoring of insulin needs during this developmental period is required due to physical growth and hormonal changes.

TABLE 6.

HbA1c and Triglyceride Assays and Reference Ranges by Laboratory

Laboratory	HbA1c (glycosylated hemoglobin) reference ranges (mmol/L)	Triglyceride reference ranges (mmol/L)
County of Bruce General Hospital	.044-.064	.40 - 1.54 (female) .27 - 1.55 (male)
Dynacare Laboratories	.041-.065	.60 - 2.30
Gamma Dynacare Laboratory	.041-.065	<2.30
Hanover Hospital	.030-.060	.27 - 1.55
Hosp# D9661	.044-.064	.40 - 1.54
Hospitals in Common Laboratory, Inc.	.048-.078	<2.83 .45 - 2.22
Kincardine & District General Hospital	.030-.060	.45 - 2.83 (male) .27 - 1.55 (female)
Laurentian Hospital	.030-.060	.40 - 1.3
MDS Laboratories	.040-.085 .043-.061*	.40 - 1.65 (male) .45 - 1.45 (female)
Medical Sciences Laboratories	.040-.060	.51 - 2.29
North Bay General Hospital	.043-.061	<2.26
North Simcoe Hospital Alliance	.040-.060	.40 - 1.54
Par-Med Ltd.	.041-.065	.40 - 1.65
Penetang Hospital Clinic	.040-.060	.40 - 1.30
Stratford General Hospital	.030-.060	<2.0
Sudbury Memorial Hospital	.043-.058	.23 - 1.69 (male and female)
Timmins and District Hospital	.048-.078	not applicable

Note. * = high performance liquid chromatography (HPLC)

Additionally, since the results of the Diabetes Clinical Complications Trials (DCCT) (1994) revealed that improving metabolic control can prevent and reduce the severity of complications stemming from diabetes, there has been a shift to increasing the frequency of insulin injections prescribed and teaching patients to adjust their insulin injections in response to their blood glucose results. Consequently, the daily frequency of insulin injections, use of an insulin sliding scale or fixed insulin prescription were recorded. Whether an adolescent missed insulin or added an insulin injection was examined. Finally, although school absenteeism data was collected it was not used in analyses as the study spanned a time frame of 22 months, including the summer holidays. It was not possible to determine a school absenteeism rate. The participants were requested to follow their typical self-care behavior patterns and were not asked to maintain a journal. In summary, the following health behavior variables were determined:

1. Type of diabetes service received (diabetes clinic versus pediatrician)
2. Frequency of missing insulin injections
3. Frequency of adding insulin injections
4. Frequency of emergency room visits
5. Frequency of hospital admissions and length of hospital admissions
6. Frequency of visits to the doctor (physician or pediatrician)
7. Frequency of diabetes clinic visits
8. Prescription of a meal plan
9. Frequency of changes to the injection regime
10. Adolescent independence and parental involvement for the four aspects of the diabetes treatment regime: blood glucose testing, injections, meal planning, and exercising.

Regimen Adherence and 24-Hour Recall Interview. The 24-hour recall interview was the assessment tool used to measure adherence to treatment (Freund et al., 1991; Bennett Johnson et al., 1986; Reynolds et al., 1990). As discussed earlier, an exploratory factor analysis using principal components analysis

identified five components of adherence in childhood diabetes based on 13 adherence measures (Bennett Johnson et al., 1986; Bennett Johnson et al., 1992). The results supported a multivariate conceptualization of adherence with the factors being exercise, injection, diet type (percentage of total calories from carbohydrates and from fat), eating/testing frequency, and diet amount (concentrated sweets and total calories consumed). Thus, there are five main components of adherence to treatment in IDDM. As discussed earlier, the 24-hour recall interview, as an adherence to treatment assessment strategy in childhood diabetes, demonstrated sound reliability and validity. This measure also does not induce change in self-care behaviors, an important concern when considering an evaluation tool.

Thus, the 24-hour recall interview which will now be described (Bennett Johnson et al., 1986) was conducted separately with both parent and child on six occasions, offering a reliable method of assessing daily diabetes management over short and long terms. The following thirteen adherence measures were quantified using the 24-hour recall interview as described by Bennett Johnson et al. (1986) and S. Bennett Johnson (personal communication, May 1, 1998): Injection regularity, injection interval, injection-meal timing, regularity of injection-meal timing, exercise frequency, exercise duration, exercise type, eating frequency, calories consumed, percentage of calories from carbohydrates, percentage of calories from fat, concentrated sweets, and glucose-testing frequency. Thus, four injection, three exercise, one glucose-testing and five dietary measures were calculated. There were quantification difficulties with the 24-hour recall interview while attempting to follow the directions provided by Bennett Johnson et al. (1986). Further clarification was contained in an unpublished article forwarded by S. Bennett Johnson (personal communication, May 1, 1998).

The Nutritionist IV program, version 3.5.2, developed by N-squared computing, was the computer program used to analyze the caloric, fat, carbohydrate, and concentrated sweets components of the 24-hour recall interview. The nutrition information of food items not contained in the computer program were obtained by searching for these items in a grocery or specialty store where the item was purchased. The

Canadian Diabetes Association guide to Food Choices in the Marketplace (1987) was another source of nutrition information in foods. The food values of interest were then added to the data computer base of the Nutritionist IV program.

The 24-hour recall interviews yielded scores for five adherence constructs: exercise, injection, diet type, testing/eating frequency, and diet amount. Both higher and lower scores were indicative of relative nonadherence and scores closer to zero were indicative of relative adherence to permit across-measure consistency of the 13 adherence variables. A description of the 13 adherence variables is discussed next.

1. **Injection regularity** was defined as the degree to which a patient took injections at the same time of day. The standard deviations of injection times across the interviews were calculated separately for each injection time and then averaged. The average was calculated by summing the SDs and dividing by n. We used this method of calculating the mean SD (which followed exactly the procedure employed by Bennett Johnson et al., 1986) in order to facilitate the comparison of our results to theirs. However, it should be noted that because a SD is, by definition, simply the square root of a variance, a technically more correct way of calculating the mean SD would have been to square each SD (thus converting each SD to a variance), sum the variances, divide this sum by the number of variances, and then take the square root of this mean variance to find the mean SD. (For a similar argument, though one made in a different context, see Harris, 1975, pp. 94-95).

Using Bennett Johnson's procedure for calculating mean SDs, a standard deviation closer to zero indicated greater injection regularity and greater adherence. S. Bennett Johnson's (personal communication, May 1, 1998) procedures indicated that insulin injection was arbitrarily defined as missing if it had not occurred by 0400 hours. In this study the injection times were recorded up until the next morning when the adolescent injected. Thus, the results of this study were based on a 24 hour sample and provided a sample of actual behavior rather than defining an arbitrary time cut-off point.

2. **Injection interval** was defined as the calculation of the absolute difference between a patient's

average interval between injections and an ideal injection interval. For example, the ideal interval was calculated as 10 hours between the morning and evening injections on the same day for those who take two injections and 14 hours between the evening injection and the following morning injection. Although this is the protocol described by Bennett Johnson et al. (1986), in actual practice these authors had used a cut-off point of 0400 hours as discussed earlier. The procedure as described in Bennett Johnson et al. (1986) was not representative of actual practice because actual injection values for individuals who deviated from their ideal cut-off were excluded from analysis (S. Bennett Johnson, personal communication, April 28, 1998). Therefore, in this study, the ideal interval was calculated as the absolute difference between the adolescent's average interval between injections and an ideal injection interval on a true 24 hour schedule.

Prescribed injection intervals varied with each subject. For example, some adolescents injected twice a day: before breakfast or supper. Others injected three times a day: at breakfast, supper and bedtime. Others injected at breakfast, supper, and only at lunch time if blood glucose levels indicated insulin was required. Finally, some adolescents injected four times daily: morning, lunch, supper, and at bedtime. Additionally, some adolescents used a sliding scale to determine how much insulin to inject while others injected a fixed amount. Scores closer to zero indicated greater conformity to the prescribed injection interval and were indicative of greater adherence.

3. **Injection-meal timing** is defined as the timing of injections in relation to meals. It was calculated by subtracting meal times from injection times and then calculating the average of all these difference scores. Sixty minutes was added to the average and the sum divided by 60 so that the patient who took their injections 60 minutes to 1 minute before meals received scores from 0 to .99. A score from 0 to .5 indicated good adherence because those with diabetes were encouraged to take their injections 20 to 30 minutes before meals. A score of 1.0 or greater indicated poorer adherence and reflected a patient who took their injections during or after meals.

4. **Regularity of injection-meal timing** was defined as the intervals between injections and eating.

This was calculated by taking the mean of the standard deviations of the injection-meal intervals across the six interviews. Again, this computational procedure followed exactly the one used by Bennett Johnson et al. (1986) and allowed us to compare our results with theirs. A standard deviation closer to zero indicated high regularity in injection-meal timing and greater adherence.

5. **Exercise frequency** was measured by calculating the percentage of times the patient exercised on six possible occasions per day over the six interviews. This gave an estimate of exercise frequency. A score of 0 indicated the patient exercised on all possible exercise occasions and a score of 100 indicated no exercise on any occasion. A score less than 0 indicated more than ideal exercising.

6. **Exercise duration** was defined as the amount of time spent exercising across all possible exercise occasions and a constant (1) was added to each value to avoid subsequent division by 0. The reciprocal of this score was used and a low score indicated lengthy exercise and a high score indicated little or no exercise.

7. Each **exercise type** was given an energy expenditure rating (Katch & McArdle, 1983), with higher ratings indicating more strenuous exercise. Average expenditure ratings across all possible exercise periods were calculated and a constant of 1 added to avoid subsequent division by 0. The reciprocal of this score served as the measure of exercise type and a low score indicated more strenuous exercise, while a high score indicated less strenuous exercise.

8. **Eating frequency** was defined by Bennett Johnson et al. (1986) as the calculated percentage of snacks or meals not eaten multiplied by 100 and based on an ideal of six meals or snacks per day. Rather than recommending an ideal of six meals or snacks daily, the diabetes clinics emphasized consistency in the number of meals eaten each day and other pediatricians prescribed varied snacks and meals as well. Because some patients were prescribed either four, five or six snacks or meals daily, a change was made to the Bennett Johnson et al. (1986) protocol: Eating frequency was defined as the calculated percentage of prescribed snacks or meals not eaten multiplied by 100 rather than an ideal of six meals or snacks per day.

A high score indicated infrequent meals, a low score indicated frequent meals, and a score of 0 indicated that the meals or snacks consumed per day corresponded with the prescribed frequency.

9. **The total calories consumed** was calculated. An ideal number of total daily calories was provided by the treating pediatrician. If calories were not prescribed then a total score reflecting the daily calories was estimated based on age, sex, and ideal weight for height. Standard textbooks on childhood obesity provided ideal weight for height tables (Collipp, 1980) and ideal caloric consumption per kilogram tables (LeBow, 1995). The ideal total number of daily calories was then subtracted from the reported average daily calorie consumption. A positive score for calories consumed indicated that the adolescent ate more than his or her prescribed total number of daily calories, a score of zero indicated that the actual calorie consumption equalled his or her prescribed calorie consumption, and a negative score indicated that the patient ate less than was prescribed.

10. **Percentage of calories from carbohydrates**. Based on the exchange-unit information collected, the percentage of calories from carbohydrates was calculated. Ideal carbohydrate consumption was based on the upper limit (60%) as recommended by the American Diabetes Association (Nuttal & Brunzall, 1979) and the Canadian Diabetes Association (Position Statement, 1989; 1994). Actual carbohydrate consumption was subtracted from the ideal meal plan so that a score above zero indicated insufficient carbohydrate ingestion, a score of zero indicated perfect adherence to the prescribed percentage of carbohydrates and a score below zero indicated that more than the percentage of the calories consumed were from carbohydrates.

11. **Percentage of calories from fat** was also based on the exchange-unit collected. The ideal fat consumption recommended by the American Diabetes Association of 25% was used by Bennett Johnson et al. (1986). In this study the ideal fat consumption was based on the lower limit of 30% as recommended by the Canadian Diabetes Association (Position Statement, 1989; 1994), which is being followed by the diabetes clinics. Ideal fat consumption (30%) was subtracted from actual fat consumption. A score above

zero indicated that the patient consumed more than 30% of his or her calories in fats, a score below zero indicated that fat consumption was less than 30% of the total calories, and a score of zero indicated perfect compliance (fat consumption at 30% of total calories).

12. **Concentrated sweets.** To measure concentrated sweets a separate exchange-unit category was developed with forty calories of any concentrated sweet being equivalent to one concentrated-sweet exchange unit. The average number of these exchange units consumed per day was calculated. Standards of care at the diabetes clinics recommended that not more than 10-15% of total calories be concentrated sweets. A score near zero indicated that the adolescent was highly adherent, consuming no more than the recommended limits of concentrated sweets, whereas, in the Bennett Johnson et al. (1986) protocol the children were encouraged to eat very little or no concentrated sweets.

13. The **frequency of glucose-testing** was also calculated. The frequency of glucose tests across the interviews was divided by the prescribed number of injections per day, and multiplied by 100 rather than the ideal. Bennett Johnson et al. (1986) used an ideal of four times per day, whereas, in this study the prescribed daily glucose tests varied. For example, the Sudbury, North Bay, and Timmins diabetes clinics recommend blood glucose testing be done three times per day. Blood glucose levels must be tested prior to determining the amount of insulin to inject for those individuals using a sliding scale. The total blood glucose testing frequency was subtracted from 100 so that a high score indicated few glucose tests, a low score indicated frequent tests. A score of zero meant that the individual tested as prescribed and a score of 100 indicated no reported tests over the interviews.

Combining data from parent and child. The Bennett Johnson et al. (1986) and Freund et al. (1991) protocol were followed with data from the parent and child interviews combined with discrepancies between the parent and child handled as follows.

1. When data were available from both the parent and adolescent for each exercise period, the reports for the exercise type, exercise duration and exercise frequency were averaged. If data were missing

from one respondent, then the data from the other was accepted. If there was disagreement that an exercise occurred, then it was assumed that the exercise had occurred.

2. If data from one respondent was missing then data from the other respondent was accepted when calculating the timing of meals and injections. If data were available from both the parent and the adolescent then the reports were averaged.

3. Because it has been found that patients underestimated food ingestion (Bennett Johnson et al., 1986), the larger of the two values between the parent and child was used to calculate the diet variables.

4. A statement by either the adolescent or the parent was accepted that blood glucose-testing occurred. Freund et al. (1991) made this decision on the assumption that youth may forget a glucose test completed by a parent and that the parent was not always aware of the child's activities.

The adherence data were grouped according to the five adherence factors which were derived from factor analysis by Bennett Johnson et al. (1986). The five factors are: injection, diet type, and diet amount, eating/testing frequency, and exercise. Figure 1 summarizes the thirteen 24-hour recall interview adherence measures and their interpretation. The five factors were not standardized to the Bennett Johnson et al. (1986) sample because the prescribed treatment plan was the reference comparison rather than the ideal. Instead, the treatment of the data followed the Kuttner et al., (1990) methodology which consisted of the variables in each factor being converted to z scores and then summed, which resulted in a single score for each factor. Converting a raw score distribution to z scores has no effect on its shape and is particularly useful for indicating location or relative standing of a score in a distribution of scores because it tells us how far above or below the mean (the mean of any z distribution is zero) the score value is (Evans, 1998).

Independent Variables (Predictor variables)

1. **Demographic Variables.** As discussed earlier, socioeconomic status was calculated from the parent's occupation, using the scale developed by Blishen, Carroll, and Moore (1987). The scale is a socioeconomic index which was developed based on a combination of level of income and education for the total Canadian labour force that was derived from the 1981 Census data. The index, which is comprised of 514 occupations, has a mean of 42.74 (SD 13.28) and the scores range from 17.81 and 101.74. Three adolescent age indices were computed: time since diagnosis, age at diagnosis, and chronological age. Additionally, the following data were collected: gender, parental age, education, income and employment status, years married, and number of siblings.

2. **Parental Depression.** The revised Beck Depression Inventory (BDI, Beck, 1967; Beck & Steer, 1987; Beck, Steer, & Garbi 1988) was completed by each parent. This measure consists of 21 items designed to assess the severity of depression in adults and adolescents. The BDI surveys the cognitive, affective, somatic and vegetative symptoms associated with depression and is based upon a cognitive theory of depression. The parents were asked to select from each item how they had been feeling during the past two weeks. Each item is rated on a 4-point scale ranging from 0 to 3 and the maximum total is 63. The scale requires 5 to 10 minutes to administer. Scores under 9 are asymptomatic and a cut-off of 10 was used, with higher scores indicating more severe depression symptomatology (Beck et al., 1988).

The original version of the BDI was first introduced in 1971 by Beck, Ward, Mendelson, Mock, and Erbaugh (1961) and the revised version (Beck, Rush, Shaw, & Emery, 1979) has been distributed since 1972. It is one of the most widely used measures of depression. Research has shown the revised BDI to have high internal consistency in both clinical and nonclinical populations. There are numerous studies reporting excellent reliability and validity (Beck & Beamerderfer, 1974; Beck et al.,1988). Additionally the scale has been standardized on both clinical and nonpatient samples (Beck et al., 1988).

FIGURE 1.

Summary of the 13 Adherence Variables: 24-Hour Recall Inteview

Injection Factor

Injection regularity: Measure of whether injection time was similar each day

0 = highly regular injection times

< 0 = irregular injection times

>0 = irregular injection times

Injection Interval: Average interval between injections compared to ideal interval

0 = conformity to injection intervals

< 0 = less than ideal injection intervals

> 0 = less than ideal injection intervals

Injection Meal-Timing: Timing of injections in relations to meals

0 - .5 = indicated good adherence as injections were taken 20 to 30 minutes before meals

5 - .99 = took insulin more than 30 minutes before meals

> 1.0 injections at meal or after

Regularity Injection Meal-Timing: SD of injection meal-timing intervals

0 = regular injection meal-timing

< 0 = irregular injection meal-timing

> 0 = irregular injection meal-timing

Diet Type Factor

Calories fat: Percentage of calories from fat (ideal - ingested)

0 = calories from fat consumed equals 30% calories prescribed

<0 = ate less than prescribed 30%

>0 = ate more than prescribed 30%

Calories Carbohydrate: Percentage of calories from carbohydrates (ingested - ideal)

0 = calories from carbohydrates consumed equals 60% as prescribed

<0 = ate more than prescribed 60%

>0 = ate less than prescribed 60%

Diet Amount Factor

Concentrated sweets: Concentrated sweets consumption

0 = ate 10 - 15% of total calories consumed

<0 = ate less than 10 - 15% of total calories consumed

>0 = ate more than 10 - 15% of total calories consumed

Calories consumed: Total calories consumed (ideal-ingested)

0 = ate prescribed calories

<0 = ate less than prescribed calories

>0 = ate more than prescribed calories

FIGURE 1.

Summary of the 13 Adherence Variables: 24-Hour Recall Interview (Continued)

Exercise Factor

Exercise Frequency: Frequency of exercise during 6 possible occasions daily

0 = exercised on all possible occasions

<0 = exercised more frequently

>0 = exercised less than possible

Exercise Duration: Length of time exercising across all possible 6 occasions daily

0 = exercised

<0 = lengthy exercise

>0 = little or no exercise

Exercise Type: Energy rating of exercise

0 = average energy level

<0 = more strenuous activity level

>0 = less strenuous activity level

Eating/Testing Frequency Factor

Blood glucose test frequency: Number of times blood glucose levels were tested

0 = tested blood as prescribed

<0 = more tests than prescribed

>0 = less than ideal blood glucose testing (a score of 100 indicated no testing at all)

Eating frequency: Number of snacks and meals daily

0 = ate prescribed number of snacks and meals

<0 = ate more frequent meals

>0 = ate less than prescribed snacks and meals

The authors of the revised BDI stated that any individual scoring above a score of 10.9 provided clinical indication of possible depression in adults. A couple depression score was created by selecting the data from the partner with the higher level of depression (higher scores are indicative of greater depression). It should be noted that depression in the context of this study represents self-reported symptoms of depression as measured by a questionnaire which is not synonymous with clinical depression. Clinical depression could only be diagnosed through a clinical interview which would follow, for example, the Diagnostic and Statistical Manual of mental disorders (1994) classification system. A Cronbach's alpha of .60 was computed for this sample, a score which indicates minimally adequate internal consistency

reliability.

3. Child Depression. The Children's Depression Inventory (CDI, Kovacs, 1992) was administered to the adolescent at baseline as a measure of depression. The CDI was initially developed due to a lack of instruments to measure child depression symptomatology and it is intended to be used for the purposes of screening, clinical evaluation, monitoring of treatment progress, and for research purposes. The author noted that clinical experience suggests that false negatives are more likely than false positives with the CDI. The CDI is a 27 item self-rated symptom-based scale designed for children and adolescents which takes about 15 minutes or less to administer. Each item consists of three choices from 0 to 2, ranging from absence of symptoms to mild and definite symptomatology. This measure yields a total score ranging from 0 to 54 and includes four factors: Negative mood, interpersonal problems, ineffectiveness and anhedonia. Thus, this measure quantifies a range of depressive symptoms including disturbed mood, hedonic capacity, vegetative functions, self-evaluation, and interpersonal behaviors. High scores suggest a problem and low scores the absence of depression symptoms. Additionally, the items reflect consequences of depression in settings appropriate to children such as school, family and peer relations.

T-scores of above 60 (scores above 20) are considered clinically significant and indicative of above average levels of depression symptoms (Kovacs, 1992). Normative analyses resulted in the formation of two groups based on age: children ages 7 to 12 and older children ages 13 to 17. Separate norms exist for boys and girls and for these two age groups.

The CDI's internal consistency and factor structure vary slightly in different juvenile cohorts (Kovacs, 1992). The normative sample resulted in a Cronbach's alpha of .86, indicating good internal consistency reliability. Other studies have reported reliability coefficients ranging from .81 to .89 which indicates good internal consistency of the instrument (Kovacs, 1992; Weiss & Weisz, 1988; Weiss et al., 1991). The inventory has strong discriminant validity, as the scale discriminates normal from clinical samples (Kovacs, 1985). The CDI correlated significantly with the State-Trait Anxiety Inventory-State

($r=.71$, $p<.001$) and the State-Trait Anxiety Inventory-Trait ($r=.81$, $p<.001$), indicating congruent validity of the measure (Smith, Mitchell, McCauley, & Calderon, 1990). Test re-test reliability coefficients ranged from .74 for fifth grade girls to .77 for fifth grade boys (Smucker, Craighead, Craighead, & Green, 1986).

4. Marital functioning. The Dyadic Adjustment Scale (DAS, Spanier, 1976, 1989) was administered to each parent at the baseline phase as a measure of marital adjustment. This measure has 32 items and uses a Likert-style questionnaire with a 5, 6, and 7 point response format. Options were scored from 0 to 5, with ranges indicating either always agree to always disagree, or all the time to never. This measure yields a total scale score of overall marital adjustment and four subfactors of adjustment: dyadic satisfaction, dyadic cohesion, dyadic consensus, and affectional expression. Higher scores reflect better relationships and lower scores are indicative of marital distress. The overall marital adjustment score was used in this study.

This scale was selected because it is the most widely used measure of marital satisfaction, has sound psychometric properties, is applicable to unmarried couples, and is appropriate for parents of chronically ill children. Psychometric properties as reported by Spanier (1976) are as follows: alpha reliabilities for the total scale of .96, and reliabilities for the four subscales ranging from .73 to .94. Good construct validity is evidenced by correlations of .86 among marital couples and .88 among divorced individuals between the DAS and the Locke-Wallace Marital Adjustment Scale (L'Abate & Goodrich, 1980).

Recent findings by Gordon Walker et al., (1992) indicated that this instrument can reliably predict marital distress in couples with chronically ill children, thus showing sound criterion validity. Although Spanier (1976) reported a distress cut-off score of 97, the mean DAS score was 109.7 in the Gordon Walker et al. (1992) study of parents of chronically ill children. Following the recommendation of these researchers this higher cut-off score was used in this study. Lower scores on the DAS are indicative of greater marital distress.

Using the score of the more maritally distressed partner has been found to be a better indicator of marital functioning than averaging the couple's score (Baucom & Kaplan Mehlman, 1984). In this study, a couple score of marital distress was determined by selecting the score from the partner who indicated the greater marital distress on the DAS (lower scores are indicative of greater marital distress). This sample resulted in a Cronbach's alpha of 0.56, indicating weak internal consistency reliability.

5. Diabetes-Specific Family Support. The Diabetes Family Behavior Scale (DFBS, McKelvey et al., 1993) measures diabetes-specific family behaviors. It was administered to the adolescent at baseline, thus providing the adolescent's perspective on diabetes-specific family interactions. The DFBS is a 47 item measure which has a total score and two subscales, guidance-control and warmth-caring. Internal consistency values for the total DFBS total score are .86, .81 for guidance-control, and .79 for the warmth-caring subscales. This test was developed to measure diabetes-specific family behaviors hypothesized to be supportive or non-supportive of the child or adolescent following a treatment regime. The DFBS has been found to be negatively correlated with HbA1c values. Higher supportive diabetes-specific family behaviors (guidance-control) were negatively correlated with HbA1c values. The reader is reminded that lower HbA1c values is indicative of better metabolic control. Both the guidance-control and warmth-caring factors of this measure were used in this study. This sample resulted in a Cronbach's alpha of 0.69 for the guidance-control scale and 0.72 for warmth-caring scale, both indicating good internal consistency reliability.

6. General Family Functioning. Each parent and the adolescent completed the Family Environment Scale (FES, Moos & Moos, 1994) at baseline as the measure of general family functioning. The FES is composed of 90 true-false items that form 10 scales within three domains. The relationship domain includes cohesion, expressiveness, and conflict; the personal domain includes independence, achievement orientation, intellectual-cultural orientation, active-recreational orientation, moral-religious emphasis; and the system maintenance domain includes organization and control.

This test has demonstrated both clinical and research utility. Both normative data and a manual exist and there is an absence of obvious response set problems. Administration time is 15 minutes. Strong psychometric properties were indicated by test-retest reliabilities of .68 to .86 at 2 months, with internal consistency alphas of .61 to .78. Criterion related validity has been demonstrated through the FES's ability to differentiate normal and clinical families in numerous studies (Moos & Moos, 1994) and to predict alcoholic treatment gains and relapses (Moos & Moos, 1984). Multiple studies have reported convergent and discriminative construct validity of FES subscales with conceptually similar/dissimilar measures (Moos & Moos, 1981).

Kronenberger and Thompson (1990) factor analyzed the FES with a population of chronically ill children. Three higher order factors were delineated: supportive (Cronbach alpha = .81), conflicted (Cronbach alpha = .84), and controlling (Cronbach alpha = .65). The supportive factor reflected the level of family supportiveness, mutual interest and commitment, and active participation in activities of both a social and recreational nature. The conflicted factor reflected level of family conflict, organization, and lack of mutual commitment and support. The controlling factor reflected the family's emphasis upon control, ethical and religious values, achievement orientation and lack of independence. This factor was similar to the adaptability and organization dimension identified in previous research (Olson, 1986). The supportive and conflicted factors of the FES were selected for this study. This sample resulted in a Cronbach's alpha of 0.75 for the two factors combined, indicating good internal consistency reliability.

CHAPTER III: DATA ANALYSES AND RESULTS

Overview of Approaches to Data Analysis

To protect against a Type 1 error, the alpha level for a set of measures with more than one analysis was fixed using a Bonferroni correction (Tabachnick & Fidell, 1989). Otherwise, an alpha level of .05 was chosen to guard against a Type I error. A sample of 54 provides a statistical power of .69 for a multiple regression analysis with seven independent variables and an expected R^2 of .20. Every effort was made to reduce the number of variables in each analysis. The ratio of cases to independent variables ranged from 7.7:1 to 10.8:1 of the multiple regression analyses. Although ideally regression analyses require at least 10 subjects for every predictor variable, this ratio is within the broad range of acceptable for multiple regression analyses (Cohen &Cohen, 1983).

The SPSS 7.5 (Norušis, 1997) statistical package was used in the statistical analyses in this study. The primary objectives of the study are to (1) examine the relationship between metabolic control and treatment adherence, and (2) examine the relationships between diabetes care, as indexed by treatment adherence and metabolic control, and the family relations variables. The secondary objectives are exploratory and examine first the metabolic stability throughout the study and second, whether there is an association between treatment adherence and metabolic control and the nature of diabetes services received (diabetes clinic versus pediatrician); using an insulin sliding scale versus a fixed amount of insulin; missing insulin injections; parental involvement in the treatment regime; and, adolescent depression, as a measure of child adaptation.

Prior to examining these issues, descriptive statistics and a comparison of means of available reference groups are presented. Pearson product-moment correlations are computed to evaluate the linear relationships between the following variables: adherence to treatment, metabolic

control, family relations, health behaviors and demographic characteristics. Hierarchical multiple regression analysis was selected as the method of data analysis to clarify the complex relationships implicit to the correlational data of this nature (Cohen & Cohen, 1983). In particular, the hierarchical model was selected because it specifies the unique contribution that each independent variable makes in accounting for the variance in a dependent variable.

Therefore, for hypothesis one, a hierarchical regression analysis was employed to predict metabolic control. HbA1c, time two was utilized in analyses involving adherence factors as HbA1c measures metabolic control over the past three months, the period during which the 24-hour recall interviews are conducted. Thus, HbA1c, time two and the 24-hour recall interviews are temporally congruent. Because time since diagnosis has been linked with treatment adherence and metabolic control in previous research, this demographic variable was entered in the regression analysis prior to the five adherence factors.

Hypothesis two, which examines the relationships between the family relations variables and both metabolic control and treatment adherence, was also analyzed using hierarchical multiple regression. The data from the multiple respondents are combined where possible to reduce the number of variables in the equation. When significant intra-familial agreement exists, researchers have found that the mean of the family relations individual scores can be more representative of overall family relations than the individual reports of family members (Barnes & Olson, 1985; Cohen & Cohen, 1983; Hanson et al., 1989). Combined family measures also reduce type 1 error (Cohen & Cohen, 1983).

In this study, the adolescent, maternal, and paternal perceptions of family support (FES) were not significantly correlated (mean rs = .16); the adolescent's perception of family support was therefore used in the analyses. Both types of support variables, general family support from the FES and diabetes-specific guidance-control and warmth-caring support from the DFBS, are

representative of the adolescent's perspective only. Because the intra-family agreement for general family conflict (FES) is mean r = .33, an aggregate general family conflict score is used in the analyses. An aggregate family score was created by averaging the paternal, maternal and adolescent perceptions of general family conflict on the FES to represent the degree of family conflict. A couple marital distress score was calculated by selecting the parent with the lowest score on the DAS: Lower scores indicate greater marital distress (Baucom & Kaplan Hehlman, 1984). Similarly, a couple depression score was calculated by selecting the parent with the highest score on the BDI: Higher scores are indicative of greater self-report of depressive symptoms. The mean of HbA1c at time one and time two was used to represent metabolic control in analyses involving family relations variables because relationship variables were deemed to be relatively stable during this time frame and time as a variable was not important to consider.

The first exploratory research question, which involves evaluation of depression as an outcome measure of adjustment, was examined using correlations and hierarchical multiple regression. The second question, which involves examination of the stability of the HbA1c assay values throughout the study, was evaluated using cross-tabulation tables. Third, examining whether adolescents receiving services from a diabetes center are in better metabolic control or are more adherent to a diabetes regime was examined by t-tests. Fourth, analyses of whether using an insulin sliding scale improved metabolic control was evaluated using cross-tabulation tables and whether participants using a sliding scale are more adherent was examined by computing t-tests. Fifth, cross-tabulation tables of gender, chronological age, treatment adherence, metabolic control, family relations, and type of diabetes service (diabetes clinic versus pediatrician only), were computed to distinguish those adolescents who omitted insulin injections. Finally, sets of cross-tabulations were calculated to examine gender and chronological age patterns of parental involvement and adolescent independence in the four aspects of adherence.

Assumptions

Prior to analysis, the six demographic variables (chronological age, time since diagnosis, age at diagnosis, gender, number of siblings, family socioeconomic status and years married), the six family relations variables (parental and couple depression scores, parental and couple marital distress scores, adolescent depression, scores on general family support and general family conflict for each family member, and diabetes-specific adolescent perspective of family support as measured by guidance-control and warmth-caring), the 13 adherence variables which comprise the five adherence factors, and the metabolic control assay values of HbA1c, time one and time two, were examined through various SPSS programs for accuracy of data entry, missing values, and fit between their distributions and the assumptions of multivariate analysis. Analysis was performed using SPSS regression with an assist from SPSS frequencies in evaluation of assumptions. The transformation of variables followed the guidelines of Tabachnick and Fidell (1989).

Examination of the demographic variables resulted in the following changes being made. (1) One case was deleted because it was an outlier at the univariate level. The case was an 18 year old male who was being treated by a pediatrician in the Orillia area. This subject was the only one to be prescribed a fixed amount of pre-mixed insulin and to be prescribed three meals daily. This subject was an extreme outlier on all of the adherence factors and metabolic control measures. (2) The score of one outlier on family socioeconomic status was changed to one value larger than the next most extreme score in the distribution. (3) Log transformations of family socioeconomic status were computed to correct slight positive skewness. (4) A square root transformation of time since diagnosis was computed to correct positive skewness.

A strong correlation ($r = -.830$, $p = .000$, 2-tailed) between time since the diagnosis of diabetes and age at the time of the diagnosis indicated multicollinearity between these variables (Tabachnick & Fidell, 1989). Weaker correlations between chronological age and age at diagnosis

(r=.304, p=.024, 2-tailed) and chronological age and time since diagnosis (r=.280, p=.039, 2-tailed) were identified. Consequently, time since diagnosis and age at diagnosis were not included together in analyses as multicollinearity causes statistical instability (Tabachnick & Fidell, 1989). Time since diagnosis was chosen because this variable correlated with more of the demographic variables and was the variable identified in the literature as being more consistently related to both adherence and metabolic control.

Examination of the psychological and family relationship variables showed that there was missing data on the measure of marital satisfaction (DAS) for two of the fathers and one of the mothers. There were missing data on the measure of depression (BDI) for one of the fathers. The score from the parent who completed the BDI was used for the one case in which the partner's score was missing. Consequently analyses including the parental depression and marital distress data involved a N=53 rather than the total of N=54. Skewness and kurtosis were examined and indicated that paternal depression and maternal depression were not normally distributed due to a positive skew and kurtosis on paternal depression and kurtosis on maternal depression. Creating a couple score, which consisted of the most depressed score from each couple depression score, reduced the degree of kurtosis. However, since the majority of parents were not depressed, there was still a pileup of cases in the non-depressed range and there was positive skewness and kurtosis. Log transformations were used on the couple depression score to correct a positive skew and kurtosis.

Two adolescents did not complete the measure of depression and analyses were conducted with an N = 53. There was positive skewness of the data and log transformations of adolescent depression (CDI) resulted in normally distributed data.

Before calculating the five adherence factors, the 13 adherence variables were examined. The reader is reminded to refer to Figure 2 for a summary of the thirteen adherence variables.

First, the four injection variables which comprise the injection factor were examined. Log transformations of injection meal timing were computed to correct a severe positive skew. Next, the variables which comprise the diet type factor were examined. The one outlier on the calories consumed from carbohydrates was assigned a value one unit larger than the next extreme score in the distribution. Next, an inspection of the variables which comprise the diet amount factor revealed three outliers on the total calories consumed variable and one outlier on the concentrated sweets variable. They were assigned a raw score one unit smaller than the next most extreme score in the distribution to reduce their influence in the analysis. The variables which comprise the exercise factor were examined next. Log transformations of the exercise type variable (energy rating of exercise) were used on the measure as there was extreme positive skewness and kurtosis. Although there were two outliers, they were unchanged as the log transformations had reduced their influence. A log transformation was used on the measure of exercise duration as there was extreme positive skewness and kurtosis. Exercise frequency was normally distributed with no outliers. Finally, an examination of the two variables which comprise the eating and testing frequency factor indicated two outliers on the eating frequency variable. These two cases were assigned a raw score one unit larger than the next most extreme score in the distribution to reduce their influence in the analysis. The means and standard deviations of the transformed variables (Tabachnick & Fidell, 1989) are depicted in Table 7.

TABLE 7.

Means and Standard Deviations of Transformed Variables

Variables (type of transformation)	M	SD
Time since diagnosis (sqrt)	2.485	.700
Family socioeconomic status (Blishen) (log)	1.635	.111
Depression couple score (BDI)(log)	.840	.378
Adolescent depression (CDI) (log)	1.665	.083
Injection meal timing (log)	-.112	.169
Exercise type (log)	-1.029	.403
Exercise duration (log)	-.023	.972

Note. Sqrt = square root transformation; Blishen = Blishen Occupational codes; log = log transformation; BDI = Beck Depression Inventory; CDI = Child Depression Inventory

Once these corrections were made, the five adherence factors were calculated according to Bennett Johnson's et al. (1986) protocol and again examined for evaluation of assumptions. Outliers were identified as follows: two cases on the injection factor, one on the diet type factor and one on the eating/testing frequency factor. One case on the injection factor was assigned a raw score unit one unit smaller than the next most extreme score in the distribution. The remaining cases on diet type, injection and eating/testing frequency factors were assigned a raw score one unit larger than the next most extreme score in the distribution to reduce their influence in analyses. Inspection of the five adherence factors indicated they were normally distributed.

Inspection of the metabolic control variables showed that one female adolescent had not returned to the laboratory for HbA1c testing at time two and consequently the number of subjects for which metabolic control values could be calculated was N=54. Before the hypotheses are addressed, adherence to treatment, metabolic control, family relations, and health behavior characteristics of the sample are described and compared relative to available reference samples.

Preliminary Results: Descriptive Statistics

Descriptive Statistics: Metabolic Control

As previously discussed, because the HbA1c results were obtained from various laboratories with slightly different analysis techniques and references ranges, the HbA1c values were commuted to a percentage (Catellier et al., 1992; Daneman & Ellis, 1996). The commuted HbA1c assay levels averaged 140.91% (SD = 29.75) at the beginning of the study (time one) and 140.47% (SD = 28.80) at the end of the study (time two).

Due to small sample size, the subjects within the optimal and acceptable metabolic control ranges were combined to denote controlled glucose metabolism. Whether the subjects were in optimal or acceptable ranges of metabolic control was not relevant to the study. The compromised group was labeled the non-controlled group. Using the Canadian Diabetes Association's (CDA) recommended cut-off points as measured by HbA1c assay levels, cross-tabulations showed that 57.40% (n = 31) were within acceptable metabolic control at time one. Comparatively, at time two, 50.90% (n = 27) were within acceptable metabolic control. Metabolic control was compromised, that is HbA1c values above 140% as a cut-off level of acceptable control, in 42.60% (n = 23) at time one and 49.10% (n = 26) at time two. The correlation between HbA1c time one and time two assays was strong (r = .680, p = .000, 1-tailed). Recall that because at time two one subject did not return for HbA1c blood analysis and one subject was deleted as an outlier, the number of subjects for which the mean metabolic control values could be calculated was N=53. Analyses using HbA1c, time two assay results will be calculated with an N = 53. Table 8 presents the statistics describing metabolic control levels according to HbA1c at time one and time two.

TABLE 8.

Proportions Analysis of Metabolic Control: HbA1c Time One and Time Two

Variable	M	SD	Level of Control	% Controlled	n	Level of Control	% Controlled	n
HbA1c time 1 (N = 54)	140.91	29.75	<110%	14.80	8	<140%	57.40	31
			110-140%	42.60	23			
			>140%	42.60	23	>140%	42.60	23
HbA1c time 2 (N =53)	140.47	28.80	<110%	17.00	9	<140%	50.90	27
			110-140%	34.00	18			
			>140%	49.10	26	>140%	49.10	26

Note. <110% = optimal level of metabolic control; 110 - 140% = acceptable level of metabolic control; > 140% = compromised level of metabolic control

How does this sample compare to other studies who have examined metabolic control? Table 9 presents the studies involving children and adolescents which employed HbA1c assay values as a physiological measure of metabolic control. When the reference ranges were reported, the HbA1c assay values from the comparative studies were commuted to a percentage (Catellier et al., 1992; Daneman & Ellis, 1996) to enable comparison of the means of this study's results with other studies. Bennett Johnson et al. (1986) and Auslander et al. (1990) did not report laboratory reference ranges and consequently commuted values could not be computed. An inspection of the means of the various studies indicates that metabolic regulation of the participants in this study falls within the mid-range of metabolic control when compared to other studies of children and adolescents.

TABLE 9.

Comparison of HbA1c Assay Values in Children's Studies

Study	N	Subject age range (years)	Length of study	Recruitment	Hemoglobin level (HbA1c)	Commuted value percentage average
Anderson et al. (1990)	121	6 - 21	One week	Medical center	11.6 (SD = 2.7)	118.00
Auslander et al. (1990)	42	Mean age=10 (SD 4.1)	Three years	Hospital medical center	9.3 (SD = 2.0) 9.9 (SD = 2.3) 9.2 (SD = 2.0)	
Bennett Johnson et al. (1986)	168	6 - 19	One week	Diabetes clinic & summer camp	12.8 (SD not reported)	
Bennett Johnson et al. (1990)	78	6 - 19	Three months	Diabetes clinic & summer camp	9.1 (SD = 2.2) Beginning 9.1 (SD = 1.9) End	149.18 149.18
Champaigne (1999)	54	11 - 18	Three months	Diabetes clinic, pediatrician, support group	Time 1: 140.91 (SD = 29.75) Time 2: 140.47 (SD = 28.80)	140.91 140.47
Hanson et al. (1987b)	104	Mean age 14.5	Same day	Children's hospital	9.4 (SD not reported)[a]	127.02
Hanson et al. (1992)	95	11 - 22	Two weeks	Hospital clinic	9.3 (SD = 1.1)	126.53
Hanson et al. (1996)	270	4 - 20	Three assessment	Diabetes clinics, physicians, ADA offices, newspaper ads	8.95 (SD = 2.1) 9.07 (SD = 2.1) 9.22 (SD = 2.1)	142.06 143.97 146.35
McKelvey et al. (1993)	321	7 - 18	One week	2 diabetes summer camps	8.5 (SD = 2.4) 7.7 (SD = 1.9)	166.67 151.0
Schafer et al. (1983)	34	12 - 14	One week	Diabetes summer camp	10.7 (SD = 2.7)	155.00
Schafer et al. (1986)	18	Adoles-cents	One week	Variety of sources	11.4 (SD = 3.1)	154.00

Note. [a] = Average at time of study and year before

Descriptive Statistics: Adherence to Treatment Behaviors

The means and standard deviations of the 13 adherence variables are presented in Table 10. In summary, the adolescents in this study experienced great difficulty taking their insulin injections at the same time every day (injection regularity), with the average injection interval compared to a prescribed regime being quite inconsistent and not approaching adequate adherence levels. That is, there was great inconsistency in the timing of insulin injections. Although it is recommended that insulin be given within 20 to 30 minutes before eating, these adolescents were less adherent, taking their insulin on average 15 minutes before eating . They deviated from dietary prescriptions by eating slightly less than the ideal recommended calories, eating more than the recommended 30% of calories in fats, and eating less than the 60% of calories consumed as carbohydrates. Their consumption of concentrated sweets was within the prescribed range. They ate less than the prescribed number of meals and snacks. The adolescents exercised infrequently and the exercise was of a less strenuous nature and for briefer lengths of period of time than recommended. Ideally, CDA recommends that blood glucose testing be conducted two to four times daily. The prescribed frequency of blood glucose tests was within this range but is less stringent than the ideal comparison used in the Bennett Johnson et al. (1986) study. In this sample on average 2.98 (SD = .71) tests were prescribed daily. Even compared to this less stringent expectation, these adolescents tested their blood less frequently than prescribed and they just met CDA recommendations. As a group, the adolescents in this study were only adherent to ingesting within 10 to 15% of concentrated sweets and approached adequate adherence to timing their injections with meals eaten. Otherwise, they were not adherent to the other eleven aspects of the prescribed treatment regime.

TABLE 10.

Means and Standard Deviations of the 13 Adherence Variables (N = 54)

Adherence measures	M (Interpretation)	SD
Injection Factor		
Injection interval (hours)	1.71	.89
Injection regularity (hours)	.92	.60
Injection-meal timing (log)	-.11	.17
(minutes before meal)	(15.06)	(30.04)
Regularity of injection-meal timing (minutes)	32.50	36.90
Diet Type Factor		
% Calories: fat	5.44	4.71
(% of total intake)	(35.44%)	
% Calories: carbohydrate	11.15	4.92
(% of total intake)	(48.80%)	
Diet Amount Factor		
Concentrated sweets (per day)	1.80	.70
(% of carbohydrates)	(10.29%)	
Calories consumed (calories)	-252.17	528.90
(Less than prescribed average 2483.56 calories)	(2231.39/day)	(641.51)
Exercise Factor		
Exercise frequency (%)	75.30	16.65
	(1.49 periods/day)	(.99)
Exercise duration (minutes) (log)	-1.03	.40
	(15.09 minutes/day)	(12.59)
Exercise type (kcal/minute) (log)	-1.71	.55
	(.01)	(.19)
Eating/Testing Frequency Factor		
Blood glucose testing frequency	29.59	32.00
	(2.15/day)	(1.06)
Eating frequency	10.23	12.35
	(4.55 meals/day)	(.74)

Note. 0 = perfect adherence; > or < 0 = non-adherence; log = log transformation

TABLE 11.

Summary of Adherence Behaviors from Studies Using 24-Hour Recall Interview Protocol: Reported Means and Standard Deviations

Variable		Bennett Johnson et al. (1986)	Bennett Johnson et al. (1990)	Bennett Johnson et al. (1992)[a]		Champaigne (1999)	Freund et al. (1991)*	Kuttner et al. (1990)
Injection		Total	Total					
Injection regularity	Mean	.71	.76	.64	.66	.92	.55	55.1
	SD	.57	.39	.53	.51	.60	.43	35.2
Injection interval	Mean	.98	1.00	.94	1.18	1.71	.89	6.3
	SD	.90	3.81	.87	1.25	.89	.77	29.3
Injection-meal timing (log)	Mean	.74	.68	.74	.67	-.11	.69	12.2
	SD	.50	.45	.44	.59	.17	.51	20.6
Regularity of injection-meal timing	Mean	24.19	24.70	21.50	22.10	32.50	17.90	20.5
	SD	22.49	19.70	19.60	22.00	36.90	17.30	16.3
Diet type								
% calories from fat	Mean	22.36	24.70	21.90	23.80	5.44	25.00	17.1
	SD	5.29	5.31	5.60	6.50	4.71	6.40	4.9
% Calories from carbohydrate	Mean	22.76	25.50	22.70	24.80	11.15	25.60	21.6
	SD	6.00	5.58	6.10	6.90	4.92	6.80	6.9
Diet amount								
Concentrated sweets	Mean	1.97	1.93	1.90	2.10	1.80	2.00	7.7 exchanges
	SD	2.20	1.76	2.30	2.50	.70	2.20	7.9
Calories consumed	Mean	23.54	245.20	116.4	324.7	-252.17	172.10	35.5
	SD	691.15	697.70	757.0	887.0	528.90	817.40	710.0
Exercise								
Exercise frequency	Mean	69.43	70.55	67.00	67.00	75.30	70.52	42
	SD	13.17	11.53	13.80	15.80	16.65	13.81	19
Exercise type (log)	Mean	.97	.98	0.97	0.97	-1.71	.98	.20
	SD	.01	.01	0.01	0.01	.55	.01	.15
Exercise duration(log)	Mean	.09	.08	0.07	0.09	-1.03	.13	0.6
	SD	.14	.12	0.10	0.15	.40	.20	0.12
Frequency								
Snacks/meals	Mean	13.05	17.4	12.8	16.4	10.23	17.78	28.1
	SD	10.33	11.9	10.2	13.60	12.23	13.37	30.6
Glucose testing	Mean	56.84	61.90	52.9	62.80	29.59	63.50	46.00
	SD	27.26	24.10	27.1	26.20	32.00	26.60	0.19

Note. [a]The results of evaluation 1 and 2 are reported as the results were not summarized. [b] The results of set 3 of 3 sets of the results were not summarized. log = log transformed values; 0 = good adherence; > 0 or < 0 = non-adherence.

How does this sample compare to other studies using the 24-hour recall interview protocol? Table 11 shows the level of adherence self-care behaviors exhibited by this sample as described by means and standard deviations for each of the treatment adherence behaviors compared to other studies using the 24-hour recall interview protocol. Although statistical analyses were not conducted, a comparison of means of the injection variables with other studies showed that the present sample was: (1) slightly less adherent in terms of the regularity of injections; (2) the least adherent with injection intervals; (3) closest to the ideal in the timing of injections with meals; and, (4) much less adherent in the regularity of the injection of insulin with meal times.

A comparison of means of the diet variables showed that the adolescents in this study consumed closest to the prescribed 30% in fats and the 60% in carbohydrates, compared to the other studies. The reader is reminded that the American Diabetes Association's recommended fat consumption is 25% of the total diet, while the CDA's cut-off is 30%. The caloric consumption of the adolescents in this study was considerably less than the prescribed and they were the only comparative study sample to consume less than the prescribed calories. The adolescents in this study consumed similar amounts of concentrated sweets to the comparison study sample.

A comparison of means of the blood glucose testing and eating frequency adherence variables showed that this study group ate more frequently than the prescribed number of snacks and meals. The reader is reminded that the comparison studies were based upon an ideal of six snacks and meals daily rather than the number of snacks and meals prescribed by the diabetes clinic or pediatrician. Blood glucose testing was the only self-care behavior that was closer to the prescribed regime, which indicated better adherence than the other study groups.

When the means of the exercise variables are compared, this study group exercised less frequently, for shorter periods of time and less strenuously than the other study groups of youths

with diabetes. In general, the subjects in the current study were rather physically inactive when compared to the adolescents and children recruited from samples from summer camps and diabetes clinics in the other studies reported.

Descriptive Statistics: Family Relations Variables

The descriptive statistics for the family relations measures of general familial conflict and support, parental and adolescent depression, diabetes-specific family support (guidance-control and warmth-caring) and marital distress are presented next. The descriptive statistics for the family relations measures of general familial conflict and support, parental and adolescent depression, diabetes-specific family support (guidance-control and warmth-caring), and marital distress were compared to available reference groups and these results are described in Table 12.

1. Marital distress. The couple score of marital distress is the score from the partner who indicated the greater marital distress on the Dyadic Adjustment Scale (DAS) (lower scores are indicative of greater marital distress). The mean DAS couple score was 109.17 (SD = 12.08), a value comparable to the mean couple t-score of 109.7 found in a study of couples with chronically ill children who expressed a desire for marital therapy (Gordon Walker et al., 1992). Using the cut-off t-score 109.7 as the criterion for identifying poor marital adjustment in a population of parents with a chronically ill child (Gordon Walker et al., 1992), 50.9% (n = 28) of the couples were experiencing marital distress according to the DAS. When each partner was considered independently, 35% of the fathers and 33% of the mothers were experiencing marital distress. This variable was retained in the analyses because of the high proportion of marital distress.

2. Parental depression. A cut-off of 10.9 on the revised Beck Depression Inventory (BDI) (Beck et al., 1988) identified 18.2% (n = 10) of the husbands and slightly more of the wives (27.3%, n = 15) who scored above this clinical cut-off point of depressive symptomatology. A couple depression score was created by selecting the data from the partner with the greatest level of

depressive symptomatology (higher scores are indicative of greater depression). Using this criterion, there were 38.9% (n = 21) of the couples who reported depressive symptoms. The mean of the highest depression score between the couple was 9.5 (SD = 8.01). Thus, as a group, the couple depression score and partner's level were considered to be below the significant level of depression when compared to the normative data (Beck et al., 1988).

3. Adolescent depression. The mean t-score on the Children's Depression Inventory (CDI) was 47.13 (SD = 9.47), a score considered to be within the normal range. T-scores above 60 are considered clinically significant and indicative of above average levels of depression on the CDI (Kovacs, 1992). Norms from the general population identified an overall base rate of 9.57% of children who were classified as depressed in the general population using the CDI (Kovacs, 1992). Comparatively, in this study, 15.4% (n = 8) of adolescents obtained scores in the above average range of depression. Therefore, in this sample a slightly higher level of adolescents with diabetes were considered depressed compared to the general population.

4. Diabetes-specific family support. The Diabetes Family Behavior Scale (DFBS), a measure of diabetes-specific familial support, is comprised of two variables: guidance-control and warmth-caring. When the results are compared to the McKelvey et al. (1993) study, the guidance-control mean (38.26) was similar, whereas, the warmth-caring score (54.35) was higher in this study. These results indicate that this population of adolescents with diabetes perceived that their families offered more warmth-caring and fairly similar guidance-control type of diabetes-specific support than the clinic group in the McKelvey et al. (1993) study to which they were compared.

5. General family functioning. The Family Environment Scale (FES) provides a measure of both general family support and general family conflict. The mean FES adolescent perspective supportive factor t-score was 241.78 (SD = 32.05) and the mean aggregate FES conflict factor t-score was -55.49 (SD = 18.60); both these FES factor scores yielded fairly similar

results to those of Kronenberger and Thompson (1990). Recall that higher FES conflict and support factor scores are indicative of greater general family conflict and support respectively.

TABLE 12.

Comparative Means and Standard Deviations of Family Relations Measures

		BDI[a]	CDI[b]	DAS[c]	Conflict FES[d]	Support FES[d]	DFBS GC[e]	DFBS WC[e]
Champaigne (1999)	M	9.5 Couple mean score	47.13 t-score	109.17 Couple mean t-score	-55.49 Aggregate t-score	241.78 t-score	38.26 Score	54.35 Score
	SD	8.01	9.47	13.74	18.60	32.05	7.65	8.28
Reference groups	M	10.9 score	45 - 55 t-score	109.7a 114.8b Couple mean t-score	-51.30 t-score	249.90 t-score	36.8 Score	48.6 Score
	SD	8.10	7.30	13.70a 17.80b	31.40	43.90	8.90	5.00

Note. BDI[a] = Beck Depression Index (Beck & Steer, 1987); CDI[b] = Children's Depression Inventory (Kovacs, 1992); DAS[c] = Dyadic Adjustment Scale (Gordon Walker et al., 1992; Spanier, 1976); Conflict-FES[d] aggregate= Conflicted factor of the Family Environment Scale, mean of father, mother and adolescent scores (diabetes illness group mean: Kronenberger & Thompson, 1990; Moos & Moos, 1994); Support-FES[d] adolescent = Supportive factor of the Family Environment Scale, adolescent perspective (Moos & Moos, 1994); DFBS-GC[e] = Guidance-control factor of the Diabetes Family Behavior Scale (McKelvey et al., 1993); DFBS-WC[e] = Warmth-caring factor of the Diabetes Family Behavior Scale (McKelvey et al., 1993).

In summary, a comparison of means indicated that the family relations characteristics of this sample of families with an adolescent with diabetes differed from other families in the following ways: The adolescents self-reported slightly more depressive symptoms than the general population and the adolescents considered their families to offer more diabetes-specific warmth-caring. This study sample was similar on the following family relations variables investigated: diabetes-specific support guidance-control and levels of general familial conflict and support.

Maternal depression results in this study were comparable to other studies of populations of parents with a chronically ill child, whereas the father's depression results were lower than in other studies.

Descriptive Statistics: Health behaviors

First, the health behaviors are reported according to the various types of medical contacts the adolescents engaged in. Medical contacts are defined as contacts by the adolescent with either a diabetes clinic or doctor, whether they received services from a diabetes clinic or uniquely from a pediatrician, the frequency of diabetes-related hospitalizations and emergency room visits, and the length of diabetes-related hospital stays. The health behaviors, reported according to the various types of medical contacts experienced which are presented in Table 13 show the following. (1) Sixty-five percent (n=35) of the 55 participants were being followed by a diabetes clinic while the remaining 35.2% (n = 19) received services uniquely from their pediatrician. This variable was included in the study for further exploratory analysis in determining whether there was a difference between the participants receiving care from a diabetes clinic versus a pediatrician. (2) The mean number of diabetes clinic visits was 1.25 (SD = 1.39) with a range from 0 to 6 visits during the period of study. (3) Participants saw their pediatricians for diabetes-related concerns on average 2.40 (SD = 6.81) times during the study with a reported range from 1 to 51 times. The participants reports of their appointments to their pediatricians included regular quarterly visits to the diabetes clinics and visits to either their pediatrician or family physician outside the clinics. (4) Hospitalizations due to diabetes-related complications were rare, with the majority of adolescents (87.0%, n = 47) never being hospitalized. (5) Of the seven adolescents who were hospitalized for diabetes-related reasons during the study, the length of the hospital stay ranged from 1 to 3 days. (6) The frequency of hospital emergency room visits due to diabetes-related complications ranged

between 0 and 2 with the majority (85.2%; n = 46) never having visited the emergency hospital services.

The second group of health behaviors is organized according to the meal and insulin related health behaviors. The meal and insulin-related health behaviors include whether the adolescent was using an insulin sliding scale, the frequency of changes in insulin regime, the addition of extra insulin injections or missing insulin injections, the number of prescribed snacks and meals and blood glucose testing and whether a meal plan was prescribed. The means and standard deviations of meal and insulin related health behaviors are found in Table 14. First, the majority of the participants, 64.8% (n =34), adjusted their insulin and were prescribed between 2 and 4 injections per day. In contrast, a group of 35.2% (n = 19) were prescribed a fixed amount of insulin to be injected twice daily. This finding permitted an exploratory comparison of the participants who were adjusting their insulin to those who were prescribed a fixed insulin regime. Second, adding extra insulin injections occurred infrequently within this population of adolescents with diabetes. Nearly all of the adolescents (94.4%, n = 51) did not inject extra insulin during the day throughout the study. For the few adolescents who had added extra injections, it appeared to be an attempt to control high blood glucose levels. Third, 72.20% (n = 39) of the participants never missed an insulin injection throughout the study and the remaining 27.3% (n = 15) missed between one and seven insulin injections. This finding also permitted further exploratory analyses involving missing insulin injections.

Fourth, throughout the study, the records of the adolescent's injection schedules were recorded in addition to frequency of type, dose and amount of insulin injected. The frequency of changes to the insulin injection prescribed regime was calculated from these records. This variable indicated a change in health status and would also be more expected within a population of adolescents who was experiencing continued growth and hormonal changes. Nearly two-thirds of

the subjects (63.1%, n = 34) maintained their original prescribed insulin regime throughout the study, whereas a total of 37.0% of this population had changed their insulin regimes during the study.

TABLE 13.

Means and Standard Deviations of Medical Contact Health Behaviors

Variable	M	SD	N	Range	%	Frequency
Diabetes clinic membership			54	yes	64.8	35
				no	35.2	19
Diabetes clinic visits	1.25	1.39	54	0	29.6	16
				1	42.6	23
				2	13.0	7
				3	7.4	4
				4	3.7	2
				6	3.7	2
Doctor appointments	2.40	6.81	54	0	29.6	17
				1	24.1	13
				2	16.7	9
				3	20.4	11
				4	5.6	3
				5	1.9	1
				51	1.9	1
Hospitalization	.13	.34	54	0	87.0	47
				1	13.0	7
Hospital stay	.29	.83	54	0	87.0	47
				1	3.7	2
				2	1.9	1
				3	7.4	4
Emergency room visits	.20	.52	54	0	85.2	46
				1	9.3	5
				2	5.5	3

Fifth, between two and four daily blood glucose tests were prescribed to the adolescents in this study with the majority (50%) being prescribed three tests daily. All other studies following

the 24-hour recall interview developed by Bennett Johnson et al. (1986) used the ideal standard of four blood glucose tests in their analysis of adherence. According to the CDA (Catellier et al., 1992), individuals with diabetes are to ideally complete blood glucose tests two to four times daily.

Sixth, a descriptive proportions analysis of the range of frequency of pediatricians prescribed snacks and meals to be consumed daily showed that the majority of participants were prescribed 6 meals and snacks daily (42.3%, $n = 23$), with fairly equal proportions being prescribed four (29.6%, $n = 16$) and five (27.3%, $n = 15$) snacks and meals daily. The CDA (Catellier et al., 1992) has set an ideal of six snacks and meals to be consumed during a day. As previously discussed, the prescribed number of snacks and meals was used in the analyses of the 24-hour recall interview protocol rather than this ideal.

Seventh, over two-thirds (70.4%, $n = 38$) followed a prescribed meal plan, whereas almost a third of the participants (29.6%, $n = 16$) did not have a meal plan to follow. Ideally each individual with diabetes should have a meal plan to follow. This meal plan should consist of recommended total caloric intake, the number of starches, fruits, vegetables, milk, protein, fats and any extras to be consumed per meal and snack according to both a day of regular activity and a day of increased physical activity.

TABLE 14.

Means and Standard Deviations of Meal and Insulin Related Health Behaviors

Variable	M	SD	N	Description	%	Frequency
Insulin sliding scale-groups			54	Yes	64.8	35
Fixed injections				2 Injections	35.2	19
Insulin sliding scale				2 Injections	40.7	22
				3 Injections	11.1	6
				4 Injections	13.0	7
Changes	1.47	.69	54	0	63.0	34
				1	26.0	14
				2	11.0	6
Extra-insulin	.13	.58	54	0	94.4	51
				1	1.9	1
				3	3.7	2
Missed insulin	.69	1.49	54	0	72.2	39
				1	11.1	6
				2	5.5	3
				3	5.5	3
				4	1.8	1
				6	1.9	1
				7	1.8	1
Prescribed snacks/meals	5.09	.89	54	3	1.8	1
				4	29.6	16
				5	27.8	15
				6	42.3	23
Prescribed blood glucose tests	2.96	.72	54	2	25.9	14
				3	50.0	27
				4	24.1	13
Meal plan			54	Yes	70.4	38
				No	29.6	16

Note. Insulin sliding scale = # adjusting insulin; Changes = # of times dose or insulin type changed; Extra insulin = # of extra insulin injections; Missed insulin = # of missed insulin injections; Meal frequency = number of meals prescribed per day by doctor; Prescribed blood glucose tests = # of prescribed blood glucose tests; Meal plan = prescribed meal plan.

Hypothesis One: Relation Between Adherence and Metabolic Control

To examine the relationship between treatment adherence and metabolic control, correlational analyses were conducted and then hierarchical multiple regression was performed (Cohen & Cohen, 1983). Adherence, which was measured by Bennett Johnson's et al. (1986) 24-hour recall interview protocol, consisted of the five factors representing aspects of treatment to a diabetes regime. These five factors were: injection, diet type, diet amount, testing-eating frequency, and exercise. Recall that higher adherence factor scores indicate relative non-adherence and scores closer to zero indicate relative adherence. Metabolic control was measured by HbA1c, a measure of glucose metabolism, at time two because this was temporally congruent with adherence measurement. Recall that lower metabolic control scores are indicative of better metabolic control. Prior to conducting multiple regression analyses, correlational analyses were conducted to check for collinearity.

1. Correlational Analyses: Relationship Between Treatment Adherence and Metabolic Control

The results of this study are congruent with the findings indicating that adherence is a multivariate construct with differing levels of adherence to each self-care aspect of the regime (Bennett Johnson et al., 1986; Bennett Johnson et al., 1992; Schafer et al., 1983). However, inconsistent with the results from Bennett Johnson et al. (1986) and Bennett Johnson et al. (1990), the five factors were not separate dimensions in this study. The Pearson product-moment correlations between the five adherence factors and metabolic control are presented in Table 15. There was a weak negative correlation between the injection and diet type factors ($r = -.341$, $p = .05$, 1-tailed), a weak positive correlation between diet type and diet amount factors ($r = .327$, $p = .05$, 1-tailed) and exercise factors ($r = .340$, $p = .05$, 1-tailed), and a moderate negative correlation between diet amount and exercise factors ($r = -.480$, $p = .05$, 1-tailed). It was

nevertheless important to maintain the factor structure of the 24-hour recall interviews as developed by Bennett Johnson and her colleagues to enable comparison of the results.

TABLE 15.

Pearson Product-Moment Correlation Matrix Between Five Adherence Factors and Metabolic Control

	Factor 1 Injection	Factor 2 Diet Type	Factor 3 Diet Amount	Factor 4 Eating/ testing Frequency	Factor 5 Exercise	HbA1c Time 1	HbA1c Time 2
F 1[a]	1.000	-.341*	-.208	.328*	.149	.306*	.330*
F 2[a]		1.000	.327*	-.411**	-340*	-.251	-.115
F 3[a]			1.000	-.272*	-.480**	-.025	-.092
F 4[a]				1.000	.275*	.367**	.123
F 5[a]					1.000	-.093	-.107
HbA1c Time 1[a]						1.000	.680**
HbA1c Time 2[b]							1.000

Note. F 1 = Factor 1, Injection; F 2 = Factor 2, Diet Type; F 3 = Factor 3, Diet Amount; F 4 = Factor 4, Eating/Testing Frequency; F 5 = Factor 5, Exercise

[a] $N = 54$. [b] $N = 53$.

*$p < .05$, one-tailed. **$p < .01$, one-tailed.

2. Multivariate Analyses: Association between Adherence to Treatment and Metabolic Control

Prior to conducting the analyses, examination of the assumptions of multiple regression were undertaken and the assumptions of normal distribution, linearity, homoscedasticity of residuals and multicollinearity underlying multiple regression were satisfied. To determine whether there was, as hypothesized, a relationship between treatment adherence and metabolic control, an

hierarchical multiple regression was conducted involving HbA1c, time two, as the criterion variable. Demographic variable time since diagnosis (square root transformed values) was entered at step one. Time since diagnosis accounted for a significant 9.7% (R^2 = .097) of the variance of HbA1c at time two. The five adherence factors added another statistically non-significant 10.2% (ΔR^2 = .102) of the variance while none of the adherence factors were significant in predicting HbA1c, time two. A summary of findings from the multiple regression analyses using HbA1c as the criterion measure, with the five adherence factors as predictors, and while controlling for time since diagnosis, is presented in Table 16.

In summary, time since diagnosis was the single most significant variable to predict metabolic control as measured by HbA1c, time two as the criterion variable. The model was not significant, indicating that while controlling for time since diagnosis, the five adherence factors were not significant in predicting metabolic control.

TABLE 16.

Summary of Hierarchical Regression Analyses, using HbA1c Time Two as Criterion Measure, with Five Adherence Factors as Predictors, Controlling for Time Since Diagnosis (N = 53)

Variable	B	SE B	β	ΔR^2	F	df	ΔF	dfΔ	p
Step 1									
Time since diagnosis (sqrt)	12.789	5.451	.312	.097	5.504	1,51	5.504	1,51	.023
Constant =	108.567								
			R^2 = .097 for step 1						
			Adj R^2 = .080						
			R = .312						
Step 2									
Injection	3.955	2.171	.264						
Diet type	-.425	2.380	-.027						
Diet amount	-1.470	2.966	-.078						
Eating/testing	.425	3.199	.020						
Exercise	-6.543	4.281	-.239						
Constant =	116.681								
				.102	1.912	6,46	1.175	5,46	.336
			R^2 = .200 for step 2						
			Adj R^2 = .095						
			R = .447						

Note. sqrt = square root transformation

Hypothesis two: Relationship Between Family Relations Variables and Adherence and Metabolic Control

The objective of these next sets of analyses was to examine whether any of the six family relations variables along with the demographic variable, time since diagnosis, would explain a statistically significant amount of variance, first with regard to adherence to treatment, and second, with regard to metabolic control. First, correlations using Pearson product-moment coefficients

were calculated to determine correlations between the demographic and family relations variables. Pertinent demographic variables for entry were selected a priori because of the small sample size. Demographic variable time since diagnosis was selected for entry because it was the variable that correlated most with the family relations and adherence variables and was most often found to be a significant variable in the literature examining adjustment in diabetes. Second, the relationship between family relations and diabetes adherence was examined using hierarchical multiple regression techniques (Cohen & Cohen, 1983). Third, family relations and metabolic control relationships were also examined using hierarchical multiple-regression techniques.

The three sets of independent variables were demographic variable, time since diagnosis (square root transformed values); the continuous variables of the five adherence to treatment factors (injection, diet type, diet amount, eating/testing frequency and exercise); and, the six continuous family relations variables of general family support and conflict, diabetes-specific familial support (guidance-control and warmth-caring), marital distress, and parental depression (log transformed values).

Prior to conducting the analyses, examination of the assumptions of multiple regression were undertaken. With the use of a $p < .001$ criterion for Mahalanobis distance, a violation of homogeneity of variance was identified. As normality and homogeneity of variance are assumptions underlying multiple regression, a log transformation of mean HbA1c time one and time two, couple marital distress, and general family support variables, was conducted. The couple depression score had already been transformed due to skewness of the data at the univariate level. The assumptions underlying multiple regression were then satisfied. A multivariate outlier was identified and this case on the injection factor was assigned a raw score unit one unit smaller than the next most extreme score in the distribution. A summary of the means and standard deviations of mean HbA1c and the family relations variables which were log transformed (Tabachnick &

Fidell, 1989) are presented in Table 17. The assumptions of normal distribution, linearity, homoscedasticity of residuals and multicollinearity underlying multiple regression were satisfied.

TABLE 17.

Means and Standard Deviations of Log Transformed Variables

Variable (type of transformation)	M	SD
Marital distress couple score (DAS) (log)	2.036	.047
General family support (FES) (log)	2.380	.026
Mean HbA1c (time 1 and time 2) (log)	2.139	.081

Note. DAS = Dyadic Adjustment Scale; FES = Family Environment Scale; HbA1c = Hemoglobin A1c; log = log transformation.

1. Correlational Analyses: Relations Among Family Relations and Adherence Factors

Prior to conducting multiple regression analyses, correlational analyses among the family relations variables and among the adherence factors and family relations variables were conducted to check for collinearity. The Pearson product-moment correlations among the five adherence factors (injection, diet type, diet amount, eating/testing frequency and exercise), metabolic control, the family relations variables and demographics are presented in Table 19. The results of correlations among the family relations variables may be found in Table 18. Examination of correlational analyses showed that there was a strong negative correlation between general family conflict and marital distress (r = -.665). There were also mild correlations between diabetes-specific family support, warmth-caring and general family support (r = .442) and marital distress (r= .305) and a negative correlation with general family conflict (r =-.431). Various multiple regressions were computed to determine whether the omission of warmth-caring, general family conflict, warmth-caring and marital distress would influence the model. These observed

dependencies did not affect the model and consequently all the family relations variables were included in the analyses to determine their unique contribution to the model.

TABLE 18.

Product-Moment Correlation Matrix Among the Family Relations Variables (N = 54)

Variables	Depression couple (BDI) (log)	Guidance-control (DFBS)	Warmth-caring (DFBS)	Conflict family (FES)	Family support (FES) (log)	Couple marital distress (DAS) (log)
Couple Depression (BDI) (log)	1.000	.157	-.109	.222	-.027	-.092
Guidance-control (DFBS)		1.000	.315*	-.098	.203	-.123
Warmth-caring (DFBS)			1.000	-.431**	.442**	.305*
Family conflict (FES)				1.000	-.346*	-.655**
Family support (FES) (log)					1.000	.144
Couple marital distress (DAS)[a] (log)						1.000

Note. Couple depression (BDI) = score from parent with highest score on BDI; Couple marital distress (DAS); score from parent with lowest score on DAS; Family Support (FES) = adolescent's factor score; Family conflict (FES) =family aggregate conflict factor score of FES; Guidance-control (DFBS) = guidance-control score; Warmth-caring (DFBS) = warmth-caring score. Greater BDI and CDI scores indicate greater depression. Lower DAS scores indicate greater marital distress. Greater DFBS and FES scores are indicative of greater warmth-caring, guidance-control and greater support and conflict respectively.

[a] = N = 53

*p < .05 (2-tailed); ** p < .01 (2-tailed)

TABLE 19.

Pearson Product-Moment Correlation Matrix Between Adherence Factors, Metabolic Control, Family Relations Variables and Demographic Variables (N =54)

Variable	Factor 1 Injection	Factor 2 Diet type	Factor 3 Diet amount	Factor 4 Eating/testing	Factor 5 Exercise
Adolescent depression (CDI) (log)[a]	.052	.048	.054	-.011	.124
Couple depression (BDI) (log)	-.006	-.042	.242	-.082	-.238
Couple Marital distress (DAS) (log)[a]	-.103	-.111	.021	-.075	.083
Family support (FES) (log)	-.207	-.118	.051	.102	-.103
Family conflict (FES)	.289*	-.082	-.304*	-.101	.067
Guidance-control (DFBS)	-.099	.140	.234	.074	-.551**
Warmth-caring (DFBS)	-.109	-.038	.059	-.112	-.111
Time since diagnosis (log)	.320*	-.261	-.228	.313*	.153
Chronological age	.149	-.137	-.173	.185	.587**
Gender (m =1, f =2)	-.170	.313*	-.033	-.114	.199
Socioeconomic status family (Blishen)	-.092	.003	.052	-.144	.207
Siblings	.012	-.007	-.187	.197	-.079
Years married	-.029	-.091	-.055	.136	.340*
Mean HbA1c	.362**	-.227	-.058	.310*	-.110

Note. Adolescent depression (CDI) = score on CDI; Couple depression (BDI) = score from parent with highest score on BDI; Couple marital distress (DAS); score from parent with lowest score on DAS; Family Support (FES) = adolescent's factor score; Family conflict (FES) =family aggregate conflict factor score of FES; Guidance-control (DFBS) = guidance-control score; Warmth-caring (DFBS) = warmth-caring score. Greater BDI and CDI scores indicate greater depression. Lower DAS scores indicate greater marital distress. Greater DFBS and FES scores are indicative of greater warmth-caring, guidance-control and greater support and conflict respectively.
[a]Marital Distress (DAS), N = 53. *p < .05 (2-tailed); ** p < .01 (2-tailed).

2. Multivariate Analyses: Relationship Between Adherence to Treatment and Family Relations

To determine whether any of the family relations variables would account for any of the variance in explaining the adherence factors, hierarchical multiple regression analyses were conducted. Because adherence is a multivariate construct, each of the five adherence to treatment factors (injection, diet type, diet amount, eating/testing frequency and exercise) were entered individually as the dependent variables and the demographic and family relations variables were entered as the independent variables. For each regression conducted with the five treatment adherence factors the six family relations variables were always entered together: parental depression (log transformation), parental marital distress (log transformation), general family conflict and support (log transformation), and diabetes-specific family support, (guidance-control). To guard against type 1 error, the alpha level in the multiple regressions was fixed using a Bonferroni correction at .01 (.05/5).

Dependent Variable: Injection Adherence

In the first set of analyses, the injection factor was the first adherence factor entered as a dependent variable. Demographic variable time since diagnosis (square root transformation) was entered at step one. At step two, the six family relations variables were entered together. Time since diagnosis accounted for 6.7% ($R^2 = .067$) of the variance, whereas the family relations variables added another 11.6% ($\Delta R^2 = .116$) of the variance. Table 20 displays the results of this hierarchical regression analysis showing time since diagnosis and family relations variables were not significant in accounting for any of the variance in explaining adherence to the injection aspect of treatment.

TABLE 20.

Hierarchical Regression Analysis, Using Injection Adherence Factor as Criterion Measure, with Family Relations Variables as Predictors, Controlling for Time Since Diagnosis (N = 53)

Variable	B	SE B	β	ΔR^2	F	df	ΔF	dfΔ	p
Step 1									
Time since diagnosis (sqrt)	.726	.379	.259	.067	3.675	1,51	3.675	1,51	.061
Constant =	-1.925								
			R^2 = .067 for step 1						
			Adj R^2 = .049						
			R = .259						
Step 2									
Conflict-FES	-.031	.022	-.299						
DFBS-G-C	.006	.040	.024						
DFBS-W-C	.002	.038	.079						
BDI (log)	-.586	.728	-.116						
DAS (log)	4.270	7.568	.108						
Support -FES	-7.096	5.291	-.212						
Constant =	7.255			.116	1.443	7,45	1.067	6,45	.397
			R^2 = .183 for step 2						
			Adj R^2 = .056						
			R = .428						

Note. sqrt = square root transformation; log = log transformation

Dependent Variable: Diet Type Adherence

The diet type adherence factor was the second dependent variable entered in the next set of hierarchical multiple regression. Again, time since diagnosis was entered at step one and the six family relations variables were entered at step two. Time since diagnosis accounted for only 4.0% (R^2 = .040) and the family relations variables added another 8% (ΔR^2 = .080) of the variance.

Time since diagnosis and the family relations variables were not significant in predicting adherence to diet type adherence factor. Table 21 displays the results of this analysis.

TABLE 21.

Hierarchical Regression Analysis, using Diet Type Adherence Factor as Criterion Measure, with Family Relations Variables as Predictors, Controlling for Time Since Diagnosis (N = 53)

Variable	B	SE B	β	ΔR^2	F	df	ΔF	dfΔ	p
Step 1									
Time since diagnosis (sqrt)	-.546	.375	-.200	.040	2.122	1,51	2.122	1,51	.151
Constant =	1.547								
			R^2 = .040 for step 1						
			Adj R^2 = .021						
			R = .200						
Step 2									
Conflict-FES	.031	.022	.325						
DFBS-G-C	.029	.041	.115						
DFBS-W-C	-.020	.038	-.089						
BDI (log)	-.033	.738	-.007						
DAS (log)	-11.066	7.670	-.286						
Support -FES	-5.109	5.362	-.156						
Constant =	34.489			.080	.873	7,45	.678	6,45	.668
			R^2 = .120 for step 2						
			Adj R^2 = -.017						
			R = .346						

Note. sqrt = square root transformation; log = log transformation

Dependent Variable: Diet Amount Adherence

In the third set of multiple regression analyses, the dependent variable was the diet amount adherence factor. Again time since diagnosis was entered at step one and the family relations variables entered at step two. Time since diagnosis was not significant in predicting adherence to

diet amount adherence factor, whereas the family relations variables were significant in predicting adherence to this adherence factor. The overall model accounted for a significant 32.8% of the variance in explaining the diet amount adherence factor (Multiple R = .573, Adjusted R^2 = .224; $F_{7,45}$ = 3.143, p = .009), with parental depression and general family conflict accounting for most of the variance. Lower levels of general family conflict and parental depression were associated with improved adherence with consuming the prescribed total calories and concentrated sweets (diet amount). Table 22 displays a summary of the results of the regression.

TABLE 22.

Hierarchical Regression Analysis, using Diet Amount Adherence Factor as Criterion Measure, with Family Relations Variables as Predictors, Controlling for Time Since Diagnosis (N =53)

Variable	B	SE B	β	ΔR^2	F	df	ΔF	dfΔ	p
Step 1									
Time since diagnosis (sqrt)	-.314	.297	-.147	.021	1.120	1,51	1.120	1,51	.295
Constant =	1.084								
				R^2 = .021 for step 1					
				Adj R^2 = .002					
Step 2				R = .147					
Conflict-FES*	.052	.015	.650						
DFBS-G-C	.008	.028	.038						
DFBS-W-C	-.017	.026	-.096						
BDI (log)*	1.539	.505	.399						
DAS (log)	-10.282	5.251	-.339						
Support -FES	-1.175	3.671	-.046						
Constant =	21.239			.307	3.143	7,45	3.427	6,45	.007
				R^2 = .328 for step 2					
				Adj R^2 = .224					
				R = .573					

Note. sqrt = square root transformation; log = log transformation; * = significant

Dependent Variable: Testing/Eating Frequency Adherence

In the fourth set of regression analyses, testing/eating frequency was the adherence factor entered as the dependent variable. Again, time since diagnosis was entered at step one and the six family relations entered at step two. The results are depicted in Table 23. Time since diagnosis accounted for 7.9% ($R^2 = .079$) of the variance in explaining adherence to testing/eating frequency factor (Multiple R = .282, Adjusted $R^2 = .061$; $F_{1,51} = 4.397$, $p = .041$). That is, the longer the time since diagnosis, the less frequently they tested their blood glucose levels and ate fewer than prescribed meals. However, taking into consideration the Bonferroni correction level of .01, this finding is not significant. None of the six family relations variables and time since diagnosis were significant in predicting adherence to testing/eating frequency, adding only 5.6% ($\Delta R^2 = .056$) of the variance in predicting the model.

TABLE 23.

Hierarchical Regression Analysis, using Testing/Eating Frequency Adherence Factor as Criterion Measure, with Family Relations Variables as Predictors, Controlling for Time Since Diagnosis (N = 53)

Variable	B	SE B	β	ΔR^2	F	df	ΔF	dfΔ	p
Step 1									
Time since diagnosis (sqrt)	.610	.291	.282	.079	4.397	1,51	4.397	1,51	.041
Constant =	-1.524								
			R^2 = .079 for step 1						
			Adj R^2 = .061						
			R = .282						
Step 2									
Conflict-FES	-.017	.017	-.207						
DFBS-G-C	.017	.032	.085						
DFBS-W-C	.023	.030	.132						
BDI (log)	-.610	.579	-.156						
DAS (log)	.977	6.020	.032						
Support -FES	1.183	4.209	.046						
Constant =	-6.678			.056	1.007	7,45	.486	6,45	.815
			R^2 = .135 for step 2						
			Adj R^2 = .001						
			R = .368						

Note. sqrt = square root transformation; log = log transformation

Dependent Variable: Exercise Adherence

In the fifth hierarchical multiple regression involving adherence exercise factor as the dependent variable, again time since diagnosis was entered at step one and the six family relations variables at step two. Time since diagnosis was not significant in predicting adherence exercise factor, accounting for only 1.4% (R^2 = 0.14), whereas the model was significant in predicting

adherence to the exercise adherence factor (Multiple R = .610, Adjusted R^2 = .275; $F_{7,45}$ = 3.813, p = .002). The model accounted for 37.2% (R^2 = .372) of the variance in explaining adherence to the exercise factor, with diabetes-specific support, guidance-control accounting for most of the variance. The results of the regression analysis with exercise as the criterion variable is depicted in Table 24.

TABLE 24.

Hierarchical Regression Analysis, using Exercise Adherence Factor as Criterion Measure, with Family Relations Variables as Predictors, Controlling for Time Since Diagnosis (N = 53)

Variable	B	SE B	β	ΔR^2	F	df	ΔF	dfΔ	p
Step 1									
Time since diagnosis (sqrt)	.185	.215	.120	.014	.740	1,51	.740	1,51	.394
Constant =	-.459								
				R^2 = .014 for step 1					
				Adj R^2 = -.005					
				R = .120					
Step 2									
Conflict-FES	-.007	.010	-.123						
DFBS-G-C	-.080	.020	-.564						
DFBS-W-C	.131	.018	.106						
BDI (log)	-.401	.352	-.144						
DAS (log)	1.237	3.660	.057						
Support -FES	-.149	2.559	-.008						
Constant =	.096			.358	3.813	7,45	4.278	6,45	.002
				R^2 = .372 for step 2					
				Adj R^2 = .275					
				R = .610					

Note. sqrt = square root transformation; log = log transformation

3. Multivariate Analyses: Relationship Between Family Relations and Metabolic Control

In the next set of analyses, hierarchical multiple regression analysis was performed to investigate the relationship between the family relations variables and metabolic control. The dependent variable was mean HbA1c (time one and time two) (log transformation), while the predictor variables were demographic variable time since diagnosis and the six family relations variables.

Mean HbA1c (time one and time two) (log transformation) was the dependent variable and time since diagnosis (square root transformation) was entered at step one. The six family relations variables were entered at step 2. Results shown in Table 25 indicate that time since diagnosis accounted for a significant 10.4% ($R^2 = .104$) of the variance in explaining metabolic control while none of the six family relations variables were significant, adding only another 1.8% of the variance ($\Delta R^2 = .018$).

In summary, the results of multivariate analyses among the family relations variables and treatment adherence factors and metabolic control, controlling for time since diagnosis, revealed the following: (1) Family relations were not significant in accounting for any of the variance in predicting injection, diet type, testing/eating frequency; (2) The model was significant for predicting diet amount adherence, accounting for 32.8% of variance, with parental depression and general family conflict accounting for most of the variance. That is, lower levels of general family conflict and parental depression were associated with improved adherence with consuming the prescribed total calories and concentrated sweets; (3) The model was significant in predicting adherence to the exercise adherence factor, accounting for 37.2% of the variance, with diabetes specific support, guidance-control accounting for most of the variance; (4) Time since diagnosis was not statistically significant in predicting any of the adherence factors; (5) Time since

diagnosis was significant in predicting metabolic control; (5) None of the family relations variables were significant in predicting metabolic control.

TABLE 25.

Hierarchical Regression Analysis, using HbA1c (Mean of Time One and Time Two) (Log Transformation), as Criterion Measure, with Family Relations Variables as Predictors, Controlling for Time Since Diagnosis (N = 52)

Variable	B	SE B	β	ΔR^2	F	df	ΔF	dfΔ	p
Step 1									
Time since diagnosis (sqrt)	.038	.016	.323	.104	5.824	1,50	5.824	1,50	.020
Constant =	2.041								
				R^2 = .104 for step 1					
				Adj R^2 = .086					
				R = .323					
Step 2									
Conflict-FES	.000	.001	.065						
DFBS-G-C	-.000	.002	-.010						
DFBS-W-C	.001	.002	.103						
BDI (log)	.007	.032	.037						
DAS (log)	-.153	.338	-.091						
Support -FES	-.181	.233	-.128						
Constant =	2.706			.018	.879	7,44	.154	6,44	.987
				R^2 = .123 for step 2					
				Adj R^2 = -.017					
				R = .350					

Note. sqrt = square root transformation; log = log transformation

Exploratory Research Questions

Prior to addressing the exploratory research questions, the results of the Pearson product-moment correlations were computed to evaluate the linear relationships between the five adherence factors, metabolic control and the health behavior variables. The results of these correlational analyses are presented in Table 26. Univariate analyses indicate that more frequent emergency room visits, changes to the insulin regime, and, as expected, more missed insulin injections, are associated with less adherence to injection adherence. More frequent visits to the doctor is associated with worse diet type adherence (calories consumed from carbohydrates and fats) and with worse eating/testing adherence (eating the prescribed number of snacks/meals and blood glucose tests). Those adolescents receiving clinical services from a diabetes clinic are more adherent with the consumption of prescribed total calories and concentrated sweets (diet amount). More frequent emergency room visits is associated with worse metabolic control and less adherence to injection adherence.

1. Exploratory Research Question: Relationship Between Metabolic Control and Adherence to Treatment and Adolescent Depression

Hierarchical multiple regression analyses were conducted to investigate the relationships between metabolic control, diabetes adherence and adolescent depression. Prior to conducting hierarchical multiple regression, assumptions were examined. The assumptions of multiple regression are normal distribution, linearity, homoscedasticity of residuals, and multicollinearity: all were met. Adolescent depression was measured by the log transformed value of the CDI and metabolic control was measured by the log transformed value of mean HbA1c, (time one and time two). Recall that two of the adolescents had not completed the CDI, one adolescent had not returned for HbA1c assay testing at time two, one subject was deleted due to being an outlier and as a consequence the sample size was 51. Adherence to treatment was measured by the five

adherence factors (injection, diet type, diet amount, eating/testing and exercise frequency). First, results of the Pearson product-moment correlations showed that adolescent depression was not significantly correlated with any of the demographic variables, metabolic control, or adherence factors. The results of the correlations can be seen in Appendix G.

The first multiple regression analysis involved mean HbA1c (mean of time one and time two) log transformed values as the dependent variable, and the predictor variables were chronological age, gender, and adolescent depression (log transformed values). The demographic variables were entered at step one and adolescent depression was entered at step two. Controlling for chronological age and gender, adolescent depression (log transformed values) was not significant in predicting metabolic control (Multiple R = .230, Adjusted R^2 = -.008; $F_{1,47}$ = .874, p = .461), accounting for a total of 5.3% of the variance (R^2 = .053).

In the next set of analyses, each of the five adherence factors were entered individually as the dependent variables, chronological age and gender were entered at step one, and adolescent depression was entered at step two. The alpha level of the multiple regression was fixed using a Bonferroni correction at .01 (.05/5). Demographic variables, gender and chronological age, and adolescent depression were not significant in predicting adherence factors, injection, diet amount, diet type and eating/testing frequency, however they were significant in predicting exercise adherence factor (Multiple R = .626, Adjusted R^2 = .368; $F_{2,49}$ = 15.817, p = .000), accounting for 39.2% (R^2 = .392) of the variance. Adolescent depression added a negligible .1% (ΔR^2 = .001) of the variance in predicting exercise adherence factor.

TABLE 26.

Pearson Product-Moment Correlation Matrix Between Five Adherence Factors, Metabolic Control and Health Behaviors (N = 54)

Variable	Factor 1 Injection	Factor 2 Diet type	Factor 3 Diet amount	Factor 4 Eating/testing frequency	Factor 5 Exercise	Mean HbA1c[a]
Diabetes clinic membership	.069	-.264	-.335*	.007	.026	.266
Diabetes clinic visits	-.038	.056	.223	-.217	-.139	-.021
Doctor appointments	.128	-.285*	-.214	-.340*	-.033	.094
Emergency room visits	.274*	-.015	.175	-.057	-.023	.377**
Extra insulin	-.145	.194	.098	-.017	-.120	-.129
Hospital stay	.179	.143	-.035	.115	-.087	.217
Changes to insulin	-.316*	.189	.076	-.164	-.157	.014
Missed insulin injections	.413**	-.100	-.248	-.095	.092	.176

Note. [a] = N = 53
*p < 0.05 (2-tailed). **p < 0.01 (2-tailed)

In summary, not only did adolescent depression fail to provide a significant increment in variance in predicting any of the five adherence factors or metabolic control, it accounted for a negligible amount of variance. Whereas, the demographic variables of chronological age and gender accounted for a significant 39.2% of the variance in predicting exercise adherence factor. That is, older female adolescents were less adherent with exercise adherence. Table 27 presents a summary of the results of the multiple regression analysis of adolescent depression and metabolic control, controlling for chronological age and gender and Table 28 displays the results for the significant exercise adherence factor.

TABLE 27.

Hierarchical Multiple Regression Analysis of Adolescent Depression and Mean HbA1c (Time One and Time Two) (Log), Controlling for Chronological Age and Gender (N = 51).

Variable	B	SE B	β	ΔR^2	F	df	ΔF	dfΔ	p
Analysis 1									
Step 1									
Chronological age	-.002	.006	-.050	.035	.871	2,48	.871	2,48	.425
Gender	-.003	.023	-.181						
Constant =	2.178								
			R^2 = .035 for step 1						
			Adj R^2 =-.005						
			R =.187						
Step 2									
Adolescent depression (log)	.133	.142	.138	.018	.874	3,47	.884	1,47	.352
Constant =	1.972								
			R^2 = .053 for step 2						
			Adj R^2 =-.008						
			R =.230						

Note. log = log transformation

TABLE 28.

Hierarchical Multiple Regression Analysis of Adolescent Depression and Exercise Adherence Factor, Controlling for Chronological Age and Gender (N = 51).

Variable	B	SE B	β	ΔR^2	F	df	ΔF	dfΔ	p
Analysis 1:									
Step 1									
Chronological age	.303	.057	.595	.392	15.817	2,49	15.817	2,49	.000
Gender	.374	.229	.181						
Constant =	-4.718								
				R^2 = 392 for step 1					
				Adj R^2 =-.368					
				R =.626					
Step 2									
Adolescent depression (log)	-.330	1.456	-.026	.001	10.358	3,48	.051	1,48	.822
Constant =	-4.212								
				R^2 = .393 for step 2					
				Adj R^2 = .355					
				R =.627					

Note. Log = log transformation

2. Exploratory Research Question: Stability of HbA1c Assay Values

Although there was a strong positive correlation between HbA1c time one and time two (r=.680, p=.000, 1-tailed), it was queried whether the participants were consistently in control or non-controlled throughout the study and whether a significant number of adolescents improved or deteriorated. The stability of metabolic control over the span of the study was first examined by calculating a cross-tabulation table of HbA1c at time one and time two.

In total, 75.9% of these adolescents displayed stable metabolic regulation throughout the study with 41.5% of adolescents who were metabolically controlled at time one remaining in good

metabolic control at time two and another 34% were non-controlled throughout the entire study. Of the remaining 24% of the adolescents, a group of 15.1% deteriorated from time one to time two. That is, they were in good metabolic control at time one but were non-controlled at time two. A smaller group, 9.4%, improved during the study. The chi-square test was significant with $\chi^2(1, N = 53) = 13.867$, $p = .000$. The results, shown in Table 29, indicated that there was a significant proportion of adolescents who were stable in their metabolic control throughout the study.

TABLE 29.

Cross-Tabulation Proportions Table of Metabolic Control Status as Measured by HbA1c at Time One and Time Two (N = 53)

Metabolic control status at time one and time two	%	n
Stable: Controlled at both time 1 and time 2	41.5	22
Deteriorated: Controlled at time 1 but not time 2	15.1	8
Improved: Controlled at time 2 but not at time 1	9.4	5
Stable: Non-controlled at time 1 and time 2	34.0	18
Pearson chi-square significance, p = .000		

To examine whether there were gender differences in the stability of the results, a cross-tabulation of HbA1c time one and time two by gender was computed and Table 30 displays the results of these cross-tabulation proportions. A violation of assumptions occurred as the expected cell count was less than 5 in three cells. The results need to be viewed cautiously because of the small sample size that likely influenced the results. Despite a third of the males evidencing either a deterioration or improvement in HbA1c blood assay levels during the span of and only 16% of the females deteriorating and none improving during the study, the result of the cross-tabulation computations produced a non-significant chi-square tests $\chi^2(3, N = 53) = 5.789$, $p = .122$. However, there was a trend indicating that more females than males demonstrated good metabolic

control and more males than females were in poor metabolic control at both time one and time two. In summary, while 75% were stable controlled and non-controlled throughout the study, there was no significant difference between males and females.

TABLE 30.

Cross-Tabulation Proportions Table of Metabolic Control Status as Measured by HbA1c at Time One and Time Two by Gender (N =53)

Metabolic control status at time one and time two	Males		Females	
	%	n	%	n
Stable: Controlled at both time 1 and time 2	32.1	9	52.0	13
Deteriorated: Controlled at time 1 but not time 2	14.3	4	16.0	4
Improved: Controlled at time 2 but not at time 1	17.9	5	0.0	0
Stable: Non-controlled at time 1 and time 2	35.7	10	32.0	8
Pearson chi-square significance		.122		

Note. 50% (4 cells) have expected counts less than 5.

3. Exploratory Research Question: Relationship of Attendance at a Diabetes Clinic and Metabolic Control and Adherence

There were 64.8% (n = 35) of the adolescents in this study who received services from a clinic specializing in pediatric diabetes while the remaining adolescents (n = 19) received services only from a pediatrician. The objective of conducting group t-tests was to determine whether the participants receiving services from a diabetes clinic were more adherent to the treatment regime and in better metabolic control than those receiving services uniquely from their pediatrician. Table 31 presents the means, standard deviations, and p values of these analyses. The alpha level of the t-tests was fixed using a Bonferroni correction at .01 (.05/5). Results showed that none of the adherence factors were significant in discriminating between those adolescents who received services from a diabetes clinic or uniquely from their pediatrician.

To investigate whether those adolescents attending a diabetes clinic were in better metabolic control, a cross-tabulation two by two table (HbA1c, time two by diabetes clinic attendance) was calculated. The result of the cross-tabulation table resulted in a non-significant chi-square test χ^2 (1, N = 54) = 2.807, p = .094. In summary, both metabolic control and the five adherence factors were not significant in discriminating between those adolescents who received services from a diabetes clinic or uniquely from their pediatrician.

TABLE 31.

t-tests (2-Tailed) Relationship of Attendance at a Diabetes Clinic and Adherence

Factor	N	Mean (SD)		Df	p
		Diabetes clinic	Pediatrician		
Injection	54	-.169 (2.054)	.111 (1.760)	52	.618
Diet type	54	.504 (1.776)	-.529 (1.970)	52	.054
Diet amount	54	.616 (1.362)	-.432 (1.566)	52	.013
Eating/testing frequency	54	-.026 (1.190)	-.082 (1.190)	52	.963
Exercise	54	-.006 (1.063)	.049 (1.024)	52	.854

4. Exploratory Research Question: Insulin Sliding Scale and Metabolic Control and Adherence

The objective was to examine whether those adolescents using an insulin sliding scale were in better metabolic control and displayed improved adherence to treatment. The injection frequency data and whether the adolescent used a sliding scale or not were used to create two groups. One group administered two insulin injections daily with a fixed amount of insulin, whereas group two consisted of those adolescents who injected between two and four injections daily and adjusted their insulin dosage. That is, the adolescents were grouped according to whether they used an insulin sliding scale or not. There were 35.2% (n = 19) of the participants who were

prescribed a fixed amount of insulin to be injected twice daily. The other 64.8% (n =35) of the participants adjusted their insulin and were prescribed between a minimum of two injections and a maximum of four injections per day. Thus, one group followed a fixed insulin prescription, and the second group used a sliding scale to adjust insulin dosage depending upon self-monitored blood glucose test results.

To investigate whether those participants using an insulin sliding scale were in better metabolic control, a cross-tabulation two by two table (HbA1c, mean of time one and time 2 by insulin sliding scale) was calculated. A cross-tabulation table resulted in a significant chi-square test $\chi^2(1, N = 53) = 4.444$, $p = .035$. Using an insulin sliding scale differentiated between the groups. Of the group who were in poor metabolic control equal proportions were using either an insulin sliding scale or a fixed amount of insulin. In contrast, 31.6% of those in good metabolic control were adjusting their insulin levels and significantly more (61.8%) of the adolescents in good metabolic control were adjusting their insulin to respond to daily blood glucose tests. The cross-tabulation table of insulin sliding scale by metabolic control is displayed in Table 32.

TABLE 32.

Cross-Tabulation Analysis: Insulin Sliding Scale by Metabolic Control, Mean HbA1c (Time One and Time Two)

N = 53; df = 1	Controlled		Non-Controlled	
	n	%	n	%
Insulin Sliding Scale	21	61.8	13	50
Fixed Insulin Amount	6	31.6	13	50
Pearson chi-square significance		.035		

Group t-tests were conducted to detect treatment adherence differences between the adolescents who were using an insulin sliding scale compared to those who were prescribed a fixed amount of insulin. Table 33 presents the means, standard deviations and p values of these analyses. There was a tendency for insulin adherence to be better adolescents using an insulin sliding scale, however, with the alpha level of the t-tests fixed using a Bonferroni correction at .01 (.05/5), this was not statistically significant. In summary, the use of an insulin sliding scale to adjust insulin dosages did not statistically discriminate between those adolescents in good or poor adherence to their diabetes treatment regime.

TABLE 33.

t-tests (2-tailed) of Insulin Sliding Scale and Fixed Insulin Injection by Adherence

Factor	N	Mean (SD)		df	p
		Insulin sliding scale	Fixed insulin injection		
Injection	54	-.494 (1.706)	.651 (2.147)	52	.050
Diet type	54	.194 (1.778)	.051 (2.103)	52	.791
Diet amount	54	.356 (1.445)	.063 (1.635)	52	.496
Eating/testing frequency	54	-.080 (1.240)	.083 (1.525)	52	.671
Exercise	54	-.039 (.922)	.102 (1.236)	52	.636

In summary, the analyses of the relationships between using an insulin sliding scale versus a fixed insulin injection and adherence and metabolic control revealed that: (1) 35.2% of the participants were prescribed a fixed amount of insulin to be injected twice daily and 64.8% of participants who adjusted their insulin were prescribed between a minimum of two injections and a maximum of four injections per day; (2) the five adherence factors did not differentiate between whether they were using an insulin sliding scale or following a fixed insulin prescription regimen; (3) metabolic control was better for those adolescents who were prescribed an insulin sliding scale.

5. Exploratory Research Question: Insulin Omission and Demographics, Adherence, Metabolic Control and Family Relations

There were 27.8% (n = 15) of the sample who had skipped insulin injections between one and seven times during the study. Recall that the dichotomous variable, missing insulin injections, was created by grouping those adolescents who had never missed any insulin injections versus those who had missed at least one injection. First, a cross-tabulation two by two table was conducted to determine whether there was a gender difference between those participants who missed insulin injections. Results showed that overall there were equal numbers of males and females who missed insulin injections, with 25% of the males and 30.8% of the females missing an insulin injection at least once during the study. The cross-tabulation analysis of missing insulin injections by gender is non-significant and is presented in Table 34.

TABLE 34.

Cross-Tabulation Analysis: Missed Insulin Injections by Gender

N = 54; df = 1	Males		Females	
	n	%	n	%
Missed insulin	7	25.0	8	30.8
Never missed insulin	21	75.0	18	69.2
Pearson chi-square significance		.636		

Second, a cross-tabulation was conducted to determine whether there was an age difference between those participants who missed insulin injections and those who did not miss any injections. Results showed that overall there was no age differences for the adolescents who missed insulin injections $\chi^2(1, N = 54) = 1.630$, $p = .443$. The cross-tabulation analyses of missing insulin injections by chronological age are presented in Table 35.

TABLE 35.

Cross-Tabulation Analysis: Missed Insulin Injections by Chronological Age

N = 54; df = 2	11 to 13 years		14 to 15 years		16 to 18 years	
	n	%	n	%	n	%
Missed insulin	6	37.5	3	17.6	6	28.6
Never missed insulin	10	62.5	14	82.4	15	71.4
Pearson chi-square significance				.443		

Third, in the next analysis, a cross-tabulation table was conducted to ascertain whether the group of adolescents who were missing their insulin injections were in worse metabolic control than those who had never missed an insulin injection. This cross-tabulation two by two table consisted of the dichotomous variable missing insulin injections and the dichotomous HbA1c, mean of time one and time two. The majority of those who were metabolically regulated had never missed an insulin injection (85.2%, $\underline{n}$ = 23). Although 42.3% ($\underline{n}$ =11) of the adolescents who were metabolically non-controlled were missing insulin injections, there was a small group (14.8%, $\underline{n}$ = 4) who were controlled. There was a larger proportion of adolescents (57.7%, $\underline{n}$ = 15) who had never missed an insulin injection who were non-controlled. Overall, there was a significant difference in metabolic control for the adolescents who had missed insulin injections $\chi^2(1, \underline{N} = 53) = 4.934$, $p = .026$. Table 36 presents the cross-tabulation results of missed insulin injections by metabolic control.

TABLE 36.

Cross-Tabulation Analysis: Missed Insulin Injections by Metabolic Control, Mean HbA1c (Time One and Time Two)

N = 53; df = 1	Controlled		Non-controlled	
	n	%	n	%
Missed insulin	4	14.8	11	42.3
Never missed insulin	23	85.2	15	57.7
Pearson chi-square significance		.026		

Fourth, to examine whether adolescents who received care from a diabetes clinic missed insulin injections more or less frequently than the group of adolescents receiving services from their pediatrician, a cross-tabulation two by two table of receiving services of a diabetes clinic by the dichotomous missing insulin variable was performed. Table 37 presents the results of these calculations. Although slightly more (36.8%) of the adolescents who were being treated by pediatricians compared to 22.9% of those being treated at a diabetes clinic had missed insulin injections, there was no statistically significant difference between the groups.

TABLE 37.

Cross-Tabulation Analysis: Missed Insulin Injections by Diabetes Clinic Attendance

N = 54; df = 1	Missed insulin injection		Never missed insulin injection	
	n	%	n	%
Diabetes clinic attendance	8	22.9	27	77.1
Pediatrician care only	7	36.8	12	63.2
Pearson chi-square significance		.273		

Fifth, group t-tests were conducted to detect differences on family relations and adherence factors between adolescents who had missed insulin injections and those who had not missed any injections. The critical significance level was set at .008 (.05/6) for the family relations variables and at .01 (.05/5) for the adherence factors. None of the family relations variables and none of the adherence factors were statistically significant in discriminating between those adolescents who omitted insulin injections. However, there was a trend indicating that three of the family relations, more family conflict, more parental depression and less family support, were associated with omitting insulin injections. Table 38 presents the t-tests involving the family relations variables and Table 39 presents the t-tests involving the adherence factors.

TABLE 38.

t-tests (2-tailed) of Insulin Omission and Family Relations

Factor	N	Mean (SD)		df	p
		No insulin omissions	Insulin omissions		
Aggregate family conflict (FES)	54	-59.38 (17.17)	-45.40 (18.97)	52	.012
General family support (FES) (log)	54	2.39 (.05)	2.36 (.05)	52	.043
Diabetes-specific support warmth-caring (DFBS)	54	54.33 (8.21)	54.40 (8.75)	52	.320
Diabetes-specific support guidance-caring (DFBS)	54	38.38 (7.09)	37.93 (9.22)	52	.848
Marital distress-couple (DAS) (log)	54	2.04 (.49)	2.02 (.43)	52	.979
Parental depression-couple (BDI) (log)	54	101 (.31)	.78 (.38)	52	.041

Note. FES = Family Environment Scale; DFBS = Diabetes Family Behavior Scale; DAS = Dyadic Adjustment Scale; BDI = Beck Depression Index; log = log transformed value

TABLE 39.

t-tests (2-tailed) of Insulin Omissions and Adherence Factors

Factor	N	Mean (SD)		df	p
		No insulin omission	Insulin omission		
Injection	54	-.403 (1.561)	.795 (2.563)	52	.041
Diet type	54	.345 (1.800)	-.391 (2.067)	52	.202
Diet amount	54	.483 (1.438)	-.364 (1.569)	52	.064
Eating/testing frequency	54	.018 (1.188)	-.120 (1.721)	52	.738
Exercise	54	-.022 (1.065)	.106 (1.003)	52	.689

In summary, employing a Bonferroni correction to guard against a type 1 error, the analyses of the relationships between missing insulin injections with chronological age, gender, type of treatment received, family relations, adherence and metabolic control revealed that: (1) 27.8% of the adolescents had missed an insulin injection during the span of the study; (2) the group who had missed insulin injections was in worse metabolic control; (3) there was no gender difference between the groups; (4) there were no age differences between the groups; (5) receiving medical care from a diabetes clinic or from a pediatrician did not influence whether an adolescent omitted insulin injections; (5) there were no significant family relations variables which influenced insulin omissions; and, (6) adherence to the treatment regime was comparable for both groups.

6. Exploratory Research Question: Gender and Chronological Age Patterns of Parental Involvement and Adolescent Independence in Four Aspects of Adherence

The four aspects of the diabetes treatment regime where parental involvement in the regime was measured included involvement in meal planning, exercise, blood glucose testing, and the injection of insulin. A Bonferroni correction at .0125 (.05/4) was fixed to guard against type 1 error. First, a cross-tabulation two by two table of age, in three age groupings, by each aspect of

the treatment regime was conducted. The subjects were grouped according to the following age groups: 11-13 years, 14-15 years of age, and 16-18 years of age. The four aspects of the diabetes regimen were responsibility for meal planning, blood glucose testing, preparing and injection of insulin and exercise. These four aspects of the diabetes regime were coded as dichotomous variables with either the adolescent being totally independent with the adherence behavior or the parent sharing involvement in the responsibility for adherence behavior. The results of these cross-tabulation analyses are depicted in Table 40. A violation of assumptions occurred as several cells had expected frequency counts of less than 5 cases, a proportion which exceeds the recommended 20% (Evans, 1998). The results need to be viewed cautiously because of the small sample size that likely influenced the results. Results showed that there was a gradual increase in independence for each aspect of the regime, with blood glucose testing the responsibility of 81.3% of the adolescents by age 11 to 13, whereas, both injection and exercise components were the shared responsibility of the parent and adolescent in the 11 to 13 age range. With the exception of the meal aspect of the regime, responsibility for blood glucose testing, injection and exercise aspects of regime were the responsibility of the adolescents by 16 to 18 years. Parents remained involved in the meal aspect of the regime for the majority of the adolescents up until 14-15 years of age and remained involved for 19% of the 16 to 18 year olds.

TABLE 40.

Cross-Tabulation Analyses: Age Level by Adolescent Rather Than Parental Responsibility for Aspects of Adherence to Treatment Regime

Age	Meal		Blood glucose testing		Injection		Exercise	
N = 54; df = 2	n	%	n	%	n	%	n	%
11 to 13	4	25.0	13	81.3	8	50.0	9	57.3
14 to 15	5	29.4	16	94.1	14	82.4	13	76.5
16 to 18	17	81.0	21	100.0	20	95.2	21	100.0
Pearson chi-square significance	.001		.094[a]		.001[a]		.004[a]	

[a]3 cells have expected count less than 5

Second, a cross-tabulation of age in three age groupings by each aspect of the treatment regime by gender was conducted, with an alpha set at .025 (.05/4), to examine whether there was a difference between groups regarding parental involvement in treatment regime. A violation of assumptions occurred as several cells had expected frequencies of less than 5 cases, a proportion which exceeds the recommended 20% (Evans, 1998). The results need to be viewed cautiously because of the small sample size that likely influenced the results. There are some clear gender trends in the patterns of independence with each of the four aspects of the diabetes treatment regime that emerged. The results are presented in Table 41. The males were independent at an earlier age across all other aspects of the treatment regime. More males were given responsibility for meal planning in the 11 to 13 year range (50%) compared to none of the females, but then slightly more females were responsible for this aspect within the two older age groups. There was still parental involvement in meal planning in the 16 to 18 age group with 78% of the males and 83% of the

females being independent. All of the males were responsible for insulin injection at age 14-15 compared to only 50% of the females, with only one male was not independent within the 16 to 18 age group. The most marked gender difference was with the exercise component of the regime. The vast majority of males (87.5%) within the 11 to 13 age group were independent for exercise, whereas, only 15% of the females were independent.

TABLE 41.

Cross-Tabulation Analyses: Age Level by Adolescent Rather Than Parental Responsibility for Aspects of Adherence to Treatment Regime by Gender

Age	Meal		Blood glucose testing		Injection		Exercise	
N = 54; df = 2	n	%	n	%	n	%	n	%
Females (n = 26)								
11 to 13	0	.0	5	62.5	3	37.5	2	15.0
14 to 15	2	33.3	5	83.3	3	50.0	4	66.7
16 to 18	10	83.3	12	100.0	12	100.0	12	100.0
Pearson chi-square significance	.001b		.074b		.006a		.002b	
Males (n = 28)								
11 to 13	4	50.0	8	100.0	5	62.5	7	87.5
14 to 15	3	27.3	11	100.0	11	100.0	9	81.8
16 to 18	7	77.8	9	100.0	8	88.9	9	100.0
Pearson chi-square significance	.080a		not computed		.066b		.417a	

[a] 4 cells have expected count less than 5
[b] 3 cells have expected count less than 5

CHAPTER 4: DISCUSSION OF STUDY RESULTS

The two primary purposes of this research were first, to identify whether there is an association between treatment adherence using a multivariate conceptualization of adherence and metabolic control, and, second, to examine the relationships between diabetes care, as indexed by treatment adherence and metabolic control, and the family relations variables. These adolescents were a community sample with Type 1 diabetes from Northern and Central rural areas, towns and small urban cities in Ontario who were receiving secondary care services from diabetes clinics and pediatricians. As a field study, the secondary exploratory research objectives examined the possible associations between treatment adherence, metabolic control, demographics and adolescent depression, as a measure of child adaptation, and selected health behaviors. This chapter begins with a discussion of the relationship between metabolic control and treatment adherence (hypothesis one). Then, the stability of metabolic control comparing HbA1c assay values at time one and time two in this sample of adolescents is discussed (exploratory research question two). The role that family relations play in diabetes adherence and metabolic control is discussed (hypothesis two). Whether metabolic control and treatment adherence is associated with adolescent depression is addressed (exploratory research question one). The four remaining exploratory research questions focus upon health behavior links with metabolic control, treatment adherence, demographics and family relations. The generalizations and limitations from this study are then considered. Finally, the clinical implications and suggestions for future research are advanced.

First Hypothesis: Relation between Adherence and Metabolic Control

The first hypotheses of this study stated that:

Greater treatment adherence to a diabetes regimen will be associated with better metabolic control. However, both metabolic control and treatment adherence will be less the more time since diagnosis increases.

The statistical analyses conducted do not support a relationship between treatment adherence and metabolic control. However, there is partial support for hypothesis one as statistical analysis revealed that the longer the time since diagnosis, the worse the metabolic control. While the adherence factors as a model accounted for 20% of the variance, time since diagnosis accounted for a significant 9.7% of the variance in predicting metabolic control. Despite using the 24-hour recall interview, which provides a multivariate conceptualization of adherence and is an improved method of measuring adherence, low power (.25) may have contributed to the lack of significance. The small sample size likely attenuated the results.

The other reason for the lack of significance may be that since HbA1c provides a measure of the average glycemic levels over the past three months, it does not provide any indication of variability of glucose levels during this period. Whether an individual experienced hypoglycemia or hyperglycemia episodes would not be evidenced from the HbA1c assay value. Thus, despite HbA1c being considered the gold standard in the measurement of metabolic control, it would not necessarily be reflective of repeated measures of adherence because it would not be sensitive to variability of glucose levels or variability in adherence.

The results from this study are in contrast to findings from other studies which have used the 24-hour recall interview. Kuttner et al. (1990) found an association between exercise adherence and testing/eating frequency and glycemic control. Bennett Johnson et al. (1990) found an association between HbA1c and calories consumed, and Bennett Johnson et al. (1992) found an association between testing/eating frequency adherence and glycemic control. Despite the solid reasoning that improved treatment adherence is associated with improved metabolic regulation, research over the years has been mixed in supporting this relationship. Whether there is a direct relationship between improved treatment adherence to a diabetes regime and improvement in metabolic control as measured by HbA1c remains equivocal, whereas, there is more support for poorer metabolic control the longer the time since diagnosis.

Time since diagnosis has emerged as a finding common to numerous other studies in addition to

this one (Anderson et al., 1990; Hanson et al., 1989; Kovacs et al., 1990; Wysocki et al., 1992). Some researchers believe the association between longer time since diagnosis and poorer metabolic control may be the product of normal developmental processes associated with physiological and hormonal changes and insulin resistance which can occur during puberty (Amiel et al., 1986; Hanson et al., 1989). These findings suggest that there is a process of change in metabolic control that occurs during adolescence when adolescents have had diabetes for longer. Of course another explanation may be that perhaps adolescents are taking on more responsibility for their regime because there is an assumption that they are now able to manage their regimes fairly independently after having done so for a long time. Also, considering that more than a third (37%) of the adolescents in this study changed their insulin dosage either one or two times during the study, there is also the possibility that some adolescents did not believe that adhering to their regime would result in more stable metabolic control. This would be particularly important considering the more frequent insulin changes that may be required to deal with the physical growth and hormonal changes of puberty (Amiel et al., 1986). Adolescents at the pre-formal stage of thinking may believe that diabetes self-care behaviors are ineffective and that as a consequence they would feel less control over their diabetes (Brotman et al., 1990).

Another explanation relates to whether they feel the treatment regime is adequate and whether they believe it works. There were some adolescents who were unaware of their HbA1c assay results and of the significance of the readings. Additionally, despite the importance of the dietary component of the treatment regime, 30% of these adolescents were not following a meal plan and within the group who did have a meal plan, several were following plans which were more than a year old. It is quite reasonable to question how these adolescents would be expected to feel a sense of competence in following a diabetes treatment regime when obviously they were not provided with an adequate regimen.

While the commuted mean HbA1c assay results at time one and time two of this study were within the mid-range when compared to other studies, it is of interest to examine what proportion of these

adolescents were in acceptable and poor metabolic control. As already discussed, the acceptable clinical range of metabolic control according to CDA is less than 140% of the upper range of the normal non-diabetic HbA1c assay reference range (Catellier et al., 1992). This acceptable range of metabolic control is conservative as it is higher than non-diabetic HbA1c assay levels. In this study, using the CDA cut-off, just over half of the adolescents, 57.40% at time one and 50.90% at time two, were considered to be within the acceptable range of metabolic control, as measured by HbA1c assay levels. This represents an alarming large proportion of adolescents who are experiencing difficulty maintaining blood glucose levels within acceptable target levels. While there is a move toward maintaining blood glucose levels to within non-diabetic HbA1c assay levels since the recent results of the Diabetes Control and Complications Trials (DCCT) have been published (Catellier et al., 1992), the CDA has not revised the targets for control of diabetes. If the targets for control of diabetes were revised to be within non-diabetic HbA1c assay levels of 7-8 mmol/L (the optimal range is considered to be within normal non-diabetic HbA1c assay value range, a range less than 110%), the proportion of non-controlled adolescents would be even greater. That is, only a small group of these adolescents, 15 and 26% respectively at time one and time two, would be within the optimal range of metabolic control.

In addition to half (49.10%) of the adolescents in this study being in poor metabolic control at time two and 42.60 at time one, they also experienced great difficulty adhering to the treatment regime. This group of adolescents was adherent only with ingesting within 10 to 15% of concentrated sweets and only approached adequate adherence to timing their injections with meals eaten. Otherwise, they were not adherent with the other eleven aspects of the diabetes treatment regime and did not approach adherence on any of the self-care measures.

Moreover, despite employing the more conservative prescribed regime as a comparison standard rather than the ideal recommended treatment regime which was more stringent, compared to other studies in which the 24-hour recall interview was used (Bennett Johnson et al., 1986; Bennett Johnson et al., 1992;

Freund et al., 1991; Kuttner et al., 1990), a comparison of means indicated that the adolescents in the present study differed in terms of treatment adherence in several ways. The insulin injection times varied markedly from day to day but they were the closest to the prescribed in the timing of injections with meals. Although this is not a qualitative study, an observed difficulty with maintaining a fixed injection time in this population related to leading a less structured life style. Following a diabetic regime presented a challenge because these adolescents often retired and rose at various times, especially on weekends and during the summer holidays. Frequently adolescents would wake up early, complete their insulin routine, eat breakfast, and then return to bed. Attending school provided some structure to their lives. As an example of familial adaptability, one concerned mother woke her daughter with breakfast on a platter and handed her a syringe of insulin to accommodate her daughter's habit of sleeping in during holidays and weekends. Blood glucose testing was the only self-care behavior which was superior to levels of adherence in these other studies. Overall, the study sample was rather physically inactive when compared to the adolescents and children recruited from samples from summer camps and diabetes clinics in these other studies.

As a final point, the results of this study are congruent with the findings from previous studies that found that adherence is a multivariate construct with differing levels of adherence to each self-care aspect of the regime (Bennett Johnson et al., 1986; Bennett Johnson et al., 1992; Schafer et al., 1983). However, inconsistent with the results from Bennett Johnson et al. (1986) and Bennett Johnson et al. (1990), there were numerous correlations between the factors. The five adherence factors were not separate dimensions in this study. It was nevertheless important to maintain the factor structure of the 24-hour recall interviews as developed by Bennett Johnson and her colleagues to enable comparison of the results.

Exploratory Research Question: Stability of Metabolic Control Throughout Study

The second exploratory research question stated:

Is there deterioration, maintenance or improved metabolic control over the span of the study? Are

there gender and chronological age differences in the stability of metabolic control during the study?

In addition to there being a strong correlation (r = .680) between HbA1c time one and time two, metabolic control was consistent for 75% of the adolescents throughout the study. These results show that while patterns of metabolic control appear to be rather stable for 42% of the adolescents in good metabolic control and 34% of those in poor metabolic control, a quarter demonstrated variable control. That is, they deteriorated or improved, over the three month period of study. Moreover, there was no statistically significant difference according to gender.

Certainly these results need to be interpreted cautiously because of the violation of conditions, as cells had fewer expected counts than the 20% (Evans, 1998). Nevertheless, results indicate that a trend exists with more females than males demonstrating good metabolic control and more males than females in poor metabolic control at both time one and time two. That is, the proportion of males in poor metabolic control was 32.1% compared to 52% of the females.

The findings are mixed on the influence of gender and metabolic control in the literature with few reported gender trends. The gender differences in metabolic control found in this study are similar to those of Allen et al. (1992) who also found that females exhibit greater metabolic control. They found that glycemic control, in a group of 10 to 19 year olds, stabilized during the second year after being diagnosed with IDDM, except in male students. In contrast, Kager and Holden (1992) found that females between the ages of 7 and 15 were in worse metabolic control compared to the males. Also in contrast, Hanson et al. (1987a) found that black adolescent females displayed worse metabolic control than either the male or female White or Black groups to which they were compared.

Second Hypothesis: Relation Between Family Relations and Adherence and Metabolic Control

The second hypothesis stated:

Controlling for time since diagnosis, adolescents who are less adherent to a diabetes treatment regime and metabolically non-controlled will display family functioning characterized by lower

levels of general family support, higher levels of general family conflict, lower levels of diabetes-specific family support (guidance-control and warmth-caring), higher levels of parental depression and higher levels of marital distress compared to adolescents with good adherence to treatment and good metabolic control.

Differing patterns of relationships emerged between each of the five adherence factors and the family relations and time since diagnosis. Family relations were not significant in accounting for any of the variance in predicting injection, diet type and testing/eating frequency adherence factors and metabolic control. Whereas, time since diagnosis was significant in accounting for 9.97% of the variance in predicting metabolic control, it was not significant for any of the adherence factors. On the other hand, family relations, as a model, was significant in predicting two of the adherence factors.

First, diet amount adherence factor was predicted by the family relations variables with parental depression and general family conflict accounting for most of the variance. That is, higher levels of general family conflict and parental depression were associated with consuming more than the prescribed total calories and concentrated sweets (diet amount factor). Adolescents who consumed more than the prescribed total calories and concentrated sweets were from families who describe more general family conflict and increased parental depression. The correlation between conflict and diet amount adherence at the univariate level was $r = -.304$, $p < .05$, which indicates that more conflict was associated with less adherence. It would seem likely that depressed parents would be less involved in the daily regime, and more specifically the requirements of ensuring that daily meals are provided and snacks available, thus making adhering to a proper diet difficult. A post hoc calculation resulted in an effect size of .49 for the diet amount factor and corresponding power of .95 (Appendix H).

A systems social/ecological model of adaptation supposes that there is circular causality with interdependency among family members rather than cause and effect. From this perspective it is reasonable to question the mechanism by which family conflict and parental depression may influence adherence.

Researchers in pediatric chronic illness have consistently demonstrated a relationship between family conflict and diabetes, with an increase in parent conflict negatively affecting both metabolic control and diabetes adherence (Anderson et al., 1990; Hanson et al., 1992; Hauser et al., 1990; Miller-Johnson et al., 1994; Minuchin et al., 1975; Shafer et al., 1983; Wysocki, 1993). As already discussed, there is also a large empirical body of research showing that the psychological adjustment of children is affected by parental depressive symptoms and that parental depressive symptoms are in turn associated with parent-reported child behavioral/emotional problems (Beardslee et al., 1983; Burbach & Borduin, 1986; Downey & Coyne, 1990; Rutter, 1990). There are also numerous studies which have suggested both direct and indirect mechanisms which explain the effect of conflict on children, in addition to its influence on parenting (Emery et al., 1992). Moreover, an association between family discord and parental depression in the general populations has been found (Gotlib & Hooley, 1988; Rutter & Quinton, 1984). Researchers have also found that there is difficulty in achieving positive parent-child relations in the presence of parental depression because of the lack of parental availability as this interferes with parenting (Rutter & Quinton, 1984).

These findings provide some evidence to suggest that increased parental depression and increased family conflict create a family climate that may interfere with the parenting functions associated with the additional responsibilities related to the diet amount aspect of the diabetes regime. The dietary component of the regime may be more vulnerable to the effects of family conflict and parental depression because this is the domain which parents remain involved in for longer and also because parents do hold responsibility for the food available in the home. Using adherence to the medical treatment regimen as an index of effective coping, perhaps the mechanisms that accounts for the association between depression and parenting can be explained by the reduced effort put forth by parents in interacting with their child and the hostile, negative and coercive characteristics of the interactions. Conflict and parental depression would affect parental engagement in meal planning as this would entail grocery shopping, ensuring adequate food

is available, and having balanced meals prepared on a regular basis. There is also the possibility that adolescents may be avoiding eating at home or that general family routines around meal times have weakened because of the increased familial conflict and parental depression. Such a disruption of the rituals around meals in families who are experiencing conflict and parental depression may also be a typical finding of adolescence and their families and may not be diabetes-specific. Regardless of whether it is typical, it has serious implications for the adolescent with diabetes.

Second, family relations was also significant in predicting exercise adherence with diabetes-specific support, guidance-control, explaining most of the variance. A negative correlation ($r = -.551$, $p < .01$) between exercise adherence and diabetes support, guidance-control indicates that more parental involvement in the regime is associated with greater exercise adherence. Recall that a greater exercise adherence score indicates the person exercised less than possible. Furthermore, analyses involving depression as a predictor variable found gender and chronological age to be significant demographic variables accounting for 39.2% of the exercise adherence factor. That is, older female adolescents were less adherent with exercise adherence. A post hoc calculation resulted in an effect size of ..592 for the exercise factor and corresponding power of .98 (Appendix H).

The significant relationship between diabetes-specific support, guidance-control, and exercise adherence can be understood in terms of a combination of several individual, societal and family factors which might influence whether physical activity is part of an adolescent's lifestyle. In the general population, females are collectively less engaged in exercise in our society and an increasing number of children are being identified as obese (King, Boyce & King, 1999; LeBow, 1995). Physical activity is not a priority within the school system either. For example, at least in Northern Ontario, physical education within the school curriculum is presently considered an option beginning in grade 10. Therefore, physical activity is completely the responsibility of the individual after age 14. Unless physical activity is considered a part of the family's routine or part of the adolescent's range of interests, it will not likely

become a part of an adolescent's way of life. An alternative position could be that excessive exercise by males may be a form of denial of their illness and should be viewed as a health-compromising behavior. Whether this is indeed the case, would require that further evaluation be conducted. In addition to excessive physical activity possibly being a form of denial, it may also be an active attempt to control glucose levels. The implications for intervention would of course differ depending upon the finding.

Leading a sedentary lifestyle is of particular concern for the adolescent with diabetes as there is a greater risk for developing diabetes related complications (Catellier et al., 1992). Although there are benefits to be derived from engaging in regular exercise, in IDDM there are risks of hypoglycemia during or after exercise or of worsening metabolic control if insulin deficiency is present (Horton, 1988). Thus, engaging in exercise may make diabetes difficult to manage and this may make exercise aversive. These findings suggest that the lack of involvement in exercise relates to families providing less guidance and control over the exercise aspect of the regime. This also provides some indication that females are more vulnerable to leading a sedentary life style when there is less parental involvement. At the univariate level, the correlation between years married and exercise adherence is ($r = .340$, $p \leq .05$), which also supports the contention that older parents would provide less support for exercise, perhaps because they are less involved themselves.

The link between guidance-control diabetes-specific support and adolescent adherence to the exercise component of the diabetes regime also finds support in the view presented by Baumrind (1991). Perhaps there has been an overemphasis on the need for emotional detachment and freedom from parental control during adolescence. Baumrind (1991) and Maccoby and Martin (1983) found that an authoritative parenting style, which is defined as being high on both control and warmth, has been associated with the most positive outcome throughout childhood and adolescence. Parents with an authoritative parenting style were able to set clear limits on behavior within a context of a warm and loving parent-child relationship. Based on their findings, perhaps a more balanced approach to parenting, that involves both dimensions of

control and emotional responsiveness, is required to facilitate optimal adolescent development as it relates to adhering to a treatment regime. The findings from this study suggest that parents may balance these dimensions differently for their male and female adolescent children and that there are differential effects on adherence and metabolic control.

In summary, there is partial support for hypothesis two with increased general family conflict and parental depression being associated with less adherence to the diet amount component of the regime and less diabetes-specific guidance-control being associated with reduced adherence to the exercise aspect of the regime with older females leading sedentary lives. Post hoc power analyses indicated that there was insufficient power for the family relations variables to find an association with both the diet type and the testing/eating frequency adherence factors (.40 and .50 respectively) and just acceptable power (.60) for the injection factor (Appendix H). Although family relations are linked with adherence, an association between family relations and metabolic control was not found in the present study. Multivariate analysis found that only time since diagnosis was influential, accounting for 10.4% of the variance in explaining metabolic control.

While, there has been inconclusive evidence for the role of diabetes-specific versus more general measures of family support, similar to other studies, the results of this study demonstrate support for the role of both general measures of family functioning and diabetes-specific measures of diabetes support in understanding diabetes management (Hanson et al., 1992; McKelvey et al., 1993; Schafer et al., 1986). In the context of the systems social/ecological model of adjustment and coping in chronic illness, the findings in this study show that the quality of family relationships are indeed additional risk factors vis-à-vis the management of a diabetic regime and metabolic control. Also, these findings support the opinion expressed by other researchers that family relations do not directly influence metabolic control but do so by their influence on adherence (Hanson et al., 1989; Schafer et al., 1983). These results provide evidence for the complexity of the relations which may influence diabetes management. These differing patterns of

relationships which emerged between family relations and adherence support both the multivariate conceptualization of treatment adherence in diabetes and the relevance of both diabetes-specific family support and general family functioning, with conflict being most predictive in addition to parental depression.

How do the results on the family relations measures from this sample compare with other studies in the literature? First, marital distress was higher in this population of parents when compared to available reference groups. The results of the present study are higher than the results of the Dahlquist et al. (1993) study which found proportions of 25% and 28% for the wives and husbands respectively using the DAS in a population of couples with a child newly diagnosed with cancer. Similarly, Geiss et al. (1992) found that 28% of the mothers of children with cystic fibrosis reported marital distress. In general, the proportions of marital distress were slightly higher than other studies to which they were compared, with just over a third of the fathers (35%) and a third of the mothers experiencing marital distress. When the lowest DAS score was selected from each couple (a score indicative of greater marital distress), half of the parents as a group (50.9%) were experiencing marital distress. Considering this was a correlational study of adolescents with diabetes and their parents, and not a study of parents in therapy, nor of parents seeking therapy, this is quite a high percentage of parents who were experiencing marital distress.

Despite such a large proportion of maritally distressed parents being identified, it is noteworthy that marital distress did not emerge as a significant variable in explaining adherence or metabolic control. The reason for this finding is likely related to the lack of power: Power was .33. Moreover, a low reliability coefficient (.56) for the Dyadic Adjustment Scale in this study sample might also have contributed to the lack of findings.

While the small sample size and large number of analyses may have attenuated the results because of low power, the influence of such a high proportion of maritally distressed parents on their children's functioning in perhaps other areas not assessed by this study would nevertheless be quite likely. Although

marital distress did not emerge as a significant variable in any of the analyses, an association between marital conflict and child behavioral adjustment is unequivocal within the current developmental perspectives on child adaptation (Fincham, 1998; Masch & Barkley, 1989). Although marital distress is not significant at the univariate level with any of the adherence factors or with metabolic control, there is a strong negative correlation between family conflict and marital distress ($r=-.655$, $p = .01$, 2-tailed) which indicates that increased general family conflict is associated with increased marital distress (lower score). While it is family conflict, not marital distress, which is associated with less adequate diet amount adherence in this study, there is a strong trend for conflict to be associated with other dependent variables as well. In the analyses involving insulin omission, general family conflict was not statistically significant when a Bonferroni correction was applied. However both conflict and parental depression, along with family support, emerged as strong predictor variables that indicate a trend in the study. It is possible that a larger sample may have resulted in a statistically significant result.

Second, the findings on parental depression are characteristic of other studies. That is, just over a quarter of the mothers (27.3%) experienced depressive symptoms as measured by the BDI, whereas, less than one fifth (18.2%) of the fathers self-reported depressive symptoms. This correlational study was not designed to examine psychopathology within the selected population but to examine the presence of self-reported depressive symptoms in parents with a chronically ill child. The BDI was chosen as a measure of self-rated parental depressive symptoms because of its good reliability, validity and extensive use in research and clinical practice. Because the BDI is not meant to provide a clinical diagnosis of depression, it is recognized that the diagnosis of clinical depression would need to be conducted with a clinical interview or follow a taxonomy such as that of the DSM-IV 4th edition (American Psychiatric Association, 1994).

Even though the BDI cut-off point of 10.9 used in this study was conservative, there were mothers who did not score within the clinical range of depression despite reporting taking antidepressant medication,

being hospitalized following the diagnosis of their child with diabetes, and being frequently admitted to hospital for depression. These mothers shared that they participated in the study because they were doing well at the time of the study. Because the BDI instructions direct answering the questions as they relate to the previous two weeks, the findings do not reflect long-term emotional adjustment. Consequently, the results of the BDI likely underestimated the proportion of mothers who have experienced depressive symptoms. These mothers would probably not have participated in the study had they been experiencing any significant depressive symptoms.

Nevertheless, the mother's self-reports of depression were similar to Hauenstein et al. (1989) who found 33% of the mothers of children with diabetes were depressed. Similarly, 34% were experiencing significant anxiety and depression in the Thompson et al. (1992) study of the adjustment of mothers of both children and adolescents with cystic fibrosis. In conclusion, the proportion of mother's self-reported depressive symptoms in the present study is comparable to other studies of populations of parents with a chronically ill child, but the father's results may be lower than other studies. However, since studies of fathers of chronically ill children have been infrequently studied, comparability of results is limited. Consistent with the extant literature, these results support the premise that mothers are at increased risk for greater emotional adjustment difficulties when compared to fathers. This increased risk is maybe related to mothers assuming responsibility for more of the emotional and practical daily diabetes responsibilities. There would be a pile up of additional stressors, as caring for a child with a chronic illness requires unrelenting vigilance and is a constant burden.

Third, with regard to diabetes-specific and general family support, a comparison of means of the DFBS of the present study with the results of the McKelvey et al. (1993) study indicates that diabetes-specific family support, as measured by guidance-control, is similar, whereas the adolescents in this study perceived that their families offered more diabetes-specific warmth-caring. These adolescents also perceived their family's overall level of general support and conflict as measured by the FES to be similar

to other studies within pediatric diabetic populations which used this measure (Kronenberger & Thompson, 1990).

In summary, this group of adolescents, parents and families is fairly typical of other studies involving a chronically ill child in terms of level of parental depression and general family functioning and differed in terms of the adolescents perceiving their parents as providing more diabetes-specific family support warmth-caring. While compared to norm referenced studies, there was a greater proportion of couples experiencing marital distress, using the Gordon Walker et al. (1992) cut-off for marital distress would have resulted in even greater proportions of couples with marital distress.

First Exploratory Research Question: Relation between Adolescent Depression and Family Relations and Metabolic Control and Adherence

The first exploratory research question of the present study stated that:

> Is adolescent self-reported depressive symptoms associated with worse metabolic control and less treatment adherence to a diabetes regime? Does self-report of depressive symptoms increase with advancing chronological age and will there be a greater proportion of females who self-report depressive symptoms?

Adolescent depression was not associated with decreased metabolic control and poorer treatment adherence. There were 15.4% of these adolescents who scored within the depressed range on the CDI. The examination of the incidence of depression in this adolescent population and its possible association with worse metabolic control and treatment adherence are of interest because depression is most commonly found in adults with IDDM (Gavard et al., 1993). In the 10 year longitudinal study of children with IDDM by Kovacs et al. (1997) it was found that 26% of the children were diagnosed with major depressive or dysthymic disorder using standardized and semi-structured interviews. Considering that young women with diabetes were at a nine times greater risk for recurrent depression than males in the Kovacs study, the findings in this study provide an early indication that depression, as a measure of adjustment, is not a

psychological condition that is associated with health status and treatment adherence in diabetes as adolescents move into adulthood.

Whereas in this study adolescent depression is not isolated as a factor which contributed to worse metabolic control or to poorer diabetes treatment adherence, these findings are in contrast with the results of the 10 year longitudinal study by Kovacs et al. (1996) who found an association between a diagnosis of major psychiatric disorder and poorer HbA1c. The present study's findings are also dissimilar to the results of a study of depression and learned helplessness by Kuttner et al. (1990) who found an association between depression and metabolic control as measured by HbA1c.

Third exploratory research question: Relationship Between Treatment Adherence and Metabolic Control and Type of Medical Service

The third exploratory research question addressed in this study stated:

Will adolescents receiving clinical services from a clinic specializing in pediatric diabetes display improved metabolic control and treatment adherence compared to those adolescents receiving clinical services uniquely from a physician or pediatrician?

For the total of 64.8% (n = 35) of the adolescents who were receiving services from a diabetes clinic, there was improved adherence only to the diet amount aspect of the self-care diabetes regime. That is, the adolescents receiving services from a diabetes clinic consumed total calories and concentrated sweets which were closer to the ideal recommended percentages of 30 and 60 respectively. While adherence to diet amount was not statistically significant between the groups at alpha level (.01), a smaller sample size again may have attenuated the results. The power to detect a difference ranged from (.01) to (.29) with an average of (.13). The power for diet amount to detect a difference was (.46). Although not statistically significant, a trend was seen with the adherence to the dietary components of the regime being better for those receiving treatment from a diabetes clinic. While outcome studies of diabetes clinics have been infrequently conducted, the results of this investigation contrast with the findings from Pringle et al. (1993)

and Rosilio et al. (1998) who identified that improved glycemic control was associated with treatment at a diabetes centre. In this study, the adolescents receiving services from a diabetes clinic were not in better metabolic control.

The lack of differences in adherence and glycemic control between the diabetes clinic treated group and the physician treated groups are partially unexpected but difficult to interpret from the variables examined in this study. First, it was expected that the health status and adherence of adolescents receiving services from a diabetes center would be better because of the specialized nature of the service. However, factors which may explain the results relate to what resources are available and how the medical practices and clinics are organized (Wagner et al., 1996). The study results reveal that there is considerable variability in prescribed treatment. That is, each pediatrician and clinic has different expectations for its patients around regular visits, adherence to each aspect of the regime, metabolic control, use of an insulin sliding scale to adjust insulin injections, prescription of injections, access to laboratory, availability of dietician and prescription of a meal plan. Without access to a dietician, adjustments to the meal plan would possibly not be made to take into account the physical growth and activity level of the individual. Furthermore, there may be varying availability and involvement of the various diabetes treatment specialists, such as endocrinologists, dieticians, social workers, pediatricians, and nurses.

Moreover, the travel distance to the clinics may also be a barrier to regular use of the diabetes clinic and pediatrician. Additionally, long distance telephone fees may apply when contact is by telephone. Changes in structure, location and program delivery also affect outcome. For example, the clinic in Sudbury had undergone several changes in organization, personnel, and site locations. The clinic in Timmins was a traveling clinic from the Sudbury clinic up until the time this study commenced. A group, consisting of a nurse, dietician, social worker, and pediatrician would meet with the children in the hospital every three months. A new pediatrician took over the Timmins clinic just when the study commenced. The diabetes clinic in Timmins was being run through the hospital and did not have its own location. The

diabetes clinic in North Bay had just started operating within the past year and not all of the children in the area were being seen through the clinic. Diabetes clinic personnel in Sudbury believed they were serving all of the children with diabetes in the area while the other clinics could not identify the proportion of total diabetes cases being seen in the area. The catchment area for the clinic in Timmins was quite large and the travel distance to the clinic was extensive, typically requiring parents to take a day of work to attend the clinic. Similar problems with distance occurred with all of the clinics. Although, it was generally easier for the adolescents and their families in Sudbury, distance within the regional municipalities of Sudbury required extended travel time. Moreover, adolescents who were being treated by a pediatrician or clinic would also frequently use their family physician to deal with diabetes issues. The additional use of telephone contact with the clinics to assist them in dealing with diabetes issues varied by family and by area.

An issue that Wagner et al. (1996) raises concerns the training of health professionals in the areas of clinical and behavioral skills. Certainly there would be disparities in training between the pediatricians and diabetes health teams and among individuals in these areas. Training is highly specialized in the diabetes clinics compared to more generic practices for pediatricians and physicians, particularly in rural and small urban communities. For example, the diabetes clinic nurses and dieticians in this study typically attended two conferences yearly, preferably one in Canada and one in the United States. Whether pediatricians and general practice physicians can afford this level of up to date training also highlights the lack of financial incentives to provide comprehensive care for an identified population.

Fourth Exploratory Question: Relationship Between Insulin Sliding Scale and Treatment Adherence and Metabolic Control

The fourth exploratory research question addressed in this study stated:

Will treatment adherence and metabolic control be better for the group using an insulin sliding scale to adjust insulin dosage with either two or more injections daily compared to those

adolescents who are prescribed two insulin injections daily and do not use a sliding scale?

A total of 64.8% of the participants adjusted their insulin and were prescribed between a minimum of two and a maximum of four injections per day. Significantly more adolescents (62%) using an insulin sliding scale were in better metabolic control, whereas equal proportions of those using an insulin sliding scale and fixed insulin regime were in good and poor metabolic control (61.8% and 31.6% respectively). Additionally, both groups were equally adherent to their diabetes treatment regimen.

It is of interest to consider these findings in the context of the guideline changes which have emanated from the Diabetes Complications and Control Trials (DCCT). Despite the recommendation for tighter metabolic control in adolescence which followed the results of the DCCT (DCCT Research Group, 1994), there were still just over a third (35.2%; $\underline{n}$ = 19) of the adolescents in this study taking a fixed amount of insulin daily rather than following a more intensive diabetes injection regime, while another 40.7% ($\underline{n}$ = 22) injected insulin twice daily and adjusted dosages depending upon their self monitored blood glucose results. Only a quarter of the adolescents receiving services from a diabetes clinic were prescribed a multiple injection regime (three and four injections daily). All of the adolescents who were prescribed multiple injections were receiving services from a diabetes clinic.

Compared to a recent study by Rosilio et al. (1998), the adolescents in this study were prescribed fairly similar frequencies of daily injections, with slightly more being prescribed four daily injections. In this study 76% were prescribed two injections daily, 11.1% three injections and 13% four injections daily. In comparison, in the Rosilio et al. (1998) study, 68% were prescribed two injections, 27% were prescribed three injections and four percent were prescribed four injections daily. The proportion of adolescents using an insulin sliding scale is higher than the 40% found in a Florida study of 125 adolescents between the ages of 10 and 17 years (Bennett Johnson et al., 1995). Minimal data are available to compare the present data with, however, when compared to the Rosilio et al. (1998), it does suggest that perhaps a higher proportion of pediatric patients are using an insulin sliding scale in Northern and Central Ontario.

Moreover, although clinical impressions of diabetes health care teams indicate that parental involvement is crucial for the prescription of a more intensive diabetes regime such as using a sliding scale, the data do not support that there was greater family general support or diabetes-specific family support in those families where the adolescent was following a more intensive diabetes regime. On the family relations variables examined, the families of the adolescents using an insulin sliding scale do not differ from those who are prescribed a fixed amount. While metabolic control was not better for those using an insulin sliding scale, there is a trend indicating that there was improved adherence to the injection regime when using an insulin sliding scale ($p = .05$, 1-tailed). The constraints of a small sample and number of variables involved may have attenuated the results due to low power (.31).

Fifth Exploratory Research Question: Relationship Between Missing Insulin Injections and Demographics, Metabolic Control, Treatment Adherence, Family Relations and Type of Diabetes Treatment

The fifth exploratory research question addressed in this study is:

Will the adolescents who missed insulin injections differ in terms of gender, chronological age, time since diagnosis, metabolic control, treatment adherence, family relations and type of diabetes treatment received (diabetes clinic versus physician or pediatrician)?

More than a quarter of the adolescents (27.8%; $n = 20$) omitted insulin injections and this group was in worse metabolic control. On the other hand, there were no age or gender differences between the groups and receiving medical care from a diabetes clinic or from a pediatrician did not discriminate between those who omitted or did not omit insulin injections. While none of the six family relations variables or five adherence factors discriminated between the groups at the critical significance level set at .008, there was a trend indicating that three of the family relations, family conflict, parental depression and family support, emerged as strong discriminating variables which are associated with omitting insulin injections. However, low power, which ranged from .01 to .38 with an average of .16, and which is the

consequence of a small sample size and the number of family relations variables, may have attenuated the results.

In contrast to other studies in which females with diabetes were identified as omitting insulin injections in an attempt to control weight, this study found that fairly equal proportions of male and female adolescents were skipping injections, with slightly more females omitting insulin injections. That is, 25% of the males and 30.8% of the females missed an insulin injection at least once during the span of the study and metabolic control was worse for those missing insulin injections. Moreover, missing insulin injections occurred across all age groupings.

The examination of insulin omissions has significant clinical implications as missed insulin injections pose a serious health risk to adolescents with IDDM. Although research has focused upon the omission of insulin as part of a strategy to control weight (Affenito et al., 1997; Biggs et al., 1994; La Greca et al., 1987; Stancin et al., 1989; Wing et al., 1986), the findings from this study suggest that the omission of insulin injections cannot be understood by merely investigating this relationship and that other interpretations should be pursued. For example, in the present study one mother omitted insulin injections because she judged that her daughter had been sufficiently active throughout the day. This type of omission would suggest a denial of the need for insulin by the parent, a phenomenon which could also occur with the child. Insulin omission may also be associated with a lack of cognitive maturity and/or belief in the necessity of the treatment on the part of the child and/or parent which would consequently result in poor judgement. One male adolescent forgot to take his insulin on both a family trip and on a fishing trip. This type of omission could also be associated with poor memory and attention, stress, and/or a lack of parental support and involvement. Insulin omission could also be a symptom of depression and it may be a suicidal gesture. One older female adolescent had omitted insulin injections on a few occasions and several months post study contacted this researcher seeking support as she had not taken her insulin for three days. She was brought to the emergency department where she admitted that the insulin omissions

were suicidal gestures.

Typically, researchers have examined the occurrence of insulin omissions in females in the context of an eating disorder. Some of the girls in this study admitted to omitting insulin injections as a means of losing weight, but said that at the time of the study they were no longer following this practice. The two fold increased risk of becoming overweight which occurs on multiple injections (Tamborlane and Ahern, 1997) and the adolescent's reaction to weight gain need to be considered in clinical practice, as several females did express concern about their weight and were dismayed with what they perceived as lack of guidance on how to maintain adequate body weight. Some females were disheartened with having to accept their fate as being overweight. However, the findings of this study make it clear that the omission of insulin cannot be solely explained on the basis of weight management.

Sixth Exploratory Research Question: Relationship Between Parental Involvement and Treatment Adherence

The sixth exploratory research question examined in this study is:

Are there gender and chronological age patterns of parental involvement and adolescent independence in any of the four aspects of adherence?

As expected, adolescent independence increased with advancing chronological age with each aspect of the adherence regime: meal planning, injection, exercise, and blood glucose testing. However, patterns of parental involvement in the diabetes treatment regime differed by gender, with parents remaining involved with the treatment regime of their female adolescent longer. Across all aspects of the diabetes regime, male adolescents were independent with diabetes management at an earlier age and by 14 - 15 years old they were largely independent in taking responsibility for the injections, blood glucose testing and exercise components of their treatment regime while parents still remain involved in the meal planning aspect of the regime. There was a clear trend of male adolescents having more independence for diabetes management than female adolescents. By age 11-13, all of the males were independent in taking care of the

injection aspect of the regime, whereas it was not until the females were 16 to 18 years of age that they were independent for injections. More males were given responsibility for meal planning in the 11 to 13 year range (50% versus 0%), but then slightly more females were responsible for this aspect within the two older age groups. There was still parental involvement in meal planning in the 16 to 18 age group ,with 78% of the males and 83% of the females being independent. All of the males were responsible for insulin injection at age 14-15 compared to only 50% of the females, with only one male was not independent within the 16 to 18 age group. The most marked gender difference was with the exercise component of the regime: The vast majority of males (87.5%) within the 11 to 13 age group were independent for exercise, whereas only 15% of the females were independent.

It is of interest to understand the possible connection between the findings from this study which show that a high proportion of parents remained involved with their female adolescent's exercise regime, that both gender and chronological aged accounted for 39.2% of the variance in predicting exercise adherence and that less diabetes-specific family support, in the form of guidance-control, was associated with less exercise adherence.

These strong gender findings may perhaps be understood in the context of the systems social/ecological model of adjustment and coping and adolescent development. The greater involvement of the males in exercise may be related to the greater tendency to engage in health-compromising behaviors such as risk taking during adolescence (Arnett & Balle-Jensen, 1993; Moore & Gullone, 1996). Alternatively, perhaps it is indicative of an active approach to controlling glucose levels through exercise. Since the mothers were the primary parent responsible for monitoring and supporting the treatment regime of their adolescent, differences in mother-daughter and mother-son relationships may account for differences in the findings. It may also be that family relations influence adherence with females more because parents remain more involved in their diabetes treatment regime for much longer compared to the male adolescents. The complex and demanding daily regimens for children with diabetes requires daily

support, monitoring and responsibility from both parent and child. Since diabetes impinges on many aspects of daily living, the mother-child relationship may be the most strained as it is the mothers who are more likely to assume both active responsibilities with diabetes management and the monitoring of the adolescent's activities. Perhaps the increased maternal care-giver distress associated with having a female ill child found in the study by Canning et al. (1996) provides some further indication that there are differential relationships between mothers and sons and mothers and daughters.

The fathers in this study were largely unaware of their child's regime and few played an active role in monitoring or supporting adherence directly. Not only did few fathers report attending physician or clinic appointments but the diabetes personnel also reported dealing almost exclusively with mothers and their children. Even when the fathers had consented to be the respondent for the 24-hour recall interviews, they frequently deferred to their wives to answer the questions. Fathers also deferred to their wives from the onset of the study as a condition of participating as they did not feel knowledgeable enough to answer questions about their child's daily diabetes regime. Thus, the traditional role of the mother as the primary caretaker involving diabetes management emerged in the present study. Whether this is a trend which is more characteristic of parenting assignment of role responsibilities in these small urban centers and towns is not evident from the variables examined. The type of occupation held by the father and his salary compared to the mother would also influence how roles are shared. For example, attending a clinic would entail missing an entire shift for the father who is a miner because the cage descends only once daily for each shift. Also at a practical level, the parent with the lower salary may attend medical meetings because there is less of a financial burden.

Since this is a study of two parent families, the results reflect role assignment in this type of family constellation as there were similar proportions of stay-at-home mothers in this sample compared to employed mothers (72.7%) compared to Statistics Canada 1996 census data. Proponents of systems theory, such as Minuchin et al. (1978), would argue that this role assignment in itself could lead to the

possibility of non-normative family alliances or even coalitions over time which could then lead to marital difficulties. Conversely, it is also possible that marital difficulties could lead to the creation of parent-child alliances and coalitions.

Although several studies have shown that shared responsibility with diabetes tasks was associated with improved metabolic control and adherence (Anderson et al., 1990; Follansbee, 1989; Newbrough et al., 1986; Partridge et al., 1972), according to La Greca et al. (1995) the perception of what is considered supportive behavior can vary considerably. In the La Greca study parental support with the meal aspect of the diabetes regime was found to be most supportive and the most important type of support from families was classified as tangible support. Examples of tangible support involved sharing a similar life style, helping with regimen tasks, reminding the adolescent about tasks, preparing meals, and ensuring suitable foods and insulin and technology needed for glucose monitoring, meals, and insulin injection are available. Whether the adolescents in this study perceived their parent's involvement as supportive is not known. The findings in this study support the suggestion made by La Greca et al. (1995) that parental involvement could consist of assisting in the preparation and sharing of meals and sharing in exercise activities. La Greca et al. further recommended that an ideal approach to supporting adolescents with diabetes would be for parents to maintain some degree of active involvement while at the same time encouraging gradual independence in diabetes adherence.

Generalization of the Present Study

This study included a volunteer group of 55 adolescents between the ages of 11 and 18 years of age with Type 1 insulin-dependent diabetes mellitus, as well as both their parents. The adolescents were recruited from secondary care service providers: the diabetes clinics in Sudbury, Timmins, North Bay, and pediatricians in Midland, Orillia, Owen Sound and Peterborough. Thus, the subjects resided in rural and small urban centers and the communities surrounding these cities in Northern and Central Ontario and there

was no affiliation with any large teaching and research hospital with a specialty in diabetes. The adolescents had been diagnosed with insulin-dependent diabetes mellitus for more than one year and any with recognized physical intellectual or multiple handicaps or with other chronic illnesses were excluded. The adolescent was living in a home with two parent figures who were either married, re-married, or living common-law.

There are no other studies which have examined a sample of adolescents from various diabetes sites and cities in Northern and Central Ontario. Although this reduces the difficulty of site-specific or city specific findings, the lack of recruitment exclusion data makes it difficult to determine how representative this sample is. Nevertheless, several findings suggest that this was a representative sample. The description of the study variables is comparable to findings from norm referenced studies. The demographic characteristics of the families are fairly comparable to Statistics Canada (1996) census data in terms of employment rate, although there is a slightly higher family income. There is a blend of both Anglophone and Francophone families, there is a range of parents from low to high socioeconomic status levels and a cross section of parents experiencing varying levels of marital distress and parental depression. As well, there is a range of adolescents in both good and poor metabolic control and there are varying levels of adherence. There are no indications of a biased sample. It is known that no study is truly completely randomly selected because there will always be individuals who choose not to participate and the reason for their non-participation is not always known. While there are some clear trends in the study and there are no indications of a biased sample, the exploratory nature of the study limits the ability to generalize the results. These findings are not intended to be generalized to other urban communities, particularly since it is the first study of its kind and comparability of results is limited with the extent literature. The findings represent the treatment of juvenile diabetes in rural areas and small urban centers in Northern and Central Ontario and is also not representative of the First Nations people, as discussed in the methodology. Whereas the entire sample was Caucasian, being Caucasian was not an inclusion criterion, it was the result

of the sampling. It however, also reflects that there are very few minorities, including First Nations individuals, in the catchment areas. The non-inclusion of First Nations adolescents does not indicate a non random sample but reflects the extremely low incidence rate of IDDM in children and adolescents in this population. Until other community studies of pediatric populations with IDDM are conducted in Ontario, it is impossible to know how representative this sample is. Because this is also a study of an age-homogeneous adolescent population living with two parent figures, the findings would not generalize to other age groups and to adolescents in single parent families, either. Because there is variability in the prescribed regime and in the on-going follow-up of the adolescents seen in this study, the findings cannot be generalized to urban communities elsewhere. The findings are representative of adolescents receiving treatment from secondary care service providers. Whether individuals are adherent to an ideal regime versus a prescribed regime is an important consideration, as there is considerable variability in the prescribed regime and how services are provided. As long as the reference is defined as how adherent an individual is in relation to the prescribed regime, these variances in treatment also limit to what extent the findings are generalized to urban communities elsewhere as well. Moreover, the small sample size also affects the power to find significant results, which also limits the ability to generalize the results.

Limitations of the Present Study

It is important to note the limitations of this study. First, this population of adolescents with diabetes from Northern and Central rural areas, towns and small urban cities in Ontario has never been studied before. Even though the extant literature studies were largely recruited from large hospitals with clinics specializing in diabetes and from summer camps, the sample was similar descriptively. The most obvious limitation is that the study is correlational. The correlational nature of the study limits the ability to determine directionality of effect and to imply causation.

The next limitation of the study involves sample size and sample characteristics. Although it is typical of clinical studies, as discussed, the small sample size may have attenuated the results due to low power in various analyses, as previously discussed. A larger sample would be necessary to detect significant findings. Furthermore, the large number of statistical analyses conducted may have resulted in finding statistical significance by chance. Nevertheless, the findings followed consistent trends which do suggest that given a larger sample size, statistically significant findings may have been found.

Since all of the characteristics of the families who did not participate are unknown, it is possible that the families who did not participate in the study were experiencing more stressors than those families who participated. Additionally, because fathers were included in the study, it was much more difficult to recruit families because the fathers were frequently not willing to participate. Generally the fathers agreed to participate because their involvement was minimal, and it was not essential for them to answer questions during the 24-hour recall telephone interviews. It is possible that the fathers who were willing to participate may be from more cooperative families. Typical of most studies, however, it was the mothers who assumed the greatest responsibility for the diabetes care of their children. Few fathers were cognizant of the diabetes regime of their child and they deferred to their wives in answering questions about their child's diabetes management.

The next limitation relates to the possibility of measurement bias of the 24-hour recall interview protocol developed by Johnson et al. (1986) and her colleagues. Although the collection of the six 24-hour recall adherence interviews and the physiological measure of metabolic control measured occurred across a similar time frame, they nevertheless represent an averaged view of adherence over the three month period. Hanson et al. (1996) cautions that the use of more precise measurements, such as the 24-hour recall interview, may not represent actual behavior and that there are subjective biases in reports of specific food amounts and physical activity. The combined parent and child interviews increased the validity of the findings; however, there is still an element of measurement bias that may exist because parents are not

always aware of their adolescent's behavior. Furthermore, there is also the possibility that the 24-hour recall interviews are biased because the adolescents are cognizant of their metabolic control level. There may be measurement bias because of feelings about the adolescent's level of metabolic control. For example, adolescents in poor metabolic control and their parents may bias their ratings of adherence because there is a feeling of responsibility for their poor metabolic control. Or parents and adolescents may bias their rating of adherence favorably when the adolescent is in good metabolic control.

The next limitation concerns the measurement of depression. Although both the BDI and CDI have solid validity and reliability, they assess the frequency or severity of depressive symptoms, not the presence or absence of a clinical syndrome. Classification of parental and child depression following a classification system such as the DSM-IV (American Psychiatric Association, 1994) or through clinical examination would best provide a diagnosis of clinical depression. In addition, only one measure of depression was used and only the child's perspective was taken. For the purposes of this correlational study, depression refers to depressive symptoms and not clinical depression. Moreover, the BDI and CDI both reflect emotional functioning within the past two weeks (Beck & Steer, 1987). These measures would likely underestimate the proportion of individuals who have a history of clinical depression and have been struggling with depression but are presently functioning well, either because they are taking medication or their emotional status has improved. In particular, the results of the BDI who were administered to parents have likely underestimated the proportion of parents who have experienced depressive symptoms in the general population. As already discussed, some mothers would probably not have participated in the study had they been experiencing any significant depressive symptoms at the time of the study.

The final limitation of this study involves the use of various laboratories with different methodologies in the analysis of blood assays. In the case of HbA1c, commutation of the assay value to a percentage is a clinically recognized and valid procedure to transform the data (Catellier et al., 1992; Daneman & Ellis, 1996) that provides a valid representation of the clinical level of metabolic control.

While using one laboratory in future research, with a standard laboratory methodology and ideally one which is calibrated to the DCCT reference norms, would perhaps increase the validity of the HbA1c assay result, conducting a community based field study of this type would not have been possible with such parameters in place. Moreover, the standardization of glycohemoglobin was not underway in Ontario at the time of the data collection phase of this thesis.

Clinical Implications and Future Research

Considering the large proportion of adolescents who were in poor metabolic control, the worsening of metabolic control as time since diagnosis increased, and the lack of adherence to the majority of adherence variables, amelioration is essential both at the adherence and metabolic control levels. These findings provide support for the need to improve services to adolescents with diabetes. But what services should be provided? We know that the daily treatment for children with insulin-dependent diabetes mellitus involves a complex treatment regimen and that parents are integral to the decisions being made regarding the treatment regime. Children are also dependent upon their parents for support, guidance and providing for their needs. Attention to the emotional needs of couples and mothers is warranted, considering that a third of the mothers were experiencing some depressive symptoms, half of the couples were experiencing marital distress, and the mothers carried the burden of diabetes responsibilities. These results should help those working with families to recognize the strain that children with a chronic illness can have on parents and that interventions or suggestions need to take the needs of parents and family functioning into consideration. The evidence clusters around the importance of diabetes-specific support in the form of guidance-control and general family conflict and parental depression being associated with adherence to treatment.

First, results of this study add to the body of research which demonstrates that the Diabetes Family Behavior Scale possesses good criterion validity and that other studies are required to provide further

evidence of the reliability and validity of this newer measure of diabetes-specific family support for adolescents. Moreover, time since diagnosis emerged as an important variable which suggests that the difficulties with diabetes management may also be related to other variables associated with children being diagnosed with diabetes at a young age. Second, since both diabetes-specific and general family functioning have both emerged as predictors of some aspects of adherence, studies are required to further identify and implement interventions which examine both aspects of family functioning. Rather than a direct relationship between diabetes adherence and metabolic control, there is support for the mediational role that the family and parental relationship variables play. Family relations seem to influence metabolic control, as measured by HbA1c, by first influencing adherence (Hanson et al., 1987b). Perception of support has been found to be highly individualized (La Greca et al., 1995), which suggests that independent evaluation and implementation of adolescent specific supportive behaviors would be ideal. This type of evaluation requires time to ascertain appropriate family responsiveness and would be best implemented by therapists knowledgeable about assessing and intervening in family relationships (Wysocki, 1993).

Considering the high incidence of depression in adults with diabetes, there is a need to understand the process of the development of depression in adolescents with IDDM as they enter into adulthood and throughout adulthood. Controlled prospective and longitudinal studies are needed to examine the incidence, prevalence and mechanisms of the development of depression from adolescence into early adulthood in the context of family functioning.

Since there is evidence from other studies to show that initial adjustment at the time of diagnosis predicts future adjustment in chronic illness (Kovacs et al., 1990), identifying the need for services at the parental, familial or individual child level at the time of diagnosis, and providing the services at this crucial time, would likely decrease the risk for complications associated with diabetes. Controlled prospective intervention studies that examine whether such interventions improve adherence to the regime and lessen complications associated with poor metabolic control are warranted. Because of the interdependency

among family members, such that change in one family member can affect other parts of the system, primary care service providers need to be aware of the inter-relationship between parental depression, family conflict and its relation to meal adherence and exercise as found in this study. Identifying and providing couple, family or individual therapy during these critical formative developmental years for pediatric chronic illness populations and their parents could result in tremendous savings to the health system and to improved quality of life by lessening short and long-term complications associated with diabetes.

Perhaps the most important clinical implication of this study is the need for intervention that would provide practical guidance on how to integrate physical activity into the treatment regime. Since there is a three-fold risk of becoming overweight when following a more intensive insulin regime and a corresponding unhappiness with the fate of being overweight, perhaps the involvement of a recreation therapist on the team would provide some guidance for the females on how to integrate exercise into daily schedules.

Adolescents with diabetes are not only dependent upon their families but also upon the medical system to provide the required direction, education and treatment. Since there is always the risk of life threatening episodes of ketoacidosis (DKA) or hypoglycemia which necessitates rigorous medical intervention, the family must learn to relate to health professionals while obtaining services for their child. Good relationships between the family and larger systems such as the hospitals, diabetes nurse educators, nutritionist, pediatricians, family physicians, and endocrinologists are crucial to ensuring good diabetes management for the child. Research has infrequently examined the role of the relationships between the medical profession, the family system and diabetes management.

There is an assumption in the studies of metabolic control and adherence to a treatment regime that the patient has been prescribed an adequate treatment regime. Comparing diabetes self-care behaviors to a prescribed regime is preferred to comparing to an ideal as there are varying medical expectations. Because a significant proportion of these adolescents did not have a meal plan to follow and the prescribed regimes

varied greatly, there is a need for more standardized treatment during this developmental stage. Future research is needed to address the relationship between the family and medical aspects of relationships associated with diabetes management.

The next clinical issue concerns the use of HbA1c as a gold standard for the measurement of metabolic control. Other studies have examined blood glucose levels as an alternative to using HbA1c because this latter measure only provides an indication of mean metabolic control over a period of about three months, whereas blood glucose levels provides an index of daily variability. Whether an individual experienced hypoglycemia or hyperglycemia episodes would not be evident from the HbA1c assay value. Introducing the downloading of the memory function of a glucometer to measure variability of blood glucose values would be an improved measure of metabolic control and of blood glucose testing frequency for use at the clinical level. However, including this in a research study would likely alter the typical self-care behavior. For example, Gonder-Frederick et al. (1988) found that when individuals knew their glucometers were going to be downloaded, they were more adherent. This suggests that regular downloading of blood glucose tests would alleviate the subjective reports of patients and also improve adherence because of accountability.

The high proportion of adolescents who were non-controlled and the few family relations variables which were linked with metabolic control highlight the probability that other variables besides diabetes adherence are influencing metabolic control and the need for the inclusion of other indices of physiological stability. It appears unlikely that psychological and family relationship variables have a direct effect on metabolic control as measured by HbA1c. This finding provides some support for studying other indices of metabolic control. An aggregate measure of physiological control, such as Sando et al. (1994) used, is an alternative to using HbA1c as a unique measure of metabolic control. Unfortunately they did not provide any justification for the weighting of the measures used. Future research would need to examine this issue. There needs to be an expanded conceptualization of physiologic outcome in diabetes which could include

indicators of risk of damage to various tissues and organs, such as the heart, the kidney, the nerve cells and the retina. This would indicate a need to include, for example, lipid levels, cholesterol levels, physical growth, gender, and developmental stage in the analyses.

Although the 24-hour recall interview protocol developed by Bennett Johnson and her colleagues (1986) is an improvement in the quantification of diabetes adherence, there are practical problems associated with the protocol. These problems consist of the recall interviews requiring a significant amount of patient and research time for interviews, scoring, and the interpretation of data. In addition to the 13 adherence variables, the omission of insulin injections merits inclusion as an indicator of adjustment. Although in this study equal proportions of males and females missed insulin injections, other studies have found that females are more likely to under-treat with insulin in an attempt to lose weight. There is a lot of emphasis on eating and diet in the management of diabetes and those in excellent metabolic control have a two-fold risk of becoming overweight. Further research aimed at understanding the dynamics related to omitting insulin injections and examining who is at risk for an eating disorder is warranted. Additionally, health care service providers need to consider the misuse of insulin in both male and female adolescents who have poor glycemic control, and a subclinical or clinical eating disorder may exist, and that other explanations for omitting insulin injections need to be pursued.

Considering the difficulty with recruiting pediatric populations outside diabetes geographic clinic service boundaries, there is a need for a central registry identifying all pediatric diabetes patients. There is also a need for pediatric diabetes clinics, particularly in areas that are not associated with metropolitan or teaching hospitals specializing in diabetes, to conduct outcome studies. The course of diabetes in those who are not being seen by a diabetes specialist is a future research need. Investing in services for pediatric diabetes populations would be a preventive measure, considering the long and short-term complications associated with diabetes, as there would be an improvement in quality of life and reduced health costs associated with providing the skills and treatment required.

The health behaviors measured in this study are worthwhile alternative variables to include in future studies of diabetes. Health behavior variables are sensitive measures of diabetes management. Health behaviors also appear to add important dimensions to understanding diabetes adherence, and are also more easily identified than the more time consuming and expensive adherence studies. An area that needs further investigation is understanding the gender differences found in examining independent and shared responsibility for adherence behaviors. There is a need to understand the varying patterns of parental involvement in the diabetes regimes of their children. Since mothers carry the burden of the majority of diabetes responsibilities, the mother-daughter and mother-son relationships both deserve some attention by understanding their relationship dynamics in the context of the family system. This investigation would be particularly salient to helping parents understand how they can be supportive to their children with a chronic illness in ways that enhance diabetes adherence and metabolic control. There are clearly some gender differences in the way this population of adolescents adhered to their treatment regime and in patterns of metabolic control that merit further evaluation.

Finally, there is continued support for the multivariate conceptualization of adherence and for both diabetes adherence and metabolic control being separate constructs. Future research needs to explore these variables as unique and separate constructs rather than combining them or assuming that adherence implies good control.

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APPENDIX A: Letter to the Families

Dear parent and adolescent,

This letter is being sent to you asking for your participation in a research study of adolescents with diabetes which is being undertaken in the Sudbury, Timmins, North Bay, Orillia, Midland, Peterborough and Owen Sound areas. This study is the responsibility of Lorraine Champaigne, a doctoral student in clinical psychology at the University of Ottawa and Dr. Susan Johnson-Douglas a professor at the University of Ottawa. The study is supported by the Diabetes Education and Care centres in Sudbury, North Bay, Timmins and Peterborough, the Northern Diabetes Health Network and the North Bay General and Memorial Hospitals. The following pediatricians and physicians are also supportive of this research: Dr. R. Bergh, Dr. M. Abdurrahman, Dr. A. Ogundimu, Dr. V. Kumar, Dr. M. Moyo, Dr. J. Madden, Dr. G. Sanz, Dr. F.P. Moradhassel, Dr. M. Boyer, Dr. L.J. Loukras, Dr. T. Cormode, Dr. A.P. Hudak, Dr. E.A. Porter, Dr. J. Crysler, Dr.R.J. Creighton, Dr. P.G. Cameron, Dr. R.P. Helt, Dr. C. Thornback, and Dr. G. Laudanski.

We are interested in understanding what psychological and family factors help the adolescents with diabetes follow the diabetes treatment regime and what helps keep the diabetes stable. Your participation will greatly help us understand how to provide the best medical care to other youngsters with diabetes.

We would like your permission to include both parents living with the adolescent with diabetes and the child in our research. The parents can either be married, re-married, or living common-law, and can be adoptive parents as well. We will be asking each parent about one hour and the adolescent about one half hour to complete the questionnaires. We will be telephoning the parent and adolescent 6 times over 3 months to answer some questions about the adolescent's diabetes treatment regime. The telephone interviews will take about 20 minutes. The adolescent with diabetes will be expected to present him/herself at a selected laboratory in your area at the beginning of the study and 12 weeks later for the purpose of obtaining both fasting triglyceride and blood glucose levels.

We can coordinate your blood tests with your scheduled appointment. The questionnaires can be completed either at the Diabetes Education and Care Program centers, in the doctor's office, or in your home. Snacks will be offered at the diabetes center or at the doctor's office. Everyone will receive a donated prize of interest to adolescents in appreciation of participation in this study

Participation in this study is entirely voluntary and whether or not you become involved will not change the treatment that is received. There are no known negative side effects of this study. You may withdraw from the study at any time even if you had agreed to participate. Lorraine Champaigne will be responsible for keeping all of the information gathered. All information will be kept in the strictest confidence and locked in Lorraine Champaigne's possession and only the researchers will have access to the information. The blood test results need to be shared with your

doctor and diabetes staff, but otherwise none of the information will be revealed to anyone.

Please sign the enclosed card and mail it in the self-addressed and stamped envelope if you are interested in participating. You can also inform your physician or personnel from the diabetes program of your interest in participating. Lorraine Champaigne will then call you to answer any questions that you may have. Please feel free to reach her at (705) 523-8229 collect if you have any questions. You may also reach Dr. Susan Johnson-Douglas at (613) 562-5800, extension 4813. A summary of the results of the study can also be sent to you if you are interested.

Lorraine Champaigne, M.A.
Doctoral Student in
Clinical Psychology

Dr. Susan Johnson-Douglas
Psychologist

APPENDIX B.

Means and Standard Deviations of Familial Demographic Variables

Variable	M	SD	N	Range	Percentage	n
Family SES[a]	44.75	12.00	54	27.92 - 76.44		
Income-father	$47,351	31,681.88	54	0 - 175,000		
Income-mother	$12,785.19	14,181.82	54	0 - 64,000		
Income-family	$60,137.04	34,395.74	54	13,000 - 190,000		
Employment mother			54	Employed	72.2	39
				Unemployed	25.92	14
				Welfare	1.9	1
Employment father			54	Employed	92.6	50
				Unemployed	1.9	1
				Welfare/WSIB	1.9	2
				Disability	1.9	1
Occupation code-father	6627.57	2660.75	54	1137 - 9926		
Occupation code-mother	5628.09	2709.46	54	1142 - 64000		
Education father (years)	12.17	2.80	54	8 - 23		
Education mother (years)	12.34	1.81	54	6 - 17		
Age father (years)	43.54	4.70	54	32 - 54		
Age mother (years)	40.35	5.15	54	29 - 50		
Years married	18.01	6.26	54	.42 - 30 yrs		
Marital status			54	Married	89.1	49
				Common-law	3.6	2
				Re-married	7.3	4
Siblings	1.33	.79	54	0	13.0	7
				1	48.1	26
				2	31.5	17
				3	7.4	4

Note. [a] = Blishen Socioeconomic Index (Blishen et al., 1987); WSIB = Workplace Safety Insurance Board. N = 54 for the family demographic variables due to one couple who did not return the questionnaires.

APPENDIX C.

Means and Standard Deviations of Adolescent Demographic Variables

Variable	M	SD	N	Range	Percentage	n
Chronological Age (years)	15.13	2.07	55	11.17 - 18.17		
				11-13	29.1	16
				14-15	30.9	17
				16-18	40	22
Age at Diagnosis (years)	8.47	3.56	55	1.08 - 16.83		
Duration Since Diagnosis (years)	6.66	3.53	55	1.00 - 16.00		
Gender						
Male			29		52.7	
Female			26		47.3	

APPENDIX D. Informed Consent to Participate in a Research Study

We consent to participate in a study which will evaluate what psychological and family factors help the adolescent with diabetes follow the diabetic treatment regime and what helps keep the diabetes stable.

The following expectations have been explained to me.

1. Each parent and adolescent is expected to complete some questionnaires at the beginning of the study.
2. It will take the parent about one hour and the adolescent about a half hour to complete the questionnaires.
3. We will be telephoning one parent and the adolescent with diabetes six times over three months to answer some questions about the adolescent's diabetes treatment regime. The telephone interviews will take about 20 minutes.
4. The adolescent with diabetes needs to present him/herself at a selected laboratory in your area at the beginning of the study and 12 weeks later for the purpose of obtaining both fasting Triglyceride and blood glucose levels (HbA1c).

We understand that there are no known negative side effects of this study. We understand that we may withdraw from the study at any time even if we have agreed to participate and signed this form. We understand that participation is entirely voluntary and whether we become involved or not will not affect the care that the adolescent will receive. It is understood that the information collected about the family will be kept confidential and locked in Lorraine Champaigne's possession and only the researchers will have access to the information. The blood tests need to be shared with your doctor and the diabetes staff, but otherwise none of the information gathered will be revealed to anyone. If the results of this study are published, there will be no identifying information at all about your family members.

The responsibility of this study rests with Lorraine A. Champaigne and Dr. Susan Johnson-Douglas of the University of Ottawa. Questions can be directed to Lorraine Champaigne at (705) 523-8229 and to Dr. Johnson-Douglas at (613) 562-5800, extension 4813.

Wife's name: _____ Signature: _____

Husband's name: _____ Signature: _____

Name of adolescent with diabetes: _____ Signature: _____

Date: _____

I, Lorraine Champaigne have explained the nature of the study to the wife, husband and adolescent and believe that they have understood it.

Signature: _____ Date: _____

APPENDIX E. Demographic Information Questionnaire

Wife's name: _____

Husband's name: _____

Name of adolescent with diabetes: _____

Home address: _____

_____

Home phone number: _____

Wife's phone number: _____

Husband's phone number: _____

Please check your marital status:

Married: _____ Common-law: _____ Re-married: _____

Number of years married or living common-law: _____

Occupation: Wife _____ Husband _____

Education: Wife _____ Husband _____

Age: Wife _____ Husband _____

Employed Wife _____ Husband _____

Unemployed Wife _____ Husband _____

Income per year: Wife _____ Husband _____

Adolescent with diabetes information

Date of birth: _____

Grade Level: _____

Child's biological parent: Mother
Father_____

Date of diagnosis of diabetes: _____

APPENDIX E. Demographic Information Questionnaire (continued)

Doctor's Name _____

Other children:

Name _____ **Male** _____ **Female** _____ **Age** _____

Name _____ **Male** _____ **Female** _____ **Age** _____

Name _____ **Male** _____ **Female** _____ **Age** _____

Name _____ **Male** _____ **Female** _____ **Age** _____

Name _____ **Male** _____ **Female** _____ **Age** _____

APPENDIX F. List of Exclusions and Inclusions

Inclusion Criteria

1. Age: The adolescent must have been between the ages of 11 and 18 years and must have agreed to participate.

2. Family structure: To maintain sample homogeneity, two parent families were included. The adolescent with diabetes must have been living in a home with two parent figures. Only one adolescent with diabetes from each family was included.

3. Diagnosis: IDDM must have been diagnosed more than one year prior to the recruitment into the study to eliminate the confounding variable of continued insulin production and lack of adjustment to the required insulin dosage.

4. Blood glucose monitoring: Blood glucose monitoring using a glucometer must have been used.

Exclusion Criteria

1. Adolescent with recognized physical, intellectual or multiple handicaps, or with other chronic illnesses.

APPENDIX G.

Pearson Product-Moment Correlations of Adolescent Depression, Metabolic Control, Adherence and Demographics (N = 51)

Variables	Adolescent depression (log)
HbA1c (mean of time one and time two) (log)	.090
Injection adherence	.052
Diet type adherence	.048
Diet amount adherence	.054
Testing/eating frequency adherence	-.011
Exercise adherence	.124
Chronological age	.193
Time since diagnosis (sqrt)	.149
Socioeconomic status-family (log)	.017
Siblings	.103
Years married	-.095
Gender (male = 1; female = 2)	.185

Note. *$p < 0.05$ level (2-tailed). ** $p < 0.01$ level (2- tailed).

APPENDIX H.

Hypothesis Two Post Hoc Analyses: Calculation of Power and Effect Sizes for Five Adherence Factors (alpha = .05)

Adherence Factor	Effect Size	Power
Injection	.220	.60
Diet Type	.136	.40
Diet Amount	.490	.95
Testing/Eating Frequency	.156	.50
Exercise	.592	.98

APPENDIX I: MEASURES

DAS by Graham B. Spanier, Ph.D.

Name:_____ Sex: M F Marital Status:_____ Age:_____

Most persons have disagreements in their relationships. Please indicate below the approximate extent of agreement or disagreement between you and your partner for each item on the following list. Circle the star under one answer for each item.

	Always Agree	Almost Always Agree	Occasionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
1. Handling family finances						
2. Matters of recreation						
3. Religious matters						
4. Demonstrations of affection						
5. Friends						
6. Sex relations						
7. Conventionality (correct or proper behavior)						
8. Philosophy of life						
9. Ways of dealing with parents or in-laws						
10. Aims, goals, and things believed important						
11. Amount of time spent together						
12. Making major decisions						
13. Household tasks						
14. Leisure time interests and activities						
15. Career decisions						

	All The Time	Most Of The Time	More Often Than Not	Occasionally	Rarely	Never
16. How often do you discuss or have you considered divorce, separation, or termination of your relationship?						
17. How often do you or your mate leave the house after a fight?						
18. In general, how often do you think that things between you and your partner are going well?						
19. Do you confide in your mate?						
20. Do you ever regret that you married (or lived together)?						
21. How often do you and your partner quarrel?						
22. How often do you and your mate get on each others' nerves?						

	Every Day	Almost Every Day	Occasionally	Rarely	Never
23. Do you kiss your mate?					

	All Of Them	Most Of Them	Some Of Them	Very Few Of Them	None Of Them
24. Do you and your mate engage in outside interests together?					

How often do the following occur between you and your mate?	Never	Less Than Once A Month	Once Or Twice A Month	Once Or Twice A Week	Once A Day	More Often
25. Have a stimulating exchange of ideas						
26. Laugh together						
27. Calmly discuss something						
28. Work together on a project						

These are some things about which couples sometimes agree or disagree. Indicate if either item caused differences of opinions or were problems in the past few weeks.

	Yes	No
29. Being too tired for sex		
30. Not showing love		

31. The stars on the following line represent different degrees of happiness in your relationship. The middle point, "happy," represents the degree of happiness of most relationships. Circle the star above the phrase which best describes the degree of happiness, all things considered, of your relationship.

Extremely Unhappy	Fairly Unhappy	A Little Unhappy	Happy	Very Happy	Extremely Happy	Perfect

32. Which of the following statements best describes how you feel about the future of your relationship? Circle the letter for one statement.

A.	I want desperately for my relationship to succeed, and would go to almost any length to see that it does.
B.	I want very much for my relationship to succeed, and will do all I can to see that it does.
C.	I want very much for my relationship to succeed, and will do my fair share to see that it does.
D.	It would be nice if my relationship succeeded, but I can't do much more than I am doing now to keep the relationship going.
E.	It would be nice if it succeeded, but I refuse to do any more than I am doing now to keep the relationship going.
F.	My relationship can never succeed, and there is no more that I can do to keep the relationship going.

BDI™

Date: _____

Name: _____ Marital Status: _____ Age: _____ Sex: _____

Occupation: _____ Education: _____

This questionnaire consists of 21 groups of statements. After reading each group of statements carefully, circle the number (0, 1, 2 or 3) next to the one statement in each group which **best** describes the way you have been feeling the **past week, including today.** If several statements within a group seem to apply equally well, circle each one. **Be sure to read all the statements in each group before making your choice.**

1	0	I do not feel sad.
	1	I feel sad.
	2	I am sad all the time and I can't snap out of it.
	3	I am so sad or unhappy that I can't stand it.
2	0	I am not particularly discouraged about the future.
	1	I feel discouraged about the future.
	2	I feel I have nothing to look forward to.
	3	I feel that the future is hopeless and that things cannot improve.
3	0	I do not feel like a failure.
	1	I feel I have failed more than the average person.
	2	As I look back on my life, all I can see is a lot of failures.
	3	I feel I am a complete failure as a person.
4	0	I get as much satisfaction out of things as I used to.
	1	I don't enjoy things the way I used to.
	2	I don't get real satisfaction out of anything anymore.
	3	I am dissatisfied or bored with everything.
5	0	I don't feel particularly guilty.
	1	I feel guilty a good part of the time.
	2	I feel quite guilty most of the time.
	3	I feel guilty all of the time.
6	0	I don't feel I am being punished.
	1	I feel I may be punished.
	2	I expect to be punished.
	3	I feel I am being punished.
7	0	I don't feel disappointed in myself.
	1	I am disappointed in myself.
	2	I am disgusted with myself.
	3	I hate myself.
8	0	I don't feel I am any worse than anybody else.
	1	I am critical of myself for my weaknesses or mistakes.
	2	I blame myself all the time for my faults.
	3	I blame myself for everything bad that happens.
9	0	I don't have any thoughts of killing myself.
	1	I have thoughts of killing myself, but I would not carry them out.
	2	I would like to kill myself.
	3	I would kill myself if I had the chance.
10	0	I don't cry any more than usual.
	1	I cry more now than I used to.
	2	I cry all the time now.
	3	I used to be able to cry, but now I can't cry even though I want to.
11	0	I am no more irritated now than I ever am.
	1	I get annoyed or irritated more easily than I used to.
	2	I feel irritated all the time now.
	3	I don't get irritated at all by the things that used to irritate me.
12	0	I have not lost interest in other people.
	1	I am less interested in other people than I used to be.
	2	I have lost most of my interest in other people.
	3	I have lost all of my interest in other people.
13	0	I make decisions about as well as I ever could.
	1	I put off making decisions more than I used to.
	2	I have greater difficulty in making decisions than before.
	3	I can't make decisions at all anymore.

_____ Subtotal Page 1

CONTINUED ON BACK

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14
- 0 I don't feel I look any worse than I used to.
- 1 I am worried that I am looking old or unattractive.
- 2 I feel that there are permanent changes in my appearance that make me look unattractive.
- 3 I believe that I look ugly.

15
- 0 I can work about as well as before.
- 1 It takes an extra effort to get started at doing something.
- 2 I have to push myself very hard to do anything.
- 3 I can't do any work at all.

16
- 0 I can sleep as well as usual.
- 1 I don't sleep as well as I used to.
- 2 I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.
- 3 I wake up several hours earlier than I used to and cannot get back to sleep.

17
- 0 I don't get more tired than usual.
- 1 I get tired more easily than I used to.
- 2 I get tired from doing almost anything.
- 3 I am too tired to do anything.

18
- 0 My appetite is no worse than usual.
- 1 My appetite is not as good as it used to be.
- 2 My appetite is much worse now.
- 3 I have no appetite at all anymore.

19
- 0 I haven't lost much weight, if any, lately.
- 1 I have lost more than 5 pounds.
- 2 I have lost more than 10 pounds.
- 3 I have lost more than 15 pounds.

I am purposely trying to lose weight by eating less. Yes _____ No _____

20
- 0 I am no more worried about my health than usual.
- 1 I am worried about physical problems such as aches and pains; or upset stomach; or constipation.
- 2 I am very worried about physical problems and it's hard to think of much else.
- 3 I am so worried about my physical problems that I cannot think about anything else.

21
- 0 I have not noticed any recent change in my interest in sex.
- 1 I am less interested in sex than I used to be.
- 2 I am much less interested in sex now.
- 3 I have lost interest in sex completely.

_____ Subtotal Page 2

_____ Subtotal Page 1

_____ Total Score

68. In our family each person has different ideas about what is right and wrong.
69. Each person's duties are clearly defined in our family.
70. We can do whatever we want to in our family.
71. We really get along well with each other.
72. We are usually careful about what we say to each other.
73. Family members often try to one-up or out-do each other.
74. It's hard to be by yourself without hurting someone's feelings in our household.
75. "Work before play" is the rule in our family.
76. Watching T.V. is more important than reading in our family.
77. Family members go out a lot.
78. The Bible is a very important book in our home.
79. Money is not handled very carefully in our family.
80. Rules are pretty inflexible in our household.
81. There is plenty of time and attention for everyone in our family.
82. There are a lot of spontaneous discussions in our family.
83. In our family, we believe you don't ever get anywhere by raising your voice.
84. We are not really encouraged to speak up for ourselves in our family.
85. Family members are often compared with others as to how well they are doing at work or school.
86. Family members really like music, art and literature.
87. Our main form of entertainment is watching T.V. or listening to the radio.
88. Family members believe that if you sin you will be punished.
89. Dishes are usually done immediately after eating.
90. You can't get away with much in our family.

FAMILY ENVIRONMENT SCALE

FORM R

Rudolf H. Moos

Instructions

There are 90 statements in this booklet. They are statements about families. You are to decide which of these statements are true of your family and which are false. Make all your marks on the separate answer sheet. If you think the statement is *True* or mostly *True* of your family, make an X in the box labeled T (true). If you think the statement is *False* or mostly *False* of your family, make an X in the box labeled F (false).

You may feel that some of the statements are true for some family members and false for others. Mark T if the statement is *true* for most members. Mark F if the statement is *false* for most members. If the members are evenly divided, decide what is the stronger overall impression and answer accordingly.

Remember, we would like to know what your family seems like to *you*. So *do not* try to figure out how other members see your family, but *do* give us your general impression of your family for each statement.

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Family members really help and support one another.

2. Family members often keep their feelings to themselves.
3. We fight a lot in our family.
4. We don't do things on our own very often in our family.
5. We feel it is important to be the best at whatever you do.
6. We often talk about political and social problems.
7. We spend most weekends and evenings at home.
8. Family members attend church, synagogue, or Sunday School fairly often.
9. Activities in our family are pretty carefully planned.
10. Family members are rarely ordered around.
11. We often seem to be killing time at home.
12. We say anything we want to around home.
13. Family members rarely become openly angry.
14. In our family, we are strongly encouraged to be independent.
15. Getting ahead in life is very important in our family.
16. We rarely go to lectures, plays or concerts.
17. Friends often come over for dinner or to visit.
18. We don't say prayers in our family.
19. We are generally very neat and orderly.
20. There are very few rules to follow in our family.
21. We put a lot of energy into what we do at home.
22. It's hard to "blow off steam" at home without upsetting somebody.
23. Family members sometimes get so angry they throw things.
24. We think things out for ourselves in our family.
25. How much money a person makes is not very important to us.
26. Learning about new and different things is very important in our family.
27. Noboby in our family is active in sports, Little League, bowling, etc.
28. We often talk about the religious meaning of Christmas, Passover, or other holidays.
29. It's often hard to find things when you need them in our household.
30. There is one family member who makes most of the decisions.
31. There is a feeling of togetherness in our family.
32. We tell each other about our personal problems.
33. Family members hardly ever lose their tempers.
34. We come and go as we want to in our family.
35. We believe in competition and "may the best man win."
36. We are not that interested in cultural activities.
37. We often go to movies, sports events, camping, etc.
38. We don't believe in heaven or hell.
39. Being on time is very important in our family.
40. There are set ways of doing things at home.
41. We rarely volunteer when something has to be done at home.
42. If we feel like doing something on the spur of the moment we often just pick up and go.
43. Family members often criticize each other.
44. There is very little privacy in our family.
45. We always strive to do things just a little better the next time.
46. We rarely have intellectual discussions.
47. Everyone in our family has a hobby or two.
48. Family members have strict ideas about what is right and wrong.
49. People change their minds often in our family.
50. There is a strong emphasis on following rules in our family.
51. Family members really back each other up.
52. Someone usually gets upset if you complain in our family.
53. Family members sometimes hit each other.
54. Family members almost always rely on themselves when a problem comes up.
55. Family members rarely worry about job promotions, school grades, etc.
56. Someone in our family plays a musical instrument.
57. Family members are not very involved in recreational activities outside work or school.
58. We believe there are some things you just have to take on faith.
59. Family members make sure their rooms are neat.
60. Everyone has an equal say in family decisions.
61. There is very little group spirit in our family.
62. Money and paying bills is openly talked about in our family.
63. If there's a disagreement in our family, we try hard to smooth things over and keep the peace.
64. Family members strongly encourage each other to stand up for their rights.
65. In our family, we don't try that hard to succeed.
66. Family members often go to the library.
67. Family members sometimes attend courses or take lessons for some hobby or interest (outside of school).

Name: _____ Age: _____ Birthdate: _____ . 248
Grade in school: _____ Sex: _____ Today's date: _____

CDI

Maria Kovacs, Ph.D.

Kids sometimes have different feelings and ideas.

This form lists the feelings and ideas in groups. From each group of three sentences, pick one sentence that describes you ***best*** for the past two weeks. After you pick a sentence from the first group, go on to the next group.

There is no right answer or wrong answer. Just pick the sentence that best describes the way you have been recently. Put a mark like this ☒ next to your answer. Put the mark in the box next to the sentence that you pick.

Here is an example of how this form works. Try it. Put a mark next to the sentence that describes you ***best***.

Example:

- ☐ I read books all the time.
- ☐ I read books once in a while.
- ☐ I never read books.

When you are told to do so, tear off this top page. Then, pick the sentences that describe you best on the first page. After you finish the first page, turn to the back. Then, answer the items on that page.

Remember, pick out the sentences that describe you best in the PAST TWO WEEKS.

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Item 1

- ☐ I am sad once in a while.
- ☐ I am sad many times.
- ☐ I am sad all the time.

Item 2

- ☐ Nothing will ever work out for me.
- ☐ I am not sure if things will work out for me.
- ☐ Things will work out for me O.K.

Item 3

- ☐ I do most things O.K.
- ☐ I do many things wrong.
- ☐ I do everything wrong.

Item 4

- ☐ I have fun in many things.
- ☐ I have fun in some things.
- ☐ Nothing is fun at all.

Item 5

- ☐ I am bad all the time.
- ☐ I am bad many times.
- ☐ I am bad once in a while.

Item 6

- ☐ I think about bad things happening to me once in a while.
- ☐ I worry that bad things will happen to me.
- ☐ I am sure that terrible things will happen to me.

Item 7

- ☐ I hate myself.
- ☐ I do not like myself.
- ☐ I like myself.

Item 8

- ☐ All bad things are my fault.
- ☐ Many bad things are my fault.
- ☐ Bad things are not usually my fault.

Item 9

- ☐ I do not think about killing myself.
- ☐ I think about killing myself but I would not do it.
- ☐ I want to kill myself.

Item 10

- ☐ I feel like crying every day.
- ☐ I feel like crying many days.
- ☐ I feel like crying once in a while.

Item 11

- ☐ Things bother me all the time.
- ☐ Things bother me many times.
- ☐ Things bother me once in a while.

Item 12

- ☐ I like being with people.
- ☐ I do not like being with people many times.
- ☐ I do not want to be with people at all.

Item 13

- ☐ I cannot make up my mind about things.
- ☐ It is hard to make up my mind about things.
- ☐ I make up my mind about things easily.

Item 14

- ☐ I look O.K.
- ☐ There are some bad things about my looks.
- ☐ I look ugly.

Remember to fill out the other side

Remember, describe how you have been in the past two weeks.....

Item 15

- ☐ I have to push myself all the time to do my schoolwork.
- ☐ I have to push myself many times to do my schoolwork.
- ☐ Doing schoolwork is not a big problem.

Item 16

- ☐ I have trouble sleeping every night.
- ☐ I have trouble sleeping many nights.
- ☐ I sleep pretty well.

Item 17

- ☐ I am tired once in a while.
- ☐ I am tired many days.
- ☐ I am tired all the time.

Item 18

- ☐ Most days I do not feel like eating.
- ☐ Many days I do not feel like eating.
- ☐ I eat pretty well.

Item 19

- ☐ I do not worry about aches and pains.
- ☐ I worry about aches and pains many times.
- ☐ I worry about aches and pains all the time.

Item 20

- ☐ I do not feel alone.
- ☐ I feel alone many times.
- ☐ I feel alone all the time.

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Item 21

- ☐ I never have fun at school.
- ☐ I have fun at school only once in a while.
- ☐ I have fun at school many times.

Item 22

- ☐ I have plenty of friends.
- ☐ I have some friends but I wish I had more.
- ☐ I do not have any friends.

Item 23

- ☐ My schoolwork is alright.
- ☐ My schoolwork is not as good as before.
- ☐ I do very badly in subjects I used to be good in

Item 24

- ☐ I can never be as good as other kids.
- ☐ I can be as good as other kids if I want to.
- ☐ I am just as good as other kids.

Item 25

- ☐ Nobody really loves me.
- ☐ I am not sure if anybody loves me.
- ☐ I am sure that somebody loves me.

Item 26

- ☐ I usually do what I am told.
- ☐ I do not do what I am told most times.
- ☐ I never do what I am told.

Item 27

- ☐ I get along with people.
- ☐ I get into fights many times.
- ☐ I get into fights all the time.

MHS

Remember to fill out the other side

DIABETES FAMILY BEHAVIOR SCALE

NAME _____ DATE _____ CODE # _____

Circle the answer that best tells how often these things happen or don't happen in your family. There are no right or wrong answers. If you are not certain, make your best guess. No one else in your family will see your answers.

	All the time	Most of the time	Some times	Hardly ever	Never
1.My parent(s) watches while I test for sugar.	1	2	3	4	5
2.When there is a problem about the diabetes, we call the doctor.	1	2	3	4	5
3.My mother decides what I'm going to eat.	1	2	3	4	5
4.My parent(s) understands how I feel about having diabetes.	1	2	3	4	5
5.I ask my parent(s) for advice about my diabetes.	1	2	3	4	5
6.My parent(s) talks about my diabetes.	1	2	3	4	5
7.We know when there are problems with my diabetes.	1	2	3	4	5
8.My parent(s) does things for me that I could do myself in taking care of my diabetes.	1	2	3	4	5
9. My parent(s) reads books about diabetes.	1	2	3	4	5
10.My parent(s) reminds me to test for sugar.	1	2	3	4	5
11.My parent(s) encourages me to get some exercise every day.	1	2	3	4	5
12.My parent(s) buys sweet snacks for the family.	1	2	3	4	5
13.My parent(s) gives me rewards for taking care of my diabetes.	1	2	3	4	5
14.At home, my family eats food that is not on my diabetic diet.	1	2	3	4	5
15.My diabetes makes my parent(s) real nervous.	1	2	3	4	5
16. My parent(s) tests my sugar.	1	2	3	4	5
17.When my sugar runs high for several days, we wait and don't make any changes until my next scheduled doctor's appointment.	1	2	3	4	5
18.We wait to call the doctor until I'm very sick with my diabetes.	1	2	3	4	5
19. I take care of my diabetes myself.	1	2	3	4	5
20. My parent(s) makes sure that I don't run out of insulin.	1	2	3	4	5
21.My parent(s) writes down the sugar tests.	1	2	3	4	5
22.My parent(s) listens to my ideas about taking care of my diabetes.	1	2	3	4	5

23.If we're not sure what to do we call for help.	1	2	3	4	5
24. My parent(s) and I argue about whether I'm sticking to my diabetes diet.	1	2	3	4	5
25. My family has regular meal times.	1	2	3	4	5
26. My parent(s) seems embarrassed that I have diabetes.	1	2	3	4	5
27.My parent(s) listens to my problems about having diabetes.	1	2	3	4	5
28. My parent(s) makes my snacks.	1	2	3	4	5
29.My parent(s) fills the insulin syringe.	1	2	3	4	5
30.My parent(s) makes me feel good about taking care of my diabetes.	1	2	3	4	5
31. My parent(s) gives my insulin shots.	1	2	3	4	5
32. My family embarrasses me by talking about diabetes with other people.	1	2	3	4	5
33.When we go out to eat, I choose things from the menu in line with my exchange diet.	1	2	3	4	5
34. Other family members eat sweets in front of me.	1	2	3	4	5
35. I feel all alone with my diabetes.	1	2	3	4	5
36. My parent(s) encourages (wants) me to do the kinds of things other kids do.	1	2	3	4	5
37.My parent(s) believes (feels) that testing for sugar is up to me.	1	2	3	4	5
38.My parent(s) is always ready to help with my diabetes if I need it.	1	2	3	4	5
39.My parent(s) tells me to stop acting as if I'm sick.	1	2	3	4	5
40.My parent(s) reminds me to give my insulin shots.	1	2	3	4	5
41.I don't worry about what my sugar test shows unless I start feeling bad.	1	2	3	4	5
42.My parent(s) knows how well I'm taking care of my diabetes.	1	2	3	4	5
43.I have someone in my family to talk to about my diabetes.	1	2	3	4	5
44.My parent(s) gets angry with me when I make a slip in taking care of my diabetes (don't take care of my diabetes).	1	2	3	4	5
45. If my sugar test is too high, we check for ketones.	1	2	3	4	5
46. My family talks about diabetes.	1	2	3	4	5
47.My parent(s) is afraid to give me insulin shots.	1	2	3	4	5