CHILDCARE RESPONSIBILITIES, SIBLING RELATIONS, AND ADJUSTMENT: WELL-SIBLINGS OF CHILDREN WITH INSULIN DEPENDENT DIABETES MELLITUS

By

MAX P. COTE

Bachelor of Arts

University of Cincinnati

Cincinnati, Ohio

1996

Submitted to the Faculty of the Graduate College of the Oklahoma State University in partial fulfillment of the requirements for the Degree of MASTER OF SCIENCE December, 1998

CHILDCARE RESPONSIBILITIES, SIBLING RELATIONS, AND ADJUSTMENT: WELL-SIBLINGS OF CHILDREN WITH INSULIN DEPENDENT DIABETES MELLITUS

Thesis Approved:

Thesis Adviser

Dean of the Graduate College

ACKNOWLEDGMENTS

I wish to thank Larry L. Mullins, Ph.D., my major advisor, for his investment of time and energy in this work. His guidance, encouragement, and direction were deeply appreciated. Without his valuable assistance and confidence, the deadlines would not have been met. I also wish to thank my other committee members John Chaney, Ph.D. and Brian Neighbors, Ph.D. for their time and helpful suggestions. Dr. John Chaney provided guidance and instruction in statistical methods Dr. Brian Neighbors contributed numerous helpful suggestions for quality research. To all of these committee members, I express my sincere thanks for their assistance and involvement.

I wish to acknowledge and thank Dr. David Domek and his staff at the Pediatric Endocrinology Clinic and Integris Hospital in Oklahoma City. Their help made the actual implementation of the study possible. Appreciation is also expressed to all of the parents and children who participated in this project

I would also like to say thank you to my family, Yvan, Juanita, and Maureen, whose help, support, patience, and sacrifice made this project and my life possible. Their steadying influence and phone calls will always be remembered and appreciated

iii

TABLE OF CONTENTS

Chapter	Pa	age
I.	INTRODUCTION	. 1
Ш.	REVIEW OF THE LITERATURE	. 8
	Description and Pathogenesis Complications of IDDM Treatment of IDDM Physical Impact of Diabetes on the Child Psychosocial Consequences of IDDM Impact of Diabetes on the Family System Family Functioning and Health Outcomes Family Roles and Maintaining Equilibrium Contemporary Theoretical Approaches Chronic Illness and Well-Siblings Increased Risk to Well-Siblings No Risk to Well-Siblings Positive Effects to Well-Siblings Sibling Role and Role Status Changes	10 12 14 14 18 19 22 23 27 28 30 33
III.	STATEMENT OF THE PROBLEM	37
IV.	METHODOLOGY	40
	Participants Procedures Measures Child Behavior Checklist Teacher's Report Form Sibling Relationship Questionnaire Child Activity Inventory Proposed Analyses	40 41 41 42 43 43
V.	RESULTS	47
	Sample Description	47

Chapter

Page

Preliminary Analyses 47
Research Question 1 53
Research Question 2 53
Research Question 3 55
VI. DISCUSSION
EFERENCES
PPENDIXES
APPENDIX A - DEMOGRAPHICS
APPENDIX B - CHILD ACTIVITY INVENTORY
APPENDIX C - IRB APPROVAL FORM

LIST OF TABLES

Table	Page
1.	Means and Standard Deviations for all Primary Measures 50
2.	Correlations Among Well-Sibling Primary Variables of Interest and Demographic Variables
	 b. Correlations Among Children with IDDM Primary Variables of Interest and Demographic Variables
3.	Zero-Order Correlations for Children with IDDM and their Well-Siblings on Measures of Adjustment
4.	Hierarchical Regression Analysis Predicting Well-Sibling Total Behavior Problems
5.	Hierarchical Regression Analysis Predicting Well-Sibling Social Competency 57

LIST OF FIGURES

Figure	Page
1.	Sibling Transactional Model

CHAPTER I

INTRODUCTION

Insulin dependent diabetes mellitus (IDDM) is one of the most common chronic diseases of childhood. Of the over 300,000 Americans who have Type I Diabetes, approximately 123,000 are people under 20 years of age. One in every 600 children develop IDDM, and each year over 11,000 children in the United States alone are diagnosed with IDDM (Harris, 1995).

IDDM is a chronic condition that is associated with a number of both short and long-term physical complications, including hypoglycemia, ketoacidosis, heart disease, peripheral vascular disease, retinopathy, neuropathy, and renal disease (e.g., Cox & Gonder-Frederick, 1992). In addition to the physical sequelae of the illness, diabetic children face a number of developmental, psychological and emotional difficulties (e.g., Brown, 1985; Mayou, Peveler, Davies, Mann, & Fairburn, 1991; Ryan, Vaga, & Drash, 1985). Prevention of the many complications associated with IDDM requires an individualized regimen of daily glucose testing, insulin injections, nutrition and exercise monitoring. Given the strict nature of this program, many children, adolescents, and parents have difficulty adhering to treatment regimens (Geffken & Johnson, 1994). As a result, the impact of the illness is not only limited to the child, but to the larger family system as well (Hanson, De Guire, Schinkel, Henngeler, & Burghen, 1992).

Long-term childhood illnesses such as IDDM create a number of additional task demands for the family, including the search for adequate medical care, depletion of economic resources, burden of care, illness uncertainty, allocation of parental attention and nurturance, reconciliation of career versus family demands, and restrictions on family mobility (e.g., Moos & Tsu, 1977; Strauss et al., 1985; Thompson & Gustafson, 1996). Consequently, parents must perform a number of specific adaptive tasks, including not only accepting the child's illness, but also managing the child's condition on a day-to-day basis, managing transactions with physicians and health care personnel, meeting the developmental needs of the child and other family members, coping with ongoing stress and periodic crises, assisting family members to manage their feelings about the illness, educating others about the child's condition, establishing a support system, and coping with hospitalizations and anxieties concerning the ill child's present and future vulnerability (e.g., Canam, 1993; Meyerowitz & Kaplan, 1967; Vance, Fazan, Satterwhite & Pless, 1980). In addition, IDDM eventually leads to a number of self-care demands, as children with diabetes are expected to assume increasing responsibility for management of their disease over time (Travis, Brouhard, & Schreiner, 1987).

Given the pervasive nature of IDDM, it is not unique for members of the family system to struggle with periods of acute and/or chronic emotional crisis in their efforts to realign family priorities and meet each others' needs (Drotar, Crawford, & Bush, 1984). These crises can trigger an array of maladaptive emotional, behavioral, and somatic symptoms or, conversely, may activate adaptive coping mechanisms as well (Thompson & Gustafson, 1996). Indeed, a substantial body of literature now exists that documents the relationship between family stress and adaptation of the child with diabetes. The majority of the research has focused on child adjustment (Jacobson et al., 1987; Kovacs, Brent, Steinberg, Paulauskas, & Reid, 1986), parent adjustment (Kovacs, Finkeltstein, Feinberg, Crouse-Novak, Paulauskas, & Pollack, 1985), and on the parent-child adjustment linkage (Anderson, Miller, Auslander, & Santiago, 1981; Chaney et al., 1996).

Conspicuously absent in the literature are studies addressing the adjustment of well-siblings with some exceptions (for reviews see Lobato, Faust, & Spirito, 1988; Senapati & Hayes, 1988). Given that the family environment is often considered a primary variable associated with childhood psychopathology and dysfunction (Breslau & Prabucki, 1987), it is a natural concern that siblings of diabetic children may be potentially at risk. Unfortunately, the relative paucity of research addressing the effect of a child's chronic illness on well siblings has been both unidirectional in methodology (i.e., deficit centered) and inconsistent as to findings (e.g., Gayton, Friedman, Tavormina, & Tucker, 1977; Tew & Lawrence, 1973). Beginning with the premise that the presence of a chronically ill or handicapped child in the family causes a significant amount of potentially damaging stress to its members, researchers have focused almost solely on attempts to identify negative effects or deficits in coping and adjustment (Breslau, Weitzman, & Messenger, 1981; Deveraux, 1979; Farber, 1959; Holt, 1958; San Martino & Newman, 1974; Schipper, 1959; Trevino, 1979). Such pathology presumptive research has suggested a number of possible adverse sibling reactions to the presence of a chronically ill child in the family, including poor peer relations, anxiety, somatization, depression, and an increase in aggressive behavior (Breslau et al., 1981; Ferrari, 1984; Lobato, Barbour, Hall, & Miller, 1987; Tew & Lawrence, 1973).

3

Nervertheless, these studies largely fail to support the presumption that siblings of chronically ill children evidence more psychological adjustment problems than siblings of healthy children. In fact, some studies suggest that healthy siblings may in fact benefit from having a chronically ill or disabled child in the family (Cleveland & Miller, 1977; Grossman, 1972; Kramer, 1984). These benefits may involve cognitive, behavioral, and affective domains (e.g., increased sense of self-efficacy and empathy for others, and a decrease in maladjustment and psychopathology). Indeed, Grossman (1972) found that compared to their peers, nearly half of well-siblings of developmentally delayed children interviewed were rated as having a greater understanding of people (particularly those with handicaps), and as evidencing more compassion, more sensitivity to prejudice, and a greater appreciation for their own intelligence and good health. Further, Ferrari (1984) reported that siblings of children with IDDM displayed significantly more prosocial behavior toward peers as reflected by teacher reports.

Thus, these positive findings, (i.e., the high social competence of siblings of children with IDDM) suggest the possible beneficial effects of living with a diabetic child. However, it is important to note that these studies are unclear as to the specific familial or individual factors that are associated with adaptive or positive functioning. Enhanced adaptation may be directly related to a variety of sibling constellation variables, such as sibling gender, age spacing and birth order, or indirectly to familial variables such as socioeconomic status, parental support, and the maintenance of traditional familial roles (Williams, Lorenzo, & Borja, 1993).

Although viewing all pediatric chronic illnesses as affecting siblings similarly has been useful in identifying the presence of global effects (Lavigne & Ryan, 1979), specific illnesses elicit varying degrees of sibling responsibility, parental attention, and family burden. In addition, studies of siblings have often relied on teacher or parental report alone and have consistently failed to utilize sibling self-report measures (Drotar & Crawford, 1985). Additional difficulty lies in the inconsistent defining of "maladjustment" in siblings. Concepts of "adjustment", "adaptation", "coping", "stress", and "competence" are often used interchangeably in the literature (Compas, 1987; Perrin, Ramsey, & Sandler, 1987).

However, the literature does exhibit one common characteristic: even the best controlled studies fail to identify a direct one-to-one relationship between a chronically ill child and sibling maladjustment. Thus, it may be more useful to more carefully identify those factors which predict the siblings who may be at greater, or less, risk for adverse experiences (Lobato, 1983).

Within the last decade, there has fortunately been an increasing trend to look at families with a chronically ill child as "normal in an abnormal situation" rather than from a deficit-centered perspective (e.g., Eiser, 1990; Kazak, 1989). In fact, the focus has shifted away from definitions of maladjustment and deviance and increasingly toward identifying positive individual and family coping strategies and skills (e.g., Varni & Wallander, 1988). In addition to emphasizing the need to consider the effects of chronic illness on the family system, recent research has made significant methodological improvements. Drotar and Crawford (1985) offered a number of pertinent recommendations in this regard, including the need to: 1) focus on individual differences among siblings; 2) focus on the complexities of adjustment rather than dysfunction; 3) develop a family-centered conceptualization; 4) focus on the effects of specific illnesses with regard to siblings rather

than combining illnesses; 5) address the roles of treatment and disease variables in sibling adjustment; and 6) develop empirically tested interventions for facilitating sibling adaptation. Despite these suggestions, there remains a significant void in the research of siblings with regard to positive functioning or adaptation.

In summary, there is meager research on the adjustment of siblings of chronically ill children, with most of the extant literature being largely inconsistent. At best, siblings of chronically ill children have been identified as a population at risk for developing psychosocial problems. Although some children may experience mild to moderate psychosocial difficulties as a result of having an ill sibling, the possible presence of positive adaptation and adjustment (i.e., increased social competence and positive self-concept), with regard to responsibility in ill-child care, should be considered. These specific factors that contribute to positive adaptation warrant investigation. In addition to the benefit to the well-siblings themselves, identifying and enhancing such positive factors has the potential for alleviating some of the stress within the family unit as a whole.

To date no studies have examined the relationship of sibling responsibility and sibling relations to the adjustment of well-siblings and children with IDDM. In fact, the research examining well-sibling responsibility in ill child care has focused solely on the care of children with mental retardation (Stoneman, Brody, Davis & Crapps, 1988; Stoneman, Brody, Davis, Crapps, & Malone, 1992). Therefore, the need clearly exists to document well-sibling adjustment to IDDM and the factors associated with both positive and maladjustment.

Thus, the purpose of this study is: 1) to examine the differences between children with IDDM and their well-siblings on measures of household and child-care responsibilities; 2) to explore the relationship between parent and teacher reported adjustment of well-siblings; and 3) to explore the relative influence of a variety of adjustment predictors (i.e., age spacing and SES; HBA1c levels and illness duration; selfconcept; sibling relations; and well-sibling household and childcare responsibilities) on parent reported levels of well-sibling adjustment.

The following is a detailed review of literature regarding Insulin Dependent Diabetes Mellitus, coping and adjustment to IDDM, family systems issues related to chronic illness and diabetic control, and the effects of chronic illness on well-siblings. The nature of the current investigation will then be detailed and the method of study outlined.

CHAPTER II

REVIEW OF THE LITERATURE

Description and Pathogenesis

Insulin Dependent Diabetes Mellitus (IDDM) is a chronic condition usually beginning in childhood. It is characterized by impaired metabolism of glucose and other energy-yielding fuels, as well as late development of vascular and neuropathic complications. Over 11,000 American children are diagnosed with IDDM each year, adding to the over 300,000 children and young adults presently living with the illness (Harris, 1995).

In most individuals the pancreas automatically produces sufficient insulin to metabolize glucose. However, the diabetics' pancreas produce little or no insulin, or the body's cells do not respond to the insulin that is produced. As a result, glucose accumulates in the blood, filters into the urine, and passes out of the body, thereby depriving the body of a main source of food despite the blood carrying large amounts of glucose (Sherwin, 1996).

Type I Diabetes, also known as insulin dependent diabetes mellitus (IDDM), is primarily considered an autoimmune disease (Sherwin, 1996). Cells within the pancreas that produce insulin, the beta cells, are destroyed by the body's own immune system. Individuals with this condition have limited or no insulin secretory capacity and depend on exogenous insulin, via daily injections, to prevent ketoacidosis (metabolic decompensation) and death (Graef, 1994).

Currently, the causes of the attack on beta cells by the body's immune system are unknown. It is now believed that diabetes is a complex interplay of genetic, autoimmune, and environmental factors (Sherwin, 1996). Support for a genetic factor is bolstered by concordance rates of 30-50% in identical twins (Sherwin, 1996). Although all of the genes linked to the disease have yet to be identified, the human leukocyte antigen (HLA) genes on the short arm of chromosome 6 appear to play a dominant role (Foster, 1994). In nonaffected siblings, the risk of developing IDDM is 15-20% if they share identical HLA genes, 5 to 10% if they share one HLA gene, and less than 1% if they share no HLA genes (Foster, 1994). The fact that a large number of monozygotic twins remain discordant with diabetes (one with diabetes, one without) has suggested that nongenetic factors (i.e., environmental factors) are also required for the expression of diabetes in humans. Similar arguments derive from the fact that HLA identity does not ensure concordance (Foster, 1994). Thus, genetics appear to be only part of the etiology of the illness.

Although many environmental factors such as toxins and diet (e.g., early exposure to cow's milk or milk products) have been considered as initiating factors, research has primarily focused on the autoimmune system, specifically with regard to viruses. Increased frequency of IDDM is often associated with epidemics of congenital rubella, mumps, and the coxsackievirus (e.g., Foster, 1994). It is theorized that a virus containing an epitope (antigenic determinant) that resembles a beta cell protein could trigger an autoimmune response. In one case, a coxsackievirus B4 virus was isolated from the pancreas of a deceased ketoacidic child with diabetes and inoculated into a group of mice; the inoculation caused diabetes (Foster, 1994).

IDDM's insidious onset is believed to have a long asymptomatic preclinical stage, sometimes lasting years, during which the autoimmune system gradually destroys pancreatic beta cells resulting in the cessation of insulin production (Foster, 1994). Acute illness may exacerbate and speed the transition from the pre-clinical to the clinical stage. The evident symptoms of IDDM usually develop within a short period of time and are most often swift and severe. These symptoms include increased thirst and urination, increased appetite, weight loss, tiredness, weakness, and blurred vision (Graef, 1994). Once the symptoms of IDDM have developed, insulin therapy is required.

Complications of IDDM

IDDM is marked by a number of daily and long-term complications. Children with diabetes are susceptible to two major acute metabolic complications: diabetic ketoacidosis (DKA) and hypoglycemia (Rees, 1995). When the body fails to metabolize glucose into energy, glucose accumulates in the blood stream increasing the likelihood of ketoacidosis. Ketoacidosis is characterized by the increase of blood ketones as a result of the metabolism of the body's fats and proteins (Rees, 1995). High levels of ketones in the blood can lead to toxicity and, if untreated, result in coma and death.

Hypoglycemia results from decreased blood glucose levels. Hypoglycemia may result when the individual with IDDM skips a meal, engages in strenuous exercise, or takes an excessive dose of insulin, thus causing the blood glucose levels to drop (Rees, 1995). Common symptoms of hypoglycemia include trembling, nervousness, heavy perspiration, hunger, headache, drowsiness, or a feeling similar to drunkenness (Graef, 1994). Like ketoacidosis, hypoglycemia may lead to coma and even death.

Certainly, the greatest threat facing young children and adults with IDDM are the acute metabolic complications. Yet, as diabetic children mature, long-term complications become more important. Diabetes can damage many organs through its effects on blood vessels and the circulatory system. How the damage occurs is not clearly understood, but diabetes may lead to kidney, heart, nerve, and eye disease [i.e., diabetic nephropathy, atherosclerosis, diabetic neuropathy, and retinopathy (Foster, 1994)].

Because the brain can neither store glucose nor utilize any other metabolic fuels other than glucose, glucose deficiencies may have profound adverse effects on cognitivemotor skills (Sherwin, 1996). Any reduction in the blood glucose to the brain may result in transient dysfunctions, whereas prolonged and severe hypoglycemia or hyperglycemia may lead to permanent brain damage. Even transient reductions in cognitive-motor capabilities may have adverse and recurrent effects on academic performance. Early investigations reported that children with diabetes onset before age five experienced more cognitive deficits than children with later onset (Ryan, Vaga, & Drash, 1985). Holmes, Dunlap, Chen and Cornwell (1992), compared 95 IDDM children with 97 matched controls, and found that children with diabetes had significantly more diagnosed learning disabilities, received more remedial aid, and had more behavioral problems at school. Boys with diabetes repeated grades more often and received significantly more remediation than the three other subgroups (i.e., non-diabetic boys/girls and diabetic females).

Treatment of IDDM

Treatment of IDDM often involves a combination of strict medication regimens, dietary restrictions, and exercise (Rees, 1995). Most diabetics are required to measure blood glucose frequently for the adjustment of insulin dosage. For these individuals, estimates of mean glucose concentrations are readily available. For others, however, proper care of diabetes requires the frequent measurement of Hemoglobin A1c (HbA1c) to ensure accuracy of self-measurements and to assess long-term diabetic control (Sherwin, 1996). HbA1c, a fast-moving minor hemoglobin component, is present in healthy individuals but increases in the presence of hyperglycemia. Measurement of glycosylated hemoglobin gives an objective assessment of metabolic control and is useful in identifying errors in the measurement or reporting of self-assessment (Graef, 1994).

The nutritional needs of diabetic children do not differ significantly from those of healthy children (Rees, 1995). The total intake of calories must be sufficient to balance the daily expenditure of energy and satisfy the requirements for normal growth. Food consumption, however, must be matched to the time course of action of injected insulin. Meals and snacks must be eaten at the same time each day, and the total consumption of calories and the proportions of carbohydrates, proteins, and fats in each meal and snack must be consistent from day to day (Rees, 1995). Since insulin is released continuously from the injection site, hypoglycemia, exacerbated by exercise, may occur if snacks are not eaten between the main meals.

Children with diabetes and their parents are required to monitor the amounts of exercise in light of caloric intake to prevent acute metabolic complications. Exercise acutely lowers the blood glucose concentration, depending on the intensity and duration of the physical activity and the concurrent level of insulinemia (Sherwin, 1996). Since children's activities tend to be spontaneous, it is difficult, if not impossible, to accurately monitor and implement exercise regimens. Hence, most children receiving twice daily injections of insulin have a snack between each meal and at bedtime. Attempts to prevent acute complications through diet monitoring and exercise include the intake of snacks always preceding exercise unless the blood glucose is known to be high (Graef, 1994).

Ideally, the goals of diabetic therapy include symptom reduction, promoting a state of general well-being, and ensuring normal physical, emotional, and social growth and development, including healthy family interaction (Graef, 1994). Short term goals of therapy include preventing episodes of severe hypoglycemia and ketoacidosis while attempting to restore near normal intermediary metabolism. Long-term goals include the prevention of the numerous micro- and macrovascular complications of diabetes (Sherwin, 1996). Current evidence suggests that better control of blood glucose may delay or ameliorate the long-term complications of diabetes and improve the duration and quality of life (Graef, 1994). To determine if intense insulin therapy (i.e., those with continuous subcutaneous infusion of insulin or multiple daily injections) could prevent diabetic complications and/or retard the progression of mild retinopathy by achieving near normoglycemia, the National Institutes of Health initiated the Diabetes Control and Complications Trial (DCCT) in 1986. The DCCT found that, over a ten year period, patients who were willing and able to actively participate in their management and improve their glycemic control benefited in terms of the reduction of long-term complications (i.e., retinopathy and neuropathy). Unfortunately, the benefits of intensive control were not without risk. The frequency of severe hypoglycemia, thus requiring

intervention from another person, increased threefold in those individuals in the intense diabetic management group (Sherwin, 1996).

Physical Impact of Diabetes on the Child

In the most severe cases, complications associated with IDDM can lead to coma, premature death, and the development of early disability (Johnson, 1990). Consequently, the life expectancy of a child with Type I diabetes is reduced by one-third (Geffken & Johnson, 1994). For healthy children, the leading causes of death are accidents; for children with diabetes, diabetes-related sequelae (e.g., insulin shock, DKA) are the leading killers. As mentioned earlier, IDDM presents the ill child with a number of physical difficulties. The emotional and psychological effects of the illness, however, may be even more overwhelming to many children with IDDM and their parents.

Psychosocial Consequences of IDDM

In a longitudinal study of the psychosocial correlates of survival in patients with diabetes, Davis, Hess, and Hiss (1988) found that the psychosocial impact of diabetes to be one of the five best predictors of mortality in diabetic patients and a better predictor than many clinical and physiological variables. Given the apparent physical effects of the illness, it is not surprising that children with diabetes face a number of daily and long term stressors as a result of their illness. Research examining the impact of diabetes on the child supports the notion that while many children with IDDM evidence healthy adjustment, a subsample of these children are at greater risk for problems with adaptation, i.e., low self-esteem, social dependency, and poor ego development (Brown, 1985; Hauser

et al., 1986; Sullivan, 1978). In addition to the risk for adjustment problems associated with the illness, increased dependency conflicts (Karlson, Holmes, & Lang, 1988), and increased likelihood of psychological disturbance (Burns, Green, & Chase, 1986) have been found in children with diabetes in poor metabolic control. Although diabetes does not lead to many socially stigmatizing changes in the child's physical appearance, children with diabetes are still subject to numerous interruptions in their daily activities (e.g., school absences and hospitalizations), as well as life style modifications (e.g., daily medication requirements, special dietary considerations, set meal times, and limitations on physical activities) that are not encountered by healthy children. These interruptions may lead to further disruptions in normal social development by limiting opportunities for normal peer interaction in ways that lead to increased social anxiety (e.g., having to explain one's treatment regimens and physical limitations). However, it is unclear whether adjustment problems precede poor diabetic control, or are a consequence of the illness (Geffken & Johnson, 1994).

Traditionally, the study of the psychological impact of and adjustment to diabetes has begun with diagnosis. Research has shown that many patients experience significant psychosocial disturbance following diagnosis, including depression, anxiety, and social withdrawal. However, significant levels of distress have only been found in approximately one-third of patients, and typically resolve within the first year of diagnosis (Jacobson et al., 1986; Kovacs, Brent, Steinberg, Paulauskas, & Reid, 1986). In a recent 6-year follow-up study of newly diagnosed diabetic children, initial adjustment to diagnosis was predictive of subsequent psychosocial difficulties (Kovacs et al., 1990). Thus a subset of children with IDDM appear to manifest significant and chronic difficulties, while the remainder may be at increased risk for adjustment problems. In fact, young adults with IDDM have exhibited higher rates of psychosocial problems in comparison to young adults in the general population (Mayou, Peveler, Davies, Mann, & Fairburn, 1991; Pless, Heller, Belmonte, & Zvagulius, 1988).

Several studies have found a higher incidence of depression and anxiety disorders in patients with IDDM, independent of diabetic complications and loss of function (Popkin, Callies, Lentz, Colon, & Sutherland, 1988; Mayou et al., 1991; Kovacs et al. 1985). Mayou et al. (1991) found an increased prevalence of depression and anxiety disorders in 113 young adults with IDDM. Indeed, some researchers believe that biological abnormalities may contribute to the unique relationship between diabetes and depression (Geringer, 1990; Popkin, Callies, Lentz, Colon, & Sutherland, 1988). They postulate that factors such as elevated cortisol, decreased norepinephrine and serotonin, or cerebrovascular disease may contribute to expression of psychiatric disorders in diabetics.

Interestingly, the adverse psychological effects of intensive insulin regimens appear minimal, and research suggests that intensive regimens may actually increase perceived internal locus of control (Kuttner, Delamater, & Santiago, 1990). Although type of regimen (i.e., traditional insulin therapy versus non-insulin therapy) during childhood certainly effects physical health, the type of regimen does not appear to significantly effect subsequent adult psychological status.

It has also been suggested that after the initial adaptation to the diagnosis of diabetes, chronic diabetes related issues may become more evident over time. Notably, girls show more disturbance, such as increased anxiety, than boys (Kovacs et al., 1990). Several studies have also concluded that the prevalence of eating disorders in adolescent and young adult women with IDDM is higher than those found in the general population (Marcus & Wing, 1990). It is important to note, however, that most of these reports have been case studies involving an average of 2-3 subjects. In a survey of more than 200 adolescents with IDDM, no differences were found on eating disorder measures that could not be otherwise explained by the dietary restrictions required in the management of IDDM (Wing, Nowalk, Marcus, Koeske, & Finegold, 1986.) Although the exact prevalence of eating disorders within diabetic populations remains unclear, subclinical levels of eating disorders (e.g., frequent binge eating) appear to be prevalent in IDDM and are associated with poorer glycemic control (La Greca, Schwartz, & Satin, 1987; Wing et al., 1986). In addition, the use of insulin reduction or omission to promote glycosuria as a method of purging may be another practice of IDDM patients. La Greca et al. (1987) found that approximately 70% of young women with poor diabetic control used this method, in comparison with 0% of the females with good diabetic control.

In summary, psychosocial problems may occur as secondary sequelae to numerous negative diabetes-related experiences (e.g., diagnosis, increased stress, and onset of complications). Since the presentation of the illness is not readily apparent to the casual observer, the impact of diabetes on the quality and longevity of life may often be underestimated. It is again noteworthy that although most individuals with diabetes do not exhibit significant psychopathology, a significant minority do. Fortunately, there is evidence that social support can act as a buffer against complication-related depression, even in the most disabled patients (Littlefield, Rodin, Murray, & Craven, 1990).

Impact of Diabetes on the Family System

Families with diabetic children face a number of daily and long term obstacles including depletion of economic resources, diabetes related daily task demands, burden of care, illness uncertainty, allocation of parental attention and nurturance, restrictions on family mobility, and the search for adequate medical care (e.g., Strauss, Corbin, Fagerhaugh, Glaser, Marines, Suczek, & Wiener, 1985; Thompson & Gustafson, 1996; Moos & Toos,1977). These obstacles may disrupt interpersonal relationships within and outside family and consequently lead to considerable personal strain for one or more family members (Hanson, De Guire, et al., 1992).

In a study of the parental adjustment of 74 newly diagnosed child diabetics, researchers found mild levels of parental anxiety and depression that typically resolved within six months. Mothers, most often the primary caregivers, experienced greater demands and felt more distressed as a result of the illness compared to fathers (Kovacs, Finkeltstein, Feinberg, Crouse-Novak, Paulauskas, & Pollack, 1985). Other research has shown high levels of personal strain for mothers of children with diabetes (Hauenstein, Marvin, Snyder, & Clarke, 1989).

Although there is little evidence suggesting that increases in reported parental anxiety and depression lead to higher divorce rates (Sabbeth & Leventhal, 1984), the effects of diabetes on the marital bond may be more subtle. Less paternal involvement in ill-child care may lead to increased maternal anxiety, with negative consequences for both spouses. Hauenstein and colleagues (1989) reported that mothers of children with diabetes reported less support from their husbands than mothers of healthy controls. Furthermore, LaVigne, Traisman, Marr, & Chaisnoffe (1982) reported that fathers of children with diabetes did not differ from healthy controls with regard to adjustment. Since mothers most often serve as the primary caregiver for ill children, they may consequently experience greater demands and feel more distressed.

Family Functioning and Health Outcomes

Several studies have demonstrated the impact of family functioning and adjustment on the health outcomes of children with diabetes (e.g., Anderson, 1990; Hanson, Henggeler, & Burghen, 1987; Hauser et al., 1990). Identifying the parental and sibling factors that contribute to a diabetic child's adherence to treatment regimens and metabolic control may ultimately be very useful in developing interventions that utilize individual family resources that minimize acute metabolic crises.

The majority of family-based clinical interventions for children with IDDM have utilized social learning theory and general systems theory as conceptual bases (e.g., Hanson, DeGuire, Schinkel, Henggeler, & Burghen, 1992). The social learning perspective posits that specific proximal behaviors are linked with children's physical and psychosocial adaptation. For example, investigators have examined the associations between illness-specific parental support (e.g., maintaining consistent mealtimes) and health outcomes in youths with IDDM (Schafer, McCaul, & Glasgow, 1986). However, systems models have posited that the adaptation of youths with IDDM is influenced by the interplay of distal (e.g., parental marital satisfaction) and proximal (e.g., parent-child conflict) family relations. The systems model purports that general family relationship variables contribute to children's health outcomes and adaptation above and beyond the contributions of illness specific proximal factors. Notably, empirical findings in youths with IDDM have demonstrated significant associations between illness-specific family functioning and health outcomes (Hanson, Henggeler, & Burghen, 1987b; Waller et al., 1986) as well as between general measures of family functioning and health outcomes (Hanson, Henggeler, & Burghen, 1987a; Hauser et al., 1990).

Previous research concerned with the role of the family in childhood diabetes has also attempted to identify dimensions of family life or parenting that influence metabolic control. Quality of familial communication and interaction appear instrumental in influencing diabetic adherence to treatment and subsequent metabolic control (Jacobson, Hauser, Lavori, et al., 1990; Auslander, Bubb, Rogge, & Santiago, 1993). The available evidence also suggests that conflict within the family, poor family relationships, rigidity, and lack of family cohesion are associated with poorer metabolic control (Anderson, Miller, Auslander, & Santiago, 1981; Bobrow, AvEuckin, & Siller, 1985; Shouval, Ber, Galatzer, 1982).

The processes by which family relationships affect metabolic control may operate in two ways; directly, by enhancing physical and mental health, and indirectly, by improving adherence (Hanson, Henggeler, & Burghen, 1987b). Notably, positive family relationships have been related to strict adherence behaviors but not to metabolic control (Hanson et al., 1987). Wertlieb et al. (1986) found that behavior problems in newly diagnosed IDDM children were associated positively with family conflict and inversely with family organization. An inverse relationship was found with a comparison group of children treated for acute illnesses (i.e., behavior problems are associated with greater parental restrictions and discipline). Thus, the results suggest that family relationships are associated with metabolic control, however, any causal relationship has yet to be firmly identified.

Importantly, little is known about more specific influences of parents on the functioning of the child with diabetes. Hauser et al. (1986) examined processes of family adaptation, specifically the differential roles played by mothers and fathers in maintaining a warm, empathetic relationship with their child while establishing behavioral limits and ensuring that treatment demands were satisfactorily met. Observations of family interactions revealed that mothers engaged in more "enabling" speech patterns (e.g., problem solving and active understanding) and fathers in more "constraining" speech (e.g., indifference and judgmental).

A number of recent studies have begun to consider the transactional aspects of the adjustment process in parent-child relationships as important determinants of both parent and child psychological adjustment. The extant research on adjustment in childhood chronic illness suggests that complex behavioral and/or emotional transactions take place among family members, and that these transactions are central to the adjustment process (Chaney et. al., 1997). Research utilizing multivariate transactional stress and coping models has demonstrated that child adjustment plays an instrumental role in predicting maternal adjustment (Thompson, Gill, Gustafson, George, Keith, Spock, & Kinney, 1994; Thompson, Gustafson, George, & Spock, 1994). Chaney and colleagues (1996) examined the transactional patterns of child, mother, and father adjustment in a sample of children and adolescents with IDDM and found that variations in both children's and mother's adjustment made significant independent contributions to predicting subsequent fathers' adjustment. Recently, a few studies have attempted to examine fathers' contributions to

adaptation in pediatric chronic illness (e.g., Bristol, Gallagher, & Schopler, 1988; Chaney & Peterson, 1989). However, few other studies have examined the mother-father-sibling interactions, but have focused instead on exploring the maternal response and the attribution of maternal responsibility for daily care (Kovacs et al., 1985; Zrebiec, 1987). Consequently, little is known about how fathers and siblings adapt to childhood diabetes or how their coping styles affect the mother or the child's metabolic or social functioning.

In summary, research is still needed to delineate the influence of family variables (e.g., quality of family relationships, family structure, and social support available to family members) as they potentially effect the psychological adaptation of each family member.

Family Roles and Maintaining Equilibrium

A number of financial, structural, and environmental changes may occur in an effort to adapt to the presence of a chronically ill child within the family (Canam, 1993; Kazak & Marvin, 1984; Bruhn, 1977). The illness may require increased financial planning (e.g., decreases in family recreation, increases in financial medical assistance, etc.) and subsequent financial distress. In addition, the family's internal structure (i.e., rules, roles, and routines) may often change to accommodate the needs of the chronically ill child (e.g., Stoneman, Brody, Davis, et al., 1991).

To maintain the family equilibrium, well siblings may play a more active role in the care of their siblings, in addition to taking increased responsibility for family tasks (i.e., cooking, cleaning, etc.), contributions to family income and personal sacrifices (Rodger, 1985). These added stressors, created by the presence of a chronically ill child in the family, may result in a greater differentiation of roles and responsibilities within the family

(Lobato, Faust, & Spirito, 1988). When the chronically ill child is younger, an elder sibling's assumption of caretaking is consistent with common sibling role asymmetries. More importantly however, greater role tension and confusion would be anticipated among siblings younger than the chronically ill child, as they may be expected to assume roles that contradict birth order (Lobato et al., 1988).

As a result, role relationships and sibling relations would be expected to change as result of the presence of a chronically ill child within the family. To date, no research has examined these variables in regard to well-sibling adjustment in the presence of a child with diabetes. Evaluation of the contributions of these variables will be a critical component of the current study.

Contemporary Theoretical Approaches

Research examining the effects of chronic illness on the family system, specifically well-siblings, lacks a common theoretical approach (Senapati & Hayes, 1988). Compounded by the absence of a common basis for the majority of empirical investigations, studies examining the impact of chronic illness on well-siblings have often utilized unidirectional (i.e., effects of the ill-child on the well-sibling) and deficit centered approaches. Conversely, studies of healthy sibling relationships (i.e., no chronically-ill members) have been characterized by a multidimensional approach with multiple theoretical foundations (i.e., attachment, social mediational, and family systems approaches) (Senapati & Hayes, 1988). Only recently have studies with handicapped and chronically ill children utilized contemporary theoretical approaches, including attachment, social-mediational and family-systems approaches (Senapati & Hayes, 1988). These approaches have been useful in enabling researchers to move away from descriptive research to evaluating more specific hypotheses.

For example, the family stress theory or Double ABCX model (McCubbin & Patterson, 1983) has provided a useful theoretical orientation for the development of hypotheses regarding the specific relations between family structure and quality of life for the chronically ill child and their siblings. More specifically, the model provides a basis by which we can understand the possible role shifts and changes in sibling relations that may occur. The Double ABCX model addresses the conditions under which stressors and associated distress lead to family crises or disrupted family functioning. In this model of family stress, coping resources play a key role in influencing family members' responses to stressful events (McCubbin & Patterson, 1983). These resources are characteristics of the family system that facilitate effective problem solving and hence adaptation.

Family coping resources include the organization of roles within families, or the ways in which family members interact with one another in their daily activities. The major components of family organization include division of labor among family members, norms and sanctions that guide the behavior of family members, and the roles and expected behaviors assigned to each member of a family (Ihinger-Tallman & Pasley, 1987). Ultimately, the psychosocial adaptation of family members is determined by the coping resources at their disposal and family organization prior to and post-diagnosis.

Hill (1958) offered one possible formulation of the impact of illness upon the family's functioning. In a period of crisis, such as that caused by the illness of a family member, the family's structure is modified and members' capability to perform their usual roles is temporarily diminished. The family goes into a state of disequilibrium and goes

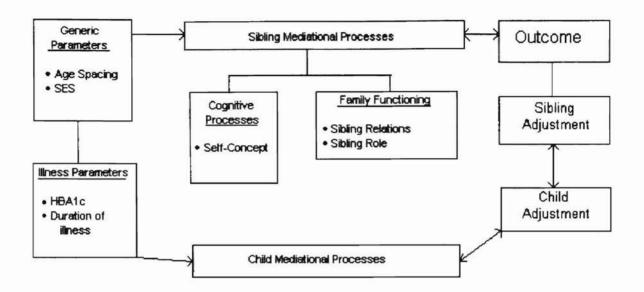
24

through a "roller coaster pattern" until a new equilibrium is established. According to Hill (1958), the new post-crisis equilibrium may result in a higher or lower level of family functioning than existed prior to the onset of the crisis. The amount of time needed to reestablish equilibrium is dependent upon the type of crisis, the members' interpretations of the crisis, and the system's resources to actively meet the crisis. Whether the crisis develops internally or externally from the family, the family determines the character of the new equilibrium and concomitant role performances and level of family functioning. More chronic and severe disturbances, such as chronic illness, may disrupt the family's equilibrium severely and recurrently, thus requiring frequent and extended periods of time to establish new equilibriums. Attributions of guilt, recriminations, and resentment may be characteristic family reactions.

Within ecological-systems theory (Bronfrenbrenner, 1977), Thompson and colleagues (Thompson & Gustafson, 1996; Thompson, Gustafson, George, & Spock, 1994; Thompson, Gil, Burbach, Keith, & Kinney, 1993a, 1993b) have developed a transactional stress and coping model. In the Transactional model, chronic illness is viewed as a potential stressor to which the individual and family system attempt to adapt. Transactions amongst biomedical, developmental, and psychosocial processes are viewed as the determinants of the illness-outcome relationship (see figure 1.)

25

Figure 1. Sibling Transactional Model



The model centers upon the patient and family processes that are hypothesized to further mediate the illness-outcome relationship over the contributions of illness and demographic parameters. The inclusion of psychosocial mediational processes in the model was based upon empirical evidence for the psychosocial process as salient foci for intervention in the impact reduction of stressors. In addition, theoretical support for the inclusion of psychosocial mediational processes was based upon Bronfrenbrenner's (1977) hypothesized relationship between the psychological adjustment of children and the levels of stress and symptoms of other family members.

Family functioning and coping methods have been included in the model as psychosocial mediational processes to account for the psychological adjustment of the family with a chronically-ill member. Developmental in nature, this model investigates the stability and change in adjustment, hypothesized maternal, paternal (Chaney et al., 1996) and child and family mediational processes, and their interrelationships over time. A number of studies have been found to support the hypothesized role of maternal and child adaptational processes in both maternal and child psychological adjustment to chronic illness. For example, when illness and demographic variables were controlled, child selfworth accounted for significant increments in the variance in mother-reported internalizing (11%) and externalizing (16%) behavior problems and child-reported symptoms (44%) (Thompson, Gustafson, Hamlett, & Spock, 1992a).

A few models, such as that proposed by Hill (1958), McCubbin and Patterson (1983), and Thompson and colleagues (1993) specifically outline changes that may take place in the family system following the diagnosis of a child with a chronic illness. These models explicitly posit that role relationships and responsibilities, throughout the family system, may shift following the diagnosis of a chronic illness. All models, especially the Transactional Model, provide a basis for understanding the impact of a chronic illness on well family members. In the section that follows, the extant data on diabetes and effects on well-siblings is reviewed.

Chronic Illness and Well-Siblings

The amount of research evaluating the effect of a sibling's illness on the experience of well-siblings has been relatively infinitesimal when compared to empirical investigations examining parental and ill-child adjustment. In fact, a significant amount of research purporting to examine the impact of chronic illness on the family often fails to include siblings (Patterson, Leonard, & Titus, 1992; Kazak & Marvin, 1984). Gradually, there has been a movement to investigate the effects of chronic illness and disability on sibling relationships and adjustment. In fact, between 1970 and 1998 over forty studies were published examining the extent and nature of risks to siblings of chronically ill children, as well as the factors that may increase or lower the risks.

Increased Risk to Well-Siblings

The deficit centered approach to well-sibling research reflects the common belief that having a chronically ill child within the family inevitably has harmful effects on siblings (i.e., higher rates of adjustment problems.) This belief is not without some merit. Several researchers have hypothesized that pediatric chronic illness has detrimental effects on the adaptation and adjustment of well-siblings, resulting in increases in psychological distress and decreases in self-esteem (Drotar et al., 1985; Lobato, Faust, & Spirito, 1988; and McKeever, 1983). Some studies have supported the speculations that a subsample of well-siblings experience increases in aggressive behavior, poor peer relations, anxiety, somatization, and depression (e.g., Breslau, Weitzman, & Messenger, 1981; Cadman, Boyle, & Offord, 1988; Cairns, Clark, Smith, & Lansky, 1979; Cohen, Friedrich, Jaworski, Copeland, & Pendergrass, 1995; Cowen, Mok, Corey, McMillan, Simmons, & Levinson, 1986; Daniels, Miller, Billings, & Miller, 1987; Engstrom, 1992; Ferrari, 1987; Harvey & Greenway, 1984; Hoare, 1984; Lavigne & Ryan, 1979; Lobato, Barbour, Hall, & Miller, 1987; Menke, 1987; Peck, 1979; Sahler & Carpenter, 1987; Sahler et al., 1994; Spinetta & Deasy-Spinetta, 1981; Tew & Lawrence, 1973; Treiber, Mabe, & Wilson, 1987; Tritt & Esses, 1988; Vance, Fazan, Satterwhite, & Pless, 1980; Walker, 1988; Wang, 1989; Williams, Lorenzo, & Borja, 1993; Wood et al., 1988).

Few studies have focused on the impact of profound physical disability on wellsiblings. However, in a longitudinal study by Breslau and Prabucki (1987), well-siblings of children with disability showed increases in aggressive behaviors, depressive affect, and social isolation over a five year period as compared to a matched control group. Tew and Lawrence (1973) utilizing teacher reported behavior problems reported maladjustment rates of 44 well-siblings of children with spina bifida to be four times that of 63 healthy control children. In addition, in a study of 24 siblings of children with congenital abnormalities and 22 controls, Lobato et al. (1987) found that over twice as many siblings had at least one CBCL subscale over the 98th percentile.

A number of studies focusing on the increase risk of well siblings have been conducted with healthy siblings of children with cancer. Cairns et al. (1979) found increased anxiety, depression, and isolation in well siblings in a sample of 76 well siblings. They reported that parents were unlikely to report knowledge of sibling concerns (e.g., isolation from parents, other family members, and friends). Cohen et al. (1995) in a study of 129 siblings of children with cancer assessed the proportion of well-sibling behavior problems expected under a normal distribution. The authors found a large proportion of siblings scored 2 standard deviations above the normative mean for internalizing and externalizing behavior problems on the CBCL. In a study utilizing semi-structured interviews, parents of 20 well-siblings of children with cancer reported increased sibling jealousy, behavior problems, school problems, somatic symptoms, and feelings of parental rejection (Peck, 1979). In a multisite study of behavior problems of well-siblings of children with cancer, Sahler et al. (1994) reported that younger siblings appeared more vulnerable than older ones. They found 10.3% of well-siblings developed problems after the diagnosis of their sibling; however, only 7.7% had problems prior to the diagnosis. The prevalence rate of 18% was based on parental report alone but utilized standardized measures of adjustment. Furthermore, in a study utilizing sibling self-report, well-siblings

UNIVERSITY

of children with cancer reported lower self-esteem, increased anxiety, depression, and perceived their families as having more conflict and less cohesion (Spinetta & Deasy-Spinetta, 1981). Lastly, in the only longitudinal study of siblings of children with cancer, Wang (1989) found more behavior problems and lower social competence when compared to norms.

An overwhelming majority of well-sibling studies have utilized samples of less than one hundred. In the largest study of well-sibling adjustment to chronic illness, Cadman et al. (1988) in a study of over 3200 children with chronic illness and their siblings found a two-fold increase in risk for emotional disorders (e.g., anxiety, depression, and obsessive-compulsive disorders); furthermore, they found a 1.6-fold increase in risk for poor peer relationships compared to siblings of healthy children. In a study of 162 children with cystic fibrosis and 142 siblings, parents reported significant problems for both groups on delinquency and somatic complaints on the CBCL (Cowen et al., 1986). In addition, parents reported increased immaturity and cruelty; however, gender and age effects were observed.

In the only study of well-siblings of children with diabetes reporting negative effects, Ferrari (1987) compared 30 siblings with 30 matched controls. The author found that well-siblings reported significantly lower self-concepts compared to the controls. No Risk to Well-Siblings

Indeed, negative findings are not consistent across all studies. The extant research has not always supported the notion that well-siblings experience higher rates of psychiatric disorders or adjustment problems (e.g., Daniels, Miller, Billings, & Moos, 1986; Crain, Sussman, & Weil, 1966; Drotar et al., 1981; Ferrari, 1984; Fielding et al., 1985; Gallo, Breitmayer, Knafl, & Zoeller, 1992; Horowitz & Kazak, 1990; Kazak & Clark, 1986; Lavigne, Irassman, Marr, & Chasnoff, 1982; Noll et al., 1995; Phillips, Bohannon, Gayton, & Friedman, 1985.)

In an observational and self-report study of 19 children with diabetes and 16 healthy siblings, Crain et al. (1966) failed to find significant differences between siblings on measures of psychosocial functioning. Furthermore, the authors examined family interaction and found no relationship between maternal behavior and sibling self-esteem, satisfaction with own behavior, academic achievement, or level of aspiration. In another study of children with diabetes and their siblings, Lavigne et al. (1982) compared 41 diabetics, 41 well-siblings, 35 well-children, and 35 well-siblings. The authors failed to find significant differences between healthy controls and well-siblings on behavior problems or social competence. However, the study relied on parental report alone. Ferrari (1984) compared 16 well-siblings of children with diabetes, 16 well-siblings of developmentally delayed children and 16 well-siblings of healthy children. The authors found few group differences on self-concept or behavior problems. The results did suggest that same-sex sibling pairs appeared to evidence more adjustment problems.

Daniels et al. (1986) found no differences between 61 healthy children and 72 wellsiblings of children with rheumatic diseases on measures of psychosocial functioning. In fact, no differences in risk were noted; however, well-siblings reported more somatic complaints than siblings of healthy children. In a multimethod study of 32 well-siblings of children with end-stage renal disease, well-siblings did not differ from ill children or healthy controls in teacher reported school performance (Fielding et al., 1985). The results suggested higher levels of parental depression and anxiety compared to the

31

CURRENT

normative sample. The impact of these findings over time or their influence on parental responding remains unclear.

Likewise, a number of studies have failed to find increased risk in well-siblings of children with cystic fibrosis. Gayton et al. (1977) examined the relationships between paternal, maternal, sibling, and ill-child report using interviews and standardized measures of adjustment. The authors found little evidence to support a detrimental effect of cystic fibrosis on well-siblings. However, the study did suggest a decrease in family satisfaction and family adjustment as a result of the illness. In another study, Phillips et al. (1985) reported only a small increase in parent reported behavior problems in well-siblings. It is important to note that the authors utilized an interview format without the inclusion of a comparison group.

Other investigators have utilized multiple illness groups in the study of risk to wellsiblings. Drotar and colleagues (1981) compared the psychosocial functioning of 91 children with cystic fibrosis, 47 with other illnesses, 71 well-siblings, and 61 healthy children. The authors collected both parental and teacher report using a battery of standardized measures. When compared to norms, no differences emerged between the well-siblings and the children with illness. Gallo et al. (1993) compared 28 well-siblings of children with chronic illness to standardized norms of psychological functioning and found no differences or risk to the well-siblings. Likewise, Noll and colleagues (1995) found no differences on measures of social competence between 37 well-siblings of children with sickle cell anemia and 37 matched controls when assessed by self and teacher report.

CUNICHNENTY

Positive Effects to Well-Siblings

A small number of studies indicate that many siblings of disabled children appear to manifest emotional and psychological health. Cleveland and Miller (1977) interviewed adult siblings of mentally retarded children and found that the majority reported that any inconveniences of the disability were outweighed by the families' overall positive adjustment. In short, adult well-siblings reported that they and other family members adapted and coped successfully with their situation. Grossman (1972) found that fortyfive percent of college age siblings of mentally retarded children reported that they had benefited from the experience of having a sibling with a developmental disability. In comparison with healthy controls, these siblings reported they were more understanding, compassionate, sensitive to prejudice, and appreciative of their own good health and intelligence. In another structured interview study of well-sibling responses to cancer, Kramer (1984) reported increased sensitivity/empathy and personal maturity in wellsiblings. However, the sample consisted of only 11 well-siblings between the ages of 6 to 16. Collectively, these findings certainly suggest that the psychosocial adjustment of well siblings deserves further empirical attention.

To date, only two studies have identified potential benefits to well-siblings of children with diabetes. In a study of involvement, understanding, and adaptation of siblings of children with diabetes, Adams and colleges (1991) examined 30 sibling and maternal responses in an interview format with self-report measures. Twenty percent of siblings reported positive effects, especially enhanced family closeness. In the second, Ferrari (1984) reported that teachers rated young siblings of children with diabetes as UNIVERSIT

more socially competent and as having more positive peer relationships as compared to siblings of unaffected children.

As mentioned previously, studies addressing well-sibling issues have largely taken a unidirectional approach (i.e., the effects ill children have on well-siblings) with a negative effects/deficit centered perspective. Simply stated, studies have focused on identifying the presence of maladjustment and untoward effects on well-siblings. Placing sole emphasis on the child who fails to manage effectively has resulted in a lack of understanding of the effective coping strategies that appear to be employed by a large subsample of children (Senapati & Hayes, 1988). Studies examining the presence of positive effects (e.g., positive self-concept, enhanced social competence, and factors contributing to positive adjustment), as well as studies assessing the impact of healthy siblings on ill or handicapped children, are virtually non-existent.

Sibling Role and Role Status Changes

The relationship between siblings and the roles that they occupy within the family may be an independent source of variance in predicting the illness-specific and general psychosocial adaptation of youths with IDDM, as well as the adaptation of well-siblings themselves (Hanson et al., 1992). Unfortunately, the impact that siblings exert on one another is often underestimated and rarely measured in chronic illness literature.

Although little is known about the daily activities that well-siblings undertake or the roles ascribed them as a result of having an ill sibling, the presumption has traditionally been that these activities/roles contribute to well-siblings emotional and behavioral problems (Breslau, Weitzman, & Messenger, 1981; Deveraux, 1979; San Martino & Newman, 1974). Certainly, the daily lives of these children may be altered significantly as a result of having a chronically ill child within the family. For example, the care that parents, most often mothers, must provide for a special sibling may cut into the time and attention that parents otherwise might devote to other children in the family (Grossman, 1972). In addition, well-siblings may be called on more often to assist with household tasks, as well as direct sibling caregiving to the identified patient and other siblings. Some researchers suggest that older siblings, especially sisters, may be the most likely candidates for acquiring extra-familial responsibilities (e.g., Gath, 1974; Grossman, 1972). Furthermore, well siblings may actually acquire what are typically thought of as parental health care delivery roles (e.g., monitoring diet and medication regimens). These alterations in family roles, in essence creating pseudocaregivers within the family, may give rise to anger and resentment in siblings (Farber & Rychman, 1965) and subsequent conflict between them and their parents. In turn, these children may feel guilty over their feelings of rivalry towards a sibling who has obvious needs. However, such arguments are speculative, and little data exists to support the notion that the acquisition of such roles leads to untoward effects.

Congruent with the Transactional Model (Thompson, Gil, Burbach, Keith, & Kinney, 1993a; 1993b), a maladaptive family environment including the superordinate or exclusion of child-care or household responsibilities, lack of social outlets, conflictual sibling relationships could hypothetically lead to increased rates of maladjustment in some children. Conversely, it can also be argued that some children may evidence a wide array of adaptive coping behaviors. In fact, well-siblings may derive a great deal of mutual benefit with the ill-child. Siblings socialize and educate each other, mediate parental I UNIVERSIT

attention and provide a peer-like context for emotion and power negotiation.

Consequently, sibling relationships are often seen as among the most important precursors to peer and later adult relationships (Hartup, 1983; Lamb & Sutton-Smith, 1982). Thus, well-siblings may in fact benefit from the experience of having a chronically ill sibling. In contrast to the traditional deficit centered perspective, these children may develop an increased social competence, self-concept, and a decrease in maladaptive externalizing and internalizing behaviors as a result of the experience. Such possibilities certainly warrant further empirical attention. Although, anecdotally, a number of families report ways in which having a chronically ill child has enriched and benefited their families' lives, this possibility has received little empirical attention in the literature on diabetes.

CHAPTER III

STATEMENT OF THE PROBLEM

A number of studies point to maladjustment in siblings of chronically ill children (for reviews see Lobato, Faust, & Spirito, 1988; Senapati & Hayes, 1988). Many studies purport that healthy siblings have lower self-concepts, are isolated, and resentful of parents' involvement with the ill child (Breslau & Prabucki, 1987; Cadman, Boyle, & Offord, 1988; Tew & Lawrence, 1973). Other research implies that siblings, especially girls, may be over-involved in excessive amounts of family childcare as well as other domestic responsibilities (Powell & Ogle, 1985; Lobato, Barbour, Hall, & Miller, 1987). Thus, a number of early studies within the well-sibling literature have focused on identifying the potentially negative aspects of illness on well-siblings. However, due to the lack of illness specific research, there are no accurate estimates of maladjustment in nonreferred samples; neither are there consistent indicators of factors which are associated with maladjustment in well-siblings (Cleveland & Miller, 1977; Ferrari, 1984; Grossman, 1972). Therefore, given the data supporting the presence of positive adaptation in wellsiblings, the overall paucity of research, disparate results, the restricted focus of sibling research, and lack of theoretical underpinnings, a more comprehensive study examining the positive adjustment of well-siblings of children with diabetes is warranted.

Positive adjustment has been operationally defined as positive functioning across social, emotional, cognitive, and behavioral areas (i.e., positive social competencies [activities, social, school], high self-esteem, and the absence of significant behavioral difficulties) (Hanson, 1992). In the current study, we will further examine positive adjustment as measured by increased social competency, positive self-concept, and the absence of significant behavioral difficulty.

In summary, the purpose of this study is: 1) to examine the differences between children with IDDM and their well-siblings on measures of household and child-care responsibilities; 2) to explore the relationship between parent and teacher reported adjustment of well-siblings; and 3) to explore the relative influence of a variety of adjustment predictors (i.e., age spacing and SES; HBA1c levels and illness duration; selfconcept; sibling relations and well-sibling household and childcare responsibilities) on parent reported levels of well-sibling global adjustment. Thus the following research questions will be addressed:

- Are there significant differences in the level of self-reported household tasks between well-siblings and children with IDDM?
- 2) Is well-sibling adjustment related to the adjustment of children with IDDM as measured by parent and teacher report?

3) Are indices of well-sibling role responsibility and sibling relations predictive of the well-siblings' psychological adaptation as measured by parent report? It is believed that a thorough examination of the responses both within and between the ill child and well-sibling groups will provide information as to the effect of the illness on well siblings. This study will employ a multimethod approach, obtaining

38

information from multiple informants (i.e., parents, teachers, and self-report) to minimize the effects of unitary-rater bias. In addition, the design is multivariate, utilizing multiple measures of adjustment (i.e., absence of behavior problems and increased adaptive behaviors) and four domains of relationship quality (i.e., warmth/closeness, relative status/power, conflict, and rivalry.)

Although the inclusion of a comparison group would be ideal, the sample size would have to be doubled; however, budgetary and sample availability precludes this approach. Therefore, the current study will seek to examine differences between children with IDDM and their well siblings, as well as, the relationships between a number of adjustment predictors.

CHAPTER IV

METHODOLOGY

Participants

Children with IDDM and well-siblings will be recruited by phone from patient lists provided by a University affiliated pediatric endocrinologist and two pediatric endocrinologists in private practice. Eligibility criteria will include: 1) children with IDDM above eight years of age and below 18; 2) children with IDDM diagnosed at least one year prior to data collection, without any other medical condition; 3) well-siblings attending regular classes (i.e., no full-time special education requirements); and 4) wellsiblings without any medical conditions. For the purpose of this study, only sibling pairs between the ages of 8 and 18 will be recruited.

Procedures

To collect data from children and their primary caregivers, a trained research assistant will make a home visit lasting approximately one hour. The visit will be scheduled during the initial phone contact and informed and written consent will be obtained from the mother and the children at the time of the visit. At that time, written consent will also be obtained to send questionnaires to the childrens' teachers. Mothers will be asked to provide the name and school of each child's homeroom teacher (or English teacher when necessary). Families will be provided with written and verbal information regarding how to complete the items in the questionnaire packets. Each packet will contain instructions for appropriately completing each questionnaire. The home visitor will work with the family in completing their questionnaires; primary caregivers will complete the questionnaires in a separate room. Upon completion of the packets, questionnaires will be marked to identify parent-child dyads. Each family will receive ten dollars for their participation in the study, or a ten dollar donation to the Juvenile Diabetes Foundation.

Teachers will also complete a "consent to participate" form and will be provided a copy of the parental consent authorizing the teacher to respond. Data from teachers will be collected by mail.

Two separate packets will be provided for the parent-child dyads. The parent packet will include a child activity inventory and the Child Behavior Checklists (CBCL; Achenbach, 1991) to be completed for the ill child and well-siblings as appropriate. The chronically ill child, and well-siblings will each complete a separate questionnaire packet, including a child activity inventory, the Piers-Harris Children's Self-Concept Scale (CSCS; Piers & Harris, 1969), and a Sibling Relationship Questionnaire (SRQ; Furman & Buhrmester, 1985). Teachers will be sent the Teacher's Rating Form (TRF; Achenbach, 1991).

Measures

The Child Behavior Checklist (CBCL) The CBCL (Achenbach, 1991) assesses the behavior problems and social competence of children, ages four to eighteen years, as

reported by parents or caregivers who know the child well (Achenbach, 1991). The CBCL scale, normed on both referred and nonreferred children (N = 1,300), is psychometrically sound with adequate reliability and validity (Freeman, 1985; Kelley, 1985). The scale consists of two main sections: the Behavior Problems and Social Competence Scales. Scale t-scores above 70 for males and 68 for females are considered in the clinical range of maladjustment. There are 118 items related to behavior problems; each is scored on a 3-point scale from not true (0), somewhat true (1), to very true (2). Parents or caregivers are asked to base their responses over the previous six months. In the social competence category, items record the amount and quality of the child's competence in sports, organization, chores, academic skills, and peer interaction.

The Behavior Problems component of the CBCL contains eight or nine factors depending on the age and sex of the child, and two broad band scales labeled Internalizing and Externalizing. Thus, the CBCL produces a total behavior problem score and a social competence score in addition to the factor and subscale scores. The higher the behavior problem score, the more negative the behavior. However, higher social competence is indicated by a higher social competence subscale score. The Social Competence Scale has three subscales: Activities, Social, and School. For the purposes of this study, both the total behavior problems T-score and social competence subscale T-score will be utilized.

<u>Teacher's Report Form (TRF)</u> The TRF (Achenbach, 1991) assesses the behavior problems and adaptive functioning of children, ages five to eighteen years, as reported by teachers or other academic professionals who know the child's academic performance and involvement well. The TRF requests teachers' ratings of performance in academic subjects, four adaptive characteristics, 118 specific problem items, and two open-ended problem items (Achenbach, 1991). Like the CBCL, the problem items are scored on a 3step response scale. However, unlike the CBCL, the TRF asks teachers to base their ratings on the previous two months. The TRF, in conjunction with the CBCL, has been a useful tool in the multifaceted descriptions of children from a teacher and parental perspectives (Achenbach, 1991). Because teachers are most often less involved with children's medical conditions and treatments, their ratings may be less vulnerable to the stress of having an ill child than ratings made by parents. As in the CBCL, a t-score of 70 for males and 68 for females indicates behavior problems in the clinical range. In this study, the total behavior problems score and total social competence scores will be employed.

Piers-Harris Children's Self-Concept Scale (CSCS) The CSCS is a self-report and self-referenced instrument designed for children Grades 4 to 12, or younger (Piers & Harris, 1969). The scale consists of 80 first-person declarative statements such as, "I am smart," requiring a response of "Yes" or "No." In addition to a total score, the CSCS yields 6 cluster scores: Factor 1: Behavior; Factor 2: Intellectual and School Status; Factor 3: Physical Appearance and Attributes; Factor 4: Anxiety; Factor 5: Popularity; and Factor 6: Happiness and Satisfaction. Higher self-concept is indicated by higher total and cluster scores. In this study, the total score will be utilized.

Sibling Relationship Questionnaire (SRQ) The SRQ (Furman & Buhrmester, 1985) is a 48-item self-report measure assessing youths' perceptions of their sibling relations. The SRQ includes fifteen 3-item scales based on principal components analysis that tap four domains of sibling relations including, warmth/closeness (21 items), relative status/power (12 items), conflict (9 items) and rivalry (6 items). Validity of the SRQ has been supported in a number of studies examining sibling relationships of children ranging in age from childhood through adolescence (Buhrmester & Furman, 1990). For the purpose of this study, all four scales of the SRQ will be utilized.

<u>Child Activity Inventory.</u> The child activity inventory is an adapted version of an instrument developed by Schwirian (1977), which elicits information on children's childcare responsibilities, household tasks, contact with friends, and out-of-home activities. This measure has been used in previous research with older and younger siblings of children with mental retardation (Stoneman et al., 1991; Stoneman, et al., 1988). The original instrument has demonstrated one-week test-retest reliabilities of .89 to .98 for mothers and .79 to .94 for children (Stoneman et al., 1991). Both the childcare and household responsibilities summary scores will be used as indices of sibling role in the family.

Proposed Analyses

The following research questions will be addressed:

1. Are there significant differences in the level of self-reported household tasks between well-siblings and children with IDDM?

Two multivariate analyses of covariance will be conducted to examine differences in the dependent measures (i.e., self-reported household chores and childcare responsibilities) adjusted for differences on the covariate, age-spacing.

2. Is well-sibling adjustment related to the adjustment of children with IDDM?

Pearson product-moment correlations will be conducted to investigate the relationships between children with diabetes and well-siblings on the following measures of adjustment:

- 1) maternal report of internalizing and externalizing behaviors,
- 2) maternal report of adaptive behavior,
- 3) teacher report of internalizing and externalizing behaviors,
- 4) teacher report of adaptive behavior.

3. Are indices of sibling responsibility and sibling relationships predictive of the well siblings' psychological adaptation?

Due to the potential for shared variance between demographic, illness severity, sibling relations, sibling responsibilities, and adjustment, hierarchical multiple regressions will be conducted to examine the relative contribution of these factors to adjustment of well-siblings. As a guide for variable selection and entry, Thompson's Transactional Stress and Coping Model (Thompson et al., 1992; Thompson et al., 1994) will be utilized. Based upon Fołkman and Lazarus' model of coping and adaptation, this model utilizes a multivariate conceptual framework that identifies chronic illness as a stressor to which the individual and the family attempt to adapt. Thompson's model incorporates multiple factors (e.g., demographics, disease parameters) believed to affect the adjustment of individuals with a variety of chronic conditions (Thompson et al., 1994). This model is used to determine the unique well-sibling adjustment variance contributed by sibling relations and sibling responsibilities above and beyond the contribution of demographic and illness parameters. For the purposes of this study, a series of two separate multiple regression analyses will be run, using parent-rated behavior problems and social

competency as the criterion variables, respectively. Each separate model will be constructed with demographics (i.e., age spacing and SES) entered first, followed by illness severity (i.e., HBA1c levels and duration of illness), well-sibling self-concept, and lastly, well-sibling responsibilities (i.e., household chores and childcare responsibilities) and sibling relations (i.e., warmth/closeness, relative status/power, conflict, and rivalry).

CHAPTER V

RESULTS

Sample Description

Twenty-nine mothers (86.3% married, 13.7% single) completed study protocols, as did children with IDDM (N = 27) and well-siblings (N = 28). The total well-sibling sample was comprised of 15 males (mean age = 12.5; $\underline{SD} = 3.2$) and 14 females (mean age = 14.2; $\underline{SD} = 2.0$) with a sample range of 7.5 to 18.6 years of age. The children with IDDM sample included 14 males (mean age = 12.8; $\underline{SD} = 3.6$) and 15 females (mean age = 13.0; $\underline{SD} = 3.1$) with a sample range of 5.7 to 18.6 years of age. In addition, teachers of well-siblings (N = 18) and children with IDDM (N = 21) completed global ratings of adjustment. Means and standard deviations of all demographic, illness parameters, and adjustment measures for both well-siblings and children with IDDM can be seen in Table I.

Preliminary Analyses

A series of preliminary analyses were performed to examine the effects of the wellsibling's gender on all primary measures. A multivariate analysis of variance revealed a significant main effect for gender on sibling household chores ($\underline{F}(1, 22) = 4.21, p < .05$). Female well-siblings reported significantly more household chore responsibilities. Female siblings also reported significantly higher warmth/closeness in their sibling relationships (\underline{F} (1, 22) = 7.38, p < .01). Mothers of female siblings also reported higher social competence in female siblings compared to male siblings (<u>F</u> (1, 22) = 6.90, p < .05). An identical MANOVA examining children with IDDM yielded a significant main effect for gender on warmth/closeness (<u>F</u> (1, 22) = 8.45, p < .05) and social competence (<u>F</u> (1, 22) = 9.66, p < .05). Female children with IDDM reported more warmth/closeness in their sibling relationships and were described by their mothers as more socially competent. Furthermore, mothers of children with IDDM reported significantly more behavior problems in their male children (<u>F</u> (1, 22) = 6.13, p < .05).

Mean T-scores for well-siblings and children with IDDM on the CBCL (parent) scales of social competency, internalizing and externalizing behavior problems, were all at least within one standard deviation of the normative group mean of 50. Likewise, wellsiblings and children with IDDM were within one standard deviation of the normative group mean on the TRF (teacher) scales of adaptive behaviors, internalizing and externalizing behavior problems.

The data was then further examined to ascertain level of adjustment as measured by the CBCL parent and teacher reports. Achenbach's (1991) criteria for behavior problems in the clinical range suggests a t-score cutoff of 70 for males and 68 for females. According to Achenbach's criteria, 3.4% of the well-siblings (n = 1; 1 female) and 10.3% of the children with IDDM (n = 3; 2 males, 1 female) evidenced significant levels of maladaptation as measured by parent report. Furthermore, none of the well-siblings or children with IDDM met clinical range criteria for total school related problems as measured by teacher report. 1

For descriptive purposes, zero-order correlations were then computed for the CBCL scale scores, self-concept, household responsibilities, childcare responsibilities, sibling relations, age-spacing, duration and severity of illness for the well-siblings (see Table II) and children with IDDM (see Table IIb).

Table I

ù,

Means and Standard Deviations for all Primary Measures

Variable	N	Range	Minimum	Maximum	Mean	Std. Deviation
CBCL-External t-score (Child w/ IDDM)	29	40.00	33.00	73.00	51.83	11.32
CBCL-External t-score (Well-Sibling)	29	44.00	32.00	76.00	48.93	11.35
CBCL-Internal t-score (Child w/ IDDM)	24	45.00	31.00	76.00	52.69	12.71
CBCL-Internal t-score (Well-Sibling)	25	40.00	32.00	72.00	49.76	9.05
CBCL-Social Comp. (Child w/ IDDM)	21	32.00	23.00	55.00	47.29	9.09
CBCL-Social Comp. (Well-Sibling)	18	26.00	29.00	55.00	47.68	10.07
TRF-External t-score (Child w/ IDDM)	21	26.00	40.00	66.00	49.71	8.57
TRF-External t-score (Well-Sibling)	18	30.00	40.00	70.00	51.56	9.15
TRF-Internal t-score (Child w/ IDDM)	21	25.00	37.00	62.00	51.95	8.67
TRF-Internal t-score (Well-Sibling)	18	28.00	37.00	65.00	49.50	8.37
TRF-Adaptive t-score (Child w/ IDDM)	21	29.00	35.00	64.00	51.14	9.12
TRF-Adaptive t-score (Well-Sibling)	18	30.00	35.00	65.00	51.72	8.91
Household Chores (Child w/ IDDM)	27	54.00	27.00	81.00	44.30	12.83
Household Chores (Well-Sibling)	28	57.00	18.00	75.00	42.82	15.79
Childcare (Child w/ IDDM)	27	31.00	0.00	31.00	9.67	8.05
Childcare (Well-Sibling)	28	36.00	0.00	36.00	9.11	9.43
SRQ-Conflict (Child w/ IDDM)	26	34.00	10.00	44.00	23.65	8.07
SRQ-Conflict (Well-Sibling)	28	45.00	9.00	54.00	27.43	9.63
SRQ-Relative Status (Child w/ IDDM)	26	41.00	-24.00	17.00	346	9.13
SRQ-Relative Status (Well-Sibling)	28	28.00	-13.00	15.00	.500	7.66
SRQ-Rivalry (Child w/ IDDM)	26	12.00	-8.00	4.00	192	2.51
SRQ-Rivalry (Well-Sibling)	28	10.00	-6.00	4.00	464	2.60
SRQ-Warmth/Closeness (Child w/ IDDM)	26	73.00	26.00	99 .00	71.27	19.58
SRQ-Warmth/Closeness (Well-Sibling)	28	76.00	23.00	99.00	67.71	17.06
Piers-Harris (Child w/ IDDM)	27	54.00	25.00	79.00	65.48	12.44
Piers-Harris (Well-Sibling)	27	56.00	24.00	80.00	66.63	12.48
Duration of Illness	29	15.75	.25	16.00	4.48	3.82
HBAlc	28	12.50	5.30	17.80	8.88	2.78
Age Spacing	29	9.25	0.00	9.25	3.34	1.85

Note: The values represent actual sample demographic and dependent measure descriptive data.

Table II

V	ariable	1	2	3	4	5	6	7	8	9	10	11	12	13
1.	CBCL-Internal	.98			20 7	-		-	(9 0	-	-		. .	-
2.	CBCL-External	.784**	-	-	-				-		1.5	-		-
3.	CBCL-Total	.910**	.921**		-	-	×	-	-	~	-			-
4.	Self-Concept	440*	548**	528**	· -	-	-		-			-	-	5
5.	Household Chores	139	186	177	.253	-	-	-	194	-	-	-	-	-
6.	Child-Care	.095	.159	.103	069	.330	-	•	-	-				-
7.	SRQ-Conflict	.282	.355	.300	636**	289	.347	-	-	-	-	-	-	
8.	SRQ-Relative	214	106	210	.070	034	.514*	* .303		-	-	÷		-
9.	SRQ-Warmth	393*	202	231	.206	.470*	074	418*	.103		-	-	-	-
10.	SRQ-Rivalry	.002	118	060	.637**	.096	268	411*	291	132	-	-	-	-
11.	Age Spacing	222	219	184	108	042	024	.292	.338	007	239	-	-	
12.	HBA1c	.249	.027	.089	.023	008	251	062	271	117	.190	132	•	Ē
13.	Illness Duration	.040	260	105	.177	.248	037	187	053	.106	.066	.045	.726**	-

Correlations Among Well-Sibling Primary Variables of Interest and Demographic Variables

Note: *p < .05, **p < .01.

IS

Table IIb

-

Correlations Among Children with IDDM Primary Variables of Interest and Demographic Variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13
1. CBCL-Internal	•	-			*				2 5 5	-	(-):	-	-
2. CBCL-External	.788**		-	•	-		-	•			,		-
3. CBCL-Total	.937**	.924**	3 .		-			-			-		-
4. Self-Concept	439*	396**	482*	. 5	-	=	-	-	-	-	ō		2
5. Household Chores	.076	.194	165	270		-	-	-	-		-		-
5. Child-Care	.347	.371	.392*	185	.351		-	-	-		6 8 .	-	-
7. SRQ-Conflict	.210	.433*	.339	368	116	.022		-	-	-	-		-
8. SRQ-Relative	013	.023	.000	156	.109	.361	.261		-	-		-	-
9. SRQ-Warmth	106*	133	194	.448*	.323	.082	527*	224	-	•		-	-
10. SRQ-Rivalry	.114	.234	.060	.051	252	.165	.223	.021	.089	-	-	-	-
11. Age Spacing	289	307	240	.140	.288	.051	396*	026	016	368	-	-	14 1
12. HBA1c	.202	037	.086	232	.155	.379	.215	.196	085	.064	132	5 4 0	
3. Illness Duration	.027	116	031	100	.290	.2 <u>64</u>	040	.093	.201	199	.045	.726**	

Note: p < .05, p < .01.

52

Research Question 1: Household and Childcare Responsibilities

Are there significant differences in the level of self-reported household tasks between well-siblings and children with IDDM?

Two 2 X 2 analyses of covariance were conducted to examine the differences between well-siblings and children with IDDM on two measures of household chores and childcare responsibilities, when controlling for age spacing. The first analysis yielded no significant differences between the well-siblings ($\underline{M} = 42.82$) and children with IDDM ($\underline{M} = 44.30$) with respect to household chores ($\underline{F}(1,50) = .041$, $\underline{p} > .05$). Likewise, the second analysis indicated no significant differences between well-siblings ($\underline{M} = 9.12$) and children with IDDM ($\underline{M} = 9.67$) on the amount of childcare responsibilities ($\underline{F}(1,50) = .156$, $\underline{p} > .05$).

Research Question 2: Relationship between well-sibling adjustment and children with IDDM

Is well-sibling adjustment related to the adjustment of children with IDDM?

An examination of the association between adjustment in children with IDDM and well-siblings yielded a significant association between maternal ratings of externalizing and internalizing behavior problems (see table III). As well-sibling's internalizing and externalizing problems increased, children with IDDM's internalizing and externalizing behavior problems increased. However, no significant relationships emerged between well-siblings and children with IDDM on teacher rated measures of internalizing (p > .05) and externalizing (p > .05) behavior problems or social competence (p > .05).

Table III

*

Zero – Order Correlations for Children with IDDM and their Well-Siblings on Measures	res of Adjustment
--	-------------------

	Variable	CBCL Internal IDDM	CBCL External IDDM	CBCL Social Comp. IDDM	TRF Internal IDDM	TRF External IDDM	TRF Adaptive IDDM
1.	CBCL-Internal Well-Sibling	.753**	.609**	252	.283	.160	267
2.	CBCL-External Well-Sibling	.671**	.695**	389	.180	.344	322
3.	CBCL-Social Competency Well-Sibling	121	138	.324	119	024	.057
4.	TRF-Internal Well-Sibling	.053	.089	103	.091	.047	321
5.	TRF-External Well-Sibling	.059	.277	.070	.251	.449	298
5.	TRF-Adaptive Well-Sibling	200	410	.170	.173	141	.387

Note: *p < .05, **p < .01.

Research Question 3: Regression Analyses

Are indices of sibling responsibility and sibling relationships predictive of the well siblings' psychological adaptation?

Two hierarchical multiple regression analyses were conducted to examine the contribution of demographic and illness parameters, cognitive processes, and indices of family function to sibling behavior problems and social competence. Entry of the variables was based upon Thompson's (1985) transactional stress and coping model for the two separate regression analyses. In each regression, demographic parameters (i.e., age spacing and family income) were entered simultaneously on Step 1; illness specific variables (i.e., HbA1c and duration of illness) were entered on Step 2; cognitive variables (i.e., sibling self-concept) were entered on Step 3; and indices of family functioning (i.e., sibling household / childcare responsibilities and sibling relationship variables) were entered on Step 4. Forced entry was utilized on each of the steps; all variables, regardless of the amount of variance or degree of significance, were allowed to enter the equation. Thus, the regression analyses were hierarchical between sets and forced entry within sets (Cohen & Cohen, 1983).

In the first regression (see Table IV), demographic variables were not significant predictors of the well siblings' maladaptive behavior (R^2 change = .16, p > .05). In addition, the illness specific variables of HBA1c and illness duration were not significant (R^2 change = .03, p > .05). However, cognitive processes (i.e., self-concept) was a significant predictor of child adjustment (R^2 change = .15, p < .05), whereas family functioning was not (R^2 change = .13, p > .05). Examination of the beta weights indicated that increased sibling self-concept was associated with decreased maladaptive behavior

55

reported by mothers. Indices of family functioning failed to contribute significant variance to the prediction model for child maladjustment.

In the second regression model (see Table V), demographic (\mathbb{R}^2 change = .03, $\mathbb{p} >$.05) and illness (\mathbb{R}^2 change = .19, $\mathbb{p} >$.05) parameters were not significant predictors of sibling social competence. As well, indices of cognitive processes failed to contribute significant variance in the prediction of the well-sibling's social competence (\mathbb{R}^2 change = .04, $\mathbb{p} >$.05). However, sibling-reported indices of family functioning were significant predictors (\mathbb{R}^2 change = .71, $\mathbb{p} <$.01) of sibling social competence as perceived by mothers. Examination of the beta weights indicated that as the number of household chores increased, so did parental ratings of social competence. Further, examination of the sibling relationship beta weights suggested that as well-siblings saw themselves as having higher status than their ill-siblings, mothers rated their social competence lower. In addition, as well-siblings saw themselves as treated better by their parents, parents' ratings of the well-siblings social competence decreased.

Table IV

Step	Predictor Variable	R ²	R ² Change	F Change	p-value	Beta weight
1.	Demographics Age Spacing Income	.162	.162	2.229	.130	218 360
2.	Illness Parameters	.194	.031	.410	.669	
	HBA1c Illness Duration					.182 264
3.	Cognitive Variables	.348	.154	4.723	.042*	
	Self-Concept					541
4.	Family Functioning	.477	.129	.577	.743	
	Household Chores					109
	Child Care					.322
	Sibling Warmth					.062
	Sibling Conflict					137
	Sibling Rivalry					.507
	Sibling Status					075

Hierarchical Regression Analysis Predicting Well-Sibling Total Behavior Problems

Note: *p < .05.

Table V

Hierarchical Regression Analysis Predicting Well-Sibling Social Competency

	Predictor		R ²	F		Beta
Step	Variable	R ²	Change	Change	p-value	weight
5.	Demographics	.027	.027	.289	.752	
	Age Spacing					.077
	Income					.152
6.	Illness Parameters	.214	.188	2.267	.131	
	HBA1c					589
	Illness Duration					.629
7.	Cognitive Variables	.254	.040	.954	.342	
	Self-Concept					.274
8.	Family Functioning	.962	.708	37.54	.001**	
	Household Chores					.649**
	Child Care					167
	Sibling Warmth					335
	Sibling Conflict					.087
	Sibling Rivalry					-1.255**
	Sibling Status					246**

Note: ******<u>p</u> < .01.

i.

CHAPTER VI

DISCUSSION

The current study sought to examine: 1) differences in childcare and household responsibilities between well-siblings and children with diabetes; 2) the relationship between well-siblings and ill-children on a number of adjustment measures; and 3) the influence of a variety of adjustment predictors in healthy siblings of children with diabetes. Primary predictors of overall level of adjustment used in this study included illness severity, cognitive processes (i.e., self-concept), and indices of family functioning (i.e., sibling household / childcare responsibilities and sibling relations). More specifically, this study focused on determining if well-siblings differ from children with diabetes in the amount of childcare and household responsibilities, whether sibling indices of adjustment were related to indices of adjustment in children with IDDM, and if family functioning, specifically sibling relations and family responsibilities, was also significantly related to adjustment.

The findings of this study are largely consistent with the few investigations that failed to show well-siblings to be at significant risk for maladjustment. Specifically, wellsiblings of children with diabetes did not appear to be at significant risk for general behavior problems as compared to their ill-siblings and normative data. In comparison to normative samples, the current results indicate that siblings of children with diabetes do not evidence maternal-reported clinical impairment as measured by an examination of mean CBCL total behavior problem scale scores. In fact, only one well-sibling in this sample reported total behavior problems in the clinical range using Achenbach's (1991) criteria. However, the same well-sibling did not evidence total school behavior problems in the clinical range as indicated by teacher report. Thus, well-siblings of children with IDDM do not appear to be at significant risk for behavior problems as indicated by both maternal and teacher report. These findings are consistent with other investigations (e.g., Daniels et al., 1986; Drotar et al., 1981; Fielding et al., 1985; Gallo et al., 1992) that failed to find well-siblings to be at risk for psychosocial and/or school problems.

Future research into illness-specific adjustment measures may prove more useful in identifying not only those siblings and chronically ill children at risk for clinically significant levels of maladjustment, but sub-clinical impairments and sequelae associated with specific chronic conditions. The current investigation utilized maternal report and utilized global measures of adjustment as the sole criterion variables. Additional, longitudinal studies of well-siblings are needed to understand the developmental impact/influence of chronic conditions on the entire family. To date, only two published studies have examined the impact of chronic disability on well-siblings over time (Breslau & Prabucki, 1987; Wang, 1989.). Therefore, the focus should not be limited to children with chronic conditions and their parents but to the long-term familial impact of subclinical maladjustment.

When examining self-reported childcare and household responsibilities, no differences emerged in the amount of household chores or childcare responsibilities between well-siblings and children with IDDM, even after statistically controlling for the

59

effect of age spacing between siblings. Such findings suggest that well-siblings of children with diabetes do not assume household responsibilities beyond those of their ill-siblings. These findings are consistent with Stoneman and colleagues (1991), who found that well-siblings of children with mental retardation did not have increased household responsibilities; however, the Stoneman study found that well-siblings did report more childcare responsibilities. Stoneman and colleagues hypothesized that parents may be concerned with the added childcare responsibilities of healthy siblings, and therefore attempt to compensate by reducing the amount of household chores. However, in the current study no differences emerged between well-siblings and children with diabetes in the amount of childcare responsibilities as well. Our findings are inconsistent with McHale and Gamble's (1988) and Stoneman and colleagues' (1988) findings.

It is possible that in these previous studies, the pervasive and severe disability associated with mental retardation had an accentuated impact upon the well-siblings' role within the family. Although a serious chronic illness, diabetes does not have as many profound cognitive or visible physical impairments or necessitate attention to many activities of daily living. If managed adequately, children with diabetes may have a relatively normal life expectancy. In the current sample, few (n=7) had emergency visits within the past year, suggesting a medically stable and well-managed sample. In addition, nearly 60% of the families in the current sample had incomes over \$50,000 a year; thus, suggesting access to adequate resources. Therefore, the results suggest that the traditional family structure may not have been comprised. Overall, the findings in the current study do not explicitly support the magnification of normative role asymmetries or

the reversal of normative roles between parents and healthy siblings when comparing wellsiblings to children with IDDM.

An examination of the relationships between well-sibling and ill-child adjustment indicated a significant association between maternal ratings of well-sibling internalizing behavior problems and ill-child internalizing and externalizing behavior problems. In addition, a significant relationship was identified between well-sibling externalizing and illchild internalizing and externalizing behavior problems. The results suggest that as wellsiblings experienced maladjustment, so did their ill-siblings. However, these findings are viewed with caution due to the possibility of shared method variance associated with mothers completing measures for both children at the same point in time. Support for this supposition is evident in the lack of associations identified between well-siblings and children with IDDM on independent teacher ratings of externalizing and internalizing school problems.

When examining mother-rated social competence and teacher-rated adaptive behavior, no relationships emerged between well-siblings and children with diabetes. These findings suggest that although behavior problems may be related between siblings, adaptive behaviors do not demonstrate the same relationship. Thus, the factors that predict adaptive behavior for both well-siblings and children with diabetes may be independent of each other. These results suggest that teachers may provide a more unbiased report of student behavior. However, due to the general lack of teacher participation any conclusions may be speculative.

To examine the potential predictors of well-sibling adjustment, hierarchical regression analyses were conducted to assess the relative contribution of demographic

parameters, illness parameters, cognitive processes, and indices of family functioning to measures of well-sibling adjustment. In the current study, adjustment was operationally defined as the absence of total behavior problems and increased social competence. Two separate models were constructed to determine the unique well-sibling adjustment variance accounted for by sibling relations and sibling responsibilities above and beyond the contribution of demographic variables, illness parameters, and cognitive processes.

Utilizing parent-rated behavior problems as the criterion measure, sibling relations and sibling responsibilities were not significant predictors of well-sibling behavior problems. These findings are inconsistent with previous research that have suggested indices of family functioning to be related to the psychological adaptation of children with chronic conditions (e.g., Daniels et al., 1987; Spinetta, 1981). Likewise, demographic and illness parameters were not found to be significant predictors of sibling behavior problems. However, cognitive processes (i.e., self-concept) was a significant predictor of total behavior problems, accounting for unique variance in sibling adaptation over and above that accounted for by demographic and illness parameters. These findings evince that higher self-concept is predictive of lower parent-rated behavior problems.

Results of the second regression analysis utilizing social competency as the criterion variable indicated that well-sibling relations and household responsibilities were significant predictors of sibling social competency above the amount of variance accounted for by demographic variables, illness parameters, and cognitive processes. The results suggest that as the amount of responsibilities within the home increased so do the parent ratings of the well-sibling's social competence. The well-siblings' perception of the sibling relationship was predictive of parent-rated social competency. Specifically, as

siblings saw themselves as treated more favorably (relative to their ill-siblings) by their parents, maternal ratings of social competence decreased. Likewise, as well-siblings saw themselves as having higher status (relative to their ill-siblings), mother-rated social competence decreased.

Thus, the findings of the current study suggest the positive psychological adaptation of the well-sibling is indeed influenced by both sibling relationships and household responsibilities within the home. However, it appeared that these indices of family functioning differed in their utility in predicting adaptive versus maladaptive behaviors. It is further possible that parents are basing their child's social competence upon the degree to which the child reduces the parent's burden of care. Additional analyses utilizing teachers' ratings of social competence and behavior problems would provide more information about the utility of sibling relations and household chores in the prediction of adaptive behavior, specifically peer based pro-social behavior. However, the lack of teacher participation in the current study precluded the examination of these factors.

In the current study, it appeared that the nature of the sibling relationship provided parents a "reference point" with which they evaluated the well-siblings' social competence. Well-siblings who perceived themselves in superordinate positions relative to their ill-siblings received lower maternal ratings of social competency. This suggests as possible misperception on the part of well-siblings or an unidentified and maladaptive coping mechanism. In addition, the results suggest that siblings who reported increased household responsibilities were viewed by their parents as more socially competent. Children who are more involved in the home, thus reducing the burden of the parent, may

63

be having more positive interactions with their parents and less conflictual and rivalrous sibling relations. Conversely, it is possible that parents are reporting higher sibling social competence as a way of compensating for increased household responsibilities, even if these responsibilities are evenly dispersed between well-siblings and children with IDDM. Although no differences emerged between well-siblings and children with IDDM, further research is needed in identifying the impact of sibling responsibilities on self-ratings of social competence. In addition, research identifying the utility of such measures in the prediction of the ill-child's self and parent-rated social competence may more clearly delineate the utility of household responsibilities in the prediction of the diabetic child's social competence.

Several limitations are recognized within the current study. First, all subjects utilized in this study were recruited from one pediatric endrocrinologist in a large Midwestern city. Individuals who are receiving treatment within the same physician practice are likely similar in the treatment received and management of medical complications and unlikely representative of the general population. Physicians who subject their practices to rigorous empirical investigations are likely different from uninvolved and uninterested primary care providers. Therefore, the current study likely reports levels of adjustment and family functioning of those who are motivated and compliant with their treatment regimens. To obtain a less biased participant sample, it is suggested that future studies include patients from multiple treatment facilities and different locales. An additional limitation of the current participant group is in the inclusionary criteria of the sibling dyads. In this sample, no differentiation was made between sibling dyads based upon gender. Consequently, no examination was made between same and mixed-gender dyads on any of the dependent measures. In addition, no information was obtained regarding the nature of the sibling relationship, adjustment, or household responsibilities prior to the diagnosis of diabetes in either the well-sibling or illchild groups.

A second limitation of this study is the use of self-report measures. Self-report methodology can result in recall bias and a variety of method variance problems (e.g., high inter-item correlations). In order to decrease the potential for these errors, future studies would benefit from incorporating a variety of independent measurement modalities (e.g., structured interviews, behavioral observations, and peer reports). In addition, little reliability and validity data was available for the adapted responsibility measures used in the current study; when self-report measures are used, they should demonstrate adequate reliability and validity. Further, the financial status and educational level of this studies' participants limits it's generalizability; the sample was largely middle class with minimal financial strain. Sampling procedures that avoid non-representative samples and attend to family structure, race and ethnicity, severity, and developmental stages will prove more useful to practicing health care professionals.

Although this study is one of the first to examine sibling responsibility and sibling relations on the adjustment of well-siblings of children with diabetes, the sample size was small and included a range of developmental stages. Therefore, it is unclear to the extent that these results are generalizable beyond the conditions of the current study. To minimize the threat to the external validity and Type II errors, an increase in sample size would be ideal. In addition, no efforts were made to control for family-wise error; thus,

65

given the small sample size and number of analyses conducted, all results should be viewed with caution.

An additional limitation of this study was the failure to include an adequate control group. Obtaining information on healthy children with similar demographics (gender, SES, and age spacing) may either support or limit the significant results found in the current study. Without the information provided from a matched control, it is unclear whether the results obtained are clinically meaningful, or merely what may be developmentally expected for "normal" individuals with similar demographic characteristics.

Several suggestions are made for future research with this population. Rather than identifying populations at risk for adjustment problems, greater emphasis should be placed on identifying the specific variables predicting "normal" and positive adjustment in wellsiblings and families with a chronically ill child. It may be that the subtle impact of disease on the family system may not be clearly identified by traditional measures of child adjustment and more comprehensive assessments of family impact may provide healthcare professionals with more useful treatment information. With the advent of more advanced medical procedures (e.g., insulin pumps) and pharmacological agents (e.g., Humalog), more research is warranted to better predict positive treatment outcomes and to anticipate potential negative treatment sequelae.

Lastly, more empirical psychosocial treatment and longitudinal investigations of the adjustment to diabetes are clearly needed. As described earlier, little research has examined the impact of chronic conditions on well-siblings over time. Longitudinal studies should be undertaken to so that the complex, recursive interactions between the chronic illness and the family may be sufficiently studied. Furthermore, a longitudinal design is required to draw conclusions regarding the temporal order of events and causality. More complex analytic procedures and models will aid in illuminating the reciprocal nature of sibling responsibility, relations, and adjustment.

During the acquisition of the data for this study, several topics of concern were routinely reported by parents during home visits attended by this researcher. Parents reported increased mood disturbances during periods of hypoglycemia and expressed concern about these effects on school performance and teacher reactions. Likewise, parents expressed concern about teachers' diabetes-related knowledge and the effects of the condition on teacher perceptions. To date, no studies have examined teacher-reported diabetes-related knowledge or teacher attributions of diabetes-related behaviors. Addressing these concerns may provide useful information in the development of educational and psychosocial interventions for the families of children with IDDM.

It is important to note that parents rarely expressed concern about the impact of the illness on healthy siblings during the home visits. It is possible that parents do not see them as a group at risk for adjustment problems, or that their attention is directed largely at the child with IDDM because of strict treatment requirements, concern for future complications, and limited resources. Research data have shown that parents of an ill child are potentially unaware of the true nature and extent of their healthy children's feelings, concerns, and behaviors. For example, Craft and Craft (1989) interviewed both parents and siblings of hospitalized children and found that when asked about the number of changes in consequent feelings and behavior changes, parents reported about half as many changes as did well-siblings. In summary, while this study provided useful information about the impact of diabetes on the healthy sibling, it is clear that the well-sibling research is in its infancy and requires more than exploratory descriptive designs. Although general information has been gathered regarding the impact of diabetes on the family, further research is needed to determine which specific factors will be useful to families in reducing the psychological and structural impact of the condition on the family system. The information obtained from well-siblings and parents will ultimately prove useful to health care professionals providing sibling interventions in a variety of health care settings. Long-term studies examining the impact of diabetes on well-siblings will provide needed information in the development of systems oriented and family-centered diabetes treatment regimens; thus, ultimately reducing or ameliorating the acute and chronic struggles faced by families with a chronically-ill child.

REFERENCES

Achenbach, T. M. (1991). <u>Manual for the Child behavior Checklist/4-18 and 1991</u> <u>Profile</u>. Burlington, VT: University of Vermont Department of Psychiatry.

Achenbach, T. M. (1991). <u>Manual for the Teacher's Report Form and 1991</u> <u>Profile</u>. Burlington, VT: University of Vermont Department of Psychiatry.

Adams, R., Peveler, R., Stein, A. and Dunger, D. (1991). Siblings of children with diabetes: involvement, understanding and adaptation. <u>Diabetic Medicine</u>, <u>8</u>, 855-859.

Anderson, B. J. (1990). Diabetes and adaptation in family systems. In C.S. Holmes (Ed.), <u>Neuropsychological and behavioral aspects of diabetes</u>. New York: Springer-Verlag. (pp. 85-101).

Anderson, B. J., Miller, J. P., Auslander, W. F., & Santiago, J. V. (1981). Family characteristics of diabetic adolescents: relationships to metabolic control. <u>Diabetes Care</u>, <u>4</u>, 596-594.

Auslander, W. F., Bubb, J., Rogge, M., & Santiago, J. V., (1993). Family stress and resources: Potential areas of intervention in children with diabetes. <u>Health & Social</u> <u>Work, 18(2), 101-113</u>.

Bobrow, E. S., AvEuskin, T. W., Siller, J. (1985). Mother-daughter interaction and adherence to diabetes regimens. <u>Diabetes Care</u>, <u>8</u>, 145-156.

Breslau, N. (1982). Siblings of disabled children: Birth order and age-spacing effects. Journal of Abnormal Child Psychology, 10, 85-96.

Breslau, N., & Prabucki, K. (1987). Siblings of disabled children. Archives of General Psychiatry, 44, 1040-1046.

Breslau, N., Weitzman, M., & Messenger, K. (1981). Psychological functioning of siblings of disabled children. <u>Pediatrics</u>, <u>67</u>, 344-353.

Bristol, M., Gallagher, J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: Adaptation and spousal support. Developmental Psychology, 24, 441-451.

Bronfenbrrenner, U. (1977). <u>The ecology of human development</u>. Cambridge, MA: Harvard University Press.

Brown, A. J. (1985). School-age children with diabetes: Knowledge and management of the disease, and adequacy of self-concept. <u>Maternal-Child Nursing</u> Journal, 4(1), 47-61.

Bruhn, J. G. (1977). Effects of chronic illness on the family. Journal of Family Practice, 4(6), 1057-1060.

Buhrmester, D. & Furman, W. (1990). Perceptions of sibling relationships during middle childhood and adolescence. <u>Child Development</u>, <u>60</u>, 1387-1398.

Burns, K. L, Green, P., & Chase, H. P. (1986). Psychosocial correlates of glycemic control as a function of age in youth with insulin dependent diabetes mellitus. Journal of Adolescent Health Care, 7, 311-319.

Cadman, D., Boyle, M., & Offord, D. R. (1988). The Ontario child health study: Social adjustment and mental health of siblings of children with chronic health problems. Journal of Developmental and Behavioral Pediatrics, 9, 117-121.

Cairns, N., Clark, G., Smith, S., & Lansky, S. (1979). Adaptation of siblings to childhood malignancy. Journal of Pediatrics, 95, 484-487.

Canam, C. (1993). Common adaptive tasks facing parents of children with chronic conditions. Journal of Advanced Nursing, 18, 46-53.

Chaney, J. M., Mullins, L. L., Frank, R. G., Peterson, L., Mace, L. D., Kashani, J. H., & Goldstein, L. (1996). Transactional patterns of child, mother, and father adjustment insulin-dependent diabetes mellitus: A prospective study. <u>Journal of Pediatric Psychology</u>, 22(2), 229-244.

Chaney, J., & Peterson, L. (1989). Family variables and disease management in juvenile rheumatoid arthritis. Journal of Pediatric Psychology, 14, 389-403.

Cleveland, D.W., & Miller, N. (1977). Attitudes and life commitments of older siblings of disabled children. <u>Pediatrics</u>, <u>67</u>, 344-353.

Cohen, D., Freidrich, W., Jaworski, T., Copeland, D. & Pendergrass, T. (1995). Pediatric cancer: predicting sibling adjustment. <u>Journal of Clinical Psychology</u>, <u>50</u>, 303-319.

Compas, B. E. (1987). Coping with stress during childhood and adolescence. <u>Psychological Bulletin</u>, 101, 393-403.

Cowen, L., Mok, J., Corey, M., McMillan, H., Simmons, R. & Levinson, H. (1986). Psychological adjustment of the family with a member who has CF. <u>Pediatrics</u>, <u>77</u>, 743-753.

Cox, D. J., Gonder-Frederick, L. A., Lee, J. H., Julian, D. M., Carter, W. R., & Clarke, W. L. (1989) Blood glucose awareness training among patients with IDDM: Effects and correlates. <u>Diabetes Care</u>, 12, 313-318.

Craft, M. J., & Craft, J. L. (1989). Perceived changes in siblings of hospitalized children: A comparison of siblings and parents. <u>Children's Health Care</u>, <u>18</u>, 42-48.

Crain, A., Sussman, M., & Weil, W. (1966). Family interaction, diabetes, and sibling relationships. International Journal of Social Psychiatry, 12, 35-43.

Daniels, D., Miller, J., Billings, A., & Moos, R. (1986). Psychosocial functioning of siblings of children with rheumatic disease. Journal of Pediatrics, 109, 379-383.

Daniels, D., Moos, R., Billings, A., & Miller, J. (1987). Psychosocial risk and resistance factors among children with chronic illness, healthy siblings, and healthy controls. Journal of Abnormal Child Psychology, 15, 295-308.

Davis, W. K., Hess, G. E., & Hiss, R. G. (1988). Psychosocial correlates of survival in diabetes. <u>Diabetes Care</u>, 11, 538-545.

Drotar, D., & Crawford, P. (1985). Psychological adaptation of siblings of chronically ill children: Research and practice implications. Journal of Developmental and Behavioral Pediatrics, 6(6), 355-362.

Drotar, D., Crawford, P., & Bush, M. (1984). The family context of childhood chronic illness: Implications for psychosocial intervention. In M. Eisenberg, L. Sutkin & M. Jansen (Eds.), <u>Chronic illness and disability through the lifespan: Effects on self and family</u>. New York: Springer. (pp. 103-129).

Deveraux, R. (1979). The psychological effects of a handicapped child on parents and siblings. Spina Bifida Therapy, 1, 146-155.

Eiser, C. (1990). Psychological effects of chronic disease. Journal of Child Psychology and Psychiatry, 31(1), 85-98.

Engstrom, I. (1992). Psychological problems in siblings of children and adolescents with IBD. European Child and Adolescent Psychiatry, 1(1), 24-33.

Farber, B. (1959). Effects of a severely mentally retarded child on family integration. Monographs of Social Research in Child Development, 24(2).

Farber, B., & Rychman, D. B. (1965). Effects of severely mentally retarded children on family relationships. <u>Child Development</u>, <u>56</u>, 448-461.

Faux, S. (1991). Sibling relationships in families of congenitally impaired children. Journal of Pediatric Nursing, 6, 175-184.

Ferrari, M. (1984). Chronic illness: Psychosocial effects on siblings-1. Chronically ill boys. Journal of Child Psychology and Psychiatry, 25, 459-476.

Ferrari, M. (1987). The diabetic child and well sibling: risks to well child's selfconcept. <u>Children's Health Care, 15, 141-148</u>.

Fielding, D., Moore, B., Dewey, M., Ashley, P., McKendrick, T., & Pinkerton, P. (1985). Children with end-stage renal failure: psychological effects on patients, siblings and parents. Journal of Psychosomatic Research, 29, 457-465.

Foster, D. W. (1994). Diabetes mellitus. In K. J. Isselbacher, E. Braunwald, J. D. Wilson, J. B. Martin, A. S. Fauci, & D. L. Kasper (Eds.), <u>Harrison's principles of internal</u> medicine. New York: McGraw Hill. (pp. 1979-2000).

Freeman, B. J. (1985). Review of child behavior checklist. In J. V. Mitchell, Jr. (Ed.), <u>The ninth mental measurements yearbook</u>. Lincoln, NE: The Buros Institute of Mental Measurements, University of Nebraska. (pp. 300-301).

Furman, W. & Buhrmester, D. (1985). Children's perceptions of the qualities of sibling relationships. <u>Child Development</u>, 56, 448-461.

Gallo, A., Breitmayer, B., Knaft, K., & Zoeller, L. (1993). Mothers' perceptions of sibling adjustment and family life in childhood chronic illness. <u>Journal of Pediatric</u> Nursing, 8(5), 318-324.

Gallo, A., Breitmayer, B., Knaft, K., & Zoeller, L. (1992). Well siblings of children with chronic illness. Pediatrics, 59, 888-894.

Gath, A. (1974). Sibling reactions to mental handicap: A comparison of the brothers and sisters of mongol children. Journal of Child Psychiatry, 15, 187-198.

Gayton, W. F., Friedman, S. B., Tavormina, J. B., & Tucker, F. (1977). Children with cystic fibrosis: I. Psychological test findings of patient, siblings and parents. <u>Pediatrics</u>, 59, 888-894.

Geffken, G., & Johnson, S. B. (1994). Diabetes: Psychological Issues. In R. A. Olson, L. L. Mullins, J. B. Gillman, & J. M. Chaney (Eds.), <u>The sourcebook of pediatric psychology</u>. Boston: Allyn and Bacon. (pp.118-129).

Geringer, E. S. (1990). Affective disorders and Diabetes mellitus. In C. S. Holmes (Ed.), <u>Neuropsychological and behavioral aspects of diabetes</u>. New York: Springer-Verlag. (pp. 239-264).

Gilbert, B. O., Johnson, S. B., Silverstein, J., & Mallone, J. (1989). Psychological and physiological responses to acute laboratory stressors in insulin dependent diabetes mellitus adolescents and non-diabetes controls. Journal of Pediatric Psychology, <u>14</u>, 577-591.

Graef, J. W. (Ed.). (1994). <u>Manual of Pediatric Therapeutics</u>. Boston: Little, Brown and Company.

Grossman, F. D. (1972). <u>Brothers and sisters of retarded children: An exploratory</u> study. Syracuse, N. Y.; Syracuse University Press.

Hanson, C. L., De Guire, M. J., Schinkel, A. M., Henggeler, S. W., & Burghen, G. A., (1992). Comparing social learning and family systems correlates of adaptation in youths with insulin-dependent diabetes mellitus. Journal of Consulting and Clinical Psychology, 60 (1), 104-112.

Hanson, C. L., Henggeler, S. W., & Burghen, G. A. (1987a). Model of the associations between psychosocial variables and health outcome measures of adolescents with IDDM. <u>Diabetes Care</u>, 10, 752-756.

Hanson, C. L., Henggeler, S. W., & Burghen, G. A. (1987b). Social competence and parental support as mediators of the link between stress and metabolic control in adolescents with insulin dependent diabetes mellitus. Journal of Consulting and Clinical Psychology, 55, 529-533.

Hanson, C. L., Henggeler, S. W., Harris, M. A., Burghen, G. A., & Moore, M. (1989). Family system variables and the health status of adolescents with insulindependent diabetes mellitus. <u>Health Psychology</u>, 8, 239-253.

Hanson, C. L., Henggeler, S. W., Harris, M. A., Cigrang, J. A., Schinkel, A. M., Rodrigue, J. R., & Klesges, R. C. (1992). Contributions of sibling relations to the adaptation of youths with insulin-dependent diabetes mellitus. <u>Journal of Consulting and</u> <u>Clinical Psychology</u>, <u>60</u>, 104-112.

Harris, M. I. (Ed.). (1995). <u>Diabetes in America.</u> Washington, DC: National Institute of Health.

Harter, S. (1982). The perceived competence scale for children. <u>Child</u> <u>Development</u>, 53, 87-97.

Harter, S. (1983). Developmental perspectives on the self-esteem. In E.M. Hetherington (Ed.), <u>Handbook of child psychology: Vol. 4. Socialization, personality, and social development</u>. New York: Wiley. (pp. 275-385).

Harter, S. (1987). The determinants and mediational role of global self-worth in children. In E. M. Hetherington (Ed.), P. H. Mussen (Series Ed.), <u>Contemporary topics in developmental psychology</u>. New York: Wiley. (pp. 219-242).

Hartup, W. W. (1983). Peer relations. Family Relations, 34, 99-108.

Harvey, D. & Greenway, A. (1984). The self-concept of physically handicapped children and their non-handicapped siblings: an empirical investigation. Journal of Child Psychology and Psychiatry, 25(2), 273-284.

Hauenstein, E. J., Marvin, R. S., Snyder, A. L., & Clarke, W. L. (1989). Stress in parents of children with diabetes mellitus. <u>Diabetes Care</u>, <u>12</u>(1), 18-23.

Hauser, S. T., Jacobson, A. M., Lavori, P., Wolfsdorf, J. I., Herskowitz, R. D., Milley, J. E., Bliss, R., Wertleib, D., & Stein, J. (1990). Adherence among children and adolescents with insulin dependent diabetes mellitus over a four-year longitudinal followup: II. Immediate and long-term linkages with the family milieu. <u>Journal of Pediatric</u> <u>Psychology</u>, 15, 527-542.

Hauser, S. T., Jacobson, A. M., & Wertlieb, D. (1986). Children with recently diagnosed diabetes: Interactions with the families. <u>Health Psychology</u>, <u>5</u>, 273-296.

Hill, R. (1958). Social stresses on the family. Social Casework, 39, 139-150.

Hoare, P. (1984). Psychiatric disturbance in the families of epileptic children. Developmental Medicine and Child Neurology, 26, 20-24.

Holmes, C. S., Dunlap, W. P., Chen, R. S., & Cornwell, J. M., (1992). Gender differences in the learning status of diabetic children. Journal of Consulting and Clinical Psychology, <u>60</u>(5), 698-704.

Holt, K. (1958). The home care of severely retarded children. <u>Pediatrics</u>, <u>22</u>, 744-755.

Horowitz, W. & Kazak, A. (1990). Family adaptation to childhood cancer: Sibling and family systems variables. Journal of Clinical and Child Psychology, 19, 221-228.

Ihenger-Tallman, M., & Pasley, K. (1987). Remarriage. Newbury Park, CA: Sage.

Jacobsen, A. M., Hauser, S. T., Lavori, P., Wolfsdorf, J. L., Herskowitz, R. D., Milley, J. E., Bliss, R., Wetlieb, D., & Stein, J. (1990). Adherence among children and adolescents with insulin dependent diabetes mellitus. *Journal of Pediatrics*, 108, 620-623. Jacobsen, A. M., Hauser, S. T., Wertlieb, D., Woldsdorf, J. I., Orleans, J., & Vicyra, M. (1986). Psychological adjustment of children with recently diagnosed diabetes mellitus. <u>Diabetes Care</u>, 9, 323-329.

Jacobsen, A. M., Hauser, S. T., Wolfsdorf, J. I., Houlihan, J., Milley, J. E., Herskowitz, R. D., Wetlieb, D., & Watt, E. (1987). Psychologic predictors of compliance in children with recent onset of diabetes mellitus. Journal of Pediatrics, 110, 805-811.

Johnson, S. B. (1990). Adherence behaviors and health status in childhood diabetes. In C. Holmes (Ed.), <u>Neuropsychological and behavioral aspects of insulin and non-insulin dependent diabetes</u>. New York: Springer-Verlag. (pp. 30-57).

Karlson, J. A., Holmes, C. S., & Lang, R. (1988). Psychosocial aspects of disease duration and control in young adults with type 1 diabetes. Journal of Clinical Epidemiology, 45, 431-440.

Kazak, A. E., (1989). Families of chronically ill children: A system and socialecological model of adaptation and challenge. <u>Journal and Consulting and Clinical</u> <u>Psychology</u>, 57, 25-30.

Kazak, A. & Clark, M. (1986). Stress in families of children with myelomeningocele. Developmental Medicine and Child Neurology, 28, 220-228.

Kazak, A. E. & Marvin, R. S. (1984). Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child. <u>Family Relations</u>, 33, 67-77.

Kazak, A. E., Reber, M., & Carter, A., (1988). Structural and qualitative aspects of social networks in families with young chronically ill children. Journal of Pediatric Research, 13, 171-182.

Kelley, M. L. (1985). Review of child behavior checklist. In J. V. Mitchell, Jr. (Ed.), <u>The ninth mental measurements yearbook</u>. Lincoln, NE: The Buros Institute of Mental Measurements, University of Nebraska. (pp. 301-303).

Kirkman, M. (1984). Adult siblings of the handicapped: Early family relationships. In <u>Proceedings Australian Family Research Conference. Vol. V.: Support Networks.</u> Melbourne: Institute of Family Studies.

Kovacs, M., Brent, D., Steinberg, T. F., Paulauskas, S., Reid, J. (1986). Children's self-reports of psychologic adjustment and coping strategies during the first year of insulin-dependent diabetes mellitus. <u>Diabetes Care</u>, 9, 472-479.

Kovacs, M., Finkelstein, R., Feinberg, T., Crouse-Novak, M., Paulauskas, S., & Pollack, M. (1985). Initial psychological responses of parents to the diagnosis of insulin dependent diabetes mellitus in their children. <u>Diabetes Care, 8</u>, 568-575.

Kovacs, M., Iyengar, A., Goldston, D., Stewart, J., Obrosky, D. S., & Marsh, J. (1990). Psychological functioning of children with insulin dependent diabetes mellitus: A longitudinal study. Journal of Pediatric Psychology, 15, 581-594.

Kramer, R. (1984). Living with childhood cancer: impact on the healthy siblings. Oncology Nursing Forum, 11, 44-51.

Kuttner, M. J., Delamater, A. M., & Santiago, J. V. (1990). Journal of Pediatric Psychology, 15, 581-594.

La Greca, A. M., Schwarz, L. T., & Satin, W. (1987). Eating patterns in young women with IDDM: Another look. <u>Diabetes Care</u>, 10, 659-660.

La Greca, A. M. & Skyler, J. S. (1991). Psychosocial issues in IDDM: A multivariate framework. In P. M. McCabe, N. Schneiderman, T. M. Field, & J. S. Skyler (Eds.), <u>Stress, coping, and disease</u>. Hillsdale, NJ: Erlbaum. (pp. 169-190).

Lamb, M. E. & Sutton-Smith, D. (Eds.). (1982). <u>Sibling relationships: Their nature</u> and significance across the life-span. Hillsdale, NJ: Erlbaum.

Lavigne, J. V. & Ryan, M. (1979). Psychologic adjustment of siblings of children with chronic illness. <u>Pediatrics</u>, <u>63</u>, 616-627.

LaVigne, J. V., Traisman, H. S., Marr, T. J., & Chaisnoff, I. J. (1982). Parental perceptions of the psychological adjustment of children with diabetes and their siblings. <u>Diabetes Care, 5</u>, 420-426.

Littlefield, C. H., Rodin, G. M., Murray, M. A., & Craven, J. L. (1990). Influence of functional impairment and social support on depressive symptoms in persons with diabetes. <u>Health Psychology</u>, *9*, 737-749.

Lobato, D. (1983). Siblings of handicapped children: A review. Journal of Autism and Developmental Disorders, 13(4), 347-364.

Lobato, D., Barbour, L., Hall, L. J., & Miller, C. T. (1987). Psychosocial characteristics of preschool siblings of handicapped children. Journal of Abnormal Child Psychology, 15, 329-338.

Lobato, D., Faust, D. & Spirito, A., (1988). Examining the effects of chronic disease and disability on children's sibling relationships. Journal of Pediatric Psychology, 13, 389-407.

Marcus, M. D., & Wing, R. R. (1990). Eating disorder and diabetes. In C. S. Holmes (Ed.), <u>Neuropsychological and behavioral aspects of diabetes</u>. New York: Springer-Verlag. (pp. 102-121).

Mayou, R., Peveler, R., Davies, B., Mann, J., & Fairburn, C. (1991). Psychiatric morbidity in young adults with insulin-dependent diabetes mellitus. <u>Psychological</u> <u>Medicine, 21</u>, 639-645.

McCubbin, H. L., & Patterson, J. M. (1983). The family stress process: The double ABCX model of adjustment and adaptation. <u>Marriage and Family Review</u>, <u>6</u>(1/2), 7-37.

McKeever, P. (1983). Siblings of chronically ill children: A literature review with implications for research and practice. <u>American Journal of Orthopsychiatry</u>, <u>53</u>(2), 209-218.

Menke, E. (1987). The impact of a child's chronic illness on school-aged siblings. <u>Children's Health Care</u>, 15(3), 132-140.

Meyerowitz, J. H., & Kaplan, H. B. (1967). Family responses to stress: The case of cystic fibrosis. Social Science and Medicine, 1, 249-262.

Moos, R. H., & Tsu, U. D. (1977). The crises of physical illness: An overview. In R. H. Moos (Ed.), <u>Coping with physical illness</u>. New York: Plenum. (pp. 3-21).

Noll, R. B., Yosua, L. A., Vannatta, K., Kalinyak, K., Bukowski, W. M., & Davies, W. H. (1995). Social competence of siblings of children with sickle cell anemia. Journal of Pediatric Psychology, 20(2), 165-172.

Patterson, J. M., Leonard, B. J., & Titus, J. C. (1992). Home care for medically fragile children: Impact on family health and well-being. <u>Developmental and Behavioral Pediatrics</u>, 13(4), 248-255.

Peck, B. (1979). Effects of childhood cancer on long-term survivors and their families. British Medical Journal, 1, 1327-1329.

Perrin, E. C., Ramsey, B. K., & Sandler, H. M. (1987). Competent kids: children and adolescents with a chronic illness. <u>Child Health Care and Development</u>, 13, 13-32.

Phillips, S., Bohannon, W., Gayton, W. & Friedman, S. (1985). Parent interview findings regarding the impact of CF on families. <u>Developmental and Behavioral</u> <u>Pediatrics, 6</u>, 122-127.

Piers, E. V., & Harris, D. B. (1969). <u>The Piers-Harris children's self-concept scale</u> (<u>The way I feel about myself</u>). Nashville: Counselor Recordings and Tests.

Pless, I. B., Heller, A., Belmonte, M., & Zvagulis, I., (1988). Expected diabetic control in childhood and psychological functioning in early adult life. <u>Diabetes Care</u>, <u>11</u>, 387-392.

Popkin, M. K., Callies, A. L., Lentz, R. D., Colon, E. A., & Sutherland, D. E. (1988). Prevalence of major depression, simple phobia, and other psychiatric disorders in patients with long-standing Type I diabetes mellitus. <u>Archives of General Psychiatry</u>, 45, 64-68.

Powell, T. H. & Ogle, P. A. (1985). <u>Brothers and sisters—A special part of exceptional families</u>. Baltimore: Paul H. Brookes.

Rees, A. M. (1995). <u>Consumer health USA: Essential information from the federal health network.</u> Pheonix: Oryx Press.

Rodger, S. (1985). Siblings of handicapped children: A population at risk? <u>The</u> Exceptional Child, <u>32(1)</u>, 47-56.

Ryan, D., Vaga, A., & Drash, A. (1985). Cognitive deficits in adolescents who developed diabetes early in life. <u>Pediatrics</u>, 75, 921-927.

Sabbeth, B. F., & Leventhal, J. M. (1984). Marital adjustment to chronic childhood illness: A critique of the literature. <u>Pediatrics</u>, 73, 762-786.

Sahler, O. & Carpenter, P. (1987). Developmental differences among siblings' perceptions of the pediatric cancer experience. Journal of Developmental and Behavioral <u>Pediatrics, 8</u>, 121.

Sahler, O., Roghman, K., Carpenter, P., Mulhern, R., Dolgin, M., Sargent, J., Barbarin, O., Copeland, D., & Zelta, L. (1994). Adaptation to childhood cancer collaborative study: Prevalence of sibling distress and definition of adaptational levels. <u>Developmental and Behavioral Pediatrics</u>, <u>15</u>, 353-366.

San Martino, M., & Newman, M. B. (1974). Siblings of the retarded: A population at risk. <u>Child Psychiatry and Human Development</u>, <u>4</u>, 168-177.

Schachter, F. F. (1982). Sibling deidentification and split-parent identification: A family tetrad. In M. E. Lamb & B. Sutton-Smith (Eds.), <u>Sibling relationships: Their</u> nature and significance across the lifespan. Hillsdale, NJ: Erlbaum.

Schafer L. C., McCaul, K. D., & Glasgow, R. E. (1986). Supportive and nonsupportive family behaviors: Relationships to adherence and metabolic control in persons with type I diabetes. <u>Diabetes Care, 9</u>, 179-185.

Schipper, M T. (1959). The child with mongolism in the home. <u>Pediatrics</u>, <u>24</u>, 132-144.

Senapati, R., & Hayes, A. (1988). Sibling relationships of Handicapped children: A review of conceptual and methodological issues. <u>International Journal of Behavioral</u> <u>Development</u>, <u>11</u>(1), 89-115.

Sherwin, R. S. (1996.). Diabetes mellitus. In J. C. Bennett & F. Plum (Eds.), <u>Cecil</u> textbook of medicine. Philadelphia: W.B. Saunders Company. (pp. 1258-1267).

Shouval, R., Ber, R., Galatzer, A. (1982). Family social climate and the social adaptation of diabetic youth. In Z. Laron (Ed.), <u>Psychological aspects of diabetes in children and adolescents</u>. Basel: Karger.

Spinetta, J. & Deasy-Spinetta, P. (1981). The sibling of the child with cancer. In J. Spinetta and P. Deasy-Spinetta (Eds.), <u>Living with Childhood Cancer</u>. Mosby, St. Louis.

Stoneman, Z., Brody, G. H., Davis, C. H., & Crapps, J. M. (1988). Childcare responsibilities, peer relations, and sibling conflict: Older siblings of mentally retarded children. American Journal on Mental Retardation, 93(2), 174-183.

Stoneman, Z., Brody, G. H., Davis, C. H., Crapps, J. M., Malone, D. M. (1991). Ascribed role relations between children with mental retardation and their younger siblings. <u>American Journal on Mental Retardation</u>, 95(5), 537-550.

Strauss, A., Corbin, J., Fagerhaugh, S., Glaser, B., Marines, D., Suczek, B., & Wiener, C. (1985). <u>Chronic illness and the quality of life (2nd ed.)</u>. St. Louis: Mosby.

Sullivan, B. J. (1978). Self-esteem and depression in adolescent diabetic girls. Diabetes Care, 1, 18-22.

Tew, B. J., & Lawrence, K. M. (1973). Mothers, brothers and sisters of patients with spina bifida. <u>Developmental Medicine and Child Neurology</u>, <u>15</u>, (Suppl. 29), 69-76.

Thompson, R., J., Jr., Gil, K. M., Burbach, D. J., Keith, B. R., & Kinney, T. R. (1993a). Psychological adjustment of mothers of children and adolescents with sickle cell disease: The role of stress, coping methods and family functioning. Journal of Pediatric Psychology Journal of Pediatric Psychology, 18, 549-559.

Thompson, R., J., Jr., Gil, K. M., Burbach, D. J., Keith, B. R., & Kinney, T. R. (1993b). Role of child and maternal processes in the psychological adjustment of children with sickle cell disease. Journal of Consulting and Clinical Psychology, <u>61</u>, 468-474.

Thompson, R., J., Jr., Gil, K., Gustafson, K., George, L., Keith, B., Spock, A., & Kinney, T. (1994). Stability and change in the psychological adjustment of mothers of children and adolescents with cystic fibrosis and sickle cell disease. Journal of Pediatric Psychology, 19, 171-188.

Thompson, R., J., Jr., Gil, K., Gustafson, K., George, L., & Spock, A.(1994). Change over a 12-month period in the psychological adjustment of children and adolescents with cystic fibrosis. Journal of Pediatric Psychology, 19, 189-203.

Thompson, R. J., Jr., & Gustafson, K. E. (1996). <u>Adaptation to chronic childhood</u> <u>illness.</u> Washington, DC: American Psychological Association.

Thompson, R. J., Jr., Gustafsen, K., George, L. & Spock, A. (1994). Change over a 12-month period in the psychological adjustment of children and adolescents with cystic fibrosis. Journal of Pediatric Psychology, 19, 189-203.

Travis, L. B., Brouhard, B. H., & Schreiner, B. J. (1987). Diabetes mellitus in children and adolescents. Philadelphia: W. B. Saunders.

Treiber, F., Mabe, P. & Wilson, G. (1987). Psychological adjustment in sickle cell children and their siblings. <u>Children's Health Care, 16</u>, 82-88.

Trevino, F. (1979). Siblings of handicapped children: Identifying those at risk. Social Casework, 488-493.

Tritt, S. & Esses, L. (1988). Psychosocial adaptation of siblings of children with chronic illness. <u>American Journal of Orthopsychiatry</u>, <u>58</u>(2), 211-220.

Vance, J. C., Fazan, L. E., Satterwhite, B., & Pless, I. B. (1980). Effects of nephrotic syndrome on the family: A controlled study. <u>Pediatrics</u>, <u>65</u>, 948-955.

Varni, J. W. & Wallander, J. L. (1988). Pediatric chronic disabilities: hemophilia and spina bifida as examples. In D. Routh (Ed.), <u>Handbook of pediatric psychology</u>. New York: Guilford Press. (pp. 190-221).

Walker, C. (1988). Stress and coping in siblings of childhood cancer patients. Nursing Research, 37, 208-212.

Waller, D. A., Chipman, J. J., Hardy, B. W., Hightower, M. S., North, A. J., Williams, S. B., & Babick, A. J. (1986). Measuring diabetes-specific family support and its relation to metabolic control: A preliminary report. Journal of the American Academy of <u>Child Psychiatry</u>, 25, 415-418. Wang, R. (1989). A longitudinal study: Behavioral Responses of healthy Chinese siblings to the stress of childhood cancer in the family. Dissertation, University of California San Francisco, CA, U.S.A., University Microfilms International. #PUZ8926418.

Wertlieb, D., Hauser, S. T., & Jacobson, A. M. (1986). Adaptation to diabetes: behavior symptoms and family context. Journal of Pediatric Psychology, 11, 463-479.

Williams, P. D., Lorenzo, F. D., & Borja, A. (1993). Pediatric chronic illness: Effects on siblings and mothers. <u>Maternal-Child Nursing Journal</u>, <u>21</u>(4), 111-121.

Wing, R. R., Nowalk, M. P., Marcus, M. D., Koeske, R., & Finegold, D. (1986). Subclinical eating disorders and glycemic control in adolescents with type I diabetes. <u>Diabetes Care, 9</u>, 162-167.

Wood, B., Boyle, J., Watkins, J., Noquiera, J., Zimand, E., Caroll, L. (1988). Sibling psychological status and style as related to the disease of their chronically ill brothers and sisters: implications for models of biopsychosocial interaction. <u>Developmental and Behavioral Pediatrics</u>, 7, 66-72.

Zrebiec, J. F. (1987). Psychosocial commentary on insulin-dependent diabetes mellitus in 5 to 9-year-old children. In S. J. Brink (Ed.), <u>Pediatric and adolescent diabetes</u> mellitus. Chicago: Year Book Medical Publishers. (pp. 79-88).

APPENDIXES

-

APPENDIX A

DEMOGRAPHICS

Background Information

Today's Date	Subject No.
1. Child's Name:	Age:
2. Mother's Name:	Age:
3. Father's Name:	Age:
4. Name of person filling out this form and	relationship to child (e.g., mother):

5. Who currently lives in the household with you and your child? Please note their relationship to the child and age (e.g., brother-15 months, stepparent - 36 yrs old).

Name	Relation to child	Age
		·
6. Telephone number:		
7. Child's Gender: Male I	Female 2	
8. Child's Race: Caucasian 1	African-American Hispanic Nat 2 3	tive American Other: 4 5
9. Child's Grade	_	
10. Special Education Yes	No	
11. Parents' Marital Status: M	arried Single Parent Remarried	d Never Married Other 4 5
12. Parents' Occupations: Fa	ather	Mother
13. Parents' Highest Level		
- 이상 방법 - 2017년 2017년 2017년 2017년 - 2017년 1187 일 - 2017년 2017년 1187년	ather	Mother
14. Please indicate your total far	nily income: 0-4,999	30, 000-39,999
(This information will be h	and the second sec	
strictly confidential).	10,000-14,999	50,000-59,000
	15,000-19,999	60,000 or greater
	20,000-29,999	

Diabetes/Health Information

1. Thow folig ha	s your child had d				
2. Current HBA	A ₁ Clevel				
How many s	hots a day is your	child suppo	sed to have?		
Blood Glucos	e Testing				
4. When during	g the day is your cl	hild suppose	ed to test his/her	blood?	
5. Does your cl	ild use a glucome	ter to read h	is/her strips?		
1	NO	YES _	TYPE		
Food Intake	ow many times di	220		<i>1</i> 79 (3)	
		and the second of	a a second a		
8. Please write	down everything	your child a		he best of yo	1991 (1997) (1997) (1997) 1997 - Maria Maria (1997)
8. Please write	down everything Lunch	your child a	te yesterday to t Dinner	he best of yo	our memory Snacks
		your child a	Dinner		1991 (1997) (1997) (1997) 1997 - Maria Maria (1997)
8. Please write		your child a	Dinner		1991 (1997) (1997) (1997) 1997 - Maria Maria (1997)
8. Please write		your child a	Dinner		1991 (1997) (1997) (1997) 1997 - Maria Maria (1997)
8. Please write		your child a	Dinner		1991 (1997) (1997) (1997) 1997 - Maria Maria (1997)
8. Please write Breakfast	Lunch		Dinner		1991 (1997) (1997) (1997) 1997 - Maria Maria (1997)
8. Please write Breakfast			Dinner		1991 (1997) (1997) (1997) 1997 - Maria Maria (1997)
 Please write Breakfast 9. How many of 	Lunch	hild eat yes	Dinner		Snacks
 Please write Breakfast 9. How many of 	Lunch	hild eat yes	Dinner		Snacks
 Please write Breakfast 9. How many of 10. How many 	Lunch	hild eat yes exchanges a	Dinner	ld supposed	Snacks
 Please write Breakfast 9. How many of 10. How many 11. Please indi 	Lunch	hild eat yes exchanges a r week your	Dinner	ld supposed	Snacks
 8. Please write Breakfast 9. How many of 10. How many of 11. Please indi Fast F Fast F 	Lunch	hild eat yes exchanges a r week your	Dinner terday? a day is your chi family eats thes Fast F Fast F	Id supposed se foods: food biscuits	Snacks
 8. Please write Breakfast 9. How many of 10. How many 11. Please indi Fast F 	Lunch	hild eat yes exchanges a r week your	Dinner terday? a day is your chi family eats thes Fast F	Id supposed se foods: food biscuits food fries fast food	Snacks

,

L

12. How worried are yo	u about cove	ering m	edical costs of you	ur child's	s illness?	,
1	2	3	4	5	6	7
not worried	-	-	moderately worri	ed		constantly worried
		your cl	uild's financial fut	ure becau	use of the	eir financial responsibility
to care for his/her illness	5?					
1	2	3	4	5	6	7
not worried			moderately worri	ed		constantly worried
14. Please indicate the	evel of char	nge in y	our child since be	ing diag	nosed wi	th illness.
1	2	3	4	5	6	7
no change			moderate chang	e		extreme change
15 Please indicate you	r feelings to	ward y	our child's doctor			
1	2	3	4	5	6	. 7
extreme dislike			moderate liking			like extremely well
16. Please indicate you	r feelings to	ward y	our child's illness	team.		
1	2	3	4	5	6	. 7
extreme dislike			moderate liking			like extremely well
17. Please indicate you	r level of tr	ust in v	our child's doctor			
1	2	3	4	5	6	7
no trust	2	2	moderate trust	5	Ŭ	extreme trust
10 17 451			moderate in ust			ownerne mast
18. Please indicate how			with the illness tre			ommendations.
1	2	3	4	5	6	7
no adherence		,	noderate adherenc	ce		complete adherence
19. Have you ever rece	eived any ty Yes	pe of p	sychological couns	seling/the	erapy?	
932X 29 A		an on ion	NAME OF A DESCRIPTION O	17-58		
If yes, was this	counseling Yes	related	to your child's illr No	ness?		
20. Are you currently	taking any p Yes	sychoa	ctive medication (No	e.g., anti	depressa	ints, antianxicty)?
21 How many illness	related cup	nort or	up maatings have	uou otto	ndad in t	ha last waar?

21. How many illness-related support group meetings have you attended in the last year?

-

HCUQ

1. Please indicate the number of outpatient clinic visits your child scheduled and attended in the last year.

2. Please indicate the number of hospitalizations for your child the past year that were directly or indirectly related to their illness.

3. If your child was hospitalized, please indicate the total number of days spent as an inpatient in the past year.

Please indicate how many visits your child made to the emergency room in the past year due to problems with their illness.

5. How do you pay for your child's medical care and medical supplies?

Yes

A)	Insurance	D)	Self-Pay	
B)	HIMO/PPO	E)	Other	
C)	Medicaid			

Please estimate the dollars per month you spent this year on health insurance premiums.

 per/month.

Please estimate the dollars per month you spent this last year on out-of-pocket expenses for the care of your child's illness.
 per/month.

8. How many hours a month do you spend working with insurance companies, hospitals, medicaid, etc. about financial aspects of your child's illness?

9a. Insurance/HMO/PPO beneficiaries: Do you stay in your current employment situation because of concern over obtaining new health benefits?

No

9b. Medicaid beneficiaries: Do you stay in your current living situation to keep medicaid benefits? Yes No

10. Are you concerned that your child will have difficulty obtaining health benefits when they are adults? Yes No

11How much do you worry about financial stress placed on the family because of your child's illness?1234567not worriedmoderately worriedconstantly worried

Exercise 12. Is exercise required as	part of	your ch	ild's treatmen	regime	n?	YESNO
13. If so, how much exerc	ise is yo	our chile	d supposed to	be doin;	g daily?	
 How much exercise d What type? 						
15. In general, was yester	day a ty	pical d	ay for your ch	ild (e.g.	, was your	child's testing, exer
eating fairly normal for his					_NO	
If not, please explain						
		.				
				_		
16. Please rate how well			- 11-12-12-12-12-12-12-12-12-12-12-12-12-1			
Doesn't	2	3	4 Copes	5	6	7 Copes
cope well			moderately			extremely
at all			well			well
17. Please rate your child	's overa	ll healt	n status in the	course o	f this past	year compared to his
health status the year befo		ii lioutt				jour compared to me
leafur status die year eere	2	3	4	5	6	7
Extremely	2	5	Average	5	0	Extremely
poor health			health			good health
18. Please rate your child	's overa	ll adher	ence with the	medical	regimen	prescribed by your do
(for example, taking his/h						
1	2	3	4	5	. 6	7
Not at all	L	5	Adheren	5	0	Adhereent
adherent			about half (50	%)		all(100%)
			of the time			of the time
19. Please list the medica	ations yo	our chil	d is currently p	prescribe	ed.	
•		_				
	_					

APPENDIX B

CHILD ACTIVITY INVENTORY

.

Name:

Age:

Part I. (Parent Measure)

Below is a list of household chores or duties which children or adolescents are sometimes asked to do. I would like you to tell whether or not ______ does these chores. If so, please tell me how often he/she does them by putting an "X" in the box that shows how often he/she does them.

	(0%) Never	(1-25%) Rarely	(25-50%) Sometimes	(50-75%) Most of the time	(75-100%) Almost all the time
1. Makes his/her own bed					
2. Makes other beds					
3. Puts away own clothes					
4. Takes out the garbage					
5. Washes the car					
6. Sets the table					
7. Helps prepare meals					
8. Prepares meals by theirself					
9. Clears the table after meals					
10. Washes dishes					
11. Drys dishes					
12. Puts dishes away					
13. Goes shopping for the family					
14. Dusts					
15. Takes out the garbage		_			
16. Takes care of pets					
17. Vacuums or sweeps the floor					
18. Picks-up toys					
19. Washes or drys laundry					
20. Mows Grass					
21. Rakes leaves	1	1			
22. Gardening					
23. Cleans up the yard					
24. Cleans the Garage					
25. Simple errands					
26. Grocery shopping					
27. Other chores ?					

Part II. (Parent Measure)

Sometimes children are asked to help care for their brothers and sisters. I would like you to tell me if _______ does any of the things in the list below)

	Never	Rarely	A few times a month	About once a week	Several times a week	Daily
 Babysits [Watches his/her Brothers or Sisters while you are away] 						
 Looks after his/her Brothers/ Sisters while you are busy. 						
 Looks after his/her brothers/ sisters while they're in the yard. 						
 Takes his/her brothers/sisters away from the home (to the store, or to play.) 						
 Dresses or helps dress their brothers or sisters. 						
 Feeds or help feeds their brothers or sisters 						
 Bathes or helps bathe his/her brothers or sisters 						
 Picks up his/her brothers' or sisters' toys. 						
 Help his/her brothers or sisters with their homework. 						
 Drives his/her brothers or sisters to school or appointments. [If Under 16, check(X)]. 						
11. Others (Specify)						

lever	Rarely	A few times a month	About once a week	Several times Daily a week	
		a monun	a week	a week	

-

Part III. (Parent Measure) I would also like to know what clubs, sports, or other activities ______ participates in during the school year. Below is a list of activities, please tell me how many hours each week ______ spends doing each of these things.

			None	1-2 3	-6	Over 6
1. School Sp	orts	Г	·			
2. Music Les		-	· · ·			
	oir, or other M	usie Club				
		(A)				
4. School Cl		⊢				
	H, or other loc					
(Specify_		-				
6. Church G						
a. Alone		-				
b. With		F				
7. Playing w						
a. At hor	ne	L				
b. Away	from home					
8. Others (S	Specify)			1		
	,					
-						
		es homes has		ted in the last mo	onth?	
3. About how	v many different i	friends has	had	visit your home	in the last	month?
4 Compared	with other child	ren his/her age, do y	ou think that		has:	
a	a	same	E	a		
lot	little	8.5	little	lot		
less than	less	other children	more	more than	1	
other	than other	his/her	other	other		
chilldren	children	age	children	children	ı	
1	2	3	4	5	child car	re responsibilities
1	2 2 2	3	4	5		hold chores
ĩ	2	3	4	5	10.000	play with friends
	2	2	4	5		proj man preside

APPENDIX C

.

-

-

IRB APPROVAL FORM

OKLAHOMA STATE UNIVERSITY INSTITUTIONAL REVIEW BOARD HUMAN SUBJECTS REVIEW

Date: March 10, 1998

IRB #: AS-98-048

Proposal Title: CHILDCARE RESPONSIBILITIES, SIBLING RELATIONS, AND ADJUSTMENT: WELL SIBLINGS OF CHILDREN WITH INSULIN DEPENDENT DIABETES MELLITUS

Principal Investigator(s): Larry L. Mullins, Max P. Cote

Reviewed and Processed as: Expedited with Special Population

Approval Status Recommended by Reviewer(s): Approved

ALL APPROVALS MAY BE SUBJECT TO REVIEW BY FULL INSTITUTIONAL REVIEW BOARD AT NEXT MEETING, AS WELL AS ARE SUBJECT TO MONITORING AT ANY TIME DURING THE APPROVAL PERIOD. APPROVAL STATUS PERIOD VALID FOR DATA COLLECTION FOR A ONE CALENDAR YEAR PERIOD AFTER WHICH A CONTINUATION OR RENEWAL REQUEST IS REQUIRED TO BE SUBMITTED FOR BOARD APPROVAL. ANY MODIFICATIONS TO APPROVED PROJECT MUST ALSO BE SUBMITTED FOR APPROVAL.

Comments, Modifications/Conditions for Approval or Disapproval are as follows:

Chair of Institutional Kellew Board Signatur

cc: Max P Cote

Date: March 17, 1998

VITA

Max P. Cote

Candidate for the Degree of

Master of Science

Thesis: CHILDCARE RESPONSIBILITIES, SIBLING RELATIONS, AND ADJUSTMENT: WELL-SIBLINGS OF CHILDREN WITH INSULIN DEPENDENT DIABETES MELLITUS

Major Field: Psychology

Biographical:

- Personal Data: Born in Sandusky, Ohio on February 8, 1974, the son of Yvan and Maureen Cote.
- Education: Graduated from Perkins High School, Sandusky, Ohio in May 1991; received Bachelor of Arts degree in Psychology from the University of Cincinnati, Ohio in August 1996, completed the requirements for the Master of Science degree with a major in Clinical Psychology at Oklahoma State University in December, 1998.
- Experience: Employed at Oklahoma State University, Department of Psychology, as a teaching assistant, a graduate teaching instructor, and a graduate researcher, 1996 to present.
- Professional Memberships: Association for the Advancement of Behavior Therapy, Southwestern Psychological Association, Oklahoma Psychological Association.