THE RELATIONSHIP OF ILLNESS UNCERTAINTY AND PERCEIVED CONTROL TO PSYCHOLOGICAL ADJUSTMENT AMONG ADOLESCENTS WITH TYPE I DIABETES

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CHAPTER I

INTRODUCTION

Diabetes is one of the most common chronic illnesses of childhood in the United States, with incidence rates second only to asthma. There are an estimated 11,000-12,000 new cases of Type 1 diabetes diagnosed each year, yielding a prevalence of 123,000 children with this illness in the United States alone (Centers for Disease Control, 1998; Harris, 1995). 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 by the cell as fuel (Grey, 1992). Therefore, insulin must be regulated through daily injections to regulate glucose levels in the blood. If glucose and insulin requirements are not balanced, serious short and long term complications can result (American Diabetes Association, 1997). 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.

The demanding nature of being diagnosed with diabetes and the subsequent management of a complicated regimen constitute a source of potential stress in the lives of children and adolescents with diabetes. It has been suggested that such stress places children with Type 1 diabetes at considerable risk for psychological maladjustment. A

number of studies have reported higher rates of psychological symptomatology, especially depression and anxiety, among children and adolescents with Type I diabetes (e.g., Mayou, Peveler, Davis, Mann, & Fairburn, 1991; Nagasawa, Smith, Barnes, & Fincham, 1990; Pless, Heller, Belmonte, & Zvagulis, 1988). However, other studies have found rates of psychological maladjustment to be similar among children with and without diabetes (Weist, Finney, Barnard, Davis, & Ollendick 1993; Wertlieb, Hauser, & Jacobson,1986). Such conflicting results are likely due to substantive methodological differences across studies, including differing definitions of psychological adjustment and methods of measuring adjustment. A growing consensus has emerged that although many children with diabetes cope well, a significant minority do not (La Greca, Swales, Klemp, Madigan, & Skyler, 1995; Rodin, Johnson, Garfinkle, Daneman & Kenshole, 1985; Rosmark et al., 1986). In this regard, children with diabetes thus constitute a population "at risk" for maladjustment. Moreover, a more pragmatic approach to examining childhood adjustment to diabetes has emerged in recent years. Instead of examining maladjustment rates in children with diabetes, researchers are now attempting to identify specific factors that place a child with diabetes at risk (Band & Weisz, 1990; Jacobson et al., 1990; Mullins, et al., 1995).

A number of individual, social and familial factors have been found to be consistently associated with adjustment in children with diabetes. Poor initial adjustment of a child to the diagnosis of diabetes has been associated with later difficulties in regimen adherence and psychosocial functioning (Jacobson et al., 1990). Girls, in general, have more difficulties adjusting to the illness than boys, reporting higher rates of depression, anxiety and eating disorders (La Greca et al., 1995; Rodin et al., 1985; Rosmark et al.,

1986). Age has also been associated with adjustment, with adolescents tending to be less adherent than younger children with diabetes (e.g., Anderson, Auslander, Jong, Miller, & Santiago, 1990; Johnson et al., 1992). Higher levels of family conflict have been associated with decreased adherence behaviors of adolescents with diabetes (Bobrow, AvRuskin, Siller, 1985; Hauser et al., 1990; Stein, 1989), while adolescents living in families reporting higher levels of cohesiveness evidence improved adherence (Hauser et al., 1990; Haustein et al., 1989) and better metabolic control (Cerreto & Mendlowitz, 1983).

Specific cognitive factors also appear to be associated with adjustment to diabetes. In particular, perceptions of greater control have been related to taking greater responsibility for one's own medical condition, better adherence behaviors and better psychological adjustment (Band & Weisz, 1990; Moffat & Pless, 1983; Strickland,1978). Increased feelings of competence have been related to increased diabetic control (Daviss et al., 1995; Hanson, Henggler, & Burghen, 1987). Similarly, perceptions of self-efficacy have been related to improved regimen adherence (Sanders, Mill, Martin, & Horne, 1975) and better blood glucose levels (Grossman, Brink, & Hauser, 1987). Conversely, Kuttner and his colleagues found a "learned helplessness style" to be related to depression and poor metabolic control among adolescents with diabetes (Kuttner, Delamater, & Santago, 1990).

The aforementioned individual, social, familial, and cognitive factors are interrelated in a complex fashion and hypothetically influence multiple levels of adjustment, including disease management and control, as well as overall psychological adjustment. Many models have attempted to demonstrate how such multiple factors are

related to disease outcome and psychological adjustment (Hanson, 1992; Johnson, 1995; Mishel & Sorenson, 1991). Notably, relatively few studies have systematically examined how various cognitive appraisal mechanisms included within these models act collectively to influence the psychological adjustment of adolescents with diabetes. This is despite the fact that cognitive variables, such as perceived control and self-esteem, have been shown to be more powerful predictors of adjustment in groups of individuals with chronic illnesses than demographic and disease parameters (Jacobson et al., 1990; Thompson et al., 1993). The current study seeks to address this deficit in the literature by examining the relationship between two cognitive appraisal variables, illness uncertainty and perceived control, and their subsequent association with the psychological adjustment of adolescents with diabetes.

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 course are all potential sources of uncertainty during an illness experience (Mishel, 1984).

Mishel (1988) conceptualized four stages of uncertainty in illness: antecedents, uncertainty appraisal, coping and adaptation. Antecedents are variables that precede, accompany and/or influence uncertainty. Uncertainty appraisal refers to the time in which the individual recognizes and cognitively classifies the uncertainty as either a threat or as an opportunity. The coping process is defined as the attitudes and behaviors used to

manage uncertainty and is believed to mediate the relationship between appraisal and subsequent adaptation. Antecedent, appraisal and coping strategies are each thought to interact to subsequently influence an individual's biopsychosocial adaptation to an illness.

A number of studies support Mishel's theory of uncertainty, demonstrating a strong relationship between illness uncertainty and psychological adjustment in adults experiencing an illness (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 factors associated with higher levels of perceived uncertainty and, subsequently, poorer overall psychosocial adjustment (Christman, 1990; Mishel & Sorenson, 1991). Increased levels of uncertainty have been related to perceiving less hope (Mishel, 1984; Christman, 1990) 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 adjustment problems such as a 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).

In contrast to studies of uncertainty in adults, research with child populations is sparse. Mullins et al. (1997) examined illness uncertainty in older adolescents and young adults with asthma, finding that both illness uncertainty and increased stable attributions for negative events were independently associated with psychological adjustment. The

authors also found that decreased illness uncertainty attenuated the effects of global negative causal attributions on adjustment. Mullins et al. (1997) thus speculated that both illness uncertainty and certainty for future negative outcomes contribute to poorer psychological adjustment in adolescents and young adults with asthma. Such findings suggest that uncertainty may influence psychological adjustment to pediatric chronic illness directly and indirectly through interactions with a number of other cognitive processes.

Mishel and Sorenson (1991) have further posited that other cognitive variables may influence the relationship between uncertainty appraisal and psychological adjustment. Specifically, Mishel identified an individual's sense of control as a critical factor in the adaptation of patients with a chronic illness (Mishel & Branden, 1987). However, no studies have examined the relationship between perceived control, illness uncertainty and psychological adjustment in samples of children with a pediatric chronic illness. This is notable given the significant evidence which has directly linked perceived control with psychological adjustment among pediatric populations (Band, 1990; Band & Weisz, 1990; Weisz, 1986).

Perceived control is thought to be the function of two factors: outcome contingency and personal competence (Weisz, 1986). Outcome contingency is defined by the degree to which an outcome depends on the behaviors of the relevant individual (Weisz, 1986; Weisz, Weiss, Wasserman & Rintoul, 1987). For example, if a child perceives that by following their nutritional regimen they will have better metabolic control, and will subsequently be healthier, a contingency results. Personal competence is an individual's perceived capacity to produce behavior which will result in an desired

outcome (Weisz, 1986; Weisz et al., 1987). In other words, it is the perception of whether one possesses the particular abilities needed to perform a particular task (Weisz, 1983). Therefore perceived control, as discussed here, is a function of both personal competence and outcome contingency. Personal competence and contingency likely influence the sense of perceived control independently, as well as interacting to create emergent perceptions of control (Weisz, 1986; Weisz et al., 1987).

Although there is literature demonstrating the independent influences of uncertainty and perceived control on psychological adjustment to illness, the relationship between these cognitive variables has not been adequately investigated. Thus, the purpose of the present study is to investigate the relationship between perceived control, uncertainty, and psychological adjustment among adolescents with diabetes. First, it is hypothesized that higher levels of illness uncertainty will be significantly associated with higher levels of psychological distress; thus, as levels of illness uncertainty increases, the level of psychological distress reported will also increase. Second, perceived control is expected to be significantly related to both uncertainty and reported psychological distress (Weisz et al., 1987). As levels of perceived control increase, levels of both illness uncertainty and psychological distress will decrease. Finally, two research questions will examine the nature of the relationship between illness uncertainty, perceived control and psychological distress:

1. Does perceived control act as a mediator between illness uncertainty and adolescent psychological adjustment?
2. Does perceived control act as a moderator between illness uncertainty and adolescent psychological adjustment?

By empirically examining illness uncertainty and perceived control, a better understanding of how these cognitive variables contribute to psychological distress can be ascertained. Using previous research findings as a guide, adolescents reporting lower levels of illness uncertainty and higher levels of perceived control will be expected to be at lower risk for experiencing psychological distress related to their illness (Band & Weisz, 1990; Mishel & Braden, 1987; Mishel & Sorenson, 1991). Further, adolescents reporting higher levels of uncertainty, and lower levels of perceived control, will be at greater risk for experiencing psychological distress such as depression and anxiety (Band & Weisz, 1990; Mishel & Braden, 1987; Mishel & Sorenson, 1991). The implications of the findings regarding uncertainty and perceived control extend beyond psychological adjustment. Psychological adjustment of adolescents with diabetes has been associated with overall regimen adherence and metabolic control (Band & Weisz, 1990; Jacobson et al., 1990; Littlefield et al., 1992; Wysocki, Hough, Ward, & Green, 1992). Therefore understanding these cognitive variables also holds importance for the ultimate physical health of adolescents with diabetes.

In the following sections, the nature of Type I diabetes will be discussed to provide a basic understanding of the disease itself. This will be followed by a review of the literature on adolescent adjustment to diabetes, as well as a discussion of the cognitive factors which may influence the psychological adjustment of adolescents with diabetes. Mishel's theory of illness uncertainty will then be explored highlighting those aspects of uncertainty which may be pertinent to Type 1 diabetes (Mishel, 1984; Mishel, 1990). The importance of perceived control in adjustment to chronic illness will be outlined (Band &

Weisz, 1990). Finally, the association between illness uncertainty, perceived control and psychological adjustment will be examined.

CHAPTER II

LITERATURE REVIEW

Type 1 Diabetes: Description of the Illness

Second only to asthma, Type 1 diabetes is the 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, 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. It therefore serves critical and essential functions 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 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 (American Diabetes Association, 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 (American Diabetes Association, 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 (American Diabetes Association, 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. People with Type 1 diabetes are also at greater risk for stroke and other forms of large blood vessel disease (American Diabetes Association, 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 (American Diabetes Association, 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 (American Diabetes Association, 1997). Close monitoring of food intake is also important because different foods have varying effects on blood sugar (American Diabetes Association, 1997). Finally, exercise is important to diabetes

management because it increases the efficiency of insulin absorption (American Diabetes Association, 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 (American Diabetes Association, 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 particularly 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 Research Group, 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).

Adolescents with Diabetes

Adolescence is a particularly high risk time for those with diabetes (Jacobson et al., 1990; Kovacs et al., 1990). It is well documented that adolescents with diabetes tend to be less adherent and have poorer metabolic control than their younger counterparts(Anderson et al., 1990; Jacobson et al., 1990). This trend occurs despite the fact that adolescents with diabetes tend to be more knowledgeable about diabetes and more skilled in administration of diabetes care (Johnson et al., 1982; Johnson et al., 1986; Johnson, Freund, Silverstein, Hansen, & Malone, 1990). A combination of factors are likely responsible for the poorer metabolic control often observed during the adolescent period. One possibility is that effects of puberty, such as increased hormone levels and increased insulin resistance, contribute to poorer metabolic control and poorer adjustment (Amiel, Sherwin, Simomson, Lauritano, & Tamborlane, 1986; Blethen, Sargeant, Whitlow, & Santiago, 1981; Bloch, Clemons, & Sperling, 1990). Environmental factors have also been proposed. In most cases, parents no longer routinely participate in their child's diabetes care once the child reaches the age of 15. Therefore the adolescent is almost

solely responsible for their own diabetes care (Johnson, 1995; Ingersoll, Orr, Herrold, & Golden, 1986). In addition, adolescents with diabetes must manage the normal developmental challenges of adolescence, such as establishing identity, independence and peer acceptance, while managing a complicated treatment regimen and respond to diabetes related health complications.

Psychological variables, (i.e., depression, anxiety, and sense of control) have also been associated with adherence and health outcomes in adolescents with diabetes. Therefore, it is also important to examine these psychological variables as they relate to the adjustment of adolescents to diabetes (Jacobson et al., 1990; Littlefield et al., 1992; Wysocki, Hough, Ward, & Green, 1992). The psychological difficulties commonly found among adolescents with diabetes will be presented and discussed followed by a discussion of specific variables found to be associated with good and poor psychological adjustment.

Adjustment Among Adolescents with Diabetes

The most common psychological symptoms associated with Type 1 diabetes are depression and anxiety. In a longitudinal study by Kovacs et al., (1990) symptoms of depression and anxiety reported by children and adolescents were examined over the first six years following initial diabetes diagnosis. Children in the Kovacs et al., (1990) study who were newly diagnosed with diabetes initially reported a number of symptoms of depression and anxiety. Six months following diagnosis, the number of symptoms reported by the children in the sample decreased (Kovacs et al., 1990). However, after this initial decline in symptoms, Kovacs et al. found that the longer female children had diabetes, the more symptoms of depression and anxiety they reported. Notably, the rates

of anxiety and depression reported by the respondents in the Kovacs et al., (1990) study were not significantly higher the means reported by the normative samples of each of the respective measures. Importantly, this study demonstrates that symptoms of depression and anxiety are likely to fluctuate throughout the course of the illness. Further, they suggest that there are certain points throughout the illness course where the risk for poor psychological adjustment is greater than others. Levels of adjustment at diagnosis may also be utilized to identify those children who are at greater risk for poor future adjustment, since those who reported being more initially anxious or depressed at the time of illness diagnosis became more anxious over time (Kovacs et al., 1990; La Greca et al., 1995).

Eating disorders are also commonly found among adolescents with Type 1 diabetes, especially in girls (Marcus & Wing, 1990). There is a higher incidence of eating disordered behaviors among girls with diabetes than among boys with diabetes or girls without diabetes (Rodin et al., 1985; Rosmark et al. 1986). One recent study found that 27% of adolescent girls with Type 1 diabetes reported purging, and 24% reported dieting to lose weight, whereas only 9% of adolescent girls without Type 1 diabetes reported purging and 14% reported dieting to lose weight (Neumark-Sztainer et al., 1996). Eating disorders have been related to poorer metabolic control (LaGreca, Schwarz & Satin, 1987) and depression (LaGreca, Schwarz, Satin, Rafkin-Mervis, Enfield, & Goldberg, 1990) in adolescents with diabetes. A number of reasons for the higher incidence of eating disorders among adolescents with diabetes have been proposed. First, it may be that dietary restraints associated with diabetes management may predispose an individual to eating disorders. Habitual dietary restraint has been associated with binge eating even in

non-diabetic populations (Hawkins & Clement, 1983). Another reason may be that increased glycemic control can often lead to weight gain, which in turn increases the risk that an individual will attempt to prevent weight gain through inappropriate means (Johnson, 1998). For example, an individual may undo the effects of a binge eating episode or induce weight loss by failing to take their insulin (Johnson, 1998). Although well-controlled studies that use rigorous diagnostic criteria are needed, these initial results indicate that adolescent girls with diabetes are at higher risk for eating disorders (Marcus & Wing, 1990).

Adolescents with diabetes also exhibit a greater number of school problems than their non-diabetic counterparts. In one report, adolescents with diabetes, missed on average of 13 school days across the school year, which was twice as much as their non-diabetic peers (Ryan, Longstreet, & Morrow, 1985). A relationship was also found between estimates of performance on reading, spelling and arithmetic achievement tests and school absences among adolescents with diabetes (Ryan et al., 1985). One explanation for the adolescents lower performance on these measures may be the cumulative effect of missing more school than there peers. Ryan (1990) suggested that cognitive impairments associated with Type 1 diabetes is another possible explanation for these observed differences.

Another measurement of adjustment commonly used with chronically ill populations is quality of life (QOL). Quality of life refers to ones satisfaction with their current ability to function in multiple contexts. The onset of diabetes-related complications was found to be associated with decreased QOL and increased anxiety and depression in a sample of adolescents (Lloyd, Matthews, Wing & Orchard, 1992).

Adolescents who perceived diabetes as having a larger impact on their QOL were also more likely to believe that management was harder and more upsetting, were less likely to use rebellious coping strategies, had lower diabetes self-efficacy and reported more symptoms of depression (Grey, Boland, Yu, Sullivan-Bolyai, Tamborlane, 1998). However, QOL was not found to be associated with metabolic control or treatment regimen adherence (Grey, et al., 1998). Thus, these results suggest that adolescents with Type 1 diabetes are clearly at risk for decreased quality of life in a number of domains.

The unpredictable short and long-term complications of diabetes may promote feelings of uncertainty among individuals experiencing the illness. However, the same diabetic complications that foster illness uncertainty present opportunities to exert control over the disease via a daily regimen of diet planning and insulin administration and blood glucose monitoring and exercise. This is supported by a number of studies which have highlighted the importance of the sense of control in diabetes adherence (Gonder-Frederick, Carter, Cox, & Clarke, 1990; Hanson & Pichert, 1986; Jacobson et al., 1986; Jacobson et al., 1990). In the following, both uncertainty and perceived control will be discussed as they relate to the adjustment process.

Variables Associated with the Adjustment of Adolescents with Diabetes

A number of factors have been identified in the pediatric psychology literature for putting a child or adolescent with diabetes at greater risk for poorer psychological adjustment, including demographic, illness, familial, and cognitive factors (Bobrow et al., 1985; Glasgow, McCaul, & Drener, 1983; Gonder-Frederick et al., 1990; Hauser et al.,

1990; Ingersoll et al., 1986; Jacobson, et al., 1990; Johnson, 1995; Kovacs et al., 1990; La Greca, et al., 1995; Schafer; Stein, 1989). Two demographic factors, age and gender are of particular import. As stated, adolescents with diabetes tend to be less adherent and have poorer metabolic control than their younger counterparts (Jacobson et al.,1990). 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). 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) while others have suggested it is due the adolescent taking over more of the diabetes care (Ingersoll et al., 1986; Johnson, 1995). Currently, it is still unknown what interrelated roles biological, environmental, and psychological factors play in the decline of metabolic control often observed during adolescence.

Gender also plays a role in adaptation to diabetes. In general, girls tend to have more difficulty adjusting to the illness than boys (Kovacs et al., 1990; La Greca et al., 1995). Girls tend to worry more about their diabetes than boys and are concerned about the long term implications of diabetes (La Greca et al., 1995). Further, girls tend to report more anxiety and depression than do boys (Kovacs et al., 1990; La Greca et al., 1995). However, it is unclear whether these results are due to developmental factors (i.e., different hormone levels in adolescent girls than boys), or due to the fact that higher rates of depression and anxiety are generally found in women, or still other explanations.

One illness parameter that has been linked to adjustment is the length of time since diagnosis. The longer children and adolescents have Type 1 diabetes, the more upset they are by the implications of the illness and the more they view management as hard to do

(Kovacs et al., 1990). Kovacs and her colleagues speculate that this result may be due to the increased awareness which develops as adolescents mature for the serious complications that may accompany their illness. As mentioned previously, length of the illness was also related to an increase in the number of anxiety and depressive symptoms reported by children, especially girls (Kovacs et al., 1990).

Family functioning has also been shown to influence illness adaptation in children and adolescents with diabetes. Family conflict has been shown to adversely influence adherence behaviors in adolescents with diabetes (Bobrow et al., 1985; Hauser et al., 1990; Schafer et al., 1983; Stein, 1989). On the contrary, families perceived by the parents and the children as more cohesive demonstrated better regimen adherence and metabolic control than those families who reported lower levels of cohesion (Cerreto & Mendlowitz, 1983; Hauser et al., 1990; Haustein et al., 1989). Family support was also found to positively influence adolescents adjustment to illness (Hauser et al., 1985; Hauser et al., 1989) and regimen adherence (Waller et al., 1986). Illness-specific and general (i.e., family affection and support) support both have been associated with increased regimen adherence and general psychological adaptation of children with diabetes (Hanson, 1992).

Stress is another factor that has been associated with metabolic control among individuals with diabetes. Stress can influence diabetic control both directly and indirectly. Directly, stress may produce marked changes in plasma glucose levels by increasing the secretion of counterregulatory hormones such as catecholamine, cortisol, growth hormone and glucagon (Stabler, Morris, Litton, Feinglos, & Surwit, 1986; Tarnow & Silverman, 1981). The release of epinephrine and cortisol have been associated with greater and more prolonged glucose elevations in adolescents with diabetes than in non-diabetic

controls (Shamoon, Hendler, & Sherwin, 1980). Indirectly, stress may affect treatment adherence. 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). Delameter et al. (1988) found a positive relationship between glycohemoglobin (GHb; a measure of the average glucose levels over the last four months) and the frequency and intensity of positive and negative life events. They also found a significant positive relationship between GHb and scores on the Diabetes Stress Questionnaire. Notably, the effects of stress on metabolic control may be due, in part, to individual differences (Delamater, 1992). Some individuals may be "stress sensitive" while others are not (Carter, Gonder-Frederick, Cox, Clarke, & Scott, 1985; Gonder-Frederick et al., 1990). Identifying why some patients are more "stress sensitive" than others may be key in intervention development.

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 development of the concept of uncertainty in illness has burgeoned over the past 18 years, an inquiry which was catalyzed by the origination 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 discussion of

Mishel's conceptualization of uncertainty for both acute and chronic illnesses is in order 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 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 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.257)

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

First, 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 (Mishel,1985). 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, Dunkelschetter, DeLongis & 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 if 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 individuals 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 the 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 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 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 Influence of Illness Uncertainty on Psychological Adjustment to Illness

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 the 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 (Mishel & Braden, 1987; 1988; Braden 1990; Mast, 1995). 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 show a strong relationship between uncertainty and emotional distress, mood disturbance and anxiety (Bennett, 1993; Braden, 1990; Christman et al., 1988; Hawthorne & Hixon, 1994; Padilla, Mishel, & Grant, 1992).

Cognitive appraisal factors that influence illness uncertainty have 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, et al., 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 both 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). Mastery mediated the impact of the appraisal of uncertainty as a danger, but was inconsistent between studies in it's strength as a mediator 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). Empirical inconsistencies regarding the model between the studies suggest the presence of other variables which may influence the relationship between uncertainty and adjustment.

Perceived Control: Contingency and Competence

Both the definitions of mastery and control imply that the individual has, or perceives they have, the ability to manipulate their environment in a desired fashion. However, the construct of control is conceptualizd as more than the individual's ability to mitigate adversiveness and therefore may be more useful when conceptualizing how individuals cope with an illness. Coping with an illness involves processing new information, attending and responding to internal cues and, in some instances, administering one's own aversive or painful treatment. The concept of control applies to all of these illness tasks, and therefore may provide a more comprehensive conceptualization of the association between appraisal and adjustment. In fact, others have long identified perceived control as an important factor in illness adaptation (Strickland,1978; Moffat & Pless, 1983). Perceptions of control have been linked to individual differences to the extent to which people learn about or take responsibility for their medical condition (Strickland,1978) and their ability to adjust to their illness (Moffat & Pless, 1983). Diabetes, in particular, presents opportunities to exert control over the disease via a daily regimen of diet planning, blood glucose monitoring, and insulin administration and exercise. The concept of control, and how it may be related to diabetes adjustment, is summarized below.

Control is one of several closely related concepts which includes efficacy (Bandura, 1977), locus of control (Moyal, 1977), and mastery (Mishel & Sorenson, 1991); all with slightly different definitions, but all referring essentially to the individuals' ability to modify their environment in an intentional manner. Perceived control has also

been described in terms of a two-factor model, wherein perceived control is defined as the perception that one has the ability to cause an intended outcome (Weisz, 1986). Control is further posited to be the joint function of two factors, namely, contingency and competence (Weisz, 1986). The two factor model provides a valuable heuristic for understanding the concept of perceived control and therefore is described as follows.

Outcome Contingency

First, outcome contingency is the degree to which an outcome depends on the behaviors of the relevant individual (Weisz, 1986). For example, if a child perceives that by following their nutritional regimen they will have better metabolic control, and will subsequently be healthier, a contingency results. The presence or absence of a contingency may not itself be as important as the consistency of the contingency. Weisz et al., (1987) studied the control, contingency and competency ratings of depressed children and found that self-reported symptoms of depression by the children were associated not with a belief in non-contingency, but the inability to find out what contingencies were associated. Weisz et al., (1987) suggested it may be contingency uncertainty which makes children prone to depression rather than the mere presence or lack of contingency.

Personal Competence

The second factor involved in perceived control is personal competence (Weisz, 1986). Personal competence is an individual's perceived capacity to produce behavior on which an outcome is contingent. In other words, it is the extent to which the individual believes that they possess particular abilities needed to perform a particular task (Weisz,

1983). Perceived competence has been shown to be lower in children who are depressed than in children who are not depressed (Weisz et al., 1987).

Perceived Control in Children and Adolescents with Diabetes

Band and Weisz (1990) have suggested that there are two subtypes of control, primary control and secondary control. Primary control refers to coping aimed at influencing objective conditions or events. This may include active efforts to change circumstances that are modifiable in one's environment. Enhancing rewards or reducing punishment by modifying the objective conditions to more closely conform to ones wishes is believed to promote the perception of primary control within an individual (Weisz, Thurber, Proffitt, Sweeney, & LeGagnoux, 1997). Secondary control refers to coping aimed at influencing the psychological impact of objective conditioned or events as they are (Band & Weisz 1990). Thought to be vital to psychological adjustment, secondary control refers to the ability to adjust oneself in response to unalterable conditions, thereby influencing the subjective impact that the unalterable conditions may have on an individual (Band & Weisz, 1990). As with primary control, enhancing reward or reducing punishment increases the sense of perceived secondary control. Keeping a positive attitude, feeling good about taking care of oneself, viewing the adversity as an opportunity, are all thought to promote the adjustment of an individual to an unalterable life event (such as a chronic illness). Alternatively, an individual may take a less adaptive approach, adopting an "I don't care about it" approach to the problem and dismissing one's ability to control and adapt to the situation (Band & Weisz, 1990).

Perceived control, as discussed here, is thus a function of both personal competence and outcome contingency. These concepts may have considerable implications for adolescents with diabetes who, through management of their illness can influence illness outcomes. Typical treatment regimens for diabetes are ideal for effecting perceptions of control through positive outcome contingencies and feelings of competency for good self-care.

In one of the only studies on controllability and chronic illness, Band and Weisz (1990), using Piaget's developmental framework and the two process model of control, examined whether coping style (i.e., their use of primary or secondary control) was differentially related to diabetes adjustment. Sixty-four children and adolescents diagnosed with Type 1 diabetes within the last 12 months participated in the study. The children were split into groups using a Piagetian task shown to differentiate formal from pre-formal children. Measures included questionnaires on perceived control, coping style, perceived coping efficacy, diabetes knowledge, physician ratings of medical adjustment and parent ratings of socio-behavioral adjustment. They found that perceived control was the best predictor of psychosomatic problems (e.g. headaches, stomachaches) in pre-formal children; as perceived control increased, psychosomatic problems decreased. They concluded that for pre-formal children, concrete bodily problems may indicate to the child that their self-care activities are not working. In other words, there appears to be a lack of contingency for the child. In the children with formal operations, they found that medical knowledge was the best predictor of the physicians ratings of medical adjustment, followed by the type of coping style that the child used. Both primary and secondary

coping styles significantly predicted both medical and sociobehavioral adjustment in formal operational children.

Seaton et al. (1998) extended the Band and Weisz (1990) findings further by examining the role of control and contingency in the psychological adjustment of children with Type 1 diabetes. Significant relationships were found between psychological adjustment and control, psychological adjustment and contingency, and control and contingency. After statistically controlling for age and gender, psychological adjustment to Type 1 diabetes was significantly associated with perceived control, with lower levels of control being associated with higher levels of maladjustment. However, findings regarding the relationship between contingency and adjustment was not significant, calling into question the exact relationship between contingency, control, and adjustment. The inconclusive results may have been due to a relatively small sample size. Notably, the study did not examine results for the children and adolescents separately; rather, the data was combined for the two age groups. This is significant given the findings by Band and Wiesz (1990) who have found that children and adolescents use control to cope with their illness in very different ways.

Summary

Type 1 diabetes involves an intensive treatment regimen, requiring an individual to maintain a delicate balance between blood glucose levels, insulin, caloric intake and expenditure. Failure to maintain the delicate metabolic balance can lead to serious short and long-term health complications. By adolescence, most individuals with diabetes have acquired self-care skills and are responsible for their disease. Yet, research has

demonstrated that adolescents, despite greater diabetes-related knowledge, have more difficulty adhering to treatment regimens and maintaining metabolic control. A significant minority of adolescents with diabetes also experience increased levels of psychological distress. These difficulties are significant, given that the changes in adherence, metabolic control and psychological adjustment may have far-reaching health future implications for the adolescent.

A variety of individual, social and familial factors have been found to be consistently associated with diabetes related difficulties. Cognitive variables, in particular, have been shown to be salient predictors of adjustment to chronic illness. Two cognitive variables, perceived uncertainty and perceived control, have particular relevance to chronic illness and are the focus of the present thesis. Studies have shown that higher illness uncertainty is strongly associated with poorer adjustment in other illness groups, but this relationship has not been demonstrated in adolescents with diabetes (Mishel & Sorenson, 1990; Mullins et al., 1997). Perceived control has also been shown to be associated with the adjustment of a number of illness groups, including children and adolescents with diabetes (Strickland, 1978; Moffat & Pless, 1983; Band & Weisz, 1990). Therefore, the purpose of the present study is to examine the relationship between perceived illness uncertainty and perceived control and their influence on psychological adjustment.

CHAPTER III

PURPOSE OF THE PRESENT STUDY

The purpose of the present study is to investigate the relationship between ilness uncertainty, perceived control and psychological adjustment reported by adolescents with Type 1 diabetes. First, the association between illness uncertainty and psychological adjustment will be examined. Illness uncertainty has been shown to be strongly associated with psychological adjustment in a number of illness groups (Mishel & Sorenson, 1990; Mishel & Braden, 1987; Mast, 1995). Given the nature of Type 1 diabetes, there are multiple sources of potential illness uncertainty (i.e., hypoglycemia, ketoacidosis and neuropathies). As has been found in other illness groups, it is predicted that those reporting higher levels of illness uncertainty in the sample are expected to report poorer psychological adjustment.

Second, previous research by Band and Weisz (1990) presents a strong argument for the role of perceived control in psychological adjustment. Band and Weisz (1990) found that higher levels of perceived control were significantly associated with better psychological adjustment among children and adolescents with Type 1 diabetes. Given the significance of these previous findings among adolescents with Type 1 diabetes, perceived control is also expected to be significantly associated with psychological adjustment in the present study.

This exploratory investigation also will examine the variables in terms of moderator and mediator variables (Baron & Kenny, 1986). To date, perceived control has not been examined as a possible moderator or a mediator in the relationship between uncertainty and psychological adjustment among adolescents with diabetes. Using the existing literature as a guide, a theoretical argument can be made for either a moderating or a mediating relationship between the relevant variables. First, perceived control may be a moderator of uncertainty and psychological adjustment, influencing the nature of the relationship between uncertainty and psychological adjustment as it varies (Mishel & Braden, 1987). However, it is also possible that perceived control serves as a mediating variable in the relationship between uncertainty and psychological adjustment. To qualify as a mediator perceived control must account for the relationship between uncertainty and psychological adjustment. This is plausible given that perceived control has previously been shown to be significantly related to psychological adjustment among children and adolescents with diabetes (Band & Weisz, 1990).

Hypothesis One

Higher Levels of Illness Uncertainty Reported by Adolescents with Diabetes Will Be Significantly Related to Higher Levels of Psychological Distress.

As levels of illness uncertainty, as measured by the Children's Uncertainty in Illness Scale (CUIS; Hartman & Mullins, 1995) increase, levels of psychological distress

adolescents with diabetes reported on the Brief Symptom Inventory (BSI; Derogratis, 1993; Derogratis and Spencer, 1982) will also increase.

Hypothesis Two

Perceived Control Will Be Significantly Related to Both Uncertainty and Reported Psychological Distress.

As levels of perceived control increase, as measured by the Multidimensional Measure of Children's Perceptions of Control (PCS; Connell, 1985) the reported levels of illness uncertainty (measured by the CUIS) and psychological distress (measured by the BSI) will decrease.

Research Question One

Does Perceived Control Qualify as a Mediator Between Illness Uncertainty and Psychological Adjustment in That the Relationship Between Illness Uncertainty and Psychological Adjustment Is Only Significant When Perceived Control Is Included in the Regression Equation?

Research Question Two

Does Perceived Control Qualify as a Moderator, Acting to Strengthen an Already Significant Relationship Between Illness Uncertainty and Adolescent Psychological Adjustment?

The hypotheses and questions are presented as guides for an exploratory analysis because, to the authors knowledge, no clear relationships between the proposed variables (illness uncertainty, perceived control and psychological adjustment) have been identified in the existing literature on adolescents with Type 1 diabetes. However, both illness uncertainty and perceived control have been independently associated with psychological adjustment to illness (Band & Weisz, 1990; Mishel & Braden,1987; Mishel & Sorenson, 1991; Weisz et al., 1987). Furthermore, models relating illness uncertainty to psychological adjustment have included concepts similar to perceived control, such as mastery and control over physical function (Mishel & Braden, 1987; Mishel & Sorenson, 1991). The present investigation will contribute to the existing body of knowledge by examining the cognitive mechanisms (i.e. illness uncertainty and perceived control) which influence psychological adjustment of adolescents with diabetes. Through identification of the cognitive mechanisms associated with psychological adjustment in adolescents with diabetes, effective interventions targeting relevant cognitive variables can be developed to reduce the risk of poor psychological adjustment.

CHAPTER IV

METHOD

Participants

Sixty-eight adolescents (35 male, 33 female) between the ages of 13 and 18 (M = 14.8) participated in the study. The participants were all diagnosed with Type 1 diabetes and were apart of a larger study examining the adjustment of children and their parents to chronic illness. Grade level of the participants ranged from 6th grade to freshman year in college (M = 9.12). Participants in the sample identified themselves ethnically as Caucasian (79.4%), African-American (4.4%), Hispanic (2.9%), Native American (5.9%) and other (7.4%). Estimated annual household incomes were obtained via self-report and are presented in Table 1 in Appendix A. The marital status of the parents were as follows: 72.5 % were married, 17.4% were single, 4.3% were remarried, 2.9% were other, and 2.9% were no response (Please see Table 1 in Appendix A).

Measures

Demographic Information – A questionnaire was developed to obtain the following information: adolescent's gender, adolescent's age, adolescent's race, adolescent'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 adolescent with diabetes. It assessed 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 adolescent 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 adolescent engages in, overall ratings of how well the adolescent copes and adheres to their treatment regimen, an overall rating of the adolescent's health status, and a list of the medications the adolescent is currently prescribed.

Children's Uncertainty in Illness Scale – (CUIS; Hartman and Mullins, 1995) is a 23-item self-report measure of the child's medical uncertainty about the course, prognosis and treatment of their illness. The CUIS is an adapted version of the Parent's Perception Uncertainty in Illness Scale (Mishel, 1983) which is developmentally appropriate for children. The CUIS items addresses four components of illness uncertainty: ambiguity, uncertainty, lack of information, and unpredictability. Respondents are asked to respond on a 5-point scale ranging from "very true" to "very false." The CUIS yields a total score of uncertainty, with higher scores indicting higher levels of uncertainty, obtained by summing across all items. Reliability analyses for the measure for the current study revealed an internal consistency coefficient of $\alpha = .89$.

Multidimensional Measure of Children's Perceptions of Control – (PCS; Cornell, 1985). The perceived control scale is a 24-item self-report inventory which measures children's perceptions of control in a variety of domains (i.e., social, cognitive and physical). The respondents rate items such as "I can get good grades if I really try," and "I can be popular with other kids, if I really try," on a 4-point scale ranging from "very true" to "very false." Scores are added across all items and within each domain. Higher scores are indicative of higher levels of perceived control. Weisz et al., (1991) report internal consistency for each of the domains ranging from $\underline{r} = .34$ to $\underline{r} = .70$. Reliability analyses for this measure for the current study revealed an internal consistency coefficient of $\alpha = .90$.

Brief Symptom Inventory – (BSI; Derogratis, 1993; Derogratis & Spencer, 1982) is an abbreviated version of the Symptom Checklist-90-Revised and is highly correlated with this measure ($\underline{r}$'s =.92-.99 across the clinical scales; Derogratis, 1983). Fifty-three items assess nine clinical dimensions of psychological distress. The respondents are asked the perceived severity of a number of psychological and physical symptoms during the previous seven days. The measure yields a Global Severity Index (GSI) which will be used to assess overall adolescent distress. The BSI has adequate internal consistency ($\underline{r}$'s =.71-.85) and test-retest reliability ($\underline{r}$'s =.68-.91) (Derogratis, 1993). The BSI has been previously used by other researchers to examine child adaptation to chronic illness (Thompson et al., 1992; Mullins et al., 1995).

Procedure

A list of addresses of adolescents with diabetes was obtained from diabetes clinics at two mid-western hospitals and one mid-western children's hospital. A postcard was mailed to the adolescent's home informing the parents about the study, asking them to check the appropriate box to indicate their interest in participating in the study and to send the postcard back to the address provided. A research assistant called each of the families who returned postcards to further explain the purpose of the study and that participation was voluntary. Parents and adolescents interested in participating were sent questionnaire packets containing a detailed cover letter, consent form and age appropriate measures. Informed consent was obtained from both the parent(s) and adolescent. The research assistant informed the adolescent that they would receive a $10 gift certificate from 'Wal-Mart' for returning the completed questionnaire in the self-addressed stamped envelope provided in their packet. Participants were provided with the telephone numbers of the two primary investigators should they have additional questions regarding the purpose of the study, or specific questions about the measures utilized in the study. Participants were asked to return the packets within two weeks. Participants who did not return packets were sent a post-card reminder to return their packets and again thanked the families for participating in the study. Adolescents who returned their completed questionnaires were sent a thank you letter for participating and a gift certificate. All procedures were 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 will be utilized for analysis of the proposed variables.

CHAPTER V

RESULTS

Preliminary Analyses

Preliminary analyses were first conducted to identify the relationship of demographic variables to the primary variables of interest. Please see Table 2 in Appendix A for means and standard deviation of the study variables. A 3 X 2 MANOVA (Clinic X Gender) was conducted to examine mean differences on illness uncertainty, perceived control, and psychological distress. No significant differences were identified for illness uncertainty, $F(2,62) = .15$, $p > .05$, perceived control, $F(2,62) = .20$, $p > .05$, or psychological distress, $F(2,62) = 1.80$, $p > .05$, as a function of clinic site. Analyses also failed to reveal significant differences for illness uncertainty, $F(1,62) = 1.97$, $p > .05$, or perceived control, $F(1,62) = .79$, $p > .05$, as a function of gender. However, there were significant differences for psychological distress as a function of gender. Females reported significantly more psychological distress than males, $F(1,62) = 4.46$, $p < .05$. The number of participants who met caseness criteria (i.e., BSI T score > 63) was also determined. Eleven adolescents in the sample (14.2%) met caseness criteria.

Zero-order correlations were then computed for all of the primary variables. Zero-order correlations revealed significant relationships between illness uncertainty and psychological distress ($r = .44$, $p < .01$) and illness uncertainty and perceived control

($r = -.42$, $p < .001$), but not between perceived control and psychological distress ($r = -.19$, $p > .05$). Other significantly related variables were income and HbA_{1c} ($r = -.27$, $p < .05$), duration of illness and HbA_{1c} ($r = .26$, $p < .05$), and gender and BSI ($r = -.27$, $p < .05$) (see Table 3). Age was not significantly related to any of the study variables.

Primary Analyses

Hypothesis One. Higher levels of illness uncertainty reported by adolescents with Type 1 diabetes will be associated with higher levels of psychological distress.

A hierarchical regression equation was constructed to test the independent contribution of illness uncertainty to the observed variance of psychological distress after controlling for demographic and disease parameters (see Table 4). Demographic (i.e., income and gender) parameters were entered on block 1and disease (i.e., duration and HbA_{1c}) parameters were entered on block 2, and CUIS scores were entered on block 3. Results indicated that illness uncertainty significantly predicted psychological distress ($b^* = .41$, $p < .05$).

Hypothesis Two. Higher levels of illness uncertainty will be significantly associated with lower levels of perceived control, and lower levels of perceived control will be significantly associated higher levels of reported psychological distress.

A hierarchical regression equation was constructed with illness uncertainty as the predictor and with perceived control as the criterion variable (see Table 5). The independent contribution of illness uncertainty to variance in perceived control was examined after controlling for demographic and disease parameters. Demographic and

disease parameters were entered on block 1 and 2, respectively. Illness uncertainty was entered on block 3. Results indicate that illness uncertainty significantly predicted perceived control ($b^* = -.47$, $p < .05$), explaining 20% of the variance in the dependent variable.

A second hierarchical regression equation was then constructed to test the independent contribution of perceived control to psychological distress after controlling for demographic and disease parameters (see Table 6). Demographic and disease parameters were entered on block 1 and 2, respectively while perceived control was entered on block 3. Although perceived control was significantly correlated with psychological distress in previous bivariate analyses, it did not account for a significant proportion of the variance in psychological distress after controlling for demographic and disease parameters ($b^* = -.24$, $p > .05$).

In summary, evaluation of hypotheses one and two indicated that illness uncertainty was significantly related to psychological distress and perceived control; however, perceived control was not significantly related to psychological distress after controlling for disease and demographic parameters.

Research Question One. Does perceived control qualify as a mediator between illness uncertainty and psychological distress, in that the relationship between illness uncertainty and psychological distress is no longer significant after controlling for perceived control?

For perceived control to qualify as a mediator, the following relationships must exist: (a) illness uncertainty must be significantly related to psychological distress,

(b) illness uncertainty must be significantly related to perceived control, (c) perceived control must be significantly related to psychological distress after controlling for illness uncertainty, (d) the relationship between illness uncertainty and psychological distress is no longer significant after controlling for the relationships between illness uncertainty and perceived control, and perceived control and psychological distress (see Figure 1).

To answer research question number one, three regression equations were examined (Baron & Kenny, 1986). In all three equations, demographic variables (i.e., gender and income) were entered on block one and disease parameters (i.e., HbA_{1c} level and time since diagnosis) were entered on block two. The first regression equation examined the relationship between illness uncertainty and psychological distress (see Table 4). Results of this analysis indicated neither demographic nor illness parameters were associated with the BSI scores. However, illness uncertainty was significantly related to psychological distress ($b^* = .41$, $p < .05$), with 16% of the variance of psychological distress uniquely accounted for by illness uncertainty.

The second regression equation examined the relationship between illness uncertainty (independent variable) and perceived control (criterion variable). Illness uncertainty accounted for a significant proportion of the variance related to perceived control after controlling for demographic variables and illness parameters, with 20% of the unique variance in perceived control associated with illness uncertainty, $b^* = -.47$, $p = .001$, (see Table 5). In the third regression equation, with psychological distress as the criterion variable, illness uncertainty (independent variable) and perceived control (mediator variable) were entered simultaneously on block three. Here, 11% of the variance in psychological distress was uniquely associated with illness uncertainty

(b* = .38, p=.001), while perceived control did not explain a significant proportion of the variance in psychological distress (b* = -.01, p > .05). In other words, perceived control was not significantly related to psychological distress after controlling for illness uncertainty. Thus the third condition for mediation was not met. Although PCS was not significantly associated with psychological distress, mediation analyses were completed to verify that no mediational relationship existed. This was done due to the nearly significant relationship between PCS and BSI, b* = -.24, p=.06, (see Table 6). Further mediation analysis verified that CUIS remained significantly related to BSI after controlling for PC S (b* = .38, p=.005). Sobel's t-test was conducted and confirmed this finding (t (65) = -.28, p > .05). Therefore, perceived control did not mediate the relationship between illness uncertainty and psychological distress (see Table 7).

Research Question Two. Does perceived control qualify as a moderator, acting to strengthen an already significant relationship between illness uncertainty and levels of psychological distress reported by adolescents with Type 1 diabetes?

A moderator is a variable that effects the direction and/or strength of the relationship between an independent variable and a dependent variable (see Figure 2). For perceived control to serve as a moderator between illness uncertainty and psychological distress, the following conditions must be met: illness uncertainty and psychological distress are significantly related, and perceived control strengthens the association between illness uncertainty and psychological distress. This is indicated by a significant effect of the interaction term (illness uncertainty X perceived control).

A hierarchical regression equation was used to examine the moderator relationship. Again, demographics (i.e., gender and income) were entered on block one and disease parameters (i.e., HbA_{1c} level and time since diagnosis) were entered on block two (Baron & Kenny, 1986; Holmbeck, 1997). Both illness uncertainty and perceived control were centered for the analyses (Aiken & West, 1991). The first regression equation examined the relationship between illness uncertainty and psychological distress (see Table 8). Illness uncertainty was significantly related to psychological distress ($b^* = .35$, $p = .005$) with 16% of the variance in psychological distress uniquely accounted for by illness uncertainty. Moderation analyses revealed that the centered interaction term was not significant, $b^* = -.04$, $p = .73$ (see Table 8). Therefore, perceived control did not moderate the relationship between illness uncertainty and psychological distress.

Exploratory Analyses

Primary analyses identified gender differences on psychological distress, with males evidencing significantly lower BSI scores than females, $F(1,62) = 4.46$, $p < .05$. Therefore, exploratory analyses were conducted to examine whether the relationships between illness uncertainty, perceived control and psychological distress were the same for both males and females.

First, a series of hierarchical multiple regression equations were constructed to test whether perceived control mediated the relationship between illness uncertainty and psychological distress among females. Demographic parameters were entered on block 1 and disease parameters were entered on block 2 and CUIS was entered on block 3 for each of the equations. A significant relationship was found between illness uncertainty

and psychological distress among females after controlling for demographic and disease parameters ($b^* = .51$, $p < .05$). Illness uncertainty was also significantly related to perceived control after controlling for demographic and disease parameters ($b^* = -.54$, $p < .005$). However, perceived control was not significantly related to psychological distress ($b^* = -.24$, $p > .05$), nullifying further mediation analyses. Thus, perceived control did not mediate the relationship between illness uncertainty and psychological distress among females.

Moderation analyses were also conducted to test whether perceived control moderated the relationship between illness uncertainty and psychological distress. A significant relationship was found between illness uncertainty and psychological distress among females after controlling for demographic and disease parameters ($b^* = .51$, $p < .05$). Results indicate that perceived control did not moderate the relationship between illness uncertainty and psychological adjustment.

A hierarchical regression equation was constructed to test the independent contribution of illness uncertainty to the observed variance of psychological distress after controlling for demographic and disease parameters among males. Demographic and disease parameters were entered on block 1 and 2 respectively. Illness uncertainty was entered on block 3. Results indicated that illness uncertainty did not significantly predict psychological distress among males ($b^* = .36$, $p > .05$), nullifying further mediation and moderation analyses.

CHAPTER VI

DISCUSSION

The present study examined the relationship between illness uncertainty, perceived control, and psychological adjustment among adolescents with Type 1 diabetes. Hypotheses one and two predicted that increased illness uncertainty and decreased perceived control would be associated with an increase in psychological distress. Research questions one and two examined whether perceived control mediated or moderated the relationship between illness uncertainty and psychological adjustment.

Results supported the predicted relationship stated in hypothesis one. Illness uncertainty was significantly associated with psychological distress after controlling for demographic and disease parameters, with increased illness uncertainty associated with increased psychological distress. Concerning hypothesis two, illness uncertainty was significantly associated with perceived control after controlling for demographic and disease parameters, with increased illness uncertainty associated with decreased perceived control. However, the second element of hypothesis two was not supported. Perceived control was not significantly associated with psychological distress after controlling for demographic and disease parameters.

Research question one examined whether perceived control qualified as a mediator between illness uncertainty and psychological adjustment. The first two

conditions required for mediation were met: (a) illness uncertainty was significantly related to psychological distress, and (b) illness uncertainty was significantly related to perceived control. However, the third condition was not met. Perceived control was not significantly related to psychological adjustment after controlling for demographic and disease parameters. Further mediation analyses confirmed this finding, showing that the relationship between illness uncertainty and psychological distress remained significant after controlling for perceived control. Thus, perceived control does not mediate the relationship between illness uncertainty and psychological adjustment.

Research question two examined whether perceived control qualified as a moderator, acting to strengthen an already significant relationship between illness uncertainty and adolescent psychological adjustment. Illness uncertainty was significantly related to psychological distress. However, perceived control did not significantly influence the relationship between illness uncertainty and psychological adjustment. Perceived control, then, did not act to significantly increase or decrease the association between illness uncertainty and psychological distress, and therefore, did not qualify as a moderator in the present study.

The present findings further elucidate the relationship of cognitive mechanisms to adjustment in adolescents with Type 1 diabetes. First, these results suggest that those adolescents with Type 1 diabetes who experience greater illness uncertainty may be at greater risk for poor psychological adjustment than their peers who experience less illness uncertainty. Illness uncertainty was also significantly associated with perceived control, suggesting that adolescents who experience increased illness uncertainty may also be likely to experience decreased perceived control. However, perceived control was not

significantly associated with psychological distress after controlling for demographic and disease parameters. Furthermore, the results of this study suggest that perceived control neither mediated nor moderated the relationship between illness uncertainty and psychological adjustment. Notably, the present results demonstrate that illness uncertainty accounts for a significant proportion of the variance observed in psychological distress above and beyond that which is accounted for by demographic and disease parameters and perceived control observed among adolescent with Type 1 diabetes.

Gender differences were examined among the variables of interest through a series of exploratory regression analyses. Males in the present sample reported significantly less psychological distress than females. This finding is consistent with previous literature which has shown that adolescent boys with Type 1 diabetes tend to report significantly less psychological distress than their female counterparts (Kovacs et al., 1990; La Greca et al., 1995). Differences between males and females were also observed in regards to illness uncertainty. Among females, illness uncertainty accounted for a significant proportion of the variance observed in psychological distress after controlling for demographic and disease parameters. However, findings indicated that illness uncertainty was not significantly related to psychological distress among males in the present sample. Certainly, this difference may be due to a decrease in power as a result of the decrease in the sample size. Alternatively, these findings may indicate differences in the cognitive appraisal process between males and females in response to Type 1 diabetes.

The results presented here are consistent with findings by Mullins et al. (1997), where increased levels of illness uncertainty were associated with negative outcome expectancies and poor psychological adjustment among young adults with long standing

asthma. Present findings are also consistent with numerous studies examining illness uncertainty in adult chronic illness populations such as gynecological cancer, myocardial infarction, and multiple sclerosis (Christman et al., 1988; Mishel et al., 1991; Wineman et al., 1993). In each of the studies mentioned, and others, illness uncertainty was shown to influence psychological adjustment among individuals with a chronic illness (Mast, 1995).

The current findings are also relevant in terms of the body of literature on perceived control. Few articles specifically address the issue of perceived control in relation to the diabetes population. One notable exception is the study by Band and Weisz (1990) who found that perceived control was significantly associated with "socio-behavioral" adjustment to Type 1 diabetes. However, the present study did not identify that relationship. This may be due to the fact that Band and Weisz (1990) used a different measure of perceived control than was used in the present study. In addition, they used parental report to assess socio-behavioral adjustment as opposed to self-report. Further, the majority of studies examining perceived control, link the construct to symptoms of depression. In the present study a global measure of symptomatology was used. These differences may account for why the expected relationship between perceived control and psychological distress was not observed. Alternatively the present findings may suggest that the concept of control may merely be a representation of a more basic cognitive process, illness uncertainty.

In other words, perceived control could possibly be one component of the larger, more encompassing construct of illness uncertainty. Indeed, the lack of perceived control is conceptually similar to previously identified components that fall under the construct of illness uncertainty (Edwards & Weary, 1998). One element of perceived control, the

concept of outcome contingency, is of particular theoretical relevance. It has been proposed that one important component of illness uncertainty is the inability to determine what contingencies exist in a given situation (Mishel, 1984). Weisz defined perceived outcome contingency as the degree to which an individual perceives that a particular outcome depends on their behavior (1986). Therefore, in conditions of high illness uncertainty, contingencies for behavior are unclear to the individual, making it difficult, if not impossible, for the individual to determine if they have the capacity to produce a behavior that will result in their intended outcome (perceived competence). Although speculative, it is possible that adolescents who experience increased illness uncertainty and, subsequently decreased perceived control, may have difficulty perceiving contingencies in their environments. Empirical support for this relationship would be of particular significance with regard to diabetes, given that adherence to treatment regimens and subsequent euglycemia are incumbent upon the adolescent's ability to exert control over the disease via a daily regimen of diet planning, blood glucose monitoring, and insulin administration and exercise.

Although the present findings are interesting, they are subject to several limitations. First, the lack of a comparison group of healthy individuals or individuals with other chronic illnesses limits interpretation. It could be argued that the relationships observed between the variables may not be specific to adolescents with Type 1 diabetes. Rather, the findings may reflect relationships that are found among adolescents regardless of illness status. Second, this study is cross-sectional in nature and only represents a single measure of the variables in question. In addition, it is possible that those adolescents who tend to be more distressed view their illness as more uncertain and feel as

though they have less control than adolescents who are generally less distressed regardless of their illness status. Next, multiple informants were not used to assess the psychological adjustment of the adolescents. The CUIS, PCS and the BSI are all self-report measures. Therefore data obtained from these measures are susceptible to measurement issues inherent to self-report measures such as the possible influence of response sets and social desirability. In addition, not all of the measures were illness specific, meaning that the questions on these measures did not specifically target issues related to chronic illness. A measure of perceived control which asked about illness related perceived control issues may have yielded significant results. In addition, the mean HbA_{1C} for the present sample was relatively low indicating good glycemic control. Therefore, it is unknown how well the relationships found in this study would generalize to individuals with poor glycemic control. Finally, the sample was fairly homogeneous both in terms of ethnicity and socioeconomic status, thus limiting the ability to generalize these results to other ethnic and socioeconomic groups.

Future studies are needed to examine the relationship between illness uncertainty and psychological adjustment among other pediatric populations so that clinicians and researchers are better able to conceptualize the unique influence of illness uncertainty on psychological distress within specific illness groups. Studies examining illness uncertainty among different ethnic groups is also a vital, yet relatively unexplored area of research.

Finally, a better understanding of how cognitive mechanisms such as illness uncertainty and perceived control influence psychological adjustment could inform researchers and clinicians regarding effective means of prevention and treatment of psychological distress among children and adolescents with chronic illnesses. A promising

intervention program for adolescents with Type 1diabetes has been developed by Wysocki et al. (2000). This particular intervention targets conflict resolution and problem-solving skills of the adolescents and their parents. However, no intervention program has been designed specifically to decrease illness uncertainty and improve psychological adjustment among children and adolescents with Type 1 diabetes. Yet, given the reliable and robust relationship observed between illness uncertainty and psychological adjustment, it seems as though development of such an intervention would be warranted. Moreover, it has been demonstrated in previous literature that initial adjustment to diabetes is predictive of later adjustment. Therefore developing preventative programs for children newly diagnosed with a chronic illness and their parents could prevent the development of, or mitigate the severity of illness uncertainty and subsequent psychological distress.

Identifying the cognitive mechanisms which are associated with adaptation to chronic illness is pivotal in understanding why some individuals with a chronic illness cope fairly well with their illness while others do not. A more thorough understanding of these cognitive mechanisms will not only allow clinicians to identify those individuals at-risk for poor psychological adjustment, but will also allow researchers and clinicians to develop prevention and intervention programs which specifically target the cognitive mechanisms through which psychological distress develops.

Implications of the present findings regarding uncertainty and perceived control extend beyond psychological adjustment. Psychological adjustment of adolescents with diabetes has been associated with overall regimen adherence and metabolic control (Band & Weisz, 1990; Feifer & Tansman, 1999; Littlefield et al., 1992; Wysocki, Hough, Ward, & Green, 1992). Therefore an understanding of psychological factors like illness

uncertainty and perceived control are not only important in regards to psychological adjustment, but also play a critical role in the ultimate physical health of children and adolescents with diabetes.

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APPENDIXES

APPENDIX A

TABLES 1 - 8

TABLE 1

DESCRIPTIVE STATISTICS

Demographic Parameters		n	Percent
Gender			
	Male	35	51
	Female	33	49
Ethnicity			
	White	54	79.4
	African-American	3	4.4
	Hispanic	2	2.9
	Native American	4	5.9
	Other	5	7.4
Income Level			
	0-4,999	3	4.4
	5,000-9,999	2	2.9
	10,000-14,999	6	8.8
	15,000-19,999	2	2.9
	20,000-29,999	3	4.4
	30,000-39,999	8	11.8
	40,000-49,999	3	4.4
	50,000-59,999	11	16.2
	60,000 or greater	30	44.1

TABLE 2

DESCRIPTIVE STATISTICS FOR STUDY VARIABLES

	Females		Males	
Variable	M	SD	M	SD
Disease Parameters				
Duration	4.76	3.45	5.71	4.62
HbA_{1c}	8.99	2.95	8.13	1.63
Study Variables				
CUIS	58.61	14.04	53.74	11.60
PCS	59.51	8.69	57.28	9.60
BSI	52.85	11.76	46.49	11.01

Note: CUIS = Children's Uncertainty in Illness Scale; PCS = Multidimensional Measure of Children's Perceptions of Control; BSI = Brief Symptom Inventory (Global Severity Index); Duration = Time since diagnosis; HbA_{1c} = HbA_{1c} at time questionnaire was completed;*$p < .05$;**$p < .01$.

TABLE 3

ZERO-ORDER CORRELATIONS FOR STUDY VARIABLES

Measure	1	2	3	4	5	6	7	8
1. CUIS	–	-.42**	.44**	.16	.18	-.19	-.04	.02
2. PCS		–	-.19	-.10	-.01	-.12	-.10	-.04
3. BSI			–	.001	.03	-.27*	-.09	-.03
4. Duration				–	.26*	.12	.08	.18
5. HbA_{1c}					–	-.18	-.27*	.13
6. Gender						–	.07	-.06
7. Income							–	-.06
8. Age								–

Note: CUIS = Children's Uncertainty in Illness Scale; PCS = Multidimensional Measure of Children's Perceptions of Control; BSI = Brief Symptom Inventory, Global Severity Index; Duration = Time since diagnosis; HbA_{1c} = HbA_{1c} at time questionnaire was completed; *$p<.05$; **$p<.01$.

TABLE 4

PRIMARY ANALYSES EXAMINING THE INFLUENCE OF ILLNESS UNCERTAINTY ON PSYCHOLOGICAL DISTRESS

Variables	B	SE B	b*	R^2	R^2Change
Block 1				.08	.08
Gender	-6.27	2.78	-.27*		
Income	-.34	.56	-.07		
Block 2				.084	.004
Duration	-.17	.37	.06		
HbA_{1c}	-.31	.66	-.06		
Block 3				.24	.16**
CUIS	.37	.10	.41**		

Note: CUIS = Children's Uncertainty in Illness Scale; BSI = Brief Symptom Inventory (Global Severity Index); Duration = Time since diagnosis; HbA_{1c} = HbA_{1c} at time questionnaire was completed; *$p < .05$; **$p < .01$.

TABLE 5

PRIMARY ANALYSES EXAMINING THE INFLUENCE OF ILLNESS UNCERTAINTY ON PERCEIVED CONTROL

Predictor Variables	B	SE B	b*	R^2	R^2Change
Block 1				.02	.02
Gender	-2.14	2.24	-.12		
Income	-.35	.45	-.09		
Block 2				03	.008
Duration	-.16	.30	-.04		
HbA_{1c}	-.14	.53	-.07		
Block 3				.23	.20**
CUIS	-.33	.08	-.47**		

Note: CUIS = Children's Uncertainty in Illness Scale; BSI = Brief Symptom Inventory (Global Severity Index); Duration = Time since diagnosis; HbA_{1c} = HbA_{1c} at time questionnaire was completed; *$p < .05$; **$p < .01$.

TABLE 6

PRIMARY ANALYSES EXAMINING THE INFLUENCE OF PERCEIVED CONTROL ON PSYCHOLOGICAL DISTRESS

Variables	B	SE B	b*	R^2	R^2Change
Block 1				.08	.08
Gender	-6.27	2.78	-.27*		
Income	-.34	.56	-.07		
Block 2				.08	.004
Duration	.17	.37	.06		
HbA_{1c}	-.31	.66	-.06		
Block 3				.14	.05
PCS	-.30	.15	-.24		

Note: PCS = Multidimensional Measure of Children's Perceptions of Control; BSI = Brief Symptom Inventory (Global Severity Index); Duration = Time since diagnosis; HbA_{1c} = HbA_{1c} at time questionnaire was completed; *$p < .05$; **$p < .01$.

TABLE 7

MEDIATION ANALYSES EXAMINING THE INFLUENCE OF ILLNESS UNCERTAINTY AND PERCEIVED CONTROL ON PSYCHOLOGICAL DISTRESS

Predictor Variables	B	SE B	b*	R^2	R^2Change
Block 1				.08	.08
Gender	-6.27	2.78	-.27*		
Income	-.34	.56	-.07		
Block 2				.08	.004
Duration	-.12	.36	.04		
HbA_{1c}	-.35	.64	-.07		
Block 3					
PCS	-.008	.16	-.01	.14	.05
Block 4					
CUIS	.35	.12	.38**	.25**	.11**

Note: CUIS = Children's Uncertainty in Illness Scale; PCS = Multidimensional Measure of Children's Perceptions of Control; BSI = Brief Symptom Inventory (Global Severity Index); Duration = Time since diagnosis; HbA_{1c} = HbA_{1c} at time questionnaire was completed; *$p < .05$; **$p < .01$.

TABLE 8

MODERATION ANALYSES EXAMINING THE INFLUENCE OF ILLNESS UNCERTAINTY AND PERCEIVED CONTROL ON PSYCHOLOGICAL DISTRESS

Predictor Variables	B	SE B	b*	R^2	R^2Change
Block 1				.08	.08
Gender	-6.27	2.78	-.27*		
Income	-.34	.58	-.10		
Block 2				.08	.004
Duration	-.17	.37	.06		
HbA_{1c}	-.31	.66	-.06		
Block 3					
CUIS	.35	.12	.38**	.25	.16**
(Centered) PCS	-.008	.16	-.07		
(Centered) Block 4					
CUIS X PCS	-.0003	.01	-.04	.25	.001

Note: CUIS = Children's Uncertainty in Illness Scale; PCS = Multidimensional Measure of Children's Perceptions of Control; BSI = Brief Symptom Inventory (Global Severity Index); Duration = Time since diagnosis; HbA_{1c} = HbA_{1c} at time questionnaire was completed; *$p < .05$; **$p < .01$.

APPENDIX B

FIGURES

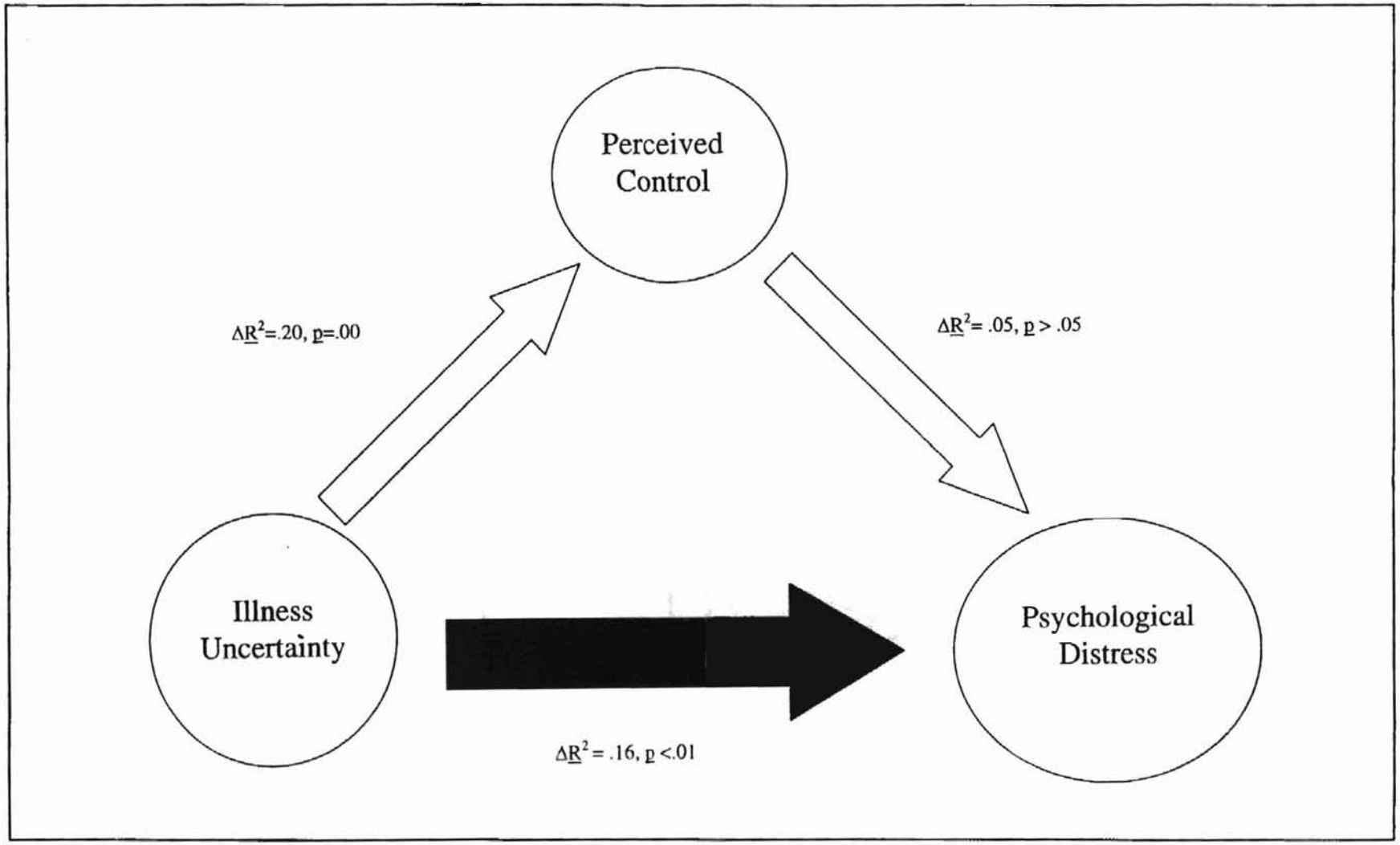

Figure 1. The Relationship Between Illness Uncertainty, Perceived Control, and Psychological Distress Represented in a Mediation Model.

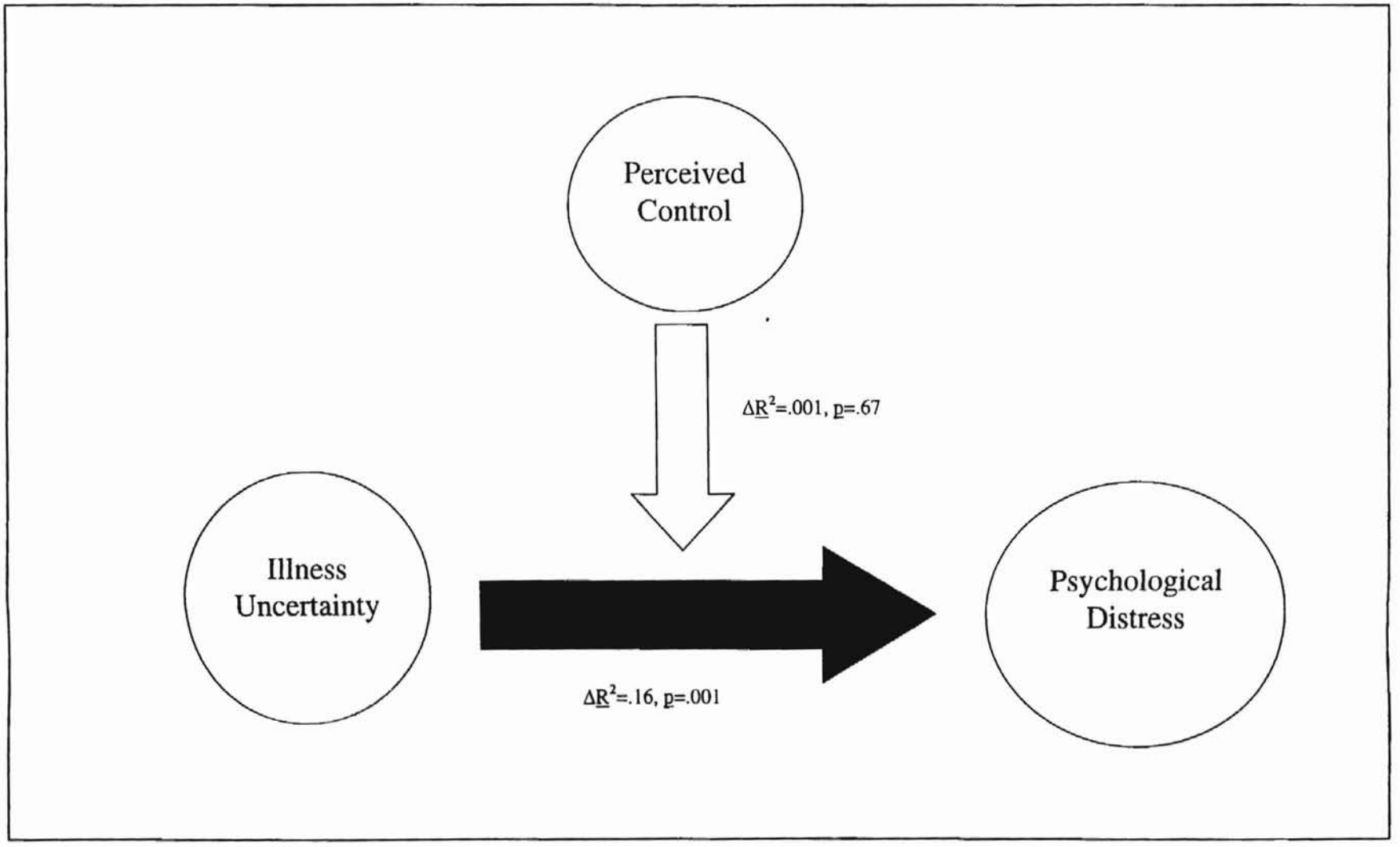

Figure 2. The Relationship Between Illness Uncertainty, Perceived Control, and Psychological Distress Represented in a Moderation Model.

APPENDIX C

INSTITUTIONAL REVIEW BOARD

APPROVAL FORM

OKLAHOMA STATE UNIVERSITY
INSTITUTIONAL REVIEW BOARD

DATE: 01-26-99 **IRB #: AS-99-030**

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

Principal Investigator(s): Larry L. Mullins

Reviewed and Processed as: Full Board

Approval Status Recommended by Reviewer(s): Approved

Signature: Carol Olson Date: January 26, 1999

Carol Olson, Director of University Research Compliance

Approvals are valid for one calendar year, after which time a request for continuation must be submitted. Any modification to the research project approved by the IRB must be submitted for approval. Approved projects are subject to monitoring by the IRB. Expedited and exempt projects may be reviewed by the full Institutional Review Board.

VITA

Ahna L. Hoff

Candidate for the Degree of

Master of Science

Thesis: THE RELATIONSHIP OF ILLNESS UNCERTAINTY AND PERCEIVED CONTROL TO PSYCHOLOGICAL ADJUSTMENT AMONG ADOLESCENTS WITH TYPE I DIABETES

Major Field: Psychology

Biographical:

Education: Graduated from Mitchell High School, Colorado Springs, Colorado in June 1989; received Bachelor of Science degree in Psychology from Colorado State University, Fort Collins, Colorado in 1993; received Master of Arts degree in Clinical Psychology from University of Colorado, Denver, Colorado, 1998. Completed the requirements for the Master of Science degree with a major in Clinical Psychology at Oklahoma State University in May, 2000.

Experience: Research – Employed as a Co-Project Coordinator for the Adaptation to pediatric chronic illness: Utilization of disease specific research methodology. A grant funded by Olsten Health Care. August, 1999 to present. Acted as a Graduate Research Assistant for the Partner's Project Grant funded by Center for Disease Control at the University of Oklahoma Health Sciences Center, February 1999 to present. Co-Project Coordinator for the Infant Directed Speech of Mothers with Depression. A grant funded by the Swan Foundation, University of Colorado, October 1996 to May 1998. Clinical – Acting Psychological Associate at the Oklahoma State University Psychological Services Center, August, 1998 to present. Provided volunteer consultation services on a pediatric psychology consultation and liaison team at the Children's Hospital of Oklahoma May 1999 to August 1999. Conducted ADHD evaluations for children at Children's Hospital of Oklahoma in the General Pediatrics Clinic, May 1999 to August 1999. Provided therapeutic services at University of

Oklahoma Health Sciences Center in the Department of Psychiatry and Behavioral Sciences, May 1999 to August 1999. Provided direct care as a Mental Health Worker on child and adolescent inpatient units at the Cleo Wallace Center, October, 1997 to July, 1998. Acted as a Cottage Coordinator and Group Living Counselor in a residential treatment setting for adolescent girls at Excelsior Youth Center, June, 1994 to July 1996.

Professional Memberships: American Psychological Association, Society of Pediatric Psychology.