FAMILIAL ADJUSTMENT RELATIONSHIPS: A LONGITUDINAL STUDY OF TYPE-1 DIABETES MELLITUS

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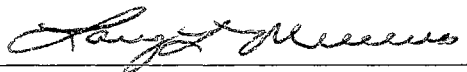

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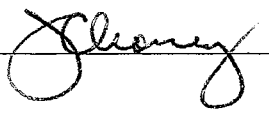

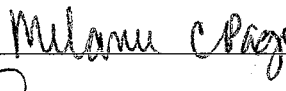

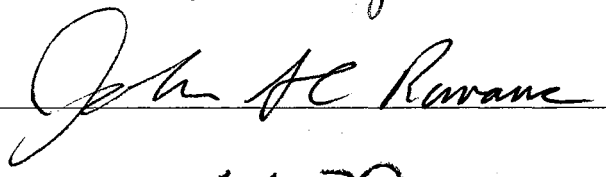

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CHAPTER I

INTRODUCTION

Insulin dependent diabetes mellitus (IDDM) or Type 1 diabetes mellitus (DM1) 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 DM1, and each year over 11,000 children in the United States alone are diagnosed with DM1 (Harris, 1995).

DM1 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, children with diabetes 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 DM1 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 (e.g., Geffken & Johnson, 1994).

As a result, the impact of the illness is not only limited to the child, but extends to the larger family system as well (e.g., Hanson, DeGuire, Schinkel, Henngeler, & Burghen, 1992). Long-term childhood illnesses such as DM1 create a number of significant 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 large number of specific adaptive tasks, including: 1) accepting the child's illness, 2) managing the child's condition on a day-to-day basis, 3) managing transactions with physicians and health care personnel, 4) meeting the developmental needs of the child and other family members, 5) coping with ongoing stress and periodic medical crises, 6) assisting family members in managing their feelings about the illness, 7) educating others about the child's condition, 8) establishing a support system, and 9) 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).

Given the intrusive nature of DM1, 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 (Thompson & Gustafson, 1996). Indeed, a substantial body of literature now exists that documents the complex relationship between family stress and adaptation of the child with diabetes. The majority of this research has focused on issues of child adjustment (Jacobson et al., 1987; Kovacs, Brent, Steinberg, Paulauskas, & Reid, 1986) and parent adjustment

(Kovacs, Finkeltstein, Feinberg, Crouse-Novak, Paulauskas, & Pollack, 1985) through the use of cross-sectional methodologies.

Importantly, the extant research on adjustment in childhood chronic illness suggests the need to further examine the complex behavioral and/or emotional transactions taking place among family members, in as much as these transactions may be central to the adjustment process (Chaney et al., 1997). In fact, a number of studies in the last decade 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. Cross-sectional research utilizing multivariate transactional stress and coping models has demonstrated that child adjustment is often associated with maternal adjustment above and beyond the variance accounted for by demographic and disease parameters (e.g., Thompson, Gustafson, Hamlet, & Spock, 1992). Likewise, of the few prospective studies using the transactional framework, research has indicated that child adjustment continues to be instrumental in the prediction of maternal adjustment (for reviews, see Thompson & Gustafson, 1996). Furthermore, Chaney and colleagues (1997) examined the temporal transactional patterns of child, mother, and father adjustment in a sample of children and adolescents with DM1 and found that decrements in fathers' adjustment, but not mothers', made significant independent contributions to predicting subsequent poorer adjustment in children with diabetes.

As a whole, the growing body of literature available underscores the importance of the reciprocal nature of adjustment between mothers, fathers and their children with various chronic conditions (Chaney, Mullins, Frank, Peterson, Mace, Kashani, & Goldstein, 1997; Thompson, Gill, Gustafson, George, Keith, Spock, & Kinney, 1994;

Thompson, Gustafson, George, & Spock, 1994). However, in contrast to child development research with healthy individuals, studies addressing the adjustment of well-siblings within the family system of the chronically ill child are almost nonexistent, with a few exceptions (for reviews see Lobato, Faust, & Spirito, 1988; Senapati & Hayes, 1988). As the family environment is often considered a primary variable associated with childhood psychopathology and dysfunction (e.g., Breslau & Prabucki, 1987), it is a natural concern that siblings of children with diabetes may be potentially at risk. Of the few studies conducted, the data suggests a number of possible adverse sibling reactions to the presence of a chronically ill child, 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).

Given the lifelong significance of sibling relationships, it seems likely that substantial changes in the health or psychological functioning of a child with diabetes will subsequently affect the well-sibling, and vice versa. These changes may correspond systematically to characteristics of the child with diabetes, the family, and the severity of the illness itself. Although family systems theory suggests that adaptation and dysfunction are shared characteristics of all family members across time, most of the studies of families with a chronically ill child are "dismembering" (i.e., omitting well-siblings themselves) and cross-sectional in nature. Therefore, the need clearly exists to examine the entire parent-child-sibling adjustment linkage and document how the disruption to child health and functioning potentially affects siblings, mothers, and children with diabetes over time. Understanding the factors that influence familial

transactional relationships will likely improve our effectiveness in treating the practical and emotional sequelae of diabetes for all family members.

To date, no study has examined the mother-child-sibling adjustment linkage, within a transactional framework, despite data from developmental literature emphasizing the importance of the parent-child-sibling context (e.g., Ambert, 1995). Consequently, little is known about how siblings adapt to childhood diabetes or how their psychosocial adjustment affects the entire family system over time. In fact, the current review found only two studies published since 1980 that both involved well-siblings in general and were longitudinal in nature (Breslau & Prabucki, 1987; Wang, 1989). Unlike the majority of previous research, the current study will utilize a longitudinal design with multiple respondents over a 1-year period. A multivariate design will be used to determine the relative influence of variations in sibling-child-mother adjustment across time while controlling for demographic and illness-specific parameters.

Thus, the purpose of this study is threefold: 1) to determine the relative influence of variations in mothers' and well-siblings' psychological adjustment (Time 1) on subsequent ill child adjustment (Time 2); 2) to determine the relative influence of variations in ill children's and well-siblings' psychological adjustment (Time 1) on subsequent mothers' adjustment (Time 2); and 3) to determine the relative influence of variations in ill children's and mothers' psychological adjustment (Time 1) on subsequent well-sibling adjustment (Time 2).

The following is a detailed review of literature regarding Type 1 Diabetes Mellitus, coping and adjustment to DM1, 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

Type 1 Diabetes Mellitus (DM1) 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 DM1 each year, adding to the 300,000 plus 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 pancreas of the child with diabetes produces 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 specific 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 DM1 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) suggests 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 DM1 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 report, 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).

DM1'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 DM1 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 DM1 have developed, insulin therapy is required.

Treatment of DM1

Treatment of DM1 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 insure 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-related 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 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 insuring 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 (e.g., 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).

Interestingly, the adverse psychological effects of intensive insulin regimens appear minimal, and research suggests that such 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.

Complications of DM1

DM1 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 DM1 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 DM1 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 cognitive-

motor 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 children with DM1 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). Thus, the impact of poor metabolic control and subsequent glucose deficiencies have significant long-term ramifications for children with DM1.

In the most severe cases, complications associated with DM1 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 (Silverstein, 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, DM1 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 DM1 and their parents.

Psychosocial Consequences of DM1

Given the apparent profound physical complications associated with DM1, many authors have examined the relationship between DM1 and psychosocial factors in an attempt to identify not only the psychological sequelae of the illness, but also those factors contributing to poor medical outcomes. 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 (e.g., depression) was not only one of the five best predictors of mortality in patients with diabetes, but was also a better predictor than many illness-related variables. The apparent relationship between psychosocial effects of the illness and mortality reflect the fact that children with diabetes face a number of daily and long term stressors as a result of their illness (Hauser, Jacobson, Lavori, Wolfsdorf, et al., 1990). Research examining the impact of diabetes on the child clearly supports the notion that while many children with DM1 evidence healthy adjustment, a subsample of these children are at greater risk for problems with adaptation, i.e., low self-esteem, social dependency, poor ego development, depression, suicidal ideation, and anxiety (e.g., Brown, 1985; Goldston, Kovacs, Ho, Parrone, & Stiffler, 1994; Hauser et al., 1986; Kovacs, Iyengar, Goldston, Stewart, et al., 1990; 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 such 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 the time period immediately following diagnosis. Research has shown that as many as 36% of patients experience significant psychosocial disturbance following diagnosis, including depression, anxiety, and social withdrawal (Kovacs, Brent, Steinberg, Paulaukas, & Reid, 1986). Although significant levels of distress tend to be found in as many as one-third of patients, these rates of distress tend to resolve within the first year of diagnosis (Jacobson et al., 1986; Kovacs, Brent, Steinberg, Paulauskas, & Reid, 1986). In a 6-year follow-up study of newly diagnosed diabetic children, initial adjustment to diagnosis was predictive of subsequent psychosocial difficulties (i.e., decreased self-esteem, increased depression and anxiety; Kovacs et al., 1990). Thus, a subset of children with DM1 appear to manifest significant and chronic difficulties, while the remainder may be at increased risk for adjustment problems but do not necessarily manifest symptomatology in the clinical range. In fact, young adults with DM1 have also

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).

As alluded to previously, several studies have found a higher incidence of depression and anxiety disorders in patients with DM1, 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 DM1. Indeed, some researchers speculate 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. However, research into the biological correlates of psychological adjustment in children with diabetes remains limited.

It has also been suggested that after the initial adaptation to the diagnosis of diabetes, other types of 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 DM1 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 DM1, no differences were found on measures of eating disorders that could not be otherwise explained by the dietary restrictions required in the

management of DM1 (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 DM1 and are associated with poorer glycemic control (LaGreca, 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 DM1 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 manifest high levels of distress and adjustment problems.

Impact of Diabetes on Parental Adjustment

Families with diabetic children face a number of daily and long term obstacles, including but not limited to the 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 & Tsu, 1977). These obstacles may disrupt interpersonal

relationships within and outside family and consequently lead to considerable personal strain for one or more family members (e.g., Hanson, DeGuire, et al., 1992). A number of studies have attempted to document the relationship of this stress on parents of children with DM1.

In a study of the parental adjustment of 74 newly diagnosed children with DM1, 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). Hauenstein and colleagues (1989) also reported that mothers of children with diabetes reported less support from their husbands than mothers of healthy controls. In addition, Phillips et al., (1985) reported that 28% mothers of children with CF viewed parental communication as a major problem when assessed from a semi-structured format; only 2% of fathers reported similar concerns. LaVigne, Traisman, Marr, & Chaisnoffe (1982) reported that fathers of children with diabetes did not differ from healthy controls with regard to adjustment. The authors speculated that since mothers most often serve as the primary caregiver for ill children, they may consequently experience greater demands and feel more distressed.

In a longitudinal study, Northam et al., (1996) showed that after diagnosis, parents of children with DM1 exhibited mild symptoms of psychological distress that largely resolved by 12-month follow-up. The impact of DM1 diagnosis on family functioning

varied with informant, SES, and the age of the child, with a tendency for families to become less flexible over the course of the study.

Although these studies suggest that the diagnosis of diabetes has a deleterious effect on a subset of parents of children with DM1, research has also considered the potential impact of family functioning on illness-related outcomes, particularly adherence and metabolic control.

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). Previous research concerned with the role of the family in childhood diabetes has 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 DM1 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 adherence behaviors, however, any direct causal relationship has yet to be firmly identified.

In a study by Miller-Johnson et al., (1994), several dimensions of parent-child relationships (e.g., parent-child discipline, warmth, and behavioral support) were examined as predictors of adherence to treatment and metabolic control in a multi-informant study of children and adolescents with DM1. Of all the predictors, only parent-child conflict was a consistent correlate of both adherence and metabolic control. Conflict accounted for unique variance in DM1 outcome beyond that associated with other measures of the parent-child relationship.

In a longitudinal study by Hauser and colleagues (1990), results demonstrated that family conflict, cohesion, and organization, were strongly associated with independently rated first-year adherence levels. The strongest predictor of longer term adherence was family conflict, as experienced by the patients. Furthermore, parents' and childrens' perceptions of family cohesion predicted improved adherence as well as overall higher levels of patient adherence.

In a recent longitudinal study examining maternal coping behaviors at diagnosis and child health outcomes (e.g., rehospitalization rates and psychopathology), Charron-Prochownik and Kovacs (2000) found no significant association between maternal coping

behavior and short-term follow-up measures of child psychopathology and rehospitalization. However, the authors did not assess sub-clinical rates of child maladjustment or changes in metabolic control.

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 optimize individual family resources in coping with acute metabolic crises. Of the family-based clinical interventions for children with DM1, the majority have utilized social learning theory or general systems theory as conceptual bases (e.g., Hanson, DeGuire, Schinkel, Henggeler, & Burghen, 1992; Wysoki, Harris, Greco, et al., 2000). 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 DM1 (Schafer, McCaul, & Glasgow, 1986). However, systems models have posited that the adaptation of youths with DM1 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 DM1 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).

Family Roles and Maintaining Equilibrium

As is clear from the above review, a number of financial, structural, and environmental changes may occur within the family as individuals attempt to adapt to the presence of a chronically ill child (Canam, 1993; Kazak & Marvin, 1984; Bruhn, 1977). For example, 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). Often neglected, however, is the role of the well-sibling, a member of the family system that researchers have consistently failed to include in their investigations.

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.), contributing to family income, and making personal sacrifices (Rodger, 1985). These added stressors, created directly and indirectly 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. 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).

Although extant literature suggests the importance of the relationship between the disability of a child and its potential impact on well-siblings, few theoretical models exist that explicitly address such relationships. In the proceeding section, a contemporary model will be reviewed that lends itself to the empirical study of complex family relationships.

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.

Contemporary ecological and transactional perspectives (e.g., Bronfenbrenner, 1979; Belsky, 1981; Sameroff, 1975; Thompson et al., 1993) assert that dyadic family relationships are best understood in the context of other family interactions, status and

resources, beliefs, and values. For example, among the strongest predictors of both prosocial and nonpunitive sibling interaction's are a mother's consistent, nonpunitive child-rearing practices and positive self-concept/attitude about her life outside the family (Brody & Shaffer, 1982; Brody & Stoneman, 1986). Thus, within the healthy child developmental literature, child development and sibling relationships are not conceptualized as the direct result of single or static child or family characteristics. Psychosocial outcome, with its multitude of definitions, is the evolving result of an interacting system of child, family, situational, and cultural variables.

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 the 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.

Developmental in nature, this model lends itself to the investigation of stability and change in adjustment, hypothesized maternal, paternal, child, and family adaptational processes, and their interrelationships over time. 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 a salient foci for interventions reducing stress. 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. Lastly, 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.

Research supporting the transactional model has emerged recently in the study of diabetes and other chronic conditions. In fact, a number of cross-sectional and longitudinal studies have found support for the role of maternal and child adaptational processes in mediating maternal and child psychological adjustment to chronic illness (Thompson & Gustafson, 1996). For example, in a cross-sectional study of cystic fibrosis, Thompson et al. (1992) found that after controlling for demographic and disease parameters, maternal anxiety accounted for significant increments in the variance in mother-reported behavior problems and child-reported symptoms.

In a longitudinal study of cystic fibrosis, Thompson and colleagues (1994) reported that maternal distress accounted for significant incremental variance in child behavior problems after controlling for initial behavior problems, illness and demographic parameters. In another longitudinal investigation of the stability and change in the psychological adjustment of children with sickle-cell disease and cystic fibrosis, Thompson et al. (1994) found that persistent poor maternal adjustment was associated with higher levels of daily stress and lower levels of family supportiveness. In addition, in the case of children with cystic fibrosis, the relationship between child adjustment and maternal adjustment was supported.

In a longitudinal study of diabetes, Chaney et al. (1997) examined the transactional patterns of child, mother, and father adjustment. Using a series of hierarchical regression analyses, they determined the relative influence of variations in parent and child adjustment (Time 1) on subsequent parent and child adjustment (Time 2) after controlling for demographic and disease parameters. Preliminary analyses demonstrated that levels of child and parental adjustment were relatively stable over the 1-year study period. More importantly, they found that increases in fathers', but not mothers', distress over time contributed significant incremental variance to poorer subsequent childrens' adjustment, after controlling for demographic and disease parameters. The findings supported the transactional nature of family relationships of children with DM1.

Thompson's Transactional Model (Thompson, Gustafson, Hamlet, & Spock, 1992) thus provides a basis for understanding the impact of a chronic illness on the adjustment of well family members, including well-siblings. The relationship between siblings within the family may be an independent source of variance in predicting the illness-specific and general psychosocial adaptation of youths with DM1, as well as the adaptation of well-siblings themselves (Hanson et al., 1992). However, the impact that siblings exert on one another is often underestimated and rarely measured in chronic illness literature. In the section that follows, the literature on chronic illness 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 small compared to empirical investigations examining parental and ill-child adjustment. As mentioned previously, 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 2001 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. These studies will be reviewed below.

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; McKeever, 1983). Numerous studies across a variety of illness populations support the speculation 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; Hollidge, 2001; 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).

Notably, few studies have focused on the impact of profound physical disability (i.e., profound developmental delays) on well-siblings. However, Tew and Lawrence (1973), utilizing teacher-reported behavior problems, reported maladjustment rates of well-siblings of children with spina bifida to be four times that of healthy control children. 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. 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. Thus, such research supports the contention that well-siblings of children with profound physical disability are also at increased risk for adjustment problems, both in and out of the home.

A number of studies focusing on increased risks to well-siblings have been conducted with healthy siblings of children with cancer. Cairns et al. (1979) found

increased anxiety, depression, and isolation in a sample of 76 well-siblings. They also reported that parents were unlikely to report knowledge of sibling concerns (e.g., isolation from parents, other family members, and friends); thus, suggesting that parents were unaware of the impact of the illness on their healthy children. In another study of 129 siblings of children with cancer, Cohen et al. (1995) assessed the proportion of well-sibling behavior problems expected under the normal distribution. The authors found well-siblings scored significantly higher relative to normative samples for internalizing and externalizing behavior problems on the CBCL. 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 that 7.7% of well-siblings had problems prior to the diagnosis of their sibling with an additional 10.3% of well-siblings developing problems after. Although an 18% total problems prevalence rate was observed using standardized measures of adjustment, the study was based on parental report alone.

In a study utilizing sibling self-report, well-siblings 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 known longitudinal study of siblings of children with cancer, Wang (1989) found more behavior problems and lower social competence in the target group when compared to norms. Thus, it would appear that for siblings of children with cancer, the psychological impact of the illness is not solely limited to the child with the illness.

Importantly, the vast majority of well-sibling studies have utilized samples of less than one hundred. However, 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). However, the severity of the illness was unrelated to the psychosocial scores of patients and well-siblings. In the largest study of well-sibling adjustment to chronic illness, Cadman et al. (1988) examined over 3200 children with chronic illness and their siblings. They 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.

Finally, in one of only two known studies 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. This differences were most profound with regard to their "Intellectual and School Status", "Happiness", and "Life Satisfaction" and to sibship with a male sibling. However, no birth-order effects were observed. Lastly, in a study of 28 well-siblings of children with diabetes, Hollidge (2001) found that well-siblings had significantly lower self-concepts and higher anxiety on standardized questionnaires when compared to normative values.

In summary, it is important to note however that many of the above studies had significant methodological short-comings, such that interpretation of the results is difficult at best. Many studies relied on parental report alone (e.g., Sahler et al., 1994), used normative means as points of comparison instead of control groups (e.g., Cohen et

al., 1995), and were cross-sectional is nature (e.g., Peck, 1979). Clearly, longitudinal studies of the psychosocial aspects of chronic disease using the entire family are needed to further explain the complex interaction between patient, parents, and siblings and the progress of disease.

Studies Finding No Risk for Well-Siblings

Indeed, negative findings are not consistent across all studies. Clearly, 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, Traisman, Marr, & Chasnoff, 1982; Noll et al., 1995; Phillips, Bohannon, Gayton, & Friedman, 1985.)

Daniels et al. (1986) found no differences between 61 healthy children and 72 well-siblings 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). However, the results revealed higher levels of parental depression and anxiety compared to the normative sample.

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 the 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. Phillips et al. (1985), using an interview format, reported only a small increase in parent-reported behavior problems in well-siblings of children with cystic fibrosis as a result of the diagnosis. It is important to note, however, that the authors utilized a descriptive design without the inclusion of a comparison group or standardized measures.

Other investigators have utilized combined illness groups in the study of risk to well-siblings. Drotar and colleagues (1981) compared the psychosocial functioning of 91 children with cystic fibrosis, 47 with asthma, 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 both self- and teacher-report.

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 interactions 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 children with diabetes, 41 well-siblings, 35 well-children, and 35 well-siblings. The authors failed to find significant differences between healthy controls and well-siblings on dimensions of behavior problems or social competence. However, this 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, however, suggest that same-sex sibling pairs appeared to evidence more adjustment problems.

It is important to consider the small of body of published research failing to identify well-siblings as a population at risk for adjustment or behavior problems may reflect a publishing bias; insignificant or inconclusive findings are often not received well by editorial reviews. However, it is also important to note that studies failing to find well-siblings at risk have utilized relatively smaller sample sizes and comparison groups than those finding siblings at higher risk.

Studies Finding Positive Effects for Well-Siblings

A small number of studies suggest that many siblings of disabled children actually appear to manifest emotional and psychological health assets attributable to their family experience. 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 forty-five 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 to 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 well-siblings. 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 colleagues (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. However, some evidenced low levels of self-esteem when compared to comparative norms. In the second study, Ferrari (1984) reported that teachers rated young siblings of children with diabetes as more socially competent and as having more positive peer relationships as compared to siblings of unaffected children. In the same study, nearly one-third of parents reported increased family closeness and marital enrichment as a consequence of the ill child's presence in the family.

Summary

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 emphasis on documenting that these children fail to adapt 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.

As a whole, these studies present significant disparities in their findings concerning well-sibling risk for maladjustment. Given the multitude of factors that have been identified as predicting outcomes for siblings with a chronically ill family member, it is easily conceivable that children adapting to a chronic illness in the family may experience the effects of the illness differently. Furthermore, there is a growing body of literature on protective factors that may serve to buffer children from the negative consequences and even put children at an advantage for the development of adaptive prosocial behavior (Leonard, 1991).

Well-Siblings and the Family Context

The relationship between siblings within the family may be an independent source of variance in predicting the illness-specific and general psychosocial adaptation of youths with DM1, 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. Despite convincing evidence that each child grows up in a "different" family regardless of commonalities in child-rearing practices and shared values, sibling interactions are worthy of study because of the socializing power of siblings (Daniels & Plomin, 1985). In fact, well-siblings may derive a great deal of mutual benefit with the ill-child. Siblings socialize and educate each other, mediate parental 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).

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 over time.

In fact, the current review found only two studies focusing on the adjustment of well-siblings published since 1980 that were longitudinal in nature (Breslau & Prabucki, 1987; Wang, 1989). They suggest that the consequences of living with a chronically ill sibling may be difficult in the initial months following a diagnosis or even during the first year; however, these difficulties may lessen significantly over time. Younger children, less capable of deferring their needs, may experience increased behavior problems initially, while older children may suppress their own needs only to have them erupt later to the surprise of their parents.

Regardless, there is not yet sufficient research to determine empirically the reciprocal relationship between a child's disease or disability and sibling development. Regardless of the diagnostic condition involved, well-controlled studies have failed to

identify a one-to-one correspondence between disease and psychological outcome between siblings. Thus, the impact of the disease or disability may best be conceptualized as a risk or stress factor, the magnitude of which is mediated by other individual or familial characteristics and resources. The transactional model described by Thompson and colleagues provides a multivariate model for the description of such relationships. By examining the variations in well-siblings and mothers psychological adjustment over a 1-year period and the relative influence of these changes on child adjustment, a greater understanding of the impact of healthy siblings on children with diabetes, and vice versa, can be achieved.

CHAPTER III

STATEMENT OF THE PROBLEM

A number of studies suggest that complex behavioral and/or emotional transactions take place between family members, and that these transactions are paramount in the psychological adjustment process (Chaney, et al., 1997; Thompson & Gustafson, 1996). These studies suggest that the transactional aspects of the adjustment process in families with chronically ill children, particularly parent-child relationships, are important determinants of subsequent psychological adjustment. Several studies using the transactional stress and coping framework have demonstrated that a significant amount of variance in child adjustment can be explained by maternal adjustment, beyond the variance due to demographic and disease parameters (Thompson, Gustafson, George, & Spock, 1994). Likewise, a significant amount of variance in child adjustment can predict maternal adjustment (Thompson, Gil, Gustafson, et al., 1994). These findings have been replicated across a variety of chronic illness states (for reviews see Thompson & Gustafson, 1996). As a whole, these studies demonstrate a complex reciprocal model of adjustment reflecting the multiple causal influence of adjustment between parents and their children. This dynamic approach recognizes the interactive nature of parental and child coping and adjustment.

Conspicuously absent in the literature are studies investigating; 1) the role of well-sibling variables in the transactional adjustment process, and 2) the temporal relationships in adjustment amongst family members with a chronically ill child. Given that only two published studies could be found that examined the effects of chronic illness on well-siblings across time, little is known about how well-siblings adjust to a sibling with a chronic condition. Longitudinal research is needed to inform researchers and clinicians about the stability of sibling adjustment and the effects of chronic stress over time. Variations in the course of disease, family strains independent of the disease, and developmental changes all require longitudinal analysis that consider the child, siblings, parents, and disease course.

Even less is known about the influence of well-sibling psychosocial variables on child and maternal functioning, and vice versa. The transactional family perspective (Belsky, 1981; Sameroff, 1975) asserts that sibling relationships are best understood within the context of other family relationships, status and resources, beliefs, and values. In essence, the family is best understood within its broader social and cultural ecology. In order to delineate more precisely how the social-ecological context is manifested through the family, more attention needs to be given to role of well-siblings in this process. Although many well-siblings may not evidence rates of clinical maladjustment greater than their healthy peers, it is unclear whether sub-clinical maladjustment or positive adjustment ultimately contribute favorably or unfavorably to the adjustment of other family members across time. Therefore, it is not only whether siblings are or are not at risk for maladjustment, but also what is the net impact on maternal and child adjustment.

It is the latter question that is the focal issue from a transactional or systems perspective (e.g., Kazak, 1989; Wood, 1993).

In the current study, Type 1 diabetes mellitus was selected as the chronic illness to investigate due to the unique characteristics of the disease. In the United States, DM1 has a high incidence for both males and female children at very early ages (Harris, 1995). As suggested previously, the illness is associated with a number of changes within the family routine and interactions. Although the illness is not necessarily terminal, it is chronic in nature, requiring medication and treatment regimens across the life-span. These characteristics allow for longitudinal analyses utilizing the entire family system.

Thus, the purpose of the current study was: 1) to determine the relative influence of variations in mothers' and well-siblings' psychological adjustment on subsequent ill child adjustment; 2) to determine the relative influence of variations in children's and well-siblings' psychological adjustment on subsequent mothers' adjustment; and 3) to determine the relative influence of variations in children's and mothers' psychological adjustment on subsequent well-sibling adjustment.

Thus the following research questions were addressed:

1) Do variations in mothers' and well-siblings' psychological adjustment at Time 1 influence subsequent child adjustment at Time 2?

2) Do variations in children's and well-siblings' psychological adjustment at Time 1 influence subsequent mother's adjustment at Time 2?

3) Do variations in children's and mothers' psychological adjustment at Time 1 influence subsequent well-siblings' adjustment at Time 2?

Similar to the 1997 study by Chaney and colleagues examining the temporal transactional patterns of child, mother, and father adjustment, the current study attempted to delineate the complex and dynamic adaptation process within family members over time. This involved an examination of interplay amongst mothers, siblings, and children with diabetes that may modify adjustment. Parents and children were asked to complete a standardized measure of psychological adjustment twice over a one year interval. To address the three questions above, hierarchical multiple regression procedures were utilized to examine the parent-sibling-child relationships.

CHAPTER IV

METHODOLOGY

Participants

Children with DM1 and well-siblings were recruited by phone from patient lists provided by a University-affiliated hospital-based pediatric endocrinologist. Eligibility criteria included: 1) children with DM1 above eight years of age and below 18; 2) children with DM1 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) well-siblings without any chronic medical conditions. For the purpose of this study, only sibling pairs between the ages of 8 and 18 were recruited. The current study was approved by the Institutional Review Board of the participating hospital and Oklahoma State University.

Procedures

To collect data from children and their primary caregivers, a trained research assistant made two home visits over a twelve-month period, with each visit lasting approximately one hour. The initial visit was scheduled by phone and written consent was obtained from the mother and the children at the time of the visit. Families were provided with written and verbal information regarding how to complete the items in the

questionnaire packets. Each packet contained instructions for appropriately completing each questionnaire. The home visitor worked with the family in completing their questionnaires; primary caregivers completed the questionnaires in a separate room. Upon completion of the packets, questionnaires were marked to identify parent-child dyads. Each family received either ten dollars for each visit, or a ten dollar donation to the Juvenile Diabetes Foundation. A follow-up visit took place in approximately twelve months from the initial visit. At that time, parents and children completed the same protocol described above.

Two separate packets were provided for the parent-child dyads. The parent packet included a demographic questionnaire and the Brief Symptom Inventory (BSI; Derogatis, 1983). The child with diabetes, and well-siblings each completed a separate questionnaire packet, including the Behavioral Assessment System for Children (BASC-SRF; Reynolds & Kamphaus, 1992). Physicians provided ratings of regimen adherence, and HbA1c levels.

Measures

Brief Symptom Inventory (BSI)

The BSI (Derogatis, 1993, 1983; Derogatis & Spencer, 1982) is a short version of the Symptom Checklist-90 Revised (SCL-90-R; Derogatis, 1983) containing 53 items instead of 90. The BSI yields measures of nine clinical dimensions of psychological distress, with T scores ranging from .30 to .80. The BSI has been shown to be highly correlated with the SCL-90R as well as having high internal consistency (.71-.83) and

test-retest reliability (rs = .68-.91) (Derogatis, 1993). Respondents are asked to indicate the frequency (e.g., "Not at all" to "Extremely") to which they experience various psychological or physical symptoms within the past seven days. The Global Severity Index (GSI) score from the BSI was used to assess overall maternal adjustment. This use of the GSI index follows from previous research assessing parental adjustment to childhood chronic illness (Kronenberger & Thompson, 1992; Noojin & Wallander, 1997). The BSI also provides *T* scores that can be examined in terms of "caseness" criteria, i.e., clinically significant psychological distress. An individual is said to meet caseness if the GSI *T* score is greater than or equal to 63, or if on any other two subscales the *T* score is greater than 63. The caseness criterion for maladaption or psychological distress has been utilized by a number of researchers investigating adaptation to chronic illness (e.g., Mullins, Cote, Fuemmeler, Jean, Beatty, & Paul, in press; Mullins, Chaney, Pace, & Hartman, 1997; Thompson, 1985; Thompson, Gustafson, Hamlett, & Spock, 1992).

The Behavior Assessment System for Children (BASC-SRP)

The BASC-SRP (Reynolds & Kamphaus, 1992) is part of the larger BASC assessment system. The Self-Report of Personality (PRS) is an omnibus personality inventory consisting of statements that are responded to as True or False. The SRP has two forms composed of similar items and scales that span childhood (8-11 years, 152 items) and adolescence (12-18 years, 186 items). The SRP assesses Clinical Maladjustment, School Maladjustment, Depression, Inadequacy, and Personal Adjustment. The SRP's internal consistencies are in the .80s for general and clinical

samples. For the purpose of the current study, only the Emotional Symptoms Index (ESI) was used. The ESI represents the scores for the six scales with the highest loadings on an unrotated first factor; this factor has been called general child psychopathology (Kamphaus, 1993). Its strengths include good reliability estimates, national norming, and scales relevant to the milieus of children (Kamphaus & Frick, 1996).

Disease Parameters

A 7 point likert-style questionnaire was developed to assess both perceived adherence to the medical regimen, compliance with treatment team recommendations, and health status compared to the previous year. For example, mothers were asked to rate their child's overall adherence with the medical regimen prescribed by their doctor. Perceived adherence was measured on 7-point likert scale with response choices ranging from *always adherent* (7) to *not at all* (1). Similarly, mothers were asked to indicate how well they complied with the illness treatment team recommendations. Compliance with treatment was measured on a 7-point likert scale with response choices ranging from *complete adherence* (7) to *no adherence* (1). Health status this year compared to last year was measured with 7 response choices ranging from *extremely good health* (7) to *extremely poor health* (1). Mothers also reported the number of diabetes related Emergency Room visits in the past year at both home visits.

Lastly, the affiliated physician provided HbA1c measures taken closest to home visitation after the initial home visit. Although values of HbA1c in children with DM1 may vary according to the method used for its measurement, values of 6% to 9%

generally represent very good metabolic control, values of 9% to 12% represent fair control, and values of more than 12% represent poor control (Sperling, 1996).

Overview of Analyses

Preliminary analyses included independent sample t-tests to examine differences on the primary variables of interest (e.g., demographic, illness-related, and adjustment measures) between participants completing both Time 1 and Time 2 visits with those families completing only Time 1 visits. An additional independent samples t-test was conducted to examine mean differences between well-siblings and children with DM1 on their levels of self-reported psychological adjustment. Paired-sample t-tests were used to identify significant changes in psychological adjustment over a 1-year study period for children with DM1, mothers, and well-siblings. Lastly, correlation coefficients were computed among: 1) the illness-related variables (e.g., HbA1c, compliance, health status) and 2) the primary variables of interest (e.g., child age, family income, HbA1c, adjustment measures).

The following research questions were addressed:

1. *What is the relative influence of variations in mothers' and well-siblings' psychological adjustment on subsequent ill child adjustment?*

Hierarchical multiple regression procedures were utilized to examine the influence of mothers' and well-siblings' psychological adjustment at Time 1 on children's adjustment at Time 2. The child's adjustment at Time 2 served as the criterion variable. The first regression equation was constructed with demographics (i.e., child age and SES) entered as a block on Step 1, followed by disease parameters (i.e., duration of illness and

Time 1 HbA1C levels) as a block on Step 2. Lastly, Step 3 included children's, mothers', and well-siblings' Time 1 adjustment scores entered as a block.

2. *What is the relative influence of variations in children's and well-siblings' psychological adjustment on subsequent mothers' adjustment?*

A second regression equation was constructed to examine the influence of children's and well-siblings' adjustment at Time 1 on mothers' adjustment at Time 2. The mothers' adjustment at Time 2 served as the criterion variable. As in the first equation, demographic variables (i.e., child age and SES) were entered as a block on Step 1, followed by disease parameters (i.e., duration of illness and Time 1 HbA1C levels) as a block on Step 2. Lastly, Step 3 included ill children's, mothers', and well-siblings' Time 1 adjustment entered as a block.

3. *What is the relative influence of variations in ill children's and mothers' psychological adjustment on subsequent well-sibling adjustment?*

A third regression equation was constructed to examine the influence of children's and mothers' adjustment at Time 1 on well-siblings' adjustment at Time 2. The adjustment of the well-sibling at Time 2 served as the criterion variable. As in the first two equations, demographic variables (i.e., child age and SES) were entered as a block on Step 1, followed by disease parameters (i.e., duration of illness and Time 1 HbA1C levels) as a block on Step 2. Lastly, Step 3 included ill children's, mothers', and well-siblings' Time 1 adjustment entered as a block.

CHAPTER V

RESULTS

Sample Description

Thirty-nine mothers (89.7% married, 11.4% single) completed Time 1 study protocols, as did their children with DM1 (N = 39) and well-siblings (N = 39); of the original sample, twenty-eight mothers, twenty-eight siblings, and twenty-eight children with DM1 completed follow-up questionnaires at Time 2. Of the final sample of twenty-eight well-siblings, 12 were male (mean age = 13.48; SD = 3.15) and 16 were female (mean age = 14.14; SD = 1.78). The children with DM1 included 13 males (mean age = 14.22; SD = 2.89) and 15 females (mean age = 13.38; SD = 3.03). The mean age difference between the identified well-sibling and child with DM1 was 2.96 (SD = 1.55; range 0 to 6.59 years). Over half of the families completing the study had annual incomes of over $60,000 (n = 16; 57.1%). The remainder of the sample had incomes that ranged as follows: $59,999 - $50,000 (n = 3; 10.7%), $49,999 - $40,000 (n = 4; 14.3%), $39,999 - $30,000 (n = 2; 7.1%), $29,999 - $20,000 (n = 2; 7.1%), less than $4,999 (n = 1; 3.6%). Of the 28 families participating, 27 (96.4%) reported having some type of private medical insurance, while 1 (3.6%) did not.

Of the eleven families not completing Time 2 protocols, seven refused or were unable to participate due to scheduling conflicts, and four families moved and were

unable to be reached by mail or phone. Non-participants at follow-up were compared to participating families on each of the primary demographic (i.e., child age and income), illness (i.e., HbA1c and duration), and Time 1 outcome measures (i.e., Child ESI, Well-Sibling ESI, and Maternal GSI). Independent sample t-tests revealed significant differences between follow-up participants and non-participants on child's age and maternal GSI score (p's < .05). Maternal follow-up participants had a mean Time 1 BSI score of 51.04 (SD = 8.32) and non-participants a mean of 58.09 (SD = 10.89). The mean age of the child with DM1 who participated in both Time 1 and Time 2 was 13.77 (SD = 2.94) whereas Time 2 non-participants' mean age was 10.90 (SD = 2.78). Thus, non-participants at follow-up were largely families with a younger child with DM1 and poorer maternal adjustment at intake.

Disease Parameters

The average illness duration at the onset of the study was 5.44 years (SD = 4.13). The average age at diagnosis was 8.26 (SD = 4.27; range = 2.33 to 16.5 years). The mean HbA1c level at intake for those children with DM1 completing both Time 1 and Time 2 assessments was 9.08 (SD = 2.76; range = 5.3 to 17.8). Means and standard deviations for the Likert rating scales assessing perceived child adherence to the medical regimen, maternal compliance with treatment team recommendations, and health status compared to the previous year can be seen in Table 1. The results suggest that, for the most part, the current sample were in good metabolic control with some exceptions. Using criteria described by Sperling (1996), 57% (n = 16) of the current sample were considered to have

very good metabolic control, 32% (n = 9) were considered to have fair control, and 11% (n = 3) poor control.

Table 1

DESCRIPTIVE STATISTICS FOR DISEASE PARAMETERS

	Time 1		Time 2	
	M	SD	M	SD
Child's Adherence to Regimen	5.21	1.2	5.04	1.07
Child's Coping with Illness	5.11	1.55	5.32	1.22
Health Status This Year Compared to Last	5.15	1.41	5.00	1.57
Maternal compliance with Treatment Recommendations	5.89	.69	5.61	1.03
ER Visits in the Last Year	.67	2.00	.22	.64
HbA1c	9.08	2.76		
Duration	5.44	4.13		

Note. No significant differences between Time and Time 2 illness-related variables

Zero-order correlations were performed to determine significant relationships among the multiple illness variables (See Table 2). The results indicated that longer duration of illness was related to higher HbA1c levels (Time 1). Therefore, the longer a child had been diagnosed, the worse was their metabolic control. Secondly, poorer metabolic control (i.e., higher HbA1c levels) at Time 1 were also related to lower maternal ratings of Time 2 health status over the previous year. Thus, children who had poorer metabolic control of their illness at the onset of the study were perceived by their

Table 2

CORRELATIONS AMONG CHILDREN WITH IDDM ILLNESS PARAMETERS

Variable	1	2	3	4	5	6	7	8	9	10
1. Illness Duration	-									
2. HBA1c	.651**	-								
3. Adherence to regimen	-.161	-.314	-							
4. Time 2 - Adherence	-.101	-.311	.600**	-						
5. Health Status This Year Compared To Last	.012	-.320	.319	.280	-					
6. Time 2 – Health Status	-.062	-.452*	.499**	.347	..523**	-				
7. Maternal Compliance With Team Recommendations	-.088	-.350*	.480**	.308	.301	.416*	-			
8. Time 2 - Compliance	-.078	-.296	.431*	.584*	.199	.290	.463*	-		
9. ER Visits in the Last Year	-.184	-.239	-.374*	-.125	-.131	-.267	.129	.153	-	
10. Time 2 – ER Visits	-.183	.181	.072	.201	.124	-.018	.314	.376*	.180	-

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

mothers as having poorer health status (over the past year) when asked at Time 2. Although poorer metabolic control at intake was associated with decreased maternal compliance with treatment team recommendations at Time 1, metabolic control at intake was not associated with maternal compliance ratings at Time 2. This suggests that the relationship between metabolic control and maternal compliance may have changed over the course of the study; however, HbA1c levels at Time 2 were not collected.

Higher maternal ratings of child adherence with the medical regimen at Time 1 were strongly related to increased ratings of child adherence at Time 2. Increased maternal ratings of child adherence with the medical regimen at Time 1 were related to higher maternal compliance with treatment team recommendations at both Time 1 and Time 2. These findings suggest that as mothers perceived themselves as more or less compliant with treatment recommendations, they also rated their children's adherence similarly.

Higher maternal compliance with treatment team recommendations at Time 1 was related to improved health status (over the previous year) at Time 2. In addition, higher maternal ratings of child adherence with the medical regimen at Time 1 were strongly related to higher Time 2 health status (over the previous year) ratings. Thus, mothers who perceived themselves and their children as more compliant/adherent at the onset of the study rated their children's health status over the past year more favorably.

Lastly, increased maternal ratings of child adherence with the medical regimen at Time 1 were related to decreased visits to the Emergency Room (during the past year) at Time 1, but not at Time 2. In fact, none of the intake illness-related variables were predictive of Emergency Room visits (for the past year) reported at Time 2. It is

important to note, however, that few ER visits were reported at Time 2 (M = .22, SD = .64).

Preliminary Analyses

Preliminary analyses were next conducted in order to examine the effect of child's gender and well-siblings gender on the primary child adjustment measures. A 2 X 2 (gender X gender) multivariate analysis of variance revealed no main effect or interaction for either the well-sibling's or child with DM1's BASC Emotional Symptom Index (ESI) ($p > .05$). Thus, the gender of the participants was eliminated in further analyses.

As shown in Table 3, the mean T-scores for the well-siblings and child with DM1's score on the ESI were well within one standard deviation of the normative group mean (50) for both Time 1 and Time 2. Likewise, maternal self-report of psychological distress was within one standard deviation of the normative group mean on the Brief Symptom Inventory-GSI. Although there were no significant differences between well-siblings and children with DM1 on levels of self-reported emotional symptoms, children with DM1 did, on the whole, tend to demonstrate higher ESI scores than well-siblings. Similarly, no significant changes in psychological adjustment were observed over the 1 year study period for children with DM1, mothers, or well-siblings. However, Time 2 mean ESI scores for children with DM1 and well-siblings were lower and approached significance at $p = .08$ and $p = .07$ levels respectively. Similarly, maternal mean GSI scores were lower at Time 2, but did not approach significance.

The data was then further examined to ascertain overall levels of maternal, child, and well-sibling adjustment as measured by caseness criteria for the Brief Symptom

Inventory-GSI and Behavioral Assessment System for Children-ESI. Using Derogatis' (1993) criteria for caseness (T score > 63), two (7.2%) of the mothers evidenced significant levels of distress according to this criteria at Time 1. Similarly, two (7.2%) mothers met caseness criteria for distress at Time 2. Using Reynolds and Kamphaus'(1992) criteria for "clear, pervasive distress" (T > 65), one (3.6%) of children with DM1 reported significant emotional distress at Time 1; none of the children reported similar symptoms of distress at Time 2. Two (7.2%) well-siblings met Reynolds and Kamphaus' caseness criteria at Time 1 and one (3.6%) at Time 2.

Table 3

DESCRIPTIVE STATISTICS FOR PRIMARY OUTCOME VARIABLES

	Time 1		Time 2	
	M	SD	M	SD
Child with DM1 (BASC)				
Emotional Symptoms Index (ESI)	46.63	8.69	44.52	7.20
Well-Sibling (BASC)				
Emotional Symptom Index (ESI)	45.73	8.68	44.15	8.25
Maternal (BSI)				
Global Severity Index (GSI)	51.04	8.32	49.64	10.47

Note. No significant differences between Time and Time 2 adjustment variables.

Relationships Among Primary Variables

Zero-order correlations were calculated to determine any significant relationships among the primary variables of interest (see Table 4). The results indicated that older

Table 4

ZERO-ORDER CORRELATIONS BETWEEN PREDICTOR AND DEPENDENT VARIABLES.

Variable	1	2	3	4	5	6	7	8	9	10
1. Child's Age	-									
2. Family Income	.107	-								
3. Duration of Illness	.357*	-.043	-							
4. HbA1c	.357*	-.174	.651**	-						
5. Child w/ DM1 ESI (Time 1)	.166	-.343*	.169	.252	-					
6. Child w/ DM1 ESI (Time 2)	.131	-.108	.260	.099	.722**	-				
7. Maternal BSI-GSI (Time 1)	-.183	-.277[a]	-.086	.112	.387*	.335[a]	-			
8. Maternal BSI-GSI (Time 2)	-.029	-.498**	.136	.366[a]	.435*	.325[a]	.834**	-		
9. Well-Sibling ESI (Time 1)	-.315[a]	-.323*	-.114	-.018	.258[a]	.212	.303[a]	.495**	-	
10. Well-Sibling ESI (Time 2)	-.121	-.521**	.005	.022	.549**	.192	.251	.421*	.879**	-

Note: *$p < .05$, **$p < .01$., [a]$p < .10$

children with DM1 evidenced significantly higher HbA1c levels. As expected, increased age was also significantly correlated with increased duration of illness. Higher levels of family income at Time 1 were found to be negatively related to the ESI score for children with DM1 at Time 1, maternal BSI-GSI score at Time 2, and the well-sibling's ESI score at both Time 1 and Time 2.

Psychological adjustment levels at intake, as reported by mothers, well-siblings, and children with DM1 were all correlated positively with their respective follow-up psychological adjustment scores. Children with DM1 ESI scores at Time 1 were found to be positively related to maternal GSI scores at both Time 1 and 2, and well-sibling ESI scores at Time 2. Well-siblings ESI scores at Time 1 were positively correlated with Time 2 maternal GSI scores.

Regression Analyses

Three hierarchical multiple regression analyses were conducted to examine the contribution of demographic characteristics, disease parameters, and initial family adjustment to family member adjustment at 1-year follow-up. Entry of the variables was based upon Thompson's (1985) transactional stress and coping model for the three separate regression analyses. In each regression, demographic parameters (i.e., child age and family income) were entered simultaneously on Step 1; disease parameters (i.e., HbA1c and duration of illness) were entered on Step 2; and Time 1 psychological adjustment variables (i.e., BASC-SRP-ESI and BSI-GSI) were entered on Step 3. 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 steps (Cohen & Cohen, 1983). This model was chosen based on the assumptions that initial well-sibling, child with DM1, and maternal psychological adjustment would explain additional variance beyond the relevant demographic and illness variables.

Research Question 1: Child Adjustment at Time 2

What is the relative influence of variations in mothers' and well-siblings' psychological adjustment on subsequent ill child adjustment?

Results of the regression analysis predicting the ill child's adjustment at time 2 can be seen in Table 5. In the first block, demographic variables did not account for a significant amount of variability in the child with DM1's adjustment at time 2 (R^2 change = .03, $p > .05$). In addition, the disease parameters (i.e., HbA1c and illness duration) were not significant predictors (R^2 change = .06, $p > .05$). After controlling for demographic and disease parameters on steps 1 and 2, there was an additive effect associated with the third block (Time 1 maternal BSI-GSI, well-sibling BASC-ESI, and child with DM1 BASC-ESI) (R^2 change = .54, $p < .001$). The set of variables accounted for a total of 63% of the variance in the child with DM1's adjustment at Time 2. An examination of the partial coefficients within the third block revealed an independent contribution to the criterion variable made by Time 1 ESI scores for children with DM1 ($\Omega = .71$, $p < .001$). Thus, higher levels of ill child distress at Time 1 were associated with higher levels of subsequent ill child distress.

Table 5

HIERARCHICAL MULTIPLE REGRESSION ANALYSIS PREDICTING TIME 2 CHILD WITH DM1 ADJUSTMENT

Step	Predictor Variable	R^2 Change	F Change	p-value	Partial Regression weight	t for Within Step Predictors
1.	Demographics	.032	.396	.677		
	Child Age				.144	.711
	Income				-.123	-.608
2.	Disease parameters	.064	.777	.472		
	HBA1c				-.175	-.628
	Illness Duration				-.337	1.239
3.	Emotional Adjustment	.536	9.210	.001		
	Child ESI (T1)				.711***	4.232
	Well-Sib. ESI (T1)				.079	.495
	Maternal GSI (T1)				.153	.942

Note. ***$p < .001$

Research Question 2: Maternal Adjustment at Time 2

What is the relative influence of variations in children's and well-siblings' psychological adjustment on subsequent mothers' adjustment?

Results of the regression analysis predicting maternal adjustment at Time 2 can be seen in Table 6. Demographic variables (block 1) were associated with Maternal adjustment (Time 2) (child age and income; R^2 change = .25, $p < .05$). However, the disease parameters (i.e., HbA1c and illness duration) were not significant predictors (R^2 change = .10, $p > .05$). After controlling for demographic and disease parameters on steps 1 and 2, there was an additive effect associated with the third block (Time 1 maternal BSI-GSI, well-sibling BASC-ESI, and child with DM1 BASC-ESI) (R^2 change = .55, $p < .001$). The entire set of variables accounted for a total of 89% of the variance in maternal adjustment at Time 2. An examination of the partial coefficients within the

third block revealed an independent contribution to the criterion variable made by the Time 1 well-sibling ESI scores ($\Omega = .28$, $p < .01$) and the maternal GSI scores ($\Omega = .73$, $p < .001$). Thus, the results demonstrated a significant association between maternal GSI scores at Time 1 and Time 2. In addition, higher well-sibling Time 1 ESI scores were positively related to higher maternal distress at Time 2.

Table 6

HIERARCHICAL MULTIPLE REGRESSION ANALYSIS PREDICTING TIME 2 MATERNAL ADJUSTMENT

Step	Predictor Variable	R^2 Change	F Change	p-value	Partial Regression weight	t for Within Step Predictors
1.	Demographics	.249	3.971	.032		
	Child Age				.024	.137
	Income				-.501**	-2.813
2.	Disease parameters	.095	1.585	.228		
	HBA1c				.392	1.655
	Illness Duration				-.108	-.465
3.	Emotional Adjustment	.548	31.873	.001		
	Maternal GSI (T1)				.730***	8.264
	Well-Sib. ESI (T1)				.279**	3.197
	Child ESI (T1)				-.071	-.780

Note. **$p < .01$, ***$p < .001$

Research Question 3: Well-Sibling Adjustment at Time 2

What is the relative influence of variations in ill children's and mothers' psychological adjustment on subsequent well-sibling adjustment?

Results of the regression analysis predicting well-sibling adjustment at Time 2 can be seen in Table 7. Demographic variables (block 1) were associated with well-sibling

adjustment (Time 2) (child age and income; R^2 change = .25, $p < .05$). However, the disease parameters (i.e., HbA1c and illness duration) did not contribute significant variance to the model (R^2 change = .06, $p > .05$). After controlling for demographic and disease parameters on steps 1 and 2, there was an additive effect associated with the third block (Time 1 maternal BSI-GSI, well-sibling BASC-ESI, and child with DM1 BASC-ESI) (R^2 change = .67, $p < .001$). The entire set of variables accounted for a total of 95% of the variance in well-sibling adjustment at Time 2. An examination of the partial coefficients within the third block revealed an independent contribution to the criterion variable made by the Time 1 well-sibling ESI scores ($\Omega = .80$, $p < .001$), child with DM1 ESI scores ($\Omega = .33$, $p < .001$), and maternal GSI scores ($\Omega = -.135$, $p < .05$). Thus, variations in the ill child's and well-siblings's ESI scores at Time 1 were positively associated with higher well-sibling Time 2 ESI scores. However, as mothers' Time 1 GSI scores increased, a decrease in well-sibling ESI scores at Time 2 was observed.

Table 7

HIERARCHICAL MULTIPLE REGRESSION ANALYSIS PREDICTING TIME 2 WELL-SIBLING ADJUSTMENT

Step	Predictor Variable	R^2 Change	F Change	p-value	Partial Regression weight	t for Within Step Predictors
1.	Demographics	.276	4.192	.029		
	Child Age				-.066	-.363
	Income				-.514**	-2.818
2.	Disease parameters	.004	.060	.942		
	HBA1c				-.090	-.345
	Illness Duration				-.060	.236
3.	Emotional Adjustment	.672	80.284	.001		
	Well-Sib. ESI (T1)				.804***	13.213
	Child ESI (T1)				.325***	5.103
	Maternal GSI (T1)				-.135*	-2.190

Note. *$p < .05$, **$p < .01$, ***$p < .001$

CHAPTER VI

DISCUSSION

The current study sought to examine the mother-child-sibling adjustment linkage, within a transactional framework, utilizing a one-year longitudinal design with multiple respondents. A multivariate design was used to determine the relative influence of variations in mother-child-sibling adjustment across time while controlling for demographic and illness-specific parameters. Thus, the purpose of this study was threefold: 1) to determine the relative influence of variations in mothers' and well-siblings' psychological adjustment (Time 1) on subsequent child adjustment (Time 2); 2) to determine the relative influence of variations in children's and well-siblings' psychological adjustment (Time 1) on subsequent mothers' adjustment (Time 2); and 3) to determine the relative influence of variations in children's and mothers' psychological adjustment (Time 1) on subsequent well-sibling adjustment (Time 2).

The results of the regression analyses suggest a complex pattern of adjustment relationships between mothers, children with DM1, and well-siblings. Collectively, in each of the regression analyses, mother, child, and sibling adjustment scores at Time 1 were significant predictors of 1-year follow-up measures of adjustment for mothers, children with DM1, and well-siblings. However, the amount of variance each regression equation accounted for varied from 63% - 95%; with the least amount of variance

accounted for in Time 2 child with DM1 adjustment, and the most in Time 2 well-sibling adjustment.

In each of the regression analyses, an examination of those Time 1 adjustment variables identified as unique, independent contributors of variance in the criterion (i.e., Time 2 adjustment variables), revealed a complex pattern of adjustment relationships. In the first regression analysis, Time 1 child with DM1 ESI scores made significant unique contributions to the criterion (i.e., child with DM1 adjustment at Time 2). Therefore, the best predictor of ill child adjustment at follow-up was their own initial level of psychological adjustment.

In the second regression analysis, the results suggested that variations in well-sibling adjustment were more closely related to subsequent maternal adjustment than were variations in the child with DM1s' adjustment. In fact, upward variations well-sibling adjustment at Time 1 were more closely related to better maternal adjustment at Time 2.

Results of the last regression demonstrated that variations in both maternal and ill child adjustment were significant predictors of variations in well-sibling adjustment at follow-up. However, variations in well-sibling adjustment at Time 2 were inversely related to mothers' adjustment at Time 1; as mothers' levels of distress increased, well-siblings exhibited better adjustment. Similar findings were reported in the Chaney et al. (1997) study, with variations in maternal adjustment inversely related to paternal adjustment. Using a biobehavioral conceptualization (see Wood, 1993), Chaney et al. (1997) suggested that as one parent's distress increased, the other parent collected his/her interpersonal resources to equalize or neutralize the level of distress in the family.

Additional support for this process of interdependence is also found in early family systems literature (e.g., Hill, 1958). Hill (1958) provided a formulation of the impact of chronic illness on the a family that suggested that frequent patterns of crisis within a family (such as that caused by the illness of a family member) results in a state of "disequilibrium" as time is needed while family members interpret the crisis and determine the roles of family members to return to a new level (higher or lower) of equilibrium. Thus, as the mothers' ability to cope with distress or provide the resources needed to actively meet chronic disturbances (e.g. family illness) diminish, well-siblings may respond in a complementary fashion to return the family to equilibrium.

Although maternal and well-sibling adjustment at Time 1 did not account for unique incremental variance in the child with DM1's adjustment at Time 2, both the child with DM1 and their mother's adjustment at Time 1 significantly contributed unique variance in well-sibling adjustment at Time 2. These findings suggest that well-siblings appear more responsive to variations in family adjustment, more so than mothers and children with DM1.

More importantly, however, the results support examining family members independently when assessing the potential impact of having a chronically ill family member. Given the current findings, the impact of the illness on the child with DM1 may represent a relatively distinct and separate construct than that of a caregiver or well-sibling.

Although different Time 1 adjustment variables were significant independent predictors of follow-up adjustment, this does not negate the importance of each of the time 1 variables in each regression equation. Variables that do not in themselves

contribute significant independent variance in the criterion variable may still affect the values of the coefficients for all other variables as well as the value of R. In fact, research demonstrates it is often possible to have a significant correlation between a combination of predictors (e.g., time 1 adjustment variables) and the criterion when none of the predictors make significant independent contributions (Licht, 1995).

Importantly, these findings support the importance of examining the complex behavioral and/or emotional transactions taking place among family members. Similar to recent studies finding support for the cross-sectional transactional aspects of the adjustment process, the current study illuminates how over time demographic, disease, and family adjustment variables interact continue to influence psychosocial adjustment. The current study also adds to chronic illness research by providing information regarding the temporal transactional patterns of adjustment amongst mothers, well-siblings, and children with DM1. Specifically, variations in family adjustment at intake appear related to individual members adjustment at follow-up, particularly for well-siblings and mothers of children with DM1.

As expected, maternal, well-sibling, and child psychological adjustment ratings were relatively stable across time. This finding is consistent with previous investigations of longitudinal adjustment relationships (e.g., Thompson et al., 1994; Chaney et al., 1997). However, follow-up psychological adjustment scores decreased for each group and approached significance for well-siblings and children with DM1. More importantly, rates of psychological distress in families participating in the current study were consistently below what would be expected using normative values. Collectively, well-siblings, children with DM1, and mothers in the current sample did not appear to be at

significant risk for emotional distress when compared to each other and normative data. In fact, only one child with DM1 at Time 1 reported emotional distress in the clinical range using Reynolds' and Kamphaus' (1992) criteria; no child with DM1 at Time 2 met the same criteria. Similarly, only two well-siblings reported clinical psychological distress at Time 1 and only one of these children reported similar symptoms at Time 2. These findings are consistent with other investigations (e.g., Daniels et al., 1986; Gallo et al., 1992; Noll et al., 1995) that failed to find well-siblings, children with DM1, and their mothers to be at risk for psychosocial problems. It is important to note, however, that several families refusing to participate or lost to follow-up, exhibited higher rates of psychological distress that those completing the study. As a result, those families completing the study may represent a sample that is relatively healthy, both medically and psychologically.

However, the findings in the current study do not suggest that all of the children in the current sample were without psychological morbidity; in fact, 6 mothers (21%) reported receiving some form of psychological counseling to help them or their child directly manage their illness effectively.

A number of strengths should be noted concerning the current study. First, it sought to fill a void in the literature regarding the role of well-siblings in the adaptation of families with a child with DM1 over time. This study helps to delineate the processes through which changes in family member adjustment effects increased risk for future psychopathology or symptomatology. Previous studies of families have often been "dismembering" (i.e., omitting well-siblings) and cross-sectional in nature. Thus, the current study took initial steps in documenting the temporal adjustment linkage between

disruption in health and functioning and the effects on siblings, mothers and children with diabetes for a relatively well-functioning and medically well-managed population. By delineating the processes through which changes in family member adjustment effects increased risk for future psychopathalogy or symptomatology, clinicians and researchers will be able to identify those patients most in need for intervention. Lastly, the study had the advantage of using several published and validated self-report measures of adjustment which reduced the potential for shared method variance.

Several limitations are recognized within the current study. First, all participants utilized in this study were recruited from one pediatric endrocrinologist in a large Midwestern city. Individuals who are receiving care from the same physician are likely similar in the treatment protocol received and management of medical complications, and may not be representative of the general population. Furthermore, 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, different locales, and during clinic visits.

Although families with a child with DM1 in the current sample were not identified as exhibiting significant clinical maladjustment, it must be recognized that a problem lies in the definition of "adjustment", "adaptation", and "distress" which are often used interchangeably in the literature (Eiser, 1990). Indeed, a wide variety of outcome measures have often been used in psychological research; particularly, general

measures of adjustment such as those used in the current study. Such general measures of psychological adjustment may lack sensitivity to the impact of a chronic illness such as DM1. Thus, the current study may not have captured the nature of these "adjustment relationships", as general or broad-based measures of psychological adjustment were used. Future studies should examine the specific characteristics of these relationships (e.g., sibling warmth/closeness, parenting style) within longitudinal frameworks.

An additional limitation of this study was the use of self-report measures. Self-report methodology can result in recall bias and a variety of method variance problems (Kazdin, 1998). 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). Further, the financial status and educational level of this studies' participants limits it's generalizability; the sample was largely Caucasian, middle class, with relatively high financial resources. It is also unclear whether the results of the current study were effected by the attrition of families, given the poorer psychological adjustment reported by a number of mothers refusing (or lost to) follow-up. The loss of participants during the course of an investigation potentially effects validity by altering the random composition of the group, limiting the generalizability of the findings to a special group (i.e., persistent participants), and by reducing the sample size and power (Kazdin, 1998).

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. A population-based study would certainly be more preferable to this clinic-based study; population-based studies are more likely to be

generalizable to diverse populations and as such, more representative of the population at-large. Although this study is one of the first to concurrently examine well-sibling and maternal adjustment on the adjustment of children with diabetes, the sample size was small and included a range of developmental stages. Therefore, it is unclear to what 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, given the small sample size and number of analyses conducted, all results should be interpreted with caution.

Future research should also include an adequate control group. Use of a control group would be helpful in determining if the transactional relationships observed between families with a child with DM1 are similar to those families without a child with DM1. 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.

A final limitation of this study is the lack of assessment regarding pre-diagnostic family functioning, as well as, history and maturation effects associated with life events prior to and during the course of the study. In addition, in each of regression analyses, no attempt was made to examine the relative impact of follow-up measures (e.g., well-sibling or maternal adjustment on children with DM1) between family members due to the limited sample size. Therefore, no conclusions can be made regarding the nature of family adjustment relationships at follow-up after statistically controlling for demographic, illness-related variables, and initial rates of psychological adjustment.

Several suggestions are made for future research with this population. Rather than identifying populations at risk for adjustment problems, continued emphasis should be placed on identifying the specific variables predicting "normal" and positive adjustment in well-siblings 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 multi-modal assessments of family impact may provide healthcare professionals with more useful treatment information. With the advent of more advanced medical procedures (e.g., implanted insulin delivery devices) 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 empirically-based psychosocial treatment studies and large sample longitudinal investigations of the adjustment to diabetes are clearly needed. As described earlier, the current study is one of the few research investigations examining the impact of chronic conditions on well-siblings over time. Additional longitudinal studies should be undertaken so that the complex, recursive interactions between the chronic illness and the family may be sufficiently studied. Furthermore, longitudinal and randomized clinical designs are 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 family adjustment relationships.

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 additional documentation of the transactional relations amongst family members, 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, the effects of DM1 on the family are clearly heterogeneous and complex. Thus, 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 health promotion and psychological 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. Ultimately, such treatments may help ameliorate the acute and chronic struggles faced by families with a chronically-ill child.

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APPENDIXES

APPENDIX A

DEMOGRAPHICS

Backgrouud 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 1 Female 2

8. Child's Race: Caucasian 1 African-American 2 Hispanic 3 Native American 4 Other: 5 _____

9. Child's Grade _____

10. Special Education Yes____ No _____

11. Parents' Marital Status: Married 1 Single Parent 2 Remarried 3 Never Married 4 Other 5

12. Parents' Occupations: Father _____ Mother _____

13. Parents' Highest Level of Education: Father _____ Mother _____

14. Please indicate your total family income: *(This information will be held strictly confidential).*

____ 0-4,999
____ 5,000-9,999
____ 10,000-14,999
____ 15,000-19,999
____ 20,000-29,999
____ 30, 000-39,999
____ 40,000-49,999
____ 50,000-59,000
____ 60,000 or greater

Diabetes/Health Information

1. How long has your child had diabetes? _____

2. Current HBA_1C level _____

3. How many shots a day is your child supposed to have? _____

Blood Glucose Testing

4. When during the day is your child supposed to test his/her blood? _____

5. Does your child use a glucometer to read his/her strips?

NO ____ YES ____ TYPE _____

6. Yesterday, how many times did your child test his/her blood sugar? _____

Food Intake

8. Please write down everything your child ate yesterday to the best of your memory

Breakfast	Lunch	Dinner	Snacks
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

9. How many calories did your child eat yesterday? _____

10. How many calories a day or exchanges a day is your child supposed to have? _____

11. Please indicate how often per week your family eats these foods:

_____ Fast Food fried chicken
_____ Fast Food burgers
_____ Fast Food pizza
_____ Other fast food

_____ Fast Food biscuits
_____ Fast Food fries
_____ Other fast food
_____ Other fast food

12. How worried are you about covering medical costs of your child's illness?

1	2	3	4	5	6	7
not worried			*moderately worried*			*constantly worried*

13. How much do you worry about your child's financial future because of their financial responsibility to care for his/her illness?

1	2	3	4	5	6	7
not worried			*moderately worried*			*constantly worried*

14. Please indicate the level of change in your child since being diagnosed with illness.

1	2	3	4	5	6	7
no change			*moderate change*			*extreme change*

15. Please indicate your feelings toward your child's doctor.

1	2	3	4	5	6	7
extreme dislike			*moderate liking*			*like extremely well*

16. Please indicate your feelings toward your child's illness team.

1	2	3	4	5	6	7
extreme dislike			*moderate liking*			*like extremely well*

17. Please indicate your level of trust in your child's doctor.

1	2	3	4	5	6	7
no trust			*moderate trust*			*extreme trust*

18. Please indicate how well you comply with the illness treatment team recommendations.

1	2	3	4	5	6	7
no adherence			*moderate adherence*			*complete adherence*

19. Have you ever received any type of psychological counseling/therapy?

Yes No

If yes, was this counseling related to your child's illness?

Yes No

20. Are you currently taking any psychoactive medication (e.g., antidepressants, antianxiety)?

Yes No

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. _____

4. 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?

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

6. Please estimate the dollars per month you spent this year on health insurance premiums.
$ _____ per/month.

7. 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?

Yes 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

11. How much do you worry about financial stress placed on the family because of your child's illness?

1 2 3 4 5 6 7
not worried *moderately worried* *constantly worried*

Exercise

12. Is exercise required as part of your child's treatment regimen? ____ YES ____ NO

13. If so, how much exercise is your child supposed to be doing daily?

_____

14. How much exercise does your child usually get? _____

What type? _____

15. In general, was yesterday a typical day for your child (e.g., was your child's testing, exercise, eating fairly normal for him/her)? ____ YES ____ NO

If not, please explain _____

_____

_____

16. Please rate how well you think your child copes with his/her disease.

1	2	3	4	5	6	7
Doesn't cope well at all			*Copes moderately well*			*Copes extremely well*

17. Please rate your child's overall health status in the course of this past year compared to his/her health status the year before.

1	2	3	4	5	6	7
Extremely poor health			*Average health*			*Extremely good health*

18. Please rate your child's overall adherence with the medical regimen prescribed by your doctor (for example, taking his/her medication, following his/her diet).

1	2	3	4	5	6	7
Not at all adherent			*Adherent about half (50%) of the time*			*Adhereent all (100%) of the time*

19. Please list the medications your child is currently prescribed.

_____ _____

_____ _____

_____ _____

_____ _____

APPENDIX B

INSTITUTIONAL REVIEW BOARD

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

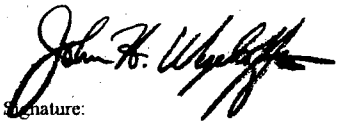
Principal Investigator(s): Larry L. Mullins, Max P. Cote

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:



Signature: Date: March 17, 1998

Chair of Institutional Review Board
cc: Max P. Cote

VITA

Max P. Cote

Candidate for the Degree of

Doctor of Philosophy

Thesis: FAMILIAL ADJUSTMENT RELATIONSHIPS: A LONGITUDINAL STUDY OF TYPE-1 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, receive Master of Science degree in Clinical Psychology from Oklahoma State University in December 1998, received Master of Public Health degree from University of Oklahoma Health Sciences Center in May 2000, and completed the requirements for the Doctor of Philosophy with a major in Psychology at Oklahoma State University in August, 2001.

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.