AN INTERVENTION TO DECREASE ILLNESS UNCERTAINTY AND PSYCHOLOGICAL DISTRESS AMONG PARENTS OF CHILDREN NEWLY DIAGNOSED WITH TYPE 1 DIABETES:

A RANDOMIZED CLINICAL TRIAL

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CHAPTER I

INTRODUCTION

Type 1 diabetes is one of the most common chronic illnesses of childhood in the United States, with incidence rates second only to asthma (Centers for Disease Control Media Relations, 1998). Type 1 diabetes is a condition in which the body ceases to produce insulin or produces insufficient amounts of insulin. Insulin is an essential hormone that "unlocks" the body's cells, allowing glucose to enter the cell where it can be used as fuel (Grey, 1992). In the case of type 1 diabetes, insulin must be regulated through daily injections to manage glucose levels in the blood. Therefore, individuals with diabetes are required to monitor blood glucose, administer insulin, and monitor their diet on a daily basis in order to prevent and address diabetes-related complications. If glucose and insulin requirements are not balanced, serious short and long term complications can result (American Diabetes Association [ADA], 1997).

Examining parental adjustment to pediatric chronic illness is an important area of investigation, not only for understanding overall parental functioning and well-being, but also because of the significant relationship between parent adjustment and child adjustment. Parents of children with type 1 diabetes are confronted with the management of a complicated treatment regimen, including insulin administration, monitoring glucose levels, maintaining a strict and balanced diet, and exercise plan. In addition, parents must manage such complications as hypo- and hyperglycemia, as well as attend regular follow-up visits. Potentially, hospitalizations may occur. Thus, the demanding nature of having a child diagnosed with diabetes and the subsequent management of a complicated regimen constitute potential stressors in the lives of these parents. It has been suggested that such stress places parents of children with type 1 diabetes at considerable risk for experiencing psychological distress (e.g., Mullins et al., 1995).

Indeed, across a number of illness groups, parents of children with a chronic illness report higher rates of distress when compared to parents of medically well children and to normative data (Cadman, Rosenbaum, Boyle, & Offord, 1991; Silver, Westbrook, & Stein, 1998; Timko, Stovel, & Moos, 1992; Wallander et al., 1989). Specific to the current study, significantly more parents of children newly diagnosed with type 1 diabetes score in the clinically significant range on measures of psychological distress than a normative sample (Northam, Anderson, Adler, Werther, & Warne, 1996). Collectively, these findings suggest that parents of children with a chronic illness are at greater risk for experiencing psychological distress than parents of children without a chronic illness. However, many parents and their children adjust well. Determining those factors that predict distress in the context of chronic illness remains a primary goal.

Thus, research on the distress of parents has now evolved beyond examining rates of distress to use of theory-driven models to identify risk and resilience factors that influence psychological functioning. Environmental factors, such as socioeconomic status (Baskin, Forehand, & Saylor, 1986; Kovacs, Gastonia et al., 1990) and concurrent stress (Hauenstein, Marvin, Snyder, & Clarke, 1989) have been identified as variables that potentially influence adjustment and distress among parents of a child with a chronic illness. Illness duration has also been associated with parental adjustment. Specifically, parents tend to experience increased distress immediately following diagnosis which diminishes during the subsequent year (Kovacs, Iyengar, Goldston et al., 1990; Northam et al., 1996; Parker, Swift, Botha, & Raymond, 1994). Parent perceptions of social support have also been associated with distress, with greater social support associated with less distress (Barakat & Linney, 1992; Morrow, Hoagland, & Carnike, 1981; Timko et al., 1992) and better physical health (Wallander et al., 1989) among a number of illness groups.

Individual factors, such as coping strategies and cognitive appraisals, also appear to influence parental adjustment and distress (Mullins et al. 1991; Thompson, Gil, Burbach, Keith, & Kinney, 1993; Thompson, et al., 1994; Timko et al., 1992). For example, it has been demonstrated that mothers who utilize primarily emotion-focused coping styles report poorer adjustment than mothers who utilize more problem-focused coping styles (Thompson et al., 1993; Thompson et al., 1994). Identifying ways in which each of these variables collectively influence parental distress holds important implications for the psychological functioning and physical health of both the parent and child.

Parental distress has been found to significantly influence child distress both in the context of pediatric chronic illness and medically-well populations (Bleil, Ramesh, Miller, & Wood, 2000; Chaney, 1991; Chaney et al., 1997; Hauser, Jacobson, Wertlieb, Brink, & Wentworth, 1985; Mullins et al., 1995; Parker et al., 1994; Thompson, Zeman, Fanurik, & Sirortkin-Roses, 1992; Thompson et al., 1993; Thompson & Gustafson, 1996). Interestingly, increased distress among fathers (Chaney et al., 1997) and mothers

(Mullins et al., 1995; Chaney, 1991) has been significantly associated with child distress independent of demographic and disease parameters. Findings from these studies highlight the significant relationship of parental to child functioning in the context of type 1 diabetes. Therefore, a greater understanding of the variables that influence parental distress are important for both overall parent *and* child functioning.

Increasingly, cognitive appraisal variables have been identified as salient predictors of psychological distress. One cognitive variable that potentially influences parental distress is parental illness uncertainty. Uncertainty in illness is defined as "the inability to determine the meaning of illness-related events that occur in situations where the decision maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes because sufficient cues are lacking" (Mishel, 1990; p. 257). Ambiguity concerning the state of the illness, complexity regarding treatment, lack of information about the seriousness of illness and prognosis, and unpredictability of the illness course are all potential sources of uncertainty during an illness experience (Mishel, 1984).

A number of studies support Mishel's theory of uncertainty, demonstrating a strong relationship between illness uncertainty and psychological distress among adults from a variety of illness groups (e.g., Bennett, 1993; Christman et al., 1988; Hawthorne & Hixon, 1994; Warrington & Gottlieb, 1987; Webster & Christman, 1988; Wineman, 1990; Wineman, O'Brian, Nealon, & Kaskel, 1993). Overall, these studies have found that a lack of information regarding one's illness or treatments (Mishel & Braden, 1988), a lack of social support (Mishel & Braden,1987), and a lack of perceived control (Mishel & Braden,1987) are all associated with higher levels of perceived uncertainty, and subsequently poorer overall psychosocial functioning (Christman, 1990; Mishel & Sorenson, 1991). Increased levels of uncertainty have been related to perceiving less hope (Christman, 1990; Mishel, 1984) and perceiving the feeling of uncertainty as a danger (Mishel, Padilla, Grant, & Sorenson, 1991; Mishel & Sorenson, 1991). Higher levels of uncertainty have also been related to psychological problems such as decreased quality of life (Braden, 1990; Padilla, Mishel, & Grant, 1992), as well as increased mood disturbance and feelings of anxiety (Bennett, 1993; Christman et al., 1988). Clearly, illness uncertainty bears a robust relationship to adjustment to illness.

Notably, relatively few intervention studies have targeted parents of children with chronic illness, particularly early in the course of the illness and, to date, no interventions have been developed to specifically decrease illness uncertainty among parents. Still, the treatment intervention studies conducted with parents of children with a chronic illness have produced some promising results. First, extant studies have demonstrated that interventions with parents of children with an illness can result in improvements in treatment adherence and physical health of the child (Delamater et al., 1990). Second, interventions have resulted in improved parent-child relations and reductions in illness-related conflict (Wysocki, White, Bubb, Harris, & Greco, 2000). Third, interventions with parents of children with a chronic or life-threatening illness have yielded improvements in both parent and child psychological functioning (Melnyk, Albert-Gillis, Hensel, Cable-Beiling, & Rudenstein, 1997). More specifically, psychosocial interventions for parents have resulted in decreased marital distress (Walker, Johnson, Manion, & Clotier, 1996), as well as decreased maternal stress, increased maternal participation and support during medical procedures, fewer post traumatic stress disorder

(PTSD) symptoms, and increased role certainty (Melnyk et al., 1997). Further, given the association between parental and child adjustment, it stands to reason that interventions improving parental functioning will subsequently influence child adjustment to chronic illness as well.

Thus, effective interventions have been developed for parents of children from a number of illness groups. And although, interventions have been developed to decrease parent-child conflict among adolescents with type 1 diabetes, no interventions have been developed to decrease illness uncertainty and subsequent distress among parents of children newly diagnosed with type 1 diabetes. Therefore, the purpose of the current study is to evaluate the efficacy of a treatment intervention for parents of children newly diagnosed with type 1 diabetes. This intervention is also unique in that: (a) it will target a decrease in parental distress, (b) it will target reduction of uncertainty as a method of decreasing parental distress, and (c) will examine changes in child adjustment and distress following a parent-based intervention. The following literature review begins with a description of the nature of type 1 diabetes so as to provide a basic understanding of the disease itself, and to illustrate the relevance of the uncertainty construct to those with type 1 diabetes. This is followed by a review of the literature regarding the adjustment of parents with children with diabetes, including a discussion of the cognitive factors that may influence their psychological adjustment. Specifically, Mishel's theory of illness uncertainty will be explored, highlighting those aspects of illness uncertainty that may be pertinent to parents of children with type 1 diabetes (Cohen, 1993; 1995;

Stewart & Mishel 2000). Finally, extant psychosocial treatment intervention studies for parents of children with a chronic illness or for children and adolescents with type 1 diabetes will be examined.

CHAPTER II

LITERATURE REVIEW

Type 1 Diabetes: Description of the Illness

Second only to asthma, type 1 diabetes is the next most common childhood chronic illness in the United States. Each year, approximately 11,000 to 12,000 new cases of type 1 diabetes are diagnosed, with an estimated 123,000 children in the United States presently living with diabetes (Centers for Disease Control Media Relations, 1998; Harris, 1995). The peak age for onset of diabetes is during the pubertal years, but it may be diagnosed at any age (LaPorte, Matsushima, & Chang, 1995). Type 1 diabetes is one of a group of conditions in which glucose (sugar) levels in the blood are abnormally high. Type 1 diabetes occurs when the pancreas stops making enough insulin, which is necessary for the proper metabolism of digested foods. When an individual eats, foods containing proteins, fats, and carbohydrates are broken down into simpler, easily absorbed chemicals, one of which is called glucose. Glucose circulates in the blood stream where it is available for body cells to use to as energy for various cell functions. Insulin is the hormone that “unlocks” the cells of the body so glucose is able to enter and fuel them (Grey, 1992). Insulin also allows the body to store excess glucose as fat, proteins as muscle protein, and regulates enzymes involved in the control of metabolism. Insulin therefore serves a critical and essential function for life itself.

Insulin is produced by the pancreas, a large gland located behind the stomach. In individuals with diabetes, the pancreas produces too little or no insulin because the insulin producing beta cells located there have been destroyed by the body’s immune system (Grey, 1992). Currently, it is still unknown as to why the body's immune system attacks and destroys insulin-producing beta cells. A combination of factors may be involved, including exposure to viruses or other substances early in life, as well as an inherited risk for type 1 diabetes (Thai & Eisenbarth, 1993).

The initial symptoms of type 1 diabetes result from the build-up of glucose in the blood and its loss in the urine. To eliminate glucose in the urine, the kidney "borrows" water from the body. The loss of this extra glucose and water in the urine results in dehydration, which causes increased thirst. Thus, initial symptoms of type 1 diabetes can include frequent urination (particularly at night), increased thirst, unexplained weight loss (in spite of increased appetite), and extreme tiredness.

Individuals with diabetes must always balance food, exercise, and insulin to control blood sugar levels. When this balance is disrupted, low blood sugar (hypoglycemia) or high blood sugar (hyperglycemia) may result. Hypoglycemia occurs when there is very low blood sugar, a condition which is caused by too much insulin, too little or delayed food, exercise, alcohol, or any combination of these factors (Grey, 1992). When hypoglycemia occurs, a person can become cranky, tired, sweaty, hungry, confused, and shaky. If blood sugar levels drop too low, a person can lose consciousness or experience a seizure. Hyperglycemia is the opposite of hypoglycemia, occurring when the body has too much sugar in the blood. This condition may be caused by insufficient insulin, overeating, inactivity, illness, stress, or a combination of these factors. Symptoms of hyperglycemia include extreme thirst, frequent urination, fatigue, blurred vision, vomiting, and weight loss (ADA, 1997).

If blood sugar levels remain high, a build up of ketones may also occur. Ketones are chemicals that the body makes when insulin levels are very low and excessive amounts of fat are being burned. Ketoacidosis occurs when ketones buildup over several hours, and can lead to coma or death. Signs of ketoacidosis include vomiting, weakness, rapid breathing, abdominal pain, extreme tiredness, and drowsiness and a sweet breath odor (ADA, 1997).

Complications

Over time, failure to effectively manage diabetes may result in a host of health-related problems. Diabetes can cause damage to both large and small blood vessels, resulting in complications affecting the kidneys, eyes, nerves, heart, and gums (ADA,1997). Diabetic nephropathy is caused by damage to the blood vessels of the kidneys and may cause the kidneys to stop working, a condition referred to as end-stage renal disease. Obviously, this can be a life-threatening complication, and individuals who experience kidney failure must either have their blood cleaned by a dialysis machine or have a kidney transplant. Diabetic retinopathy is caused by changes in the tiny vessels that supply the retina with blood. In severe cases of retinopathy, vision may be impaired.

Neuropathy (neuronal disease), may also occur in some patients with diabetes. Symptoms of neuropathy can include pain, numbing, burning, loss of feeling, and in more severe cases, paralysis. Neuropathy may also cause digestive problems, impotence and incontinence. Individuals with diabetes, especially those with poor control of their blood sugar, are also at risk for developing periodontal disease, such as gingivitis. In addition, there is a higher incidence of high blood pressure and heart disease among individuals with diabetes than in individuals without diabetes. People with type 1 diabetes tend to have more fat and cholesterol in their arteries, which increases their risk for experiencing a heart attack. Those with type 1 diabetes are also at greater risk for stroke and other forms of large blood vessel disease (ADA, 1998).

Type 1 Diabetes Management

Type 1 diabetes requires constant attention and daily care to keep blood sugar levels in balance. Injecting insulin, testing blood sugar, following a diet, and exercising are some of the day-to-day requirements. Insulin injections are administered via needle and syringe, or an insulin pump (ADA, 1997). There are different types of insulin available, which differ primarily in terms of onset and duration. The different types of insulin are generally used in combination to achieve optimum insulin and glucose regulation. The amount of insulin needed depends the individual's height, weight, age, food intake, and activity level. Insulin doses must be balanced with meal times and activities, and dosage levels can be affected by illness, stress, or unexpected events. Self-monitoring of blood glucose (SMBG), which typically occurs three to four times per day, helps individuals monitor their diabetes control and determine if adjustments in insulin, diet, or exercise are needed (ADA, 1997). Close monitoring of food intake is also important because different foods have varying effects on blood sugar (ADA, 1997).

Finally, exercise is important to diabetes management because it increases the efficiency of insulin absorption (ADA, 1997).

Due to the complicated nature of type 1 diabetes, a multidisciplinary team is often required to provide comprehensive care to the child with this illness. The team may include an endocrinologist or diabetologist, a diabetes educator, a nutritionist or dietitian, a mental health professional, a podiatrist and a dentist. However, the most important person on the treatment team is considered to be the individual with diabetes themselves (ADA, 1998). The individual with diabetes is responsible for monitoring blood glucose, administering insulin, monitoring their diet, noticing any problems, and taking action when needed. Therefore the adjustment of the individual with diabetes is central to successful diabetes management (Blake, 1991).

Although research has been conducted on diabetes for many years, considerable gains have been made during the last decade in the prevention, management and in finding a potential cure for diabetes. In terms of prevention, antibodies have been identified in the blood that make a person susceptible to type 1 diabetes, thus making it possible to screen relatives of people with diabetes and determine their risk for developing the disease (National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], 1994). The Diabetes Prevention Trial-Type 1 began in 1994, the goal being to identify relatives at risk for developing type 1 diabetes and treating them with low doses of insulin or with oral insulin-like agents in the hope of preventing type 1 diabetes.

Advances in the management of type 1 diabetes also continue to develop. The Diabetes Control and Complications Trial (DCCT; 1993) compared two approaches to managing type 1 diabetes: intensive versus standard treatment. Intensive diabetes management involved attempts to maintain normal or near normal glycemic control through individualized medication regimens, more frequent SMBG, active adjustment of food, medication and activities, carbohydrate counting and ongoing involvement with a health care team. The standard treatment plan is the less strict, traditional form of treatment. Patients in the standard treatment group tested their blood glucose one to two times a day and took their insulin less often. At the end of the DCCT, volunteers receiving intensive treatment had lower rates of kidney, eye, and nerve damage than volunteers in the standard treatment group. Thus, results showed that efforts to improve control of blood sugar made a major difference in terms of decreasing health complications due to diabetes. In fact, the study found that any long-term lowering of blood sugar levels tended to reduce the risk of diabetic complications. However, intensive treatment does increase the risk of hypoglycemia, and therefore is not recommended for certain groups, particularly older adults, children under age 13, individuals with heart problems or advanced complications, and people with a history of frequent severe hypoglycemia (DCCT, 1993).

Other advances in diabetes management focus on the development of new insulin administration techniques and new types of treatments. Researchers have recently developed alternatives to injected insulin such as oral or inhaled insulin (Juvenile Diabetes Foundation [JDF], 1998). In addition, there have been advances in the development of genetically-engineered insulin, which reduces a patient's risk of developing skin and other allergic reactions. These advances seek to facilitate regimen adherence and prevent complications until a cure for diabetes is found.

Research efforts to cure diabetes are focusing on treatment innovations that can permanently restore normal blood sugar levels in diabetes patients, prevent and reverse the complications caused by diabetes, and prevent new cases of diabetes and its recurrence (JDF, 1998). Transplantation of human insulin-producing cells, improvements in transplantation tolerance, gene transfer and cell engineering, and prevention of kidney disease and other complications are some of the present projects aimed at developing a cure for diabetes (JDF, 1998).

Parental Adjustment to Pediatric Chronic Illness

Examining parental adjustment to pediatric chronic illness is an important area of investigation, not only for understanding overall parental functioning and well-being, but also because of the significant relationship of parent to child distress. Although, there is an extensive body of literature examining parental distress in the context of childhood chronic illness, literature examining psychological distress among parents of children with type 1 diabetes is relatively limited. In addition, most studies have examined family adjustment as a whole, rather than adjustment and distress among parents themselves (e.g, Hanson, De Guire, Schinkel, Henggeler, & Burghen, 1991; Seiffge-Krenke, 1998), leaving a critical gap in the literature. This lack of research is striking given that parents of children with type 1 diabetes confront a complicated treatment regimen including insulin administration, monitoring glucose levels, maintaining a strict and balanced diet and exercise plan. Parents also must appropriately respond to unpredictable complications such as hypo- and hyperglycemia and manage routine and unanticipated medical care. Thus, the demands placed on these parents are quite unique. In the following section, the current literature on rates of distress and correlates of psychological adjustment and distress are reviewed. This review will include a brief synopsis of chronic illness in general, followed more specifically with a discussion of type 1 diabetes.

Rates of Distress Among Parents of Children with Chronic Illnesses

Although most parents of children with a chronic illness adapt fairly well to their child's illness, a significant minority do not. Across a number of illness groups, parents of children with a chronic illness report higher rates of distress when compared to parents of medically well children and to normative data (Cadman et al., 1991; Silver et al., 1998; Wallander et al., 1989). The types of distress observed among parents of children with chronic illness include increased depressive symptoms (Mullins et al., 1991), greater negative affective states (Cadman et al., 1991), higher global psychological distress (Chaney et al., 1997; Northam et al., 1996; Silver et al., 1998), and more self-reported physical health symptoms (Wallander et al., 1989). Higher rates of distress across illnesses suggest that, as a group, parents of children with chronic or life-threatening illness constitute a population at-risk for experiencing chronic distress.

Very few studies have examined rates of distress specifically among parents of children with type 1 diabetes. Of the studies that have been conducted, the majority have demonstrated that the prevalence of distress among parents of children with diabetes tend to change based on the duration of the illness. Parents of children newly diagnosed with type 1 diabetes tend to score significantly higher on measures of psychological distress in comparison to a community sample (Northam et al., 1996) or normative data (Kovacs, Iyengar, Goldston, Obrosky et al., 1990) immediately following initial diagnosis. Yet, in both studies, rates of distress among parents of children with diabetes were not significantly different from community norms or normative data one-year post diagnosis (Kovacs, Iyengar, Goldston, Obrosky et al., 1990; Northam et al., 1996). The potential influence of illness duration on distress will be discussed further later in the chapter.

In another longitudinal study, Chaney et al. (1997) examined rates of distress among parents of children with diabetes over a one-year period. They found that a fairly large proportion of the mothers and fathers met caseness criteria on a multidimensional measure of distress, and that these rates remained stable over time. At time one, 27% of the mothers and 31% of the fathers met caseness criteria, demonstrating that a significant proportion of the sample was experiencing distress. At one-year follow-up, 21% of the mothers and 32% of the fathers met caseness criteria. The relative stability of the distress rates observed in this study, compared to previous studies that observed declining rates of distress (Kovacs, Iyengar, Goldston, Obrosky et al., 1990; Northam et al., 1996), could potentially be due to the fact that the majority of the parents in the Chaney et al., (1997) sample had children diagnosed for longer than a year. This suggests that a subset of parents continue to experience psychological distress well beyond the first year following diagnosis.

Although studies examining rates of distress among parents are plagued by a number of methodological and measurement issues (i.e., use of different measures, populations, and criterion), they are important in that they demonstrate that parents of children with a chronic illness are potentially at greater risk for experiencing psychological distress than parents of children without a chronic illness. However, only examining rates of distress between illness groups neglects possible subtle disease differences (i.e., disease features, course, task demands), as well as other cognitive variables, and environmental factors, that possibly influence the process by which distress develops (Mullins et al., 1995; Thompson, Hodges, & Hamlett, 1990). Research on the adjustment of parents has now evolved beyond exclusively examining rates of distress to using theory driven models to identify risk and resistance factors that influence adjustment.

Correlates of Parental Adjustment to Childhood Illness

Increasingly, theoretical models have guided the examination of risk and resistance factors among parents (e.g., Thompson et al., 1994; Wallander & Varni, 1992). A number of environmental, social, and individual variables have been found to be associated with distress among parents of children with a chronic illness. In the following sections, studies examining distress among parents of children from other illness groups will be presented due to the limited number of studies examining distress specifically among parents of children with diabetes. Each section below will begin with a discussion of relevant findings from studies examining other illness groups, followed by studies examining diabetes specifically.

Socioeconomic Status

Socioeconomic status (SES) has been found to be a significant risk factor for parents of children with a chronic illness (Baskin et al., 1986; Walker, Oritz-Vales, & Newbrough, 1989). Walker and colleagues (1989) examined the relationship of SES to maternal depression and child behavior among mothers of children with diabetes, cystic fibrosis, or mental retardation. Regardless of diagnostic group membership, SES independently accounted for a significant proportion of the variance in maternal depression and maternal-rated child behavior problems. Contrary to other studies where low SES is associated with increased distress, Kovacs and colleagues (1990) found mothers of children with diabetes from *higher* SES groups reported more depressive symptoms than mothers from lower SES groups. The authors speculated that mothers from higher SES groups may be more educated and more knowledgeable about diabetes, and as a result, view it in a more discouraging light (Kovacs, Iyengar, Goldston, Obrosky et al., 1990).

Notably, findings regarding SES and its relationship to distress among parents of children with type 1 diabetes are somewhat limited. A more informative direction for future research would be to examine specific SES factors, such as poor housing and poor education, that often accompany being a member of a low SES group and determine how these specific factors are related to increased distress among parents of children with a chronic illness.

Concurrent Stress

Among illness groups such as cystic fibrosis (Mullins et al., 1991), and leukemia (Kupst & Schulman, 1988) increased concurrent stress has been associated with poor parental adjustment and distress. For example, Mullins et al. (1991) found that reported levels of maternal anxiety and hostility, but not depression, were related to higher levels of family stress within the past year among mothers of children with cystic fibrosis. Levels of concurrent stress have also been associated to the parent's ability to effectively cope with their child's leukemia (Kupst & Schulman, 1988). Parents who reported lower levels of concurrent stress were able to cope more effectively (i.e., retain objectivity, maintain concentration, tolerate ambiguity, and maintain responsiveness) with their child's illness.

Similar findings have been found among mothers of children with diabetes. In a study by Hauenstein et al. (1989) mothers of children with Type 1 diabetes reported higher rates of parenting stress than mothers of healthy children. In addition, Hauenstein et al. (1989) identified specific factors associated with levels of stress experienced among parents. Specifically, they found that the age of the child was associated with increased levels of stress among mothers in their study. Mothers of children with diabetes, who were under the age of three, reported higher levels of stress than parents of older children. Such findings are consistent with the results of another study which found higher parental stress to be associated with their child's age and the complexity of their child's treatment regimen (Hatton, Canam, Thorne, & Hughes, 1995). Both of these studies are important in that they illustrate potential illness-specific stressors that parents may confront in the context of diabetes. Unfortunately, neither of these studies examined the relationship of stress to psychological functioning.

Illness Duration

Psychological distress among parents of children with a chronic illness tends to change over the duration of the illness. Findings suggest that parents tend to experience increased distress immediately following diagnosis (Northam et al., 1996). Specifically, studies suggest that parents of children with type 1 diabetes endorse higher rates of psychological distress at the time of diagnosis than parents of healthy children or of normative groups (Kovacs, Iyengar, Goldston, Obrosky et al., 1990; Northam et al., 1996; Parker et al., 1994). However, parental distress tends to diminish within the year following diagnosis. At a one-year follow-up, Northam et al.(1996) found no significant differences in distress rates between parents of children with diabetes and the normative group.

However, other studies suggest that parental distress may persist for some individuals beyond the first year following diagnosis. Parker and colleagues (1994) found that while parents' anxiety about hypoglycemia and blood and urine monitoring diminished over time, they reported increased concerns about employment prospects and long-term diabetic complications and increased anxiety about vascular complications (Parker et al., 1994). Likewise, in a longitudinal study of mothers of children with type 1 diabetes, levels of maternal psychological distress decreased six to nine months after initial diagnosis (Kovacs, Iyengar, Goldston, Obrosky et al., 1990). However, a six-year follow-up study revealed that after the initial decline in depressive symptoms over the first year, maternal psychological distress (i.e., symptoms of anxiety, somatization, anger, suspiciousness, depression, and dysphoria) again increased over the remaining duration of the illness. The increase in maternal-reported distress continued despite the fact that mothers reported that the diabetes regimen was easier to manage over time, indicating that maternal distress increased over the duration of the illness independently of the perceived complexity of the treatment regimen. Notably, the emotional distress reported by mothers immediately after the diagnosis was significantly associated with later symptomatology (Kovacs, Iyengar, Goldston, Obrosky et al., 1990). These findings illustrate the need for additional longitudinal research to examine the potential long-term effects of having a child with type 1 diabetes on parental psychological functioning.

Social Support

Social support factors have also been associated with parental adjustment to chronic illness. Greater social support has been associated with better adjustment and better physical health among a number of illness groups, including juvenile rheumatic disease (Timko et al., 1992), cancer (Morrow et al., 1981) and the physically handicapped (Barakat & Linney, 1992; Wallander et al., 1989). The relationship between family supportiveness and adjustment has also been demonstrated among parents of children with Duchenne muscular dystrophy (Thompson et al., 1992), spina bifida (Kronenberger & Thompson, 1992), and sickle cell disease (Thompson et al., 1994).

Greater social support has also been associated with decreased psychological distress among mothers of children with diabetes. For example, mothers of children with diabetes reported that they felt less support from their spouses, viewed their child as more demanding, and described themselves as having poorer health than mothers of medically well children (Hauenstein et al.,1989). Hence, increased social support appears to serve a protective function for parents of children with a chronic or life-threatening illness.

Cognitive Appraisals and Coping

Individual factors also appear to influence parental adjustment and distress. Studies suggest that mothers of children with a chronic illness who primarily use emotion-focused coping strategies tend to demonstrate poorer adjustment than mothers who utilized more problem-focused strategies (Mullins et al., 1991; Thompson et al., 1993; Thompson et al., 1994; Timko et al., 1992). Among mothers of children with diabetes, Kovacs and colleagues (1990) found that the extent to which mothers perceived the treatment regimen as "difficult" was associated with higher levels of concurrent distress. Maternal psychological distress was also related to how "bothersome" management of the illness was perceived to be by the mother (Kovacs, Iyengar, Goldston, Obrosky et al., 1990).

In a recent study by Charron-Prochownik and Kovacs (2000), mothers of children with diabetes considered family integration and understanding the medical situation as helpful coping strategies. Unfortunately, parental distress was not examined in this study. However, in another study, maternal coping style was associated with maternal depressive symptoms, where a more behaviorally-oriented coping style was associated with fewer symptoms of depression (Blankfeld & Holahan, 1996). These studies add further support for the hypothesis that illness specific cognitive appraisals and coping style influence levels of psychological distress among parents of children with a chronic illness.

Although a plethora of research has examined overall family functioning and diabetes (e.g., Cerreto & Mendlowitz, 1983; Hanson et al., 1991; Hauser et al., 1985; Hauser et al., 1990; Hauenstein et al., 1989; Seiffge-Krenke, 1998) literature specifically examining parental distress is limited. Type 1 diabetes is unique in that it presents acute and chronic illness events that are potential sources of stress for both parent and child. Therefore, more research is needed to identify disease specific processes by which distress develops among parents of children with type 1 diabetes. Identifying ways in which these and other variables independently and collectively influence parental distress holds important implications for the psychological functioning and physical health of both the parent and child.

Relationship of Parental Adjustment to Child Adjustment in Pediatric Illness

Parental adjustment has been found to significantly influence child adjustment both in the context of pediatric chronic illness and in medically-well populations (Bleil et al., 2000; Chaney, 1991; Chaney et al., 1997; Hauser et al., 1985; Mullins et al., 1995; Parker et al., 1994; Thompson, Gustafson, Hamlett, & Spock, 1992; Thompson et al., 1993; Thompson & Gustafson, 1996). These studies serve to illustrate the transactional nature of distress and adjustment in the context of pediatric illness. Transactional relationships have been found to be especially pertinent among diabetes populations, as illustrated in the following.

In the context of type 1 diabetes, maternal distress has been frequently associated with child distress. Among mothers of children with type 1 diabetes, maternal level of distress at the time of diagnosis was a better predictor of child distress at a one-year follow-up than initial child distress (Chaney, 1991). Likewise, maternal depressive symptoms were associated with increased depressive symptomatology among children with type 1 diabetes, independent of disease and demographic parameters (Mullins et al., 1995). Still, other investigators have not found a significant relationship between maternal and child depressive symptoms in the same population (Kovacs, Iyengar, Goldston, Obrosky et al., 1990). However, this may be due to methodological and measurement issues unique to this study, as the association between maternal distress and child distress has been well documented in the literature in medically well and non-medically well populations (Beardslee, Bemporad, Keller, & Klerman, 1983; Burge & Hammen, 1991; Rubin, Both, Zahn-Waxler, Cummings, & Wilkinson, 1991).

Notably, parental adjustment has also been associated with the child's regimen adherence and metabolic control. Child regimen adherence and metabolic control has been related to parental perceptions of family functioning; children of parents who view their family as more cohesive demonstrated better regimen adherence and metabolic control than those children of parents who reported lower levels of family cohesion (Cerreto & Mendlowitz, 1983; Hauser et al., 1990; Hauenstein et al., 1989). In another study, metabolic control of adolescents with diabetes was significantly associated with the physiological reactivity of parents to an acute stressor (Mengel et al., 1992). Finally, maternal sense of empowerment has been shown to significantly influence adherence and control among children with diabetes (Florian & Elad, 1998). Florian & Elad (1998) defined empowerment as a psychological resource, including the mother's attitudes, knowledge and behavior in a variety of contexts. Maternal sense of empowerment was significantly associated with their adolescents' adherence to treatment regimens and metabolic control, especially for girls.

Transactional patterns of mother, father, and child, distress in families with a child with type 1 diabetes was most clearly illustrated in a study by Chaney et al. (1997). Interestingly, Chaney et al. (1997) found that increased distress among fathers, but not mothers, was significantly associated with child adjustment independent of demographic and disease parameters. Reciprocally, levels of maternal and child distress were associated with levels of paternal distress. Further, at a one-year follow-up Chaney et al. (1997) found that increased paternal distress was associated with decreased maternal distress. Findings of this study underscore the significance of the father-child relationship in adjustment to type 1 diabetes. Moreover, this study demonstrates the transactional relationship between maternal and paternal distress. The authors concluded that these findings highlight the importance of a "biobehavioral family treatment" approach to management of families of children with type 1 diabetes and other chronic illnesses.

Findings from these studies clearly demonstrate the relationship of parental distress to child distress, treatment adherence, and metabolic control. Clearly, more research is needed to determine factors that influence parental adjustment to having a child with type 1 diabetes and how parental adjustment transactionally influences child adjustment. Given the unpredictable, ambiguous and uncertain nature of type 1 diabetes, illness uncertainty may be a cognitive appraisal variable that holds particular significance for adjustment among parents of children with type 1 diabetes. Consequently, the construct of illness uncertainty is examined in detail in the next section followed by a review of the extant literature on parental uncertainty.

Illness Uncertainty

Illness uncertainty has been found to influence psychological adaptation during diagnosis, treatment, and stabilization periods of an illness (Mishel, 1984; Mishel & Braden, 1987). The concept of uncertainty in illness has burgeoned over the past 18 years, an inquiry which was facilitated by the development of the Mishel Uncertainty in Illness Scale (MUIS) in 1981. Mishel (1988; 1990) has formulated two models of uncertainty in illness. Initially, Mishel's concept of uncertainty only applied to those experiencing acute illness events. In 1990, she reconceptualized the theory, making the concept applicable to chronic illnesses as well (Mishel, 1990). Mishel (1995) emphasizes that the two uncertainty models are not interchangeable.

A detailed discussion of Mishel's conceptualization of uncertainty for both acute and chronic illnesses is warranted for two reasons. First, it allows deeper understanding of the concept of uncertainty through an examination of both models. Second, acute and chronic illness events occur simultaneously and are overlapping throughout the course of type 1 diabetes. Acute illness refers to those individuals receiving "active medical treatment" and long-term chronic illness refers to those individuals receiving ongoing "maintenance treatment." In the case of diabetes, an acute illness event would be a hypoglycemic or hyperglycemic attack and the long-term chronic illness phase is the prevention of complications such as neuropathies through near-normal glycemic control. Thus, both models are potentially applicable in the case of diabetes.

Mishel defines uncertainty as:

> the inability to determine the meaning of illness-related events that occur in situations where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes because sufficient cues are lacking. (1990, p. 27)

There are four potential sources of uncertainty proposed by Mishel (1988) during an illness experience: ambiguity concerning the state of the illness, complexity regarding treatment, lack of information about the seriousness of illness and prognosis, and unpredictability of the course (Mishel, 1984). Mishel (1988) developed the first model of illness uncertainty to address the acute phase of illness and individuals undergoing active medical treatment. She outlined four stages of illness uncertainty: antecedents, uncertainty appraisal, coping and adaptation. Each of these stages are discussed below.

Antecedents

Antecedents are variables that precede, accompany and/or influence uncertainty. Mishel (1988) grouped antecedent variables into three main categories: the stimuli frame, cognitive capacities of the individual, and structure providers. The stimuli frame includes variables such as symptom pattern, event familiarity, and event congruence. The symptom pattern refers to the intensity, severity, frequency, number, location and duration of symptoms. Interestingly, Mishel (1988) suggests that the consistency of the characteristics of the symptom pattern is more important than the quality of characteristics. The more consistent the symptom pattern is, the less illness uncertainty expected to be experienced. Familiarity with the illness and symptoms and treatments, including the novelty and complexity of the situation, may also influence uncertainty. The newer the situation, the higher the degree of uncertainty in that situation. Likewise, as the complexity of a situation increases, familiarity decreases and the perception of uncertainty in the situation increases. Finally, event congruence refers to the disparity between what is expected in a situation and what actually occurs. For example, when a treatment does not produce the expected results or improve the way the patient feels, incongruence may be perceived. As disparity between expected and actual events increase, the level of uncertainty is also expected to increase.

A second antecedent factor which may influence the level of uncertainty is the cognitive capacity of the individual. Cognitive capacities refer to the individual's processing ability relative to the illness-related event and personal beliefs regarding the illness event. Cognitive capacities not only vary interpersonally, but also intrapersonally. Clearly, different individuals will bring to an illness event their own intellectual abilities and preexisting knowledge. However, these capacities may fluctuate throughout the illness intrapersonally (i.e., within the person) as the effects of illness symptoms, treatment and stress affect cognitive processing abilities (Mishel, 1988).

The last element of stimuli frame outlined by Mishel (1988) are structure providers. Structure providers include the individual's level of education, confidence in health care providers, social support, and demographic variables. The level of illness-specific and general education may influence the way in which uncertainty is managed and experienced. Social support is vital in helping the individual process the illness related information, likely through feedback regarding illness related thoughts and events (Mast, 1995). Demographic variables such as age, marital status, socioeconomic status

(SES), employment, and education may also influence the uncertainty experience (Mishel, 1988).

Uncertainty Appraisal

The second stage of acute illness uncertainty is uncertainty appraisal, in which the individual recognizes and cognitively classifies the uncertainty. Uncertainty appraisal is mediated by inferences and illusions (Mishel, 1988). Inference refers to the evaluation of uncertainty using related experience that one recalls, and is influenced by personality dispositions, general knowledge, previous experience with similar situations and contextual cues (Mishel, 1988). Through uncertainty appraisal, the event may be classified as either a threat or as an opportunity. The situation is classified as a threat or danger when the event is experienced as uncontrollable. Events that are viewed as controllable are viewed as an opportunity. Illusions are beliefs that are generated through uncertainty. When uncertainty is mediated by an illusion, the uncertainty is appraised as an opportunity. The beliefs are generally positive in nature and are thought to be particularly beneficial to the patient when the disease outcome is projected to be a negative certainty. In other words, the perception of uncertainty allows for the illusion of hope in an seemingly hopeless situation (Mishel, 1988).

Coping

The relationship between appraisal and subsequent adaptation is thought to be mediated by coping strategies (Mishel & Sorenson, 1991). Coping refers to the attitudes and behaviors used to manage the uncertainty. Mishel and Sorenson (1991), incorporating concepts of Folkman, Lazarus, Dunkel-Schetter, DeLongis, and Gruen, (1986), posit two ways of coping with illness uncertainty: problem-focused or emotion-focused coping. Problem-focused or emotion-focused coping strategies are employed to manage the uncertainty generated by a danger appraisal. Problem-focused coping involves direct actions, vigilance and/or information seeking. Emotion-focused coping strategies are thought to be employed when problem-focused coping techniques have not been effective in reducing levels of uncertainty, and there is a lack of perceived control or ability to modify uncertainty. Emotion-focused coping strategies are sometimes referred to as buffering strategies. Buffering strategies include thoughts and behaviors such as avoidance, selective ignoring, reordering priorities and neutralizing. According to Mishel and Sorenson (1991) these strategies serve to maintain uncertainty which may otherwise be replaced by a negative certainty.

Adaptation

Thus, appraisal and coping strategies are theorized to subsequently influence adaptation. The more effective the coping strategies, the better the adaptation is expected to be. Successful adaptation by the individual experiencing uncertainty is defined as the ability to maintain functioning within the normal range of their behavior. Conversely, unsuccessful adaptation is indicated by engagement of behaviors outside of the individual's previous level of function, and a reduction in goal directed behaviors. Psychosocial adjustment, quality of life, and health are identified as indicators of an individual's positive adaptation (Mishel, 1988).

Reconceptualization of Illness Uncertainty Theory:

Uncertainty in Chronic Illness

As stated, Mishel's original model of uncertainty applies to patients with acute illnesses in the active phases of treatment. Mishel (1990) reconceptualized the original uncertainty model to create a second model which addresses the uncertainty experienced by those experiencing chronic illness or life threatening illness following an acute active illness phase (p. 258). The amended model of uncertainty emphasizes the continual and unpredictable experience of uncertainty that accompanies chronic illnesses, and suggests that eventually the individual may begin to view uncertainty as an inherent and less threatening part of reality. From this perspective, the uncertainty is eventually accepted and viewed as an opportunity, possibly leading to personal growth. The philosophy of the amended theory represents a shift in focus from a model where successful adaptation is viewed as the achievement of equilibrium and stabilization to a model where the focus is "self-organization and growth" (Mishel, 1990, p. 258).

The process Mishel (1990) describes is one in which the uncertainty itself is a catalyst for self-organization. She proposes that as the length of uncertainty increases, there is an increased sense of disorganization and instability. The preexisting cognitive schema of the individual experiencing the uncertainty is no longer adequate in assigning meaning to the illness related events. Therefore, there is a breakdown of the previous cognitive schema and subsequently a loss of meaning and structure to life events. The resulting disorganization and uncertainty is influenced by factors such as ambiguity, complexity, inconsistency and unpredictability of the illness events. Eventually, uncertainty itself is integrated into the individual's self-schema through gradual approximation, assimilation and accommodation. A new cognitive schema emerges which is more complex and bridges the gap between one's schema and reality. Uncertainty itself is accepted as part of reality, leading to a more probabilistic and conditional way of thinking than previously experienced (Mishel, 1990). As a result, subsequent illness uncertainty is less distressing to the individual than it was previously.

Theoretically, formation of a new orientation is influenced by the individual's life experience, physiological status, social resources, and health care providers (Mishel, 1990). She postulates that the formation of revised cognitive schemas and the reevaluation of illness uncertainty may be delayed or blocked by four situations: (a) when supportive resources do not promote a probabilistic view of life, (b) when the individual processing the uncertainty is a caretaker of others, thereby leading to a delayed response to the uncertainty itself, (c) when the individual experiencing the uncertainty is isolated from social resources, and (d) when health care providers look for predictability and certainty. However, little empirical research has been conducted on Mishel's new model of illness uncertainty.

The Relationship of Illness Uncertainty to Psychological Adjustment

The influence of uncertainty on psychological adjustment has been well documented in adults experiencing an illness event (Mast, 1995). In these studies, many elements of Mishel's original uncertainty in illness theory have been supported empirically (Bennett, 1993; Christman et al., 1988; Hawthorne & Hixon, 1994; Mishel &

Braden, 1988; Warrington & Gottlieb, 1987; Webster & Christman, 1988; Wineman, 1990; Wineman et al., 1993). Antecedent factors, such as personal factors, social supports and illness situation variables indeed appear to influence the experience of uncertainty (Mishel & Braden, 1987; 1988). More specifically, greater familiarity with the illness events tends to reduce uncertainty; increased social support mitigates feelings of uncertainty (Mishel & Braden, 1987; 1988) and, an increased sense of personal control is related to decreased feelings of uncertainty (Braden, 1990; Mast, 1995; Mishel & Braden, 1987; 1988). These factors also influence the way in which uncertainty is appraised as either a threat or an opportunity (Mishel & Sorenson, 1991). The greater the uncertainty, the more likely the situation is to be labeled as a threat and the more likely that emotion-focused coping strategies will be utilized (Hilton, 1989; Mishel & Sorenson, 1991; Webster & Christman, 1988). Those individuals who perceive uncertainty as a danger may be at greater risk for emotional distress (Mast, 1995). This conclusion is supported by a number of studies which suggest a strong relationship between uncertainty and emotional distress, mood disturbance, and anxiety (Bennett, 1993; Braden, 1990; Christman et al., 1988; Hawthorne & Hixon, 1994; Padilla et al., 1992).

Cognitive appraisal factors that influence illness uncertainty have also been examined. In two studies, an original and a replication, mastery was examined as a mediator between uncertainty and appraisal according to the acute illness model of uncertainty (Mishel & Sorenson, 1991; Mishel, Padilla, Grant, & Sorenson, 1991). They defined mastery as the "ability to behave in a way that can mitigate the aversiveness of an event" (Mishel & Sorenson, 1991; p. 167). Participants in both studies were women receiving treatment for gynecological cancer. In these studies, mastery was found to be a situationally bound factor where uncertainty was negatively related to mastery, (i.e., uncertainty rises as the sense of danger is enhanced). In both studies, the appraisal of uncertainty as a danger was accounted for by the level of mastery reported. However, mastery did not consistently account for the relationship observed between uncertainty and opportunity. Under higher levels of uncertainty, however, the sense of mastery was attenuated and there was increased danger appraisal and decreased opportunity appraisals. Higher perceived uncertainty was also related to emotion-focused coping and lower uncertainty associated with problem-focused coping (Mishel & Sorenson, 1991; Mishel et al., 1991). Such empirical inconsistencies regarding the model between the studies suggest the presence of other unidentified variables which may influence the relationship between uncertainty and adjustment.

Parental Illness Uncertainty

Many studies have examined the illness uncertainty experienced among parents of children with a chronic or life-threatening illness. However, with few exceptions (Sasser, 1995; Tomlinson, Kirchbaum, Harbaugh, & Anderson, 1996), studies examining the relationship of illness uncertainty to parental distress have been primarily descriptive and qualitative in nature (Cohen, 1993; 1995; Horner, 1997; Tomlinson et al., 1996). To date, findings are comparable to the aforementioned adult studies on illness uncertainty, where increased illness uncertainty is associated with increased psychological distress. However, questions unique to parental uncertainty such as what influences parental uncertainty, the influence of parental uncertainty on child uncertainty, and the influence of parental uncertainty on child distress have yet to be adequately examined. The following reviews the potential relationship between parental illness uncertainty and distress.

Variables Associated with Parental Uncertainty

Qualitative studies have provided a rich description of parental uncertainty among parents of a child with a life-threatening illness. Cohen (1993;1995) examined the nature of illness uncertainty, obtaining data from four sources: existing tape-recorded and transcribed interviews with 10 families of children with cancer, recorded and transcribed interviews obtained from 21 parents of children with a life-threatening illness, published autobiographies of parents of children with illnesses, and existing literature from other disciplines. Utilizing data from each of these sources, Cohen (1993) categorized six interactive dimensions of illness uncertainty that parents of children with a life-threatening illness must manage: time, social interactions, information, awareness, illness, and environment.

The first dimension is time. Time, in relation to illness uncertainty, refers to changes in parents' perceptions of time and future for their child. The span of the child's life, previously taken for granted, may suddenly be a focus of concern. Cohen found that many parents reported that thinking of and planning for the future was often too frightening, given the multiple uncertainties that their child's illness presented. The second dimension addresses parental management of social interactions. Parents reported that managing social interactions became more complex once their child was diagnosed. Parents must decide to whom, how much, and under what circumstances they provide information about their child's illness. Many parents reported that withholding, limiting, or disguising information prevented the often unpleasant consequences of a full disclosure. Management of information about the child's illness was identified as the third dimension influencing parental uncertainty. Parents reported that the timing, type, and amount of information they received about their child's illness influenced their feelings of uncertainty. Depending on the context and personal preferences, parents extracted, limited, discounted, and transformed information to maintain tolerable levels of uncertainty.

Awareness, the fourth dimension identified by Cohen, refers to the cognitive strategies that parents use to lessen their awareness of the threat of uncertainty, including deliberate efforts not to think about the illness. Parents reported that management of the child's illness itself imposed an increased level of awareness due to constant vigilance, scanning and periodic monitoring of the child. The last dimension identified by Cohen was management of the child's environment. For parents of children with an illness, an incorrect decision regarding the child's activities can result in serious consequences for the child, increasing the weight of otherwise routine parental judgments. Parents are routinely faced with questions such as, "How much should the child be protected," and "How much control should be exerted?" Cohen hypothesized that the way in which parents manage these interactive dimensions of uncertainty will influence level of parental uncertainty and distress.

Cohen (1995) emphasizes that parental uncertainty is not a static construct. She acknowledges that uncertainty is experienced most acutely and intensely when an illness is first diagnosed or when there is a change in the child's health status (i.e., exacerbation, relapse, etc.). Both qualitative and quantitative studies examining parental uncertainty have noted factors influencing parental uncertainty in addition to those identified by Cohen (1993; 1995). They are summarized below.

Unpredictability

Unpredictability regarding illness course and outcome has been shown to constitute a significant source of stress and uncertainty for parents of children in a pediatric intensive care unit (PICU; Turner, Tomlinson, & Harbaugh, 1990), parents of children with asthma (Horner, 1997), and a variety of other chronic health conditions (Burkhart, 1993). In a qualitative exploration by Turner et al. (1990), parents of children in a PICU identified unpredictability of outcome and lack of information regarding situational and environmental factors in PICUs as the primary sources of uncertainty regarding their child's illness. Similarly, mothers of children with asthma attributed their feelings of uncertainty to unpredictability regarding the course and outcome of their child's illness, frequency of illness recurrence, the amount of previous experience with their child's illness, and details regarding the care of their child's illness (Horner, 1997). Therefore, unpredictability regarding the course and outcome of a child's illness directly impacts parental perceptions of uncertainty.

Socioeconomic Status

Socioeconomic status has also been associated with perceptions of illness uncertainty. Sasser (1995) examined the potential influence of select environmental, illness, and social factors on perceptions of illness uncertainty among parents of a chronically disabled child. She found that lower socioeconomic status was significantly associated with both increased ambiguity and perceived lack of information about the child's illness, two commonly identified dimensions of illness uncertainty (Sasser, 1995). In addition, perceived financial impact of the illness on economic status was significantly associated with increased ambiguity and unpredictability regarding the child's illness. Such results could reflect the fact that those from lower SES groups are less likely to have medical insurance to defray health care costs.

Illness Severity

Perceptions of illness uncertainty have also been associated with illness severity. Tomlinson et al. (1996) recruited mothers of children with unplanned, first time admissions to the PICU for an acute onset, life-threatening illness. They identified a significant relationship between maternal illness uncertainty and illness severity, whereby increased illness severity was associated with heightened illness uncertainty. Together, illness severity, family cohesion and social support accounted for 22% of the variance in maternal illness uncertainty. Thus, increased unpredictability of symptoms and complexity of the treatment regimen that often accompany increased illness severity likely contributes to heightened perceptions of illness uncertainty. Increased illness severity may also increase perceptions of uncertainty through the increased probability of poor negative medical outcomes.

Uncertainty Post-Treatment

Van Dongen-Melman et al. (1995) empirically examined parental uncertainty among parents of children who underwent cancer treatment, finding that 90 percent of the parents continued to experience uncertainty after the completion of their child's treatment. Parents reported that they experienced uncertainty about the possible late medical and psychosocial sequelae for their child, as well as the survival of their child. Evidence from this study demonstrates that parental illness uncertainty regarding their child's well-being persists long after the completion of the child's treatment.

Relationship of Parental Uncertainty to Parental Distress and Coping

Psychological Distress

Few quantitative studies have examined the relationship of illness uncertainty to psychological distress among parents of children with a chronic or life-threatening illness. Of the studies conducted, illness uncertainty has most often been associated with symptoms of anxiety. Minutun (1984) found that uncertainty accounted for a large proportion of the variance in anxiety reported by parents of children admitted to a pediatric ICU. In a later qualitative study, parents independently associated uncertainty with feelings of anxiety and a perceived lack of control (Turner et al., 1990). More recently, parental illness uncertainty was found to be significantly associated with increased post traumatic stress and general parental distress among parents of children who had survived brain tumors (Fuemmeler, Mullins, & Marx, 2001). Specifically, illness uncertainty independently accounted for a significant proportion of the variance in PTSD symptoms. Further, both illness uncertainty and emotion-focused coping significantly predicted parental psychological distress above and beyond variance accounted for by age of the parent and time since diagnosis (Fuemmeler et al., 2001).

Adjustment

Uncertainty has also been associated with other types of psychological adjustment. Lack of information, a component of illness uncertainty, was significantly associated with lower levels of caregiver esteem as well as a greater perceived impact of the child's illness on the parent's own health (Sasser, 1995). In addition, increased ambiguity was associated with greater perceived impact on the family schedule due to the illness (Sasser, 1995). This study demonstrates the potential influence of illness uncertainty on multiple domains of adjustment. However, more empirical studies are needed to assess the influence of uncertainty on various types of parental adjustment before these findings can be generalized.

Coping

In studies exploring how parents cope with uncertainty, a number of specific behavioral responses have been identified. In response to illness uncertainty, mothers report that they search for answers (i.e., engage in activities designed to manage or respond to an event in a given context), question medical personnel (i.e., about symptoms, prescribed medications and expected outcomes), try alternatives (i.e., alternative medical therapies and tested folk beliefs), and demand attention (i.e., demand a change in the treatment plan, seeking referrals, or finding another doctor) and adopt an advocacy role for their child (Horner, 1997; MacDonald, 1996). Similarly, parents report that they respond with increased vigilance regarding their child as a means by which they cope with increased illness uncertainty (Brett & Davies, 1988).

Relationship of Parental Uncertainty to Child Uncertainty and Distress

Only one study has empirically demonstrated a relationship between parent and child illness uncertainty. Specifically, illness uncertainty experienced by a parent about their own illness was shown to influence their child's perceptions of illness uncertainty. Steele, Tripp, Kotchick, Summers, & Forehand (1997) examined uncertainty among members of families where the father had been diagnosed with hemophilia, approximately half of which were HIV positive. They found that paternal uncertainty was significantly related to both maternal- and child-reported uncertainty; however, maternal and child reports of uncertainty regarding the father's illness were not related. The child's uncertainty was significantly related to increased internalizing behaviors. Children who reported increased uncertainty regarding their father's illness reported more symptoms of anxiety and depression. Although this study examined uncertainty related to the father's illness rather than a child's illness, it is highly relevant here for two reasons. First, it demonstrates that parental uncertainty is associated with child uncertainty. Second, this study demonstrates that child reported uncertainty is associated with increased self-reported internalizing symptoms among children.

Collectively, qualitative and empirical studies examining parental illness uncertainty have identified factors influencing the perception of illness uncertainty and begun to illustrate the significant relationship of illness uncertainty to parental distress. The unpredictability, complexity, and ambiguity that characterizes the course of type 1 diabetes makes illness uncertainty a particularly salient construct for parents of children with this disease.

Psychosocial Treatment Interventions

Family-Based Psychosocial Treatment Interventions

Notably, a number of studies have documented the negative impact of poor family functioning and maladjustment on the health outcomes of children with diabetes (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Hanson, Henggeler, & Burghen, 1987; Hauser et al. 1990). Correspondingly, many treatment interventions have included family-based components. One of the earliest studies to examine a family-based intervention for adolescents with diabetes was conducted by Satin, La Greca, Zigo, and Skyler (1989). They compared the efficacy of three different treatments: (a) a multifamily treatment group plus parental simulation of the diabetes treatment regimen for one week, (b) a multifamily group treatment presented alone, and (c) a no treatment control group. They found that those adolescents whose parents were in the multifamily group plus parental simulation group demonstrated improved glycosylated hemoglobin levels compared to adolescents whose parents were in the multifamily group alone or the control group. Moreover, these improvements were maintained at a six-month follow-up. This study is notable in that it demonstrates that a parent-based intervention (i.e., regimen simulation) can lead to improvements in adolescent metabolic control.

Delamater and colleagues (1990) evaluated the efficacy of a family-based behavior therapy program for adolescents with diabetes designed to increase metabolic control and improve parent-adolescent relationships. The intervention consisted of six, 90-minute group sessions with a booster session held four weeks after the last session. Sessions focused on self-management as well as parent-adolescent communication skills. Findings revealed initial improvements in patient-rated parent-adolescent relationships. However, these improvements were not maintained at follow-up (Delamater et al., 1990). In addition, no significant improvements in parent-rated parent-adolescent relationships were found. This study was significant in that it demonstrated that family-based interventions can lead to improvements in parent-adolescent relationships. Although no significant differences were found at follow-up, this was likely due to a small sample size (seven in the treatment group and six in the control group).

Wysocki and colleagues (2000) compared the effectiveness of two types of family-based intervention programs that included both parents and adolescents: (a) an education and support group (EDSP), and (b) behavioral-family systems therapy (BFST). Each intervention was also compared to a "current treatment" condition with no psychosocial intervention. Behavioral-family systems therapy (i.e., a manualized treatment designed for targeting parent-adolescent conflict) demonstrated efficacy in decreasing family diabetes-related conflict (Wysocki et al., 1997; 2000). Following treatment, the BFST group showed decreased family composite scores for diabetes-related conflict, whereas no significant differences were found for EDSP or the current treatment condition (Wysocki et al., 2000). In addition, boys and younger girls showed improved behavioral and attitudinal adjustment to diabetes, as well as significantly decreased glycated hemoglobin following BFST. However, older adolescent girls in the BFST group reported diminished behavioral and attitudinal adjustment to diabetes and had increased glycated hemoglobin. Notably, Wysocki et al. (2000) demonstrated that psychosocial interventions such as BFST are effective in decreasing diabetes-related conflict among families. Further, Wysocki et al. (2000) identified potential gender and developmental differences in treatment mechanisms for adolescents with diabetes.

Harris, Greco, Wysocki, & White (2001) also compared the clinical significance of BFST to EDSP and to a normative diabetes sample. They found that mothers in the BFST group reported significantly less diabetes-related conflict than mothers in the normative sample or EDSP. However, no differences were observed in father- or adolescent-reported conflict (Harris et al., 2001). This study provides empirical evidence that BFST may be especially effective treatment for decreasing maternal perception perceptions of parental-child diabetes-related conflict.

Psychosocial Treatment Interventions for Parents

Although a number of intervention studies have been conducted with families, adolescents and children with type 1 diabetes, none have specifically assessed the psychological adjustment of the parents as a specific outcome measure, despite the fact that researchers have consistently demonstrated a relationship between parent and child adaptation to type 1 diabetes (Chaney et al., 1997; Mullins et al., 1995). Importantly, interventions targeting parental psychological functioning among other illness groups have yielded intriguing findings. Walker et al. (1996) examined the efficacy of Emotionally Focused Therapy (EFT) for improving communication, enhancing dyadic adjustment, and reducing stress among parental dyads of children with chronic and potentially life-threatening illnesses. Emotionally Focused Therapy resulted in significantly decreased marital distress and negative communication among couples with chronically ill children; this decrease was maintained at a five-month follow-up. In another important study, Melnyk and colleagues (1997) implemented parent-focused interventions designed to provide role information and enhance coping of mothers of children hospitalized with a variety of critical illnesses. The interventions led to decreased maternal stress and increased maternal participation and support during medical procedures. In addition, mothers reported fewer PTSD symptoms, increased role certainty, and a reduced discrepancy between previous standards of parenting and those imposed by the illness. Further, the children of the mothers who participated in the intervention demonstrated less negative behavioral change during hospitalization.

Intervention studies that have been conducted to date are valuable in that they provide preliminary evidence that psychological, interpersonal, and physical gains result from psychosocial treatments. However, the current intervention studies have not addressed several important treatment issues. For example, BFST, although relevant for parent-adolescent conflict, has not addressed other forms of parental or child distress sometimes associated with chronic illness. In addition, BFST was designed to address existing parent-adolescent conflict rather than preventing conflict or distress. Notably, BFST was not designed to treat children under 12 years of age, and therefore does not address issues relevant to parents of younger children, a growing segment of the type 1 diabetes population. In addition, none of the existing treatment interventions address issues related to the initial diagnosis of a chronic illness in childhood and subsequent parental and child adaptation to the illness. Given that initial adjustment to type 1 diabetes has been associated with later adjustment (Kovacs, Iyengar, Goldston, Obrosky et al., 1990; Kovacs, Iyengar, Goldston, Stewart et al., 1990) early intervention could decrease the probability of distress developing, and potentially could result in long-term treatment effects.

Summary

The relatively high rates of psychological distress reported by parents of children with a chronic or life-threatening illness suggest that, as a group, they are potentially at greater risk of experiencing psychological distress. A variety of environmental, social, and individual factors have been associated with distress among parents of children with type 1 diabetes, including social support, duration of illness, and disease-specific cognitive appraisals. Parental adjustment is often significantly associated with child adjustment, both in the context of pediatric chronic illness as well as medically-well populations (Bleil et al., 2000; Chaney, 1991; Chaney et al., 1997; Hauser et al., 1985; Mullins, et al., 1995; Parker et al., 1994; Thompson et al., 1992; Thompson et al., 1993; Thompson & Gustafson, 1996). More specifically, increased distress among fathers (Chaney et al., 1997), and mothers (Mullins et al., 1995) of children with diabetes has been associated with child adjustment, independent of demographic and disease parameters. In addition, parental adjustment has been associated with treatment adherence and metabolic control of their children (Florian & Elad, 1998). Moreover, early adjustment to the illness predicts later adjustment for both parent and child (Kovacs, Iyengar, Goldston, Obrosky et al., 1990; Kovacs, Iyengar, Goldston, Stewart et al., 1990). Therefore, early intervention in the course of the illness could serve to decrease initial distress and, subsequently, future distress. These studies, as well as others, illustrate the importance of minimizing parental distress in promoting child adjustment and preventing child distress.

In particular, illness uncertainty is a salient cognitive appraisal variable that both parents and children encounter in the context of a chronic or life-threatening illness. Studies examining adult illness groups have shown that higher illness uncertainty is significantly associated with increased distress (Mishel & Sorenson, 1990; Mullins, Chaney, Pace, & Hartman, 1997). Moreover, illness uncertainty has also been shown to be an important variable associated with the adjustment of parents of children with a chronic illness. Parents report that illness uncertainty persists throughout a child's illness (Tomlinson et al., 1996) and often after treatment has been completed (Van Dongen-Melman et al., 1995). Clearly, illness uncertainty is a critical variable in the development of parental and child distress.

Preliminary treatment studies conducted with families of adolescents with type 1 diabetes have produced a number of important findings. First, these studies have demonstrated that interventions with families can result in improvements in metabolic control for the child, as well as improve parent-child relations. Second, studies conducted with parents of children with a chronic or life-threatening illness have yielded improvements for both parent and child functioning. Interventions for parents have resulted in decreased marital distress (Walker et al., 1996), decreased maternal distress, increased maternal participation and support during medical procedures, and increased role certainty (Melnyk et al., 1997). More importantly, it appears that interventions with the parents may directly or indirectly influence child adjustment to chronic illness (Melnyk et al., 1997).

Therefore, the purpose of the present study is to evaluate the efficacy of a treatment intervention designed to decrease illness uncertainty and subsequently psychological distress among parents of a child diagnosed with type 1 diabetes within the last six months. This investigation will significantly contribute to the existing literature in two ways: (a) it will provide further evidence for the significant influence of illness uncertainty on parental and child distress, and (b) it will test the efficacy of a treatment intervention targeting illness uncertainty and psychological distress among parents of children with type 1 diabetes.

CHAPTER III

PURPOSE OF THE PRESENT STUDY

The purpose of the present study is to evaluate the efficacy of an intervention designed to decrease illness uncertainty and psychological distress among parents of children newly diagnosed with type 1 diabetes (DM1). Illness uncertainty has been shown to be a salient variable among parents of children with a chronic or life threatening illness (Cohen 1993; 1995; Horner, 1997; Sasser, 1995; Stewart & Mishel, 2000; Tomlinson et al., 1996; Turner et al., 1990; Van Dongen-Melman et al., 1995). In addition, illness uncertainty has also been shown to be strongly associated with psychological distress among parents of children with a serious chronic illness (Fuemmeler et al., 2001). Further, parental uncertainty has been associated with child uncertainty and distress (Steele et al., 1997). Finally, existing literature demonstrates that child adherence and/or metabolic control is related to parental distress (Cerreto & Mendlowitz, 1983; Florian & Elad, 1998; Hauser et al., 1990; Hauenstein et al., 1989; Kinsman et al., 1999). Therefore, decreasing parental uncertainty is important for the emotional and physical well-being of both parent and child.

Thus, the purpose of the present study is to examine the efficacy of a parent-based intervention in reducing illness uncertainty and distress in parents of children newly diagnosed with DM1. Parent(s) of children newly diagnosed with DM1 will be recruited from two Midwestern pediatric endocrinology clinics to participate in the study. To be eligible to participate, the child must be under 18 years of age and have been diagnosed with DM1 within the last six months. All parents and children between ages eight and eighteen who agree to participate in the study will complete questionnaires at baseline, one-month, and six-months. Parents who agree to participate in the study will be randomly assigned to either the intervention group (IG) or the treatment as usual group (TAU). Parents assigned to the IG will be attending two, three-hour sessions that present the construct of illness uncertainty and ways to manage uncertainty. Parents who are assigned to the TAU group will not participate in an intervention and their children will continue to receive routine medical care and illness education from their treating physicians.

Thus, the following questions will be addressed in the current study: (a) does the intervention result in decreased parental illness uncertainty? (b) does the intervention result in decreased parental distress? (c) does the intervention result in decreased parent-reported child behavior problems? and (d) does the intervention result in improved parent-reported child adaptive skills? Using the existing literature as a guide, a theoretical argument can be made for the following hypotheses:

Hypothesis 1: Parents who participate in the IG will evidence lower illness uncertainty at the one- and six-month follow-up than at baseline. No changes will be observed for the TAU as a function of time.

At baseline, no significant differences will be observed between the IG and TAU groups in parent-reported illness uncertainty, as measured by the Parent Perceived Uncertainty Scale (PPUS; Mishel, 1983), regarding their child's illness. At one- and six-month follow-up, parents who participate in the IG will report significantly less illness uncertainty than at baseline. No change in PPUS scores will be observed for parents in the TAU group.

Hypothesis 2. Parents who participate in the IG will report lower psychological distress at the one- and six-month follow-up than at baseline. No changes will be observed for the TAU as a function of time.

At baseline, no significant differences will be found between IG and TAU group parent-reported levels of distress as measured by the Global Symptom Index (GSI) of the Symptom Checklist-90-Revised (SCL-90-R; Derogratis, 1993). At the one- and six-month follow-up, parents who participate in the IG will report significantly lower psychological distress than at baseline. No change in GSI scores will be observed for parents in the TAU group.

Hypothesis 3. Parents who participate in the IG will report fewer behavior problems for their child with DM1 at the one- and six-month follow-up than at baseline. No changes will be observed for the TAU as a function of time.

At baseline, no significant differences will be identified between the two groups for parent-reported child behavior problems as measured by the Behavioral Symptom Index (BSI) of the Behavioral Assessment System for Children-Parent Rating Scale (BASC-PRS; Reynolds & Kamphaus, 1992). At the one-and six-month follow-up, parents who participate in the IG will report fewer child behavior problems than parents in the TAU group. No change in BSI scores will be observed for parents in the TAU group.

Hypothesis 4. Parents who participate in the IG will report more adaptive behaviors for their child with DM1 at the one- and six-month follow-up than at baseline. No changes will be observed for the TAU as a function of time.

At baseline, no significant differences will be identified between the two groups for parent-reported child adaptive behaviors, as measured by the Adaptive Skills Composite (ASC; Reynolds & Kamphaus, 1992) on the BASC-PRS. At the one- and six-month follow-up, parents who participate in the IG will report more child adaptive behaviors than at baseline. No change in ASC scores will be observed for parents in the TAU group.

CHAPTER IV

METHOD

Participants

Parent(s) of children newly diagnosed with type 1 diabetes (DM1) were recruited to participate from two pediatric endocrinologists in private practice who were affiliated with Midwestern children's hospitals. Eligibility criteria for participants were as follows: (a) the child with diabetes was under 18 years of age, and (b) diagnosed with type 1 diabetes within the last six months. In addition, participants diagnosed with another chronic illness or who evidenced a developmental disability were not be eligible to participate.

One hundred seventy newly diagnosed patients and their families from two outpatient endocrinology clinics were recruited by mail to participate in the study. Of these, 60 families returned postcards indicating their desire to participate in the study and were subsequently randomized to either the IG or TAU condition. Twelve of the participants who initially agreed to participate discontinued the study due to either personal time constraints or traveling distance. Five were not eligible to participate due to exclusionary criteria (e.g., having a co-morbid chronic illness). A total of 42 families completed the baseline measures. Of those, 29 families completed baseline and the one-month follow-up, including 15 in the IG (15 mothers and 11 fathers) and 14 in the TAU

(14 mothers and 10 fathers). Nineteen families completed both one- and six-month follow-ups, including nine in the IG (nine mothers and six fathers) and 10 in the TAU (10 mothers and seven fathers). One family in the IG did not attend the second session of the intervention.

Measures

Parent Protocol

Demographic Information. A questionnaire was developed to obtain the following information: child's gender, child's age, child's race, child's grade, parent age, parent marital status, parent occupation, parent educational level, parent annual income, and current members of the household.

Diabetes Health Information. This questionnaire was designed to obtain information about the health status of the child with diabetes. It assesses the following information: the length of the duration of illness, most current HbA_1C level, how many insulin shots are supposed to be administered per day, when the child tests their blood, what instrument has been used to read blood sugar, how many times a day the testing of their blood sugar is done, the food intake on the previous day, how many calories were eaten the previous day, how many calories a day have been recommended by the dietitian, how often the family eats fast food, the amount and type of exercise the child engages in, overall ratings of how well the child copes and adheres to their treatment regimen, an overall rating of the child's health status, and a list of the medications the child is currently prescribed.

Parent Perception of Uncertainty Scale (PPUS; Mishel, 1983) is a 31-item self-report measure of medical uncertainty in reference to a child's illness. Items include questions such as: "I don't know what is wrong with my child," "My child's treatment is to complex to figure out," and "The results of my child's tests are inconsistent." Respondents are asked to respond on a 5-point scale ranging from (1) "strongly disagree" to (5) "strongly agree." The scale has four factors including ambiguity, lack of clarity, lack of information, and unpredictability. The MUIS yields a total score of uncertainty by summing across all dimensions, with higher scores indicating greater uncertainty. The PPUS has high internal consistency ($\alpha = .91$). Coefficient alpha on the PPUS for the current sample was .85 and .90 for mothers and fathers, respectively (Cronbach, 1951).

Symptom Checklist 90-Revised (SCL-90-R; Derogratis, 1993) is a 90-item self-report inventory that yields nine clinical dimensions of psychological distress (e.g., depression, anxiety, hostility, somatization, obsessive compulsive) and a composite index of overall distress [i.e., Global Severity Index (GSI)]. Respondents are asked to indicate the frequency to which they experience various psychological or physical symptoms within the past seven days. The GSI score from the SCL-90-R was used to assess overall parental distress. Previous studies have utilized the GSI index to assess parental adjustment to childhood chronic illness (Kronenberger & Thompson, 1992; Miller, Gordon, Daniele, & Diller, 1992; Mullins et al., 1991). The SCL-90-R has good internal consistency, .77 - .90, and test-retest reliability, .78 - .90 (Derogratis, 1993). Coefficient alpha on the GSI for the current sample was .97 and .93 for mothers and fathers, respectively (Cronbach, 1951).

Behavior Assessment System for Children: Parent Rating Scale (BASC: PRS; Reynolds & Kamphaus, 1992). The BASC:PRS is a comprehensive measure of a child's adaptive and problem behaviors in community and home settings. Items include questions such as, "Hits other children," "Is easily frustrated," and "Worries about what others think." The PRS uses a four-choice response format ranging from (0) "Never" to (4) "Always." The PRS has two forms composed of similar items and scales that span childhood (6 - 11 years, 138 items) and adolescence (12 - 18 years, 126 items). The Behavioral Symptom Index (BSI) of the PRS was used to assess externalizing and internalizing behavior problems, and the Adaptive Skills Composite (ASC) was used to assess adaptive skills. Internal consistencies for the PRS's are approximately .80 for both the general and clinical samples. Internal consistencies for the current sample ranged from .67 to .94 on the BSI, and .75 to .96 on the ASC (Cronbach, 1951).

Procedure

A list of addresses of children diagnosed with DM1 within the last six months was obtained from diabetes clinics at two mid-western hospitals. A postcard was mailed to the parents' home which informed them about the nature of the study, and asking them to return the postcard should they choose to participate. Families who agreed to participate were then contacted by phone and offered further explanation of the purpose of the study. During the phone contact parents were given a detailed description of the study including the time that was required of themselves and their child.

Treatment As Usual Condition (TAU)

Parents assigned to the TAU condition did not receive the intervention and their child continued to receive routine medical care and illness education from their treating physicians. Parents who assigned to the TAU group were informed of the date that a packet containing questionnaires would be sent to them. Parents assigned to the TAU group were informed upon entry into the study that they were be eligible to participate in the intervention at a later date. Parents and children assigned to the IG and TAU group were mailed an informed consent, along with the intake packet of questionnaires and a return envelope.

Intervention Group Condition (IG)

During the initial phone call, parents assigned to the IG group chose the cohort time that best fit their schedule in order to minimize group attrition. Parents attended two, three hour sessions. Intervention sessions were conducted at two medical practices located in Oklahoma City and Tulsa. The intervention taught the parents about the construct of illness uncertainty, coping mechanisms that can be used to manage uncertainty (i.e., problem solving, stress management, and communication skills) as well as basic diabetes education. Please see Appendix A for the complete treatment manual.

Follow-up

Parents and children assigned to both groups were each sent questionnaire packets containing a detailed cover letter, consent form and age-appropriate measures that were completed prior to the first session of the IG. All parents and children participating in the study were subsequently mailed a questionnaire packet for one- and six-month follow-up. Packets were completed at home and returned by mail in the provided self-addressed stamped envelope. Measures of illness severity, adherence, and HbA_{1c} at baseline, one- and six-months were obtained from the child's physician.

All procedures are in keeping with standards established by the Oklahoma State University Institutional Review Board (IRB) and the IRB approved research protocol (See Appendix C). The data obtained through this procedure process were utilized for analysis of the proposed variables.

CHAPTER V

RESULTS

Overview of Analyses

Descriptive statistics were first calculated, as were group means, standard deviations and zero-order correlations for all dependent variables at all three time periods. Preliminary analyses were conducted at baseline to determine if differences existed between the IG and the TAU group on demographic parameters (i.e., child age, parent age, family income level, and parent education). Illness parameters (i.e., HbA_{1c}, physician rated adherence, and illness severity) were not examined due to insufficient data.

In lieu of overall ANOVA's, a series of planned comparisons were conducted within each group (IG and TAU) across time (baseline assessment versus one-month post-intervention assessment and one-month post-intervention assessment versus six-month post-intervention assessment) to examine intervention effects. The *F* values, as well as effect sizes, parital eta squared, were calculated. Because of the lack of independence of the data accrued from dyads, all analyses were conducted separately for mothers and fathers.

Summary of Demographic Data

Fifteen (52%) of the families (15 mothers and 11 fathers) were randomly assigned to the intervention group (IG) and 14 (48%) families (14 mothers and 10 fathers) were assigned to the treatment as usual group (TAU). Mean age of mothers was 37.61 (*SD* = 6.61); mean age of fathers was 40.42 (*SD* = 6.05). Twenty-five (86 %) of the parents were married, two (7%) were single parents, and two (7%) were remarried. Participants in the sample identified themselves as Caucasian (n = 27; 93%) and African-American (n = 2; 7%). The mean educational level of mothers in the sample was 14.40 years (*SD* = 1.94) and fathers was 14.85 years (*SD* = 2.42). Ninety percent of the sample reported a total annual family income of $30,000 or greater.

In the IG, seven (46%) of the participating children were male and eight (54%) were female. In the TAU group five (36%) of the children were male and nine (64%) were female. Mean age of children was 9.37 (*SD* = 4.21). See Appendix D, Table 1 for a summary of demographic statistics.

Preliminary Analyses

Preliminary analyses were conducted at baseline to determine if differences existed between the IG and the TAU group on demographic parameters (i.e., child age, parent age, family income level, and parent education). No significant between group differences were observed. Analyses were also conducted at baseline to determine if differences exist between the clinics from which participants were recruited on demographic parameters (i.e., child age, parent age, family income level, and parent education). No significant between group differences were observed.

For descriptive purposes, zero-order correlations were also conducted independently for the IG and the TAU to examine relationships between the dependent variables at all time periods. Correlations between all dependent variables reported by mothers (see Appendix D, Table 2 and 3) and fathers (see Appendix D, Table 4 and 5) were reported. In addition, correlations between maternal PPUS, maternal GSI, paternal PPUS, and paternal GSI were reported for each time period (see Appendix D, Table 6 and 7).

Primary Analyses

Hypothesis 1: Parents who participate in the IG will evidence lower illness uncertainty at the one- and six-month follow-up than at baseline. No changes will be observed for the TAU as a function of time.

Mothers. Planned comparisons were calculated to determine whether maternal illness uncertainty, as measured by the PPUS, changed within group (IG and TAU) as a function of time (baseline versus one-month post-intervention assessment and one-month versus six-month post-intervention assessment). For baseline versus one-month post-intervention assessment, analyses failed to reveal differences in maternal PPUS for either group. However, comparison of the one-month versus six-month post-intervention assessment revealed a trend for the IG group, where mothers reported lower PPUS scores at six- month than at the one-month follow-up, $F(1, 17) = 3.39, p = .08,$ *partial* $\eta^2 = .17$ (see Appendix D, Table 8).

Fathers. Planned comparisons were calculated to determine whether paternal illness uncertainty, as measured by the PPUS, changed within group (IG and TAU) as a function of time (baseline versus one-month post-intervention assessment and one-month versus six-month post-intervention assessment). Analyses failed to reveal significant differences in paternal PPUS for either group as a function of time (see Table 8).

Hypothesis 2. Parents who participate in the IG will report lower psychological distress at the one- and six-month follow-up than at baseline. No changes will be observed for the TAU as a function of time.

Mothers. Planned comparisons were calculated to determine whether maternal psychological distress, as measured by the Global Severity Index (GSI) of the SCL-90-R, changed within group (IG and TAU) as a function of time (baseline versus one-month post-intervention assessment and one-month versus six-month post-intervention assessment). Analyses revealed that the IG group had lower GSI scores at one-month assessment than at baseline, $F(1, 26) = 12.80$, $p < .01$, *partial* $\eta^2 = .33$. Comparisons failed to reveal differences in maternal GSI for the one-month versus six-month post-intervention assessment comparison for either group. However, maternal GSI scores in the intervention group did not return to baseline values (see Table 8).

Fathers. Planned comparisons were calculated to determine whether paternal psychological distress, as measured by the Global Severity Index (GSI) of the SCL-90-R, changed within group (IG and TAU) as a function of time (baseline versus one-month post-intervention assessment and one-month versus six-month post-intervention assessment). Analyses failed to reveal significant changes in GSI for either group as a function of time (see Appendix D, Table 8).

Hypothesis 3. Parents who participate in the IG will report fewer behavior problems for their child with DM1 at the one- and six-month follow-up than at baseline. No changes will be observed for the TAU as a function of time.

Mothers. Planned comparisons were calculated to determine whether maternal report of child behavior symptoms, as measured by the Behavioral Symptom Index (BSI) of the PRS of the BASC, changed within group (IG and TAU) as a function of time (baseline versus one-month post-intervention assessment and one-month versus six-month post-intervention assessment). Analyses revealed that the IG group had lower BSI scores at one-month than at baseline, $F(1, 27) = 5.70, p < .05,$ *partial* $\eta^2 = .17$. Although comparisons failed to reveal differences in maternal BSI for the IG group at the one-month versus six-month post-intervention assessment, scores did not return to baseline values (see Table 8).

Fathers. Planned comparisons were calculated to determine whether paternal report of child behavior symptoms, as measured by the BSI of the PRS of the BASC, changed within group (IG and TAU) as a function of time (baseline versus one-month post-intervention assessment and one-month versus six-month post-intervention assessment). Analyses revealed that at one-month, the TAU group reported lower BSI scores than at baseline, $F(1, 18) = 5.48, p < .05,$ *partial* $\eta^2 = .23$. No differences were revealed for fathers in the IG as a function of time (see Table 8).

Hypothesis 4. Parents who participate in the IG will report more adaptive behaviors for their child with DM1 at the one- and six-month follow-up than at baseline. No changes will be observed for the TAU as a function of time.

Mothers. Planned comparisons were calculated to assess whether maternal report of child adaptive skills, as measured by the Adaptive Skills Composite (ASC) of the PRS, changed within group (IG and TAU) as a function of time (baseline versus one-month post-intervention assessment and one-month versus six-month post-intervention assessment). Comparisons failed to reveal differences in ASC for either group as a function of time for the baseline versus one-month post-intervention assessment. Analyses revealed that at six-months, mothers in the IG group reported significantly higher ASC scores than at the one month follow-up, $F(1, 17) = 17.40, p < .01$, *partial* $\eta^2 = .51$ (see Table 8).

Fathers. Planned comparisons were calculated to assess whether parental report of child adaptive skills, as measured by the ASC of the PRS, changed within group (IG and TAU) as a function of time (baseline versus one-month post-intervention assessment and one-month versus six-month post-intervention assessment). Analyses failed to reveal significant changes in ASC for either group as a function of time (see Table 8).

CHAPTER VI

DISCUSSION

The purpose of the current study was to examine the efficacy of a parent-based intervention designed to reduce illness uncertainty and distress in parents of children newly diagnosed with type 1 diabetes (DM1). Specifically, it was hypothesized that parents in the intervention group (IG) would report less illness uncertainty and psychological distress than those in the treatment as usual (TAU) group at a one-month follow-up. In addition, it was hypothesized that parents in the IG would report fewer child behavioral symptoms and more child adaptive behaviors than parents in the TAU at a one-month follow-up. Further, the current study assessed whether observed differences in the dependent variables would be maintained over time as evidenced by significant differences between the IG and the TAU at the six-month follow-up. Thus, it was predicted that the intervention would be associated with improvement in both parent and child functioning. The following summarizes the findings for each hypothesis.

Parental Uncertainty

Contrary to prediction, no differences were observed for illness uncertainty as a function of time for either mothers or fathers. This finding suggests that the components of the current intervention did not effectively elicit changes in the cognitive appraisal mechanisms that determine whether specific illness-related events are appraised as uncertain. Assuming that future studies validate the current results, it would indicate that the individual and/or combination of treatment components are not sufficiently effective in decreasing uncertainty. Although this conclusion is the most parsimonious, there are other potential explanations for the current findings regarding uncertainty.

The null findings regarding illness uncertainty are consistent with an adult study examining an intervention designed to decrease illness uncertainty among men with prostate cancer (Mishel et al., 2002). Although uncertainty significantly decreased over time for participants regardless of group assignment (intervention or control group), no differences in uncertainty were observed as a function of treatment group. Notably, changes in participant's uncertainty management skills were observed, where the combined treatment group utilized significantly more cognitive reframing at the four-month follow-up than the control group. Though no decrease in uncertainty was observed for the treatment group, changes occurred in the way in which those in the treatment group managed uncertainty. Thus, it is conceivable that the intervention in the current study modified *uncertainty management* techniques, despite the fact that no decrease in the level of uncertainty was observed for mothers or fathers. These findings demonstrate the importance of examining uncertainty management variables in addition to illness uncertainty itself among parents of children with a chronic illness.

Considering the population from which the sample was drawn, and the mean scores obtained for uncertainty, an alternative explanation for the current findings can be offered. The mean baseline parental uncertainty scores for the current study, (mothers $M = 65.9$ and fathers $M = 65.4$) were much lower than those cited in Mishel's manual for parents with children with various illnesses including cystic fibrosis, leukemia, spina bifida, and premature infants (mothers $M = 80.7$ and fathers $M = 80.6$). Parents in the current sample may have had an especially low level of uncertainty at baseline due to the high quality of care that they received from their health care providers. Indeed, at one clinic from which participants were recruited, parents have the physician's home phone number and can contact him at any time. Furthermore, both clinics provide *extensive* diabetes training as the standard of care. The relatively low PPUS scores in this particular sample fall closer to the minimum score for the measure. Therefore, the findings may represent a "floor" effect, where the magnitude of the score reduction is not large enough to obtain a significant difference.

Another potential explanation may be found in Mishel's reconceptulized model of uncertainty. She posits that following diagnosis, illness uncertainty is a source of disruption, but as the illness progresses, uncertainty is ultimately viewed as "an inherent part of reality (Mishel, 1990, p. 261)." By accepting uncertainty as an inherent part of reality, parents view illness outcomes in probabilistic and conditional terms rather than expecting definitive answers. Based on this reconceptualization, it is conceivable that no changes in levels of uncertainty would be exhibited; rather, changes in how uncertainty is interpreted may result. Unfortunately, the appraisal of uncertainty or uncertain situations (i.e., as dangerous, as an opportunity, or as an inherent part of reality) was not measured in the current study, thus prohibiting empirical examination of such an explanation.

Alternatively, it is possible that uncertainty appraisals are the manifestation of characterological traits rather than transient states. For example, uncertainty-orientation theory views the construct of uncertainty as a personality factor, which describes how individuals seek out and deal with information (Brouwers & Sorrentino, 1993; Roney & Sorrentino, 1995; Walker & Sorrentino, 2000). Based on this theory, it would stand to reason that parents who are certainty-oriented would be at risk for experiencing distress related to their child's illness. However, a brief intervention such as the one examined here is not designed to modify personality traits. Thus, if uncertainty is personality based, then no changes in levels of uncertainty would be predicted as a result of this intervention.

Parent Distress

Mothers in the IG reported significantly less psychological distress at the one-month follow-up than at baseline. These results suggest that the intervention initially decreased psychological distress among mothers, but the reductions in distress were transient as the groups did not differ in levels of psychological distress at the six-month follow-up. For fathers, levels of psychological distress did not differ between groups at either the one- or six-month follow-up.

Although the intervention did not decrease maternal reports of uncertainty, it did result in decreased psychological distress among mothers in the IG. What accounts for the observed decrease in maternal distress at one month? Rather than the specific elements of the treatment intervention, the transient decrease in maternal psychological distress in the IG may possibly be attributed to the increased social support received from the facilitators and other group members during the intervention. Social support is one coping mechanism commonly associated with decreased psychological distress among parents of children with chronic illnesses (Thompson et al., 1992; Kronenberger &

Thompson, 1992; Thompson et al., 1994). Indeed, mothers of children with diabetes who perceived less social support described their child as more demanding than mothers of medically well children (Hauenstein, et al.,1989). Thus, the increased support obtained during the groups potentially served to temporarily decrease psychological distress. However, the completion of the group eliminated the additional source of support for group members. Hence, the effects of the additional social support on distress likely diminished over time.

Findings of this study are consistent with other intervention studies where initial treatment effects were observed, but the effects were not maintained over time (Mishel et al, 2002; Gil et al., 2001). Thus, these findings suggest that the skills that individuals acquire during interventions tend to diminish over time. To prevent skill loss, booster sessions have been effectively employed to promote skill maintenance (Ball et al., 2002). If replications of this study find that the treatment effects are not maintain over time, the design of the intervention will require modification.

Child Behavioral Symptoms

As hypothesized, mothers in the IG reported significantly fewer behavioral symptoms for their child at one-month follow-up than at baseline. However, contrary to the hypothesis, fathers in the TAU group, but not the IG group, reported significantly fewer behavioral symptoms at the one-month follow-up than at baseline. Hence, the current findings only partially support the hypothesis that the intervention serves to decrease parent-reported child behavioral symptoms.

What accounts for the significant decrease in maternal reports of child behavioral symptoms? Given that the intervention is parent-based, it stands to reason that changes in maternal functioning and/or responding are associated with the decrease in child behavioral symptoms at one-month. The association between maternal and child psychological distress is well documented (Chaney et al., 1997; Downey & Coyne, 1990; Rae-Grant, Thomas, Offord, & Boyle, 1989). Indeed, for those in the IG, maternal distress at baseline was significantly correlated with child behavioral symptoms at baseline and at six-months. However, the mechanisms that account for the relationship between parent distress and child distress are ill-defined in the extant literature. Although speculative, changes in parental responses to the child may account for these relationships. Fabes and colleagues (2001) found that parental distress is related to harsh parental responding to child negative emotions. Future investigations will need to examine potential mediating variables, such as parent-child interactions, to better clarify transactional relationships and guide intervention development.

Contrary to prediction, fathers in the TAU reported significantly fewer behavioral symptoms for their children at the one-month follow-up than at baseline. This finding is perplexing given that the fathers in the TAU did not receive any type of intervention. Indeed, it has been demonstrated that fathers typically rate children's internalizing behaviors as less severe than mothers (Huberty, Austin, Harezlak, Dunn, & Ambrosious, 2000). Some investigators have posited that many fathers are simply less sensitive to their children's problems than mothers (Jensen, Traylor, Xenakis, & Davis, 1988) and, as a result, underestimate internalizing behaviors. In addition, the sample size for this analysis was quite small which seriously compromises the accuracy of this finding.

Further, the effect size for this particular finding was very small, and thus this finding may not be clinically meaningful. As with all of the findings from this study, further replication is required before conclusions can be drawn.

Child Adaptive Skills

Significant changes in parent-reported child adaptive skills were also demonstrated in the current study. Although an increase in adaptive behavior was not reported by mothers or fathers at the one-month follow-up, mothers in the IG reported significantly more child adaptive behaviors at the six-month follow-up than they did at the one-month follow-up. No changes in adaptive behaviors were observed for mothers in the TAU or fathers in either group.

Although speculative, mothers who participated in the intervention may have developed more appropriate expectations for their child's behaviors as a result of components of the intervention. Specifically, the intervention teaches parents to clarify their child's role in diabetes care, while at the same time emphasizing the importance of the parents' continued involvement in their child's daily care. In conjunction with increased monitoring, parents are instructed in problem-solving skills to utilize with their child, which may ultimately culminate in the establishment of more adaptive behavior patterns. Previous studies have demonstrated that distressed mothers of medically well children can accurately rate their child's behaviors (Sawyer, Streiner, & Baghurst, 1998). Thus, it is unlikely that the aforementioned results can be attributed solely to changes in maternal perceptions. Hence, findings of the current study will need to be replicated before definitive conclusions are drawn regarding the effects of the intervention on child adaptive behaviors.

Finally, decreases in maternal psychological distress may be related to these results. Just as maternal perceptions of behavioral symptoms decreased, perceptions of child adaptive behaviors may have increased. It is possible that mothers experiencing decreased distress over time, subsequently began to view their child's adaptive behaviors in a more positive light overall. However, changes in maternal report of adaptive behavior did not coincide with maternal reductions of psychological distress, making this explanation tenuous.

Implications of Findings

Several important implications can be drawn from this study regarding the utility of an intervention targeting psychological distress among a chronic illness population. Previous interventions have primarily targeted diabetes-related conflict (Harris et al., 2001; Wysocki et al., 1997; 2000) as well as regimen adherence and metabolic control (Satin et al., 1989) among families with children with DM1. This study demonstrates that parental psychological distress is a relevant target of direct intervention for parents with a child with DM1, especially in families where the child was recently diagnosed. Parents of children newly diagnosed with DM1 experience increased levels of psychological distress (Kovacs, Iyengar, Goldston, Obrosky et al., 1990; Northam et al., 1996; Parker et al., 1994) and, at least for mothers, that distress can be temporarily diminished. This is important in that initial maternal distress is related to future maternal (Kovacs, Iyengar, Goldston, Obrosky et al., 1990) and child psychological distress (Chaney, 1991), as well

(Chaney, 1991), as well as child illness outcomes (Mengel et al., 1992). Finally, the current intervention was associated with decreased child behavioral symptoms and increased child adaptive skills, both of which have been associated with illness outcome (Jacobson et al., 1990; Littlefield et al., 1992; Wysocki, Hough, Ward, & Green, 1992; LaGreca, Schwarz & Satin, 1987; LaGreca, Schwarz, Satin, Rafkin-Mervis, Enfield, & Goldberg, 1990).

Moreover, this study highlights the importance of examining both maternal and paternal functioning when conducting intervention research. Clear differences emerged between fathers and mothers on each of the outcome measures. These findings are consistent with previous studies that have found that maternal and paternal distress do not temporally coincide (Chaney et al., 1997). Further, maternal and paternal ratings of child behavior often differ, as fathers tend to report fewer child internalizing symptoms than mothers (Huberty et al., 2000). Such findings indicate that more research needs to be conducted to examine how mothers and fathers differentially experience their child's illness and to develop interventions accordingly.

The relatively minimal intervention effects detected may indicate the need to target those individuals who are more prone to experience uncertainty-related distress. As suggested above, parents with certainty-oriented personality styles or who lack effective coping skills may represent a subsample at-risk for experiencing uncertainty-related distress. Thus, treatment effects for this portion of the sample may have been quite large, but the effects were washed out by those in the sample who did not experience distress in the context of illness uncertainty. Other investigators have targeted samples identified as being at risk due to family conflict (Wysocki et al., 1997; 2000), poor adherence, or metabolic control (Ellis, Naar-King, Frey, Rowland & Greger, 2003). Screening parents to identify those at higher risk for experiencing uncertainty-related distress may be an effective method of determining who may benefit most from this type of intervention.

Finally, this study has implications for the development of future interventions designed to decrease illness uncertainty. Although the purpose of the intervention was to decrease uncertainty among parents, no significant reductions in self-reported illness uncertainty were observed. Yet, the intervention still yielded significant reductions in psychological distress for mothers. Perhaps, uncertainty-related distress can be managed despite the fact that the uncertainty persists. Thus, the *management* of uncertainty may need to be the actual target of the intervention, rather than the reduction of uncertainty itself. More research needs to be conducted to determine whether coping mechanisms indeed mediate the relationship between uncertainty and distress before such an approach is adopted.

Strengths

As stated previously, this study was the first to evaluate an intervention designed to decrease illness uncertainty among parents of children newly diagnosed with type 1 diabetes. At the time of this writing, no extant studies had examined interventions targeting illness uncertainty during the immediate post-diagnostic period when there is a heightened likelihood of uncertainty and distress. Further, the majority of intervention studies have focused on adherence behaviors as the primary outcome measure. Although adherence is clearly important for enhancing illness outcome, psychological functioning contributes to the overall quality of life of the child and family. Given that illness uncertainty is consistently associated with psychological distress, this study makes a unique and potentially clinically relevant contribution to the existing literature.

In addition, participants were randomized into groups to minimize the effects of a selection bias that could potentially influence study outcomes. Randomization also controls for maturation effects, meaning that the changes observed are not simply due to changes that occur over time regardless of the intervention. In addition, this study examined outcomes longitudinally, which allowed for the assessment of long-term treatment effects rather than immediate post-test treatment effects. Follow-up data was collected by individuals who did not facilitate the groups, decreasing the possibility of a social desirability effect. In addition, this relatively short intervention yielded effects despite a small sample size.

Limitations

The current results must be considered in light of several limitations. First, the sample size was relatively small, limiting power to detect differences in the IG over time. Where significant differences were found, the effect sizes were small, calling into question the clinical significance of the findings. Second, participants were recruited from two private endocrinology practices in the Midwestern United States. Consequently, the sample was fairly homogenous in terms of ethnicity and socioeconomic status, thereby limiting the generalizability of the findings to other groups. On a related note, only 25 percent of those recruited completed the baseline measures. Thus, the generalizability of the findings are compromised by the relatively low recruitment rate, increasing the probability of a sampling bias unduly affecting the current findings. It is possible that the results are applicable to parents with a fundamental level of resources that enabled them to fully participate in the study.

Further, the design of the intervention itself limits the conclusions that can be made. For instance, the design of the study precludes examination of specific elements of the treatment intervention, therefore it cannot be determined whether the observed effects were due to one component of the treatment or a combination of components. Moreover, studies comparing intervention to support groups are needed to demonstrate that the intervention is more effective than non-specific supportive therapies. Although, the brevity of the intervention may make the intervention more attractive to third party payers in terms of expense and to parents in terms of time commitment, the length of the intervention may have limited the clinical efficacy. Indeed, some studies have demonstrated a "dose effect" where longer treatments result in meaningful treatment effects for more individuals (Howard, Kopta, Krause, & Orlinsky, 1986). Given these limitations, further randomized clinical trials will be required to determine the utility of the intervention examined here.

Future Studies

Future studies are needed to further determine the efficacy of the intervention examined here. As mentioned previously, the conclusions drawn from the current study are limited by the size and the homogeneity of the sample. Therefore, studies with larger and more diverse sample sizes are needed to determine whether these effects generalize across socioeconomic and ethnic groups. Developing multi-site studies will be particularly important in achieving this goal. It has been demonstrated that parents of children from a number of illness groups experience significant feelings of uncertainty (e.g., Fuemmeler et al., 2002; Steele et al., 1997). Therefore, modifying the intervention for other illness groups could potentially be a clinically valuable endeavor.

Studies are also needed to examine the effects of the intervention on adherence, health care utilization, and illness outcomes. It has been demonstrated that decreased psychological distress of the child (Jacobsen, Goldberg, Burns, Hoeper, Hankin, & Hewitt, 1980; Janicke, Finney, & Riley, 2001) and the parents (Floyd & Gallagher, 1997; Wolkind, 1985) are associated with better health care utilization. Thus, measuring these outcomes will be essential in determining whether the intervention can actually improve overall health outcomes. Further, the cost-effectiveness of such an intervention will need to be established before it can be implemented on a large scale. Therefore, future studies evaluating whether the intervention is associated with a reduction of health care utilization will be required in order to justify wide spread dissemination.

Summary

The current study reports findings from a randomized clinical trial examining the first intervention designed to decrease illness uncertainty among parents of children newly diagnosed with DM1. This study demonstrates that the intervention was effective in temporarily decreasing maternal distress and child behavioral symptoms. Further, improvements in child adaptive skills were reported by mothers at the six-month follow-up. Contrary to predictions, fathers receiving no treatment reported fewer behavioral symptoms for their children at the one-month follow-up. Findings from this study demonstrate that parental distress can be mitigated during the post-diagnostic period. Although a relatively small homogeneous sample restricts the conclusions that can be drawn, the current findings are promising. Thus, future studies with larger sample sizes are needed to validate the efficacy of the intervention and to determine ways to maintain treatment effects.

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APPENDIXES

APPENDIX A

PARENTS OF CHILDREN WITH TYPE 1 DIABETES: SESSION ONE–INTRODUCTION AND OVERVIEW OF THE PROGRAM

PARENTS OF CHILDREN WITH TYPE 1 DIABETES
SESSION ONE

INTRODUCTION AND OVERVIEW OF THE PROGRAM

SLIDE 1
I. **Introduction- Welcome to all parents and group members.**

We want to welcome you all to the Parents of Children with Type 1 Diabetes group. We are glad you are here. My name is ____________ and (motion to the other facilitator) I am ____________. (Each facilitator should tell a little about their background, i.e. I am a doctoral student at Oklahoma State University. I am interested in learning how to help parents cope with their child's chronic illness.) We will be your group facilitators for each of the sessions. Before we get started we want to go over a few important guidelines that are essential to make this program better for you.

Guidelines regarding participation
Insert Co-facilitators name __________ and I view this as an opportunity **to learn from each other**. We know that you all have a lot to teach us and we hope that we provide you with information that is useful to you too. Throughout all the groups we **encourage your participation**. However, you never have to share anything that you do not want to share. We will **never force you to speak** during any of the sessions. But we do encourage you to participate as much as possible because we feel that **each of you has something important to contribute** to this group. Feel free to ask questions or make comments at any point during the group.

Confidentiality
Because we respect your privacy and so that everyone can feel free to be honest and share their feelings, we will not repeat what is said during the group outside of this room or to anyone who is not a member of this group. And we ask that you all do the same for each other. That way everything is kept confidential. There are three times that ________________ and I would have to break this group rule. That is if any one said that they were going to hurt themselves, someone else or reported on-going child abuse. In these instances we would take the appropriate actions that are required of us by law.

Participants Introduction
Before we go on any further, we would like to have everyone introduce themselves. Choose one of the following introductory activities.

> ~**Tell us your name** and **one thing that you would like to learn from this group**. (*Take notes on what the parents want to learn so we can attempt to meet the parents' needs).* **OR**
>
> ~**Tell us your name** and **one thing neat about your kid!**
> Great! It great to meet you all!

Program Rationale and Common Questions

Before we start we want to address a few questions that parents often have about the program. Often parents participating in the program ask, "Why are you doing this program?" We will answer this question as throughout the program. The short answer is that research shows time and time again that the better parents and children adjust to type 1 diabetes within the first year of being diagnosed the better they do in the future. In other words, initial adjustment to the illness predicts later adjustment. It is a preventative philosophy. We want to help you as parents now so that you and your child will adjust to life and diabetes better in the future.

The next question that you may be asking yourself is, "why are you doing the group with the parents instead of the kids?" Here again the research demonstrates repeatedly that the parent adjustment associated with child adjustment. In other words, the better you are coping with all the demands of life the better your child is going to cope with the events in their life whether it is related to diabetes or to one of the many other aspects of their life. So the better that you are taking care of yourself emotionally and physically, the better it is for your child.

Another question that you might have is, "how did you decide what to do during the sessions?" Well, through our research with over 200 parents of children with chronic illness, parents told us about how they felt about their child's chronic illness and how their child's illness effected their lives. Through this group we address the feelings and emotions that these parents told us often come from being a parent of a child with an illness.

Activity #1 - Parents thoughts and feelings

But first it is important to us to know **what it was like for YOU right before your child was diagnosed**, to find out that your **child had diabetes**, and the feelings that you have **now about your child's illness**.

> We are handing out a **pen and paper**. We want you to write down as many of **the thoughts and feelings** that you had:
>
> 1. Immediately prior to your child's diagnosis. Be as honest as you can. (Wait 2-3 minutes).
> 2. When **you found out that your child had diabetes** (Wait 2-3 minutes).
> 3. The **feelings that you have now** about your child's illness (Wait 2-3 minutes).

Give the parents 5-10 min. When most of the participants appear to be done ask for ***volunteers to share their responses****. Do not force the issue of getting a volunteer for to long. This is the first activity so the group members may be a little reluctant. If none of the participants want to share their responses say something like,* ***"many parents***

***report feeling scared, confused, in the dark, out of control, and in general uncertain.*"**

If participants respond put their feelings on the **newsprint or chalkboard**. Once all the responses are up star the responses that reflect or are closely related to uncertainty. Point out the feelings that are related to uncertainty. Indicate that these are the same feelings, in particular the experience of uncertainty that many parents feel.

In fact, we found that one feeling that parents most often feel is uncertainty. Parents of children with an illness often report feeling uncertain about how to care for their child's illness, uncertain about the meaning of symptoms that their child has, uncertain about how to care for their child's illness, uncertain about how the illness is going to influence their child's schoolwork, peer relationships and participation in activities, and uncertain about how the illness is going to influence their child's life in the future. Uncertainty is that feeling that some people feel when they are waiting to find out a diagnosis, when they are trying a treatment for the first time or when a treatment does not work. And sometimes parents and children do not feel that they have enough information about the illness or the information is unclear increasing their feelings of uncertainty.

Purpose of Group

The purpose of this group is **educate and empower** you about the different sources of **uncertainty**, **the influence of uncertainty** on you and your child, as well as provide you with the **skills to identify and reduce feelings** of **uncertainty in your and your child's lives.** Another purpose is to learn from each other "tricks of the trade." Each of you bring a wealth of information to share with the group.

Hand out the "Parents of Children with Type 1Diabetes" program folders. In each of the folders there are sections for each session of the group where you can insert the handouts we give you throughout the course of the group. Bring **your folder to group every week.** The folders are yours to keep. Hopefully they will be useful to you as a **resource after the group is over**.

First let's briefly review the goals of the program.

SLIDE 2

Goals of the program- Reductions in uncertainty about Type 1 diabetes through two sessions:

Session 1:
- Illness uncertainty
- Thoughts and Coping.

Session 2:
- Problem solving
- Communication
- Role identification
- Stress management

UNCERTAINTY APPRAISAL AND COGNITIVE COPING

GOAL FOR SESSION ONE: Introduce the concept of illness uncertainty appraisal and coping by:

1. *Building and promoting rapport and cohesiveness within the group.*
2. *Introducing the concept of uncertainty.*
3. *Emphasizing the importance of social support in reducing uncertainty.*

II. Overview of session one.

- A. Overview of uncertainty in illness.
- B. The role of social support in reducing illness uncertainty.

SLIDE 3

III. The nature of perceived uncertainty in illness.

What is uncertainty? Mishel defines uncertainty as "the inability to determine the meaning of illness related events that occur in situations where the decision maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes because sufficient cues are lacking" (Mishel, 1990; p.257). What DOES that MEAN?!! It is a feeling experienced when a situation is ambiguous, unfamiliar, unclear, or information is lacking. Uncertainty may occur when the meaning of the symptoms are unclear, the medical procedures are unfamiliar and the results of the medical procedures are uncertain. You may feel uncertain when there are unidentified factors that contributed to the development or worsening of the illness. Many parents say they feel high levels of uncertainty prior to diagnosis or when they are just learning their child's treatment regimen. Parents often feel uncertain about the long-term implications of their child's illness. Many parents report uncertainty about how their child's diabetes will affect them as adults, whether they will be able to have children, whether they have any long-term complications of their illness.

Do any of these descriptions of illness uncertainty sound familiar or hit home for you? OR Can you think of a situation related to your child's illness that brought up this type of feeling or experience for you? *(If none of the parent's respond say, "Take time to think about it as we are going through today's session. As the concept of uncertainty becomes clearer to you, may have some ideas. Feel free to bring your ideas up as we go along.")*

SLIDE 4

Let's consider why this concept is important.

A. Research has demonstrated that as the perceived illness uncertainty among individuals with an illness, or family members of a person with an illness increases, the level of distress the individual or family members feel increases.

1. In a study by (Mulllins et al., 1997) Uncertainty was found to be associated with the psychological adjustment of college students.
2. In another study by (Turner et al., 1990) uncertainty was found to be associated with a feeling a lack of control and distress among parents with children in an ICU.
3. In two other studies parents describe feelings of uncertainty and feelings of anxiety and depression during the pre-diagnostic and immediate post-diagnostic phases of their child's illness.
4. Research also has shown that initially parents feel a great deal of uncertainty about their child's illness. Parents who feel more uncertain tend to experience higher levels of distress than parents who report fewer feelings of uncertainty (Cohen, 1993).

SLIDE 5

All of these studies show that as uncertainty increases distress increases. We will return to the importance of uncertainty a little later, but first let's find out what the sources of uncertainty are.

SLIDE 6
Four Potential Sources of Uncertainty

B. There are four potential sources of uncertainty within an illness experience:
   1. Ambiguity concerning the state of the illness.
   2. Complexity regarding treatment.
   3. Lack of information about the illness.
   4. Unpredictability of the course. These are factors that tend to create uncertainty in illness situations.

We will discuss each of these. *(Allow parents to comment freely throughout the description of the different sources of uncertainty.)*

SLIDE 7

1. **Ambiguity concerning the state of the illness.** Ambiguity about the cause of the illness, the prognosis and/or the meaning of symptoms may increase feelings of uncertainty. (*Explain the concept of ambiguity further using your own words touching on each of the following points).*

   Can anyone give me a definition of ambiguity? OR How would you define ambiguity?

   a. Unclear prognosis. This most generally occurs prior to diagnosis or right after diagnosis when the doctors are trying to determine the severity of the illness.
   b. Unknown cause of the illness. Sometimes it increases uncertainty when the cause of the illness is unknown. If the cause is uncertain parents will sometimes wonder if they are at fault for their child's illness and if they could have prevented it.

parents will sometimes wonder if they are at fault for their child's illness and if they could have prevented it.

c. Symptoms that are difficult to identify and/or symptoms that are seemingly the same sometimes may be indicative of different things. This is particularly relevant in diabetes. Sometimes feelings of uncertainty are increased because you have not yet had time to be able to discriminate between illness symptoms (i.e. such as hypoglycemia) and what is fatigue or "feeling lazy". Discriminating these slight differences can be difficult.

SLIDE 8

2. **Complexity regarding treatment :** The more complex a treatment regimen is, the greater the uncertainty. (*Explain the concept of complexity further using your own words touching on each of the following points).*

   a. Complexity of the treatment regimen- Diabetes, in particular, has a complex treatment regimen. A diabetes treatment regimen involves blood glucose monitoring, insulin administration, diet and exercise management. This complexity can initially be daunting and increase your feelings of uncertainty.
   b. Multiple types of doctors. As a parent of a child with diabetes you have to deal with a variety of doctors with different personalities and approaches. You may at times even receive conflicting information from different doctors which can increase your feelings of uncertainty regarding your child's illness.
   c. Multiple body systems involved. Diabetes can affect multiple bodily systems such as the cardiovascular system, vision, etc.

SLIDE 9

3. **Lack of information about the seriousness of illness and prognosis.** This source of uncertainty is most commonly experienced during the pre-diagnostic period or during a complication related to the illness. (*Explain the concept of lack of information further using your own words touching on each of the following points).*

   a. Prognosis-Impact: Initially, it may be difficult to know what the **prognosis** will be for your child. Sometimes the doctors have few definite answers about **the impact** that the illness will have on your child and consequently your family. In addition, prognosis is variable for each individual patient.
   b. Communication
   c. Course
   d. Treatments
   e. For example: the lack of information before you child is diagnosed may increase feelings of uncertainty. You know that your child is sick and

something is not right but you don't know what is wrong or how serious it is.

SLIDE 10

4. **Unpredictability of the course** (Mishel, 1984). (*Explain the concept of unpredictability further using your own words touching on each of the following points).*
   a. When the frequency, number, location and duration of the symptoms are unpredictable it tends to increase uncertainty regarding the illness.
   b. Event incongruence- when your expectations for a situation do NOT match what actually happens. When there is a high degree of event incongruence if feels as though things are really unpredictable.
   c. For example: Think of when you first noticed your child having symptoms. During that time right after diagnosis parents sometimes feel like the symptoms (i.e., hypoglycemic attacks) appear unpredictably. In this situation your feeling of illness uncertainty is likely to increase.

   (If there has been little discussion or comments from the parents up to this point go to section C.)

C. What are some of the potential sources of uncertainty that you can identify from your experience with caring for your child thus far? Have any of you experienced ambiguity regarding you child's illness? *(Use follow-up questions as appropriate: What was that like for you? How did you cope? Has the complexity of your child's treatment regimen ever increased your feelings of anxiety or uncertainty? Encourage the group members to mention any sources of ambiguity, complexity, lack of information regarding their child's illness. Reflect the comments that the parents make. When appropriate point out how one situation can include all of these sources of uncertainty. If possible highlight the similarities of the feelings and experiences among the parents. Allow approximately 15 min for discussion.*

SLIDE 11

D. Let's Recap! Situations that increase feelings of uncertainty include:

1. Ambiguity concerning the state of the illness. Ambiguity regarding the symptoms that your child is displaying. For example: when your child complains that they are really tired.
2. Complexity regarding treatment.
3. Lack of information about the illness.
4. Unpredictability of the course. These are factors that tend to create uncertainty in illness situations.
   i. Increasing severity of the illness. Hypoglycemic attacks become more frequent despite good adherence.

ii. Unexpected complications regarding the illness. For example: your child begins to have circulation problems.
iii. Feeling a lack of control over the circumstances regarding the illness. Example: Despite good regimen adherence your child is having a difficult time achieving euglycemia.
iv. Event incongruence- when your expectations of a situation does not match what is happening. For example: when the expected effects of a treatment do not match the actual results of a treatment.

SLIDE 12
IV. Reducing uncertainty in illness.

The good news: there are ways to decrease illness uncertainty. Situations that decrease feelings of uncertainty include:

1. Increased levels of social support. The more social support that we have the better we tend to handle feelings of uncertainty.
2. Increased knowledge about the illness and its treatments. Uncertainty about the illness and its treatments can be decreased by knowledge of the illness. Many parents feel that the better they understand the illness and the treatments the less uncertain they will tend to feel.
3. Good communication with health care providers. The better communication that you have with your health care providers the less uncertain you will tend to feel because you will be more likely to understand them and feel free to ask them questions.
4. Previous experience with the illness situation. The more experience that you have had with an illness situation the more certain you will feel. You will be more familiar with the possible outcomes and how to deal with them.
5. Perceived control over the care and symptoms of the illness. The more control you feel you have over the illness the less uncertain you will feel.

A. To a certain extent, we can all manage the level of uncertainty that we experience. (*Pointing to the lists you just talked about*) The goal of this group is to promote the skills needed to effectively manage illness uncertainty by addressing the factors that increase and decrease illness uncertainty.
B. First we will look at how uncertainty influences the ways that we feel. By understanding and identifying uncertainty we can take action to decrease the amount of uncertainty we experience and subsequently make ourselves feel better.

V. Introduction to uncertainty appraisal and cognitive coping strategies.
Now, we are going to introduce some ways that people think in uncertain situations that influence that influences their mood and how they cope with the illness. It will become clearer as we explain. Feel free to ask questions as we go along.

SLIDE 13

VI. **Automatic thoughts.**

A. We will begin at the left of this diagram with a situation. You are in a group and there is a group leader that is talking about homework, support, diabetes, etc..... Moving to the right in this diagram. Automatic thoughts are the stream of thinking that we have, in the moment or situation. They are our immediate thoughts in response to someone or something. For example, right now, the situation (*point to the chart*) is you sitting in a group, listening to what I am saying. Your automatic thoughts are the thoughts that are running through your mind as I am talking. While I am standing here talking you may be thinking, "this is interesting," "I don't understand," or "this stuff is stupid." If you are thinking that "this is interesting, I am beginning to understand," this will influence the way that you are feeling (*point to the chart*). You may feel hopeful or happy or excited because you understand. Conversely, if you are having automatic thoughts such as, "I don't understand," you may feel frustrated or sad or "this is useless" and consequently you feel frustrated.

SLIDE 14

1. Therefore, automatic thoughts are the stream of thinking that we have, in the moment or situation. They are our immediate thoughts to someone or something. Thoughts about the same event may be different for different people. For example, your appraisal of an event may be different than your spouses. In addition, your thoughts and feelings about the same illness event may also change over time as the event becomes more familiar to you. Keep this in mind as we talk about thoughts.

2. ***Group activity-*** *practice identifying automatic thoughts. Show a 5 min movie clip with uncertain content. While watching the movie clip have all of the participants write down their automatic thoughts. Discuss the participants automatic thoughts for 5-10 min. Write down thoughts on the caulk board. Try to catagorize the comments as you are writing them down as threat or opportunity thoughts as you write them on the board. Use the discussion to clarify the concept of automatic thoughts. Correct the participants if needed.*

   So we are continually scanning our environment and having thoughts about the situations we encounter, including events that are related to our child and diabetes. A trip to the Dr.'s office, a big sporting event, checking the blood sugar are all events that we have automatic thoughts about. In general, researchers have found that there are two types of thoughts that we generally make regarding uncertain and illness situations.

SLIDE 15

3. Threat thought.
   a. A situation is classified as a threat or danger when the event is experienced as uncontrollable.
   b. Pre-supposes an expectation of a harmful or negative outcome.
   c. What are some diabetes related threat thoughts that you can think of? (*Allow participants to comment. If none of the group participants have ideas give them a few examples and evaluate whether they understand the concept. Ex. High keytone levels, hypoglycemic attack)*

SLIDE 16

4. Opportunity/Neutral thought.
   a. Events that are viewed as controllable are viewed as an opportunity/neutral
   b. Implies a positive or non-threatening outcome.
   c. Are there any diabetes related opportunity thoughts that you can think of? (*Allow participants to comment.)*

5. **Group activity (Approximately 10 minutes).** Let's practice automatic thoughts again, except this time you are going to have to use your imagination a little bit. **I want you to imagine that you are in each of the situations that I call out. After each situation that I read, I want you to imagine that you are in that situation, then I want you to write down all the thoughts that immediately come to your mind.**

   Situations:
   - *Blood Sugar greater than 200.*
   - *Blood sugar too low.*
   - *Dr.'s appt. coming up.*
   - *Leaving for summer vacation.*
   - *At Christmas party with lots of goodies and you find out your child ate cookies.*
   - *Graduating from high school.*
   - *Won 1st place in a track meet.*

6. *(Discuss the participant's responses 5-10 min OR If the participants are having difficulty with the activity modify it. Have each member identify a diabetes-specific event that they may have experienced at a stressful time.)*
7. When coping with difficult or uncertain situations it is helpful to examine your automatic thoughts b/c they will influence how you feel.

8. Good job. Thanks so much for sharing your thoughts. Now lets look at the last part of the diagram, feelings/emotions.

SLIDE 17

VII. Emotions- Teach the relationship between emotions and thoughts.

A. The thoughts that we have will influence our emotions or how we are feeling. Emotions accompany and are influenced by thoughts. But emotions are different than thoughts.
  1. Feelings are what we feel emotionally.
  2. Thoughts are ideas that you have, you think them in words or pictures (Beck, 1995).
  3. **Feelings game:** (*Break the group into teams.* ***Have the participants name as many feelings as they can off the top of their head in one minute.*** *The group that names the most feelings gets a prize. When the game is over Handout Feeling Chart).*

  OR

  Have several slips of paper with an emotion on it. Break the group into two teams. Have one person from a group say "I feel this way when I….." Then have the opposing team guess the emotion. Whichever team has the most points wins.

B. As I said, thoughts and emotions are tied together. Take out your automatic thoughts list from the activity that we just did. Next to each automatic thought that you wrote down, I want you to write the emotion that you think would accompany that thought. Do most of you find that your thought and the emotion are tied together?

C. By identifying our automatic thoughts we can modify our emotions. *Give examples of thoughts that occur in "uncertain" situations and how they lead to different thoughts and negative emotional states. Examples of uncertain situations: Birthday parties, School, ball games*
For example: What feelings are you likely to experience when you make a dangerousness thought? *(Try to use an example of an thought that a group member brought up during this or the last exercise). Examples of emotions: Fear, sadness, confusion.*

OR

What feelings are you more likely to experience with an opportunity thought? ? *(Try to use an example of a thought that a group member brought up during this or the last exercise) Examples of emotions: Hope, relief, confident. Highlight differences between the thoughts and the emotions but emphasize how they are related.*

SLIDE 18

VIII. What is coping?

A. When we appraise a situation as a threat or an opportunity we call it the automatic thought of the situation. Coping refers to the methods that we use to manage the thoughts and emotions that we experience as a result of some of stress like uncertainty. For example, some cope by talking to their friends. Others study and learn as much as possible about their child's illness to help them cope with negative emotions or concerns related to their child's illness. Some researchers have examined how different people cope with either having an illness or being close to someone with an illness.

B. **Group Discussion**- (*Restructuring Vignettes: read the vignette, have parents come up with as many ideas as possible to cope with the situation.* ***Write all of the ideas on the board.*** *Leave all the coping strategies for all two vignettes on the board. Positively reinforce their participation.)* We are going to read two vignettes. After each vignette we are going to ask you ways that you could cope with the situation. Be as creative as you can. We are brainstorming.

1. Your child has been invited to a slumber party for the first time since being diagnosed with diabetes. As parents, a number of issues are brought up by this new situation. Who will monitor what he/she eats? Will he/she remember to take their insulin? Who will take care of him/her if he/she has a hypoglycemic attack? What are ways to cope with this new, possibly anxiety provoking situation?
2. Lately when you and your child have tested their blood glucose your child has had either extremely high blood glucose or extremely low blood glucose. This is despite close adherence to the treatment regimen. You have gone to the doctor and they are unsure about the cause of the poor metabolic control. What are ways to cope with this uncertain situation?

Excellent job! You came up with a lot of different ways to cope with each of these difficult situations. Don't worry if the ideas that we came up with do not sound like they would be helpful to you. One way of coping with a situation is not going to be right for all people. Everyone will have slightly different ways of coping that work best for them.

SLIDE 19

IX. Overview of problem-focused versus emotion-focused coping styles.

However, researchers who studied individuals with an illness and their families have identified two primary types of coping styles: problem-focused and emotion-focused coping styles (Lazarus and Folkman,1984).

A. **Problem-focused coping style.**

1. Refers to techniques that involve direct action or information seeking.

2. Examples include: going to the library to seek information about an illness, monitoring your child's behaviors such as eating habits more closely, starting a support group and attending this group.
3. Which of the coping styles on the board are examples of problem-focused coping? *(Let the participants respond). (Label all of the comments on the board that are indicative of a problem-focused coping style).*

B. Emotion-focused coping style.

1. Refers to faith, disengagement, crying, talking about the problem and your feelings, and cognitive support (Mishel, 1988).
2. Examples include: Wishful thinking, giving yourself pep talks, hoping, and ignoring events.
3. Which of the coping styles on the board are examples of emotion-focused coping? *(Let the participants respond).(Label all of the comments on the board that are indicative of a emotion-focused coping style.)*

C. Researchers have shown that people use different combinations of problem-focused and emotion-focused coping. Each one of us is different and therefore what is going to be helpful to one person may not be helpful to another. The key to successful coping is finding out what is most helpful for you. If you are feeling down about an illness situation or any other stressful situation in your life, you may want look at what problem focused and emotion focused coping strategies that you are using. This 5 step coping plan may help. *(HAND OUT)*

SLIDE 20

5 Step Coping Plan:

1. "What am I doing to cope with the uncertainty/stress?"
2. "What type of coping style am I using?"
3. "Is it working?" Meaning is it solving the problem, changing the situation to be the way that you want it, or is it making you feel more certain or better?
4. If it is not working ask yourself, "How can I change the way I am coping to make myself feel better?"
5. Try a new coping technique.

X. **Restructuring of coping styles.**

A. Changing emotion-focused coping styles on the board to problem focused coping styles. Once again let's return to the vignettes that we were discussing a few minutes ago. So let's say that we are using these emotion-focused coping styles to deal with our negative emotions regarding the potentially stressful situations described in the vignettes. Let's say that the emotion-focused coping works for a while but then it is not enough and you are feeling more down, angry, negative etc.... How can we change the emotion-focused styles to more problem-focused styles?

B. *(Have participants generate ideas. Write the coping changes on the board. Positively reinforce comments and ideas.)* Concentrate on thoughts and beliefs that are related to: *diabetes related complications, treatment regimen, conflicts related to the illness, stress related to the illness*

C. These are great ideas!! You have the hang of it!

Now that you are familiar with the concept of uncertainty is and how it influences how people feel. Now we are going to switch gears a little bit. Now we are going to shift from learning about what uncertainty is and how it influences us to how to manage it. We will do this by targeting six ways to reduce illness uncertainty:

- Providing information regarding your child's adjustment,
- Presenting ways to increase social support,
- Teaching problem-solving techniques,
- Helping you to identifying your role in your child's care,
- Giving you tips on communication
- And presenting information on stress management.

Today we will target uncertainty by increasing the amount of information about potential warning signs to look for emotionally or psychologically with you and your child. Then we will finish the session by teaching you one of the best and easiest ways to decrease illness uncertainy, increasing social support.

XI. Psychological adjustment to Type 1 diabetes. Before addressing the possible adjustment problems that children and parents sometimes have we want to emphasize that the majority of children eventually adjust relatively well to the diagnosis of diabetes. However, it is not uncommon for some children to have difficulties adjusting to having diabetes. Common reactions during the initial adjustment process may include symptoms of depression or anxiety (Kovacs et al., 1990; Johnson et al., 1990). These symptoms usually are not severe and a study in 1990 (*Kovac et al.*) showed that the rate at which children report these psychological symptoms usually decreases 6 to 9 months after diagnosis. In other words the period right after diagnosis can be difficult time and this is normal. In addition families do well after they have had time to adjust.

A. When should I be concerned? What to look out for:

SLIDE 21

1. Symptoms associated with depression:
    - Marked increase in feeling sad, blue, down, irritable or depressed more days than not. Emphasize that this may look different in younger children. Among children depression may manifest as **irritability, defiance and aloofness**.
    - Loss of interest in activities that they previously enjoyed more days than not.
    - Low self-esteem.

- Having problems sleeping or sleeping too much
- Feelings of worthlessness or inappropriate guilt
- Feelings of hopelessness
- Recurrent thoughts or statements about death (more than a just a fear of dying).

SLIDE 22

2. Symptoms associated with anxiety:
    - Increase in worrying about things that might happen.
    - Feeling jittery or keyed up
    - Muscle tension
    - Sleep disturbances

SLIDE 23

3. General signs
    - Your child is having **extreme difficulties with medical procedures**. Including refusal or experiencing excessive pain.
    - Your child starts doing **poorly in school**.
    - Your child withdraws and quits playing with friends.
    - An increase in fighting with others.

4. If you are concerned about your child's adjustment seek help from a professional who understands the unique issues involved with being a child that has been newly diagnosed with diabetes. You can ask your physician for a referral.

XII. Factors Influencing Adjustment

When is it more likely that you might see your child exhibit the behaviors we just talked about? In other words, what factors put a child at risk of developing adjustment difficulties?

SLIDE 24

A. **Age**

Adolescents with diabetes tend to be **less adherent and have poorer metabolic control** than their younger counterparts. (Jacobson et al.,1990). Reasons may be **biological, environmental or psychological**.

1. Adolescents with diabetes tend to **be less adherent** and have **poorer metabolic control** than their younger counterparts. Younger children more adherent than older children (Jacobson et al.,1990).

a. This is despite the fact that as age increases, children tend to be more knowledgeable about diabetes and more skilled in administration of diabetes care (La Greca, 1982; Johnson et al., 1982; Johnson et al., 1986; Johnson, 1995).

b. Some have offered biological explanations for the findings. Some have theorized that this is due to the **hormonal changes that occur during adolescence** (Amiel et al., 1986; Blethen et al., 1981; Bloch et al., 1990)

c. While others have suggested it is **due to environmental reasons such as the adolescent taking over more of the diabetes care (Johnson, 1995; Ingersoll et al., 1986).**

d. Currently, it is still unknown what interrelated roles biological, environmental and psychological factors play in the decline of metabolic control observed in some children during adolescence. It is most likely a **combination** of all of these factors.

2. Being aware that these two factors are statistically related to adjustment. This does not mean that if your child is a girl that she is automatically going to have adjustment problems. Likewise all of your children will pass through adolescence at some point. This does NOT mean that all children will experience adjustment difficulties. ***The important thing to remember is that as your child goes through adolescence they may have more difficulty adhering to their treatment regimen or have poor metabolic control. Do not be discouraged or angry with your child.*** *Knowledge of these factors will simply make you more aware.*

SLIDE 25

B. **Gender**

–Girls tend to have more difficulty adjusting to the illness than boys (La Greca et al., 1995; Kovacs et al., 1990).

–Girls tend to report more anxiety and depression than do boys (La Greca et al., 1995; Kovacs et al., 1990).

SLIDE 26

C. **Uncertainty-** As we now all know, the greater the levels of perceived uncertainty the poorer psychological adjustment tends to be. Remember, this means that when symptoms that are unclear or ambiguous and we do not know the severity of the symptom and what the consequences of that symptom are going to be we feel uncertain.

1. *Uncertainty-* The greater the levels of perceived uncertainty the poorer psychological adjustment tends to be.
2. This conclusion is supported by a number of studies which show a strong relationship between uncertainty and emotional distress, mood disturbance and anxiety (Bennett, 1993; Christman et al., 1988; Hawthorne & Hixon, 1994; Braden, 1990; Padilla, Mishel, & Grant, 1992). Uncertainty will be addressed further throughout this program. We feel that this is key, given the strong scientific evidence. By reducing uncertainty we believe that your adjustment process will be made much, much easier. Uncertainty is best reduced by giving you knowledge, skills and strategies for adjustment.

C. **Stress-** Stress can influence diabetic control both directly and indirectly.
  1. Directly, stress is associated with the release of epinephrine and cortisol which have been associated with greater and more prolonged glucose elevations in adolescents with diabetes than in non-diabetic controls (Shamoon, Hendler, & Sherwin, 1980).
  2. Indirectly, stress may affect treatment adherence.
  3. Adults who reported increased life stress also reported disruptions in metabolic control, such as glycosuria, changes in insulin prescription and increased clinic visits (Bradley,1979).
  4. A positive relationship has been found between GHb and the frequency and intensity of positive and negative life events (Delameter et al.,1988).
  5. This does nor mean that as parents we try to *protect* our children for all stress. That is impossible. It means that it is important that we prepare them by giving them the tools that they need to deal with stress (Chaney, 1999).

SLIDE 27

Early adjustment predicts later adjustment

SLIDE 28

XIII. Reducing uncertainty: The role of social support

Another way to reduce illness uncertainty is by improving our social support systems.

A. Social support is a factor that influences the level of uncertainty that you may feel. Fortunately, this is one of the factors that we can control. In 1988, a study conducted by leading researchers (Mishel & Braden, 1987;1988), demonstrated that the more social support an individual had, the less uncertainty the individual tends to experience.

  1. Social support provides the opportunity to clarify our situation or the illness situation through discussion and interaction with others (Mishel & Braden, 1987).
    a. This interaction may enable us to develop solutions for dealing with the problem.
    b. Sharing opinions.
    c. Encouraging positive outlooks when we can't see them.
    d. Assurance of the stability of the environment.
    e. Make illness events more manageable by dealing with them one at a time through discussion.

B. The researchers concluded that social support serves to decrease our perception of uncertainty. Therefore one of the best ways to prevent illness uncertainty is to have a good support system.

C. The social support does not have to be centered around diabetes related activities or discussions!!! Spending time shopping, church activities, etc.... are very important to taking care of yourself and decreasing your illness uncertainty.

D. What is social support? *Elicit the group's ideas of what social support is. Allow them to give examples of what social support is to them. Positively reinforce participation (i.e., good ideas, great suggestions, etc..) If no one in the group offers ideas provide the following examples.* Social support may include:

   1. Spending time and talking with friends and family.
   2. Talking with friends and family.
   3. Attending support groups for parents (This group can be used as a source of social support and if you choose to meet other parents).
   4. Volunteer for fund raising activities for diabetes related events.
   5. Going to church.
   6. Spending alone time with your spouse.

E. **Group Activity 15-20 minutes.** Now that we know the importance of social support let's figure out how to get more of it! **Break into groups of 3-4**. We are handing out a piece of paper and **we want your group to list as many sources of social support that you can think of. The group that thinks of the most sources of social support will win a prize.** (*Hand out activity sheet. Depending on the group size, break groups in to 3-4 people each. Allow couples to break up. The more exposure that they have to other group members the better. Allow the groups time to come up with ideas. Encourage a fun atmosphere. Mingle around the room and listen to the ideas that the participants are coming up with. After 5-10 minutes have the groups share their ideas. Write these ideas on a chalkboard or overhead).*

   1. *(Problem-solve how to create new sources of social support. Write the Parent's ideas on the board. Add any on the following list that they do not come up with. Write down items that we don't have on this list for future groups).*
      - ❖ Join organizations such as your local chapter of JDF or ADA.
      - ❖ Start or Join support groups for parents (This group can be used as a source of social support and if you choose to meet other parents).
      - ❖ Initiate and maintain friendships with other parents with children with Type 1 diabetes.
      - ❖ Volunteer for fund raising activities for diabetes related events.
      - ❖ Go to church.
      - ❖ Go out with friends after work.
      - ❖ Spouse
      - ❖ Parents

- Siblings
- Internet is also a source of information and support.

2. Your child's medical providers can also be a source of social support. Utilize your child's diabetes care team. Ask physicians, nurses, pharmacists, and diabetes educators questions. They should have a lot of ideas to help you manage your child's diabetes because they have worked with a lot of parents who are going through what you are going through right now. We will discuss more about communication with medical providers in session five.

F. Now that we have listed sources of social support, **let's take some time to apply this to each of our own lives**. We are passing out another ***handout***. The purpose of this handout is to help you recognize the sources of social support that you already have in you life. But we all can always use **more social support**!! So we also want you to take a few minutes to yourself and think of **three ways** that you can increase the amount of social support in your life. In addition, identify **one new source of social support** that you can begin to utilize in your life.

(*If the participants ask, this can include increasing the time spent with an existing source of support or a new source all together. Allow the participants approximately 10 minutes to complete their lists. Mingle around the room. Offer suggestions to individuals who seem stuck. Positively reinforce the ideas of the parents).*

SLIDE 29

XIV. **Summary of session one, highlighting the critical points.** Today we introduced the concept of illness uncertainty.

A. Uncertainty in illness has four primary sources, lack of information regarding the illness, ambiguity regarding the state of the illness, unpredictability regarding the state of the illness and the complexity of the treatment regimen. Uncertainty will be addressed by teaching you ways to increase social support, to obtain information regarding your child's illness, identifying your role in your child's care, and how to best communicate with health care professionals to get you and your child's needs met.

B. The risk factors that may put you and your child at risk for adjustment difficulties will be addressed through out this program.

C. The role of social support in reducing illness uncertainty. Social support serves a protective function against the feelings of uncertainty that we have. Social support can decrease the feelings and effects of illness uncertainty.

SLIDE 30

XV. **Homework assignment number one.**

A. During the first half of the session today we talked about illness uncertainty in general. We all experience the feelings of uncertainty in slightly different ways. It is important that you identify for yourself what are the sources of uncertainty in regards to your child's illness.

1. Discuss the nature and sources of uncertainty regarding your child's illness.
2. Identify one new source of social support or identify one way to increase the social support that you are getting from your current sources.

APPENDIX B

PARENTS OF CHILDREN WITH TYPE 1 DIABETES: SESSION TWO–MANAGING ILLNESS UNCERTAINTY

Parents of Children with Type 1 Diabetes
SESSION TWO
MANAGING ILLNESS UNCERTAINTY

GOAL FOR SESSION 2: Teach parents to appraise diabetes related illness uncertainty and methods of coping by:

1. The use of problem solving strategies.
2. *Helping parent's define their role in their child's care.*
3. *Solidifying problem solving skills.*
4. *Teaching communication skills*
5. *Presenting information on stress management.*

SLIDE 1

Welcome back to session two!! Before we begin today are there any questions? *(Pause. Address any questions that the parents might have. If you do not know the answer to the question, tell the parents that you don't know the answer but you will find out by the next session).* Today we will cover the following topics:

SLIDE 2

I. **Overview of session two.**
   - A. Review homework from session one.
   - B. Illness Education.
   - C. Problem Solving Technique
   - D. Communication skills.
   - E. Identify your role in your child's care.
   - F. Stress management.

II. **Review of homework assignment number one.**

   A. Let's look at this week's homework. Let's look at question 1. What sources of uncertainty regarding your child's illness were you able to identify? (*If possible highlight the similarity among the comments that the parents make regarding uncertainty Allow the parents to respond. Use their comments as much as possible.).*

   B. Great job on your homework. These are tough assignments and you all did a great job.

III. **Illness education.**

   A. One of the best ways to decrease illness uncertainty is to increase your knowledge about the course and treatments of your child's illness, so that is what we are going to focus on now. We want to introduce _________insert CDE's name. She is a __________(tell a little about their professional background).

She is here for half an hour to answer any questions that you may have about diabetes and your child. Please, if you have ANY questions, feel free to ask. The CDE will be happy to answer your questions and if we do not know the answer to your question, we will find out and tell you HOW we found out!

SLIDE 3

B. Seeking resources. Clearly you can never know everything there is to know about your child's illness but that is normal. No one can know it all, even the professionals. That is why you have a team to help you.

List of team members- Diabetes requires daily attention. It is important to remember that you are not alone. There are a lot of people to help you with all the aspects of diabetes. It is helpful if you form your child's own diabetes "team". This team should include the following specialists who are knowledgeable about the unique aspects of diabetes. By taking a team approach your health care providers will be able to share information and work together to provide your child with the best care possible. Your team may include:

A doctor experienced in treating diabetes
These doctors are called endocrinologists or diabetologists. They will work with you to develop an individualized management routine for your child and help you determine your child's ideal blood sugar range and ways for them to stay within that range.

A diabetes educator
Diabetes educators specialize in teaching people how to manage their diabetes. Most are registered nurses, pharmacists, dietitians, or physician assistants with advanced training and experience. They help you, your child and your physician develop a management plan based on your child's age, school schedule, daily activities, and eating habits. They can teach you and your child the importance of good nutrition, exercising regularly, and testing blood sugar. These professionals can also help your child adjust to having diabetes. Diabetes educators who use the initials C.D.E. (Certified Diabetes Educator) after their names have passed an examination qualifying them to provide health education to people with diabetes.

A nutritionist or dietitian
Nutritionists or dietitians trained in diabetes care provide diet guidelines and meal planning advice. They can teach you and your child how to balance food intake and insulin requirements and how to handle special situations such as low blood sugar (hypoglycemia) and sick days. Some dietitians are also C.D.E.'s.

A mental health professional

A person with diabetes can never take a vacation from daily management chores. For this and other reasons, diabetes can affect the way a person feels. If you need advice on managing your child's diabetes during stressful or difficult times, or if your child having diabetes makes you feel sad or depressed, talking to a social worker, psychologist, or psychiatrist may be helpful.

A podiatrist
A doctor who treats foot and foot related lower extremity disorders. The podiatrist can help with corns, calluses or other sores that arise on the feet in addition to educating you and your child on how to best care for your child's feet.

A Dentist
The dentist helps your child maintain a healthy mouth and strong teeth. Inform your child's dentist that he/she has diabetes so they can be aware of your child's dental needs.

Your child and YOU!!
You know your child the best. Educate yourself and be proactive with your child's health care needs. Participative management. Set an example for your child and encourage your child to be active in their own care.

a. Participate as an active member of the treatment team.
b. Evaluate environmental factors that may influence your child's adherence.
c. Communicate frequently and honestly with the treatment team about regimen and/or concerns about implementation of regimen behaviors.
d. **Remember** there are NO dumb questions. If there is something about your child's care that you don't understand, ASK!! We will practice in session six talking to health care providers to get the information that you need about your child.

C. In addition there are many organizations that can offer advise and support.
Hand out list of organizations and resources

American Diabetes Association- Regional Offices
1211 North Shartel Avenue
Suite 603
Oklahoma City, OK 73103-2425
phone: 405/235-1991
fax: 405/235-1989

NATIONAL ORGANIZATIONS
American Diabetes Association
ADA National Service Center
1660 Duke Street
Alexandria, VA 22314
(800) 232-3472

website: http://www.diabetes.org

Juvenile Diabetes Foundation International
120 Wall Street
New York, NY 10005-4001
(212) 785-9500
(800) JDF-CURE
Fax: (212) 785-9595
website: http://jdfcure.org/

American Association of Diabetes Educators
444 N. Michigan Avenue
Suite 1240
Chicago, IL 60611
(800) 832-6874

WEBSITE FOR KIDS WITH DIABETES
website: http://www.childrenwithdiabetes.com

Additional publications about diabetes are available from the National Diabetes Information Clearinghouse. The clearinghouse can also provide information about research and clinical trials supported by the National Institutes of Health. The address and telephone number are:

National Diabetes Information Clearinghouse
1 Information Way
Bethesda, MD 20892-3560
(301) 654-3327

For more information about improving blood sugar control, write:

National Diabetes Outreach Program
1 Diabetes Way
Bethesda, MD 20892-3600

COPING AND PROBLEM-SOLVING STRATEGIES

SLIDE 4

III. Introduction to problem-solving.

- *First provide the rationale for learning the problem-solving techniques.* This problem solving technique provides parents and their children a systematic, objective way to approach problems, disagreements, and conflicts. This technique was developed by top researchers (Robin and Foster, 1989) to be used for resolving conflicts between parents and their children. However, it can be applied to almost any problem situation. This is a problem-focused coping technique. This technique attempts to decrease the influence of emotions in the conversation, allowing those involved to think clearer and think of more creative solutions. This approach attempts to objectify the conflict/argument and increase the chance that the child will view the decisions as fair.

- *Give examples where the problem solving technique may be useful.* For example: your daughter Suzie is beginning to approach adolescence and as a result is spending hours at a time on the phone, making it difficult for your associates to get in contact with you. Adding another phone line is not financially feasible. She says it is the only way that she can keep in contact with her friends since you live out in the country and she is not old enough to drive yet.

- *Emphasize to the parents that they will have to lead this process with their children.* As the adults in conflict with our children we must model appropriate behavior for a conflict situation. As difficult as it is, this sometimes means that we, as the adults in the situation, have to keep our cool. The problem solving approach is one tool that you can use to help you successfully set an example. It is a tool that you can use that is a form of coping that we discussed yesterday. It is a problem-focused way to resolve conflicts between you and your child. At the same time you are teaching your child a proactive and productive way to approach their own problems.

A. We will start off by giving you a definition of Problem-Solving:
   1. Problem-Solving is a learned skill that can be applied to a variety of situations, including management of diabetes. It is a way of directly approaching problems to facilitate an effective solution. It is also a skill that can be taught to children.
   2. Problem-Solving is a means to increase your sense of perceived control and reduce your sense of uncertainty.

SLIDE 5 - PASS OUT HANDOUT

   3. Let's look at the problem-solving steps in more detail:
      Step 1: Identifying problem situations- using operational definitions.
      Step 2: Brainstorming various options to a given problem.
      Step 3: Evaluate the positive and negative consequences of a given solution.
      Step 4: Collectively choose the best possible solution and implement the plan.
      Step 5: Evaluate.

SLIDE 6

B. We will now cover each of these steps in more detail. Step 1: Identifying problem situations- using operational definitions.
   1. What is the problem or conflict?
   2. It does not matter who identifies that there is a problem. Either the parent OR the child can identify a problem and use this problem-solving technique to resolve it.
   3. Be very specific. Identify the frequency, when the problem happens or does not happen.
   4. For example: Your child needs to be home by a certain time to administer their insulin on time and they have been late for the last two weeks. Despite repeated requests your child is still coming home late and argues that it isn't going to make that big of a difference anyway.

SLIDE 7

C. Step 2: Brainstorming various options to a given problem. This is similar to the technique that we used in the last session when we listed all the different ways that we could cope with the situations that were presented in the vignette.
   1. All problems have multiple solutions. List as many ideas as possible without evaluating the ideas. Be creative!! Use silly and wild ideas as well as realistic ideas.
   2. The Goal: Increase the flexibility and creativity regarding possible solutions.
   3. *Emphasize the NON-evaluative nature of the Brainstorming step.* The Brainstorming step must be free from evaluation of the ideas that are generated to be effective. This is your chance to add use some humor to lighten the situation. Mention anything that comes to your mind and your child's mind. When you have run all out of ideas THEN you can begin to evaluate the ideas in terms of feasibility etc..
   4. *List the examples of the brainstorming activity on the caulk board:* Going back to the example that I just presented with your child getting home late to take their insulin, some examples from a brainstorming session may include: Run home, Buy a new car, get new friends, leave your activities earlier, plan dinner for later, Speed more, don't go to any activities anymore, ask your friends to come to your house, take your insulin with you so you can take it on the way home, etc....

SLIDE 8

D. Step 3: Evaluate the positive and negative consequences of a given solution. Each person involved in the conflict should independently rate each solution according to it's positive and negative consequences.
   1. What effects will the solution have on the problem?

2. What will the short and long-term effects of the solution be on the problem?
3. What problems may be created by the solution?
4. Each person put a plus or a minus by the "solution."

SLIDE 9

E. Step 4: Collectively choose the best possible solution and implement the plan.
    1. Choose a solution that is amenable to the most parties.
    2. Specify the details necessary to put the plan into action. For example, who is going to pick Jimmy up at the gym so he can get home on time to take his insulin.
    3. Attempt to anticipate any difficulties that may arise during implementation. How can these difficulties be dealt with?

F. Evaluating the success of the solution. Is the initial problem gone? Are all parties happy with the solution? Is the solution causing more problems than it has solved? Through experimentation have you discovered another solution that may work even better?

G. Establish whether a new solution needs to be implemented and problem-solve again as necessary. If the solution has created new problems than do you want a new solution or do you need to solve the new problems.

H. **Group activity- Break the Group into groups of three to four.**
    1. As a group, identify common problems related to diabetes, pick one and practice the above problem-solving approach. Choose a common problem that you have in your home that happens on a recurrent basis. (*If the parents are having difficulty coming up with situations use some of the following examples Allow 15 -20 minutes so the parents have time to go through the whole process at least once during the session. When it is a group of 4 or less do this activity together.)*
        a. Child wants to go to a friends for a slumber party. You are willing to let hem go however you require that they tell one adult that he/she has diabetes in case anything happens. Your child does not want this because they have not told anyone that they have diabetes yet.
        b. Your child is not testing their blood sugar regularly, stating that they feel fine. This conflict has been ongoing for the last week.

    2. Focus on brainstorming and coming up with multiple solutions. When brainstorming DO NOT evaluate the feasibility or the quality of the solution. Make the activity fun by coming up with silly ideas as well as real ones. Write down anything that comes to mind without judging it.

    3. How did you evaluate your ideas?

4. *A given solution for one individual may not be best suited for another individual. Also emphasize again that solving problems has the effect of reducing uncertainty and enhancing a sense of control).*

I. In what situations should this approach not be used. In other words in what situations should you make the choices for your child whether they like it or not? Some examples may include flat refusal to test their blood sugar or take their insulin injections. Are there other situations that you as parents can think of where you would set a limit rather than using the problem-solving technique?
   1. Allow for 10-15 minutes of discussion.
   2. *Make the point that in life threatening situations or situations involving safety it is the parent's responsibility to make choices for the child.* In situations where the decision could possibly result in life threatening or unsafe situations for your child then, as parents it is your responsibility to make the correct decision for your child. In these situations do not be hesitant to set firm, clear, limits with your child.

COMMUNICATION AND STRESS MANAGEMENT

SLIDE 10

IV. **Introduction to communication skills**- Today we are going to spend the nextt part of the session **talking about communication skills.** In session one we learned that lacking of information about the diagnosis, the seriousness and the care of your child's illness is one source of illness uncertainty. **Lacking information that we want or need regarding any aspect of your child's illness can increase feelings of uncertainty.** Our ability to get the information that we want from our child, spouse, friends or physician depends on our ability to communicate. The ability to communicate effectively is especially important in situations where there is added stress or situations that are more complicated such as, having a child with a chronic illness. **Effective communication skills are helpful in variety of different settings. Effective communication skills will help you to get the information that you want regarding your child and enable you to express your needs.** Parents of children with an illness must communicate in a number of diverse of settings. **These settings include: being at home with your child, communicating with your child's school, and with your child's doctor.** Good communication skills are also essential in the problem solving process that you have just learned. **Today we will teach you some of the basic communication skills in addition to some skills that are particularly useful in medical settings. Much of this you may already know.** We encourage you to share any ideas that you may have, especially techniques that you have found particularly helpful when communicating working with medical professionals.

The basics are as follows: The basic communication skills that we are going to cover today include:

- Active Listening
- Expressing feelings
- Setting goals
- Asking questions
- Giving information

SLIDE 11

A. **Active Listening-** Talking to your child about diabetes is important for your relationship with them and your ability to work together to manage diabetes. Use a communication approach that matches your style and that you and your child will be comfortable with. At some point you should discuss the issues surrounding diabetes with them. In general, the parents are the ones to bring the topic of diabetes up. So don't wait for your child to bring it up. Set an example for them by approaching them about the topic and by encouraging them to share their feelings about the diagnosis. Ask yourself, have I ever sat down and had a discussion with my child about diabetes? If so how did it go? If so how did it go? **Active listening such as, just listening to the child vent their feelings is important. Remember you don't have to have all the answers. Nobody does. The important part is that you are there listening.** (Kaslow, 1997).

Keys to active listening

1. Listening and do not interrupt while the other person is talking.
2. Repeating in your own words what the other person has said to be sure that you understand what they are trying to tell you. Reflecting
3. Offering support/comfort (when appropriate). This can be in the form of hugs or encouragement.
4. Reinforcing the other person for communicating with you and sharing their thoughts. This can be as simple as responding directly to what they said or thanking them for letting you know what they were upset about.

SLIDE 12

B. **Expressing feelings-**

1. Identifying/labeling feelings
    a. First let's quickly review the difference between and automatic appraisals and an emotion. What is the difference between an emotion and an appraisal. (*Wait for a volunteer and allow them to highlight the distinction. If no one volunteers say: Automatic thoughts or appraisals are the streams of thought that we have, in the moment or situation. Remember feelings are the emotions that you feel such as happiness, sadness, anger, excitement.)*

   b. Expressing feelings is especially important when communicating with your spouse or partner.
2. Increasing feeling vocabulary- Increasing your feelings vocabulary increases your ability to accurately communicate what you are feeling to you spouse or other support system. This enables your support system to respond to your needs in a more effective manner. (*Refer to the Handout from session three- Feelings Handout*).

SLIDE 13

C. **Setting goals-** Set goals for the interaction that you are going to have with the other person. **Ask yourself, "What am I trying to achieve?"**
   1. What information do you want to get from the other person?
   2. What information do you want the other person to know?
   3. What feelings do you want the other person to know about?

SLIDE 14

D. **Asking questions**- Open-ended and close-ended questions.
   1. Open ended questions are questions that cannot be answered with a yes or a no. Close-ended questions can be answered with a yes or a no. Open ended questions generally facilitate conversation with the other person more so than closed ended questions.
   2. Examples: A closed ended question may ask, "Do you like to ride bikes?" whereas an open ended question would ask "What do you like to do?" A closed ended question may ask, "Do you like school?" whereas an open ended question would ask "What do you like about school?"
3. Other examples of open ended questions are: What can you remember about the situation yesterday? What was it like for you? What do you like to play the best? What did you feel like when you had to stay back from the field trip?

SLIDE 15

E. **Giving information-** Know your child-know diabetes. Provide relevant individuals (i.e. teachers and doctors) the information that they need to know to most effectively care for your child. When communicating with medical professional provide them with as much information about the symptoms as possible. **When communicating with individuals such as baby-sitters and teachers it is best to give them the information in verbal AND WRITTEN form.** Here are some useful forms that can be used with teachers and baby-sitters that communicates common information that parents like to pass on.

SLIDE 16

V. **Applying communication skills in different settings, with different people.**
Highlight the fact that the parents are required to communicate with a large number of people. Each of these people may require different approaches and information.

A. Communication with your child.
B. Communication with spouses.
C. Communication with well-siblings.
D. Communication with your treatment team.
    1. What to ask? Anything...there are no stupid questions especially when it comes to the care of your child. Talk other parents for recommendations.
    2. Who to ask? If a professional does not know the answer to your question then ask them where you can find out the information that you need to know.
    3. Clarifying inconsistencies. Don't hesitate to clarify inconsistencies.
E. Communication community and educational system.
    1. Handouts.
F. Communication with a baby-sitter.
    1. Handouts.
G. **Group Discussion.**
Have group members identify for themselves what situations are the hardest for them as a parent to communicate well in. Summarize what the parents say, elicit feedback from other group members on how they communicate in tough situations.

VI. **Changing roles in the family as a function of diabetes and the child's age.**
Lets talk about the ways in which diabetes influences or changes the roles of individual family members.

A. Being a parent can be a balancing act. A balancing act which can be more difficult when you are the parent of a child with diabetes. It is difficult.

B. There are some common questions regarding roles that generally arise for parents: **At what age is it appropriate to let the child assume responsibility for their care and to what extent? What types of support does my child need? How does this change as they get older?** Unfortunately there are no clear cut answers. Every child is different so you, your child and your health care providers must decide what is right for you and your child.

C. Decisions should be made in a team fashion, with the physician and health care team having input regarding roles related to diabetes care.

SLIDE 17

VII. **Developmental Stages and Management of Diabetes.**
We are going to present some basic guidelines for you in terms of your role in your child's care based of their developmental level. Again, you know your child best and these are NOT hard and fast rules, just general guidelines.

SLIDE 18

A. Years 0 through 7 -
   1. Who will manage what aspects of the diabetes regimen? The parent. How much supervision? Parent is primarily responsible for diabetes care during this age group.
   2. Involve the child as much as possible.
   3. Offer choices to the child, such as picking a spot to inject or selecting which finger to get the drop of blood from.
   4. Describe blood test results as "high," "low," or "normal," NOT "good" or "bad."

SLIDE 19

B. Years 7 through 12 -
   1. Who will manage what aspects of the diabetes regimen? How much supervision? As you might expect these questions are most difficult to answer for this age group. **The parent should continue to take a lot of responsibility for the care during this time and should still continue to supervise regimen closely.**
   2. During this period the **child can take over blood glucose testing and insulin injections some of the time. Parents and children and health care providers can decide when the child is ready to take over the bulk of the care. *Be aware of your child's continued need for your emotional support even if they are self-sufficient in regards to their daily management.***

SLIDE 20

C. Years 12 through 17 -
   1. Who will manage what aspects of the diabetes regimen? How much supervision? Many adolescents participate fully in treatment decisions and are responsible for most of their care. As the child moves into later adolescence you as the parent should fade out of the daily routine care. It is important that your child become proficient at performing these skills before they move out of your home.
   2. Provide social and emotional support. As your child matures the type of support they need will change from supervising medical management to emotionally based support.

D. **Group activity.** These categories are not hard and fast rules. Next we are going to do an activity to help you identify your role in your child's care and in other aspects of their lives. **By explicitly identifying your role you will decrease your feelings of uncertainty regarding what you should be doing for your child and what your child should be doing for themselves.** It will help you identify who is responsible for what. This sounds simple but the waters can get murky when you are worried about our child. Where am I on the care continuum with my child? Am I in transition from one stage to another? *Handout individual in-group worksheets. 10-15 minutes of questions and discussion.*

VIII. **What is stress?**

A. For the last part of the session we are going to talk about a topic that we are all familiar with, stress. Uncertainty is strongly related to the amount of stress that we feel. The greater the level of uncertainty we feel, the more stressed we will feel (Mishel, 1984). Although we can't totally eliminate uncertainty from our lives, we can reduce the stress that we feel as a result of the uncertainty.

SLIDE 21

B. What is stress? (*Encourage the group to share what their ideas of stress are.)* Stress can be classified in a number of different ways. There are physical and emotional sources of stress. For example an injury is one form of physical stress, having to give a big presentation at work the next day is a example of emotional stress. We are going to talk about two different ways to classify stress. Stress can also be classified as positive or negative and short or long term.

1. First we will discriminate between positive and negative stressors. **Stress can be positive or negative. Examples of positive stress may include getting married or getting a promotion at work. Examples of negative stress include getting a divorce or a death in the family.**
2. Short and Long term stressors. **Stress can also be classified as short or long term stressors.**
   - Short term stressors: Someone cutting you off in traffic or being startled by someone coming up behind you.
   - Long-term stressors: For example, having a stressful job that you have to go to day in and day out.
   - **Is diabetes a long-term stressor, short-term stressor, or both?** (*Allow for group response.*) It can be both then can't it. There are the short term stressors of *(use an example a group member mentioned*) or (your child experiencing a hypoglycemic attack). And there are long-term stressors *(use*

an example a group member mentioned) or (There can be many day to day care activities).

E. *(Hand out worksheets and have each group member write down their top ten stressors on a worksheet. Allow 5-10 min).* We are going to hand out a stress worksheet to each of you and we want you to take a few minutes to write down your top ten stressors. They can be positive or negative stressors. And they can be short or long term.

Has everyone had enough time to write down your stressors? *(Make sure that everyone is done before moving on).* Hold on to this piece of paper because we are going to need it later on. Now we are going to look at different ways stress can effect the body. In particular, how stress effects metabolic control.

D. **How stress effects metabolic control.**

1. Transient stress- may cause underinsulization by producing counterregulatory hormones and leading to hyperglycemia. In other words during times of transient (or shorter term) stress the body seeks to conserve energy. Hormones act to conserve energy by not allowing insulin to act as effectively as in times of less stress. Therefore the glucose is not allowed into the cells and remains in the blood stream and blood glucose levels rise.

2. Chronic stress- The effects of chronic stress on metabolism is not fully understood. However the classic physiological responses to stress may be changed making it difficult to identify signs of stress. It is important to identify you and your child's individual sources of stress. During periods of high stress you want to be aware of how it may affect you and your child physically and therefore may want to take precautions such as monitoring blood glucose more closely during these times.

SLIDE 22

E. **Recognizing the signs of stress.**

1. Next we are going to identify what our own signs of stress are. Signs of stress may be **physical signs** such as fatigue, muscle tension and illness. **Emotional signs** of stress may be things such as short temper and moodiness. **We are handing out a Stress sheet and we would like you to think of all the different ways that you know when you are stressed.** (*This activity is designed to help each group member identify their own signs of stress. After 5 to 10 minutes of listing their own signs of stress have group members share what their signs of stress are.)*

F. There are a number of physical and emotional signs of stress. Here is a list that we created. *Acknowledge the items on the slide that the group members have already mentioned.*
  1. tense muscles.
  2. short temper.
  3. irritability.
  4. feelings of depression or feeling blue.
  5. feeling overwhelmed.
  6. feeling out of control.
  7. jittery.
  8. higher blood pressure for some.
  9. difficulty sleeping well.
  10. feeling uncertain.
  11. tired all the time.

SLIDE 23

IX. **Stress management.**

A. Next, let's brainstorm all the different things that you presently do to manage or reduce your stress. *(Now have the group members brainstorm the different ways that they manage their stress. Allow the group members approximately five minutes to write down their present stress management techniques.)*

> Look at your list of stress management techniques. What do you do to relieve stress? How often do you do these activities? What works best for you? What do you need to do more of?

B. *Emphasize the importance of stress management in terms of enhancing controllability and reducing uncertainty.*

> Stress and feeling a lack of control and uncertainty tend to go hand in hand. Let's think about it. The more out of control of a situation that you feel the more stressed you are likely to feel and visa-versa. The more uncertain about a situation you feel the more stressed you are likely to feel and visa-versa. Therefore you can often reduce your feelings of, uncertainty and lack of control through stress management.

C. By reducing your stress you are also reducing a potential source of stress for your child. Research has shown that the adjustment of the parents to their child's illness, influences the adjustment of their children to their illness (Mullins et al., 1995; Chaney et al., 1997).

D. Given this it is important for you as parent to have an armory of stress relievers at your disposal. We want that armory to be as varied and as full as possible. The purpose of the next exercise is to help you fill your stress relieving armory as full as possible. By the end of this exercise we want each of you to identify at least one new stress reliever that you can use for yourself. Let's Brainstorm some stress management ideas. ***(Suggest stress management techniques if the group is having difficulties coming up with ideas. Write suggestions up on the board. After group has listed all of their ideas present slide 5. Acknowledge the items on slide five that the group participants came up with, Highlight the items on slide that weren't mentioned.)***

1. Relaxation exercises
    a. Guided imagery tapes
    b. Begin counting backward from ten. Count off a number each time you exhale.
2. Attend support groups or if there is not one available to you start a support group.
3. Seek supportive therapy.
4. Taking personal "breaks" for yourself- do something for yourself that you like to do. What are things that you can do in the home if you can't get away?
    a. Taking a long bath
    b. Going shopping alone
    c. Going out to dinner with a friend
    d. Get a massage.
5. Exercise- Find an activity that you enjoy and make time for yourself to do it. The long-term benefits of exercising will greatly outweigh the initial hassle of getting started.
    a. Walk around the block
    b. Go to the gym
    c. Work in the garden
6. Build in vacations.
    a. Vacations for you and your spouse (i.e. send your child to diabetes camp. Who is someone you can leave the kids with, that knows about diabetes, when you need to get away?).
    b. Vacations with the entire family. Plan vacations so that you and your child can spend time together in a non-stressful environment. It helps build relationships and provides them with an opportunity to escape the day to day grind.

E. These are great ideas. Now, on the sheets we are handing out we want you to pick a daily, weekly, monthly, and yearly stress management activities. Use the stress management techniques that you have chosen and the ones we wrote on the board to create a stress management plan for the next year. *(Hand out stress management sheets. Make a stress management plan with the stress relievers that are right for them and write the plan on the stress management worksheet.)*

SLIDE 24

X. Summary

A. Communication is vital to a number of situations related to your child's care and is therefore a skill that should not be taken for granted.
B. Your role in your child's diabetes care will change as your child grows. Being aware of your present role in your child's care will decrease uncertainty regarding your child's treatment.
C. There are situations where the parent makes decisions for the child because the situation holds consequences for the child's safety. In these situations do not be hesitant to set firm, clear, limits with your child. The role of Stress in your life.

XII. Termination. Over the past two weeks we have covered a lot of topics. We have learned what illness uncertainty is and how it can influence how we feel. We also learned different ways that we can decrease illness uncertainty, such as learning more about our child's illness, learning problem-solving techniques and learning ways to improve our communication skills. For our last group activity we want you to take a little time to reflect and think about what you learned and what information was most useful to you. We are passing out your last worksheet. On it we want you to list what components of the group were most helpful to you. Below each component you list we want you to describe how you plan to incorporate these new skills into your life.

A. What were the most helpful aspects of the group to me?!
B. I plan to incorporate _______________into my life by_______________.

(Allow the parents approximately 10 min for this activity. Discuss their worksheets. After the parents have spoken, tell them what they have taught us. Communicate to the parents how their participation has been helpful to us). We want to thank you all for teaching us about the needs of parents of a child with diabetes. We truly appreciate all of the feedback that you have given us throughout the group. Your comments are vital. You all are the most important participants in this process. With your help, we can to develop ways to help children and families cope with diabetes.

SLIDE 25

XIII. **Confirmation of contact sheets for post-group questionnaires.** *(Pass out original contact sheets for each group member to correct if needed.)*

Before you go today we are going to ask you to do a couple of things. First, we are going to pass out the contact sheets that you filled out during the first session. Check the sheets to see if any changes need to be made. While you do that we are passing out a sheet with our address and phone number so that you are able to contact us if you move or if you have any questions regarding the group.
(Collect the contact sheets.)

XIV. Program evaluations.

Second, we would like to give you a chance to provide us with feedback on the group. This is a questionnaire with a number of questions for you to answer but feel free to write additional comments in the space provided on the last page. We are interested in what you found helpful about the group and what you felt was not so helpful? Are there any topics that we did not cover that you feel that we should cover? Please be candid in your remarks. The more honest you are with us the more that we can improve the group. As soon as you are done with your questionnaire you can put them in this envelope and you are done.

We want to thank all of you very much for your participation in this group. You have all taught us a great deal about being a parent of a child with diabetes. With the information that you have provided us and will provide us in the future, we will be able to improve this program and develop other programs to minimize the impact of illnesses on parents and children.

APPENDIX C

INSTITUTIONAL REVIEW BOARD
APPROVAL FORM

Oklahoma State University
Institutional Review Board

Protocol Expires: 11/13/2003

Date : Tuesday, August 19, 2003 IRB Application No AS99030

Proposal Title: REDUCING ILLNESS UNCERTAINTY: AN INTERVENTION TO PROMOTE ADJUSTMENT IN FAMILIES OF NEWLY DIAGNOSED CHILDREN WITH INSULIN DEPENDENT DIABETES MELLITUS

Principal Investigator(s) :

Ahna Hoff	Larry Mullins
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Reviewed and Processed as: Full Board

Approval Status Recommended by Reviewer(s) : Approved **Modification**

Please note that the protocol expires on the following date which is one year from the date of the approval of the original protocol:

Protocol Expires: 11/13/2003

Signature Carol Olson

Carol Olson, Director of University Research Compliance

Tuesday, August 19, 2003
Date

Approvals are valid for one calendar year, after which time a request for continuation must be submitted. Any modifications to the research project approved by the IRB must be submitted for approval with the advisor's signature. The IRB office MUST be notified in writing when a project is complete. Approved projects are subject to monitoring by the IRB. Expedited and exempt projects may be reviewed by the full Institutional Review Board.

APPENDIX D

TABLES

Table 1

Descriptive Statistics for Demographic Variables

Variable	IG n = 15 (52%)	TAU n =14 (48%)	Total n = 29
Parent Age			
Mothers (n = 29)	38.33 (SD = 7.56)	36.85 (SD = 5.57)	37.61 (SD = 6.61)
Fathers (n = 22)	41.53 (SD = 5.81)	39.08 (SD = 6.45)	40.42 (SD = 6.05)
Parent Education			
Mothers	15.57 (SD = 1.87)	13.93 (SD = 1.86)	14.40 (SD = 1.95)
Fathers	12.67 (SD = 8.93)	12.64 (SD = 6.56)	14.85 (SD = 2.42)
Child Age	9.00 (SD = 4.86)	9.83 (SD = 3.38)	9.37 (SD = 4.21)
Child Gender			
Male	7 (24%)	5 (17%)	12 (41%)
Female	8 (28%)	9 (31%)	17 (59%)
Martial Status			
Married	12 (41%)	13 (45%)	25 (86%)
Remarried	1 (3.5%)	1 (3.5%)	2 (7%)
Single	2 (7%)	0 (0%)	2 (7%)
Ethnicity			
Caucasian	13 (45%)	14 (48%)	27 (93%)
African-American	2 (7%)	0 (0%)	2 (7%)
Total Income			
0-9,999	1 (3%)	0 (0%)	1 (3%)
10,000-19,999	1 (3%)	0 (0%)	1 (3%)
20,000-29,999	0 (0%)	1 (3%)	1 (3%)
30,000-39,999	0 (0%)	2 (7%)	2 (7%)
40,000-49,999	1 (3%)	1 (3%)	2 (7%)
50,000-59,999	3 (10%)	5 (17%)	8 (28 %)
60,000 or greater	9 (31%)	5 (17%)	14 (48%)
n[a]	15 (52%)	14 (48%)	29

Note. Information based on baseline data. [a]Sample size for baseline data.

*$p < .05$. **$p < .01$.

Table 2

Maternal Report Dependent Variables: TAU

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. Baseline PPUS	--	.63*	.65*	.61**	.64*	.65*	.51*	.40	.50	-.19	-.10	-.11
2. 1-month PPUS		--	.78*	.31	.38	.53	.20	.41	.34	-.74**	-.64*	-.59
3. 6-month PPUS			--	.54	.76*	.84**	.46	.63	.64*	-.69**	-.55	-.44
4. Baseline GSI				--	.88**	.80**	.30	.28	.55	.00	-.20	-.12
5. 1-month GSI					--	.94**	.39	.48	.62	-.46	-.27	-.32
6. 6-month GSI						--	.62*	.73*	.73**	-.51	-.46	-.39
7. Baseline BSI							--	.87**	.81**	-.33	-.31	-.40
8. 1-month BSI								--	.89**	-.62*	-.48	-.52
9. 6-month BSI									--	-.39	-.59	-.32
10. Baseline ASC										--	.85**	.88**
11. 1-month ASC											--	.85**
12. 6-month ASC												--

Note: PPUS = Parental Perceptions of Uncertainty in Illness Scale; GSI = Global Severity Index; BSI = Behavioral Symptom Index; ASC = Adaptive Skills Composite.

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

Table 3

Maternal Report Dependent Variables: IG

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. Baseline PPUS	--	.34*	.30*	.24**	-.35	-.04	.28	-.29	-.06	-.39	-.19	-.41
2. 1-month PPUS		--	.04	.44	.45	.55	-.13	-.08	-.12	-.05	-.11	-.01
3. 6-month PPUS			--	.51	.69	.71*	.51	.22	.42	-.40	.11	.31
4. Baseline GSI				--	.80**	.94**	.45*	.24	.66*	.15	-.04	-.44
5. 1-month GSI					--	.95**	.01	.18	.46	.13	.03	-.19
6. 6-month GSI						--	.55	.28	.61*	-.51	-.19	-.48
7. Baseline BSI							--	.78**	.87**	-.40	-.19	-.84
8. 1-month BSI								--	.92**	-.027	-.27	-.75*
9. 6-month BSI									--	-.59	-.56	-.78**
10. Baseline ASC										--	.82**	.83**
11. 1-month ASC											--	.90**
12. 6-month ASC												--

Note: PPUS = Parental Perceptions of Uncertainty in Illness Scale; GSI = Global Severity Index; BSI = Behavioral Symptom Index; ASC = Adaptive Skills Composite.

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

Table 4

Paternal Report Dependent Variables: TAU

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. Baseline PPUS	--	-.08	.66*	.27	.36	.05	.34	.40	.25	-.31	-.15	-.44
2. 1-month PPUS		--	.54	.10	.38	.69	.30	.25	.60	-.60	-.68*	-.71
3. 6-month PPUS			--	.60	.44	.49	.76*	.38	.74**	-.71*	-.47	-.64*
4. Baseline GSI				--	.85**	.91**	.46	.44	.63*	-.12	-.21	-.51
5. 1-month GSI					--	.84*	.67*	.36	.60	-.44	-.29	-.39
6. 6-month GSI						--	.73*	.35	.55	-.36	-.333	-.36
7. Baseline BSI							--	.78*	.91**	-.63**	-.27	-.78*
8. 1-month BSI								--	.96**	-.68*	-.34	-.52
9. 6-month BSI									--	-.82**	-.62	-.61*
10. Baseline ASC										--	.69*	.77**
11. 1-month ASC											--	.89**
12. 6-month ASC												--

Note: PPUS = Parental Perceptions of Uncertainty in Illness Scale; GSI = Global Severity Index; BSI = Behavioral Symptom Index; ASC = Adaptive Skills Composite.

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

Table 5

Paternal Report Dependent Variables: IG

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. Baseline PPUS	--	.83**	.51	.01	.36	-.02	.16	.47	.51	-.38	-.33	-.30
2. 1-month PPUS		--	.94**	.79**	.56	.52	.78**	.76*	.88*	-.62	-.65*	-.69
3. 6-month PPUS			--	.87**	.75	.63	.61	.60	.67	-.79*	-.67	-.56
4. Baseline GSI				--	.85**	.81*	.52*	.51	.84*	-.16	-.35	-.59
5. 1-month GSI					--	.66	.48	.52	.90*	-.08	-.14	-.62
6. 6-month GSI						--	.30	.12	.52	-.56	-.35	-.37
7. Baseline BSI							--	.88**	.94**	-.61**	-.69*	-.61
8. 1-month BSI								--	.86*	-.67*	-.73**	-.71
9. 6-month BSI									--	-.90*	-.88*	-.77*
10. Baseline ASC										--	.82**	.68
11. 1-month ASC											--	.97**
12. 6-month ASC												--

Note: PPUS = Parental Perceptions of Uncertainty in Illness Scale; GSI = Global Severity Index; BSI = Behavioral Symptom Index; ASC = Adaptive Skills Composite.

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

Table 6

Maternal and Paternal Report of Uncertainty and Distress: TAU

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. Maternal Baseline PPUS	--	.63*	.65*	.61**	.64*	.65*	.46	.27	.70*	.16	.05	.50
2. Maternal 1-month PPUS		--	.78**	.31	.38	.53	.08	.29	.39	.19	.13	.72*
3. Maternal 6-month PPUS			--	.54	.76*	.84**	.02	.90**	.66*	.69*	.51	.81**
4. Maternal Baseline GSI				--	.88**	.80**	.45	.14	.46	.52*	.25	.60*
5. Maternal 1-month GSI					--	.94**	.40	.21	.69*	.60*	.43	.70*
6. Maternal 6-month GSI						--	.04	.48	.57	.71*	.43	.82**
7. Paternal Baseline BSI							--	-.08	.66	.27	.35	.05
8. Paternal 1-month BSI								--	.54	.10	.38	.69
9. Paternal 6-month BSI									--	.60	.44	.49
10. Paternal Baseline ASC										--	.85**	.91**
11. Paternal 1-month ASC											--	.84*
12. Paternal 6-month ASC												--

Note: PPUS = Parental Perceptions of Uncertainty in Illness Scale; GSI = Global Severity Index; BSI = Behavioral Symptom Index;

ASC = Adaptive Skills Composite.

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

Table 7

Maternal and Paternal Report of Uncertainty and Distress: IG

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. Maternal Baseline PPUS	--	.34	.30	.24	-.35	-.04	.05	.31	.23	-.16	-.19	.27
2. Maternal 1-month PPUS		--	.04	.44	.45	.55	-.15	.35	.30	.65*	.34	.66
3. Maternal 6-month PPUS			--	.51	.69	.75*	-.003	.39	.46	.33	.08	.10
4. Maternal Baseline GSI				--	.80**	.94**	.37	.58	.65	.27	.51	.78*
5. Maternal 1-month GSI					--	.95**	.46	.54	.74	.73*	.87**	.98**
6. Maternal 6-month GSI						--	.28	.87*	.86*	.81*	.77	.74
7. Paternal Baseline BSI							--	.83**	.51	.005	.36	-.02
8. Paternal 1-month BSI								--	.94**	.79**	.56	.52
9. Paternal 6-month BSI									--	.87**	.75	.63
10. Paternal Baseline ASC										--	.85	.81*
11. Paternal 1-month ASC											--	.66
12. Paternal 6-month ASC												--

Note: PPUS = Parental Perceptions of Uncertainty in Illness Scale; GSI = Global Severity Index; BSI = Behavioral Symptom Index;

ASC = Adaptive Skills Composite.

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

Table 8

Means and Standard Deviations of Parent-Reported Dependent Variables

	IG		TAU	
	Maternal	Paternal	Maternal	Paternal
PPUS				
Baseline	62.33 (6.50)	62.40 (11.56)	69.43 (17.13)	68.40 (17.40)
1-Month	63.97 (9.80)	63.80 (14.44)	63.76 (15.11)	65.50 (7.63)
6-Month	58.67 (7.33)	62.33 (17.92)	72.80 (21.03)	65.57 (15.96)
GSI				
Baseline	52.57 (13.20)	52.56 (9.15)	55.07 (13.09)	52.90 (9.45)
1-Month	45.79 (11.37)**	49.72 (12.41)	54.64 (11.91)	51.10 (8.76)
6-Month	49.00 (13.69)	50.00 (10.71)	52.00 (13.54)	48.43 (9.81)
BSI				
Baseline	48.40 (9.96)	46.18 (9.45)	47.79 (10.88)	45.67 (7.28)
1-Month	44.73 (9.49)*	44.55 (8.48)	47.14 (9.76)	41.89 (8.34)*
6-Month	45.33 (6.38)	40.50 (6.19)	50.90 (11.10)	44.14 (7.67)
ASC				
Baseline	45.93 (9.07)	46.64 (11.78)	48.86 (7.99)	48.67 (8.75)
1-Month	45.67 (7.64)	46.91 (12.41)	49.36 (9.13)	49.11 (10.55)
6-Month	52.44 (8.08)**	52.00 (7.10)	47.00 (8.70)	50.14 (11.71)
n[a]	15	11	14	10
n[b]	9	10	6	7

Note. PPUS = Parental Perceptions of Uncertainty in Illness Scale; GSI = Global Severity Index; BSI = Behavioral Symptom Index; ASC = Adaptive Skills Composite. [a]Sample size for baseline and 1-month data. [b]Sample size for 6-month data.

* $p < .05$.

**$p < .01$.

VITA

Ahna L. Hoff

Candidate for the Degree of

Doctor of Philosophy

Thesis: AN INTERVENTION TO DECREASE ILLNESS UNCERTAINTY AND PSYCHOLOGICAL DISTRESS AMONG PARENTS OF CHILDREN NEWLY DIAGNOSED WITH TYPE 1 DIABETES: A RANDOMIZED CLINICAL TRIAL

Major Field: Psychology

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