

ILLNESS UNCERTAINTY AND ATTRIBUTIONAL
STYLE AS PREDICTORS OF DISTRESS AMONG
PARENTS OF CHILDREN WITH DIABETES:
A LONGITUDINAL STUDY

By

MELISSA Y. CARPENTIER

Bachelor of Arts

Our Lady of the Lake University

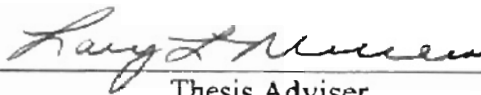
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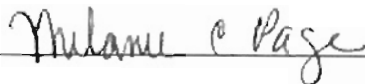
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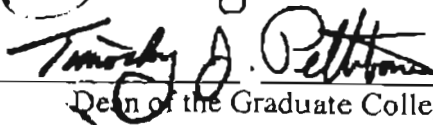
Thesis Approved:



Thesis Adviser







Dean of the Graduate College

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CHAPTER I

INTRODUCTION

Diabetes mellitus 1 (DM1) is one of the most common chronic illnesses of childhood, with an estimated 850,000 to 1.7 million individuals in the United States having this disease (American Diabetes Association [ADA], 2002). DM1, also referred to as juvenile-onset diabetes, is an auto-immune disease with a relatively rapid onset. Specifically, the risk of a child developing DM1 is higher than other chronic diseases of childhood, affecting 1 in 600 children (McMahon, Lambros, & Sylva, 1998). In this disease state, the child's pancreas produces very little or no insulin, therefore, subcutaneous administration of this hormone is necessary in order to sustain life (National Institute of Diabetes & Digestive & Kidney Diseases, 2002).

In addition to regular insulin injections, management of DM1 also requires daily management of blood glucose levels, exercise, and diet, as well as learning how to balance energy demands and insulin needs (Thompson & Gustafson, 1996). Other factors, such as stress, medications, illness/infection, and fatigue can also affect glucose control (Juvenile Diabetes Research Foundation International, 2001). Because it can be quite difficult to maintain metabolic control in children, adherence to the medical regimen is a critical issue (Thompson & Gustafson, 1999). To further aggravate this problem, children also face the normal developmental tasks of developing identity, competency, and autonomy (Greene, 1991). The lifestyle adjustments required to master such tasks may eventually render the diabetic child susceptible to other psychosocial

stressors, such as frequent school absences, problems interacting with peers and siblings, and adjustment problems in general (Johnson, 1995). Relative to other diseases, a considerable amount of research has been conducted on the psychosocial aspects of DM1. Notably, a number of psychosocial variables have been found to be predictive of adjustment to diabetes (Overstreet et al., 1995), including life stress, coping behaviors, treatment adherence, family resources, and perceived control (Grey, Cameron, & Thurber, 1991; Jacobson et al., 1990; Wallander, Varni, Babani, Banis, & Wilcox, 1989). Recent research has also focused on the parent-child transactional process (Chaney et al., 1997; Mullins et al., 1995). More specifically, research has demonstrated that maternal psychological adjustment influences child adjustment, and in turn, child adjustment influences maternal adjustment, beyond the variance which can be attributed to demographics and illness variables (Chaney et al., 1997). Clearly, psychosocial variables appear to play a substantial role in the adjustment to DM1, both in terms of parental and child psychological distress in response to the illness.

Notably, recent research also points to the importance of investigating cognitive appraisal variables as they concern the prediction of parental adjustment to DM1 (Chaney et al., 1997; Kazak, Segal-Andrews, & Johnson, 1995; Rapaport, 1998). Such research also suggests that pediatric chronic illness issues (e.g., emotional and social development, adjustment) are best understood within a family/systems perspective (Rapaport, 1998). However, relatively little research has been devoted to the longitudinal investigation of the role of cognitive appraisal variables to adjustment. Thus, the focus of the current investigation is to explore the relationship of specific cognitive appraisal mechanisms (i.e., illness uncertainty, attributional style) to longitudinal adjustment outcomes. In this

manner, it is possible that we may identify potential predictor variables that lend themselves to intervention, and ultimately aid parents who are at high risk for psychological distress through education and clinical application.

Specifically, it will be argued that both perceived illness uncertainty and attributional style are significant predictors of psychological distress over time in parents of children with diabetes. Perceived illness uncertainty is defined as the inability to assign meaning to illness-related events and to accurately predict outcomes (Mishel, 1984). Attributional style, which has its origins in the reformulated model of learned helplessness, posits that particular cognitive appraisals may place individuals at risk for adjustment problems (Abramson, Seligman, & Teasdale, 1978). Previous cross-sectional research on pediatric chronic illnesses has identified these cognitive appraisal mechanisms (i.e., perceived illness uncertainty and attributional style) as significant predictors of psychological distress (Cohen, 1995; Mullins, Chaney, Pace, & Hartman, 1997; Sharkey, 1995). However, it remains unseen whether perceived illness uncertainty and attributional style can predict distress in parents of children diagnosed with DM1 in longitudinal fashion.

Thus, the goal of the present study is to evaluate the above-mentioned two specific cognitive appraisal mechanisms as predictors of psychological distress over time. A related goal is to single out potential predictors that may prove useful in developing interventions for parents who are exhibiting substantial psychological distress in response to their child's DM1. To accomplish this, a comprehensive review of the relevant literature is presented. First, a review of the literature related to the physiological nature of DM1 is detailed, as well information regarding the prevalence, morbidity, and

mortality of DM1. Second, literature examining psychological distress present in both children and parents in relation to DM1 adjustment outcomes is reviewed. Next, literature on cognitive appraisal variables associated with DM1, specifically illness uncertainty and attributional style, is presented. Finally, a completed study is described in which illness uncertainty and attributional style were examined as potential significant predictors of psychological distress over time in parents of children with DM1.

CHAPTER II

REVIEW OF THE LITERATURE

The Nature of Type I Diabetes

Illness Characteristics. Approximately 30,000 Americans are diagnosed with DM1 annually, and over 13,000 of these individuals are children (Juvenile Diabetes Research Foundation International, 2001). Typically, peak incidence of onset occurs during puberty and between 20 and 35 years of age (Tuch, Dunlop, & Proietto, 2000). DM1 is more common among whites than non-whites, however, it does appear to occur equally among boys and girls (National Institute of Diabetes & Digestive & Kidney Diseases, 2002). Moreover, DM1 is becoming increasingly common in the American population, not because individuals are living longer, but simply due to the fact that a vast number of new cases are being diagnosed each year (Centers for Disease Control & Prevention [CDC], 1999). Unfortunately, cross-sectional data makes it virtually impossible to determine whether this increased prevalence of DM1 is due to a true increase in incidence, an increase in case diagnoses, or a combination of both.

DM1 is an autoimmune disease in which an individual's immune system destroys insulin-producing beta cells of the islets of Langerhans in the pancreas (ADA, 2002; Silverstein, 1994). This destruction leaves the pancreas with little or no ability to produce insulin (National Institute of Diabetes & Digestive & Kidney Diseases, 2002). Insulin is extremely vital in sustaining life; in fact, it is needed to signal cells that they should allow natural glucose that is naturally in the blood to permeate their outer layer

(Krall & Beaser, 1989). Since the glucose cannot enter the body's cells, it accumulates in the blood, overflows into the urine, and exits the body (National Institute of Diabetes & Digestive & Kidney Diseases, 2002). In this manner, the body loses its main source of fuel. Presently, research has yet to determine what causes the body's immune system to attack the beta cells, however, it is hypothesized that both genetic and environmental factors are involved (ADA, 2002; Silverstein, 1994).

DM1 typically goes undiagnosed in the initial stages because many of its symptoms, at first glance, seem harmless. These symptoms often develop over a relatively short period of time and may include excessive thirst, hunger, weight loss despite excessive eating, frequent urination, fatigue, irritability, blurry vision, and increased infections (ADA, 2002; National Institute of Diabetes & Digestive & Kidney Diseases, 2002; Thomas & Greene, 1999). Since the body's blood sugar levels are quite high and cannot be utilized within the body's cells, the individual begins to feel starved despite excessive eating (Johnson, 1988). In response to this starvation state, the body begins to tap into its fat and protein reserves, which ultimately leads to weight loss (Thomas & Greene, 1999). Further, the kidneys respond to high blood sugar by producing more urine to flush out excess sugar. Consequently, as more urine is produced, the body becomes dehydrated, which further increases thirst (Johnson, 1988). Dehydration of the body also causes moist membrane tissues, such as the lens of the eye, to shrivel and result in blurred vision. Lastly, the body is subject to increased infections due to potential bacteria and/or fungi generating as a result of an abundance of sugar in the blood. Moreover, because immune system cells are deprived of glucose they cannot function adequately, thus jeopardizing the immune system (Thomas & Greene, 1999).

Illness Management. Notably, the daily life of a person diagnosed with diabetes is one that demands adherence and careful monitoring (Johnson, 1995). In fact, the typical diabetes care regimen is one that calls for multiple daily insulin injections, blood glucose monitoring, exercise, and a restricted diet (Johnson et al., 1992; La Greca et al., 1995; Thomas, Peterson, & Goldstein, 1997). Careful adherence to this regimen results in blood glucose levels within the normal range, which prevents, delays, or minimizes short-term complications stemming from diabetes.

Short-Term Complications. Despite careful adherence, mimicking normal pancreatic function is relatively difficult to accomplish and can often result in hyperglycemia (excessively high blood sugar) or hypoglycemia (excessively low blood sugar) (Johnson, 1995). Hyperglycemia typically occurs when the patient has overeaten and increased the available supply of insulin in the body. Therefore, patients are usually asked to eat small amounts throughout the day, usually three meals and three snacks. In addition, hyperglycemia can also result when illness and stress impair the actions of insulin.

Conversely, hypoglycemia (or insulin shock) can occur when the patient has eat too little; this state can lead to cognitive disorientation, convulsions, or coma (Johnson, 1988). Exercise can also induce hypoglycemia if the patient has consumed insufficient calories. Therefore, the effects of diet, exercise, insulin, illness, and emotional state must always be considered on a daily basis (Johnson, 1995).

Another common short-term complication of DM1 is known as acute diabetic ketoacidosis, or DKA (Thomas & Greene, 1999). In this condition, the body is increasingly starved for glucose as its sugar cannot permeate the body's cells due to a

lack of insulin. As a result, the body begins to burn fat in order to fuel its cells, which leads to the excessive buildup of ketones in the blood (Thomas & Greene, 1999). The kidneys are responsible for eliminating ketone bodies; however, if sufficient amounts of ketone bodies cannot be removed, ketoacidosis will occur (Johnson, 1988). This condition, if left untreated, can result in nausea, labored breathing, coma, and even death (Johnson, 1988; Thomas & Greene, 1999).

Long-Term Complications. Most individuals who have had DM1 for a number of years will eventually suffer long-term complications as a function of glucose levels that are not properly maintained within the normal range (Dunlop & Proietto, 2000). Diabetes-related complications can affect almost every organ system of the body, including the eyes, kidneys, nerves, and arteries (Thomas & Greene, 1999). In fact, DM is the most frequent cause of blindness among working-age adults, and it also increases the risk of developing glaucoma and cataracts (CDC, 1999; Thomas & Greene, 1999). Additionally, retinopathy, the most common and serious complication affecting the eyes develops as a result of damage to the blood vessels supplying the retina. Moreover, DM causes the nephrons (filtering structures that excrete toxins and waste products) of the kidneys to decline in function (Thomas & Green, 1999; Tuch et al., 2000). This condition, known as nephropathy, can eventually result in end-stage renal disease, in which the kidneys can no longer filter toxins/waste. Further, DM1 may lead to neuropathy, or nerve damage, because high levels of blood sugar may disrupt the chemical balance between nerves which consequently impedes the nerves' ability to transmit electrical signals (Thomas & Greene, 1999). Finally, DM1 may also cause macrovascular complications such as atherosclerosis (hardening of the arteries due to t

accumulation of fat on the walls of the blood vessels), which can lead to heart disease, stroke, and circulatory disorders in the legs and/or feet (National Institute of Diabetes & Digestive & Kidney Diseases, 2002; Thomas & Greene, 1999; Tuch et al., 2000).

DM1 Morbidity and Mortality. Despite a lifetime of insulin injections, individuals with DM1 typically suffer a reduction in the quality of life and a shortened life span of about 15 years (Juvenile Diabetes Research Foundation International, 2001). In 1996, diabetes was cited as the seventh leading cause of death in the United States, although deaths resulting from diabetes are still believed to be underreported, both as a condition and as a cause of death (CDC, 1999). The reason for this stems from the fact that many individuals who have DM1 are yet to be diagnosed, and those who ultimately die as a result of the disease typically do so due to diabetic complications. Further, it is important to note that the risk of death among people with diabetes is about twice that of people without DM1 (CDC, 2000). Further, younger people aged 25-44 years and women aged 45-64 years have an increased risk of death.

Economic Impact. The overall economic impact of diabetes is considerable. In 1992 alone, diabetes accounted for approximately 11% of the total U.S. health care expenditures (Rubin, Altman, & Mendelson, 1994). In 1995, over 13,291,000 office visits, 1,916,000 outpatient clinic visits, and 358,000 emergency room visits were either directly or indirectly attributed to diabetes (Schappert, 1997). Additionally, diabetes cost the U.S. approximately \$98 billion in 1997. Direct medical costs for diabetes care and management, including hospitalizations and treatment supplies, reached \$44 billion. Similarly, indirect costs associated with work loss, disability, and premature mortality

reached \$54 billion (National Institute of Diabetes & Digestive & Kidney Diseases, 2001).

Psychological Distress in Response to DM1

A diagnosis of DM1 undoubtedly places major demands on both the child and his/her family; attempting to adjust to such demands is therefore an inherent task. Such an adjustment process has been described as the “affective and behavior alterations made in response to a set of immediate external events, developmental stages, and long-term situations” (Jacobson et al., 1990, p. 512). Each individual’s adjustment process is one which can, at times, be quite generalizable to others’ experiences, and yet at other times is very unique to him/her. Often times, cognitive appraisal mechanisms play a role in determining the course of adjustment and can explain individual differences in adjustment as well (Hemenover & Dienstbier, 1998). However, before discussing specific cognitive appraisal mechanisms, representative studies looking at adjustment outcomes are reviewed in order to provide a foundation for the current proposal. An overview of the existing literature on child adjustment to DM1 is first presented, followed by a summary of extant literature on parental adjustment to DM1.

Child Adjustment. Children who have been diagnosed with DM1 experience psychosocial stressors from the day they receive their diagnosis. However, the available literature is inconsistent regarding whether or not children diagnosed with diabetes are likely to develop pathological characteristics or long-term emotional damage as a result of their illness. Such variability in outcome has been attributed to difficulties in sampling children with diabetes, utilization of inappropriate control groups, and selection of measures (Jacobson et al., 1986).

Jacobsen and colleagues (1986) conducted a longitudinal study of children diagnosed with DM1 to examine the self-reported adjustment of children at illness onset. Two groups of children were studied; one group consisted of children with a recent onset of diabetes, and the second group consisted of children who had experienced a recent acute medical problem. Results suggested that children with DM1, as a group, had levels of self-esteem, locus of control, and psychological symptoms comparable to those experienced by the children with an acute medical problem. In addition, the children diagnosed with DM1 were not necessarily overwhelmed by the onset of their illness, per their own report. Moreover, sociodemographic factors did not appear to influence early adjustment of the children with DM1. Instead, family functioning emerged as an important factor in determining adjustment. Specifically, family environment was strongly related to level of perceived competence, diabetes adjustment, and psychological symptomatology in the children. However, it was also evident that individual variability in response was present. Further, Jacobson et al. (1986) found that early adjustment to DM1 was only one aspect of the child's overall pattern of adaptation. In fact, general coping patterns of the child prior to diagnosis proved to be salient predictors of adjustment as well. Consequently, children's initial adjustment to the diagnosis of DM does not fully predict psychosocial outcomes across time. Instead, other factors appear also play a role in adjustment, thereby necessitating further research into which variables may indeed predict adjustment outcomes over time.

In a follow-up to the study highlighted above, Jacobson et al. (1990) continued to monitor their sample of children with DM1 over a 4-year period. Taking into account individual psychosocial and demographic factors at the study's inception, they attempt

to predict adherence over the course of the study. Results indicated that an initial assessment of the patient's coping skills (i.e., defense level, adaptive strength, and locus of control), as well as the patient's level of adjustment at Time 1 was indicative of the patient's level of adherence to the diabetes regimen over the four years of the study. To illustrate, individuals who utilized more mature defenses and employed greater adaptive capacity were more likely to adhere to their regimen over time. Additionally, psychosocial variables predicted adherence defined in terms of diet, insulin adjustment, and metabolic monitoring. Specifically, age, adjustment, and ego defense level (at the study's inception) accounted for 47% of the variance in adherence.

Kovacs and colleagues (1990) examined school-aged children (ages 8 to 13) over the course of the first 6 years of their diabetes to assess their self-perceived psychological adjustment. Their results indicated that the children exhibited mild increases in depressive symptomatology after the initial year of living with diabetes, however these symptoms began to subside over the subsequent 6 months. Further, as the illness progressed, anxiety symptoms decreased for males, yet continued to increase for female. On the other hand, self-esteem regarding rehospitalizations and degree of metabolic control remained relatively stable for both males and females. Additionally, level of initial adjustment (evidenced through levels of depression, anxiety, and self-esteem) was predictive of later adjustment. Overall, children reported that time played a role in how they viewed the implications of their illness and the degree of difficulty of their regimen (i.e., as time elapsed, their views became more negative). This was particularly the case with girls in contrast to boys. However, the degree to which children were upset by

implications of diabetes and regimen difficulty varied as a function of their anxiety and depressive symptomatology.

Grey et al. (1991) also sought to examine the adjustment of preadolescents and adolescents diagnosed with DM1. Specifically, they proposed that age, coping behaviors and self-care behaviors would influence adjustment. Results obtained via self-reports suggested that older adolescents experienced significantly higher levels of anxiety and depression, while younger adolescents reported significantly better peer relations. In addition, metabolic control appeared to worsen with increasing age, as was expected. Findings also suggested that preadolescents and adolescents cope with their illness in a significantly different manner. Notably, younger adolescents stated that they would be more likely to cope through ventilation of feelings (e.g., yelling, arguing), while older adolescents stated that they would be more likely to cope through avoidance behaviors (e.g., drinking, smoking, or avoiding the home). Overall, age and coping behaviors were predictive of later adjustment, although self-care behaviors appeared not to be. These findings illustrate that preadolescents and adolescents cope differently in response to diabetes. Therefore, interventions should be individually tailored toward helping those with inappropriate coping styles.

In a related study, Kager and Holden (1992) attempted to examine the direct and stress-moderating effects of child and family variables on the adjustment (both psychological and physiological) of children and adolescents diagnosed with diabetes. They hypothesized that both child and maternal coping skills would buffer the stress-outcome relationship. Additionally, they proposed that the children's Type A behavior and mothers' disease-related family disruption reports would be stress-potentiating

factors. Sixty-four children with DM1 and their mothers participated in the study. Their results documented direct relationships between maternal and child coping and measures of psychosocial adjustment. Specifically, mothers' reports of the perceived helpfulness of coping behaviors were negatively associated with the child's global self-worth. In other words, mothers' attempts to manage the stress through use of coping behaviors were more helpful when children exhibited poorer self-competence. Conversely, children's coping skills were positively related to peer relations, such that those children with more extensive coping strategies reported a general sense of security in their relationships with peers. Furthermore, results found that children who displayed Type A behavior were more reactive than children who exhibited Type B behavior when exposed to low levels of stress. Consequently, children displaying Type A behavior exhibited higher HbA_{1c} levels. When exposed to higher levels of stress, however, children displaying Type B behavior had higher HbA_{1c} levels than children exhibiting Type A behavior. Finally, a significant relationship emerged between age and gender; a significant association was also observed between psychosocial functioning and diabetes adjustment. Notably, older children perceived their self-competence as lower than that of their younger counterparts, and girls reported better illness adjustment and peer relations than boys.

In terms of children's social adjustment to chronic illness, Nassau and Drotar (1995) compared social competence in a sample of 25 children with DM1, 19 children with asthma, and 24 healthy controls. The authors used Cavell's (1990) model of social competence, which holds that social competence is multidimensional and includes three dimensions: social adjustment, social performance, and social skills. They hypothesized

that children's social performance and social skills would be especially sensitive to the social burden of DM1, but children's global social adjustment would not be. Specific to the social performance domain, it was also hypothesized that children with DM1 or asthma would report less frequent positive peer interactions than healthy controls. Additionally, it was predicted that parents and teachers would report peer group entry as more problematic for children with DM1 and asthma versus healthy controls. In the social skills domain, the authors hypothesized that children with DM1 and asthma would find it more difficult to be verbally assertive in both conflictual and nonconflictual peer situations than would healthy controls. After obtaining child, parent, and teacher reports of the three dimensions of social competence, they demonstrated that the three groups of children did not differ significantly in their own perceived social competence, or in psychosocial functioning (i.e., social adjustment), according to parents or teachers. In addition, results also suggested that the chronic illness groups (i.e., DM1 and asthma) did not differ significantly from the healthy control group on measures of social performance and social skills. Overall, these results argue for the resiliency of children's social competence in adapting to the stresses of chronic illness.

Collectively, several studies (Grey et al., 1991; Jacobson et al., 1986, 1990; Kager & Holden, 1992; Kovacs et al., 1990; Nassau & Drotar, 1995) illustrate that child adjustment to DM1 can be influenced by many factors. For one, the family system plays a substantial role in how the child adjusts to his/her illness. The general family environment, including how the family functions, may indeed predict adjustment outcomes. Additionally, age and the selection of coping behaviors at diagnosis also seems to predict later adjustment to DM1. Gender differences also appear to exist, such

that young girls are likely to evidence better adjustment outcomes than young boys. Finally, the studies mentioned above also suggest that level of adjustment to DM1 at Time 1 is indicative of later adjustment and adherence to treatment regimens. Therefore, it appears that many psychosocial factors can account for a significant amount of variance in adjustment outcomes in children with DM1. Notably, this appears to be the case with parental adjustment to DM1 as well.

Parent Adjustment. Parents of children with DM1 face numerous challenges. Parents must learn how to balance the many daily demands of managing the chronically ill child, as well as provide a healthy environment for the rest of the family (Johnson, 1995). This frequently calls for differential treatment of the child with diabetes as compared with siblings, including management of behavior problems (McMahon et al., 1998). Dealing with DM1 also entails dealing with frequent insulin injections, frequent doctor's office visits, and frequent monitoring of blood glucose levels, in addition to a restricted diet and exercise regimen (Cox & Gonder-Frederick, 1992). Further, a diagnosis of diabetes forces parents to educate the school system about their child's illness, as frequent school absences, social interaction problems with peers, and educational difficulties in academic areas are at times inevitable (McMahon et al., 1998). Consequently, DM1 is one of the most behaviorally demanding of the chronic illnesses (Fisher, Delamater, Bertelson, & Kirkley, 1982). In addition, because of the intensity of the behavioral demands placed both upon the patient and his/her family, numerous psychological factors come into play (Cox & Gonder-Frederick, 1992; Kovacs et al., 1985). Specifically, families of children with DM1 must deal with other stressors, such

as promoting autonomy of the ill child, and relinquishing fears about the ill child's future (McMahon et al., 1998).

A number of studies have attempted to document patterns of adjustment in parents of children with DM1. Mullins et al. (1995) examined both child and maternal emotional adaptation both across and within samples of children with cystic fibrosis (CF) and DM1 utilizing a transactional model. Their findings were congruent with previous research which revealed no significant differences in adaptation between disease states, although significant differences emerged within disease states. Specific to diabetes, a significant relationship was found between higher maternal depression and child depression. The same was not observed in the CF group. Mullins and colleagues speculated that the relationship observed in the diabetes group could be explained by the fact that diabetes poses an *ongoing* daily process of emotional adaptation (thereby possibly contributing to the development of depression), while CF adaptation processes reflect more of a long-term *result* of emotional adaptation to the illness. However, Mullins et al. also found that maternal adjustment problems due to DM1 exist not only in relationship to child adjustment, but also in isolation. Therefore, a need to further investigate adjustment processes in parents of children with DM1 arises, particularly through the use of longitudinal designs.

Holden, Chmielewski, Nelson, Kager, & Foltz (1996) examined children's self-competence, family functioning, and maternal coping among samples of children with either DM1 or asthma. Seventy-two children with DM1 and 40 children with asthma participated in the study. Mothers of the children with diabetes and asthma completed measures of family functioning, coping, and disease severity. Holden et al. (1996)

hypothesized that disease-specific effects would be found in general analyses of child and family functioning. A second hypothesis predicted that by controlling general family stress factors and general chronic illness factors, disease-specific effects would subside and general gender effects would remain. Indeed, results suggested that neither gender nor the presence of either DM1 or asthma was associated with maternal coping. Further, families of children with asthma were more adaptable than families with children with diabetes. Holden et al. (1996) argued that general family stress variables and disease-related factors are more salient predictors of adjustment outcomes than individual illness categories such as DM or asthma. Thus, these results provide support for non-categorical approaches to chronic illness research.

Knafli & Zoeller (2000) examined how mothers and fathers of a child with a chronic illness view their experience, as well as the impact the illness has placed on their family life. Chronic illnesses in their sample included DM1, asthma, and juvenile rheumatoid arthritis. Slightly more than half of the children in the sample were diagnosed with DM1. Forty-three couples and 7 women, whose husbands did not participate, completed interviews and structured measures designed to assess psychological functioning and mood. Results demonstrated that within families, parents typically shared the same view of their child's illness as well as the impact on family life. Further, parental total mood disturbance scores did not differ significantly; however, there were significant differences in parental scores on both the confusion and fatigue subscales. Mothers indicated significantly higher mood disturbance than their husbands in these areas, thereby emphasizing the negative impact of a child's chronic illness on mothers. These findings are consistent with previous research which holds that fathers

typically experience less depressive symptomatology and psychological distress associated with their child's chronic illness (Chaney et al., 1997; Eiser & Havermans, 1992). Overall, the extent of the mood disturbance across parents in this sample was comparable, or even lower in some instances, to that of the adult normative sample used in developing the instruments (e.g., Feetham Family Functioning Survey, FFFS; Profile of Mood States, POMS) utilized in the study. Such results suggest this was a comparatively healthy sample in terms of both individual and family functioning.

Charron-Prochownik & Kovacs (2000) investigated whether maternal coping patterns related to a diagnosis of DM1 in their children were associated with psychopathology, the child's gender, duration of illness, or the child's age. In addition, the relationship of maternal coping to subsequent health and adjustment outcomes for the children was also evaluated. The sample consisted of newly diagnosed children with DM1. Results revealed no significant associations between maternal coping patterns and any of the variables examined. Notably, mothers reported that "maintaining family integration" and "understanding the medical situation" as important coping patterns. Moreover, maternal coping patterns were not associated with subsequent health outcomes for children with DM1, although this has not been the case in other studies (Hamlett, Pellegrini, & Katz, 1992; McCubbin et al., 1983).

Interestingly, fathers of chronically ill children are not as frequently studied as mothers (Chaney et al., 1997). The literature that does exist regarding fathers of chronically ill children suggests that their reactions to a chronic illness diagnosis in their children are different than those of mothers. Specifically, they typically experience less

depressive symptomatology and difficulties compared to mothers (Eiser & Havermans, 1992; Timko, Stovel, & Moos, 1992).

Chaney et al. (1997) examined transactional patterns of child, mother, and father adjustment in a sample of children/adolescents diagnosed with DM1. Consistent with previous investigations, adjustment across both child and parent domains remained relatively stable over the course of the 1-year study. However, any variation in fathers' adjustment was inversely related to mothers' adjustment, such that as father's distress increased, mothers experienced better adjustment. Results also suggested that a downward variation in fathers' adjustment was more closely related to poorer child adjustment than was a decline in mothers' adjustment over the same time period. Moreover, variations in maternal and child adjustment made significant independent contributions to fathers' subsequent adjustment. Furthermore, paternal adjustment was positively related to child adjustment, and maternal adjustment was inversely related to fathers' adjustment. As a whole, however, similar levels of adjustment for mothers and fathers were found at both baseline and follow-up procedures.

The Chaney et al. (1997) findings are relatively incongruent with the existing literature suggesting that mothers frequently experience poorer adjustment than do fathers. Such research has suggested that mothers experience an additive effect of both illness-related and daily demands (Johnson, 1988; Manuel, 2001). Mothers must deal with their children's illness-related stressors (e.g., insulin injections, doctor's visits) in addition to normal everyday living (Manuel, 2001). However, a probable explanation for these findings stems from the fact that most studies define adjustment using measures of depression exclusively. On the other hand, Chaney et al. (1997) chose to define

adjustment in a more global nature and across a number of symptoms (e.g., depression, anger, anxiety, etc.). Since men do not often endorse depressive symptomatology, it could be the case that they appear relatively well-adjusted, when this may not indeed be reality. When fathers are assessed across multiple domains, however, they are more likely to exhibit levels of adjustments similar to mothers.

Summary. In evaluating the psychological adjustment of children diagnosed with DM1 and their parents, it is clear that much individual variability exists. However, the extant research demonstrates a robust relationship between parent adjustment and child adjustment (Chaney et al., 1997; Holden et al., 1996; Knafl & Zoeller, 2000; Mullins et al., 1995). Indeed, determining specific variables that predict adjustment would be a critical next step, not to mention examining these relationships over time. Unfortunately, the child and parental adjustment studies which do exist tend to be cross-sectional in nature and fail to give a longitudinal view of adjustment. Therefore, the present project represents an attempt to combine two facets of diabetes research that still warrant further study. Specifically, two cognitive variables, perceived illness uncertainty and attributional style, will be utilized as potential predictors of psychological distress over time.

Cognitive Appraisal Variables Associated with DM1

Perceived Illness Uncertainty. An individual with diabetes has the responsibility of mimicking the normal pancreatic function of balancing insulin and glucose levels (Thompson & Gustafson, 1999). However, the complicated interplay of diet, exercise, insulin, stress, and illness makes such regulation difficult (Johnson, 1995). Daily management of diabetes involves insulin injections, glucose monitoring, exercise, and a

restricted diet (Johnson et al., 1992). These lifestyle behavior changes are lifelong, and it seems likely that a certain degree of uncertainty would stem from such complex daily demands (Thompson & Gustafson, 1999). Perceived uncertainty is, according to Cohen and Martinson (1988), one of the greatest psychosocial stressors affecting families with a child diagnosed with a chronic health condition. Although the threat posed by the illness generally remains constant, the family's perception of the threat fluctuates over time, usually due to changes in what has previously been considered "normal" (Sharkey, 1995). These changes may be in reference to the family's social relationships, financial status, and basic home care needs. In all regards, changes from what was once considered normal, healthy functioning is a task that families with a child diagnosed with DM1 must face. Due to the chronic nature of the disease, some level of illness uncertainty must undoubtedly be experienced by the parents of children diagnosed with DM1. Therefore, exploring facets of uncertainty with respect to diabetes across time has the potential to significantly contribute to the existing literature, as well as provide insight into future clinical applications.

Mishel's Theory of Uncertainty. Much of the research to date on the construct of illness uncertainty has been conducted by Mishel. Specifically, she has defined illness uncertainty as the inability to assign meaning to illness-related events and to accurately predict outcomes (Mishel, 1984). Accordingly, uncertainty develops when an individual is not able to form a consistent cognitive schema for illness events. This cognitive schema consists of a subjective interpretation of the illness at hand, its course, and its treatment. According to Mishel, stimuli frame, cognitive capacity, and structure providers (level of education, social support, and authority) all precede the development

of uncertainty. Specifically, the stimuli frame refers to the structure of the stimuli that is perceived, and it is broken down into three components: symptom pattern, event familiarity, and event congruence. Symptom pattern reflects a consistency of symptomatology that can be perceived as depicting an established pattern, in which the meaning of symptoms in the future can be evaluated against (Mishel, 1988).

Specific to DM1, it can be posited that once parents of children diagnosed with this disease accustom themselves to a set sequence of events and/or symptoms, they can begin to reduce their perceptions of uncertainty regarding the outcomes of the disease. Related to symptom pattern, event familiarity refers to the categorization of specific events as being deemed habitual, thereby allowing future events to be compared with events from memory and, consequently, meaning can be attached. Finally, event congruence reflects a consistency between what is expected and actually experienced in illness. Because consistency implies stability, uncertainty regarding illness-related events is reduced. This is often the case when parents of children with DM1 have created and implemented a set schedule of insulin treatment. It is expected that the set schedule will lead to a sense of stability, and when this is actually experienced, event congruence has taken place.

The stimuli frame, composed of symptom pattern, event familiarity, and event congruence, is influenced by two variables: cognitive capacity and structure providers (Mishel, 1988). In this regard, a person with only limited cognitive capacity (i.e., information-processing abilities) will experience a decrease in his/her ability to perceive the stimuli frame adequately, thus increasing uncertainty. Mishel has also introduced the notion of structure providers, which are resources that aid in interpretation of the stimuli

frame, as potential reducers of uncertainty. Such structure providers include level of education, social support, and authority.

As was mentioned at the onset of the discussion on illness uncertainty, the inability to form particular cognitive schema results in uncertainty (Mishel, 1984). More specifically, uncertainty has four dimensions: a) ambiguity concerning the illness state, b) complexity of treatment, c) lack of adequate information about one's own diagnosis, and d) unpredictability related to the course of the illness (Mishel, 1981). In this regard, parents with a child diagnosed with DM1 would appear to face each of these dimensions, and therefore are at risk to display higher levels of illness uncertainty.

Uncertainty in Chronic Illness. To date, the construct of illness uncertainty has been examined in a number of studies. In one of the first studies Mishel attempted to explain perceived uncertainty in relation to the perception of hospital events (Mishel, 1984). She proposed that the perceived seriousness of illness would lead to increased stress due to the construct of uncertainty. Specifically, she predicted that a direct relationship between seriousness of illness and uncertainty would emerge, and an indirect relationship between seriousness of illness and stress would also be found. In addition, education was predicted to be directly related to uncertainty and indirectly related to stress. Results revealed a significant relationship between uncertainty and stress, suggesting that vagueness, lack of clarity, and lack of information accounted for the perception of events as stressful, rather than the event itself.

In a later study conducted by Mishel and Braden (1987), an attempt was made to investigate the psychological adjustment of women with gynecological cancer. Specifically, it was posited that uncertainty and optimism were primary variables

affecting adjustment, whereas social support and control over physical function were secondary variables via their relationship with uncertainty. Further, it was expected that uncertainty would differ in each phase, (i.e., diagnosis, treatment, and stabilization). Forty-four women, ages 20-83, participated in the study. Results for the diagnosis phase indicated that women who had significant social support experienced less ambiguity about the state of their illness. During the treatment phase, however, no significant relationship emerged between social support and uncertainty. In the stabilization phase, significant associations were once again seen between social support and uncertainty. Overall, such findings suggest that social support fluctuates over time and influences different aspects of uncertainty.

More recently, illness uncertainty has been consistently isolated as a significant predictor of psychological distress across a number of other illness groups, including multiple sclerosis (Mullins et al., 2001; Wineman, 1990), asthma (Mullins et al., 1997), myocardial infarction (Mishel, 1983; Painter, 1981), and adolescent diabetes (Hoff, Mullins, Chaney, & Hartman, 2001). In a study of young adults with long-standing asthma, illness uncertainty was found to be associated with higher levels of depressive symptomatology, with a maximized effect under conditions of increased illness severity (Mullins, Chaney, Balderson, & Hommel, 2000). In a rare exception to the above results, Sanders, Mullins, and Chaney (2001), found that illness uncertainty was not a significant predictor of distress in a sample of individuals with Parkinson's Disease. However, Sanders and colleagues point out that their research findings may be best explained by the fact that their sample had experienced such a level of disease progression that little doubt about future outcomes existed. Overall, the findings in the literature are largely

consistent; the relationship between illness uncertainty and psychological distress is clearly robust (Hoff et al., 2001).

Attributional Style. Attributional, or explanatory style, has historically had its roots in the fundamental learned helplessness research paradigm (Abramson, Seligman, & Teasdale, 1978). In this regard, attributional style emerged as a way of explaining individuals' reactions to uncontrollable events, as well as the motivational, cognitive, and emotional deficits associated with them. Motivational deficits consist of the inhibited initiation of voluntary responses, often seen as the result of the individual learning that any specific response was futile (Abramson, Garber, & Seligman, 1980). Cognitive deficits are displayed as difficulties in acknowledging that certain responses produced specific outcomes. Finally, emotional deficits take the form of depressive symptomatology as individuals learned that outcomes were independent of responses.

Reformulation of the Original Model. Notably, two major problems were raised concerning the original learned helplessness theory specific to human behavior. Namely, the theory: 1) failed to make a distinction between universal helplessness (i.e., outcomes are uncontrollable for all people) and personal helplessness (i.e., outcomes are uncontrollable for only some people) and 2) failed to explain when helplessness deficits would be generalized across situations and whether they would remain chronic or acute (Abramson et al., 1980; Peterson, Maier, & Seligman, 1993). As a result, Abramson et al. (1978) proposed a cognitive reformulation of the learned helplessness model. According to the revision, individuals must first objectively experience a non-contingent condition. In other words, they must perceive that their responses hold no value in determining outcomes. Then, the individual must seek a causal explanation of why this

non-contingency occurred. This explanation will later influence his/her expectation of future noncontingencies and will subsequently determine the nature of his/her helplessness deficits (e.g., motivational, cognitive, and emotional).

Dimensions of Causal Explanations. Abramson et al. (1978) suggest three dimensions of causal explanations: internal versus external, stable versus unstable, and global versus specific. Specific to the internal versus external continuum, an internal explanation for uncontrollable events is related to personal helplessness, because the lack of control over the situation is attributed to something in particular about the individual (Peterson et al., 1993). Conversely, an external causal explanation is associated with universal helplessness because the uncontrollability is attributed to the nature of the situation. Internal explanations jeopardize an individual's self-esteem, while external explanations typically preserve self-esteem.

Causal explanations along the stable versus unstable continuum involve distinguishing whether the uncontrollability of a situation is due to permanent (i.e., stable) or temporary (i.e., unstable) factors (Abramson et al., 1978). Individuals who make stable attributions will be likely to manifest chronic deficits because of their belief that they lack the ability to produce a controlling response in the future (Abramson et al., 1980). Alternatively, those individuals who make unstable attributions will not necessarily experience helplessness when an uncontrollable event arises once again, simply because the factor influencing uncontrollability was transient.

The global versus specific continuum distinguishes between causes that are global (i.e., affecting a vast variety of situations) versus specific (i.e., affecting only few situations) (Abramson et al., 1978). Global attributions affect generalization across

situations; therefore, widespread difficulties are likely to emerge (Peterson et al., 1993). On the other hand, specific attributions tend to lead to proportionately less overall difficulties (i.e., only in relation to the initial scope of the problem) (Abramson et al., 1978).

Attributional Style in Chronic Illness. Given the level of uncontrollability that chronic illness inflicts on individuals, it is no surprise that attributional style is frequently studied in relation to various disease states (Chaney et al., 1996; Hommel et al., 1998; Schoenherr, Brown, Baldwin, & Kaslow, 1992). Previous research on pediatric chronic illness has identified attributional style as a significant predictor of psychological distress in a college sample of young adults with asthma (Mullins et al., 1997). For example, Mullins and colleagues (1997) found that greater perceived asthma uncertainty and increased negative, stable attributions were associated with poorer psychological adjustment. Moreover, uncertainty emerged as a moderator of the attribution-adjustment relationship, thereby supporting a cognitive diathesis-stress model of adjustment in young adults with asthma.

Specific to the current study, research has found that children with negative attributional styles who are diagnosed with DM1 have significantly greater difficulty adjusting to their illness than children with more positive attributional styles (Kuttner, Delamater, & Santiago, 1990). In addition, this line of research has also proposed that individuals with diabetes may attribute failures to maintain good metabolic control as due to internal, global, and stable causes, and that this may eventually foster feelings of helplessness and depression. Helplessness could give way to a lack of future self-

management of the disease, and patients could wind up in a vicious self-perpetuating cycle.

Attributional Style in Healthy Populations. Interestingly, the effects of negative causal explanations can be seen in healthy populations as well. Healthy college students who possess negative attributional styles are more likely to report a higher incidence of illnesses and to rate their overall health as poorer (Lin & Peterson, 1990). Indeed, the role that attributional style plays in both healthy and ill populations is one that undoubtedly needs to be further explored. Therefore, the proposed project seeks to contribute to the existing literature by examining attributional style as a predictor of parental adjustment to a diagnosis of DM1 in their child. This specific cognitive appraisal variable is one which has yet to be explored in the parental adjustment to the DM1 research arena.

CHAPTER III

THE PRESENT STUDY

The current study seeks to examine the relationships of perceived illness uncertainty and attributional style to psychological distress reported by parents of children with DM1 over time. The rationale for this study is fourfold. First, DM1 is an extremely common chronic illness of childhood (McMahon et al., 1998). In fact, current figures estimate that there are 11,000-12,000 new cases of diabetes mellitus 1 diagnosed each year in the United States alone (Hoff et al., 2001). Second, a diagnosis of DM1 not only affects the child, but the entire family as well (Hanson, De Guire, Schinkel, & Henggeler, 1992; Johnson, 1988). Therefore, it is necessary to examine not only child but also parental reactions to diabetes in order to develop useful interventions for alleviating distress. Third, the relationship between these appraisal mechanisms themselves (i.e., perceived illness uncertainty and attributional style) is one that is often overlooked (Hoff et al., 2001). Finally, it has been established that psychological distress associated with diabetes begins with diagnosis and extends over time (Cox & Gonder-Frederick, 1992). However, little is known about the course of adjustment, or what cognitive variables predict psychosocial outcomes. Thus, predictors of the progression of this distress over time should be identified.

Primary Hypotheses

Hypothesis One. It was anticipated that higher levels of parent perceived illness uncertainty at Time 1, as measured by the Parent Perception of Uncertainty Scale (PPUS;

Mishel, 83), would be significantly associated with an increase in parent psychological distress at Time 2, as measured by the Brief Symptom Inventory Global Severity Index score (BSI; Derogatis, 1993), after controlling for demographic, illness, and Time 1 distress parent variables.

Hypothesis Two. It was also hypothesized that parent causal attributions for negative events at Time 1, as measured by the Attributional Style Questionnaire (ASQ; Peterson et al., 1982), would contribute significantly to an increase in parent psychological distress at Time 2, as measured by the Brief Symptom Inventory Global Severity Index score (BSI; Derogatis, 1993).

Research Question One. In addition to the stated hypotheses, a more general research question will examine the possibility of an interaction between parent perceived illness uncertainty and attributional style at Time 1 in the prediction of psychological distress at Time 2.

The aforementioned hypotheses and research question are thus presented as frameworks for exploratory analysis since, to the author's knowledge, this is an area that has been overlooked in the area of adjustment to chronic illness (Hoff et al., 2001). Additionally, the cognitive appraisal mechanisms of focus in this study, illness uncertainty and attributional style, have previously been shown to independently predict adjustment outcomes for both parents and children with chronic illness (Hoff et al., 2001; Kuttner et al., 1990; Mullins et al., 1997; Mullins et al., 2000). Further, this exploratory investigation also seeks to study illness uncertainty and attributional style through a longitudinal design, which clearly appears to be underutilized in the existing literature. Thus, the current study has the potential to contribute significantly to the extant literature.

By examining illness uncertainty and attributional style as predictors of distress within a longitudinal design, as well as addressing limitations in the literature, subsequent advancement of knowledge within theory and research in the area of parental psychological distress in response to child chronic illness will be possible. Additionally, such research holds the possibility of the development of new interventions designed specifically to aid parents in adjusting to a diagnosis of DM1 not only immediately following diagnosis, but throughout the course of time.

CHAPTER IV

METHOD

Participants

Thirty parents (26 mothers; 4 fathers) between the ages of 31 and 52 ($M = 43.67$, $SD = 5.08$), who have children previously diagnosed with DM1 participated in the study. The participants had previously taken part in a larger study examining parent and child adjustment to chronic illness. With regard to ethnicity, participants identified themselves as Caucasian ($n = 26$, 86.7%), followed by Native-American ($n = 3$, 10.0%), and African-American ($n = 1$, 3.3%). The majority of participants were married ($n = 27$, 90.0%), while 3.3% ($n = 1$) were single, 3.3% ($n = 1$) were remarried, and 3.3% ($n = 1$) were never married. Their estimated annual household incomes were also obtained and are presented in Table 1 in Appendix A.

Participants were recruited from two pediatric endocrinologist clinics in a Midwestern state. Inclusionary criteria for participation were as follows: (a) participants must have previously participated in baseline measures collection as part of a larger project conducted approximately 5-6 years ago, and (b) participants must not have a child who has been diagnosed with another chronic illness beside DM1, nor a developmental disability, since baseline. These criteria were set to ensure that parents presently fit into a Time 2 (5-6 years post-baseline) category, thereby allowing for the collection of follow-up data. The study coordinator, as well as staff at the pediatric endocrinologists' clinics verified the inclusion criteria before participants were contacted. Participants had the

choice of receiving a \$10.00 personal reimbursement or a \$10.00 donation in their name to the American Diabetes Association for compensation for their time in the study.

Instruments (See Appendix B)

Parent-Report Measures

Background Information Questionnaire. Parents were asked to provide basic demographic data about themselves and their child. Information regarding the child's gender, age, and grade, parents' age, marital status, occupational status, as well as current members of the household will be collected through use of this questionnaire.

Health Information Questionnaire (HIQ). The HIQ is a measure developed specifically for the purposes of the proposed study. Parents were asked questions regarding their child's diagnosis of DM1, such as time since diagnosis and age at which the child was diagnosed. In addition, questions regarding the child's daily and weekly food intake and exercise regimen were asked. Further, parents were asked how they feel their child copes with his/her illness, how their child's current health status compares to the previous year's status, and how adherent their child is towards his/her medical treatment program. Lastly, parents were asked to list all medications their child is currently being prescribed.

Health Care Utilization Questionnaire (HCUQ). Parents were asked to complete the HCUQ (Mullins et al., 1996), which is designed to assess information related to the use of health care resources for their child with diabetes. Specific questions assess the number of inpatient and outpatient visits, emergency room visits, and hospitalizations the child has experienced over the past year. The HCUQ also contains items pertaining to the amount of money spent in treating the child's illness, and amount of time spent

working with health care agencies in managing the financial aspects of the child's illness. Parents were asked to complete several Lickert-style ratings that assess their level of stress for financial strain produced by their child's illness, as well as items regarding their relationship with their child's doctor or treatment team.

Brief Symptom Inventory (BSI; Derogatis, 1993). The BSI is a 53-item self-report symptom inventory which asks parents to rate their level of psychological distress during the past seven days on a four-point Likert scale. The Likert-style ratings range from "not at all distressed" (0) to "extremely distressed" (4). Under most circumstances, the BSI takes approximately 8 to 10 minutes to complete. The BSI is scored in terms of nine clinical dimensions of psychological distress (e.g., somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism), with t-scores ranging from 30 to 80. The BSI also yields three global indices, the Global Severity Index (GSI), the Positive Symptom Total (PST), and the Positive Symptom Distress Index (PSDI). For the purposes of the current study, the Global Severity Index, or GSI, was used as the primary index of distress. Caseness criteria was also assessed as a means of characterizing level of distress. Caseness on the BSI is defined as a GSI score greater than or equal to a T score of 63, or two or more primary clinical scales with a T score ≥ 63 (Derogatis, 1993).

Previous research has demonstrated that the BSI correlates highly with the SCL-90-R, as well as possesses high reliability and validity (Derogatis, 1993). Specifically, the BSI has high internal consistency, ranging from .71 to .85, and high test-retest reliability, ranging from .68 to .91. The BSI Global Severity Index, or GSI, has a test-retest reliability coefficient of .90, thereby providing strong evidence that the BSI

represents consistent measurement across time (Derogatis, 1993). Internal consistency estimates for the current study ranged from .92 to .96 for Time 1 and Time 2 distress, respectively.

Parent Perception of Uncertainty Scale (PPUS; Mishel, 1983). The PPUS is a 31-item self-report instrument which measures parental uncertainty in reference to their child's diagnosis of diabetes mellitus 1. The PPUS was developed in 1983 through a modification of the Mishel Uncertainty in Illness Scale (MUIS; Mishel 1981), which measures the perception of uncertainty as it pertained to one's self. In this regard, items on the MUIS were altered slightly to reflect parental evaluation of events occurring within their own children. Examples of such items include: "I don't know what is wrong with my child", "The doctors say things to me that could have many meanings", and "There are so many different types of staff, it's unclear who is responsible for what" (Mishel, 1983). Responses to such items are based along a 5-point Likert scale ranging from strongly disagree (1) to strongly agree (5).

The PPUS has four dimensions including: ambiguity, complexity, inconsistency of information, and unpredictability. Each dimension is summed independently in order to provide a single score for each dimension. Additionally, the PPUS yields a total score of uncertainty by summing scores across all dimensions. The PPUS can be utilized across varied populations and its four-factor structure has remained consistent across studies (Mishel, 1983). In addition, the PPUS has acceptable reliability scores, ranging from .86 to .93 (Mishel, 1990). Reliability for the current study yielded an alpha coefficient of .88.

Attributional Style Questionnaire (ASQ; Peterson et al., 1982). The Attributional Style Questionnaire (ASQ) is a 48-item instrument that measures causal explanations to events. It yields three composite attributional style scale scores (i.e., Composite Negative Attributional Style [CoNeg], Composite Positive Attributional Style [CoPos], and the Composite Positive minus Composite Negative [CPCN]). CoNeg is a measure of the attributional style for negative events, while CoPos is a measure of the participants' attributional style for positive events. CPCN is a measure of the difference between the participants' attributional style for positive events and negative events. In addition to the composite scale scores, the ASQ yields eight individual dimension scale scores that represent a breakdown of the positive and negative composite scores along the Locus of Control, Stability, and Globality dimensions posited by Abramson et al.'s (1978) reformulated learned helplessness model (Welter, 2002).

The ASQ consists of 12 hypothetical events, of which 6 are positive and 6 are negative. Participants are instructed to read each event, provide a major cause of the given event, and rate the cause of the event along a seven-point Likert-style. The Likert scale continuum is anchored at one end by internal, stable, or global causations and at the other end by external, unstable, or specific causations. Since attributions for positive events are not central to the purpose of the present study, only negative dimensions (CoNeg) will be examined. Therefore, the lower the CoNeg score, the more optimistic the participants' attributional style for negative events; conversely, the higher the CoNeg score, the more pessimistic the participants' attributional style for negative events.

The ASQ has been widely utilized in research examining attributional style since its introduction in 1982 (Welter, 2002). Moreover, its composite scale scores have

consistently demonstrated acceptable internal consistency ranging from .71 to .75 (Peterson et al., 1982, Welter, 2002). However, due to the poor to moderate internal consistency of the individual dimension scales (ranging from .21 to .69), they will not be utilized in the current study. This is concurrent with the authors' (Peterson et al., 1982) caution that users only utilize the individual dimension scales if a strong theoretical rationale exists for doing so. For the purposes of the current study, only Composite Negative (CoNeg) scores will be utilized. Internal consistency estimates for the Composite Negative scores in the present study were approximately .71.

Physician-Report Measure

Ratings of Illness Information, Illness Severity, and Treatment Adherence Questionnaire. Physicians were asked to provide information on the children's health status upon entry into the research study. They were asked to provide the child's most recent HbA_{1c} data (measure of metabolic control). In addition, physicians were also asked to complete a 7-point Likert-style measure of illness severity, ranging from "extremely good health" to "extremely poor health." The rating scale has previously been shown to be sensitive to illness-related changes (i.e., number of hospitalizations over the past year), as well as parental ratings of illness severity. In addition, the severity scale has also been utilized in other pediatric chronic illness research (Mullins et al., 1991). Attending physicians were also asked to complete a 7-point Likert-style measure of treatment compliance, ranging from "extremely compliant" to "not compliant at all." Ratings reflect the child's most recent compliance level.

Procedure

Eligible participants were recruited by obtaining their addresses from the staff at the two pediatric endocrinologist's office. A letter was mailed to the participant's home informing them about the study, along with a postcard asking them to check the appropriate box to indicate their interest in participating in the study and to send it back to the address provided. Of 110 parents contacted, 31 expressed interest in taking part in the study and subsequently completed measures, yielding an overall participation rate of 28.2%. The primary reason given for refusal was simply "not being interested" in participating.

Those participants who expressed interest were mailed a questionnaire packet containing a cover letter, two copies of consent forms (one for the participant and one for the researcher's records), and the instruments described above. The participants were also instructed on the cover letter to indicate which form of reimbursement (personal check or a donation to the American Diabetes Association) they would prefer. Participants were provided with the telephone numbers of the study personnel in the case of any questions or concerns regarding the study or the questionnaires. They were also asked to return the packets as soon as possible.

Participants who had not returned their packets after approximately two weeks were contacted by phone as a reminder and were also thanked again for their participation. If no verbal contact was made with the participants, they were then sent a final letter as a small reminder. Those participants who returned their completed packets were sent a thank-you letter. Personal reimbursements or verification of a donation to the American Diabetes Association in their name was then mailed under separate cover. All procedures were in keeping with the standards established by the Oklahoma State

University Institutional Review Board, the University of Oklahoma Health Sciences Center Institutional Review Board, the Integris Baptist Medical Center Institutional Review Board, and the IRB approved research study (See Appendix C).

CHAPTER V

RESULTS

Preliminary Analyses and Selection of Covariates

Preliminary analyses were first conducted to explore the relationship of both Time 1 and Time 2 demographic variables to the primary variables of interest. A 2 X 2 MANOVA (Gender X Clinic Site) was first conducted to examine potential mean differences on Time 1 perceived illness uncertainty, negative attributional style, and psychological distress. Please refer to Table 2 in Appendix A for means and standard deviations of the variables of interest. No significant differences emerged for perceived illness uncertainty, $F(1, 27) = .89, p = .355$, negative attributional style, $F(1, 27) = .24, p = .627$, and psychological distress, $F(1, 27) = .51, p = .481$, as a function of gender. Similarly, analyses revealed no significant differences on these same variables as a function of clinic site, all p 's > .05.

An additional 2 X 2 MANOVA (Gender X Clinic Site) was then conducted to examine potential mean differences on Time 2 perceived illness uncertainty, negative attributional style, and psychological distress. Again, no significant gender differences emerged for perceived illness uncertainty, $F(1, 27) = .14, p = .715$, negative attributional style, $F(1, 27) = .04, p = .849$, and psychological distress, $F(1, 27) = .00, p = .989$. In addition, analyses revealed no significant differences on these same variables as a function of clinic site, all p 's > .05.

Analyses were also conducted to examine the number of participants who met caseness criteria on the BSI (i.e., a BSI GSI T score ≥ 63 , or any two primary dimension scores ≥ 63) at both Time 1 and Time 2 (Derogatis, 1993). Seven parents in the sample (23.3%) met caseness criteria at Time 1, while eight parents (26.7%) met caseness criteria at Time 2. Exploratory analyses were then conducted in order to determine whether participants who met caseness criteria for psychological distress at Time 1 to Time 2 were the same individuals. It was found that of the seven participants who met caseness criteria at Time 1, only two of these participants continued to meet caseness criteria at Time 2. Thus, the other five participants who met caseness at Time 1 no longer evidenced clinical distress 5-6 years later; instead, it appeared that six other participants emerged as meeting criteria for significant psychological distress.

Zero-order correlations were then computed for the primary variables of interest (please refer to Table 3 in Appendix A). Significant relationships were revealed between perceived illness uncertainty at Time 1 and psychological distress at Time 1 ($r = .46, p = .010$), as well as perceived illness uncertainty at Time 1 and psychological distress at Time 2 ($r = .47, p = .008$). A significant relationship also emerged between psychological distress at Time 1 and distress at Time 2 ($r = .38, p = .036$). No significant relationships emerged between negative attributional style and psychological distress for either time point.

Parent gender, duration of the child's illness, and Time 1 parent psychological distress were included as covariates due to theoretical reasons, as research suggests that they may potentially play an important role in cognitive appraisal mechanisms and their subsequent relationship to psychological distress (Thompson & Gustafson, 1996).

Primary Analyses

Hypothesis One. It was predicted that higher levels of parent perceived illness uncertainty at Time 1 would be significantly associated with an increase in parent psychological distress at Time 2, after controlling for parent gender (i.e., a demographic variable), duration of the child's illness (i.e., an illness parameter), and Time 1 distress. In order to examine this hypothesis, a hierarchical regression equation was constructed to examine the independent contribution of perceived illness uncertainty at Time 1 to psychological distress at Time 2 (as measured by the BSI; Derogatis, 1993). Parent gender was entered on block 1, duration of the child's illness was entered on block 2, and Time 1 parent psychological distress was entered on block 3. Finally, perceived illness uncertainty at Time 1 was entered on block 4 (please refer to Table 4 in Appendix A). Results indicated that illness uncertainty at Time 1 significantly predicted psychological distress at Time 2 ($t(25) = 2.05, p = .05$).

Hypothesis Two. It was also hypothesized that parent causal attributions for negative events at Time 1 would contribute significantly to an increase in parent psychological distress at Time 2. To examine this second hypothesis, a hierarchical regression equation was constructed to examine the independent contribution of Time 1 negative attributional style (as measure by the ASQ composite negative score) to Time 2 psychological distress. Similar to the first regression equation, parent gender was first entered on block 1, duration of the child's illness was then entered on block 2, followed by the entry of parent psychological distress at Time 1 on block 3. Negative attributional style was then entered on block 4 (please refer to Table 5 in Appendix A). Results

indicated that Time 1 negative attributional style did not significantly predict Time 2 psychological distress ($t(25) = -.48, p = .636$).

Research Question One. An additional focus of the current study involved examining whether an interaction between parent perceived illness uncertainty and negative attributional style at Time 1 would predict psychological distress at Time 2. To examine this research question, a third hierarchical regression equation was constructed. Parent gender was once again entered on block 1, duration of the child's illness was entered on block 2, parent psychological distress at Time 1 was entered on block 3, and parent perceived illness uncertainty and negative attributional style at Time 1 were entered on block 4. The interaction term generated by Time 1 illness uncertainty and negative attributional style was then entered on block 5, with both variables being centered in order to help reduce multicollinearity with the interaction term (Aiken & West, 1991; please refer to Table 6 in Appendix A). Results suggested that the interaction of illness uncertainty and negative attributional style at Time 1 did not significantly predict psychological distress at Time 2, ($t(23) = .44, p = .667$).

In summary, evaluation of the primary hypotheses and research question suggested that illness uncertainty at Time 1 was indeed predictive of psychological distress at Time 2; however, negative attributional style at Time 1, as well as the interaction of illness uncertainty and negative attributional style at Time 1, did not significantly predict psychological distress at Time 2 after controlling for parent gender and duration of the child's illness.

Exploratory Analyses

Preliminary analyses had suggested a number of significant interrelationships between illness uncertainty at Time 1 and distress at both Time 1 and Time 2. Thus, further analyses were conducted to determine whether illness uncertainty potentially mediates the association between Time 1 and Time 2 distress. In order for illness uncertainty to qualify as a mediator, the following relationships must be significant: a) the association between Time 1 distress and Time 2 distress, b) the association between Time 1 distress and illness uncertainty at Time 1, and c) the association between illness uncertainty at Time 1 and distress at Time 2, after controlling for Time 1 distress. Further, the relationship between Time 1 distress and Time 2 distress should no longer be significant after controlling for the relationships between Time 1 distress and uncertainty at Time 1, as well as uncertainty at Time 1 and distress at Time 2 (Holmbeck, 2002).

To test for mediation, Baron & Kenny (1986) require the construction of three regression equations. In all equations, parent gender was entered on block 1 and duration of the child's illness was entered on block 2. The first equation examined the relationship between Time 1 and Time 2 psychological distress. Results suggested that Time 1 distress was significantly related to Time 2 distress, ($t(26) = 2.15, p = .041$), with 22.6% of the variance of Time 2 distress being uniquely accounted for by Time 1 distress.

The second regression equation looked at the relationship between psychological distress and illness uncertainty at Time 1. Results from this analysis suggested that distress at Time 1 was significantly related to uncertainty at Time 1, with approximately 21.6% of the variance of illness uncertainty at Time 1 being associated with psychological distress at Time 1, ($t(26) = 2.50, p = .019$).

The last regression equation involved examining whether the relationship between Time 1 psychological distress and Time 2 psychological distress was significantly lower when illness uncertainty at Time 1 (i.e., potential mediating variable) was held constant. Results for this equation suggested that the relationship between Time 1 and Time 2 distress was indeed nonsignificant while controlling for uncertainty, ($t(25) = 1.14, p = .263$). Thus, the role of illness uncertainty at Time 1 as a mediator of the relationship between Time 1 and Time 2 psychological distress was established.

According to Holmbeck (2002), post-hoc probing of mediated effects is then necessary in order to examine whether significant mediation has occurred, and not simply a drop from significance to nonsignificance between the predictor and outcome. Since the drop to nonsignificance was not sufficient for full mediation (i.e., $p = .00$), Sobel's (1982) method was then utilized to test for partial mediation. Thus, two regression equations were constructed to test for the significance of the mediated effect of illness uncertainty at Time 1:

- 1) Hypothesized mediator (i.e., illness uncertainty at Time 1) regressed on the predictor (psychological distress at Time 1).
- 2) Outcome (i.e., psychological distress at Time 2) regressed on the mediator (i.e., illness uncertainty at Time 1), while controlling for the predictor (i.e., psychological distress at Time 1) and other covariates (e.g., parent gender, duration of the child's illness).

First, illness uncertainty at Time 1 (hypothesized mediator) was regressed on psychological distress at Time 1 (predictor; $B = .691, SE = .277, p = .019$). Then, psychological distress at Time 2 (outcome) was regressed on illness uncertainty at Time 1

(hypothesized mediator), after controlling for the influence of psychological distress at Time 1 (predictor), as well as other covariates (e.g., parent gender, duration of the child's illness; $B = .261$, $SE = .127$, $p = .051$). Results indicated a nonsignificant mediated effect of illness uncertainty at Time 1 on Time 1 and Time 2 psychological distress ($z = 1.59$, $p = .11$). Thus, the indirect effect of Time 1 distress on Time 2 distress is not significantly different from zero when illness uncertainty is introduced into the model (Holmbeck, 2002).

CHAPTER VI

DISCUSSION

The present study examined illness uncertainty and attributional style as predictors of distress in parents of children with DM1 through utilization of a longitudinal design. Hypothesis one predicted that higher illness uncertainty at Time 1 would predict greater psychological distress at Time 2, after controlling for distress at Time 1. Similarly, hypothesis two predicted that negative attributional style at Time 1 would predict greater psychological distress at Time 2, after controlling for distress at Time 1. A related research question examined whether the interaction of illness uncertainty and attributional style at Time 1 would predict psychological distress at Time 2.

Results of the present study supported the relationship stated in hypothesis one. Increased illness uncertainty at Time 1 significantly predicted increased psychological distress at Time 2 after controlling for both demographic and illness parameters. However, current results did not lend support to hypothesis two. Specifically, negative attributional style at Time 1 did not significantly predict increased distress at Time 2, while also controlling for both demographic and illness parameters.

A related research question in the present study examined whether the interaction between illness uncertainty and attributional style at Time 1 would be predictive of greater psychological distress at Time 2. Results failed to demonstrate an interaction between these variables.

The present findings clearly highlight the importance of continued examination of cognitive appraisal mechanisms (e.g., illness uncertainty, attributional style) in relation to psychological distress among children and families coping with chronic illness. Such mechanisms have served as important predictors of distress in a number of previous studies, both across illness groups and age of participants (e.g., children, adolescents, parents) (e.g., Chaney et al., 1996; Hoff et al., 2001; Mullins et al., 1997). More specifically, the current results indicate that increased illness uncertainty significantly predicts later manifestations of psychological distress among parents of children diagnosed with DM1. These results are consistent with cross-sectional findings by Mullins et al. (2000), whereby increased levels of illness uncertainty among young adults with long-standing asthma were predictive of higher levels of depressive symptomatology. Additionally, the extant literature has also demonstrated that illness uncertainty serves as a robust and significant predictor of psychological distress among other illness groups, including multiple sclerosis (Mullins et al., 2001; Wineman, 1990) and gynecological cancer (Padilla et al., 1992). Thus, not only are the present results highly consistent with previous research, but they also extend such findings by illustrating that perceived illness uncertainty can predict adjustment outcomes many years later.

The finding that negative attributional style at Time 1 did not significantly predict psychological distress at Time 2 among parents of children with DM1 is somewhat surprising in light of previous literature. For example, research by Kuttner et al., (1990) found that children diagnosed with DM1 with more negative attributional styles were more likely to experience greater difficulty in adjusting to their illness than those with

more positive attributional styles. More recently, Mullins and colleagues (1997) also established attributional style as a significant predictor of distress among a college sample of young adults with asthma. Further, the robustness of attributional style as a significant predictor of distress is not confined to only those experiencing chronic illness. Research with healthy populations has yielded results suggesting that healthy college students with more negative attributional styles are more likely to report a higher incidence of illness and poorer health (Lin & Peterson, 1990). Thus, attributional style appears to be a consistent predictor of distress among both chronically ill and healthy populations. A number of factors may explain the current findings. First, it may not have emerged as a significant predictor in the current study due to the relatively small sample size and subsequent low power to be able to detect significance. Second, the fact that reliability estimates for the ASQ in the current study were only acceptable (.71) may also aid in explaining why the current results were nonsignificant, especially when coupled with a small sample. Lastly, since the Composite Negative score of the ASQ is comprised of three dimensions (e.g., internal negative, stable negative, global negative) whose inter-correlations are relatively small, the utility of the Composite Negative as a target variable of interest is diminished (Robins & Block, 1989).

A related research question of the present study sought to examine whether the interaction of illness uncertainty and negative attributional style at Time 1 would predict psychological distress at Time 2 among parents of children with DM1. This interaction was also nonsignificant. As mentioned earlier, both illness uncertainty and attributional style have been identified as significant predictors of distress among a number of illness groups, as well as healthy populations (Chaney et al., 1996; Chaney et al., 1997; Mullins

et al., 1997). However, it appears that in the current study, low sample size, power, and only acceptable reliability estimates for the ASQ could have once again contributed to the lack of significance in the interaction term.

The examination of illness uncertainty at Time 1 as a potential mediator in the relationship between Time 1 and Time 2 psychological distress was also assessed through exploratory analyses. Specifically, regression analyses indicated that illness uncertainty at Time 1 indeed mediated the relationship between distress at Time 1 and Time 2. In other words, uncertainty accounted for a portion of the association between distress at the two time points. However, it was also important to examine the significance of this mediator into the predictor -- outcome model. Thus, post-hoc probing of the mediated effect, as suggested by Holmbeck (2002) was undertaken. Results suggested that illness uncertainty at Time 1 was not a significant mediator of Time 1 and Time 2 distress. In other words, the indirect effect of distress at Time 1 on distress at Time 2, via illness uncertainty as the mediator, was not significantly different from zero. Certainly, it appears that uncertainty continues to play a very important role in its relationship to distress, although in the current case it appears to be a nonsignificant mediator. And, since post-hoc probing of both moderated and mediated effects is still relatively new to the literature (i.e., 2002), it is impossible to examine whether illness uncertainty serves as a significant mediator among other variables of interest in chronic illness.

Other exploratory analyses were aimed at determining whether the participants who met caseness criteria for psychological distress at Time 1 were different from those who met caseness at Time 2 (Derogatis, 1993). Interestingly, only two of the seven participants who met caseness criteria at Time 1 still met criteria at Time 2. Also notable

was the fact that six additional participants who were not distressed at Time 1 later met caseness criteria. Thus, it appears that a number of individuals experienced stabilization of their level of adjustment over time. It may also be the case that the participants who appeared distressed at Time 2, but were not at Time 1, may have experienced a number of other significant life events (e.g., loss of a loved one, unemployment) since baseline. Certainly, it is impossible to delineate whether their parental distress levels at Time 2 are directly or indirectly related to their child's diagnosis of DM1. Regardless of the reason, however, it still appears that for the most part, there are a small subsample of participants who remain distressed over time. In fact, some research suggests that level of initial adjustment is predictive of later adjustment across a number of illness groups (Kovacs et al., 1990). Consequently, it becomes important to identify such individuals early on, and develop interventions designed to reduce their levels of psychological distress.

Strengths and Limitations

There are several strengths of the present study, one of which involves the utilization of a longitudinal design. Previous research has explored the psychological adjustment of both parents and children with DM1; however, this research has focused solely on short-term, cross-sectional outcomes (Charron-Prochownik & Kovacs, 2000; Mullins et al., 1995). Thus, longer term outcomes for both children with DM1 and their parents have virtually gone unexamined. Thus, the present study contributes to the extant literature by longitudinally investigating predictors of psychological adjustment of parents of children with DM1.

Another strength of the present study involves the investigation of parent adjustment outcomes through utilization of specific cognitive appraisal mechanisms,

specifically illness uncertainty and attributional style. To the author's knowledge, this is the first examination of its kind in the literature in that it includes both illness uncertainty and attributional style as potential predictors of distress over time in parents of children with DM1. Thus, findings from this present study have the potential to open up new areas of research regarding how parents of children with DM1 adjust to such a chronic illness, and what, if any, interventions can be developed to aid those parents who are not adjusting as well as might be expected.

Lastly, the current study recognizes the need to further explore the nature of mediated effects, as recently suggested by Holmbeck (2002). Although a mediated effect of illness uncertainty on Time 1 and Time 2 psychological distress was demonstrated, it was then important to decipher how significant this effect was. Despite the fact that the current mediated effect was nonsignificant, these findings pave the path for future researchers to continue post-hoc probing of both moderated and mediated effects.

Importantly, the present study is not without its limitations. First, the small sample size limits the power to detect differences. In other words, the nonsignificant relationships between the predictor and criterion variables in hypothesis two and research question one does not mean that no such relationships exist, but rather that we may have simply not had sufficient power to be able to detect them. Additionally, generalization of the present findings to other populations may be limited by the self-selected nature of the sample; clearly, differences may exist between those who participated and those who chose not to take part in the study. Thus, it is possible that the current individuals chose to participate because they were not as distressed as nonparticipants. Indeed, previous

research with parents of children with DM1 has suggested that those who choose not to participate may be more distressed than those that do participate (Cote, 2001).

Another limitation of the present study concerns its exclusive use of self-report inventories. Reliance upon these types of measures indeed brings up the possibility of shared method variance and social desirability. Although for the most part, reliability estimates for the BSI and PPUS were quite good (i.e., $r = .92-.96$, $.88$, respectively), such estimates for the ASQ were not quite as high and even somewhat questionable (i.e., $r = .71$). Thus, this brings up the question of whether the nonsignificance of attributional style as a predictor of psychological distress is the result of this lower reliability. In fact, prior research has even shown that the three dimensions utilized to form the composite negative attribution score (which was one of the primary foci of the current study), have very low reliability estimates themselves (Robins & Block, 1989). Thus, it seems likely that utilizing a more psychometrically sound instrument may result in detection of differences. Further, future studies could benefit from utilization of a multi-method, multi-informant approach. For example, researchers would do well to include not only self-report inventories, but also diagnostic interviews, as well as utilize multiple sources (e.g., parents, children, friends, acquaintances). Lastly, the sample was relatively homogeneous in terms of both ethnicity and socioeconomic status, making it difficult to be able to generalize these results to other groups.

Clinical Implications

The results of the present study lend support for a number of clinical interventions. Illness uncertainty certainly appears to be an important predictor of Time 2 psychological distress. Consequently, clinical interventions should focus on reducing

illness uncertainty in parents of children with DM1. Indeed, research is beginning to emerge that documents the effectiveness of such efforts (Hoff et al., 2002; Wysocki et al., 2000). Such interventions should take place as soon after diagnosis as possible, as this may maximize the possibility of positive adjustment to occur. This timing may be especially important in planning interventions, as prior research has indicated that initial adjustment is predictive of later adjustment, among both children with chronic illness and their parents (Kovacs et al., 1990; Jacobson et al., 1986).

In addition, examination of the zero-order correlation matrix indicated that Time 1 distress was significantly related to Time 2 distress. Such results hold important clinical implications. Specifically, further research should aim at providing parents of children with chronic illness with a number of interventions designed to decrease their initial level of psychological distress. Such interventions should focus largely on education about the child's illness and its course, but should also incorporate cognitive coping skills and the establishment of social support networks. These clinical interventions have proven to be widely successful in aiding individuals suffering from psychological distress across a number of conditions and ages (Barlow, 2001). Thus, it would seem likely that the same mechanisms could be utilized with parents of children with chronic illness.

Summary and Future Directions

The results of the current study indicate that increased illness uncertainty at Time 1 is predictive of greater psychological distress at Time 2, even after controlling for demographic (i.e., gender) and illness (i.e., illness duration) variables. Additionally, it appears that negative attributional style at Time 1 is not predictive of distress at Time 2. Further, the interaction of illness uncertainty and negative attributional style at Time 1

also does not significantly predict distress at Time 2. Interestingly, illness uncertainty at Time 1 appears to mediate the relationship between Time 1 and Time 2 distress, although not to a significant degree according to Holmbeck's (2002) criteria for post-hoc probing.

Given the fact that these cognitive appraisal mechanisms (i.e., illness uncertainty, attributional style) have consistently shown to predict distress and/or adjustment across a number of illness groups (Chaney et al., 1996; Hoff et al., 2001; Mullins et al., 1997), further exploration of these constructs is warranted. In continuing this line of research, researchers would do well to gain access to larger samples of parents and children with chronic illness. In this manner, more power could be generated to detect differences that may otherwise go unnoticed. Additionally, samples with more heterogeneity, whose results could thus be extrapolated to other groups, would also be wise to recruit. Third, future work in this line of research should strive to accumulate data from multiple time points, thus allowing a more thorough comparison of adjustment outcomes over an extended period. The selection of time points might also be aimed at including critical developmental periods in children's lives (e.g., transition from childhood to adolescence, transition from adolescence to adulthood), as adjustment at these times may be likely to fluctuate. Moreover, future research should attempt to identify other possible mediators and their subsequent relationship to adjustment outcomes, both in parents and children with chronic illness. Lastly, researchers should aim to include multi-method, multi-informant measures in their data collection procedures. Interview components, aside from self-report inventories, could potentially contribute important information not necessarily gathered through a standard pencil-and-paper measure. Researchers should also attempt to utilize self-report inventories which are disease-specific, and thus have the

ability to assess more relevant constructs than a more general measure. In this manner, a more comprehensive evaluation of all mechanisms and adjustment outcomes would be possible.

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APPENDIXES

APPENDIX A

TABLES 1 - 6

Table 1

Parent Demographic Variables

Variable	<i>n</i>	<i>M</i>	<i>P</i>	<i>SD</i>
Age		43.67		5.08
Gender				
Male	04		13.3	
Female	26		86.7	
Ethnicity				
Caucasian	26		86.7	
Native-American	03		10.0	
African-American	01		3.3	
Annual Income Level				
20,000-29,999	02		6.7	
30,000-39,999	03		10.0	
40,000-49,999	06		20.0	
50,000-59,999	01		3.3	
60,000 or greater	18		60.0	

Table 2

Descriptive Statistics for Study Variables

Variable	<i>M</i>	<i>SD</i>
Illness Parameters		
Duration	8.67	3.82
Time 1 Variables of Interest		
PPUS	63.47	13.41
ASQ	77.07	11.85
BSI	52.47	8.65
Time 2 Variables of Interest		
PPUS	64.00	16.25
ASQ	78.77	11.98
BSI	53.33	9.29

Note. Duration = Time since diagnosis; PPUS = Parent Perception of Uncertainty Scale; ASQ = Attributional Style Questionnaire, Composite Negative; BSI = Brief Symptom Inventory Global Severity Index.

Table 3

Zero-Order Correlations for Selected Study Variables

Variable	1	2	3	4	5	6	7	8
1. Age	---	.16	.10	.17	-.28	-.17	-.03	.11
2. Gender		---	.01	-.18	-.11	.02	-.15	-.28
3. Income			---	.10	-.10	-.12	-.25	-.23
4. Duration				---	-.11	.22	-.15	.15
5. PPUS, T1					---	-.00	.46*	.47**
6. ASQ, T1						---	-.10	-.01
7. BSI, T1							---	.38*
8. BSI, T2								---

Note. Duration = Time since child's diagnosis; PPUS T1 = Parent Perception of Uncertainty Scale, Time 1; Attributional Style Questionnaire, Composite Negative, Time 1; Brief Symptom Inventory, Global Severity Index, Time 1; Brief Symptom Inventory, Global Severity Index, Time 2, * $p < .05$, ** $p < .01$.

Table 4

Summary of Hierarchical Regression Analysis For Examining the Influence of Illness Uncertainty at Time 1 in Predicting Psychological Distress at Time 2 (N = 30)

Variable	<i>B</i>	<i>SE B</i>	β
Block 1			
Gender	-8.52	5.52	-.28
Block 2			
Duration	.25	.45	.10
Block 3			
BSI, T1	.41	.19	.38*
Block 4			
PPUS, T1	.26	.13	.38*

Note. Duration = Time since diagnosis; BSI T1 = Brief Symptom Inventory, Global Severity Index, Time 1; PPUS T1 = Parent Perception of Uncertainty Scale, Time 1; * $p < .05$.

Table 5

Summary of Hierarchical Regression Analysis For Examining the Influence of Negative Attributional Style at Time 1 in Predicting Psychological Distress at Time 2 (N = 30)

Variable	<i>B</i>	<i>SE B</i>	β
Block 1			
Gender	-8.52	5.52	-.28
Block 2			
Duration	.25	.45	.10
Block 3			
BSI, T1	.41	.19	.38*
Block 4			
ASQ, T1	-.01	.14	-.01

Note. Duration = Time since diagnosis; BSI T1 = Brief Symptom Inventory, Global Severity Index, Time 1; ASQ T1 = Attributional Style Questionnaire, Composite Negative, Time 1; * $p < .05$.

Table 6

Summary of Hierarchical Regression Analysis For Examining the Interaction of Time 1 Illness Uncertainty and Attributional Style in Predicting Psychological Distress at Time 2 (N = 30)

Variable	B	SE B	β
Block 1			
Gender	-8.52	5.52	-.28
Block 2			
Duration	.25	.45	.10
Block 3			
BSI, T1	.41	.19	.38*
Block 4			
PPUS, T1	.26	.13	.38†
ASQ, T1	-.02	.13	-.03
Block 5			
PPUS X ASQ	.00	.01	.08

Note. Duration = Time since diagnosis; BSI T1 = Brief Symptom Inventory, Global Severity Index, Time 1; PPUS T1 = Parent Perception of Uncertainty Scale, Time 1; ASQ T1 = Attributional Style Questionnaire, Composite Negative, Time 1; PPUS X ASQ = Interaction term; † = * p = .055.

APPENDIX B
INSTRUMENTS

Background Information

Today's Date _____ Subject Number _____

1. Child's Name: _____ Age: _____
 2. Mother's Name: _____ Age: _____
 3. Father's Name: _____ Age: _____
 4. Name of person filling out this form and relationship to child (e.g., mother): _____

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

Name	Relation to child	Age
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

6. Telephone number: _____

7. Child's Gender: Male Female
 1 2

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

Other: _____

9. Child's Grade: _____

10. Special Education: Yes _____ No _____ If yes, please specify what type:

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

12. Parents' Occupations: Father _____ Mother _____

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

14. Please indicate your total family income: _____ 0-4,999 _____ 30,000-39,999
 (This information will be held _____ 5,000-9,999 _____ 40,000-49,999
 strictly confidential). _____ 10,000-14,999 _____ 50,000-59,000
 _____ 15,000-19,999 _____ 60,000 or greater
 _____ 20,000-29,999

Health Information Questionnaire (HIQ)

Subj. No. _____

1. How long has your child had his/her chronic illness? _____

2. At what age was your child diagnosed with his/her chronic illness?

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

1	2	3	4	5	6	7
<i>Doesn't cope well at all</i>			<i>Copes moderately well</i>			<i>Copes extremely well</i>

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

1	2	3	4	5	6	7
<i>Extremely poor health</i>			<i>Average health</i>			<i>Extremely good health</i>

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

1	2	3	4	5	6	7
<i>Not at all compliant</i>			<i>Adherent about half (50%) of the time</i>			<i>Adherent all (100%) of the time</i>

6. Please list below the medications your child is currently prescribed.

_____	_____
_____	_____
_____	_____
_____	_____

1. Please indicate the number of outpatient clinic visits your child scheduled and attended in the last year that were directly or indirectly related to their illness.

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

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

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

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

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

6. How do you pay for your child's medical supplies?

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

7. Please estimate the dollars per month you spent this year on health insurance premiums. \$_____per/month

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

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

10a. **Insurance/HMO/PPO beneficiaries:** Do you stay in your current employment situation because of concern over obtaining new health benefits?

Yes No

10b. **Medicaid beneficiaries:** Do you stay in your current living situation to keep medicaid benefits?

Yes No

11. Are you concerned that your child will have difficulty obtaining health benefits when they are adults?

Yes No

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

1	2	3	4	5	6	7
<i>Not</i>			<i>Moderately</i>			<i>Constantly</i>
<i>Worried</i>			<i>Worried</i>			<i>Worried</i>

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

1	2	3	4	5	6	7
<i>Not</i>			<i>Moderately</i>			<i>Constantly</i>
<i>Worried</i>			<i>Worried</i>			<i>Worried</i>

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

1	2	3	4	5	6	7
<i>Not</i>			<i>Moderately</i>			<i>Constantly</i>
<i>Worried</i>			<i>Worried</i>			<i>Worried</i>

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

1	2	3	4	5	6	7
<i>No</i>			<i>Moderate</i>			<i>Extreme</i>
<i>Change</i>			<i>Change</i>			<i>Change</i>

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

1	2	3	4	5	6	7
<i>Extreme</i>			<i>Moderate</i>			<i>Like</i>
<i>Dislike</i>			<i>Liking</i>			<i>Extremely Well</i>

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

1	2	3	4	5	6	7
<i>Extreme</i>			<i>Moderate</i>			<i>Like</i>
<i>Dislike</i>			<i>Liking</i>			<i>Extremely Well</i>

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

1	2	3	4	5	6	7
<i>No</i>			<i>Moderate</i>			<i>Extreme</i>
<i>Trust</i>			<i>Trust</i>			<i>Trust</i>

19. Please indicate how well you comply with the illness management team recommendations.

1	2	3	4	5	6	7
<i>No</i>			<i>Moderate</i>			<i>Complete</i>
<i>Adherence</i>			<i>Adherence</i>			<i>Adherence</i>

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

Yes No

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

Yes

No

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

Yes

No

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

Please read each statement. Take your time and think about what each statement says. Then circle the number under the words that most closely reflect how you feel about your child's illness and its treatment. Your choices range from "Strongly Agree" to "Strongly Disagree." Please respond to every statement.

1. I don't know what is wrong with my child.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

2. I have a lot of questions without answers.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

3. I am unsure if my child's illness is getting better or worse.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

4. It is unclear how bad my child's physical discomfort will be.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

5. The explanations they give about my child seem hazy to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

6. The purpose of each treatment for my child is clear to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

7. I don't know when to expect things will be done to my child.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

8. My child's symptoms continue to change unpredictably.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

9. I understand everything explained to me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

10. The doctors say things to me that could have many meanings.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

11. I can predict how long my child's illness will last.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

12. My child's treatment is too complex to figure out.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

13. It is difficult to know if the treatments and medications my child is getting are helping.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

14. There are so many types of medical staff, it is unclear who is responsible for what.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

15. Because of the unpredictability of my child's illness, I cannot plan for the future.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

16. The course of my child's illness keeps changing. He/she has good and bad days.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

17. It is vague to me how I will manage the care of my child after leaving the hospital/doctor's office.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

18. It is not clear what is going to happen to my child.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

19. I usually know if my child is going to have a good or bad day.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

20. The results of my child's tests are inconsistent.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

21. The effectiveness of the treatment for my child's illness is undetermined.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

22. It is difficult to determine how long it will be before I can care for my child's illness by myself.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

23. I can generally predict the course of my child's illness.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

24. Because of the treatment, what my child can do and cannot do keeps changing.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

25. I'm certain they will not find anything else wrong with my child.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

26. They have not given my child a specific diagnosis.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
5	4	3	2	1

27. My child's physical distress is predictable; I know when it is going to get better or worse.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

28. My child's diagnosis is definite and will not change.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

29. I can depend on the nurses to be there when I need them.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

30. The seriousness of my child's illness has been determined.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

31. The doctors and nurses use everyday language so I can understand what they are saying.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1	2	3	4	5

Directions:

Read each situation and VIVIDLY imagine it happening to you. Decide what you believe would be ONE major cause of the situation if it happened to you and write this cause in the blank provided. Answer three questions about the cause by circling ONE NUMBER per question. DO NOT circle the words.

YOU MEET A FRIEND WHO COMPLIMENTS YOU ON YOUR APPEARANCE.

1) Write down the ONE major cause:

2) Is the cause of your friend's compliment due to something about you or something about other people or circumstances?

Totally due to other people or circumstances 1 2 3 4 5 6 7 Totally due to me

3) In the future when you are with a friend, will this cause again be present?

Will never again be present 1 2 3 4 5 6 7 Will always be present

4) Is the cause something that just affects interacting with friends, or does it also influence other areas of your life?

Influences just this particular situation 1 2 3 4 5 6 7 Influences all situations in my life

YOU HAVE BEEN LOOKING FOR A JOB UNSUCCESSFULLY FOR SOME TIME.

5) Write down the ONE major cause:

6) Is the cause of your unsuccessful job search due to something about you or something about other people or circumstances?

Totally due to other people or circumstances 1 2 3 4 5 6 7 Totally due to me

7) In the future when you look for a job, will this cause again be present?

Will never again be present 1 2 3 4 5 6 7 Will always be present

8) Is the cause something that just influences looking for a job, or does it also influence other areas of your life?

Influences just this particular situation 1 2 3 4 5 6 7 Influences all situations in my life

YOU BECOME VERY RICH.

9) Write down the ONE major cause:

10) Is the cause of your becoming rich due to something about you or something about other people or circumstances?

Totally due to other people or circumstances 1 2 3 4 5 6 7 Totally due to me

11) In your financial future, will this cause again be present?

Will never again be present 1 2 3 4 5 6 7 Will always be present

12) Is the cause something that just affects obtaining money, or does it also influence other areas of your life?

Influences just this particular situation 1 2 3 4 5 6 7 Influences all situations in my life

A FRIEND COMES TO YOU WITH A PROBLEM & YOU DON'T TRY TO HELP HIM/HER.

13) Write down the ONE major cause:

14) Is the cause of your not helping your friend due to something about you or something about other people or circumstances?

Totally due to other people or circumstances 1 2 3 4 5 6 7 Totally due to me

15) In the future when a friend comes to you with a problem, will this cause again be present?

Will never again be present 1 2 3 4 5 6 7 Will always be present

16) Is the cause something that just affects what happens when a friend comes to you with a problem, or does it also influence other areas of your life?

Influences just this particular situation 1 2 3 4 5 6 7 Influences all situations in my life

YOU GIVE AN IMPORTANT TALK IN FRONT OF A GROUP & THE AUDIENCE REACTS NEGATIVELY.

17) Write down the ONE major cause:

18) Is the cause of the audience's negative reaction due to something about you or something about other people or circumstances?

Totally due to other people or circumstances 1 2 3 4 5 6 7 Totally due to me

19) In the future when you give talks, will this cause again be present?

Will never again be present 1 2 3 4 5 6 7 Will always be present

20) Is the cause something that just influences giving talks, or does it also influence other areas of your life?

Influences just this particular situation 1 2 3 4 5 6 7 Influences all situations in my life

YOU DO A PROJECT WHICH IS HIGHLY PRAISED.

21) Write down the ONE major cause:

22) Is the cause of your being praised due to something about you or something about other people or circumstances?

Totally due to other people or circumstances 1 2 3 4 5 6 7 Totally due to me

23) In the future when you do a project, will this cause again be present?

Will never again be present 1 2 3 4 5 6 7 Will always be present

24) Is the cause something that just affects doing projects, or does it also influence other areas of your life?

Influences just this particular situation 1 2 3 4 5 6 7 Influences all situations in my life

YOU MEET A FRIEND THAT ACTS HOSTILELY TOWARDS YOU.

25) Write down the ONE major cause:

26) Is the cause of your friend acting hostile due to something about you or something about other people or circumstances?

Totally due to other people or circumstances 1 2 3 4 5 6 7 Totally due to me

27) In the future when interacting with friends, will this cause again be present?

Will never again be present 1 2 3 4 5 6 7 Will always be present

28) Is the cause something that just influences interacting with friends, or does it also influence other areas of your life?

Influences just this particular situation 1 2 3 4 5 6 7 Influences all situations in my life

YOU CAN'T GET ALL THE WORK DONE THAT OTHERS EXPECT OF YOU.

29) Write down the ONE major cause:

30) Is the cause of your not getting your work done due to something about you or something about other people or circumstances?

Totally due to other people or circumstances 1 2 3 4 5 6 7 Totally due to me

31) In the future when doing work that others expect, will this cause again be present?

Will never again be present 1 2 3 4 5 6 7 Will always be present

32) Is the cause something that just affects doing work that others expect of you, or does it also influence other areas of your life?

Influences just this particular situation 1 2 3 4 5 6 7 Influences all situations in my life

YOUR SPOUSE (BOYFRIEND/GIRLFRIEND) HAS BEEN TREATING YOU MORE LOVINGLY.

33) Write down the ONE major cause:

34) Is the cause of your spouse (boyfriend/girlfriend) treating you more lovingly due to something about you or something about other people or circumstances?

Totally due to other people or circumstances 1 2 3 4 5 6 7 Totally due to me

35) In the future with your spouse (boyfriend/girlfriend), will this cause again be present?

Will never again be present 1 2 3 4 5 6 7 Will always be present

36) Is the cause something that just affects how your spouse (boyfriend/girlfriend) treats you, or does it also influence other areas of your life?

Influences just this particular situation 1 2 3 4 5 6 7 Influences all situations in my life

YOU APPLY FOR A POSITION THAT YOU WANT VERY BADLY (E.G., IMPORTANT JOB, GRADUATE SCHOOL ADMISSION, ETC.) & YOU GET IT.

37) Write down the ONE major cause:

38) Is the cause of your getting the position due to something about you or something about other people or circumstances?

Totally due to other people or circumstances 1 2 3 4 5 6 7 Totally due to me

39) In the future when you apply for a position, will this cause again be present?

Will never again be present 1 2 3 4 5 6 7 Will always be present

40) Is the cause something that just influences applying for a position, or does it also influence other areas of your life?

Influences just this particular situation 1 2 3 4 5 6 7 Influences all situations in my life

YOU GO OUT ON A DATE & IT GOES BADLY.

41) Write down the ONE major cause:

42) Is the cause of the date going badly due to something about you or something about other people or circumstances?

Totally due to other people or circumstances 1 2 3 4 5 6 7 Totally due to me

43) In the future when you are dating, will this cause again be present?

Will never again be present 1 2 3 4 5 6 7 Will always be present

44) Is the cause something that just influences dating, or does it also influence other areas of your life?

Influences just this particular situation 1 2 3 4 5 6 7 Influences all situations in my life

YOU GET A RAISE.

45) Write down the ONE major cause:

46) Is the cause of your getting a raise due to something about you or something about other people or circumstances?

Totally due to other people or circumstances 1 2 3 4 5 6 7 Totally due to me

47) In the future on your job, will this cause again be present?

Will never again be present 1 2 3 4 5 6 7 Will always be present

48) Is the cause something that just affects getting a raise, or does it also influence other areas of your life?

Influences just this particular situation 1 2 3 4 5 6 7 Influences all situations in my life

**Physician Ratings:
Illness Information, Illness Severity, and Treatment Adherence**

Date:

Physician's Name:

Child's Name:

Most recent HbA_{1c} :

Please circle the number which reflects the **overall severity** level of this child's chronic illness.

1	2	3	4	5	6	7
Extremely good health		Moderate health			Extremely poor health	

Please circle the number which reflects **how well this child adheres** to the treatment recommendations.

1	2	3	4	5	6	7
Extremely compliant		Moderately compliant			Not Compliant at all	

APPENDIX C
INSTITUTIONAL REVIEW BOARD
APPROVAL FORMS

Oklahoma State University
Institutional Review Board

Protocol Expires: 11/25/2003

Date: Tuesday, November 26, 2002

IRB Application No AS0334

Proposal Title: PARENTS OF CHILDREN DIAGNOSED WITH DIABETES: A LONGITUDINAL STUDY

Principal
Investigator(s):

Melissa Carpenter
215 N. Murray
Stillwater, OK 74078

Larry Mullins
414 N Murray
Stillwater, OK 74078

Reviewed and
Processed as: Expedited

Approval Status Recommended by Reviewer(s): Approved

Dear PI :

Your IRB application referenced above has been approved for one calendar year. Please make note of the expiration date indicated above. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 45 CFR 46.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be submitted with the appropriate signatures for IRB approval.
2. Submit a request for continuation if the study extends beyond the approval period of one calendar year. This continuation must receive IRB review and approval before the research can continue.
3. Report any adverse events to the IRB Chair promptly. Adverse events are those which are unanticipated and impact the subjects during the course of this research; and
4. Notify the IRB office in writing when your research project is complete.

Please note that approved projects are subject to monitoring by the IRB. If you have questions about the IRB procedures or need any assistance from the Board, please contact Sharon Bacher, the Executive Secretary to the IRB, in 415 Whitehurst (phone: 405-744-5700, sbacher@okstate.edu).

Sincerely,



Carol Olson, Chair
Institutional Review Board



The University of Oklahoma

Health Sciences Center

OFFICE OF RESEARCH ADMINISTRATION

IRB Number: 03694
Meeting Date: May 20, 2002
Amendment Approval Date: August 21, 2002

August 30, 2002

Larry Mullins, Ph.D.
Oklahoma State University
215 N. Murray
Stillwater, OK 74078

RE: IRB No. 03694: An Assessment of Coping in Children With Chronic Illness and Their Families

Dear Dr. Mullins:

The Institutional Review Board (IRB) reviewed your protocol modification form at the meeting on May 20, 2002. It is the Board's judgement that this modification allows for the rights and welfare of the research subjects to be respected. Further, the Board determined that the study will continue to be conducted in a manner consistent with the requirements of 45 CFR 46 or 21CFR 50 & 56 as amended; and that the potential benefits to subjects and others warrant the risks subjects may choose to incur.

This letter documents approval to conduct the research as described in:

Protocol Dated: June 25, 2002

Consent form - Subject Dated: August 01, 2002

Amend Form Dated: June 25, 2002

Amendment Summary:

Protocol Revision - Acquisition of longitudinal data from participants who previously completed baseline measures.

On behalf of the IRB, the Chair has verified that the specific changes requested by the Full Board at the convened meeting have been made. Therefore, on behalf of the Board, approval for this study has been granted based on the information reviewed by the Board.

This letter covers only the approval of the above referenced modification. All other conditions, including the original expiration date, from the approval granted July 15, 2002 are still effective.

If consent form revisions are a part of this modification, then you will be provided with a new stamped copy of your consent form. Please use this stamped copy for all future consent documentation. Please destroy all outdated versions of this consent form.

If you have any questions about these procedures or need additional assistance from the Board, please do not hesitate to call the IRB office at (405) 271-2045 or send an email to irb@ouhsc.edu.

Sincerely yours,

Alberta Yadack, R.N., M.P.H.

Assistant Director, Human Research Participant Protection

Ltr_Amend_Final_Appv

Post Office Box 20901 • 1000 S.L. Young Blvd., Room 121
Oklahoma City, Oklahoma 73190 • (405) 271-2090 • FAX: (405) 271-8651

 **INTEGRIS**
Baptist Medical Center

3100 Northwest Expressway
Oklahoma City, OK 73112-4481
(405) 949-3011
www.integris-health.com

April 15, 2002

Larry Mullins M.D.
Department of Psychology
215 N. Murray Hall
Stillwater, OK 74078

Dear Dr. Mullins:

The Institutional Review Board of INTEGRIS Baptist Medical Center, Inc. met on Monday, 04/15/02 at 12:30 p.m. in the Bennett Conference Room and reviewed the amendment/revision to this previously approved protocol:

Adaptation to Pediatric Chronic Illness: Utilization of Disease Specific Research
Methodology (G9701151)

Type of Amendment - Change in both the protocol, *c.f.* and letter of approach

The Principal Investigator and sub-investigators were not present during the vote. The Board *approves* this amendment/revision to the previously approved protocol. *This amendment does not affect the renewal date of the protocol; renewal is still required on a yearly basis.* Unanticipated problems involving risks to subjects or others must be promptly reported to the I.R.B. In the event the study closes prior to the renewal date, proper notification to the I.R.B. is required.

Sincerely,


R.C. Brown, M.D., Chairman
Institutional Review Board

RCB/sm



VITA

Melissa Y. Carpentier

Candidate for the Degree of

Master of Science

Thesis: ILLNESS UNCERTAINTY AND ATTRIBUTIONAL STYLE AS
PREDICTORS OF DISTRESS IN PARENTS OF CHILDREN DIAGNOSED
WITH DIABETES: A LONGITUDINAL STUDY

Major Field: Psychology

Biographical:

Education: Graduated from Hebbronville High School, Hebbronville, Texas in May 1998; received Bachelor of Arts degree, Magna Cum Laude, in Psychology from Our Lady of the Lake University, San Antonio, Texas in May 2001. Completed the requirements for the Master of Science degree with a major in Clinical Psychology at Oklahoma State University in August, 2003.

Experience: Research – Acting Graduate Research Assistant for the Adaptation to pediatric chronic illness: Utilization of disease specific research methodology, a grant funded by Olsten Health Care Corporation, August, 2001 to present. Employed as a Graduate Research Assistant for the OCAST project, a grant funded by the Oklahoma Center for the Advancement of Science and Technology, May 2003 to August 2003. Clinical – Acting Psychological Associate at the Oklahoma State University Psychological Services Center, August 2001 to present. Provide group treatment for preschool children at the University of Oklahoma Health Sciences Center, Center for Child Abuse and Neglect, a grant funded by Children's Medical Research Fund, June 2003 to present. Conduct ADHD/developmental evaluations and provide therapeutic services for children/families at the University of Oklahoma Health Sciences Center, Child Studies Center, July 2003 to present.

Professional Memberships: American Psychological Association; Division 38, Health Psychology; Division 53, Society of Clinical Child and

Adolescent Psychology; Division 54, Society of Pediatric Psychology;
Association for Advancement of Behavior Therapy; Southwestern
Psychological Association; Oklahoma Psychological Association.