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ADJUSTMENT TO DIABETES: A FAMILY PERSPECTIVE

By

Alison Ward

A DISSERTATION

Submitted to Michigan State University in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

Department of Psychology

ABSTRACT

ADJUSTMENT TO DIABETES: A FAMILY PERSPECTIVE

By

Alison Ward

This study examined psychosocial factors that affect the adjustment of families to diabetes (N=105 families; 103 mothers, 35 fathers, 107 children). Specifically, the effects of family functioning (cohesion, expressiveness, control), coping strategies (approach, avoidance), and illness-related concerns or demands on parental depression and anxiety as well as child psychological well-being and metabolic control were examined. Self-report inventories and HbA_{1c} values were used to measure the research variables. Results indicated that maternal depression was significantly related to cohesion (r=-0.42, p<.01), expressiveness (r=-0.48, p<.01), conflict (r=0.28, p<.01), approach (r=-0.44, p<.01), avoidance (r=0.48, p<.01), and illness-related concerns or demands (r=0.53, p<.01). Maternal anxiety was also significantly related to cohesion (r=-0.44, p<.01), expressiveness (r=-0.55, p<.01), conflict (r=0.46, p<.01), approach (r=-0.49, p<.01), avoidance (r=0.61, p<.01), and illness-related concerns or demands (r=0.44, p<.01). Paternal depression was significantly related to avoidance (r=0.53, p<.01). p<.01) and illness-related concerns or demands (r=0.40, p<.01). Paternal anxiety was also significantly related to avoidance (r=0.38, p<.05) and illness-related concerns or demands (r=0.49, p<.01). Children's psychological well-being was significantly related to mothers' report of cohesion (r=-0.31, p<.01), conflict (r=0.24, p<.05), and illnessrelated concerns or demands (r=0.44, p<.01) and fathers' report of expressiveness

(r=-0.66, p<.01) and illness-related concerns or demands (r=0.32, p<.05). Metabolic control was related to mothers' report of conflict (r=.23, p<.05). Further analyses revealed illness-related concerns or demands as being a possible mediating variable. Based on results of paternal adjustment, further research is needed to examine differences between maternal and paternal experiences and perceptions of having a child with diabetes. For my parents.

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INTRODUCTION

It is estimated that up to 31% of children under the age of 18 are affected by chronic health conditions of varying severity (Adams & Benson, 1989 as cited in Perrin et al., 1993; Newacheck & Taylor, 1992). Chronic health conditions refer to illnesses, impairments, disabilities or other abnormal health manifestations (Stein, Bauman, Westbrook, Coupey, & Ireys, 1993). Children experience a wide range of conditions such as asthma, cerebral palsy, cystic fibrosis, phenylketonuria, sickle-cell disease, and spina bifida (Eiser, 1993; Thompson & Gustafson, 1996). Although these conditions are characterized by their own unique features, they share common features as well. For example, the etiology of chronic health conditions are biologically-based, their duration is three months or more, they require ongoing medical attention, they limit the child's daily functioning and activities, they restrict the child's physical growth and development, they may present behavioral, emotional, and social problems for the child as well as disrupt normal family functioning (Perrin et al., 1993; Stein, Bauman, Westbrook, Coupey, & Ireys, 1993). But what are the psychosocial factors that put these patients and their families at risk for continual problems with adjustment? Similarly, how can mental health professionals identify those who may be in need of help?

One type of chronic childhood health condition is insulin-dependent diabetes mellitus (IDDM) or Type I diabetes. Diabetes is characterized by abnormalities in glucose metabolism. It is caused by a combination of genetic and autoimmunological processes which destroy the pancreatic beta cells needed to produce insulin. Insulin is a hormone necessary for glucose utilization and storage. When the balance between glucose and insulin in the bloodstream (known as metabolic control) is not regulated

properly, short- and long-term complications result. Short-term complications include hyperglycemia or hypoglycemia both which can result in seizures or coma followed by death if emergency medical intervention is not administered. Long-term complications of diabetes include cardiovascular disease, neuropathy, retinopathy, nephropathy, infections and the subsequent complications related to these conditions including shortened life expectancy (American Diabetes Association (ADA), 1996; Cox & Gonder-Frederick, 1992; Kovacs, Iyengar, Goldston, Obrosky, Stewart, & Marsh, 1990; Martin, Miller-Johnson, Kitzmann, & Emery, 1998; Peyrot, McMurry, & Kruger, 1999; Sills, 1985).

In order to manage diabetes, glucose in the blood and urine must be routinely monitored and daily injections of insulin must be administered to maintain metabolic control. Additionally, specific dietary rules need to be observed and meals and snacks need to be scheduled and planned ahead of time. The amount of physical activity expended by the diabetic needs to be monitored and regular medical visits are required as well. And all of these precautions must be performed for the remainder of the person's life. Yet, despite the fact that great care may be taken to ensure proper metabolic control, diabetes can be a precarious condition with blood glucose levels rising or falling for a variety of reasons (e.g., illness, menstruation, emotional lability) (ADA, 1996).

Many adjustments are required when children are diagnosed with diabetes. Children must manage the physiological changes as well as the changes in their schedules, activities, and eating habits. Depending on their age, they may be responsible for managing their own medical care. Children with diabetes may be concerned that they are different from others as a result of their medical condition as well as having to manage the stressors that often occur with developmental changes (e.g., adolescence)

(Amer, 1999; Wysocki, Huxtable, Linschield, & Wayne, 1989). Children with diabetes are restricted from those everyday things that most children take for granted.

Having a child with diabetes presents parents with many challenges as well. For example, they need to learn about the illness, its symptoms, and its management. They must develop skills to carry out daily diabetic treatment and integrate it into the existing routines of the family. Parents must learn to handle medical emergencies and educate others as to what to do in their absence. Indeed, parents are often placed in a role where they need to be the medical caregiver in addition to being just a parent. They are also faced with concerns of finances, insurance, and their child's future health. Finally, they must adapt to the emotional challenges of the illness including sadness, anxiety, fear, helplessness, grief, guilt, and resentment (ADA, 1996; Amer, 1999; Cox & Gonder-Frederick, 1992; Faulkner, 1996; Hauser & Solomon, 1985; Kovacs, Iyengar, Goldston, Obrosky et al., 1990; Sargent, 1985; Sills, 1985; Wysocki et al., 1989). Overall, as a result of the medical concomitants of diabetes and its strict medical regimen, the child, parents, and even siblings must adapt to the many behavioral and psychological demands of this chronic and intrusive illness.

Children with chronic health conditions are at risk for emotional and behavioral difficulties as well as difficulties in social competence and school performance (Thompson & Gustafson, 1996; Pless & Nolan, 1991; Noll, Bukowski, Rogosch, LeRoy, & Kulkarni, 1990). Evidence for these difficulties has been found in children and adolescents with asthma (Padur et al., 1995), cystic fibrosis (Thompson, Hodges, & Hamlett, 1990; DiGirolamo, Quittner, Ackerman, & Stevens, 1997), and congenital heart disease (Casey, Sykes, Craig, Power, & Mulholland, 1996). The psychological well-being

of parents of children with chronic health problems has also been examined. Studies conducted on these mothers and fathers indicate that, overall, they experience more symptoms of psychological distress than mothers and fathers of healthy children (Cadman, Rosenbaum, Boyle, & Offord, 1991; Holmbeck, et al., 1997; Nagy & Ungerer, 1990; Northam, Anderson, Adler, Werther, & Wayne, 1996; Quittner, DiGirolamo, Michel, & Eigen, 1992; Wallander, Varni, Babani, DeHaan, Wilcox, & Banis, 1989) with mothers tending to experience higher levels of distress than fathers (Nagy & Ungerer, 1990; Quittner et al., 1992; Timko, Stovel, & Moos, 1992), most likely due to the strain and restrictions placed on mothers since they are typically the primary caretakers of children (Quittner et al., 1992).

Because of the particularly difficult demands, challenges, and necessary adjustment faced by children with diabetes and their parents, their psychological and social well-being has also been examined but findings have been inconsistent. Results indicate that many children with diabetes experience psychosocial problems including depression, anxiety, sleeping problems, somatic complaints, social withdrawal, and school absenteeism (Blanz, Rensch-Riemann, Fritz-Sigmund, & Schmidt, 1993; Close, Davies, Price, & Goodyer, 1986; Fonagy, Moran, Lindsay, Kurtz, & Brown, 1987; Kovacs, Iyengar, Goldston, Stewart, Obrosky, & Marsh, 1990; Lernmark et al., 1996; Schultz, 1982; Wysocki, et al., 1989). Indeed, a nine year longitudinal study found that up to 50% of its sample had one or more episodes of a psychiatric disorder during that period of time (Kovacs, Iyengar, Mukerj, & Drash, 1996) and results of a meta-analytic review indicated that children with diabetes were at risk for psychosocial problems (Lavigne & Faier-Routman, 1992, as cited in Overstreet et al., 1995). There is also evidence, however, which suggests that children with diabetes do not experience significant problems (Hamlett, Pellegrini, & Katz, 1992; Nassau & Drotar, 1995; Northam et al., 1996; Thernlund et al., 1996; Vera, Nollet-Clemencon, Vila, Mouren-Simeoni, & Robert, 1997).

Similarly, results of studies examining the psychological well-being of parents of children with diabetes have also been equivocal. Chaney and his colleagues (Chaney et al., 1997) found that only a small portion of parents experienced clinical levels of psychological distress over a one year study period. The results of one longitudinal study indicated that both parents exhibited psychological distress but that this distress decreased over time (Northam et al., 1996). Contradictory results were obtained, however, in another longitudinal study (Kovacs, Iyengar, Goldston, Obrosky et al., 1990), which indicated that levels of depression and emotional distress increased slightly for many mothers over time. Parents who initially have extreme psychological problems after the initial diagnosis were more likely to later continue experiencing problems (Kovacs, Iyengar, Goldston, Obrosky et al., 1990; Thernlund et al., 1996

Unlike the extensive attention given to the psychosocial well-being of children with diabetes, limited attention has been given to their parents' well-being. This is surprising given the pertinent and integral role which parents play in their child's medical treatment and care. According to the Diagnostic and Statistical Manual of Mental Disorders (4th ed.) (American Psychiatric Association, 1994), depression and anxiety contribute to mood changes, feelings of worthlessness, and guilt as well as to impairments in attention, motivation, information processing, and decision making, all of which could hinder parents' ability to properly care for their children with diabetes.

Indeed, research has found that parental psychological adjustment (e.g., depression, anxiety, somatization, anger) and parental involvement with medical care contribute to the psychosocial functioning and treatment adherence of their children (Anderson, Ho, Brackett, Finklestein, & Laffel, 1997; Chaney et al., 1997; Frank, et al., 1997; Martin et al., 1998). Similarly, the well-being of children with diabetes contributes to parental adjustment and parental stress (Chaney et al., 1997; Wysocki et al., 1989).

Overall, the results of studies examining the psychological well-being of children with chronic health conditions and their parents suggest that they experience psychological distress at some point during the illness and to varying degrees. Due to the variability in results of psychological well-being, researchers have attempted to identify factors which mediate the adjustment process of children and their parents (McCubbin & Patterson, 1982; Patterson, 1988; Thompson, Gustafson, Hamlett, & Spock, 1992; Thompson & Gustafson, 1996; Varni & Wallender, 1988; Wallender, Varni, Babani, Banis et al., 1989; Wallender, Varni, Babani, DeHaan et al., 1989). These models incorporate demographic, biomedical, developmental, and psychosocial factors which affect both child and parental adjustment. Such models are useful in identifying the conditions under which families are most vulnerable to psychological problems and if treatment is needed, when and how best to intervene (Quittner & DiGirolamo, 1998). The purpose of this study was to examine the role of several of these factors in the adjustment process. In particular, this study examined how family functioning, coping strategies, and illness-related concerns or demands affect the adjustment of children with diabetes and their parents.

Family Functioning

For the most part, research conducted on mothers of children with spina bifida, cerebral palsy, sickle cell disease, and cystic fibrosis has shown that illness and demographic parameters play a limited role in the prediction of child and maternal adjustment (Thompson et al., 1992; Thompson, Gil, Burbach, Keith & Kinney, 1993; Thompson et al., 1994; Wallender, Varni, Babani, Banis et al., 1989; Wallender, Varni, Babani, DeHaan et al., 1989; Wallander & Venters, 1995). Consequently, a majority of the research has focused on the psychosocial factors which contribute to psychological adjustment of children and parents. One such factor is family functioning. According to Kronenberger and Thompson (1990) family functioning refers to the degree of support, control, and conflict in the family environment. The role of family functioning has been evaluated in diabetes research with the primary focus being on predicting the child's physical and emotional adjustment.

Children's Adjustment. Cox and Gonder-Frederick (1992) report that the environment in which the child resides is associated with treatment adherence and metabolic control. The family environment can affect metabolic control in two ways. Family factors may influence the behavioral management of the diabetes, for example, the frequency of blood testing or the adherence to diet (ADA, 1996; Faulkner, 1996). Additionally, the family's psychological functioning can have a direct effect on the child's physiological system; that is, when a child resides in a stressful family environment this external stress influences his or her physiological system (ADA, 1996; Lawler, Vol, Vivani, & Mengel, 1990; Liss et al., 1998; Marteau, Bloch, & Baum, 1987; Minuchin, Rosman, & Baker, 1978; Peyrot et al., 1999). When individuals experience

stress, the adrenal glands of the sympathetic nervous system release the hormones, epinephrine and cortisol, into the bloodstream. Epinephrine causes the pancreas to decrease insulin production whereas cortisol causes the liver to increase the production of glucose and causes body tissues to decrease glucuse utilization. In addition to causing an increase of glucose levels in the blood, a lack of insulin causes a breakdown of fatty acids and increases the amount of ketone bodies produced by the liver. Both increased glucose levels and ketone levels produce serious health complications which require emergency medical attention and hospitalization; that is, stress increases the possibility of hyper- and hypoglycemia (ADA, 1996; Watkins, Drury, Howell, 1996; Surwit, Feingloss, & Scovern, 1983). Therefore, living in a stressful environment can impede proper glucose, ketone, and insulin regulation. Consequently, how well or in what way the family functions can have serious ramifications for the child's ability to maintain effective metabolic control and remain as healthy as possible.

There is extensive research which indicates that certain dimensions of family functioning play a significant role in treatment adherence and metabolic control. Minuchin and his colleagues (Minuchin, Rosman, & Baker, 1978) found that children whose families were characterized as enmeshed, overprotective, rigid, and unable to resolve conflict effectively were more likely to have poor metabolic control. In their study, they exposed children with diabetes to induced parental conflict in a laboratory setting. They found that children who had a history of ketoacidosis showed higher levels of free fatty acid production at these times than children who had fewer diabetic complications.

In recent research, investigators have used the child's blood glucose level rather than the amount of free fatty acids in the blood as a measure of metabolic control. Similar to the results of Minuchin and his colleagues, investigators have found that psychological environment of the family is associated with treatment adherence and effective metabolic control. For example, Hanson and her colleagues (Hanson, Henggler, Harris, Burghen, & Moore, 1989) found that poor metabolic control was associated with low marital satisfaction, family rigidity, and low family cohesion. In addition, Auslander and her colleagues (Auslander, Bubb, Rogge, & Santiago, 1993) found that better metabolic control was related to fathers' reports of higher levels of total family resources, greater levels of communication and cooperation among family members, and lower levels of family stress. Mothers' reports of family resources and stress, however, were not related to metabolic control. Further analyses revealed that after controlling for the effects of family resources and endogenous insulin, family stress was the only variable which made significant contributions to metabolic control.

In Wysocki's (1993) study of adolescents with diabetes and their parents, three dimensions of the adolescent-parent relationship (problem-solving communication, irrational beliefs, and family structure) related to the adolescents' treatment adherence and metabolic control were examined. Overall, effective communication and conflict resolution were the strongest predictors of treatment adherence and metabolic control. Additionally, adolescents in better metabolic control were more likely to come from families which had fewer functional and structural difficulties.

Longitudinal studies have also demonstrated the importance of family functioning in treatment adherence and metabolic control. For example, Jacobson and his colleagues

(Jacobson et al., 1994) found that over a four year period, children whose families encouraged open communication and expression of feelings were more likely to be in better metabolic control. Although initially both boys and girls were likely to have the worst metabolic control when their family environment was characterized as conflicted and not cohesive, this pattern was only evident for boys over time, suggesting that boys were, perhaps, more sensitive to changes within the family environment. Dumont and his colleagues (1995), however, found that girls were more likely to experience subsequent recurrent diabetic complications when their families were conflicted, not cohesive, poorly organized, and uncommunicative.

Hauser and his colleagues examined the short- and long-term effects of family functioning on treatment adherence of children and adolescents with diabetes (Hauser et al., 1990). Their results revealed that when the patients and their parents perceived their family as being highly conflicted, the patients were initially more likely to have difficulties adhering to treatment. Conversely, patients and parents who perceived their families as being well coordinated and organized in family activities were more likely to report better initial treatment adherence. Additionally, initial treatment adherence was related to the parents' perception of familial cohesiveness; that is, patients who were able to adhere to treatment were likely to have parents who perceived the family as cohesive. After a four-year period patients from families perceived as being more cohesive by the parents as well as the patient were more likely to show improved treatment adherence. Overall, the strongest predictor for long-term treatment adherence was the patient's perception of family conflict.

Just as family functioning plays an important role in metabolic control and treatment adherence, it is also influential in the psychosocial adjustment of children with diabetes. For example, Hanson and her colleagues examined the relationship between illness-specific support and various dimensions of family functioning with children's self-esteem, social competence, and behavioral problems (Hanson, DeGuire, Schinkel, Henggeler, & Burghen, 1992). The results suggested that children whose families were affectionate and provided support specific to the illness and its treatment regimen were more likely to perceive themselves as worthy, socially competent, and report fewer behavioral problems. In addition, children were more likely to adhere to their treatment regimens when their families were flexible and generally supportive.

Similar results were found by Hauser and his colleagues (Hauser, Jacobson, Wertlieb, Brink, & Wentworth, 1985). They found that children whose families facilitated independence, who participated in activities together, and who were well organized were more likely to perceive themselves as being competent in school, in peer relationships, and in physical activities, as well as having high levels of self-esteem.

Finally, in their examination of family cohesiveness and organization, Safyer and his colleagues (Safyer et al., 1993) found that overall, children with IDDM were more likely to report better levels of adjustment when their families were cohesive and organized. Indeed, such environments are related to better peer and family relationships and better adjustment at school.

Notably, in addition to the family functioning research, investigators have also examined the relationship between metabolic control and psychosocial adjustment. In one study it was found that behavior problems were related to more diabetes-related

hospitalizations for girls and more diabetes-related adjustment problems for boys (Lernmark et al., 1996). In addition to behavior problems, there is evidence that the level of depression reported by adolescents is positively correlated with metabolic control (Lawler et al., 1990); that is, adolescents who reported significant levels of depressive symptomatology were more likely to have poor metabolic control. Research has also shown that a diabetic child's sense of self-competence, level of self-esteem, emotional well-being, and social functioning were predictive of both short-and long-term metabolic control (Daviss et al., 1995; Jacobson et al., 1987; Marteau et al., 1987). According to Marteau and her colleagues, children living in a less stressful environment are more likely to be happier and consequently less likely to disrupt their physiological systems. Conversely, children who are depressed may be more likely to make suicidal gestures such as forgetting to take insulin or not following the appropriate diet (Lawler et al., 1990). Similarly, children with diabetes with recurrent hypoglycemic episodes were shown to be at greater risk for developing psychological problems (Liss et al., 1998). As a result, the psychosocial well-being or adjustment of children could compromise their metabolic control and, subsequently, their physical health.

The relationship between the psychosocial factor of family functioning and child adjustment is not necessarily a unidirectional, linear one. Indeed the child's psychological well-being and metabolic control can affect family functioning and family functioning can, in turn, affect the child's adjustment. Typically, studies that examined adjustment and family functioning have used cross-sectional designs. Such designs do not allow for the determination of causality. In addition, longitudinal studies have examined the role of family functioning in the adjustment of children with diabetes,

however, they have not examined the effects of adjustment on long-term family functioning. For example, although Northam and her colleagues (1990) examined changes in family functioning over a four year period, they did not specifically address the relationship between metabolic control and family functioning, per se. Indeed, the complex demands of diabetes can alter the structure of the family (e.g., change roles of family members) and family life as well. As a result, metabolic control could lead to such occurrences as conflict, disruptions, or lack of cohesiveness within the family system. Because this area has seemingly received little attention, this present study expanded upon previous research by determining the effects of metabolic control on family functioning.

Parental Adjustment. Overall, it appears that how well the family is functioning is influential in determining both the practical and emotional adjustment of children with diabetes. Just as family functioning is instrumental in understanding the adjustment process of these children, there is evidence which suggests that it is an important component in the adjustment process of parents of children with chronic health conditions. For example, mothers of children with juvenile rheumatoid arthritis who reported greater levels of family cohesion and expressiveness experienced less depression and personal strain (Timko et al., 1992). Thompson and his colleagues have found that high levels of support and control as well as low levels of conflict are associated with lower levels of psychological distress in mothers of children with cystic fibrosis and sickle cell disease (Thompson et al., 1992; Thompson et al., 1993; Thompson et al., 1994). Similarly, better family support was associated with fewer physical complaints in

mothers of children with either cerebral palsy or spina bifida (Wallander, Varni, Babani, DeHaan et al., 1989).

In reviewing the literature, however, there appeared to be limited research examining how family functioning affects the adjustment process of parents of children with diabetes. The research that has been conducted indicated that mothers who perceive their families as supportive and use effective coping strategies are less likely to experience symptoms of depression (Blankfeld & Holahan, 1996). Despite the limited research with parents of children with diabetes, research conducted on parents of children with other chronic health conditions has indicated that different dimensions of the psychological functioning of the family are important determinants of adaptation to the multiple stressors associated with having a chronically ill child. As Northam and her colleagues note (1996), families must modify their routines and take on new responsibilities as well as find a balance between healthy attachment and overprotectiveness on a continual basis. Family functioning is of particular importance to parental adjustment in this population because parents are not only instrumental in the functioning of the entire family system (Minuchin, 1974) but also play a crucial role in the ongoing management of their child's illness. Therefore, how supportive, engaged, and flexible a family is could affect how well parents are able to emotionally and practically adjust to their child's diabetes. Consequently, identifying the family factors which influence the adjustment process for parents of children with diabetes warranted further investigation.

Parental Coping Strategies

Because these parents face many challenges, how they cope with them is of particular importance. The types of coping strategies used by parents are instrumental in determining their level of adaptation. In general, coping strategies are cognitive, behavioral, and emotional attempts at managing challenging or stressful situations. Roth and Cohen (1986) propose that coping strategies utilized by an individual can be defined as attempts to either move toward (approach) or away from (avoid) the problem or stressor. Although we are capable of utilizing either mode of coping, individuals tend to have consistent preferences for either avoidance or approach strategies.

Approach strategies enable the individual to take appropriate action to manage the problem. They reflect attempts at orienting one's self to the problem and its consequences. Examples of approach coping include making attempts at understanding or appraising the problem, finding resolution, gathering information, making plans, expressing emotions, and seeking support. Avoidance strategies, on the other hand, define those attempts made by individuals to ignore or avoid the problem and its consequences. Denying, procrastinating, seeking distraction, and intellectualizing are examples of strategies for avoiding problems and associated emotions (Roth & Cohen, 1986).

According to Hauser and Solomon (1985), parents cope with their child's diabetes in a variety of ways. Some parents use approach coping such as learning to accept their child's illness and its accompanying limitations and demands. In addition, they attempt to incorporate their child's treatment regimen into daily family routines with limited disruptions. Furthermore, they choose to seek out support from medical professionals,

family members, friends, and support groups. On the other hand, Hauser and Solomon (1985) report that parents may engage in avoidance coping as well. Parents may deny the existence of their child's illness as evidenced by neglecting to administer or monitor their child's treatment regimen appropriately. In addition, some parents may become overpermissive whereas as other parents may become overprotective or overcontrolling in regard to their child's treatment and daily activities. Finally, some parents have reported becoming overwhelmed by their child's illness and needing to distract themselves (Faulkner, 1996).

According to Roth and Cohen (1986) there are costs and benefits to utilizing approach and avoidance coping strategies. Approach coping is beneficial because it enables the individual to be instrumental in gaining control over the problem, enables the individual to fully experience and express his/her emotions, as well as facilitate some kind of resolution. Unfortunately, approaching the problem may lead to increased distress and nonproductive and consuming worry. Avoidance strategies enable the individual to reduce stress and anxiety and allow for a gradual assimilation to the stressor. Avoidance strategies are useful because the individual is able to take his or her time acclimating to the problem and they provide a sense of hope or optimism. These strategies protect the individual from the distressing consequences of the problem so that the individual is more able to mobilize himself or herself into action. Despite the benefits of these strategies, there are drawbacks. For example, although it is proposed that these strategies can facilitate approach strategies, they may not do so. If an individual relies heavily on avoidance coping, this reliance can interfere with the individual's ability to mobilize himself or herself to handle the problem. These strategies can also lead to an

inability of the individual to experience or express his or her emotions, an inability to understand or be aware of the relationship between the problem and psychological symptoms, or lead to withdrawal or reduction in activities or behaviors.

As indicated by Roth and Cohen (1986), the extent to which individuals rely on approach or avoidance coping can influence how well they are able to adapt to stressful situations. There has been much research examining which coping strategies influence the adjustment process of parents of children with chronic health conditions. For example, in their study examining mothers of children with cerebral palsy, Sheeran, Marvin, and Pianta (1997) found that mothers who engaged in more approach coping strategies such as a reorienting to the present and future, having a realistic view of the child, terminating the search for existential reasons for their child's condition, expressing emotions, and having an understanding and recognition of the impact of the child's condition on themselves were more likely to experience lower levels of parenting stress and were satisfied with the help that they received from their social networks. Conversely, mothers who engaged in more avoidance coping strategies such as having unrealistic expectations of their child's condition and potential, continuing to search for existential reasons for their child's condition, denial, selective attention, and passivity experienced clinically significant levels of parenting stress and reported being dissatisfied with their social networks as well as needing more help than they were given.

Holmbeck and his colleagues (1997) studied the coping strategies and psychosocial adjustment of parents of children diagnosed with spina bifida and parents of healthy children. They found that across the two groups, fathers who were emotionally expressive or who seldom relied on behavioral disengagement as a means of coping

reported fewer psychological symptoms. Additionally, fathers who engaged in the coping strategy of "positive reinterpretation and growth" were more likely to report being satisfied as a parent and in their marriage. Mothers who seldom relied on behavioral disengagement as a coping strategy also reported fewer psychological symptoms and were more likely to be satisfied with their marriage.

In their study of parents of children with rheumatoid arthritis, Timko et al. (1992) found that mothers and fathers who relied on avoidance coping strategies (e.g., refusing to believe that it happened, reducing tension by drinking) were more likely to experience symptoms of depression and strain resulting from the demands of their child's illness. Conversely, among both mothers and fathers, approach coping strategies (e.g., preparing for the worst, trying to find out more about the situation, making a plan of action and following it) were positively related to their engagement in more social activities as well as related to their ability to handle the stressors associated with their child's illness. Similar results were found one year later: Mothers and fathers who engaged in avoidance coping strategies were more likely to experience symptoms of depression. Additionally, mothers were more likely to experience personal strain whereas fathers were more likely to be socially isolated. Similar findings were found for mothers of children with cystic fibrosis and sickle cell disease (Thompson et al., 1994) with mothers who engaged in more avoidance coping strategies (e.g. wishful thinking, self blame) than approach coping strategies (e.g. cognitive restructuring, seeking information, seeking social support) being more likely to experience psychological distress.

Research on the effectiveness of coping strategies has also been examined in parents of children with diabetes. For example, in Blankfield and Holahan (1996)'s study

of family support and coping strategies, the relationship between family support and the amount of depression experienced by mothers was found to be mediated by the percentage of approach coping strategies utilized by mothers. In Hauser, DiPlacido, Jacobson, and Willett's (1993) case study analysis they found that adolescents with diabetes were better adjusted and in better metabolic control when their families utilized approach coping strategies such as actively seeking out information and social support as well as drawing on previous experience to guide them in managing their child's diabetes. In contrast, families of adolescents with minimal compliance used more avoidance coping strategies (e.g., minimizing their emotional reactions and using denial) and appeared to be more anxious.

Although some contradictory results have been found regarding the effectiveness of approach and avoidance coping (e.g., Kupst et al., 1995), the majority of research reviewed indicates that avoidance coping is related to poor adaptation whereas approach coping is related to better adaptation. As Timko and her colleagues (1992) conclude, the use of avoidance coping by mothers and fathers interferes with their ability to confront and adapt to their child's condition and its associated stressors and subsequently proves to be detrimental to the adaptation process. When mothers and fathers rely on approach coping strategies, however, they are more likely to seek support, seek information, regulate their emotional responses, and determine alternative methods for managing their child's condition and associated stressors. As a result, parents are better informed and better equipped to adjust to the demands of their child's condition. Therefore, parents who utilize approach coping more than avoidance coping are less likely to experience psychosocial difficulties. Because of the integral role that parents play in their child's

well-being, the manner in which parents cope with the demands of diabetes is important to examine not only because of its effects on parental psychological well-being but its potential effects on these children.

The Role of Stress

According to Quittner and DiGirolomo (1998), models of adjustment consider the chronic medical condition as the stressor to which the family must adapt. Their review of the literature, however, reveals that this area has received little empirical attention. However, based on the limited research, they outlined four ways in which this concept of "stress" has been examined empirically: 1) examining the presence or absence of the illness by comparing the results from families in which there is a child with a chronic illness to families in which the child is healthy (in this case, the disease is, in and of itself, the stressor); 2) examining parameters related to the medical condition (e.g., duration of illness, illness severity, medical indicators); 3) daily hassles and life events and; 4) tasks or demands that are illness-related.

Research conducted on families with a diabetic child in which a general measure of "stress" was used have produced inconsistent results. For example, research which examined the number of life events found that the number was not significantly related to the child with diabetes' metabolic control or psychological well-being (Blanz et al., 1993; Smith, Mauseth, Palmer, Pecoraro, & Wenet, 1991). Auslender and her colleagues (1993), however, used a measure which reflected the total intensity of a variety of strains and demands faced by the family over the previous year and found a significant relationship between this measure of stress and metabolic control. Finally, in another study examining the effects of parental stress specific to the parent-child relationship, it

was found that maternal stress was significantly related to diabetes-related behavior problems in children (e.g., child refusing to take insulin or not eating properly) (Wysocki et al., 1989).

Quittner and DiGirolomo (1998) argue that variability in such research may be due to the fact that the research fails to effectively or appropriately examine "stress." For example, in two of the studies just discussed, stress was measured by instruments which reflected everyday hassles or stressful life events that we commonly experience. However, these types of stressors are not necessarily specific to concerns or demands of families in which there is a diabetic child. On the other hand, in Wysocki et al.'s study (1989), a measure specific to the demands faced by parents of a diabetic child was used. It appeared that this measure may have better captured the types of behaviors or events that are particularly distressing to these particular parents. Quittner and DiGirolomo (1998) have also found similar results. In their research on childhood disability, they found that using a measure of stress related to the medical condition was a better predictor of parental psychological well-being than was a general measure of stress. Investigators suggest that research examining predictors of family adjustment would benefit from incorporating measures that are specific to or at least reflect the medical condition in question; that is, using measures that reflect those tasks, demands, or concerns often faced by families in which there is a child with a chronic health condition (Drotar, 1997; Ouittner & DiGirolomo, 1998). Because so few studies have examined the effects of specific illness-related concerns on the well-being of children with diabetes and their parents, this study was designed to address this issue.

Mediation Models

Previous studies examining the effects of family functioning and coping strategies have been useful in determining which particular components negatively or positively affect the well-being of children with chronic health conditions and their parents. However, many investigators tend not to consider the possibility of causal or mediating relationships in their analyses (Drotar, 1997; Quittner & DiGirolomo, 1998). This phenomenom may result from investigators treating the mere presence of the chronic health condition as being the stressor to which the family must adapt. Being able to measure the extent of the effects of this stressor is difficult to do unless data from these families is compared to nonclinical families. Similarly, without a specific measure of the stressor, it is difficult to test mediating relationships. Because this study used a measure reflecting illness-related concerns or demands, however, it provided an opportunity to explore possible mediating relationships. As discussed earlier, families characterized by warmth, support, open communication, cohesion, flexibility, and low conflict buffer the stress associated with chronic health conditions such as diabetes. Similarly, effective coping strategies such as positive reframing, problem solving, and support seeking serve as stabilizing factors as well. Therefore it was expected that family functioning and coping strategies would serve as mediators in the relationship between illness-related concerns or demands and child and parental well-being.

Rationale for Study

The purpose of this study was to examine psychosocial factors which mediate the adjustment process of children with diabetes and their parents. Specifically, it examined the role of family functioning, coping strategies, and the impact of having a diabetic child

on the psychological well-being of parents. Similarly, it examined the role of family functioning and impact on the physical and emotional well-being of children with diabetes. Although extensive research has been conducted on parents and children with chronic health conditions (in particular, children with diabetes), this study attempted to build upon and extend previous research.

Little empirical attention has been given to parents of children with diabetes. Similarly, there is a paucity of research examining the relationships between family functioning and coping strategies and their psychological well-being. The lack of attention that has been given to parental adjustment is surprising given that they play such an important and integral role in the maintenance of the family system and the medical care of their children. Briefly, research conducted on mothers of children with chronic health conditions indicated that the functioning of the family and the types of coping strategies used by parents affect their psychological well-being. Given that mothers and fathers of children with diabetes are presented with many daily challenges to which they must adapt, the ability of the family to be committed, supportive, expressive, cohesive, and well organized becomes an important factor in their adjustment. Similarly, the manner in which the parent chooses to cope with the challenges associated with having a diabetic child is also an important influence as well and warrants further empirical attention. Notably, this study recruited fathers as participants. As discussed earlier, fathers are often not included such research because mothers typically identify themselves as the primary caretaker. Because fathers are often not included in research, however, it does not allow for examining and understanding the experiences specific to fathers of children with diabetes. According to Quittner and DiGirolomo (1998) and Seagull

(2000), the role fathers play in the family and in their child's care may be different from the mother and as a result they may be differently affected by their child's illness, dimensions of family functioning, and coping strategies.

In regard to children, this study built upon previous research by examining the role of family functioning in both psychological well-being and metabolic control. Previous research on families of chronically ill children indicated that high levels of familial support and low levels of conflict and control are predictive of better psychosocial adjustment in parents. Similarly, children with diabetes are more likely to adhere to their treatment regimen, maintain better metabolic control, and experience fewer psychosocial difficulties when their family environment is supportive, organized, and able to manage conflict effectively. However, this present study also extended this research by examining the interrelationship between family functioning and metabolic control by attempting to identify whether or not metabolic control affects family functioning or vice versa.

In addition, this study examined the effects of illness-related tasks and demands on the adjustment of children with diabetes and their parents. Although previous research has examined the relationship between "the stressor" and well-being, they typically have included global measures of stress. These types of measures may not necessarily account for the impact that the illness can have on a family. As a result, this study employed a questionnaire that reflected some of the demands faced by families in which there is a child with a chronic health condition.

Relatedly, this study built on previous research on risk and resistance models by examining potential mediating relationships. It was expected that family functioning and

coping strategies would buffer the relationship between illness-related burdens and the well-being of both children and parents. Overall, it was expected that clarifying the role of these psychosocial variables in the adjustment of these families would help provide a more comprehensive picture of who may be at risk.

Hypotheses

Below are the hypotheses and additional analyses examined in this study. Table I provides an outline of the hypotheses, research variables, measures, and plan of analyses.

Family Functioning and Parents' Psychological Well-Being. For the purpose of this study, family functioning was defined by the amount of cohesion, expressiveness, and conflict in the family. According to Moos and Moos (1994), cohesion refers to how committed, helpful, and supportive are family members. Expressiveness refers to how much family members are encouraged to express themselves; that is, their thoughts, feelings and opinions. Conflict refers to how much anger and conflict is expressed among family members. These subscales have been used in other research examining family functioning and psychological well-being (Blankfield & Holahan, 1996; Holohan & Moos, 1990). Three hypotheses were proposed:

1) Family cohesion is negatively correlated with psychological distress in parents; that is, parents from families low in cohesion are more likely to experience symptoms of depression and anxiety;

2) Family expressiveness is negatively correlated with psychological distress in parents; that is parents from families low in expressiveness are more likely to experience symptoms of depression and anxiety and;

3) Family conflict is positively correlated with psychological distress; that is, parents from families high in conflict are more likely to experience symptoms of depression and anxiety.

<u>Coping Strategies and Parents' Psychological Well-Being</u>. Two hypotheses were proposed for this area:

4) Approach coping strategies are negatively correlated with psychological distress; that is, parents who do not use Approach coping strategies to a great extent are more likely to experience symptoms of depression and anxiety and;

5) Avoidance coping strategies are positively correlated with psychological distress; that is, parents who use Avoidance coping strategies to a great extent are more likely to experience symptoms of depression and anxiety.

Illness-Related Concerns or Demands and Parents' Psychological Well-Being. One hypothesis was made regarding the effects of illness-related stressors:

6) Illness-related concerns or demands are positively correlated with psychological distress; that is, parents who report experiencing illness-related problems are more likely to experience symptoms of depression and anxiety.

<u>Family Functioning and Children's Well-Being</u>. The following six hypotheses were made in regard to the effects of family functioning on the well-being of children with diabetes:

7) Family cohesion is negatively correlated with psychological distress and poor metabolic control in children; that is, children from families low in cohesion are more likely to experience emotional and behavioral problems as well as have difficulties maintaining proper metabolic control.

8) Family expressiveness is negatively correlated with psychological distress and poor metabolic control in children; that is, children from families low in expressiveness are more likely to experience emotional and behavioral problems as well as have difficulties maintaining proper metabolic control.

9) Family conflict would be positively correlated with psychological distress and poor metabolic control in children; that is, children from families high in conflict are more likely to experience emotional and behavioral problems as well as have difficulties maintaining proper metabolic control.

<u>Illness-Related Concerns or Demands and Children's Psychological Well-Being</u>, <u>and Metabolic Control</u>. The following hypotheses were proposed for the effects of illness-related stressors:

10) Illness-related concerns or demands are positively correlated with children's psychological distress; that is, children from families with illness-related concerns or demands are more likely to experience emotional or behavioral problems and have difficulties maintaining proper metabolic control.

<u>Other analyses.</u> In addition to the aforementioned hypotheses, the following hypotheses were examined:

11) Poor metabolic control is positively correlated with psychological distress in children; that is, children with emotional or behavioral problems are more likely to experience problems maintaining proper metabolic control.

12) Dimensions of family functioning and two coping styles mediate the relationships between illness-related concerns or demands and child and parental wellbeing. Specifically, family cohesion, expressiveness and conflict each account for the

variation in parental and child psychological well-being as well as for the variation in metabolic control. Similarly, Approach and Avoidance coping strategies each account for the variation in parental psychological well-being.

The following ideas were also examined in this study:

13) The direction of the relationships between family functioning and illnessrelated concerns or demands and metabolic control.

14) The effects of children's age and illness duration were also examined. Research suggests that the challenges faced by parents of young children are different from those of parents with adolescent children because of their degree of involvement in medical care or because of developmental changes of the children, for example. The challenges faced by parents of young children are different from those of parents with adolescent children. Parents of young children are typically in charge of the maintenance of the medical regimen but as these children age, they become more responsible for the diabetes care themselves. In this example, parents of younger children may feel more in control of the children's well-being whereas parents of older children may be apprehensive of their children's understanding the necessity of following the prescribed medical regimen as well as their ability to adhere to it. Likewise, parents of adolescents are faced with the challenges of children who are at an age where they desire to be independent of their parents, who want to be "normal." Unfortunately, being diabetic does not necessarily facilitate this sense of normalcy and adolescent diabetics may rebel by not properly adhering to treatment, therefore, putting themselves in danger.

Similarly, the length of time since the child's diagnosis is also an important consideration that was not examined in this study. For example, parents often report

experiencing shock and grief in response to the recent diagnosis of diabetes. Relatedly, these particular parents and children must educate themselves in diabetes (e.g., what it is, what are the implications, and what are the short- and long-term potential complications) and in proper diabetes care. Families often report being overwhelmed by these experiences. Parents and children who have lived with diabetes for a few years, however, may not have the same stressors; that is, instead of short-term complications which they may be better prepared to manage, the long-term considerations including financial and medical concerns for their children in adulthood become important concerns. As a result, the relationship between illness duration and each of the following variables were examined: the psychosocial variables, emotional and behavioral problems, and metabolic control.

Hypotheses and Data Analyses

Hypothesis	Variable	Measure	Plan of Analysis
1)Parents from families low in cohesion are more likely to	Cohesion Depression	FES: Cohesion CES-D	Pearson correlations
experience symptoms of depression and anxiety.	Anxiety	STAI: Trait Anxiety	
2)Parents from families low in expressiveness are more likely to experience symptoms of depression and anxiety.	Expressiveness Depression Anxiety	FES: Expressiveness CES-D STAI: Trait Anxiety	Pearson correlations
3)Parents from families high in conflict are more likely to experience symptoms of depression and anxiety.	Conflict Depression Anxiety	FES: Conflict CES-D STAI: Trait Anxiety	Pearson correlations
4)Parents who do not use Approach coping strategies to a great extent are more likely to experience symptoms of depression and anxiety.	Approach coping Depression Anxiety	COPE (revised): Approach CES-D STAI: Trait Anxiety	Pearson correlations
5)Parents who use Avoidance coping strategies to a great extent are more likely to experience symptoms of depression and anxiety.	Avoidance coping Depression Anxiety	COPE (revised): Avoidance CES-D STAI: Trait Anxiety	Pearson correlations

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Table 1 (cont'd).

Hypothesis	Variable	Measure	Plan of Analysis
6)Parents who report experiencing illness-related concerns or demands	Illness-related concerns or demands	Impact on the Family	Pearson correlations
are more likely to experience	Depression	CES-D	
symptoms of depression and anxiety.	Anxiety	STAI: Trait Anxiety	
7)Children from families low in	Cohesion	FES: Cohesion	Pearson correlations
cohesion are more likely to	Emotional and behavioral	CBCL	
experience emotional and behavioral	problems		
problems as well as have difficulties	Metabolic control	HbA _{lc}	
maintaining metabolic control.			
8)Children from families low in	Expressiveness	FES: Expressiveness	Pearson correlations
expressiveness are more likely to	Emotional and behavioral	CBCL	
experience emotional and behavioral	problems		
problems as well as have difficulties	Metabolic control		
maintaining metabolic control.			
9)Children from families high in	Conflict	FES: Conflict	Pearson correlations
conflict are more likely to experience	Emotional and behavioral	CBCL	
emotional and behavioral problems as	problems		
well as have difficulties maintaining	Metabolic control	HbA _{lc}	
metabolic control.			

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Hypothesis	Variable	Measure	Plan of Analysis
10)Children from families with	Illness-related concerns or	Impact on the Family	Pearson correlations
illness-related concerns or demands	demands		
are more likely to experience	Emotional and behavioral	CBCL	
emotional and behavioral problems	problems		
and have difficulties maintaining	Metabolic control	HbA _{lc}	
proper metabolic control.			
11)Children with emotional or	Emotional and behavioral	CBCL	Pearson correlations
behavioral problems are more likely	problems		
to experience problems maintaining	Metabolic control	HbA _{1c}	
proper metabolic control.			
12)Family cohesion, expressiveness	Cohesion	FES: Cohesion	Multiple regressions
and conflict each account for the	Expressiveness	FES: Expressiveness	Mediation model as
variation in parental and child	Conflict	FES: Conflict	proposed by Baron
psychological well-being as well as	Approach	COPE (revised): Approach	and Kenny (1986)
for the variation in metabolic control.	Avoidance	COPE (revised): Avoidance	
Similarly, Approach and Avoidance	Illness-related concerns or	Impact on the Family	
coping strategies each account for the	demands		
variation in parental psychological	Depression	CES-D	
well-being.	Anxiety	STAI: Trait Anxiety	
	Emotional and behavioral	CBCL	
	Problems		
	Metabolic control	HbA _{lc}	

Table 1 (cont'd).

Other Analyses	Variable	Measure	Plan of Analysis
13)Direction of relationship between family functioning and metabolic control as well as direction of relationship between illness-related concerns or demands and metabolic control.	Cohesion Expressiveness Conflict Illness-related concerns or demands Metabolic control	FES: Cohesion FES: Expressiveness FES: Conflict Impact on the Family	Partial correlations
Other Analyses	Variable	Measure	Plan of Analysis
14)Examination of relationship between illness duration, the psychosocial variables, emotional and behavioral problems, and metabolic control.	Illness duration Cohesion Expressiveness Conflict Illness-related concerns or demands Emotional and behavioral problems Metabolic control	Number of months since diagnosis FES: Cohesion FES: Expressiveness FES: Conflict Impact on the Family CBCL HbA _{1c}	Pearson correlations

METHOD

Procedures

Participants were recruited through three pediatric diabetes clinics: Michigan State University Clinical Center, East Lansing, Michigan; Michigan State University at the Kalamazoo Center for Medical Studies, Kalamazoo, Michigan; and The Children's Clinics for Rehabilitative Services, Tucson, Arizona. The study protocol was approved by all three clinic's respective institutional review boards (see Appendices A through C). Potential participants were identified from each clinic's patient roster. A letter explaining the purpose of this study was mailed to the families (see Appendix D for sample letter). Parents being served by both Michigan State University pediatric diabetes clinic were instructed to write down their name and telephone number on an enclosed stamped, addressed postcard and mail it back to the investigator if they were interested in learning more about the study. In the letter from the Children's Clinics for Rehabilitative Services, interested parents were asked to leave a voice mail message at the investigator's workplace. Parents were then contacted by the investigator who described the purpose and procedures of the study (see Appendix E). Those parents who expressed an interest in participating were sent a letter with directions, consent form (see Appendices F through I) and a packet of questionnaires to complete. If both parents of the family agreed to participate, they were asked to complete the questionnaires on their own. All participants were offered the opportunity to participate in a random drawing for a single seventy-five dollar award. A stamped, self-addressed envelope was also provided in order for the parents to mail back their completed consent forms and questionnaires.

A list of the participating children was developed from information on the consent form. Each appropriate clinic received a list of these names from the investigator. Medical staff obtained each child's glycohemoglobin values (HbA_{IC}) from the child's medical records.

Participants

A total of 105 families participated in this study. The study sample was comprised of 103 females who identified themselves as a parent (100 mothers, 2 stepmothers, and 1 grandmother).⁷ Mothers ranged in age from 26 to 58 years (M=0; SD=6). This study was also comprised of 35 males who identified themselves as a parent (33 fathers, 2 step-fathers).² Fathers ranged in age from 26 to 57 years of age (M=43; SD=7). Of the 138 parents participating in this study, there were 33 couples. All parents resided in the same home as the diabetic child. Although both parents were invited to participate, the majority of participants were mothers. Such limited paternal participation in studies examining childhood chronic illness is not unusual and hypothesized to be due to the mother having a greater role in caretaking (Kazak, 1997; Quittner et al., 1992). See Table 2 for complete demographics.

One hundred and seven children participated in this study. Notably, two of the participating families had two children with diabetes. There were 61 boys and 46 girls with ages ranging from 4 to 17.5 years of age (M=12; SD=4). The children had been diagnosed with diabetes for at least 6 months to 204 months (M=58.61; SD=41.04).³ Table 3 contains frequencies of children's age and illness duration.

¹For purposes of this study, they will be referred to as mothers.

²For purposes of this study, they will be referred to as fathers.

³Children's demographic information based on mothers' report.

Parents' Demographics

		Number	
Total number of participating	families	105	
Total number of participating	parents	138	
Total number of participating of	children	107	
MOTHERS		Number	
Total number of participatin	-	103 70	
Total number of mothers pa Total number of mothers w		33	
Total number of momens w	nose spouse participated	55	
		Number	Percent
Relationship to Child			
	Mother	100	97
	Step-Mother	2	2
	Other	1	1
Ethnic Background		100	07.0
	Caucasian/White	100	97.0
	African American/Black	1	1.0
	Asian American	1	1.0
	Other	1	1.0
Current Education Level			
	High school grad/GED	28	27.5
	Some college or 2 year degree	35	34.3
	Bachelor's degree	27	26.4
	Post-bachelor's degree	12	11.8
Gross Annual Family Income	L ago than \$10,000	2	2.0
(N=101)	Less than \$10,000 \$10,000 to \$20,000	2 7	2.0 6.9
	\$20,001 to \$30,000	8	0.9 7.9
	\$30,001 to \$40,000	13	12.9
	\$40,001 to \$50,000	13	12.9
	\$50,001 to \$60,000	16	17.8
	\$60,001 to \$70,000	8	7.9
	\$70,001 to \$80,000	5	5.0
	\$80,001 to \$90,000	5 7	6.9
	Above \$90,000	17	16.8
	• •		

Table 2 (cont'd).

FATHERS		Number	
Total number of participating	ng fathers	35	
Total number of fathers par	ticipating alone	2	
Total number of fathers wh	ose spouse participated	33	
		Number	Percent
Relationship to Child		22	0.4
	Father Stars Eather	33	94
	Step-Father	2	6
Ethnic Background			
	Caucasian/White	34	97
	Hispanic/Latino	1	3
Current Education Level			
	High school grad/GED	6	17.1
	Some college or 2 year degree	14	40.0
	Bachelor's degree	7	20.0
	Post-bachelor's degree	8	22.9
Gross Annual Family Income			
2	\$20,001 to \$30,000	4	12.1
	\$30,001 to \$40,000	2	6.1
	\$40,001 to \$50,000	5	15.2
	\$50,001 to \$60,000	7	21.2
	\$60,001 to \$70,000	5	15.2
	\$70,001 to \$80,000	2	6.1
	Above \$90,000	8	24.2

Frequency Distribution of Age

Children's Age	Frequency	Percent
(years)		
4	3	2.9
5	3	2.9
6	4	3.9
7	6	5.7
8	7	6.7
9	5	4.8
10	8	7.6
11	8	7.6
12	9	8.6
13	6	5.7
14	12	11.4
15	6	5.7
16	18	16.2
17	10	1.0

Table 4

Frequency Distribution of Illness Duration

Illness Duration (months)	Frequency	Percent
6-12	7	6.8
13-24	18	17.5
25-36	15	14.6
37-48	11	10.7
49-60	18	17.5
61-72	7	6.8
73-84	6	5.8
85-96	6	5.8
97-204	15	14.6

J

Measures

<u>Demographics.</u> Demographic information was collected including parents' age, sex, education, and ethnicity, annual family income, child's age, sex, and duration of the child's diabetes (See Appendix J).

Family Functioning. The Family Environment Scale-2nd edition (FES; Moos & Moos, 1994) is a 90 item, true-false, self-report measure (See Appendix K). The FES is designed to measure the social climate of the family. The ten subscales of the FES measure three dimensions of family functioning: Personal Growth (Independence, Achievement, Intellectual-Cultural, Activity-Recreation, and Moral-Religious Orientations); Relationship (Cohesion, Expressiveness, and Conflict); and System Maintenance (Organization, Control). The scales have shown adequate internal consistency, ranging from .61 to .78. Test-retest reliabilities range from .68 to .86 for a two-month interval. Adequate construct and discriminant validity have also been found for the subscales (Moos & Moos, 1994). The scores from the subscales of Cohesion, Expressiveness, and Conflict were used for this study. Moos and Moos (1994) reported adequate internal consistency for these subscales ranging from .69 to .78. Cronbach alphas for these scale for this study were: Cohesion = .70; Expressiveness = .56; and Conflict = .73. Tables 5 through 7 provide the means, standard deviations, and corrected item-total correlations for these scales. Reliability analyses conducted on these and subsequent scales are based on mothers' data.

<u>Coping Strategies.</u> Two coping variables were derived from a 30-item measure. This 30-item measure reflects cognitive and behavioral coping strategies which typify

Item	Item Mean	Standard Deviation	Corrected Item-Total Correlation
Family members really help and	0.88	0.33	0.45
support one another.			
We often seem to be killing time at	0.84	0.37	0.20
home.			
We put a lot of energy into what we do	0.77	0.42	0.23
at home.			
There is a feeling of togetherness in our	0.89	0.32	0.20
family.			
We rarely volunteer when something	0.70	0.46	0.32
has to be done at home.			
Family members really back each other	0.74	0.44	0.45
up.			
There is little group spirit in our family.	0.80	0.40	0.39
We really get along well with each	0.87	0.34	0.43
other.			
There is plenty of time and attention for	0.73	0.45	0.43
everyone in our family.			
Alpha = 0.70 Scale Me	an = 7.22	Scale S	D = 1.91

Psychometric Properties of the Cohesion Scale

Psychometric Properties of the Expressiveness Scale

Item	Item Mean	Standard Deviation	Corrected Item-Total Correlation
Family members often keep their feelings to themselves.	0.73	0.45	0.50
We say anything we want to around home.	0.58	0.50	0.14
It's hard to "blow off steam" at home	0.45	0.50	0.39
without upsetting somebody.			
We tell each other about our personal problems.	0.86	0.35	0.17
If we feel like doing something on the spur of the moment we often just pick up and go.	0.77	0.42	0.26
Someone usually gets upset if you complain in our family.	0.75	0.44	0.36
Money and paying bills is openly talked about in our family.	0.78	0.42	0.12
We are usually careful about what we say to each other.	0.40	0.49	0.08
There are a lot of spontaneous conversations in our family.	0.85	0.36	0.31
Alpha = 0.56 Scale Mean = 6	5.16	Scale S	D = 1.84

Psychometric Properties of the Conflict Scale

Item	Item Mean	Standard Deviation	Corrected Item-Total Correlation
We fight a lot in our family.	0.15	0.36	0.45
Family members are rarely ordered around.	0.60	0.49	0.61
Family members sometimes get so angry they throw things.	0.17	0.38	0.49
Family members hardly ever lose their tempers.	0.52	0.50	0.44
Family members often criticize each other.	0.30	0.46	0.50
Family members sometimes hit each other.	0.20	0.41	0.41
If there's a disagreement in our family, we try hard to smooth things over and keep the peace.	0.17	0.38	0.18
Family members often try one-up or out-do each other.	0.12	0.33	0.38
In our family, we believe you don't ever get anywhere by raising your voice.	0.57	0.50	0.23
Alpha = 0.73 Scale Mean =	2.82	Scale S	D = 2.17

Approach coping and Avoidance coping (see Appendix L). This measure is a modified version of the COPE (Carver, Scheier, and Weintraub, 1989). Parents were asked to indicate how often they used each of the coping strategies when managing stressful situations relative to their child's illness. Items were chosen based on how theoretically relevant they were to the Approach and Avoidance constructs proposed by Roth and Cohen (1986). Specifically, Approach was measured by items from the subscales of Active Coping, Planning, Seeking Support for Instrumental Reasons, Seeking Social Support for Emotional Reasons, and Focus On and Venting of Emotions. Avoidance was measured by the items from the subscales of Denial, Behavioral Disengagement, and Mental Disengagement. Scores for Approach and Avoidance were determined by the sum of the item scores within each construct. Each participant received a score for Approach and a separate score for Avoidance.

All items were submitted to a principal axis factor analysis with oblique rotation. Kaiser's criterion indicated eight factors with an eigen value of one or greater whereas the scree plot indicated six factors. Review of the factor matricies from PFAs imposing an eight and six factor solution, respectively, revealed that the variables were not welldefined by either of these solutions. Given that two factors derived from the thirty items originally proposed, a PFA was conducted imposing a two factor solution. Oblique rotation was used because the coping strategies were considered theoretically related and a correlation between the factors was expected. Items measuring Approach and Avoidance loaded onto their respective factors, though, the results suggested that the items loaded on the Approach factor (see Table 8). However, based on theoretical

Principal Axis Factor Analysis

Item	Approach	Avoidance
I talk to someone who could do something concrete about	0.79	0.11
the problem.		
I talk to someone about how I feel.	0.70	0.41
I try to get emotional support from friends and relatives.	0.69	0.36
I discuss my feelings with someone.	0.68	0.27
I talk with someone to find out more about the situation.	0.68	0.28
I make a plan of action.	0.68	-0.23
I concentrate my efforts on doing something about it.	0.68	-0.01
I think hard about what steps to take.	0.66	-0.16
I let my feelings out.	0.62	0.36
I try to come up with a strategy about what to do.	0.62	-0.01
I get sympathy and understanding from someone.	0.59	0.32
I ask people who have had similar experiences what they did.	0.58	0.24
I try to get advice from someone about what to do.	0.55	0.41
I think about how I might best handle the problem.	0.53	-0.17
I take additional action to try to get rid of the problem.	0.48	0.00
I take direct action to get around the problem.	0.39	0.16
I do what has to be done, one step at a time.	0.36	-0.01
I get upset and let my emotions out.	0.29	0.27
I admit to myself that I can't deal with it, and quit trying.	-0.30	0.49
I go to the movies or watch tv, to think less about it.	-0.17	0.47
I just give up trying to reach my goal.	-0.48	0.47
I say to myself, "This isn't real."	-0.48	0.41
I give up the attempt to get what I want.	-0.40	0.44
I daydream about things other than this.	0.18	0.33
I pretend that it hasn't really happened.	-0.44	0.33
I reduce the amount of effort I'm putting into solving the problem.	-0.41	0.31
I act as though it hasn't even happened.	-0.43	0.29
I refuse to believe that it has happened.	-0.43	0.23
I sleep more than usual.	-0.16	0.25
I turn to work or other substitute activities to take my mind off of things.	-0.27	0.19

considerations and the fact that the correlation between the two factors was modest (r=-0.25), keeping the two factor solution was justifiable. Cronbach alphas for the Approach and Avoidance scales were .91 and .82, respectively. Tables 9 and 10 provide the means, standard deviations, and corrected item-total correlations for these scales.

Illness-Related Concerns or Demands. The Impact on the Family Scale is a 24 item measure assessing the concerns, demands, and burdens that a child's chronic illness has on a family (Stein and Reissman, 1980; see Appendix M). Items reflect the financial, personal, social, and familial strain and that can occur as a result of the illness as well as the parent's sense of mastery over illness-related problems. Parents indicated how much they agreed with each statement on a 4-point scale of 1 (strongly agree), 2 (agree), 3 (disagree), 4 (strongly disagree). The scale generated a total score, with lower scores reflecting a greater impact. Good internal consistency was reported by the authors with the alpha level being .88. For this study, Cronbach alpha was .92. For the purpose of this study, the Impact on the Family Scale was reverse coded so that high scores indicated higher levels of illness-related concerns or demands. Table 11 provide the means, standard deviations, and corrected item-total correlations for these scales.

Parents' Psychological Well-Being. Depression and anxiety were both examined in this study. Depression was examined using the Center for Epidemiologic Studies -Depression (CES-D; Radloff, 1977). This is a 20 item measure assessing the frequency or duration of cognitive, affective, and behavioral symptoms associated with depression (See Appendix N). For each item, the parent indicated the frequency or duration with which he or she has experienced that symptom on a 4-point scale of 0 (rarely or none of

Psychometric Properties of the Approach Scale

Item	Item Mean	Standard Deviation	Corrected Item-Total Correlation
I get upset and let me emotions out.	2.37	0.87	0.33
I try to get advice from someone about what to do.	2.67	0.93	0.55
I concentrate my efforts on doing something about it.	3.23	0.77	0.64
I discuss my feelings with someone.	3.00	0.86	0.62
I talk with someone to find out more about the situation.	3.10	0.79	0.71
I make a plan of action.	3.10	0.93	0.62
I try to get emotional support from friends and relatives.	2.96	1.05	0.66
I take additional action to get rid of the problem.	2.88	0.95	0.49
I let my feelings out.	2.69	0.95	0.64
I talk to someone who could do something concrete about the problem.	2.92	0.93	0.77
I try to come up with a strategy about what to do.	3.10	0.85	0.61
I get sympathy and understanding from someone.	2.40	0.95	0.59
I think about how I might best handle the problem.	3.39	0.71	0.50
I ask people who have had similar experiences what they did.	2.85	1.03	0.58
I take direct action to get around the problem.	2.63	1.04	0.42
I talk to someone about how I feel.	2.84	0.89	0.67
I think hard about what steps to take.	3.28	0.80	0.63
I do what has to be done, one step at a time.	3.63	0.59	0.36
Alpha = 0.92 Scale Mean =	52.92	Scale S	SD = 10.09

Psychometric Properties of the Avoidance Scale

Item	Item Mean	Standard Deviation	Corrected Item-Total Correlation
I turn to work or other substitute activities	2.29	1.00	0.41
to take my mind off of things.			
I say to myself, "This isn't real."	1.32	0.67	0.50
I admit to myself that I can't deal with it,	1.32	0.65	0.53
and quit trying.			
I daydream about things other than this.	1.73	0.87	0.36
I just give up trying to reach my goal.	1.34	0.63	0.62
I refuse to believe that it has happened.	1.22	0.51	0.47
I sleep more than usual.	1.46	0.78	0.28
I give up the attempt to get what I want.	1.52	0.71	0.48
I pretend that it hasn't really happened.	1.19	0.49	0.53
I go to movies or watch tv, to think about	1.69	0.85	0.47
it less.			
I reduce the amount of effort I'm putting	1.54	0.71	0.54
into solving the problem.			
I act as though it hasn't even happened.	1.25	0.58	0.45
Alpha = 0.82 Scale Mean	= 17.86	Scale SI) = 4.85

Psychometric Properties of the Impact on the Family Scale

Item	Item Mean	Standard Deviation	Corrected Item-Total Correlation
The illness is causing financial problems for the family.	1.87	0.81	0.70
Time is lost from work because of hospital appointments.	2.17	0.89	0.43
I am cutting down the hours I work to care for my child.	1.90	0.89	0.54
Additional income is needed in order to cover medical expenses.	1.97	0.86	0.52
Because of the illness, we are not able to travel out of the city.	1.44	0.68	0.60
People in the neighborhood treat us specially because of my child's illness.	1.56	0.70	0.60
We have little desire to go out because of my child's illness.	1.54	0.79	0.75
It is hard to find a reliable person to take care of my child.	2.21	1.21	0.68
Sometimes we have to change plans about going out because of my child's illness.	2.27	0.99	0.68
We see family and friends less because of the illness.	1.52	0.68	0.72
Because of what we have shared we are a closer family.	2.04	0.80	0.04
Sometimes I wonder whether my child should be treated "specially" or the same as a normal child.	2.22	0.96	0.33
My relatives have been understanding and nelpful with my child.	1.86	0.77	0.45
think about not having more children because of the illness.	2.04	1.04	0.54
Ay partner and I discuss my child's problem together.	1.75	0.70	0.21
Ve try to treat my child as if he/she were a ormal child.	1.39	0.59	0.35
don't have much time left over for other family members after caring for my child.	1.85	0.84	0.76

Table 11 (cont'd).

Item	Item Mean	Standard Deviation	Corrected Item-Total Correlation
Our family gives up things because of my child's illness.	2.15	0.92	0.67
Fatigue is a problem for me because of my child's illness.	1.95	0.93	0.74
I live from day to day and don't plan for th future.	e 1.68	0.79	0.67
Nobody understands the burden I carry.	2.23	0.96	0.67
Traveling to the hospital is a strain on me.	1.98	0.85	0.61
Learning to manage my child's illness has made me feel better about myself.	2.22	0.74	0.20
Sometimes I feel like we live on a roller coaster; in crisis when my child is acutely ill, OK when things are stable.	2.63	0.98	0.54
Alpha = 0.92 Scale Mean =	= 46.65	Scale SI	D = 12.15

the time/less than one day), 1 (some or a little of the time/one to two days), 2 (occasionally or a moderate amount of time/three to four days) and 3 (most or all of the time/five to seven days). Higher scores reflected greater distress.

The CES-D demonstrates good internal consistency, with Cronbach alphas ranging from .84 to .90 (Radloff, 1977; Corcoran & Fisher, 1987). Test-retest scores range from . 49 (12 month interval) to .51 (2 week interval) (Radloff, 1977). These moderate correlations may be a function of the test's instructions as it requires the individual to respond to the frequency or duration of *current* depressive symptomatology (Devins & Orme, 1985). The CES-D also highly correlates with the Beck Depression Inventory (r=.87; Santor, Ramsay, & Zuroff, 1995) and is able to discrimate among different clinical samples (Weisman, Sholomskas, Pottenger, Prusoff, & Locke, 1977) as well as between clinical and nonclinical samples (Radloff, 1977). See Devins and Orme (1985) for a complete review. Cronbach alpha for the CES-D for this study was .92. Table 12 provides the means, standard deviations, and corrected item-total correlations for these scales.

Anxiety was measured using the State Trait Anxiety Inventory (STAI; Spielberger, Gorusch, Lushene, Vagg, & Jacobs, 1970). This is a 40-item measure which assesses both the level of stable (State) and transitory (Trait) anxiety. For the purpose of this study, only the Trait scale was administered in order to determine the level of anxiety the parent had been experiencing (See Appendix O). The Trait scale is made up of 20 items. For each item the parent indicates how he/she "generally feels" using a 4-point scale of 1 (almost never), 2 (sometimes), 3 (often), and 4 (almost always). Each

Psychometric Properties of the CES-D

Item	Item Mean	Standard Deviation	Corrected Item-Total Correlation
I was bothered by things that usually don	't 0.39	0.64	0.52
bother me.			
I did not feel like eating; my appetite was	0.33	0.61	0.51
poor.			
I felt that I could not shake off the blues even with the help from my family and	0.34	0.65	0.70
friends.			
I felt I was just as good as other people.	0.58	0.85	0.36
I had trouble keeping my mind on what I	0.59	0.76	0.55
was doing.			
I felt depressed.	0.53	0.79	0.77
I felt that everything I did was an effort.	0.59	0.90	0.53
I felt hopeful about the future.	0.63	0.87	0.40
I thought my life had been a failure.	0.17	0.50	0.50
I felt fearful.	0.29	0.61	0.68
My sleep was restless.	0.77	0.88	0.50
I was happy.	0.53	0.71	0.65
I talked less than usual.	0.43	0.58	0.44
I felt lonely.	0.32	0.61	0.60
People were unfriendly.	0.27	0.62	0.50
I enjoyed my life.	0.53	0.72	0.62
I had crying spells.	0.32	0.69	0.53
I felt sad.	0.54	0.77	0.63
I felt that people disliked me.	0.26	0.55	0.68
I could not get "going".	0.55	0.74	0.68
Alpha = 0.92 Scale Mean	= 8.98	Scale SI	0 = 8.69

participant's score on the Trait scale was then computed into a T-score, according to sex and age (Speilberger et al., 1983). A higher score indicated greater anxiety.

The STAI-Trait demonstrates good internal consistency with Cronbach alphas ranging from .89 to .91 and test-retest scores range from .65 to .86. The Trait scale correlates highly with the Taylor Manifest Anxiety Scale (.80) and with the IPAT Anxiety Scale (.75). The Trait scale is also able to discriminate between clinical and nonclinical groups. See Chaplin (1985) for a complete review. The scale demonstrated good internal consistency with Cronbach alpha being .93. Table 13 provides the means, standard deviations, and corrected item-total correlations for these scales.

Children's Psychological Well-Being. In order to examine psychological wellbeing in children the Child Behavior Checklist (CBCL; Achenbach, 1991) was used. The CBCL is a measure of social competence and behavioral/emotional problems of 4-to 18year olds and is completed by the parent or guardian (See Appendix P). The CBCL contains 119 items assessing the degree to which the child has exhibited certain behaviors over the past six months. The behavior problems are rated on a 3-point scale of 0 (not true), 1 (somewhat or sometimes true), 2 (very true or often true). The CBCL is comprised of eight narrow-band factors and two broad-band factors. The narrow-band factors are labeled Withdrawn, Somatic Complaints, Anxious/Depressed, Attention Problems, Thought Problems, Social Problems, Delinquent Behavior, and Aggressive Behavior. The broad-band factors are Internalizing and Externalizing. The Internalizing category contains Withdrawn, Somatic Complaints, and Anxious/Depressed scales and the Externalizing category contains Delinquent Behavior and Aggressive Behavior.

Psychometric Properties of the STAI - Trait Anxiety

Item	Item Mean	Standard Deviation	Corrected Item-Total Correlation
I felt pleasant.	1.84	0.72	0.60
I felt nervous and restless.	1.82	0.66	0.53
I feel satisfied with myself.	2.14	0.77	0.73
I wish I could be as happy as others seem to	1.87	0.89	0.62
be.			
I feel like a failure.	1.43	0.57	0.59
I feel rested.	2.70	0.81	0.45
I am "calm, cool, and collected".	2.46	0.77	0.66
I feel that difficulties are piling up so that I	1.66	0.72	0.58
cannot overcome them.			
I worry too much over something that really	1.95	0.72	0.59
doesn't matter.			
I am happy.	1.74	0.66	0.75
I have disturbing thoughts.	1.40	0.55	0.63
I lack self-confidence.	1.82	0.73	0.52
I feel secure.	1.76	0.80	0.70
I make decisions easily.	2.24	0.82	0.51
I feel inadequate.	1.62	0.67	0.56
I am content.	1.92	0.74	0.79
Some unimportant thoughts run through my	1.65	0.54	0.46
mind and bothers me.			
I take disappointments so keenly that I can't	1.72	0.66	0.45
them out of my mind.			
I am a steady person.	1.88	0.76	0.72
I get in a state of tension or turmoil as I	1.67	0.76	0.62
think over my recent concerns and interests.			
Alpha = 0.93Scale Mean = 3	7.27	Scale SI	D = 9.34

Scores for total competence, total behavior problem and broad-band factors are expressed as standardized T-scores ($\underline{M} = 50$, $\underline{SD} = 10$).

Discriminant validity is demonstrated by significant differences on all Social Competence and Behavior Problems scales between referred and nonclinical children. Internal reliability of the Behavior Problem narrow-band scales range from .62 to .92. Alphas for the Internalizing scale and Externalizing scale are .89 and .93, respectively. For the Social Competence scale, alphas range from .42 to .64. Test-retest reliabilities (one week interval) of the Behavior Problem scale were .89 and for the Social Competence scales was .87 (Achenbach, 1991).

For the purpose of this study, only the total behavior problem score was used because it represented the amount of problems the child is experiencing rather than specific types of problems the child is experiencing (as represented by the Internalizing and Externalizing factors). Internal consistency for this scale was adequate, with a Cronbach alpha of .96. Table 14 provides the means, standard deviations, and corrected item-total correlations for these scales.

Metabolic Control. The children's level of metabolic or blood glucose control was evaluated with the hemoglobin A_{IC} (Hb A_{IC}), or glyclated hemoglobin, values taken at the time of the child's clinic visit. This is a commonly used measure which reflects the amount of hemoglobin molecules in red blood cells that have attached, or glycated, themselves to glucose. The more glucose produced by the body means a higher rate of glycated hemoglobin. The hemoglobin stays glycated until the end of the red blood cell's life, which is typically 120 days. Therefore, the Hb A_{IC} reflects the overall metabolic or glucose control over a period of three to four months (ADA, 1996; Martin et al., 1998;

Psychometric Properties of the Child Behavior Checklist

Item	Item Mean	Standard Deviation	Corrected Item-Total Correlation
Acts to young for his/her age.	0.31	0.51	0.49
Allergy	0.47	0.75	0.13
Argues a lot	0.87	0.69	0.53
Asthma	0.17	0.48	0.32
Behaves like the opposite sex	0.11	0.41	0.22
Bowel movements outside toilet	0.07	0.25	0.28
Bragging, boasting	0.41	0.58	0.40
Can't concentrate, can't pay attention for long	0.38	0.63	0.58
Can't get his/her mind off certain thoughts; obsessions	0.40	0.63	0.61
Can't sit still, restless, or hyperactive	0.27	0.51	0.66
Clings to adults or too dependent	0.20	0.43	0.33
Complains of loneliness	0.20	0.48	0.39
Confused or seems to be in a fog	0.14	0.38	0.52
Cries a lot	0.20	0.45	0.42
Cruel to animals	0.04	0.21	0.52
Cruelty, bullying, or meanness to others	0.19	0.47	0.55
Day-dreams or gets lost in his/her thoughts	0.32	0.56	0.51
Deliberately harms self or attempts suicide	0.01	0.10	0.45
Demands a lot of attention	0.49	0.71	0.67
Destroys his/her own things	0.11	0.35	0.68
Destroys things belonging to his/her family	0.13	0.37	0.64
Disobedient at home	0.36	0.53	0.63
Disobedient at school	0.16	0.45	0.40
Doesn't eat well	0.33	0.56	0.28
Doesn't get along with other kids	0.21	0.44	0.64
Doesn't seem guilty after misbehaving	0.27	0.54	0.63
Easily jealous	0.34		0.48
Eats or drinks that are not food	0.10		0.37
Fears certain animals, situations, or places	0.28	0.56	0.49
other than school			
Fears going to school	0.03	0.18	0.41
Fears he/she might think or do something bad	0.11	0.35	0.38

Table 14 (cont'd).

Item	Item Mean	Standard Deviation	Corrected Item-Total Correlation
Feels he/she has to be perfect	0.40	0.63	0.25
Feels or complains that no one loves	0.24	0.50	0.54
him/her			
Feels others are out to get him/her	0.11	0.32	0.57
Feels worthless or inferior	0.24	0.46	0.45
Gets hurt a lot, accident prone	0.16	0.42	0.59
Gets in many fights	0.08	0.27	0.56
Gets teased a lot	0.27	0.54	0.45
Hangs around with others who get in trouble	0.10	0.30	0.27
Hears sounds or voices that aren't there	0.00	0.00	0.00
Impulsive or acts without thinking	0.41	0.60	0.64
Would rather be alone than with others	0.27	0.56	0.49
Lying or cheating	0.26	0.49	0.45
Bites fingernails	0.36	0.64	0.21
Nervous, highstrung, or tense	0.31	0.59	0.72
Nervous movements or twitching	0.11	0.38	0.49
Nightmares	0.23	0.43	0.31
Not liked by other kids	0.13	0.37	0.65
Constipated, doesn't move bowels	0.03	0.18	0.36
Too fearful or anxious	0.18	0.44	0.62
Feels dizzy	0.18	0.41	0.40
Feels too guilty	0.12	0.36	0.32
Overeating	0.30	0.51	0.31
Overtired	0.32	0.52	0.56
Overweight	0.22	0.49	0.09
Physical problems without known medical			
cause:			
a. aches or pains	0.22	0.49	0.49
b. headaches	0.38	0.55	0.43
c. nausea, feels sick	0.27	0.51	0.42
d. problems with eyes	0.16	0.45	0.23
e. rashes or other skin problems	0.30	0.62	0.32
f. stomachaches or cramps	0.37	0.57	0.40
g. vomiting, throwing up	0.08	0.27	0.32
h. other	0.02	0.21	0.21
Physically attacks people	0.10	0.34	0.66
Picks nose, skin, or other parts of body	0.20	0.48	0.31
Plays with own sex parts in public	0.02	0.15	0.20

Table 14 (cont'd).

Item	Item Mean	Standard Deviation	Corrected Item-Total Correlation
Plays with own sex parts too much	0.01	0.10	0.20
Poor school work	0.21	0.49	0.20
Poorly coordinated or clumsy	0.17	0.43	0.60
Prefers being with older kids	0.43	0.60	0.35
Prefers being with younger kids	0.26	0.49	0.60
Refuses to talk	0.21	0.44	0.22
Repeats certain acts over and over; compulsions	0.07	0.33	0.60
Runs away from home	0.00	0.00	0.00
Screams a lot	0.17	0.46	0.49
Secretive, keeps things to self	0.29	0.52	0.43
Seen things that aren't there	0.03	0.23	0.44
Self-conscious or easily embarrassed	0.38	0.53	0.21
Sets fires	0.01	0.11	-0.05
Sexual problems	0.01	0.11	0.12
Showing off or clowning around	0.51	0.64	0.57
Shy or timid	0.40	0.54	0.08
Sleeps less than most kids	0.19	0.49	0.51
Sleeps more than most kids during day and/or night	0.17	0.46	0.18
Smears or plays with bowel movements	0.02	0.21	0.44
Speech problems	0.10	0.40	0.40
Stares blankly	0.09	0.32	0.48
Steals at home	0.06	0.23	0.39
Steals outside the home	0.03	0.18	0.14
Stores things he/she doesn't need	0.24	0.53	0.58
Strange behavior	0.07	0.33	0.39
Strange ideas	0.10	0.37	0.51
Stubborn, sullen, or irritable	0.64	0.64	0.64
Sudden changes in mood or feelings	0.64	0.68	0.65
Sulks a lot	0.28	0.47	0.51
Suspicious	0.08	0.27	0.64
Swearing or obscene language	0.17	0.43	0.39
Talks about killing self	0.06	0.27	0.51
Talks or walks in sleep	0.20	0.50	0.49
Talks too much	0.37	0.61	0.52
Teases a lot	0.24	0.48	0.31
Temper tantrums or hot temper	0.40	0.61	0.68

Table 14 (cont'd).

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Item	Item Mean	Standard Deviation	Corrected Item-Total Correlation
Thinks about sex too much	0.03	0.23	0.20
Threatens people	0.07	0.29	0.67
Thumb-sucking	0.07	0.33	0.18
Too concerned with neatness or cleanlines	s 0.03	0.18	-0.03
Trouble sleeping	0.22	0.51	0.56
Truancy, skips school	0.02	0.15	0.01
Underactive, slow moving, or lacks energy	0.19	0.42	0.25
Unhappy, sad, or depressed	0.30	0.55	0.57
Unusually loud	0.21	0.49	0.66
Uses alcohol or drugs for nonmedical	0.04	0.26	0.45
purposes			
Vandalism	0.02	0.15	0.23
Wets self during the day	0.16	0.45	0.25
Wets the bed	0.00	0.00	0.00
Whining	0.31	0.53	0.53
Wishes to be the opposite sex	0.01	0.11	0.24
Withdrawn, doesn't get involved with other	ers 0.19	0.42	0.45
Worries	0.47	0.54	0.64
Alpha = 0.96 Scale Mean	= 24.78	Scale SI	D = 23.29

Peyrot et al., 1999). It should noted, though, that this value is not sensitive to acute crises or extreme periods of poor metabolic control but rather reflects an average of the metabolic control over the past few months (Keith Dveirin, M.D., personal communication, August, 2000). The testing of glycated hemoglobin was completed by various labs and each lab had its own range of what is considered normal glycated hemoglobin values. As a result, the values needed to be standardized by computing a percentage; each HbA_{ic} value was divided by the upper limit of its respective lab's normal range and then multiplied by the upper limit of the normal range (6.0) proposed by the Diabetes Control and Complications Trial (Bruce Wilson, M.D., personal communication, November, 1998). Higher HbA_{ic} values indicate poor metabolic or blood glucose control.

In order to examine effects of the predictor on metabolic control, only data from children who had an HbA_{1c} value taken either three months (90 days) prior or three months (90 days) after the completion of the questionnaires by their parents were included in the analyses. As mentioned earlier, the HbA_{1c} value is a reflection of the child's metabolic control over the previous three to four months. Therefore, it was believed that the HbA_{1c} values falling within this time period would serve as appropriate indicators of the possible concurrent effects that family functioning, illness-related stressors, psychological well-being could have on metabolic control. Of the 107 children participating in this study, 62 children had a reading taken up to three months prior to the completion of the questionnaires and 58 children had a reading taken up to three months

each child, the value closest to the completion date was chosen to use in these analyses (N=75).

In order to examine the potential effects that metabolic control could have on family functioning, illness-related stressors, and psychological well-being, only the data from children who had both an HbA_{1c} value taken six months (180 days) prior to (pre-test value) and an HbA_{1c} value taken at least four to six months (180 days) after (post-test value) the completion of the questionnaires were included in the analyses. Out of the 107 children participating in this study, 88 children had a value taken up to six months prior to the completion of the questionnaires whereas 36 children had a value taken four to six months after the completion of the questionnaires. If more than one value was available for either the pre- or post-test value, the value closest to the complete data from only 27 mothers and 7 fathers. Because of the small sample size of fathers, only the data from the mothers were used in the analyses.

Scoring Revision. To ensure that as many participants' data were included in the analyses as possible, mean item scores were used to account for missing data. Mean items scores were used for all measures except for metabolic control and the CBCL. In order to determine the mean item score the following steps were taken for each participant on each scale. First, the total score was determined for each participant by summing the scores of the items to which the participant responded. Second, this total score was then divided by the number of items in that scale in order to determine the average, or mean, of the item scores. These mean scores were then used in the analyses.

Data Analyses

Hypotheses regarding the relationships between family functioning, coping strategies, and illness-related concerns or demands and parental adjustment (Hypotheses 1 through 6) were tested using Pearson correlations. Pearson correlations were also used to test the hypothesized relationships between family functioning and illness-related concerns or demands and children's adjustment (Hypotheses 7 through 10). The relationship between children's psychological well-being and metabolic control (Hypothesis 11) was tested using Pearson correlations as well. Multiple regressions were used to determine if illness-related concerns or demands was a mediating variable between dimensions of family functioning and parental and child adjustment (Hypothesis 12). The details of this analysis strategy, as outlined by Baron and Kenny (1986), are described below in the Results section. In order to examine the direction of the relationships between metabolic control and the psychosocial variables (Hypothesis 13), partial correlations were used. Finally, Pearson correlations were used to examine the potential relationships between children's age and the psychosocial variables, psychological-well-being, and children's adjustment, respectively. They were also used to examine illness duration and the psychosocial variables, and children's adjustment, respectively (Hypothesis 14). Please refer to Table 1 which contains a complete outline of the measures and statistical analyses used for each of the hypotheses.

RESULTS

Tables 15 and 16 provide the results of the univariate correlations amongst the predictor variables for mothers and fathers. Below are the results for the hypotheses proposed for this study.

Family Functioning and Parents' Psychological Well-Being

Pearson correlations were used to assess the relationships between family functioning and parental psychological well-being. It was predicted that parents from families low in cohesion and expressiveness and high in conflict would be more likely to experience distress. These hypotheses were partly supported. As seen in Table 17, mothers were more likely to experience symptoms of depression and anxiety when their families exhibited low levels of cohesion and expressiveness and high levels of conflict. Fathers, however, were not as affected by these dimensions; no significant relationships were found between cohesion, expressiveness, conflict and paternal depression or anxiety.

In order to determine if there were significant differences between the correlations obtained for mothers and fathers, Fisher's Z coefficients were calculated. As seen in Table 18, significant differences were found between the correlation for maternal depression and expressiveness and the correlation for paternal depression and expressiveness. No other significant differences were found for the other family functioning dimensions.

Coping Strategies and Parents' Psychological Well-Being

In order to assess the relationships between coping strategies and maternal and paternal psychological well-being Pearson correlations were used. As expected, mothers

		Family Functioning	<u>م</u>	Coping	Coping Strategies	Illness-related Concerns or
	Cohesion	Expressiveness	Conflict	Approach	Avoidance	Demands Impact on the Family
Cohesion	1.00 (103)	0.51** (102)	-0.47** (102)	0.28** (103)	-0.47** (103)	-0.44** (103)
Expressiveness		1.00 (102)	-0.30** (102)	0.33** (102)	-0.33** (103)	-0.41** (102)
Conflict			1.00 (102)	-0.15 (102)		0.39** (102)
Approach				1.00 (103)	-0.23* (103)	-0.32** (103)
Avoidance					1.00 (103)	0.33** (103)
Impact on the Family						1.00 (103)

Pearson Correlations for Psychosocial Factors (Mothers' Data)

Table 15

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		Family Functioning	a	Coping	Coping Strategies	Illness-related Concerns or
	Cohesion	Expressiveness	Conflict	Approach	Avoidance	Demands Impact on the Family
Cohesion	1.00 (35)	0.20 (35)	-0.25 (35)	0.13 (35)	-0.18 (35)	-0.27 (35)
Expressiveness		1.00 (35)	-0.35* (35)	0.03 (35)	-0.22 (35)	-0.17 (35)
Conflict			1.00 (35)	-0.01 (35)	-0.19 (35)	0.17 (35)
Approach				1.00 (35)	-0.01 (35)	0.14 (35)
Avoidance					1.00 (35)	0.27 (35)
Impact on the Family						1.00 (35)

Pearson Correlations for Psychosocial Factors (Fathers' Data)

Table 16

		Family Functioning	ත	Copinę	Coping Strategies	Illness-related Concerns or Demands
	Cohesion	Expressiveness	Conflict	Approach	Avoidance	Impact on the
Psychological Well-being						Family
Mothers						
CES-D	-0.42** (103)	-0.48** (102)	0.28** (102)	-0.44** (103)	0.48** (103)	0.53 ** (103)
STAI-Trait	-0.44** (103)	-0.55** (102)	0.46** (102)	-0.49** (103)	0.61** (103)	0.44** (103)
Fathers						
CES-D	-0.12 (35)	-0.11 (35)	0.11 (35)	-0.11 (35)	0.53** (35)	0.40** (35)
STAI-Trait	-0.19 (35)	-0.15 (35)	0.19 (35)	-0.03 (35)	0.38* (35)	0.49** (35)

Pearson Correlations for Psychosocial Factors and Parents' Psychological Well-Being

Table 17

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Fisher's Z Coefficients for Comparisons Between Mothers and Fathers

	Cohesion	Expressiveness	Conflict	Approach
CES-D	-1.635	-2.065*	0.89	-1.810
STAI-Trait	-1.400	-2.335*	1.525	-2.530*
*a<.05				

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were more likely to experience symptoms of depression and anxiety when they relied to a lesser extent on Approach coping strategies. Similarly, mothers were more likely to experience psychological distress when they relied to a greater extent on Avoidance coping strategies. Fathers, on the other hand, were more likely to experience depression and anxiety when they relied to a greater extent on Avoidance coping strategies (See Table 17). No significant relationships were found for paternal psychological well-being and Approach coping strategies.

Additional analyses were conducted to determine if there were significant differences between the correlations for mothers and fathers psychological well-being and Approach coping. According to the results of the Fisher's Z computations, only a significant difference was found between the correlation for maternal anxiety and Approach coping and the correlation for paternal anxiety and Approach coping (See Table 18).

Illness-Related Concerns or Demands and Parents' Psychological Well-Being

The relationship between illness-related concerns or demands faced by families with a diabetic child and parental well-being were assessed using Pearson correlations. The hypothesis that the more a family was affected by illness-related stressors, the more distressed parents would be was supported. The results indicated that both mothers and fathers experienced symptoms of depression and anxiety when their families experienced higher degrees of illness-related concerns or demands (See Table 17).

Family Functioning, Children's Psychological Well-Being, and Metabolic Control

As discussed in the Method section, only data from children who had an HbA_{1c} value taken either three months (90 days) prior or three months (90 days) after the

completion of the questionnaires by their parents were included in the analyses (N=75). It was believed that the HbA_{1c} values falling within this time period would serve as appropriate indicators of the possible effects that the examined psychosocial factors could have on metabolic control.

The relationship between aspects of family functioning and children's psychological well-being were also assessed using Pearson correlations (See Table 19). The prediction that low family cohesion and expressiveness and high family conflict would be significantly related to psychological problems in children was partially supported. According to the mothers' report, children were more likely to have behavioral or emotional problems when their families were low in cohesion and high in conflict. Though no significant relationship was found between family expressiveness and psychological well-being, results indicated that the relationship was in the hypothesized direction (r=-0.19, p=0.054). Analyses using the fathers' data indicated that children from families characterized by low levels of expressiveness were significantly more likely to have problems. Similar to the results found using the mothers' data, the relationships between family cohesion and conflict and psychological well-being, though not significant, were in the predicted direction (r=-0.30, p=-0.067 and r=0.26, p=0.098, respectively).

The prediction that low levels of family cohesion and expressiveness and high levels of family conflict would be associated with poor metabolic control was partially supported. According to the results of the Pearson correlations, mothers' report of high family conflict was significantly related to poor metabolic control in children. No other findings were significant (See Table 19).

Pearson Correlations for Psychosocial Factors and Children's Psychological Well-Being and

Metabolic Control

		Family Functioning		Illness-related Concerns or Demands
	Cohesion	Expressiveness	Conflict	Impact on the Family
Mothers' Report				
CBCL	-0.31**	-0.19	0.24*	0.44**
	(75)	(75)	(75)	(75)
HbA _{1c}	-0.02	-0.13	0.23*	0.08
	(74)	(74)	(74)	(74)
Fathers' Report				
CBCL	-0.30	-0.66**	0.26	0.32*
	(27)	(27)	(27)	(27)
HbA_{1c}	-0.01	-0.08	-0.20	0.05
	(27)	(27)	(27)	(27)

Illness-Related Concerns or Demands and Children's Psychological Well-Being, and Metabolic Control

It was predicted that children whose families were affected by illness-related concerns or demands would be more likely to experience behavioral and emotional problems. This hypothesis was partially supported. According to both mothers' and fathers' reports, children were more likely to experience problems if their families were greatly affected by illness-related concerns or demands. The prediction that children whose families were affected by illness-related concerns or demands would be significantly less likely to maintain proper metabolic control was not supported (See Table 19).

Relationship Between Children's Psychological Well-Being and Metabolic Control

The prediction that children with behavioral and emotional problems would be more likely to have poor metabolic control was not supported by either the mothers' (r=-.06, n.s.) or fathers' (r=.11, <n.s.) reports.

Association Between Metabolic Control and Family Functioning, Controlling for Pre-Test Metabolic Control

Because of this study's design it was not possible to directly assess the direction of the relationship between metabolic control and the psychosocial variables. Instead, partial correlation analyses were conducted to determine if dimensions of family functioning and illness-related concerns or demands account for any change in metabolic control over time.

As previously discussed, only the data from children who had both an HbA_{1c} value taken six months (180 days) prior to (pre-test value) and an HbA_{1c} value taken four

to six months (180 days) after (post-test value) the completion of the questionnaires were included in the analyses (N=27). Values taken prior to the completion of the questionnaires were controlled for in these analyses. Table 20 contains the correlations among the variables based on the mothers' report. Analyses were not conducted using fathers' report due to the small sample size. As seen in Table 21, none of the results were significant. These non-significant results suggested that there was no relationship between the psychosocial variables of family functioning and illness-related concerns or demands and changes over time in metabolic control.

Mediation Model Analyses

Baron and Kenny's (1986) model for testing the mediation effect was used to examine these hypotheses. This model is tested using multiple regression analyses. According to Baron and Kenny, three steps are involved in testing the mediation model when using three variables. To clarify, the following example is given. It is proposed that variable B mediates the relationship between variables A and C. In order to test this hypothesis, the first step is to determine if there is a significant relationship between variables A and B. The second step is to determine if there is a significant relationship between variables B and C. The final step in testing this model is to examine whether the hypothesized mediation variable, B, explains the relationship between variables A and C. When variable B is entered into the model (and controlled for), the relationship between A and C is expected to become non-significant. This non-significant result demonstrates that the relationship between A and C is mediated by their relationships with B.

In this study, the first step was to determine if there was a significant relationship between illness-related concerns or demands and well-being (be it maternal depression,



Pearson Correlations Using Pre-Test HbA_{1c} and Post-Test HbA_{1c} Values Based on Mother's Report

Metabolic Control Post-Test HbA _{lc} Post-Test Value	0.43 ** (32)	-0.15 (32)	-0.13 (32)	0.08** (32)	0.11 (32)	1.00 (32)
Illness-related Concerns or Demands Impact on the Family	0.15 (32)	-0.54** (32)	-0.49** (32)	0.41** (32)	1.00 (32)	
Conflict	0.01 (32)	-0.53** (32)	-0.28 (32)	1.00 (32)		
Family Functioning Expressiveness	-0.19 (32)	0.42** (32)	1.00 (32)			
Cohesion	0.10 (32)	1.00 (32)				
Metabolic Control Pre-Test HbA _{lc} Pre-Test Value	1.00 (32)					
	HbA _{lc} Pre-Test Value	Cohesion	Expressiveness	Conflict	Impact on the Family	HbA _{le} Post-Test Value

Partial Correlation Coefficients Controlling for Pre-Test HbA_{1c} Value Based on Mothers'

<u>Report</u>

		Family Functioning		Illness-related Concerns or Demands
	Cohesion	Expressiveness	Conflict	Impact on the Family
HbA _{1c}	0.12	-0.05	0.09	0.19
Post-Test Value	(29)	(29)	(29)	(29)

maternal anxiety, etc.). The second step was to determine if there was a significant relationship between the proposed mediation variable (e.g., family cohesion, expressiveness, conflict or approach, avoidance coping) and well-being. The final step was to determine whether the proposed mediation variable explained the relation between illness-related concerns or demands and well-being. When the mediation model was entered into the model (and controlled for), the relation between illness-related concerns or demands and well-being was expected to become non-significant. If a non-significant result was obtained, it demonstrated that the relation between the illness-related concerns or demands and well-being was due the mediation variable in question.

Mediation Model for Mothers. As stated above, univariate correlations revealed significant relationships between the three dimensions of family functioning and the two styles of coping strategies with the psychological well-being of mothers. Therefore, each of these variables was examined using separate mediation models. Tables 22 through 26 report the results of the mediation model analyses. Contrary to predictions, though, none of the psychosocial variables served as mediators for illness-related stressors and maternal psychological well-being. Notably, as illustrated in Table 24, results indicated that illness-related concerns or demands served as a mediating variable for family conflict and maternal depression instead.

<u>Mediation Model for Children.</u> According to the results of the univariate correlations conducted on the mothers' report, illness-related concerns or demands as well as family cohesion and conflict were significantly related to children's psychological well-being. Therefore, the mediation model analyses were conducted on these particular psychosocial variables respectively (See Tables 27 and 28). Neither predicted mediation

Standardized Regression Coefficients for Family Cohesion as a Mediator of Illness-

Related Concerns or Demands and Maternal Psychological Well-Being

CES-D	Predictor	Beta Step 1	Beta Step2	R ² Change Step 1	R ² Change Step 2
Model 1	Impact on the Family	0.53**		0.28**	
Model 2	Impact on the Family		0.42**		
	Cohesion		-0.23**		0.04**
STAI- Trait	Predictor	Beta Step 1	Beta Step 2	R ² Change Step 1	R ² Change Step 2
Model 1	Impact on the Family	0.44**		0.19**	
Model 2	Impact on the Family		0.31**		
** < 01 *	Cohesion		-0.30**		0.07**

Standardized Regression Coefficients For Family Expressiveness as a Mediator of

Illness-Related	Concerns or	Demands and	d Maternal Pa	sychologica	l Well-Being
and the second se					

CES-D	Predictor	Beta Step 1	Beta Step 2	R ² Change Step 1	R ² Change Step 2
Model 1	Impact on the Family	0.52**		0.28**	
Model 2	Impact on the Family		0.39**		
	Expressiveness		-0.32**		.09**
STAI- Trait	Predictor	Beta Step 1	Beta Step 2	R ² Change Step 1	R ² Change Step 2
Model 1	Impact on the Family	0.44**		0.19**	
Model 2	Impact on the Family		0.26**		
	Expressiveness		-0.45**		0.17**

Standardized Regression Coefficients for Family Conflict as a Mediator of Illness-

CES-D	Predictor	Beta Step 1	Beta Step 2	R ² Change Step 1	R ² Change Step 2
Model 1	Impact on the Family	0.52**		0.27**	
Model 2	Impact on the Family		0.48**		
	Conflict		0.09		0.01
STAI- Trait	Predictor	Beta Step 1	Beta Step 2	R ² Change Step 1	R ² Change Step 2
Model 1	Impact on the Family	0.44**		0.19**	
Model 2	Impact on the Family		0.31**		
	Conflict		0.34**		0.10**

Related Concerns or Demands and Maternal Psychological Well-Being

**p<.01, *p<.05

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Standardized Regression Coefficients for Approach Coping as a Mediator of Illness-

CES-D	Predictor	Beta Step 1	Beta Step 2	R ² Change Step 1	R ² Change Step 2
Model 1	Impact on the Family	0.53**		0.28**	
Model 2	Impact on the Family		0.43**		
	Approach		-0.30**		0.08**
STAI- Trait	Predictor	Beta Step 1	Beta Step 2	R ² Change Step 1	R ² Change Step 2
Model 1	Impact on the Family	0.44**		0.19**	
Model 2	Impact on the Family		0.32**		
	Approach		-0.39**		0.14**

Related Concerns on	Demands an	d Maternal Ps	vchological	Well-Being

Standardized Regression Coefficients for Avoidance Coping as a Mediator of Illness-

CES-D	Predictor	Beta Step 1	Beta Step 2	R ² Change Step 1	R ² Change Step 2
Model 1	Impact on the Family	0.53**		0.28**	
Model 2	Impact on the Family		0.41**		
	Avoidance Coping		0.35**		0.11**
STAI- Trait	Predictor	Beta Step 1	Beta Step 2	R ² Change Step 1	R ² Change Step 2
Model 1	Impact on the Family	0.44**		0.19**	
Model 2	Impact on the Family		0.27**	-	
	Avoidance Coping		0.52**		0.24**

Related Concerns or Demands and Maternal Psychological Well-Being



model was supported. Again, illness-related concerns or demands appeared to serve as a mediator for the relationships between family cohesion and conflict and children's psychological well-being.

Overall, results of the mediation models for mothers and children provided little support for the proposed models. Instead, the results indicated that illness-related concerns or demands served as a mediating variable between dimensions of family functioning and coping strategies and child and parental well-being.

Exploratory Analyses About Developmental Processes

Pearson correlations were used to examine the relationships between children's age and the psychosocial variables, emotional and behavioral problems, and metabolic control, respectively. In addition the relationships between illness duration and the psychosocial variables, emotional and behavioral problems, and metabolic control, respectively, were examined. Results were obtained using both mothers' and fathers' reports (see Table 29). According to the mothers' report, children's age was significantly related with illness-related concerns or demands whereas according to the fathers' report, children's age was significantly related to not only illness-related concerns or demands but families who experienced fewer illness-related concerns or demands were more likely to have an older child with diabetes. In addition, the results suggested that, according to fathers, families higher in conflict were more likely to have a young child with diabetes. No significant findings were found for illness duration.

Standardized Regression Coefficients for Family Cohesion as a Mediator of Illness-

Related Concerns or Demands and Children's Psychological Well-Being (Mothers'

Report)

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CBCL	Predictor	Beta Step 1	Beta Step 2	R ² Change Step 1	R ² Change Step 2
Model 1	Impact on the Family	0.44**		0.44**	
Model 2	Impact on the Family		0.37**		
	Cohesion		-0.20		0.47

Standardized Regression Coefficients for Family Conflict as a Mediator of Illness-

Related Concerns or Demands and Children's Psychological Well-Being (Mothers'

Report)

CBCL	Predictor	Beta Step 1	Beta Step 2	R ² Change Step 1	R ² Change Step 2
Model 1	Impact on the Family	0.44**		0.44**	
Model 2	Impact on the Family		0.40**		
	Conflict		0.13		0.45

Correlation Coefficients for Children's Age, Illness Duration, Predictor Variables, and

Outcome Variables

Mathems' Demost	Children's Age	Illness Duration
Mothers' Report Cohesion	-0.01	0.02
	(105)	(104)
Expressiveness	0.08	-0.04
	(104)	(103)
Conflict	-0.12	-0.01
	(104)	(103)
Impact on the Family	-0.25*	0.02
	(105)	(104)
CBCL	-0.14	0.09
	(104)	(103)
HbA _{1c} value	0.19	0.17
	(74)	(73)
Fathers' Report		
Cohesion	0.08	-0.08
	(35)	(35)
Expressiveness	0.15	-0.15
	(35)	(35)
Conflict	-0.36*	-0.13
	(35)	(35)
Impact on the Family	-0.41*	0.02
	(35)	(35)
CBCL	-0.27	0.17
	(35)	(35)
HbA _{1c} value	0.07	-0.11
	(27)	(27)

*p<.05

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DISCUSSION

The purpose of this study is to examine the effects of psychosocial factors on the well-being of children with diabetes and their parents. Specifically, this study examines the role of family functioning, coping strategies, and illness-related stressors on the psychological well-being of parents. Additionally, it examines the role of family functioning and illness-related stressors on the physical and psychological well-being of children with diabetes. This study builds upon and extends previous research examining the effects of such factors on children with chronic health conditions and their parents.

Major Findings for Parents

It was hypothesized that low levels of family cohesion and expressiveness and high levels of family conflict would be related to increased psychological distress in parents. These hypotheses were partially supported. Maternal psychological well-being was related to these dimensions of family functioning such that they were significantly more likely to experience symptoms of depression and anxiety. These results provide support for previous studies which have also shown that low levels of family cohesion, expressiveness, support, control and high levels of family conflict were associated with maternal psychological distress and physical complaints (Blankfeld & Holahan, 1996; Timko et al., 1992; Thompson et al., 1992; Thompson et al., 1994; Wallander et al., 1989).

The psychological well-being of fathers, on the other hand, was not related to these dimensions as no significant relationships were found for either depression or anxiety. Additional analyses revealed that when the results examining the relationship between cohesion and conflict, respectively, and maternal psychological well-being were

compared with the results examining the relationships between cohesion and conflict, respectively, and paternal psychological well-being there were no significant differences.

On the other hand, further analyses comparing the relationships between expressiveness and maternal psychological well-being with the relationships between expressiveness and paternal psychological well-being indicated significant differences. These findings suggest that mothers and fathers differ in how sensitive they are to family expressiveness. To review, expressiveness refers to the extent to which the family is encouraged to express their thoughts, feelings, opinions, etc. According to research on gender differences, women are said to be emotionally-expressive (Eagly & Wood, 1991, Ptacek, Smith, & Zanas, 1992). It may be that mothers are in more need of having the opportunity to express themselves within the family than are fathers; that is, the psychological well-being of mothers may be more affected by their ability to share or communicate their thoughts and concerns or to express their emotions with other family members. For fathers, their psychological well-being may be dependent on factors other than family functioning including spousal and children's well-being (Chaney et al., 1997; Nagy & Ungerer, 1990), and, as found in this study, coping strategies, and illness-related concerns or demands.

The coping strategies employed by mothers and fathers were examined as well. It was hypothesized that parents who were less likely to use Approach coping strategies or more likely to use Avoidance coping strategies were more likely to experience psychological distress. Again, partial support was found for these hypotheses. Indeed, mothers were more likely to experience symptoms of depression and anxiety when they relied to a lesser extent on Approach coping strategies or to a greater extent on Avoidance

coping strategies. Although no significant results were found for Approach coping strategies and paternal psychological distress, results indicated that fathers who relied to a greater extent on Avoidance coping were more likely to experience anxiety. Overall, these findings provide partial support for the several studies which indicate that Approach-focused coping is related to healthful adjustment whereas Avoidance-focused coping is related to poor adjustment in parents of children with chronic health conditions (Blankfield & Holahan, 1996; Hauser et al., 1993; Holmbeck et al., 1997; Timko et al., 1992; Thompson et al., 1994).

Interestingly, additional analyses revealed that the relationships between Approach coping and maternal anxiety and Approach coping and paternal anxiety were significantly different. These results suggest that mothers could be more affected than fathers by the extent to which they use Approach coping strategies when managing diabetes-related stressors. As previously discussed, mothers are typically more involved with their children's care than are fathers. Optimal diabetes treatment requires a great deal of information seeking, problem-solving, and taking action on the parent's part. If mothers are not relying to a great extent on these strategies, they may, for example, be less prepared and feel overwhelmed by the responsibilities involved in their children's care. Relatedly, father's level of anxiety was significantly affected by reliance on Avoidance coping strategies when managing problems and emotions related to their child's diabetes. A father's reliance on Avoidance coping strategies in this context may potentiate anxiety because these strategies are counterproductive, potentially jeopardizing the child's health. It is conceivable, however, that fathers may experience symptoms of anxiety when using Avoidance coping strategies for diabetes-related stressors due to

reasons of socialization. According to research on gender differences in coping styles, men tend to use problem-focused coping strategies such as seeking out information, problem-solving, and taking action (Ptacek et al., 1992). Avoidance coping strategies do not incorporate such strategies, therefore, if fathers used them to a great extent it may be incongruent to how they typically manage stress and, thus, be even more ineffective at reducing their anxiety.

In regard to examining the impact of chronic health conditions on adjustment, the majority of previous research has either assumed that the mere presence of the chronic health condition is the stressor or employed measures of daily hassles or life events to reflect the stressor. The findings of these studies have been equivocal. This study attempted to improve on these studies by employing a measure that outlined illnessrelated concerns or demands faced by families in which there is a child with a chronic health condition. It was proposed that these specific stressors would affect parental psychological well-being. Support was found for this hypothesis. Both mothers and fathers were more likely to experience symptoms of depression and anxiety when their families were affected by illness-related concerns or demands. The results of these analyses are comparable to the results examining the effects of family functioning, particularly on maternal psychological well-being. Although similar results were not found for paternal psychological well-being, there is an indication that fathers are nevertheless affected by the strain that diabetes can have on them financially, personally, and socially, if not familially. Notably, these findings are comparable to studies that have incorporated similar types of measures (Quittner et al., 1992; Wysocki et al., 1989) and

provide support for the utility of measuring illness-related concerns or demands in studies examining familial adjustment.

The conclusions made regarding the psychological well-being of fathers are only speculative, however, and should be interpreted with caution. Notably, the measures used in this study may have failed to validly measure the psychological well-being fathers. First, research indicates that the prevalence of depression is lower than it is in women (Weissman, Bruce, Leaf, Holzer, 1991; as cited in Silverstein, 1999). Second, results of gender differences in social behavior suggest that men are emotionally controlled (Eagly & Wood, 1991). Therefore, it is conceivable that the fathers in the study may have not highly endorsed items that measure psychological well-being, subsequently affecting the results of this study.

Methodological considerations also need to be addressed when interpreting the results of fathers in this study. Indeed, the small sample size of fathers increases the likelihood of making a Type II error when interpreting the results of this study. In addition, the generalizability of the results of this study is limited by the fact that there may be unique characteristics innate to the fathers who chose to participate as opposed to fathers who chose not to participate. Future studies would need to be conducted with a larger sample size of fathers in order to determine the relationship between family functioning and paternal adjustment.

Major Findings for Children

It was proposed that low levels of family cohesion and expressiveness and high levels of family conflict would be related to behavioral and emotional problems in children with diabetes. These hypotheses were partly supported. Indeed low levels of

family cohesion and high levels of family conflict as reported by mothers were associated with psychological problems in children. Conversely, low levels of family expressiveness as reported by fathers were related to psychological problems in children. Of importance, however, is that although the results regarding mothers' report of family expressiveness and fathers' report of family cohesion and conflict did not reach levels of significance, they were in the predicted direction. Overall, the results support the conclusions from previous studies which indicate that family functioning does indeed relates to the psychological well-being of children with diabetes (e.g., Hanson et al. 1992; Hauser et al., 1985; Safyer et al., 1993).

Based on the findings of previous research on family functioning and metabolic control (e.g., Auslander et al., 1993; Hanson et al., 1989; Jacobson et al., 1994), it was expected that low family cohesion and expressiveness and high family conflict would be significantly related to poor metabolic control. Limited support was found in this study, however, for these hypotheses. Results indicated that only high levels of family conflict as reported by mothers were related to poor metabolic control. It was proposed that children living in family environments in which there is a lot of expressed anger and conflict among family members is particularly stressful. This stress can have both direct physiological effects and indirect effects (e.g., by affecting treatment adherence) on the child resulting in subsequent poor metabolic control. It appears that extent to which a family is conflicted may be more influential in the child's health rather than the extent to which a family is supportive, engaged, and expressive.

It was also hypothesized that children's psychological well-being and ability to maintain optimal metabolic control would be compromised by the personal, financial,

social, and familial strains that can occur in their families. Results indicated that similar to their parents, children are affected by the impact that the diabetes has on their families; that is, based on the reports of mothers and fathers, children were more likely to exhibit behavioral and emotional problems when their families were affected by illness-related concerns or demands. Support was not found, however, for the effects of illness-related concerns or demands on metabolic control. Nor was support found for the proposed relationship between children's psychological well-being and metabolic control.

The lack of significant findings in this study regarding metabolic control are surprising given the extensive research which indicates that aspects of family functioning and psychological well-being are in fact related to metabolic control. The results of this study may have been affected by the small sample size. Another methodological consideration is that the dimensions of family functioning examined in this study. Although support was found for family conflict, perhaps dimensions of family functioning other than those that reflect family relationships would be better predictors of metabolic control. These include the system maintenance dimensions, organization and control. Briefly, organization refers to how well planned or organized are the family's activities. Control refers to the extent to which rules are enforced in the family (Moos & Moos, 1994). Both of these dimensions would be critical in regard to maintaining treatment adherence (e.g., making sure blood glucose levels are tested, making sure that insulin is injected in a timely manner, making sure that the child is eating properly) and, therefore, subsequent metabolic control.

Another possibility regarding the insignificant findings for metabolic control may have been the measure of metabolic control used in this study; the HbA_{1c} value. This

value is an overall measure of how well maintained was the child's blood glucose over the past few months. What this measure does not capture, though, are the daily variations in blood glucose levels that can result from adherence or nonadherence to prescribed treatment regimen (e.g., blood glucose testing, timing of insulin injections, diet, and exercise) that could be sensitive to aspects of family functioning, illness-related concerns or demands, and psychological well-being.

Indeed, previous research has found that high levels of family conflict and low levels of family expressiveness were related to poor compliance to treatment regimens (e.g., Hauser et al., 1990; Wysocki, 1993). Similarly low family support, cohesion, expressiveness, and organization, have been found to be related to increased incidences of hypoglycemia and DKA, both of which result from poor adherence (e.g., Dumont et al., 1995; Liss et al., 1998). Relatedly, research on the adjustment of children has also found significant relationships between the psychological well-being of children with diabetes and hypoglycemia and diabetes-related hospitalizations (Lermark et al., 1996; Liss et al., 1998). Notably, patients with eating disorders such as bulimia or patients who omit insulin injections in order to lose weight are not only engaging in behaviors that make it difficult to adhere to treatment but are also putting themselves at risk for subsequent health complications (Johnson, 1995; LaGreca, Swales, Klemp, Madigan, & Skyler, 1995). In conclusion, this study may have benefited from measuring behaviors associated with treatment adherence in addition to using HbA_{1c} values. Support for this recommendation comes from the results of a study conducted by Peyrot and his colleagues who found that the relationship between psychosocial factors and HbA_{1c}

values was mediated by treatment adherence in adults with diabetes, suggesting that both manners of measuring physical well-being are informative (Peyrot et al., 1999).

Related to the idea of examining treatment adherence behaviors in future research, it is also recommended that future research use time series data in which daily or weekly logs of diabetes care behaviors, blood glucose levels, significant events occurring in the family, etc., are collected. Data such as these would allow for more discriminant analyses of the relationships among the variables examined in this study. In addition, longitudinal designs which include the collection of repeated measures of HbA_{1c} values and the other variables examined in this study would be useful in not only identifying what psychosocial variables influence metabolic control over time but also clarify the directions of these relationships over time.

Findings from Mediation Models

It was proposed that the relationships between illness-related concerns or demands and parental and child well-being would be mediated by the psychosocial variables of family cohesion, expressiveness, conflict as well as Approach and Avoidance coping strategies. No support was found for these proposed relationships. Instead, illnessrelated concerns or demands appeared to be a mediating variable in certain cases. Results indicated that illness-related concerns or demands mediated the relationship between family conflict and maternal depression as well as child psychological well-being. Apparently, the more conflicted was the family, the more likely it compounded the strain that the families were under as a result of the diabetes. These combined effects, in turn, increased the likelihood of depressive symptomatology in mothers as well as behavioral and emotional problems in children with diabetes. Illness-related concerns or demands

also served as a mediator for the relationship between family cohesion and maternal depression suggesting that, once again, the less helpful or supportive was the family, the more likely the family was to feel burdened by the diabetes, and subsequently result in increased levels of maternal depression.

Findings from Exploratory Analyses

This study attempted to determine the direction of the relationships between metabolic control and the psychosocial factors of family functioning and illness-related concerns or demands. Given the design of this study, however, the question of direction could not properly be addressed. However, results indicated that family cohesion, expressiveness, and conflict as well as illness-related concerns or demands did not account for any significant changes in metabolic control. The small sample size, though, raises the question of the validity of this interpretation.

Finally, this study examined the potential effects of children's age and illness duration. Although no significant relationships were found for illness duration, significant relationships were found for children's age. According to both mothers and fathers, families in which their child with diabetes was older were less likely to experience illness-related concerns or demands. Older children are typically at an age where they are independent and responsible for their medical care. These children are better able to take care of themselves and are less reliant on parents and family members for help. In addition, they are at an age where they begin to separate themselves from the family. As a result, as children grow older their families may be less impacted by their child's illness.

The results also suggested that family conflict was related to age. Based on the reports of fathers, families were more conflicted if their child with diabetes was young in age. Having a young child is difficult in and of itself but having a young child with diabetes can potentially compound the experience (child being unable to understand why it is important to eat certain foods or to limit physical activities, unable to identify or articulate the experience of physical symptoms of diabetes, being scared of needles and therefore refusing insulin injections, etc.). Again, for young children, parents are primarily responsible for the care of their children. This experience can be overwhelming and stressful. As a result, families may experience a great deal of conflict as they continually adjust to their child's diabetes. It should be noted that the previous findings regarding children's age were based on correlations. Further studies would be needed in order to support these findings and conclusions.

Methodological Limitations

There are many methodological limitations in the study that should be considered when interpreting the results. The current study was cross-sectional in nature and, as a result, it is difficult to determine directional effects. In order to better address this issue studies such as epidemiological or longitudinal studies which utilizing different designs may be better able to address some of the questions raised in this study (e.g., direction of relationship between family functioning and metabolic control or the effects of illness duration on adjustment). Another obvious limitation in this study was the relatively small sample size. This small sample size was particularly applicable in analyses conducted on fathers and children. This appeared to contribute to fewer significant results, therefore, it is difficult to make assured conclusions.

In addition, the results of this study are mostly based on self-report measures. Although an economical way of collecting data, it did not allow for parents to provide a more comprehensive description of ways in which their children's diabetes have affected them both on a personal and familial level as well as how they choose to manage the emotional and practical concomitants of their children's diabetes. Using open-ended questions or an interview format would be useful in providing such an opportunity. Similarly, a drawback to this study is that although children were considered in this study, they themselves did not actively participate. Rather, their parents provided their perspective on their children's psychological well-being.

Implications and Future Directions

Despite the methodological limitations, the results of this study have implications in understanding the family's adjustment to diabetes. First, this study provided an opportunity to examine the adjustment of parents of children with diabetes. Parents, and in particular fathers, of children with diabetes have received little empirical attention. For mothers, it appeared that their psychological well-being was strongly related to family functioning and coping strategies. Fathers, on the other hand, appeared to be differently affected by these psychosocial variables, with only their use of Avoidance-focused coping strategies having a significant negative effect on their psychological well-being. As indicated, fathers are typically not included in such research but it appears that their experiences with having a diabetic child may differ from mothers' experiences and deserves more attention in research.

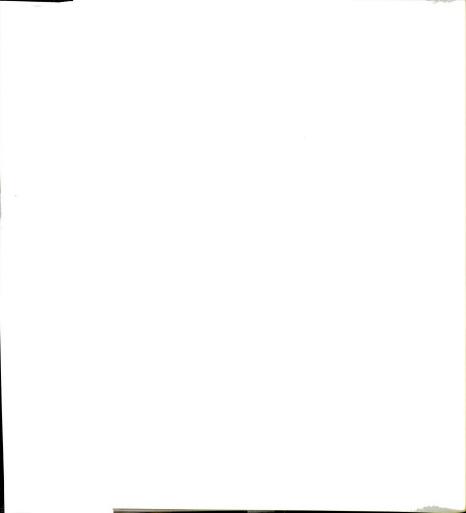
Second, this study provided the opportunity to examine the role of family functioning in the well-being of children. Although support was found for the

relationships between dimensions of family functioning and children's psychological well-being, no significant relationships were found for metabolic control. These particular results indicate that further research is needed in clarifying the role of family functioning in metabolic control as well as the identification of other possible variables that could influence metabolic control.

In addition, this study provided the opportunity to examine the effects illnessrelated concerns or demands on family well-being, an area which has received little empirical attention. Interestingly, the results of univariate correlations and regression analyses suggest that illness-related concerns or demands play a pertinent role in the adjustment of children with diabetes and their parents. Future research would benefit from utilizing measures which reflect either general illness-related burdens or specific illness-related burdens as they may serve as better predictors of familial adjustment than do the traditionally examined variables of family functioning and coping strategies.

Finally, this study attempted to provide a better understanding of the role of psychosocial factors in parental and children's well-being. Although some of the questions were answered and partial support was found for findings of previous studies, many questions need to be answered. An effective research program designed to understand these dynamics should be developed in order to do so. Further research is necessary for medical and mental health professionals so that they are better able to identify those children with diabetes and parents who are at risk and prepared to intervene appropriately and in a timely manner.

APPENDICES



APPENDIX A

MSU UCRIHS APPROVAL LETTER

MICHIGAN STATE

February 27, 1998

Thomas M. Reischl 36 Baker Hall TO:

RE · IRB#

98-100 THE ADAPTATIONAL PROCESS OF CHILREN WITH INSULIN-DEPENDENT DIABETES MELLITUS AND THEIR TITLE: PARENTS REVISION REQUESTED: N/A CATEGORY: 2-H, I APPROVAL DATE: 02/27/98

The University Committee on Research Involving Human Subjects' (UCRIES) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project and any revisions listed above

UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review. RENEWAL :

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.



OFFICE OF RESEARCH AND GRADUATE

-STUDIES

Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)432-1171.

University Committee on **Research Involving** Human Subjects

(UCRIHS) Michigan State University 246 Administration Building East Lansing, Michigan 48824-1046 517/355-2180 FAX: 517/432-1171

Sincerely, Ł, V David E. Wrig UCRIHS Chair Wright, Ph.D. DEW:bed

cc: Mison Ward

PROBLEMS/ CHANGES :

The Michigan State University IDEA is Institutional Diversity: Excellence in Action

MSU is an affirmative-action equal-opportunity institution

APPENDIX B

BRONSON METHODIST HOSPITAL/KCMS IRB APPROVAL LETTER

BMH1152 - The adaptational process of children with Insulin-dependent diabetes mellitus (IDDM) and their parents (Ward/Reischl)

At the May 5, 1998 Meeting of the Expedited Review Committee Meeting, BMH1152 was approved as submitted.

- 1. The Expedited Review Committee determined the continuing review interval for this study to be set at 12 months.
- 2. Before this protocol can be implemented i.e., prior to a drug being given or a procedure undertaken, all changes must be made and a corrected signed copy of the protocol and informed consent filed with the BMH Human Use Committee Chairman (or designee). The clinical investigator is required to receive approval from the BMH Human Use Committee prior to initiating any changes in approved research during the period for which BMH Human Use Committee approval has been given.

Robert H. Hume M. D.

Robert H. Hume, M.D., Chairman Bronson Methodist Hospital Human Use Committee 252 East Lovell Street Kalamazoo, MI 49007 (616) 341-7988

cc: Ward/Reischl

18 may 98

Date

APPENDIX C

CCRS IRB APPROVAL LETTER



January 4, 1999

Alison Ward, M.A. Doctoral Candidate Department of Psychology Michigan State University

This letter is a written confirmation of the approval for your research proposal "The Adaptational Process of Children with Insulin-Dependent Diabetes Mellitus and Their Parents," that was reviewed by our institutional review board (IRB), the Medical Executive Committee (MEC) on December 17, 1998. This approval was granted based on the supporting documents submitted and the information you presented to the MEC that includes informed consents, patient confidentiality and no monetary costs to the subjects or expectation of in kind services or financial support from the Children's Clinics.

Thank you for your research interests and enhancement of knowledge regarding children with special health care needs. If possible, we would like to have a copy of your aggregate results when your research is completed.

Cordially,

Vicky Lewis

Vicky Lewis Ph.D., RN Director of Research Children's Clinics 520-324-3027

Affiliated with Tucson Medical Center & University Medical Center Square & Compass Children's Clinic Building 2600 North Wyatt Drive • Tucson, Arizona 85712 (520) 324-KIDS (5437) 1-800-231-8261

APPENDIX D

SAMPLE LETTER SENT TO PARENTS

Dear Parents:

In cooperation with the Pediatric Diabetes Clinic, Alison Ward, M.A., of the Department of Psychology at Michigan State University, is conducting a study on the impact of insulin-dependent diabetes mellitus (IDDM) on children and parents. From this study, we hope to better understand how parents and children perceive and experience potentially stressful aspects of IDDM and how this may affect the child's glycohemoglobin (hemoglobin A1c) values. In order to understand these aspects, though, we need your help.

Participation would require you to complete a series of questionnaires designed to provide us with information regarding yourself, your family, and your child. In addition, participation in this study would also need for us to review your child's medical records to determine his/her previous glycohemoglobin (hemoglobin A1c) values.

In order to be able to participate in this study, your child must be between 4 and 17 years old, living at home with you, and must have been diagnosed with IDDM at least six months ago. Although we would like as many families as possible to participate in this study, it is not necessary for both the mother and father to agree to participate; that is, either the mother, father, or both parents can choose to participate.

If you are interested in participating, or at least would like to learn more about the study, please complete and mail the enclosed stamped, addressed postcard. You will then be contacted by Ms. Ward who will describe the study further and ask if you are interested in participating in the study. If you do agree to participate, questionnaire packets will then be mailed to you. The questionnaires will take approximately one hour to fill out and can be completed at your leisure in your home. Your participation in this study will also allow you the opportunity to be entered into a random drawing for a \$75.00 award.

Any information provided by you in the questionnaires as well as in your child's medical record will be kept **confidential** and **your decision to participate in this project will not affect your child's treatment at the Clinic in any way**. In addition, you may choose not to participate in the study at any time and you may refuse to answer any questions.

Thank you for taking the time to consider participating in this study. We hope that it will be an interesting and beneficial experience to all who participate.

APPENDIX E

STUDY DESCRIPTION GIVEN TO PARENTS OVER TELEPHONE

Hi ______, this is Alison Ward. I'm calling on behalf of the Michigan State University Pediatric Diabetes Clinic. We received your postcard stating that you are interested in learning more about and possibly participating in our study examining the impact of diabetes on children and parents.

Just to tell you a little bit about the study....Previous research has shown that how we perceive and respond to stress can affect our physical health and emotional wellbeing. Therefore, this study is designed to examine how you and your family perceives and experiences the potentially stressful aspects of diabetes as well as how this may affect your child's glycohemoglobin levels. If you choose to participate, you will be sent a packet of questionnaires. There are seven questionnaires in all. The questions cover a variety of topics including general information about yourself such as age, educational level, etc. There are questions about aspects of your life that have been affected by your child's diabetes, activities that your family does together or how your family solves problems, how you personally cope with the stressful and challenging aspects of your child's diabetes, and questions about the feelings and behaviors of you and your child. This packet will take approximately one hour to complete. You'll be provided with a stamped, self-addressed envelope to mail back the questionnaires when you're done. In addition, we would need to review your child's medical records to determine his/her previous glycohemoglobin levels.

Of course, I want to stress that your participation in this study is strictly voluntary so you are able to choose not to participate at any time or to not answer specific questions. In addition, any information that you provide will be kept confidential and none of the information you provide will be included with your child's medical records. Finally, if you do participate, you will be entered in a random drawing for \$75.00 as a way of thanking you for your participation in this study. I also wanted to let you know that once the study is finished, we'd be happy to share with you a report of the information that we've gathered. Do you have any questions of me? Any concerns?

Does this sound like something that you would be interested in doing? (YES/NO) (If YES) Great! I'll be sending out the packet of questionnaires within the next week. I'll include my telephone number so that if you have any questions you can contact me. May I have your address?

I noticed that your wife/husband is also interested in this study. Shall I speak to her/him (call back?) or do you think that this is something that he/she would be interested in participating and that I should go ahead and include a packet of questionnaires for him/her?

Thank you so much _____!

APPENDIX F

COVER LETTER SENT WITH QUESTIONNAIRES TO PARENTS

Dear

We appreciate your willingness to participate in our study examining how parents and children perceive and experience potentially stressful aspects of IDDM and how this may affect you and how this may affect your child's glycohemoglobin (hemoglobin A1c) values.

Attached you will find a consent form and a packet of questionnaires. Please read and sign the consent form if you agree to participate in this study. Then, please put it in the enclosed white envelope labeled "Informed Consent." As discussed with you on the phone, the questionnaires are designed to provide us with information regarding yourself, your family, and your child. All instructions are included and are fairly self-explanatory. However, if you should have any questions on how to complete the forms or about the study, please do not hesitate to contact me, Alison Ward, M.A., at (XXX) XXX-XXXX. Leave a message and I will get back to you as soon as possible.

It is <u>very important</u> that <u>you</u> complete these questions <u>on your own</u>. If you would like to discuss your answers with others, please do so only after you have completed them.

We have also provided you with a self-addressed, stamped envelope for returning the consent form and questionnaires to us. We appreciate your investment of time and effort and hope that this will be an interesting and beneficial experience to you.

APPENDIX G

CONSENT FORM FOR PARENTS FROM MSU

Informed Consent

Purpose

The purpose of this study is to understand how parents and childern perceive and experience potentially stressful aspects of insulin-dependent diabetes mellitus and how this may affect the child's glycohemoglobin (hemoglobin A1c) levels. In order to participate in this study you will be required to fill out a series of questionnaires which will take approximately one hour to complete. In addition to the questionnaires, information regarding your child's glycohemoglobin (hemoglobin A1c) levels will be obtained from the Clinical Center's medical records.

Confidentiality

All information obtained from this consent form, the questionnaires, and your child's medical records will be treated with strict confidentiality. Your answers will not be made a part of your child's medical records nor shared with any medical staff. In addition, any information that you provide or that is taken from your child's medical report will remain anonymous in any report of the research findings; any information that is reported is not based on individual responses but rather a summary of responses of all participants. A copy of the findings will be sent to participants who request such material.

Voluntary Participation

By signing this consent form, you are stating that you understand all that has been explained to you and that your participation in this study is volunatry. At anytime during this study, you have the right to discontinue your participation without being penalized.

Your decision to participate in this study will not affect in anyway the quality or type of medical attention that your child receives at the Clinical Center.

Random Drawing

Upon the return of this consent form, your name will be entered into a random drawing for a \$75.00 award. If you choose not to answer any or all parts of the questionnaires of this study, you are still eligible to participate in this random drawing.

If you should have any questions regarding this study, you may telephone Alison Ward, M.A. at (XXX) XXX-XXXX or Thomas Reischl, Ph.D. at (XXX) XXX-XXXX. If you have any questions regarding your rights as a research participant, please contact David E. Wright, Ph.D. at (517) 355-2180 or at UCRIHS - Michigan State University, 225 Administration Building, East Lansing, MI 48824.

Thank you very much for your participation!

Mother (if applicable):

Father (if applicable):

(please print your name here)	(please print your name here)
(please sign your name here)	(please sign your name here)
date	date
(please print child's name here)	_

APPENDIX H

CONSENT FORM FOR PARENTS FROM KCMS

Family Acknowledgement

"I have been given an opportunity to ask questions regarding this research study, and these questions have been answer to my satisfaction. I understand that if I have any additional questions, I can contact Alison Ward, M.A. at (XXX) XXX-XXXX or Thomas Reischl, Ph.D. at (XXX) XXX-XXXX."

"In giving my consent, I understand that I/my child's participation in this research project is voluntary, and that I may withdraw myself/him/her at any time without affecting my/my child's future medical care. I also understand that the investigator in charge of this study, with my/my child's welfare as a basis, may decide at any time that I/he/she should no loger participate in this study."

"I hereby authorize Alison Ward, M.A. and Thomas Reischl, Ph.D. to release the information obtained in this study to the medical science literature. I understand that I/my child will not be identified by name. Additionally, I understand that the Food and Drug Administration (FDA) may inspect Bronson Methodist Hospital's research files and may wish to interview me regarding my/my child's participation in this study."

"In the event of physical injury or illness resulting from the research procedures, Bronson Methodist Hospital and/or Alison Ward, M.A. and Thomas Reischl, Ph.D. will provide or arrange to provide for all necessary medical care to help me/my child recover, but they do not commit themselves to pay for such care, or to provide any additional compensation. I also understand that neither Bronson Method Hospital nor Alison Ward, M.A. and Thomas Reischl, Ph.D., agree to bear the expense or medical care for any new illness or complications which may develop during my/my child's participation in this study, but are not a result of the research procedures. If I have further questions or concerns regarding my/my child's participation in this study, I may direct them to Alison Ward, M.A. at (XXX) XXX-XXXX or Thomas Reischl, Ph.D. at (XXX) XXX-XXXX. If I have questions about research subjects' rights, I may direct them to Robert H. Hume, M.D., Chairman, Bronson Methodist Hospital Institutional Review Board at (616) 341-7988."

"I acknowledge that I have read and understand the above information, and that I agree to allow myself/my child to participate in this study. I have received a copy of this document for my own records."

Signature of Patient

Date

If minor is older than five (5) years of age, was assent obtained?	Yes	No
--	-----	----

Signature of Legal Guardian/Parent	Date
Signature of Legal Guardian/Parent	Date
If both parents/guardians do not provide info this study, please explain why:	rmed consent for their child to participate in

"I have witnessed that the information in this Patient Consent Form was adequately explain to the patient."

Signature of Witness

Date

Informed Consent

Purpose

The purpose of this study is to understand how parents and childern perceive and experience potentially stressful aspects of insulin-dependent diabetes mellitus and how this may affect the child's glycohemoglobin (hemoglobin A1c) levels. In order to participate in this study you will be required to fill out a series of questionnaires which will take approximately one hour to complete. In addition to the questionnaires, information regarding only your child's glycohemoglobin (hemoglobin A1c) levels will be obtained from the Kalamazoo Clinic's medical records.

Confidentiality

All information obtained from this consent form, the questionnaires, and your child's medical records will be treated with strict confidentiality. Your answers will not be made a part of your child's medical records nor shared with any medical staff. In addition, any information that you provide or that is taken from your child's medical records will remain anonymous in any report of the research findings; any information that is reported is not based on individual responses but rather a summary of responses of all participants. A copy of the findings will be sent to participants who request such material.

Voluntary Participation

By signing this consent form, you are stating that you understand all that has been explained to you and that your participation in this study is volunatry. At anytime during this study, you have the right to discontinue your participation without being penalized.

Your decision to participate in this study will not affect in anyway the quality or type of medical attention that your child receives at the Clinical Center.

Risks and Benefits

By signing this consent form, you are stating that you understand that this study should expose you and your child to minimal risk; that you are being asked to respond to questions examining your perceptions, experiences, and the emotional well-being of both you and your child. Additionally, the physical well-being of your child, as measured by glycohemoglobin (hemoglobin A1c) levels, will be collected from already existing data in your child's medical records.

The results of this study will further elucidate the unique factors which influence how parents and children with IDDM adapt to the potentially stressful aspects of this condition. This understand will allow medical and mental health professionals to better serve you and your child.

Random Drawing

Upon the return of this consent form, your name will be entered into a random drawing for a \$75.00 award. While you are free not to participate in this study, you will only be eligible to participate in this random drawing if you complete the questionnaires. The award recipient will be contacted by ______ to be notified of his/her status.

If you should have any questions regarding this study, you may telephone Alison Ward, M.A. at (XXX) XXX-XXXX or Thomas Reischl, Ph.D. at (XXX) XXX-XXXX or write to either of us at the Department of Psychology, Psychology Research Building, Michigan State University, East Lansing, MI 48823. If you have any questions regarding your rights as a research participant, please contact Robert H. Hume, M.D., Chairman, Bronson Methodist Hospital Institutional Review Board at (616) 341-7988."

Thank you very much for your participation!

(please print your name here)

(please print child's name here)

(please sign your name here)

date

APPENDIX I

CONSENT FORM FOR PARENTS FROM CCRS

Informed Consent

Purpose

The purpose of this study is to understand how parents and children perceive and experience potentially stressful aspects of insulin-dependent diabetes mellitus and how this may affect the child's glycohemoglobin (hemoglobin A1c) levels. In order to participate in this study you will be required to fill out a series of questionnaires which will take approximately one hour to complete. In addition to the questionnaires, information regarding your child's glycohemoglobin (hemoglobin A1c) levels will be obtained from the medical records at Dr. Wheeler's office.

Confidentiality

All information obtained from this consent form, the questionnaires, and your child's medical records will be treated with strict confidentiality. Your answers will not be made a part of your child's medical records nor shared with any medical staff. In addition, any information that you provide or that is taken from your child's medical report will remain anonymous in any report of the research findings; any information that is reported is not based on individual responses but rather a summary of responses of all participants. A copy of the findings will be sent to participants who request such material.

Voluntary Participation

By signing this consent form, you are stating that you understand all that has been explained to you and that your participation in this study is voluntary. At anytime during this study, you have the right to discontinue your participation without being penalized.

Your decision to participate in this study will not affect in anyway the quality or type of medical attention that your child receives at the Children's Center for Rehabilitative Services.

Random Drawing

Upon the return of this consent form, your name will be entered into a random drawing for a \$75.00 award. If you choose not to answer any or all parts of the questionnaires of this study, you are still eligible to participate in this random drawing.

If you should have any questions regarding this study, you may telephone Alison Ward, M.A. at (XXX) XXX-XXXX or Thomas Reischl, Ph.D. at (XXX) XXX-XXXX. If you have any questions regarding your rights as a research participant, please contact Vicky Lewis, Ph.D., R.N. Director of Research at Children's Clinics at (520) 324-3027.

Thank you very much for your participation!

Mother (if applicable):	Father (if applicable):
(please print your name here)	(please print your name here)
(please sign your name here)	(please sign your name here)
date	date
(please print child's name here)	_

APPENDIX J

DEMOGRAPHIC QUESTIONNAIRE

Please answer the following questions:

- 1. Your Age:
- 2. Sex:

4.

- Male 1.
- 2. Female
- 3. Relationship to the child:
 - Mother 1.
 - 2. Father
 - 3. Step-mother
 - 4. Step-father
 - 5. Other (specify)
 - What is your race or ethnic background:
 - 1. Caucasian/White
 - 2. African American/Black
 - 3. Hispanic/Latino or Latina
 - 4. Asian American
 - 5. Native American
 - Other (specify) 6.
- What is your current education level: 5.
 - less than high school 1.
 - 2. some high school
 - 3. high school grad/GED
 - some college or 2 year degree 4.
 - 5. bachelor's degree
 - 6. post-bachelor's degree
- What is your gross (before taxes) annual family income: 6.
 - less than \$10,000 \$50,001 to \$60,000 1. 6. 2.
 - \$10,000 to \$20,000 7. \$60,001 to \$70,000
 - 3. \$20,001 to \$30,000 8. \$70,001 to \$80,000
 - \$30,001 to \$40,000 \$80,001 to \$90,000 4. 9.
 - \$40,001 to \$50,000 above \$90,000 5. 10.
- 7. How long ago was your child diagnosed with diabetes:
- What is your child's age: 8.
- 9. What is the sex of your child:
 - 1. Male
 - 2. Female

APPENDIX K

FAMILY ENVIRONMENT SCALE

Below are 90 statements. They are statements about families. You are to decide which of these statements are true of your family and which are false. If you think the statement is *True* or mostly *True* of your family, circle the T for True. If you think the statement is *False* or mostly *False* of your family, circle the F for False.

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

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

1 Family members really help and support one another	т	F
	_	
2. Family members often keep their feelings to themselves.	Τ	F
3. We fight a lot in our family.	Τ	F
4. We don't do things on our own very often in our family.	Τ	F
5. We feel it is important to be the best at whatever you do.	Т	F
6. We often talk about political and social problems.	Т	F
7. We spend most weekends and evenings at home.	Т	F
8. Family members attend church, synagogue, or Sunday School fairly often.	Τ	F
9. Activities in our family are pretty carefully planned.	Т	F
10. Family members are rarely ordered around.	Т	F
11. We often seem to be killing time at home.	Т	F
12. We say anything we want to around home.	Т	F
13. Family members rarely become openly angry.	Т	F
14. In our family, we are strongly encouraged to be independent.	Т	F
15. Getting ahead in life is very important in our family.	Т	F
16. We rarely go to lectures, plays or concerts.	Т	F
17. Friends often come over for dinner or to visit.	Τ	F
	 We fight a lot in our family. We don't do things on our own very often in our family. We feel it is important to be the best at whatever you do. We often talk about political and social problems. We spend most weekends and evenings at home. Family members attend church, synagogue, or Sunday School fairly often. Activities in our family are pretty carefully planned. Family members are rarely ordered around. We often seem to be killing time at home. We say anything we want to around home. Family members rarely become openly angry. In our family, we are strongly encouraged to be independent. Getting ahead in life is very important in our family. We rarely go to lectures, plays or concerts. 	 2. Family members often keep their feelings to themselves. T 3. We fight a lot in our family. 4. We don't do things on our own very often in our family. 5. We feel it is important to be the best at whatever you do. 6. We often talk about political and social problems. 7. We spend most weekends and evenings at home. 8. Family members attend church, synagogue, or Sunday School fairly often. 9. Activities in our family are pretty carefully planned. T 10. Family members are rarely ordered around. T 11. We often seem to be killing time at home. T 12. We say anything we want to around home. T 13. Family members rarely become openly angry. T 14. In our family, we are strongly encouraged to be independent. T 15. Getting ahead in life is very important in our family. T 16. We rarely go to lectures, plays or concerts.

18. We don't say prayers in our family.	Т	F
19. We are generally very neat and orderly.	Т	F
20. There are very few rules to follow in our family.	Τ	F
21. We put a lot of energy into what we do at home.	Τ	F
22. It's hard to "blow off steam" at home without upsetting somebody.	Т	F
23. Family members sometimes get so angry they throw things.	Τ	F
24. We think things out for ourselves in our family.	Τ	F
25. How much money a person makes is not very important to us.	Т	F
26. Learning about new and different things is very important in our family.	Τ	F
27. Nobody in our family is active in sports, Little League, bowling, etc.	Τ	F
28. We often talk about the religious meaning of Christmas, Passover, or other holidays.	Τ	F
29. It's often hard to find things when you need them in our household.	Τ	F
30. There is one family member who makes most of the decisions.	Τ	F
31. There is a feeling of togetherness in our family.	Т	F
32. We tell each other about our personal problems.	Τ	F
33. Family members hardly ever lose their tempers.	Τ	F
34. We come and go as we want to in our family.	Т	F
35. We believe in competition and "may the best man win."	Т	F
36. We are not that interested in cultural activities.	Т	F
37. We often go to movies, sports events, camping, etc.	Т	F
38. We don't believe in heaven or hell.	Т	F
39. Being on time is very important in our family.	Т	F
40. There are set ways of doing things at home.	Т	F
41. We rarely volunteer when something has to be done at home.	Т	F
42. If we feel like doing something on the spur of the moment we often just pick up and go.	Т	F
43. Family members often criticize each other.	Т	F
44. There is very little privacy in our family.	Т	F
45. We always strive to do things just a little better the next time.	Т	F
46. We rarely have intellectual discussions.	Т	F

47. Everyone in our family has a hobby or two.	Т	F
48. Family members have strict ideas about what is right and wrong.	Т	F
49. People change their minds often in our family.	Т	F
50. There is strong emphasis on following rules in our family.	Τ	F
51. Family members really back each other up.	Т	F
52. Someone usually gets upset if you complain in our family.	Τ	F
53. Family members sometimes hit each other.	Т	F
54. Family members almost always rely on themselves when a problem comes up.	Т	F
55. Family members rarely worry about job promotions, school grades, etc.	Τ	F
56. Someone in our family plays a musical instrument.	Τ	F
57. Family members are not very involved in recreational activities outside work or school.	Т	F
58. We believe there are some things you just have to take on faith.	Т	F
59. Family members make sure their rooms are neat.	Т	F
60. Everyone has an equal say in family decisions.	Ţ	F
61. There is little group spirit in our family.	Т	F
62. Money and paying bills is openly talked about in our family.	Т	F
63. If there's a disagreement in our family, we try hard to smooth things over and keep the peace.	Τ	F
64. Family members strongly encourage each other to stand up for their rights.	Τ	F
65. In our family, we don't try that hard to succeed.	Т	F
66. Family members often go to the library.	Т	F
67. Family members sometimes attend courses or take lessons for some hobby or interest (outside of school).	Τ	F
68. In our family each person has different ideas about what is right and wrong.	Τ	F
69. Each person's duties are clearly defined in our family.	Т	F
70. We can do whatever we want to in our family.	Т	F
71. We really get along well with each other.	Т	F
72. We are usually careful about what we say to each other.	Т	F

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

APPENDIX L

COPE - MODIFIED

Having a child with insulin-dependent diabetes mellitus can be a challenging and stressful experience. We are interested in learning how you usually cope with you child's illness. There may be different ways in which you respond to these stressful experiences as well as to your feelings associated with these experiences, however, think about what you *usually* do to deal with them.

Then respond to each of the following items. Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully and make your answers as true FOR YOU as you can. Please answer every item. There are no "right" or "wrong" answers, so choose the most accurate answer for you -- not what you think "most people" would say or do. Indicate what YOU usually do to cope with your child's illness.

	I usually don't do it all	I usually do it a little bit	I usually do it sometimes	I usually do it a lot
1. I turn to work or other substitute activities to take my mind off of things.	1	2	3	4
2. I get upset and let my emotions out.	1	2	3	4
3. I try to get advice from someone about what to do.	1	2	3	4
4. I concentrate my efforts on doing something about it.	1	2	3	4
5. I say to myself, "this isn't real."	1	2	3	4
6. I admit to myself that I can't deal with it, and quit trying.	1	2	3	4
7. I discuss my feelings with someone.	1	2	3	4
8. I talk with someone to find out more about the situation.	1	2	3	4
9. I daydream about things other than this.	1	2	3	4
10. I make a plan of action.	1	2	3	4

	I usually don't do it all	I usually do it a little bit	I usually do it sometimes	I usually do it a lot
11. I try to get emotional support from friends and relatives.	1	2	3	4
12. I just give up trying to reach my goal.	1	2	3	4
13. I take additional action to try to get rid of the problem.	1	2	3	4
14. I refuse to believe that it has happened.	1	2	3	4
15. I let my feelings out.	1	2	3	4
16. I talk to someone who could do something concrete about the problem.	1	2	3	4
17. I sleep more than usual.	1	2	3	4
18. I try to come up with a strategy about what to do.	1	2	3	4
19. I get sympathy and understanding from someone.	1	2	3	4
20. I give up the attempt to get what I want.	1	2	3	4
21. I think about how I might best handle the problem.	1	2	3	4
22. I pretend that it hasn't really happened.	1	2	3	4
23. I go to movies or watch TV, to think about it less.	1	2	3	4
24. I ask people who have had similar experiences what they did.	1	2	3	4
25. I take direct action to get around the problem.	1	2	3	4
26. I reduce the amount of effort I'm putting into solving the problem.	1	2	3	4
27. I talk to someone about how I feel.	1	2	3	4
28. I think hard about what steps to take.	1	2	3	4

	I usually don't do it all	I usually do it a little bit	I usually do it sometimes	I usually do it a lot
29. I act as though it hasn't even happened.	1	2	3	4
30. I do what has to be done, one step at a time.	1	2	3	4

APPENDIX M

IMPACT ON THE FAMILY SCALE

Below are some statements that people have made about living with an ill child. Please read each statement and circle the response which indicates whether at the present time you would strongly agree, agree, disagree, or strongly disagree with the statement.

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. The illness is causing financial problems for the family.	1	2	3	4
2. Time is lost from work because of hospital appointments.	1	2	3	4
3. I am cutting down the hours I work to care for my child.	1	2	3	4
4. Additional income is needed in order to cover medical expenses.	1	2	3	4
5. Because of the illness, we are not able to travel out of the city.	1	2	3	4
6. People in the neighborhood treat us specially because of my child's illness.	1	2	3	4
7. We have little desire to go out because of my child's illness.	1	2	3	4
8. It is hard to find a reliable person to take care of my child.	1	2	3	4
9. Sometimes we have to change plans about going out because of my child's illness.	1	2	3	4
10. We see family and friends less because of the illness.	1	2	3	4
11. Because of what we have shared we are a closer family.	1	2	3	4
12. Sometimes I wonder whether my child should be treated "specially" or the same as a normal child.	1	2	3	4

	Strongly Agree	Agree	Disagree	Strongly Disagree
13. My relatives have been understanding and helpful with my child.	1	2	3	4
14. I think about not having more children because of the illness.	1	2	3	4
15. My partner and I discuss my child's problem together.	1	2	3	4
16. We try to treat my child as if he/she were a normal child.	1	2	3	4
17. I don't have much time left over for other family members after caring for my child.	1	2	3	4
18. Our family gives up things because of my child's illness.	1	2	3	4
19. Fatigue is a problem for me because of my child's illness.	1	2	3	4
20. I live from day to day and don't plan for the future.	1	2	3	4
21. Nobody understands the burden I carry.	1	2	3	4
22. Traveling to the hospital is a strain on me.	1	2	3	4
23. Learning to manage my child's illness has made me feel better about myself.	1	2	3	4
24. Sometimes I feel like we live on a roller coaster; in crisis when my child is acutely ill, OK when things are stable.	1	2	3	4

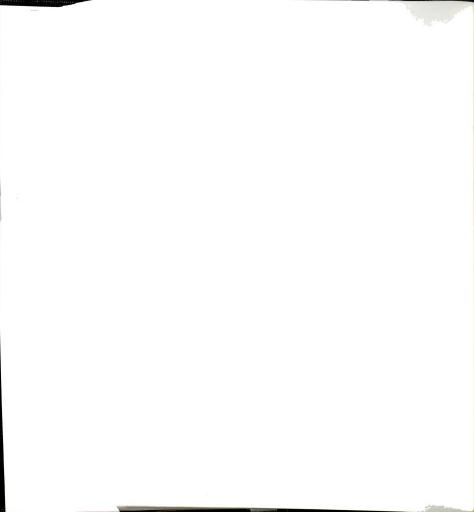
APPENDIX N

CENTER FOR EPIDEMIOLOGIC STUDIES – DEPRESSION SCALE

Circle the number for each statement which best describes how often you felt or behaved this way — **DURING THE PAST WEEK.**

		Rarely or None of the Time	Some or a Little of the Time	Occasionally or a Moderate	Most or All of the Time
		(Less than 1 Day)	(1-2 Days)	Amount of Time (3-4 Days)	(5-7 Days)
DU	RING THE PAST WEEK:				
1.	I was bothered by things that usually don't bother me.	0	1	2	3
2.	I did not feel like eating; my appetite was poor.	0	1	2	3
3.	I felt that I could not shake off the blues even with help from my family and friends.	0	1	2	. 3
4.	I felt I was just as good as other people.	0	1	2	3
5.	I had trouble keeping my mind on what I was doing.	0	1	2	3
6.	I felt depressed.	0	1	2	3
7.	I felt that everything I did was an effort.	0	1	2	3
8.	I felt hopeful about the future.	0	1	2	3
9.	I thought my life had been a failure.	0	1	2	3
10.	I felt fearful.	0	1	2	3
11.	My sleep was restless.	0	1	2	3
12.	I was happy.	0	1	2	3

		Rarely or None of the Time (Less than 1 Day)	Some or a Little of the Time (1-2 Days)	Occasionally or a Moderate Amount of Time (3-4 Days)	Most or All of the Time (5-7 Days)
13.	I talked less than usual.	0	1	2	3
14.	I felt lonely.	0	1	2	3
15.	People were unfriendly.	0	1	2	3
16.	I enjoyed life.	0	1	2	3
17.	I had crying spells.	0	1	2	3
18.	I felt sad.	0	1	2	3
19.	I felt that people disliked me.	0	1	2	3
20.	I could not get "going".	0	1	2	3

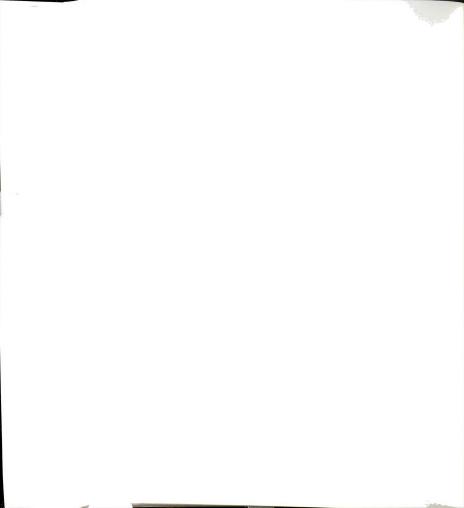


APPENDIX O

STATE TRAIT ANXIETY INVENTORY – TRAIT ANXIETY

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the answer to the right of the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

	Almost Never	Sometimes	Often	Almost Always
1. I feel pleasant.	1	2	3	4
2. I feel nervous and restless.	1	2	3	4
3. I feel satisfied with myself.	1	2	3	4
4. I wish I could be as happy as others seem to be.	1	2	3	4
5. I feel like a failure.	1	2	3	4
6. I feel rested.	1	2	3	4
7. I am "calm, cool, and collected".	1	2	3	4
8. I feel that difficulties are piling up so that I cannot overcome them.	1	2	3	4
9. I worry too much over something that really doesn't matter.	1	2	3	4
10. I am happy.	1	2	3	4
11. I have disturbing thoughts.	1	2	3	4
12. I lack self-confidence.	1	2	3	4
13. I feel secure.	1	2	3	4
14. I make decisions easily.	1	2	3	4
15. I feel inadequate.	1	2	3	4
16. I am content.	1	2	3	4
17. Some unimportant thought runs through my mind and bothers me.	1	2	3	4
18. I take disappointments so keenly that I can't put them out of my mind.	1	2	3	4



	Almost Never	Sometimes	Often	Almost Always
19. I am a steady person.	1	2	3	4
20. I get in a state of tension or turmoil as I think over my recent concerns and interests.	1	2	3	4

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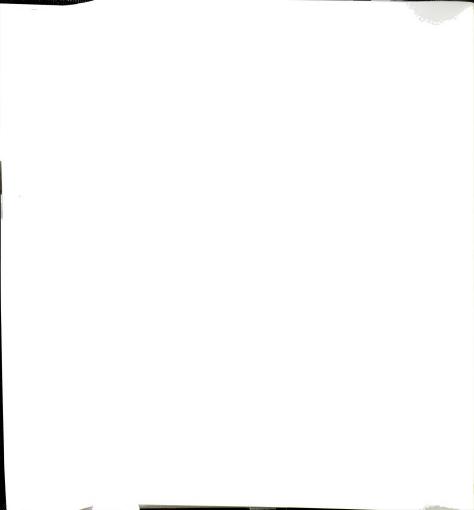


APPENDIX P

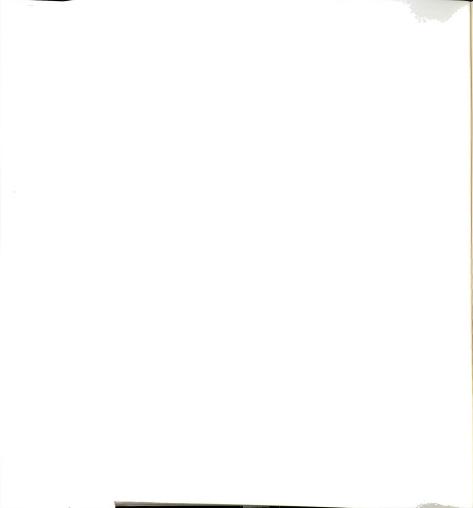
CHILD BEHAVIOR CHECKLIST

Below is a list of items that describe children and youth. For each item that describes your child **now or within the past six months**, please circle the 2 if the item is **very true** or **often true** of your child. Circle the 1 if the item is **somewhat** or **sometimes true** of your child. If the item is **not true** of your child, circle the 0. Please answer all items as well as you can, even if some do not seem to apply to your child.

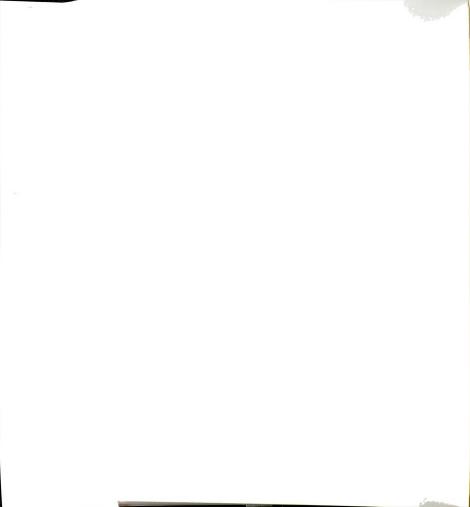
		Not True (as far as you know)	Somewhat or Sometimes True	Very True or Often True
1.	Acts too young for his/her age	0	1	2
2.	Allergy (describe):	0	1	2
3.	Argues a lot	0	1	2
4.	Asthma	0	1	2
5.	Behaves like the opposite sex	0	1	2
6.	Bowel movements outside toilet	0	1	2
7.	Bragging, boasting	0	1	2
8. atter	Can't concentrate, can't pay ntion for long	0	1	2
9. thou	Can't get his/her mind off certain ghts; obsessions (describe):	0	1	2
10. hype	Can't sit still, restless, or eractive	0	1	2
11.	Clings to adults or too dependent	0	1	2
12.	Complains of loneliness	0	1	2
13.	Confused or seems to be in a fog	0	1	2
14.	Cries a lot	0	1	2
15.	Cruel to animals	0	1	2
16. othe	Cruelty, bullying, or meanness to rs	0	1	2
17. thou	Day-dreams or gets lost in his/her ghts	0	1	2



	Not True (as far as you know)	Somewhat or Sometimes True	Very True or Often True
18. Deliberately harms self or attempts suicide	0	1	2
19. Demands a lot of attention	0	1	2
20. Destroys his/her own things.	0	1	2
21. Destroys things belonging to his/her family	0	1	2
22. Disobedient at home	0	1	2
23. Disobedient at school	0	1	2
24. Doesn't eat well	0	1	2
25. Doesn't get along with other kids	0	1	2
26. Doesn't seem guilty after misbehaving	0	1	2
27. Easily jealous	0	1	2
28. Eats or drinks things that are not food - don't include sweets (describe):	0	1	2
29. Fears certain animals, situations, or places other than school (describe):	0	1	2
30. Fears going to school	0	1	2
31. Fears he/she might think or do something bad	0	1	2
32. Feels he/she has to be perfect	0	1	2
33. Feels or complains that no one loves him/her	0	1	2
34. Feels others are out to get him/her	0	1	2
35. Feels worthless or inferior	0	1	2
36. Gets hurt a lot, accident-prone	0	1	2
37. Gets in many fights	0	1	2
38. Gets teased a lot	0	1	2
39. Hangs around with others who get in trouble	0	1	2



		Almost Never	Sometimes	Often
40. ther	Hears sounds or voices that aren't e (describe):	0	1	2
41.	Impulsive or acts without thinking	0	1	2
42. othe	Would rather be alone than with ers	0	1	2
43.	Lying or cheating	0	1	2
44.	Bites fingernails	0	1	2
45.	Nervous, highstrung, or tense	0	1	2
46. (des	Nervous movements or twitching cribe):	0	1	2
47.	Nightmares	0	1	2
48.	Not liked by other kids	0	1	2
49.	Constipated, doesn't move bowels	0	1	2
50.	Too fearful or anxious	0	1	2
51.	Feels dizzy	0	1	2
52.	Feels too guilty	0	1	2
53.	Overeating	0	1	2
54.	Overtired	0	1	2
55.	Overweight	0	1	2
56. med	Physical problems without known ical cause:			
	Aches or pains (<i>not</i> headaches)	0	1	2
	. Headaches . Nausea, feels sick	0 0	1 1	2 2
	. Problems with eyes (describe):	0	1	2
P	Rashes or other skin problems	0	1	2
	Stomachaches or cramps	ů 0	1	2
	. Vomiting, throwing up	0	1	2
h	. Other (describe):	0	1	2
57.	Physically attacks people	0	1	2
58. body	Picks nose, skin, or other parts of (describe):	0	1	2



		Almost Never	Sometimes	Often
59.	Plays with own sex parts in public	0	1	2
60.	Plays with own sex parts too much	0	1	2
61.	Poor school work	0	1	2
62.	Poorly coordinated or clumsy	0	1	2
63.	Prefers being with older kids	0	1	2
64.	Prefers being with younger kids	0	1	2
65.	Refuses to talk	0	1	2
66. com	Repeats certain acts over and over; pulsions (describe):	0	1	2
67.	Runs away from home	0	1	2
68.	Screams a lot	0	1	2
69.	Secretive, keeps things to self	0	1	2
70. (des	Seen things that aren't there acribe):	0	1	2
71. emb	Self-conscious or easily parrassed	0	1	. 2
72.	Sets fires	0	1	2
73.	Sexual problems (describe):	0	1	2
74.	Showing off or clowning around	0	1	2
75.	Shy or timid	0	1	2
76.	Sleeps less than most kids	0	1	2
77. day	Sleeps more than most kids during and/or night (describe):	0	1	2
	Smears or plays with bowel rements	0	1	2
79.	Speech problems (describe):	0	1	2
80.	Stares blankly	0	1	2
81.	Steals at home	0	1	2
82.	Steals outside the home	0	1	2



	Not True (as far as you know)	Somewhat or Sometimes True	Very True or Often True
83. Stores up things he/she doesn't need (describe):	0	1	2
84. Strange behavior (describe):	0	1	2
85. Strange ideas (describe):	0	1	2
86. Stubborn, sullen, or irritable	0	1	2
87. Sudden changes in mood or feelings	0	1	2
88. Sulks a lot	0	1	2
89. Suspicious	0	1	2
90. Swearing or obscene language	0	1	2
91. Talks about killing self	0	1	2
92. Talks or walks in sleep (describe):	0	1	2
93. Talks too much	0	1	2
94. Teases a lot	0	1	2
95. Temper tantrums or hot temper	0	1	2
96. Thinks about sex too much	0	1	2
97. Threatens people	0	1	2
98. Thumb-sucking	0	1	2
99. Too concerned with neatness or cleanliness	0	1	2
100. Trouble sleeping (describe):	0	1	2
101. Truancy, skips school	0	1	2
102. Underactive, slow moving, or lacks energy	0	1	2
103. Unhappy, sad, or depressed	0	1	2
104. Unusually loud	0	1	2
105. Uses alcohol or drugs for nonmedical purposes (describe):	0	1	2

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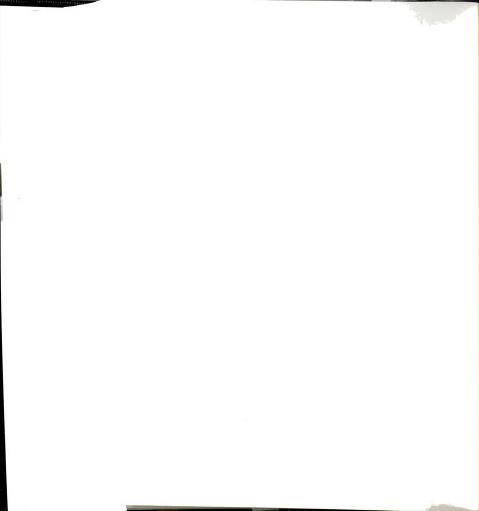
	Not True (as far as you know)	Somewhat or Sometimes True	Very True or Often True
106. Vandalism	0	1	2
107. Wets self during the day	0	1	2
108. Wets the bed	0	1	2
109. Whining	0	1	2
110. Wishes to be the opposite sex	0	1	2
111. Withdrawn, doesn't get involved with others	0	1	2
112. Worries	0	1	2
113. Please write in any problems your child has that were not listed above:a.	0	1	2
b.	0	1	2
с.	0	1	2

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