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Examination of the Impact of Age, Family Conflict, And Perceived Parental Involvement on Treatment Adherence for Children and Adolescents with Cystic Fibrosis and Diabetes

Blake M. Lancaster
Western Michigan University

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EXAMINATION OF THE IMPACT OF AGE, FAMILY CONFLICT, AND
PERCEIVED PARENTAL INVOLVEMENT ON TREATMENT
ADHERENCE FOR CHILDREN AND ADOLESCENTS WITH
CYSTIC FIBROSIS AND DIABETES

by

Blake M. Lancaster

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Submitted to the
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EXAMINATION OF THE IMPACT OF AGE, FAMILY CONFLICT, AND
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Blake M. Lancaster, Ph.D.

Western Michigan University, 2006

The success of medical interventions for patients with diseases that require consistent adherence to a medical regimen is largely contingent upon the patient's ability to consistently follow medical recommendations. Medical regimen adherence significantly influences the patient's health and impacts the health care providers' ability to treat any disease or medical problem. Adherence levels are particularly low in the pediatric population among young patients with diabetes and cystic fibrosis. Researchers and clinicians hypothesize that levels of adherence are particularly low during adolescence (ages 11-15) because this may be the period in which primary responsibility for daily adherence is transferred from the parent to the child patient (Miller & Drotar, 2003).

The current investigation is designed to provide a systematic analysis of how age, perceived responsibility for treatment procedures, levels of parental involvement in treatment procedures, and conflict are related to treatment adherence in diabetic and cystic fibrosis populations. Data were collected from 64 diabetic parent-child dyads, and 27 cystic fibrosis parent-child dyads (children ages 7-18). Several significant results are reported from the current data set. First, internal consistency

and test-retest psychometric data are provided for previously established adherence assessment instruments including the Cystic Fibrosis Family Responsibility Questionnaire (CFFRQ), the Diabetes Family Responsibility Questionnaire (DFRQ), the Conflict Subscale of the Diabetes Responsibility and Conflict Scale (Conflict Subscale-DRCS) and the Self-Care Inventory (SCI). In addition, the internal consistency and test-retests reliability results are reported for the newly developed versions of the Modified Conflict Subscale for the Cystic Fibrosis Responsibility and Conflict Scale (Conflict Subscale-CFRCS) and the Modified Self-Care Inventory-Cystic Fibrosis (SCI-CF).

Results of this investigation suggest that agreement between parents and their children regarding who is primarily responsible for completing treatment tasks on a daily basis may be the most significant predictor of adherence levels within both the diabetic and cystic fibrosis populations. These findings are discussed in relation to the impact they may have on providing medical recommendations for similar patients in the medical setting, and how these results compare to the findings in similar studies that have been conducted in the area of pediatric medical regimen treatment adherence.

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CHAPTER 1

INTRODUCTION

Treatment adherence to medical regimens significantly affects the overall delivery of health care services by altering levels of intervention success and altering patient health. Treatment adherence is defined as, “the extent to which a person’s behaviors (e.g., medication administration, following diets) coincide with medical or health advice” (Haynes, 1979, p. 2). Nonadherence can negatively impact patient health and complicate clinician decision-making, increase healthcare costs, and distort treatment efficacy research (Rapoff, 2001). Research on adherence is considered critical in the psychological and medical communities because understanding how to increase adherence could lead to increases in the overall quality of healthcare service and patient quality of life (Allen & Warzak, 2000).

Many medical and psychological investigations have examined factors that influence adherence levels and techniques for increasing patient's compliance with recommended treatments (Rapoff, 2001). These investigations have all faced challenging measurement issues such as forced reliance on patient report that are inherent in the study of treatment adherence. Patient or parent reports are often influenced by factors such as social desirability and distorted memory of the past (McDonald, Garg, & Haynes, 2002). Clinicians’ personal judgment and predictions of adherence have also proven an inaccurate measure of treatment adherence (Stephenson, Rowe, & Haynes, 1993) leading most researchers to rely on

patient/parent report in spite of the aforementioned drawbacks. The studies described in this literature review are based on measures of patient/parent report unless otherwise indicated.

Adherence to medical regimens is surprisingly low and is typically not significantly affected by clinician instruction. Adherence rates for short-term treatment regimens that last 2 weeks or less are approximately 50% and are significantly lower for more demanding treatment regimens that require lifetime adherence on a daily basis (McDonald et al., 2002). Furthermore, research suggests that clinician instruction does not significantly affect the long-term behavior or levels of treatment adherence for individuals who suffer from chronic disease (McDonald et al., 2002). Poor adherence to long-term treatment regimens is particularly concerning because long-term regimens are associated with chronic diseases that greatly impact lifelong health, viability and livelihood of patients.

Treatment of chronic disease presents challenges to families and physicians, particularly when the patient is a child or adolescent. Chronic pediatric diseases such as cystic fibrosis (CF) and insulin dependent diabetes mellitus (IDDM) often have low and variable rates of adherence, with estimates for CF regimen adherence ranging from 16% to 90% and estimates for IDDM ranging from 10% to 80% (Anderson, Ho, Brackett, Finkestein, & Laffel, 1997; Jacobson, et al., 1990; Lask, 1994). Regimens for these diseases include multiple daily treatment components targeting overall health of the patient (Bartholomew, Parcel, Seilheimer & Czyzewski, 1993; Eaton, Larson, Mengel, Campbell, Mengel, & Montague, 1992). Management of these diseases requires the family and the child to regularly administer medication, alter

their diet, and make various other lifestyle changes (Bartholomew et al., 1993; Eaton et al., 1992). These demands require the family to become experts on the disease during the course of monitoring and improving the child's condition. After acquiring knowledge about the disease and treatment, the family must commit to implementation, alter their lifestyle, and deal with the stress associated with these changes (Kyngas, Kroll, & Duffy, 2000). For the medical professional, the greatest challenge is determining whether the patient's health status is related to non-compliance, non-responsiveness to appropriately delivered medical intervention, or the general, inevitable, deterioration of the health of the patient.

Several factors influence the adherence of individuals with chronic disease regimens: (a) general demographic factors, (b) characteristics of the specific disease, (c) specific aspects of the regimen itself, and (d) variables associated with the patient and family. The following sections review the primary variables investigated for individuals with CF and IDDM. General demographic factors such as family income and level of education are positively associated with treatment adherence and these correlations remain relatively stable throughout the course of the patients' disease (Johnson, Kelly, Henretta, Cunningham, Tomer, & Silverstein, 1992; Kovacs, Kass, Schnell, Goldston, & Marsh, 1989). In addition to demographic factors, three groups of variables influence treatment adherence for pediatric CF and IDDM regimens (LeBlanc & Goldsmith, 2003; Lemanek, Kamps & Chung, 2001). The first category includes the characteristics of the specific disease (e.g., severity, age of onset, impact on cognitive functioning), which influence the probability that patients will comply with treatment regimens. The second category includes specific aspects of regimen

itself (e.g., procedural complexity, frequency of implementation, efficacy, and side effects). The third category refers to variables associated with the patient and their family such as level of family dysfunction and related skills (e.g., poor communication, high levels of stress, lack of problem solving skills, coping strategies). The following sections will provide a brief general overview of the first two categories, disease characteristics, and intervention regimens for each disease. The third category will be examined in greater detail and will be the focus of the proposed investigation.

CHAPTER 2

LITERATURE REVIEW

IDDM Disease Characteristics

IDDM results from a failure of the pancreas to produce or effectively regulate the release of insulin. This failure often leads to medical complications such as vascular disease, blindness, renal impairment, and neuropathology (Drash, 1978). Researchers believe that the malfunction of insulin producing cells within the pancreas is related to the autoimmune process; however, the specific mechanism of change responsible for this breakdown has not yet been identified (Thai & Eisenbarth, 1993).

The current literature does not provide a clear picture of the impact of IDDM on the cognitive functioning of patients or how any impaired functioning might influence an individual's adherence to the recommended treatment regimen. There appears to be consensus within the literature that IDDM may be associated with long-term degenerative changes in the central nervous system (Prescott, Richardson, & Gillespie, 1990; Ehrlich, 1999). However, there is disagreement as to whether or not this neurological decay presents individuals with any significant performance difficulties either immediately or over time. Some research suggests that hypoglycemia has little impact on patient's cognitive functioning or academic performance (Hough, 1995). Findings on the impact of hypoglycemia on cognitive functioning are equivocal. The researchers found no statistically significant

difference between the cognitive performance of individuals who suffer from IDDM and those who do not (Ehrlich, 1999; Prescott et al., 1990). Other literature has demonstrated delays on some developmental tasks when comparing adolescents who suffer from IDDM to their healthy peers (Rovet, Ehrlich, & Czuchta, 1990).

IDDM Regimen Characteristics

IDDM treatment recommendations require potentially dramatic shifts in lifestyle. Treatments designed for IDDM include procedures to normalize serum glucose by providing exogenous insulin paired with altered dietary practices in order to regulate intake of simple sugars and saturated fats (Greydanus, Draznin, & Hare, 1997). The first required activity is the administration of some form of insulin and monitoring of blood glucose. Some diabetics inject insulin while others take pills that help their bodies produce more insulin and/or use produced insulin more effectively. Individuals with IDDM also monitor their blood glucose levels daily to evaluate how well their regimen is keeping blood sugars in a normal range and to indicate when insulin administration is required to bring blood sugar into the normal range (Greydanus et al., 1997). The second group of critical activities includes a healthy diet and consistent exercise. Dietary changes include increased starch intake (e.g., breads, cereals, and nuts) to clean the lower gastrointestinal tract, increased fruit and vegetable intake to reduce the absorption of glucose from the intestines, and decreased consumption of sugars to help stabilize blood glucose levels. A consistent exercise regimen can assist the body in more productively and efficiently managing insulin to convert glucose into energy for cells (Greydanus et al., 1997).

The daily management of IDDM requires that the pediatric patient become partially responsible for daily monitoring of glucose, administration of insulin, and dietary control and exercise activities. Younger children typically follow adult instruction during the implementation of each of these components while preadolescents and adolescents may assume more independence for treatment implementation. Implementation of treatment components may prove particularly difficult for children aged 11 to 15 who are not developmentally capable (i.e., maturity and cognitive abilities) of following through with aspects of treatment on a consistent, daily, basis but are constantly striving for independence from their parents in all aspects of their lives (Davis, Delamater, Shaw, La Greca, Edison, Perez-Rodriguez, & Nemery, 2001; Greydanus et al., 1997). Additionally, the most distressing negative effects of non-adherence in IDDM are usually cumulative and delayed (e.g., renal failure, heart failure, growth failure) rather than immediately evident while immediate effects (e.g., fatigue, weight loss, frequent urination) are often less aversive than regimen compliance (Greydanus et al., 1997; Silverstein, 1994).

CF Disease Characteristics

CF is a chronic illness hypothesized to result from genetic variance on chromosome 7 (Wilmott & Fielder, 1994). This variance appears responsible for the development of symptoms such as excessive secretions in the lungs, pancreas, small bowel, liver and reproductive glands. In addition to excessive secretions, an excessive amount of salt and water are lost through sweat glands during exercise

(Bartholomew & Schwartz, 1991). These two factors produce complications including lung damage and high levels of lung mucus and infections. Pulmonary complications of this nature lead to impaired functioning, respiratory failure, and ultimate fatality for 90% of CF sufferers (Greydanus & Homnick, 1997). While some individuals avoid symptoms of CF until the third or fourth decade of life, most patients will experience gastrointestinal and pulmonary complications from the onset of the disease (Greydanus & Homnick, 1997). If a physician identifies CF soon after birth, the family becomes responsible for implementing the treatment regimen and responsibilities gradually shift to the patient as they mature (Sherbourne, Hays, Ordway, DiMatteo, & Kravitz, 1992). Treatment adherence in CF often becomes a practice incorporated into daily life from birth.

Though it is rare for patients that suffer from CF to live a normal life span, life expectancy does increase with regimen adherence (Jackson, 1989). Improved treatment methodologies for CF have increased the average life expectancy dramatically over the past 30 years. Life expectancy rates vary from country to country, but the average life expectancy increased from approximately seven years in the 1960's to approximately 17 years in the 1970's and to almost 35 years in 1995 (NIH, 1997). It is estimated that children with CF born in 1990 will live approximately 40 years (Elborn, Shale, & Britton, 1992). The perception of unavoidable fatality appears to significantly impact compliance with treatment recommendations within the adolescent population (Lask, 1994) as high levels of optimism are associated with engagement in the various complicated aspects of the CF management routine. As treatment methodologies improve, adolescents may look

forward to a life that extends well into the 30's, however, the reality of a truncated lifespan will continue to challenge patients and their families as they try to remain optimistic.

CF does not appear to be associated with any cognitive impairment that might influence levels of treatment adherence; however there is evidence to suggest that adolescents who are diagnosed with this disease might be impacted in regards to psychosocial development. Research suggests that individuals, especially females, who suffer from CF might be slightly delayed in regards to self-esteem and overall adjustment compared with individual who do not suffer from CF (Sawyer, Rosier, Phelan, & Bowes, 1999). Furthermore, other research suggests that individuals who suffer from CF have a lower level of peer interaction than individuals without chronic disease (Meijer, Sinnema, Bijstra, Mellenbergh, & Wolters, 2000). Lower levels of peer interaction might lead to a restricted social skills set due to limited opportunities to develop and practice them. These factors suggest that decisions about treatment responsibility should be based on developmental maturity, rather than on age, because of the potential for slightly delayed psychosocial development.

CF Regimen Characteristics

Treatment regimens for CF include complicated procedures requiring extensive resources and knowledge to execute interventions (Greydanus & Homnick, 1997). These regimens include daily physiotherapy (e.g., back pounding to loosen mucus secretion followed by suctioning) and/or exercise to reduce the risk of lung infection (Greydanus & Homnick, 1997). An antibiotic regimen is often

implemented to reduce the chances of lung infection. A high calorie diet may also be recommended to reduce the risk of rapid weight loss and to stimulate digestive enzymes that assist in absorption of nutrients that are otherwise prematurely secreted (Willis, Miller, & Wyn, 2001).

Treatment regimens for IDDM and CF entail some level of complexity and require daily adherence making them tedious and time consuming (Kyngas et al., 2000). Research suggests that the level of procedural complexity does not necessarily prevent good adherence, but the constant attention and consistency required strongly influences adherence. Current research suggests that treatment adherence decreases as the responsibility for treatment implementation and monitoring passes from the parent to the child (Eaton et al., 1992), however, it is not clear why this drop occurs. The decrease in adherence may be due to the loss of a structure for reinforcement and support provided by the family system for younger children (Eaton et al., 1992), or might occur if the responsibility transition precedes the developmental readiness of the adolescent. Additionally, several questions remain unanswered about the psychosocial factors that might impact treatment adherence for adolescents becoming more autonomous in their health care. The following sections provide a literature review of selected articles that investigate these psychosocial factors and their relationship to treatment adherence within the pediatric population.

Psychosocial Factors that Impact Adherence

Research indicates that three sets of interconnected individual and family functioning variables can impact adherence. The age and developmental functioning

of the child patient, the level of parental involvement in the intervention, and the overall level of family conflict can each affect levels of treatment adherence. These three variables also interact to produce a complex picture of the impact of psychosocial variables on treatment adherence. The following sections will review the impact of these three factors on adherence for IDDM and CF regimens.

Age and Developmental Level

There is a great deal of interest in the relationship between age and treatment adherence for both IDDM and CF (Davis et al., 2001; Drotar & Ivers, 1994; Johnson et al., 1992; Ricker, Delamater, & Hsu, 1998; Rubin, Young-Hyman, & Peyrot, 1989). In much of the literature regarding treatment adherence, chronological age is measured and examined as a predictor of the ability of a patient to complete tasks independently. However, the reader should note that chronological age is not necessarily equivalent to developmental level in terms of cognitive functioning, level of psychosocial development, or maturity. It is currently unclear which psychosocial characteristics are critically related to age and its' impact on treatment adherence. However, in spite of the limitations of using chronological age rather than a measure of developmental level, age is a commonly measured variable in psychological and medical literatures. Many investigations have attempted to determine whether age is strongly correlated with treatment adherence and to identify the ages that might be associated with higher and lower levels of treatment (Davis et al., 2001; Drotars & Ivers, 1994; Johnson et al., 1992; Ricker et al., 1998; Rubin et al., 1989). Developmental theories are then often used to interpret the potential factors contributing to success or difficulties with compliance at a given age.

Several studies support the finding that age is associated with levels of treatment adherence. Johnson et al. (1992) assessed the relationship between age and treatment regimen adherence in 193 youngsters who suffered from IDDM. This two-year longitudinal study used structural equation modeling to examine the impact of patient age and disease duration on several measures of treatment adherence. Results of the models created during this investigation suggested that age was a predictor of levels of treatment adherence and metabolic control. The models suggested that older youngsters were less successful with adherence and with achieving metabolic control. Additionally, regimen aspects of diet, frequency of glucose testing, and frequency of injections were most closely associated with greater metabolic control suggesting that some regimen components may be more critical than others.

Ricker et al. (1998) also assessed the relationship between levels of treatment adherence and age in 50 children. Researchers conducted phone interviews on three separate occasions to obtain information regarding treatment adherence and correlated the results with survey responses measuring health locus of control, self-competency, and age using a hierarchical multiple regression analysis. They suggested that younger age is correlated with higher levels of regimen adherence among children who suffer from CF.

Finally, Jacobson et al. (1990) conducted a 4-year longitudinal study of treatment adherence in individuals with IDDM. Factors associated with higher levels of treatment adherence were child “ego defense level,” level of adjustment to the disorder, and age. Patient’s level of diet adherence, insulin adjustment, and metabolic monitoring were higher for preadolescents (age 9-12) than for adolescents (13-16)

suggesting that younger children were more compliant to treatment recommendations. However, this study did not include an investigation into the level of involvement of parents in the treatment process, which has been shown to affect adherence.

Parental Involvement

Drotar & Ivers (1994) compared the relations between age and level of child treatment responsibility in pediatric populations with CF and IDDM. Twenty-six individuals and their parents completed the Diabetes Family Responsibility Questionnaire and the Cystic Fibrosis Family Responsibility Questionnaire to indicate who was responsible for treatment implementation. No measures of actual adherence were collected and no examination of the relation between parental level of involvement and child age were conducted. Their results suggest that older children may perceive themselves as more responsible for implementing the treatment regimen independently. However, parents reported that their involvement in treatment components did not change significantly as children grew older (11-14 years) suggesting a discrepancy between child and parent perception of responsibilities. Children may inaccurately perceive themselves as achieving independence when levels of parental involvement may continue at a relatively stable level throughout adolescent development.

In another investigation of the association between levels of parental involvement and treatment adherence, Wiebe et al. (2005) suggested that parents levels of involvement in treatment was a predictor of levels of treatment adherence measured through Glycosylated Hemoglobin. A sample of 127 children, ages 10 – 15 years, diagnosed with IDDM completed surveys assessing parental involvement

among other factors that might influence treatment adherence. According to the children surveyed in this investigation, there was a strong relationship between higher reported levels of parental involvement and treatment adherence. These results also suggested that children report a strong association between lower levels of parental involvement and increased age of the child. Taken together, these results suggest that parents are less involved in treatment as children age, and that levels of treatment adherence are lower as children grow older.

Though the results of the Wiebe et al. (2005) investigation did not take into account parent report of their level of involvement in treatment, the Drotar and Ivers (1994) investigation suggested discrepancies in the report between parent and their children regarding levels of parental involvement in treatment resulted in lower levels of treatment adherence. Conflicting perceptions of child independence may contribute to the third relevant psychosocial variable, increased levels of conflict between parents and their offspring that emerge as children enter late childhood and early adolescence.

Increased Family Conflict

While parental knowledge and involvement is instrumental in increasing pediatric treatment adherence (Anderson, Auslander, Jung, Miller, & Santiago, 1990; Anderson et al., 1997; Kyngas et al., 2000), older children are generally less receptive to instruction from their parents, which may produce greater levels of conflict within the family (Graetz, Shute, & Sawyer, 2000; Schafer, McCaul, & Glasgow, 1986). If family conflict increases, adherence is usually impacted negatively (Martin, Miller-Johnson, Kizmann, & Emery, 1998; Miller-Johnson, Emery, Marvin, Clarke,

Lovinger, & Martin, 1994). If the family system, however, is successful in increasing family involvement and providing an emotional support system without increased conflict, then increased family involvement has been demonstrated to have a positive impact on levels of treatment adherence (Martin et al., 1998).

In a recent study examining family factors associated with treatment adherence in IDDM, Miller and Drotar (2003) investigated the relation between levels of conflict and child/parent perceptions of decision making in regards to treatment. Eighty-two mother-child dyads were issued a series of questionnaires designed to assess perceptions of child autonomy in treatment decision-making, the level of treatment adherence, and the level of parent-child conflict. Results suggested an association between discrepant reports of the child's level of autonomy in decision-making and levels of parent-child conflict. Specifically, when children reported greater levels of autonomy in decision-making than mothers acknowledged, there was a greater level of reported conflict. Results also suggested that there was a significant negative correlation between mothers' report of conflict and mothers' report of treatment adherence. That is, from the perspective of the mothers surveyed, higher levels of diabetes-related conflict were associated with lower levels of treatment adherence. Associations between age and autonomy or age and conflict, however, were not investigated due to the limited participant age range (11 - 17 year olds). This study was specific to IDDM and did not include individuals with CF, leaving the question about potential parallels between these two diseases unanswered.

Summary of Current Findings and Rationale for the Proposed Study

Several studies suggest that psychosocial development associated with age, levels of parental involvement, and levels of family conflict significantly impact treatment adherence for children with chronic diseases such as IDDM and CF. However, several critical questions about these three psychosocial factors still remain. It is unclear whether increased parental involvement is always associated with levels of conflict within the family or if it is only problematic for adolescents. Additionally, it is unclear when parental and child reports of disease management autonomy become discrepant. Research that compares the impact of these three factors in families of children who suffer from IDDM and CF may be useful because unique aspects of each disease or regimen might influence perceived autonomy or the age at which reports of perceived autonomy become discrepant.

Clinicians who make recommendations about child and adult responsibility for regimen implementation are faced with conflicting findings. Older children are less likely to adhere to treatment regimens (Anderson et al., 1997) and parental involvement decreases with age. Increased parental involvement for older children often produces increased family conflict, which is in turn associated with poor adherence. Clinicians may be reluctant to recommend that parents become more involved knowing that increased parental involvement may lead to increased conflict and a decrease in treatment adherence. However, without their involvement many adolescents may lose ground in their health status. Information regarding when and which treatment responsibilities should be delegated to the parent and the child could be useful for clinicians when attempting to reduce conflict and increase adherence.

Researchers hypothesize that by explicitly assigning specific treatment tasks, medical professionals might eliminate the discrepancy between perceptions of autonomy, which may reduce conflict and increase treatment adherence (Anderson et al., 1997).

Further research is needed to clarify the age at which children's level of adherence begins to decrease and the level of parental involvement that is useful in increasing adherence without increasing conflict. Currently, there are reliable tools for assessing these factors and normative data for these factors with children with IDDM. However, tools for children with CF either have not yet been developed or have less available psychometric information. Development of additional tools and norms and further evaluation of psychometric properties of existing tools for variables such as conflict within the family and levels of treatment adherence are needed. Data of this nature could contribute to the development of guidelines regarding recommendations for treatment responsibilities when working with the CF population. Furthermore, clear research findings regarding age and appropriate level of treatment autonomy could lead to clinical guidelines for transfer of treatment responsibilities from the family as a whole to adolescents who suffer from both IDDM and CF. Recommendations of this nature could lead to lower levels of conflict within the family and possibly increase the probability of treatment adherence. Additional research is also needed to examine potential parallels or differences in CF and IDDM populations.

The current investigation is designed to provide a systematic analysis of how age, perceived responsibility for treatment procedures, level of parental involvement in treatment responsibilities and conflict are related to treatment adherence for both

CF and IDDM patients. The current investigation has three specific goals. First, we will provide psychometric data including further reliability data for the Cystic Fibrosis Family Responsibility Questionnaire (CFRCS), the Diabetes Family Responsibility Questionnaire (DRCS), Conflict Subscale of the Diabetes Responsibility and Conflict Scale (Conflict Subscale – DRCS) and the Self-Care Inventory (SCI). In addition, we will assess the internal consistency of the newly developed versions of the Modified Conflict Subscale of the Cystic Fibrosis Responsibility and Conflict Scale (Conflict Subscale – CFFCS) and the Modified Self-Care Inventory – Cystic Fibrosis (SCI – CF). Second, we will attempt to clarify the relationship between age, perceived responsibility for treatment procedures, level of family conflict and treatment adherence for children with IDDM and CF. Finally, we will attempt to determine the combined level of prediction these variables may have in regards to levels of treatment adherence for each disease.

CHAPTER 3

METHOD

Participants

Participants were recruited from three separate community outpatient medical clinics that also serve as research training facilities for large university medical schools. These clinics were all dedicated to the long term care of children who suffer from IDDM and CF. Patients were seen in these clinics on a semi-regular basis; approximately every two months for children with CF and approximately every three to six months for children who suffer from IDDM. All participants attended a minimum number of five scheduled appointments to ensure that they had been followed by outpatient clinic for approximately one year. This level of attendance also ensured that the family received instructions on the treatment regimen they were recommended to follow. Clinic staff reviewed the records of potential participants to determine their eligibility for the study.

Data were collected from 64 parent-child dyads with a child (ages 7 to 18) diagnosed with IDDM and 27 parent-child dyads (ages 7 to 18) with children diagnosed with CF. Participant demographics and characteristics are included in Tables 1 and 2 (IDDM) and Tables 3 and 4 (CF).

The mean Glycohemoglobin levels for IDDM group were 8.88 which is similar to the average for the clinic in which these data were collected. Children in the IDDM group primarily came from homes where parents were continuously

married ($n = 49$, 76.6%) and most lived with their biological mother and father ($n = 47$, 73.4%). Almost half of the children surveyed reported that it had been seven years, or more, since they were diagnosed with IDDM ($n = 29$, 45.3%). The average age of children in the IDDM group was 13.89 years (*range*, 8 – 18).

Table 1
Characteristics of IDDM Child Participants

Characteristic	Value
Gender	
Male	32
Female	32
Age	
<i>M</i>	13.89
<i>SD</i>	2.77
Range	8 – 18
Glycohemoglobin (HbA1)	
<i>M</i>	8.87
<i>SD</i>	1.93
Range	5.20 – 14.50

Table 2***Demographics of IDDM Child Participants***

Demographic	Frequency (Percent)
Duration Since Diagnosis	
1 year	4 (6.3 %)
2 years	11 (17.2 %)
3 years	2 (3.1 %)
4 years	9 (14.1 %)
5 years	3 (4.7 %)
6 years	6 (9.4 %)
7 years or more	29 (45.3 %)
Living Status of Child	
Lives with Mother and Father	47 (73.4 %)
Live with Mother	6 (9.4 %)
Lives with Father	1 (1.6 %)
Lives with Mother and Stepfather	5 (7.8 %)
Lives with Father and Stepmother	2 (3.1 %)
Other	3 (4.7 %)
Marital Status of Biological Parents	
Continuously Married	49 (76.6 %)
History of Separation or Divorce	13 (20.3 %)
One Parent Deceased	2 (3.2 %)

Table 3***Characteristics of CF Child Participants***

Characteristic	Value
Gender	
Male	15
Female	12
Age	
<i>M</i>	13.70
<i>SD</i>	2.52
Range	8 – 18

In the CF group, almost all children had been diagnosed with the disease for seven years or more ($n = 22$, 81.5%, range, 1 – 7 or more). Parents were continuously married for the majority of children who participated ($n = 20$, 74.1%) and all of the children who reported that their parents were continuously married, reported that they lived with their biological parents ($n = 20$, 74.1%). Children in the CF group were an average of 13.7 years of age (*range*, 9 – 18).

Table 4***Demographics of CF Child Participants***

Demographic	Frequency (Percent)
Duration Since Diagnosis	
1 year	1 (3.7 %)
2 years	0 (0 %)
3 years	0 (0 %)
4 years	1 (3.7 %)
5 years	1 (3.7 %)
6 years	2 (7.4 %)
7 years or more	22 (81.5 %)
Living Status of Child	
Lives with Mother and Father	20 (74.1 %)
Live with Mother	2 (7.4 %)
Lives with Father	1 (3.7 %)
Lives with Mother and Stepfather	2 (7.4 %)
Lives with Father and Stepmother	0 (0 %)
Other	2 (7.4 %)
Marital Status of Biological Parents	
Continuously Married	20 (74.1 %)
History of Separation or Divorce	6 (22.2 %)
One Parent Deceased	1 (3.7 %)

Procedures

Administration of Measures

During their appointment, a medical staff member not involved in the research project, asked potential participants if they were interested in hearing about the study. A researcher personally offered to talk with the family about the study and invited them to participate in the study if they expressed interest. While the family waited for their appointment, they were approached by a medical professional or researcher with the informed consent document and letter of invitation to participate in the study. The presenter then briefly reviewed the letter of invitation for the patient and their family. At this time, potential participants were also told that they would receive a \$10.00 gift card to Target after they completed all of the surveys.

Patients who signed the informed consent and assent forms were issued several measures to be completed onsite while waiting for the physician (see descriptions of measures below): the demographic questionnaire, the DFRQ or the CFFRQ (depending upon diagnosis), the Conflict Subscale - DRCS, modified Conflict Subscale – CFRCS, and the SCI or the modified SCI - CF. Parents and children completed the questionnaires in separate rooms to minimize demand effects from parental instruction or reactivity due to the presence of the parent or child. If younger children (i.e., 7-10-year-olds) were unable to read the items contained in the questionnaires, a researcher read the questions to them. Participants were offered the opportunity to retake the questionnaire packet for an additional gift card at a later appointment in order to obtain test-retest reliability on all of the measures in the questionnaire packets. In the IDDM group, eight participants were willing to return

to the clinic setting and retake all questionnaires, and in the CF group six participants were willing to retake the questionnaires.

Measures of Treatment Adherence

Self-Care Inventory (SCI). The Self-Care Inventory (SCI) measures treatment adherence in individuals with IDDM over the previous two-week period (See Appendix A). This measure was selected because it is well established for assessing reported treatment adherence in children with IDDM (Harris, Greco, Wysocki, Elder-Danda & White, 1999; Miller & Drotar, 2003). The coefficient alpha was .51 for parent report and .78 for child report in the current sample. This level of internal consistency for parental report is significantly lower than previous estimates (.83 for parent report) but similar to previous estimates for child report (.86) (Greco, La Greca, Ireland, Wick, Freeman, & Agramonte, 1990).

Modified Self-Care Inventory - CF (SCI - CF). The standard version of the SCI was modified to assess adherence to the treatment components for CF (See Appendix B). This modified version was developed with the help of two Pediatric Pulmonologists who reviewed the original SCI for children with diabetes, and developed items that asked about adherence to specific components of the CF treatment regimen. As on the original SCI, 14 items were developed for this modified version and the items were designed to parallel items from the original SCI in regards to content and similarity of treatment components. This measure was developed specifically for this investigation; therefore there was no psychometric data available prior to this investigation. In this sample the coefficient alpha was .32 for child report and .95 for parent report. Based on the low internal consistency of the child report on

the modified SCI - CF, only the parent report served as a measure of treatment adherence for CF participants.

Glycohemoglobin (HbA1). A measure of Glycohemoglobin was obtained by drawing blood samples at the time of the visit to determine the patient's glycemic control, or levels of treatment adherence. Lower levels of Glycohemoglobin indicate better glycemic control and suggest higher levels of adherence to the diabetes treatment regimen. Total glycolated hemoglobin (HbA1) was measured using electrophoresis. This measure was compared to parent and child reported adherence on the SCI to determine the accuracy of parent and child report of adherence on the SCI.

No comparable physiological measure was available for individuals who suffer from CF because of the variability of the disease and the progressive degenerative nature of the disease. These factors made it difficult to estimate adherence levels based on physiological measures for individuals with CF. The SCI-CF (parent report) was therefore used to measure the levels of adherence in participants with CF.

Measures of Perception of Responsibility

Diabetes Family Responsibility Questionnaire (DFRQ). Individuals who suffer from IDDM were administered this measure, developed by Drotar and Ivers (1994), to assess the level of parental involvement in treatment responsibilities (See Appendix C). The internal consistency of this measure was previously reported at .92 based on Cronbach's alpha (Drotar & Ivers, 1994). The coefficient alpha in this sample was .83 for parents and .79 for children. This measure was issued to the child

and the primary caregiver to determine the level of consistency between the two reports. Levels of exact agreement were calculated to determine the extent to which parents and children agreed on who was responsible for completing treatment tasks on a daily basis. Discrepancies between parents and their children regarding treatment responsibilities were assessed using exact agreement between responses on this measure. For the DFRQ, exact agreement was defined as both the parent and the child providing the same response as to who they perceive as primarily responsible for treatment adherence on a given item. Exact agreement between parent and child report on the DFRQ was calculated by dividing the number of agreements by the number of agreements plus disagreements and multiplying by 100%. The mean percentage agreement between parents and children on this measure for the IDDM group was 56.69% (*range*, 32.00% – 88.00%).

In addition to measuring the level of agreement between parents and children regarding treatment responsibilities, this measure was also used to assess the level of perceived parental involvement in completing the diabetes treatment regimen. The questionnaire asks parents and children who they perceive as responsible for treatment adherence. A lower score indicates that the responder perceived a higher level of parental involvement in completing the various treatment tasks queried within the DFRQ.

Cystic Fibrosis Family Responsibility Questionnaire (CFFRQ). The level of reported parental involvement in treatment implementation was assessed using this measure developed by Drotar and Ivers (1994) for children with CF (See Appendix D). The internal consistency of this measure was previously reported at .75 based on

Cronbach's alpha (Drotar & Ivers, 1994). An evaluation of the internal consistency in this analysis revealed an alpha of .80 for parents and .85 for children. This measure was issued to both the child and the primary caregiver in order to determine if discrepancies existed between the two reports in regards to perceived responsibilities for completing various aspects of the treatment regimen for diabetes. Discrepancies between parents and their children regarding treatment responsibilities were assessed using exact agreement between responses on this measure. For the CFFRQ, exact agreement was defined as both the parent and the child providing the same response as to who they perceive as primarily responsible for treatment adherence on a given item. Exact agreement between parent and child report on the CFFRQ was calculated by dividing the number of agreements by the number of agreements plus disagreements and multiplying by 100%. For the CF group, the mean exact agreement between parents and children regarding treatment responsibilities on this 18 item instrument was 59.87% (*range*, 33.33% – 88.89%).

Similarly to the DFRQ, the CFFRQ was also used to assess the level of perceived parental involvement in completing the CF treatment regimen. The questionnaire asks parents and children who they perceive as responsible for treatment adherence. As with the DFRQ, a lower score indicates that the responder perceived a higher level of parental involvement in completing the various treatment tasks queried on CFFRQ.

Measures of Level of Family Conflict

Conflict Subscale of the Diabetes Responsibility and Conflict Scale (Conflict Subscale – DRCS). The levels of family conflict were assessed using the Conflict

Subscale of the Diabetes Responsibility and Conflict Scale, which has been used by both Miller & Drotar (2003) and Rubin et al. (1989) and found to significantly correlate to the Conflict subscale of the Family Environment Scale (Rubin et al., 1989). This measure assesses levels of conflict associated with each typically recommended treatment component for IDDM and was issued to both the child and the parent (See Appendices E & F). Miller and Drotar (2003) calculated the coefficient alpha of this measure at .85 for parental report and .94 for adolescent report within their study. This investigation revealed a significantly lower coefficient alpha of .59 for parent report and .65 for child report.

Conflict Subscale of the Cystic Fibrosis Responsibility and Conflict Scale (Conflict Subscale – CFFCS). For this investigation, items on the standard version of the Conflict Subscale of the Cystic Fibrosis Responsibility and Conflict Scale were modified to assess treatment related conflict for individuals and families with CF (See Appendices G & H). The CF conflict scale was developed with the help of two Pediatric Pulmonologists who had reviewed the original IDDM conflict measure. The Pulmonologists and primary investigator collaboratively developed items that paralleled items from the IDDM conflict measure, and that reflected all aspect of the CF treatment regimen. This instrument measured levels of conflict associated with each typically recommended treatment component for CF. Assessment of the internal consistency for this new measure revealed a coefficient alpha of .71 for parents and .52 for children.

Conflict Behavior Questionnaire (CBQ). This instrument measures the overall level of conflict and the negative communication in parent-child relations

outside the realm of diabetes and diabetes treatment (See Appendix I). The 73 item version has been shown to have good internal consistency ($\alpha = .90$; Prinz et al., 1979) and reasonable test-retest reliability (correlations range from .37 to .85), as well as construct validity (Robin & Foster, 1984). The shortened 20-item version used in this study has been shown to correlate highly ($r = .96$) with scores from the longer version (Robin & Foster, 1989). Assessment of the internal consistency for this new measure revealed a coefficient alpha of .85 for parents and .88 for children.

Demographic Information

A demographic survey was given to participating parents to gain information regarding number of parents involved in treatment or living in the home, patient's age, marital history of the parents, gender of the child, and duration of diagnosis (See Appendix J).

CHAPTER 4

RESULTS

Test-Retest Reliability

Test-Retest Reliability for Previously Established Measures

Test - retest reliability for the DFRQ, CFFRQ, SCI, Conflict Subscale – DRCS, CBQ - parent, and the CBQ - child are presented in Table 5. Test reliability was assessed by administering all measures a second time approximately two months following the first administration. Tests were administered to patients who returned to the clinic for follow-up appointments and were willing to complete the measure a second time. The average amount of time between test administrations was 87 days for the IDDM group (range = 29 days - 94 days) and 65 days for the CF group (range = 17 days - 77 days). Cicchetti's interpretive guidelines were used to rate the test-retest reliability of the instruments on a scale from *poor* to *excellent* (*poor* = < .40, *fair* = .40-.59, *good* = .60-.74, and *excellent* = .75 – 1.00). For the DFRQ, Pearson *r* test-retest reliability was .83 for parents and .81 for children ($N = 8$), placing the reliability of the DFRQ in the *excellent* category for both parents and children. CFFRQ Pearson's *r* test-retest reliability was .80 for parents and .85 for children ($N = 6$), again placing both parent and child reliability in the *excellent* range for the CFFRQ. For the SCI, Pearson *r* test-retest reliability was .51 for parents and .81 for children ($N = 8$), suggesting that the parents reliability was *fair* and child reliability was *excellent*. The Conflict Subscale – DRCS revealed *fair* reliability for parents and

good reliability for children with a Pearson r test-retest reliability of .59 for parents and .65 for children ($N = 8$).

Table 5

Test-Retest Reliability Coefficients of the Previously Established Measures

Measure	N	Test-Retest		Internal Consistency	
		Parent	Child	Parent	Child
DFFRQ	8	.83	.81	.87	.83
CFRCS	6	.80	.85	.80	.74
SCI	8	.51	.81	.80	.48
Conflict Subscale – DRCS	8	.59	.65	.89	.95
CBQ	14	.39	.80	.85	.88

DFRQ = Diabetes Family Responsibility Questionnaire
 CFRQ = Cystic Fibrosis Family Responsibility Questionnaire
 SCI = Self-Care Inventory
 DRCS = Diabetes Responsibility and Conflict Scale
 CBQ = Conflict Behavior Questionnaire

Pearson r test-retest reliability for the CBQ was .39 for parents and .80 for children ($N = 14$), placing the reliability in the *poor* range for parents and the *excellent* range for children. The discrepancy between parent and child test retest reliability is not entirely unexpected and might be explained by the nature of conflict and the measuring device itself (CBQ). This instrument is designed to detect the

levels of conflict over a two week period, and the possibility of levels of conflict being variable during the extended time between test-retest periods leaves open the possibility that various conflict events might have occurred that changed reports on this measure. Results suggest that parents might be more sensitive to the conflict events that possibly occur during any given two week period and may be more likely to report these events, thus reducing the reliability of a test-retest instrument such as the CBQ when test-retest is conducted over an extended period of time like the 2-3 month period that elapsed between test-retest administrations in this investigation.

Test-Retest Reliability for Newly Developed Measures

Retest reliability for the newly developed SCI - CF and the Conflict Subscale - CFRCS are presented in Table 6. For the SCI - CF, Pearson's *r* test-retest reliability was .95 for parents and .32 for children (*N* = 6), suggesting that the parents

Table 6

Test-Retest Reliability Coefficients of the Newly Developed Measures

Measure	<i>N</i>	Test-Retest		Internal Consistency	
		Parent	Child	Parent	Child
SCI – CF	6	.95	.32	.91	.84
Conflict Subscale - CFRCS	6	.71	.52	.82	.79

SCI – CF = Self-Care Inventory

CFRCS = Cystic Fibrosis Responsibility and Conflict Scale

reliability was *excellent* and child reliability was *poor*. The Conflict Subscale – CFRCS revealed Pearson’s r test-retest reliability was .71 for parents and .52 for children ($N = 6$), placing the reliability of the Conflict Subscale – CFRCS in the *good* category for parents and the *fair* category for children.

Convergent Validity Analysis

In IDDM research and clinical practice, Glycohemoglobin levels are often used to measure the patient’s levels of adherence to the treatment regimen (Drotar & Ivers, 1994; Miller & Drotar, 2003; Wiebe et al., 2005). In order to assess the appropriateness of the SCI – CF as a measure of adherence in the CF group, levels of Glycohemoglobin were correlated with the parent and child report of adherence (SCI) using Pearson’s r to determine the association between Glycohemoglobin and SCI scores for children with IDDM. In the 64 participants with IDDM, parent report of adherence on the SCI correlated significantly negatively with treatment adherence measured through Glycohemoglobin levels, $r = -.56$, $p = < .01$. In addition, child report of adherence on the SCI correlated significantly negatively with levels of Glycohemoglobin, $r = -.39$, $p = < .01$. This pattern of results suggested that parent report on the SCI correlated adequately with physiological measure of adherence (Glycohemoglobin levels) in the IDDM group.

No similar physiological measure of adherence was available for the SCI-CF measure. The SCI - CF, therefore, was used as the measure of adherence for participants in the CF group while Glycohemoglobin levels were used to assess adherence in the IDDM group (see Table 7).

Correlation Analyses

Glycohemoglobin and Reported Adherence

To demonstrate that the SCI was an adequate measure of adherence, SCI scores were correlated with Glycohemoglobin levels for participants in the IDDM group. In the 52 participants with IDDM, parent report of adherence on the SCI correlated significantly negatively with treatment adherence measured through Glycohemoglobin levels, $r = -.56$, $p = < .01$ (see Table 7). These results suggest that higher levels of adherence reported by parents on the SCI are significantly associated with higher levels of adherence measured using Glycohemoglobin levels. As noted earlier, lower levels of Glycohemoglobin indicate higher levels of treatment adherence, therefore this negative correlation indicates parents are correlated with accurate reporting regarding treatment adherence. Child report of adherence on the SCI also correlated significantly negatively with levels of Glycohemoglobin, $r = -.39$, $p = < .01$.

Adherence and Parent-Child Agreement Regarding Treatment Responsibility

For the 64 IDDM participant dyads, the exact agreement (calculated using the number of agreements divided by the number of agreements plus disagreements and multiplying by 100%) between parent and child perception regarding treatment responsibilities correlated significantly in a negative direction with adherence (Glycohemoglobin levels) in the IDDM group ($r = -.30$, $p < .05$). That is, higher levels of exact agreement between parents and their child on task responsibility were associated with lower levels of Glycohemoglobin; indicating higher levels of adherence (see Table 7).

Table 7***IDDM Correlations***

Variable	1	2	3	4	5	6	7	8	9	10	11
1. Age	-										
2. Duration of illness	.30**	-									
3. Diabetes related conflict, parent report	.17	.15	-								
4. Diabetes related conflict, child report	-.18	-.10	.35**	-							
5. Overall family conflict, parent report (CBQ)	.06	-.05	.33**	.16	-						
6. Overall family conflict, child report (CBQ)	.31*	-.03	.25*	.21	.39**	-					
7. Parent Involvement, parent report (DFRQ)	.69**	.20	-.10	-.16	-.13	.10	-				
8. Parent Involvement, child report (DFRQ)	.63**	.25*	-.04	-.21	-.06	-.05	.68**	-			

Table 7 – Continued

Variable	1	2	3	4	5	6	7	8	9	10	11
9. Parent and child agreement of perceived responsibility	.00	.06	-.18	-.26*	-.01	.04	.08	.16	-		
10. Adherence, parent report (SCI)	-.35**	-.21	-.55**	-.27*	-.30*	-.24	-.14	-.24	.13	-	
11. Adherence, child report (SCI)	-.20	-.15	-.41**	-.25*	-.33**	-.21	-.12	.09	.23	.51**	-
12. Glycohemoglobin	.23	.31*	.43**	.27*	.12	.23	.00	-.01	-.30*	-.56**	-.39**

CBQ = Conflict Behavior Questionnaire

DRCS = Diabetes Responsibility and Conflict Scale

SCI = Self-Care Inventory

** $p < .01$

* $p < .05$

For the 27 CF participant dyads, the exact agreement between parent and child perception of treatment responsibilities correlated significantly with adherence measured through parent report on the SCI, $r = .47, p < .05$. Child report of adherence on the SCI also correlated significantly with exact agreement between parents and their children's perceptions of who is responsible for treatment adherence $r = .42, p < .05$. That is, parent and child report of higher levels of adherence for the CF group was associated with greater levels of agreement between parent and child regarding treatment responsibilities (see Table 8).

Adherence and Perceived Parental Involvement

The level of perceived parental involvement was assessed using the DFRQ and the CFFRQ. On both of these measures parents and children were asked about their perceptions about the person primarily responsible for treatment adherence. Lower scores indicate perceptions associated with higher levels of parental involvement in the treatment regimen. According to this measure, parent and child report of level of parental involvement was not significantly correlated with adherence (Glycohemoglobin levels) in the IDDM group (*parents* $r = .00, p = .99$; *children* $r = -.01, p = .96$) (see Table 7). These results suggested that parent and child report of perceived parental involvement in treatment were not associated with levels of treatment adherence.

For the 27 CF participant dyads, parent and child report of level of parent involvement were also not associated with levels of treatment adherence (SCI – CF parent) (*parents* $r = .23, p = .26$; *children* $r = .20, p = .31$). Results of this analysis suggest that parent and child report of parental involvement in completing treatment

Table 8***CF Correlations***

Variable	1	2	3	4	5	6	7	8	9	10
1. Age	-									
2. Duration of illness	.05	-								
3. CF related conflict, parent report	.25	.00	-							
4. CF related conflict, child report	.00	.15	.60**	-						
5. Overall family conflict, parent report (CBQ)	.36	-.32	.37	.35	-					
6. Overall family conflict, child report (CBQ)	.32	.00	.10	.25	.49*	-				
7. Parental involvement, parent report (CFRCS)	.28	-.9	-.16	-.36	-.15	-.12	-			
8. Parental involvement, child report (CFRCS)	.09	.37	.28	-.11	-.37	-.34	.56*	-		
9. Parent and child agreement of perceived responsibility	-.16	.34	-.44*	-.28	-.41*	-.05	.35	.05	-	
10. Adherence parent report (SCI - CF)	-.24	.13	-.32	-.08	-.37	-.14	.23	.06	.47*	-
11. Adherence, child report (SCI - CF)	-.48*	-.06	-.09	-.03	-.25	-.32	.21	.09	.42*	.57**

CBQ = Conflict Behavior Questionnaire

CFRCS = Diabetes Family Responsibility Questionnaire

SCI - CF = Self-Care Inventory – Cystic Fibrosis

** $p < .01$

* $p < .05$

components was not associated with levels of treatment adherence in either the IDDM or CF groups (see Tables 7 and 8).

Adherence and Disease Related Conflict

Levels of conflict related to the IDDM treatment reported by parents on the Conflict Subscale – DRCS correlated significantly in a positive direction with adherence (levels of Glycohemoglobin), $r = .43, p < .01$. These results suggest that parent report of higher levels of conflict surrounding the IDDM treatment components are associated with lower levels of IDDM treatment adherence (see Table 7). Conflict regarding IDDM treatment according to child report was also significantly correlated with levels of adherence ($r = .27, p < .05$).

For the 27 CF participant dyads, neither parent nor child report of CF related conflict correlated with levels of treatment adherence (SCI – CF parent) (*parents* $r = -.32, p = .12$; *children* $r = .08, p = .69$). That is, parent and child report of CF related conflict were not associated with levels of treatment adherence according to data collected in this investigation (see Table 8).

Overall, levels of disease related conflict were not related to levels of adherence in the CF and IDDM groups. The exception was in the IDDM group, where parent report of diabetes related conflict was associated with lower levels of treatment adherence, but child report was not. In the CF group, neither parent nor child report of CF related conflict was associated with treatment adherence levels.

Adherence and Age

Age was not correlated with adherence as measured by levels of Glycohemoglobin in the IDDM group ($r = .23, p = .07$). Based on the fact that lower

levels of Glycohemoglobin indicate higher levels of treatment, these results suggest that within the ages of 7-18, increased age is associated with lower levels of adherence in the IDDM group (see Table 7).

For the 27 CF participant dyads, age was not significantly correlated with levels of treatment adherence (SCI – CF parent), $r = -.24, p = .24$. It should be noted, however, that child report of treatment adherence (SCI – CF child) correlated significantly negatively with age, $r = -.48, p < .01$. These results suggest increased child age is associated with significantly lower levels of treatment adherence in the CF group (see Table 8). These results, however, should be interpreted with caution as child report of adherence was not demonstrated to be a valid measure of adherence within this investigation.

The analyses investigating the relationship between adherence and age suggest that age was not significantly correlated with levels of treatment adherence (Glycohemoglobin levels) in the IDDM group. In the CF group, however, older children were also associated with lower levels of treatment adherence according to child report (SCI – CF child). These results should be interpreted with some level of caution because child report has demonstrated to be less accurate than parent report throughout this investigation.

Between and Within IDDM and CF Group Differences

IDDM Within Group Differences

Paired-sample *t*-tests were conducted to assess potential differences between parent and child report on the SCI, the DRCS, the Conflict Subscale – DRCS, and the

CBQ within the IDDM group. This analysis revealed a statistically significant difference between the mean parent and child report of parental involvement in the IDDM group measured on the DFRQ, $t(64) = 6.00, p < .01$ (see Table 9). These results suggest that parents report a significantly greater level of parent involvement in treating their child's diabetes than do their children. Difference were not significant on the SCI, the Conflict Subscale – DRCS, and the CBQ in the IDDM group, suggesting that any difference between parent and child report on these measures were likely due to measurement error. Data collected in this study suggest

Table 9

Within Group Comparisons for IDDM Group

Measure	Mean		SD		<i>t</i> -test	<i>p</i> value
	Parent	Child	Parent	Child		
SCI	3.59	3.60	.63	.73	.14	$p = .89$
DFRQ	1.94	2.12	.29	.34	6.00	$p < .01^{**}$
Conflict Subscale – DRCS	11.27	13.56	8.70	13.23	1.41	$p = .16$
CBQ	7.25	6.96	3.89	4.00	.51	$p = .61$

SCI = Self-Care Inventory

DFRQ = Diabetes Family Responsibility Questionnaire

DRCS = Diabetes Responsibility and Conflict Scale

CBQ = Conflict Behavior Questionnaire

** $p < .01$

* $p < .05$

that there are few significant differences between parent and child report within the there IDDM group, other than parents reporting they are more involved in treatment than their children.

CF Within Group Differences

To assess the differences between parent and child report in the CF group on the modified SCI – CF, the CFRCS, the Conflict Subscale – CFFCS, and the CBQ, paired-sample *t*-tests were also conducted (see Table 10). In the CF group, parents

Table 10

Within Group Comparisons for CF Group

Measure	Mean		SD		<i>t</i> -test	<i>p</i> value
	Parent	Child	Parent	Child		
SCI - CF	3.81	3.89	.59	.61	1.61	<i>p</i> = .12
CFFRQ	29.37	33.00	5.23	5.27	4.47	<i>p</i> < .01**
Conflict Subscale – CFRCS	9.22	19.26	7.43	19.09	3.30	<i>p</i> < .01**
CBQ	7.14	8.00	3.11	2.48	1.65	<i>p</i> = .11

SCI - CF = Self-Care Inventory - Cystic Fibrosis
 CFFRQ = Cystic Fibrosis Family Responsibility Questionnaire
 CFRCS = Cystic Fibrosis Responsibility and Conflict Scale
 CBQ = Conflict Behavior Questionnaire
 ***p* < .01
 **p* < .05

reported a significantly lower level of treatment adherence than did their children according to responses on the SCI – CF, $t(27) = 3.36, p < .01$. Results of these analyses also suggested that parents reported that they were significantly more involved in completing treatment components than their children reported on the CFFRQ, $t(27) = 3.36, p < .01$. Children in the CF group reported a significantly higher level of disease related conflict than did parents according to responses on the Conflict Subscale – CFRCS, $t(27) = 3.30, p < .01$. Within the CF group, there were no significant differences between parent and child report of overall level of conflict as measured by the CBQ. On average, these results suggest that there were several significant differences between parent and child report within the CF group. Parents reported higher levels of involvement in treatment, lower levels of adherence, and disease related conflict than their children.

Between IDDM and CF Group Differences

Independent-sample *t*-tests were conducted to determine differences between the IDDM and CF groups (see Table 11). For these analyses parent and child mean responses from the IDDM and CF participants were compared on the SCI & the modified SCI – CF, the DFRQ & the CFFRQ, the Conflict Subscale – DRCS & CFRCS, and the CBQ. In addition an independent-sample *t*-test was conducted to determine if there was a significant difference between the level of agreement between parent and children in the IDDM group versus the CF group regarding treatment adherence responsibilities. This analysis was conducted by comparing the mean level of agreement between parents and children in the IDDM group and the CF group. *T*-test results suggested that children in the CF group reported higher levels

Table 11***Between IDDM and CF Group Comparisons***

Measure	Mean		SD		<i>t</i> -test	<i>p</i> value
	IDDM	CF	IDDM	CF		
SCI - Parent	3.60	3.81	.63	.59	1.51	<i>p</i> = .14
SCI - Child	3.60	4.02	.73	.55	2.93	<i>p</i> < .05*
FRQ - Parent	1.94	1.70	.29	.30	3.61	<i>p</i> < .01**
FRQ - Child	2.12	1.87	.34	.26	3.77	<i>p</i> < .01**
Conflict Subscale RCS - Parent	11.27	9.22	8.70	7.43	1.13	<i>p</i> = .26
Conflict Subscale RCS - Child	13.56	19.26	13.23	19.08	1.41	<i>p</i> = .16
CBQ - Parent	7.25	7.15	3.89	3.11	.13	<i>p</i> = .89
CBQ - Child	7.00	8.00	4.03	2.48	1.71	<i>p</i> = .14
Parent - Child Agreement on the FRQ	14.17	10.78	3.08	3.06	4.83	<i>p</i> < .01**

SCI = Self-Care Inventory

FRQ = Family Responsibility Questionnaire

RCS = Responsibility and Conflict Scale

CBQ = Conflict Behavior Questionnaire

***p* < .01

**p* < .05

of treatment adherence than did children in the IDDM group, $t(91) = 2.93, p < .05$. Furthermore, these analyses suggested that both parent and children reported a higher level of parental involvement in treatment within the CF group compared to the IDDM group, *parents* $t(91) = 3.61, p < .01$; *children* $t(91) = 3.77, p < .01$. Lastly, IDDM parent and child dyads had a significantly higher level of agreement regarding treatment responsibilities than did parents and children in the CF group, $t(91) = 4.83, p < .01$.

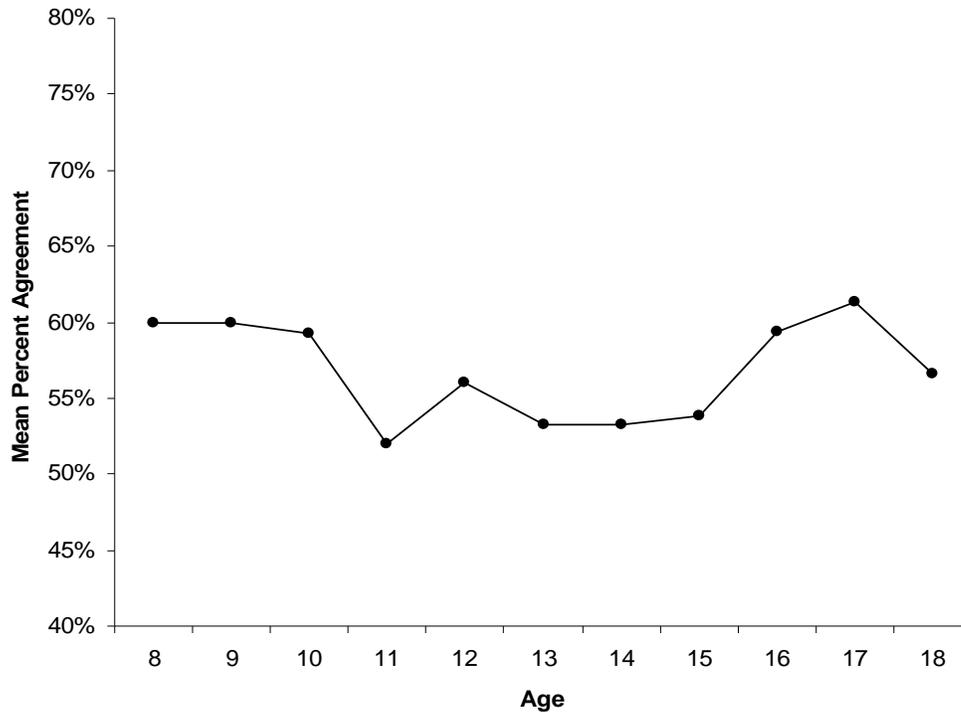
ANOVA Analysis

Relationship between Parent and Child Agreement Regarding Treatment and Age

One-way ANOVAs were conducted to determine if there was a significant difference in the levels of agreement between parents and their children regarding treatment adherence responsibilities at different ages in both the IDDM and CF groups. Visual inspection of the mean level of agreement for each age in the IDDM group suggested that there was a drop between parent and child levels of agreement from the ages eleven to fifteen (see Figure 1). An ANOVA with a Fisher's Least Significant Difference test (LSD) correction for multiple comparisons was conducted to determine if there were significant differences between the mean parent and child treatment agreement at different ages in the IDDM group. Based on visual inspection, three IDDM groups were developed for comparison; consisting of ages: (a) eight through ten ($N = 6$) (young), (b) 11 through 15 ($N = 30$) (adolescent), and (c) 16 through 18 ($N = 16$) (older adolescent). The one-way ANOVA revealed no main effects between these age groups regarding treatment adherence agreement in the

Figure 1

Average Percent Agreement between Parents and their Children Regarding Treatment Responsibilities by Age of Child (IDDM Group)



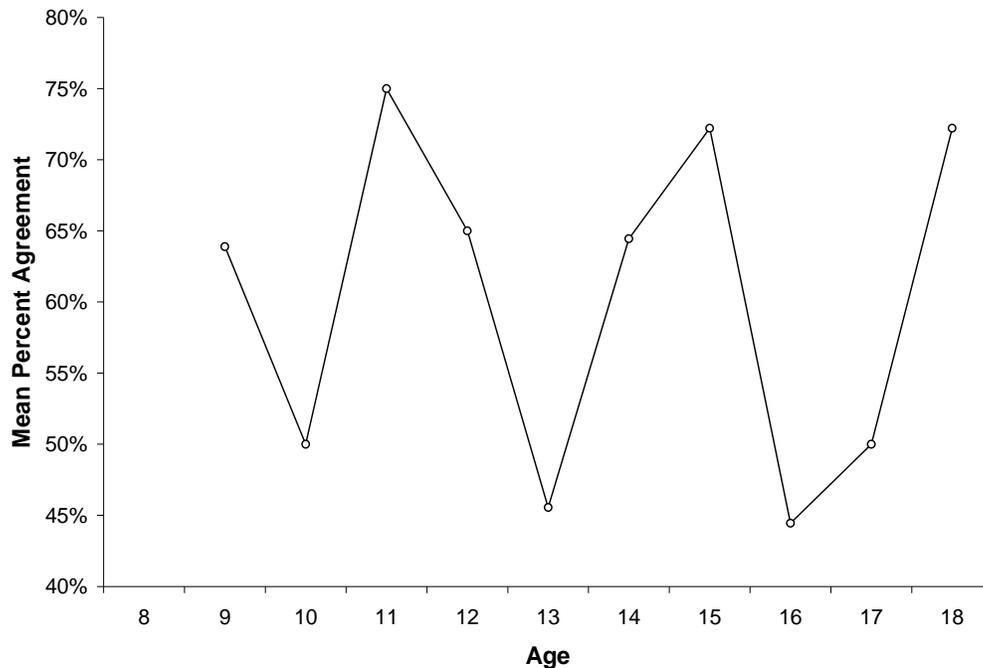
IDDM group. A curvilinear correction was also conducted for this analysis, and again no main effects were found between age groups and level of parent and child agreement regarding treatment adherence in the IDDM group.

For the CF group, visual inspection suggested variable patterns of agreement between parent and child across ages, therefore an ANOVA was not conducted on this group due to lack of justification for developing age groups due to variable levels of agreement across ages (see Figure 2).

These results suggest the visually apparent curvilinear relationship between children and parents agreement regarding diabetes treatment responsibilities and age was not statistically significant. Furthermore, visual inspection revealed no patterns

Figure 2

Average Percent Agreement between Parents and their Children Regarding Treatment Responsibilities by Age of Child (CF Group)



worthy of statistical analysis when agreement and age were evaluated for the CF group. Parent and child responses in this data set, therefore, do not suggest that discrepancies between parent and children regarding treatment responsibilities begin at any particular age.

Relationship between Level of Parental Involvement and Age

A one-way ANOVA with an LSD correction for multiple comparisons was conducted for both parent and child report of parental involvement in the CF and IDDM groups. Results of the four one-way ANOVAs conducted between age and level of parent involvement can be observed in Table 12. According to the report of children within the IDDM group there was a significantly lower level of parent involvement as they get older $F(2, 62) = 23.00, p < .01$. Parents in the IDDM group,

Table 12***Parent and Child Reported Mean Scores of Parental Involvement in Treatment by Age Group and Disease***

Responder	Mean			<i>F</i>	<i>p</i> value
	Younger (ages 8-10)	Adolescent (ages 11-15)	Older Adolescent (ages 16-18)		
Parent Report					
IDDM	1.57 _a	1.92 _b	2.16 _c	23.00	<i>p</i> < .01**
CF	1.53 _a	1.63 _a	1.91 _b	3.21	<i>p</i> < .05*
Child Report					
IDDM	1.61 _a	2.16 _b	2.31 _c	23.95	<i>p</i> < .01**
CF	1.80 _a	1.84 _a	1.94 _a	.37	<i>p</i> = .69

Within any row, means with different subscripts differ significantly from each other according to Fisher's Least Significant Differences test.

***p* < .01

**p* < .05

also reported that their level of involvement significantly decreased as their child grew older, $F(2, 62) = 23.95, p < .01$. Children in the CF group reported lower levels of parental involvement only when comparing the younger & adolescent groups to the older adolescent group ($F(2, 62) = 3.21, p < .05$) and parents of children with CF reported no significant difference in their level of involvement as their children aged.

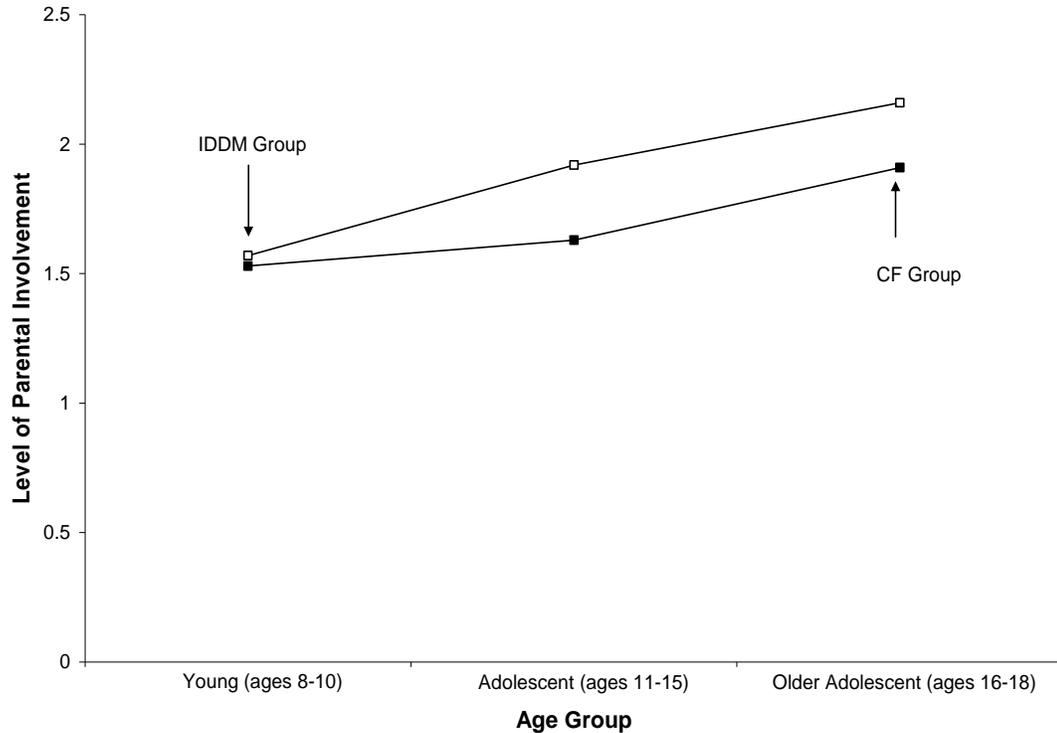
To further assess the potential difference in the IDDM and CF groups regarding the level of parental involvement at different ages a 2 x 3 (disease x age)

factorial analysis of variance was conducted. For this analysis, age groups (young 8-10, adolescent 11-15, and older adolescent 16-18) were identical to those used in the one-way ANOVA investigating the relationship between age and level of parent and child agreement. The purpose of this analysis was to determine if there was a significant difference between the IDDM and CF groups in regard to the level of parental involvement in treatment as children grow older.

According to parent report, there was a significant difference between age groups ($F(2, 89) = 13.79, p < .01$) and between diseases ($F(2, 89) = 8.61, p < .01$), however there was no significant interaction between parental involvement, age group and disease when all were taken into account. These results can be observed in Figure 3 where higher levels of responding indicate lower levels of perceived parental involvement. Child report, however, revealed a interaction effect between age group ($F(2, 89) = 7.19, p < .01$), disease group ($F(1, 90) = 4.01, p < .01$), and the combination of age group and disease group ($F(2, 89) = 4.75, p < .01$). These results suggest that, according to child report, there is a significant interaction effect between the IDDM group and the CF group in regards to the level of parental involvement and how it changes over time. In the CF group parent involvement appears to remain high and stable as age increases, where in the IDDM group, parents appear to gradually remove themselves from treatment responsibilities as their child grows older. These results can be observed in Figure 4, and it should again be noted that higher levels of responding are associated with lower levels of perceived parental involvement.

Figure 3

Level of Parental Involvement According to Parent Report by Age Group and Disease



Note: Scores for parental involvement come from the DFRQ for participants with diabetes and the CFFRQS for participants with CF. Higher scores indicate lower levels of parental involvement.

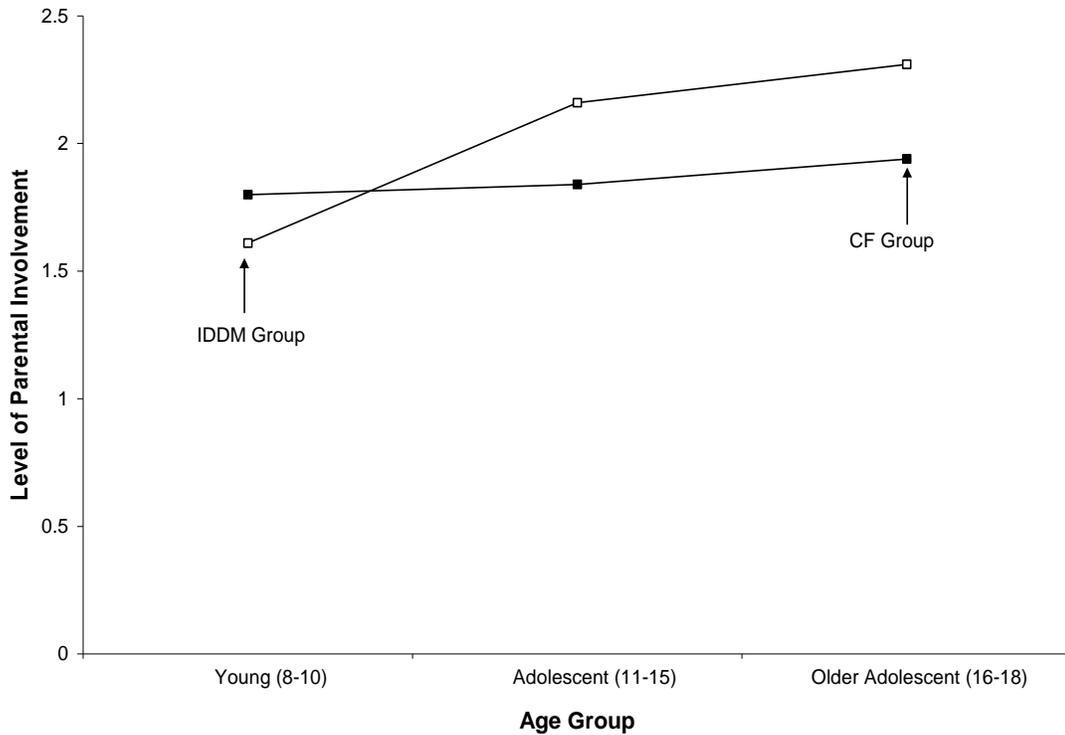
Regression Analysis

Approach to Regression Analysis

Regression analyses were completed to determine those variables that best predicted levels of adherence and the relationship between agreement in parent and child perceptions of responsibility, level of parental involvement, level of conflict and age. All comparisons were plotted for visual inspection to determine if adjustments were needed to accommodate curvilinear relationships between any of the variables. Visual inspection suggested no curvilinear relationship between variables; therefore,

Figure 4

Level of Parental Involvement According to Child Report by Age Group and Disease



Note: Scores for parental involvement come from the DFRQ for participants with diabetes and the CFRQ for participants with CF. Higher scores indicate lower levels of parental involvement.

linear regression analyses were conducted for both the IDDM and CF groups.

Regression Analysis Predicting IDDM Treatment Adherence

As a first step in the regression analysis for the IDDM group, all potential predictor variables were correlated with the child's Glycohemoglobin levels. Those variables that were significantly correlated with Glycohemoglobin levels were retained for a separate multiple regression analyses (enter and remove criteria of $p < .05$). The retained variables and their correlations with Glycohemoglobin levels

were: (a) parent report of diabetes related conflict ($r = .43, p < .01$), and (b) agreement between parent and child report of parental involvement ($r = .30, p < .05$).

The final regression model for levels of adherence to the IDDM treatment regimen as measured by Glycohemoglobin levels included two variables (see Table 13), $F(2, 62) = 9.42, p < .01, R^2 = .24$. This regression analysis implicates parent report of diabetes related conflict and discrepancies between parent and child report of perceived responsibility regarding treatment adherence as significant predictors of treatment adherence (Glycohemoglobin levels) in children with IDDM. It appears that when parents and children agree on who is responsible for completing the various aspects of the treatment regimen that levels of adherence may be higher. Furthermore it appears that lower levels of conflict surrounding the diabetes treatment regimen may predict higher levels of treatment adherence, or better Glycohemoglobin levels.

Regression Analysis Predicting CF Treatment Adherence

As a first step in the regression analysis for the CF group, all potential predictor variables were correlated with the child's adherence measured through parent report. Those variables that were significantly correlated with adherence (measured with the SCI - CF) were retained for a regression analyses (enter and remove criteria of $p < .05$). Only agreement between parent and child report of parental involvement ($r = .47, p < .05$) was significantly correlated with levels of reported adherence by the parent.

The final regression model for levels of adherence to the CF treatment regimen as measured by parent report of adherence on the SCI - CF included one variable (see Table 14), $F(1, 27) = 7.09, p < .01, R^2 = .22$. This regression analysis

Table 13***Predictors for Glycohemoglobin (HbA1)***

Predictors	Standardized coefficients Beta	T	p value
Parent report of diabetes related conflict	.39	3.43	.00**
Exact agreement between parent and child report on Diabetes Family Responsibility Questionnaire	-.23	-1.98	.05*

Note. R^2 values for Glycohemoglobin .24.

** $p < .01$

* $p < .05$

suggests that discrepancies between parent and child report of perceived responsibility regarding treatment adherence are a significant predictor of treatment adherence (measured by parent report on the SCI - CF) in children with CF. In other words, when parents and children agreed on perceived responsibility for aspects of the CF treatment regimen, levels of adherence were higher.

Comparison of Regression Analysis Results in IDDM and CF Group

Within both the IDDM and CF groups it appears that agreement between parents and children on their perceptions of responsibility regarding completion of treatment components was a significant predictor of adherence. It is important to note

Table 14***Predictors for Reported CF Adherence (SCI-CF)***

Predictors	Standardized coefficients Beta	<i>T</i>	<i>p</i> value
Reliability score between parent and child report on Diabetes Family Responsibility Questionnaire - CF	.49	2.66	.01**

Note. R^2 values for higher levels of reported adherence .22.

** $p < .01$

* $p < .05$

that treatment adherence was reported through different measures in the IDDM group and the CF group. As previously mentioned, in the IDDM group, treatment adherence was measured through Glycohemoglobin levels and in the CF group adherence was measured through parent report. In both groups, however, results suggest that agreement on who is responsible for treatment adherence predicts adherence more accurately than other variables evaluated in this study including level of parent involvement in treatment, levels of general family conflict and age of the child.

CHAPTER 5

DISCUSSION

Overview of the Current Investigation

Adherence to medical regimens for children and adolescents with IDDM and CF is an important clinical issue in pediatric primary care. Low levels of adherence impact overall health for the patient and complicate clinical decision-making for the health care provider. Poor adherence, though, is common with levels of non-adherence estimated as high as 80-90% for individuals with chronic illness such as IDDM and CF (Anderson, et al., 1997; Jacobson, et al., 1990; Lask, 1994). Previous research suggests that several psychosocial variables may impact adherence to medical regimens including agreement between parents and children regarding treatment responsibilities, conflict, and level of parental involvement. The current study examined the impact of several of these factors on adherence in children with IDDM and CF to clarify their relationship to adherence and determine if they have similar impact across diseases.

Agreement on Perceived Treatment Responsibility and Conflict

Two previous studies have investigated the relationship between parent - child agreement on perceived level of responsibility and adherence in IDDM with mixed results. Anderson et al. (1990) reported that low levels of treatment adherence for IDDM were predicted when parents and children reported that they both perceived

the other as responsible for treatment tasks. In contrast to these results, Miller and Drotar (2003) did not find a predictive relationship between parent and child agreement regarding perceived treatment responsibilities and IDDM treatment adherence. No prior studies have investigated the relationship between agreement and CF treatment adherence. A central finding of the current investigation is that agreement between parents and children on treatment responsibilities was a significant predictor of treatment adherence for both the IDDM and CF groups. Previous studies assessed agreement by comparing mean scores and total scores from parent and child measures of perceived responsibility. The current investigation, however, compared parent and child responses on each individual item of the instrument with a calculation of exact agreement. Exact agreement is likely a more sensitive measure of agreement than comparing parent and child total scores, which is the method used in several of the previous investigations into agreement. The use of exact agreement eliminates the potential situation where parent and child mean scores might agree, but their item by item scores do not agree.

The results of this investigation suggest that in both the IDDM and CF groups, levels of exact agreement predict levels of treatment adherence over other variables such as overall family conflict, level of parental involvement and the age of the child. These data suggest that if parents and children disagree regarding who is responsible for treatment tasks, steps should be taken to clarify treatment roles as a potential means of increasing levels of agreement and, hopefully, levels of treatment adherence.

The direction and nature of disagreements between parents and children regarding treatment responsibilities was not evaluated in this study. Previous studies have investigated the impact of agreement on treatment adherence by comparing mean levels of Glycohemoglobin for groups of parents and children that agree versus groups that do not agree on treatment responsibilities (Drotar & Ivers, 1994; Miller & Drotar, 2003). Investigations that used group means have been unsuccessful in finding statistically significant relationships between agreement and levels of treatment adherence. The fact that agreement was found to be a significant predictor of adherence in this investigation brings two possible explanations to bear.

First, it is possible that the method of using exact agreement between dyads to measure agreement is a more sensitive method than group mean comparison for measuring levels of agreement between parents and children regarding treatment responsibilities. That is, it is possible that the differences may have existed in the previously mentioned data sets, but that the different method used for data analysis did not allow them to discover this phenomenon. For example, Drotar and Miller (2003) defined agreement as both parent and child providing a child autonomy score that fell on the same side of the median split, a potentially insensitive measure of agreement. The second possible explanation is that the previously mentioned sample and their resulting data sets were in some way palpably different from the current data set in which differences in agreement were found to predict levels of treatment adherence. Future investigations would need to conduct both methods of data analysis to determine which explanation fully accounts for the differences found in

this investigation versus the others that studied the relationships between adherence and levels of agreement.

If future investigations demonstrate that the method of data analysis was responsible for the different results obtained in this investigations versus previously conducted studies in this area; it may suggest that the direction and nature of the disagreements between parents and children may not be as critical as identifying the mere presence of disagreements. This information may have clinical implications as clinicians might simply attempt to identify families where parents and children did not agree on treatment responsibilities, instead of attempting to identify who might be more, or less, responsible for completing treatment procedures. In other words, it may not be important to know in what direction parents and children disagree regarding who might be responsible for the IDDM or CF treatment, the critical variable may be that they disagree on any level.

Previous studies establish a clear relationship between levels of conflict and treatment adherence in the IDDM population (Martin et al., 1998, Miller & Drotar, 2003; Miller-Johnson et al., 1994) but the relationship between conflict and treatment adherence has not been well investigated within the CF literature. This study confirmed the relatively well-established relationship between conflict and treatment adherence within the IDDM population. Interestingly, however, only parent report of diabetes related conflict and overall levels of family conflict were related to reported treatment adherence (both parent and child report) and levels of treatment adherence measured through Glycohemoglobin levels. Child report of conflict, either IDDM-specific or overall family, were not related to levels of treatment adherence. For both

IDDM related conflict and overall family conflict, higher levels of parent reported conflict were associated with lower levels of treatment adherence.

For the CF group there did not appear to be a significant relationship between levels conflict reported by parents or children and reported levels of treatment adherence. It is interesting to note, however, that children in the CF group reported significantly higher levels of disease related conflict than did parents in the CF group. In fact, children in the CF group reported the highest levels of disease related conflict in this investigation. These results are interesting because parents and children in the CF group reported much lower levels of overall family conflict when compared to the IDDM group. Though the overall levels of conflict were not significantly different among parents or children when comparing the IDDM and CF groups, overall family conflict was substantially higher in the IDDM group. In contrast, levels of disease related conflict was similar when comparing parents in the IDDM and CF groups. However, children in the CF group reported particularly high levels of disease related conflict. It is possible that children and adolescents with CF are particularly sensitive or susceptible to disease related conflict, though; the increased report of conflict does not appear to have a direct bearing on adherence. Future investigations should examine the impact of disease-related conflict on overall psychosocial well-being of patients with CF.

In summary, the results of this investigation confirm that there is a predictive relationship between parent - child agreement regarding treatment responsibilities and treatment adherence and that disease-related conflict within the IDDM population is also associated with adherence. However, the relationship between adherence and

conflict in the CF population remains unclear despite the fact that this group experiences particularly high disease-related conflict. One might assume that there is a relationship between agreement regarding treatment responsibilities and conflict (i.e., parents and children who agree about responsibility would have less disease related conflict). Within the CF group, there does appear to be a relationship between parent reported levels of disease related conflict, overall family conflict, and levels of agreement regarding treatment responsibilities with greater levels of parent reported conflict associated with lower levels of agreement regarding perceived treatment responsibilities. However, there does not appear to be any notable relationship between levels of conflict and agreement in the IDDM group. These results suggest that, though agreement and conflict are related to treatment adherence, agreement is not necessarily related to levels of conflict.

Though it is certainly desirable for families to exist and work towards treatment in a harmonious manner, agreement on treatment responsibility may be more important than conflict levels for clinicians who wish to increase levels of treatment adherence. The relationship between conflict and level of treatment adherence is difficult to interpret based on the results of this study, as conflict appears to be related to IDDM treatment adherence and does not appear to relate to CF treatment adherence, but the relationship between agreement and treatment adherence is clear. As stated earlier, agreement predicts treatment adherence over general family conflict and other variables investigated within this study, therefore future investigations in this area may want to focus on agreement alone and assess the impact of agreement on adherence before delving into issues related to conflict.

Mediating Effects of Age

Another variable investigated in this study was the age of the child and the mediating effects of age on other variables in both the IDDM and the CF groups. For the IDDM group, data collected in this investigation support the findings in previous studies that younger children have higher levels of treatment adherence (Davis et al., 2001; Johnson et al., 1992; Ricker et al., 1998; Rubin et al., 1989). In the CF literature, Giess et al. (1992) and Zindani, Streetman, Streetmen, and Nasr (2006) suggest that older children engage in higher levels of treatment adherence while other investigations suggest that older children have lower levels of treatment adherence (Abbott, & Gee, 1998; Drotar & Ivers, 1994; Patterson, 1985). The results of this investigation support the latter studies with older children with CF having lower levels of treatment adherence according to their own report.

In the current investigation, analyses were conducted to determine if there was a relationship between levels of parent and child agreement and age. In other words, attempts were made to identify at what age children and parents begin to disagree regarding treatment responsibilities. The results suggest that there is no statistically significant difference between age and levels of agreement between parents and children regarding treatment responsibilities in either the IDDM or the CF group. Visual inspection, however, suggests that levels of agreement in the IDDM group were lower for the ages of 11 through 15 than they are for ages 8 through 10 and ages 16 through 18. For the CF group, there were no identifiable patterns between agreement and age though the relatively small sample size compared to the IDDM group leads to cautious interpretation of this finding.

Some cautious conclusions might be drawn from visually inspecting both the IDDM group and the CF group. First, the pattern of responding in the IDDM group suggests that more discrepancies between parents and their children occur during the ages that are associated with onset of puberty and the traditional age that disease related treatment responsibilities are passed from the parent to the child. Data in this study support previous research that suggest parents are significantly less involved in IDDM treatment as children grow older (Drotar & Ivers, 1994; Wiebe et al., 2005), and corroborate the limited literature that suggest parental involvement is not necessarily related to levels of treatment adherence in children with IDDM (Dashiff, Bartolucci, Wallander & Abdullatif, 2005). In the IDDM group, parental involvement in treatment tasks decreases significantly as children grow older and treatment adherence deteriorates, however, visual inspection suggests that the level of agreement between parent and children is lowest during the ages of 11-15. It appears, therefore, that as parents withdraw from assisting in the completion of treatment tasks in the IDDM group that there may be confusion between parents and children regarding who is responsible for completing treatment tasks.

The transition of treatment responsibility during the ages of 11-15 appears to be a critical period for the IDDM group, however similar results were not found in the CF group. Within the CF group, there is no discernable pattern between age and parent - child agreement on perceived responsibilities. Furthermore, both parent and children report suggests that there is no significant difference in the level of parent involvement as children age. The current study does not reveal why this difference occurs across diseases but future studies should attempt to determine if these

differences might be due to the specific characteristics of the diseases and treatment regimen. For example, parents of children with CF may stay more involved in treatment due to fear that poor adherence will reduce the length of their child's likely shortened life (Foster, Eiser, Oades, Sheldon, Tripp, Goldman, Rice, & Trott, 2000). Alternatively, aspects of the CF treatment that require assistance from other individuals (e.g., back pounding to break up mucus that gathers in the lungs) may facilitate more consistent parental involvement, where treatment tasks for IDDM can essentially be complete independently (Zindani, Streetman, Streetmen, & Nasr, 2006).

Clinical Implications and Future Research

As stated earlier, a central finding within the current investigation was that agreement between parents and children on who was perceived responsible for completing treatment tasks was the best predictor of treatment adherence. These results suggest that treatment outcome studies, targeting agreement, might be conducted to assess how manipulating levels of agreement might influence levels of treatment adherence. In other words, researchers may want to conduct studies that compare groups where physicians or other medical staff specifically assign treatment responsibilities to parents and children (targeting children ages 11-15) to groups that implement a traditional method of addressing adherence (i.e., control group). Levels of adherence and agreement could be assessed prior to, and following, these clinical instructions. A study of this nature would provide more conclusive data regarding the relationship between levels of agreement and treatment adherence. Furthermore, an

investigation of this nature would provide valuable information regarding treatment recommendations for physicians who treat child with IDDM or CF.

There are several other techniques that might be employed to investigate the relationship between agreement and treatment adherence. One method might be to systematically begin transferring responsibilities from the parent to the child when the child reaches the ages of 10 or 11. The transfer of responsibility might be controlled or recommended by the physician or medical staff personnel who commonly discuss treatment adherence issues with the parents and the child. The medical staff could systematically train the child to complete one treatment component at a time and monitor the child's progress in mastering each specific treatment task. Data might be collected on how often the child is completing their treatment responsibilities, and only when a child demonstrated high levels of competence and consistent adherence for each newly introduced task would they be given responsibility for another treatment component. To conduct this type of research, it would likely be important to train the child on each specific task and monitor their ability to technically complete the task as well as their ability to adhere to the task on a daily basis.

Despite the fact that there are some limitations to what conclusions can be drawn regarding the relationship between age and treatment adherence in both the IDDM groups and the CF groups based on the results of this study, these results do suggest that physicians and clinicians that work with IDDM and CF populations should consider agreement when conducting an assessment and when encountering treatment adherence issues. Recently, Wysocki (2006) published treatment recommendations for clinicians who work with IDDM children. These

recommendations include making proper referrals when treatment adherence problems arise, and conducting behavioral interventions focused on the specific problems that are hypothesized to be preventing higher levels of treatment adherence. The results of the current investigation support this notion, and suggest that future research should investigate behavioral interventions focused on eliminating ambiguity regarding who is responsible for the completion of treatment components by systemically managing the transition of disease related responsibility from the parent to the child.

There are several limitations that may influence the interpretation of the results in this investigation. One limitation within the current investigation revolves around the finding that the CF group reported higher levels of treatment adherence but lower levels of agreement when compared to the IDDM group. This finding is interesting because it appears to undermine the notion that agreement is predictive of treatment adherence, a central finding with this investigation. This seemingly contradictory result may be the result of using parent and child recall to measure treatment adherence in the CF group. Report and recall methods have been established as highly variable in regards to reliability and validity, therefore all of the measures used in this investigation should be interpreted with some level of caution. Future studies in this area may consider exploring alternative methods, other than participant report, to measure factors such as parental involvement in treatment and levels of conflict.

Another potential weakness of the current investigation included the fact that different measures of adherence were used in the IDDM group versus the CF group.

Reports of adherence within the CF group should be interpreted with a greater level of caution than in the IDDM group because adherence was measured through parent and child report for the CF group. In contrast, the levels of adherence in the IDDM group were measured using a physiological measure of adherence (Glycohemoglobin levels) that has been well established in the adherence literature as an acceptable means of assessing adherence within the diabetes population. All of the results in the IDDM group, especially those that relate directly to levels of adherence, can be interpreted with more confidence than the CF group.

Information regarding the proportion of the child's life spent diagnosed with diabetes or CF may also have been useful information in this study. Future studies should attempt gain more information regarding the age and length of time that participants have been diagnosed with chronic disease. This type of information (i.e., age of onset data) might be useful in determining the extent to which familiarity with the regimen might influence levels of adherence. This type of information might be particularly useful when studying the diabetes population as the length of diagnosis and levels of treatment adherence were variable when compared to the more stable CF group.

A final potential limitation to the current investigation lies within the time that elapsed between the first and second administrations of the measures for which test-retest reliability was calculated. There are different lengths of time that can be appropriate for test-retest reliability, and a two-month interval between testing is not unreasonable for the measures used in this study according to literature on test-retest reliability. The test-retest reliability in this investigation was taken as a sample of

convenience because patients were not willing to take time off of work, and remove their children from school, to make a return visit to the clinic in order to take surveys that could take them about 5 – 10 minutes to complete. The test-retest reliability data in the current investigation does, however, appear to still make a substantial contribution to the literature regarding the reliability (and the validity of the SCI) of the measures implemented in this investigation as there was essentially no reliability information regarding most of these measures previous to this investigation.

In all, the current investigation provides several contributions to the current literature on adherence with the IDDM and CF populations. First, this investigation provides data that implicates agreement as the most potent predictor of treatment adherence in both the IDDM and CF groups. Physicians and researchers should consider investigations and protocols that target agreement between parents and children regarding treatment responsibilities for future investigations and clinical practice. A second main finding of this study is that levels of parental involvement in the IDDM group decrease as children get older, and those parents of children with CF appear to remain consistently involved in the daily treatment of their children as they age. Physicians should take these group differences into account when making treatment recommendations to families treating IDDM versus CF, especially when making recommendations regarding who should be responsible for specific aspects of the treatment regimen.

The intricate relationship between the level of parental involvement, age, agreement, and treatment adherence will require extensive investigation to unravel. Information gathered in this investigation appears to enhance the body of adherence

knowledge by providing direction for future research that could influence the development of “best practice” guidelines for clinicians who treat IDDM and CF in their clinical practice. Ultimately, the goal of this line of research is to develop effective strategies that help children with IDDM and CF live healthy and fulfilling lives, especially during the ages of 11-15 where levels of treatment adherence can be lowest. These results suggest that research leading to this end may revolve around levels of agreement between parents and children regarding completion of the daily aspects of their particular disease regimen. Treatment outcome research in this area appears to be the next logical step in unearthing information that may directly impact adherence, and the lives, of individuals with IDDM and CF.

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Appendix A
Self-Care Inventory (SCI-IDDM)

Self-Care Inventory (SCI-IDDM)

Please rate each of the items according to HOW WELL YOU FOLLOWED YOUR PRESCRIBED REGIMINE FOR DIABETES CARE in the past month. Use the following scale:

- 1 = Never do it
- 2 = Sometimes follow recommendations; mostly not
- 3 = Follow recommendations about 50% of the time
- 4 = Usually do this as recommended; occasional lapses
- 5 = Always do this recommendation without fail
- N/A = Cannot rate this item / Not applicable

In the past month, how well have you followed recommendations for:

1. Glucose testing	1	2	3	4	5	N/A
2. Glucose recording	1	2	3	4	5	N/A
3. Ketone testing	1	2	3	4	5	N/A
4. Administering correct insulin Dose	1	2	3	4	5	N/A
5. Administrating insulin at right Time	1	2	3	4	5	N/A
6. Adjusting insulin intake based on blood glucose values	1	2	3	4	5	N/A
7. Eating the proper foods; sticking to meal plan	1	2	3	4	5	N/A
8. Eating meals on time	1	2	3	4	5	N/A
9. Eating regular snacks	1	2	3	4	5	N/A
10. Carrying quick acting sugar to treat reactions	1	2	3	4	5	N/A
11. Coming in for appointments	1	2	3	4	5	N/A
12. Wearing a medical alert ID	1	2	3	4	5	N/A
13. Exercising regularly	1	2	3	4	5	N/A
14. Exercising strenuously	1	2	3	4	5	N/A

Appendix B

Modified Self-Care Inventory – CF (SCI - CF)

Modified Self-Care Inventory – CF (SCI - CF)

Please rate each of the items according to HOW WELL YOU FOLLOWED YOUR PRESCRIBED REGIMINE FOR CYSTIC FIBROSIS CARE in the past month. Use the following scale:

- 1 = Never do it
- 2 = Sometimes follow recommendations; mostly not
- 3 = Follow recommendations about 50% of the time
- 4 = Usually do this as recommended; occasional lapses
- 5 = Always do this recommendation without fail
- N/A = Cannot rate this item / Not applicable

In the past month, how well have you followed recommendations for:

1. Taking enzymes	1	2	3	4	5	N/A
2. Taking vitamins	1	2	3	4	5	N/A
3. Administering aerosal treatment	1	2	3	4	5	N/A
4. Administrating postural drainage treatment	1	2	3	4	5	N/A
5. Eating the proper foods; sticking to meal plan	1	2	3	4	5	N/A
6. Checking for weight change	1	2	3	4	5	N/A
7. Checking for infection	1	2	3	4	5	N/A
8. Determining right dose of antibiotics	1	2	3	4	5	N/A
9. Administering correct antibiotic Dose	1	2	3	4	5	N/A
10. Administering antibiotics at right time	1	2	3	4	5	N/A
11. Coming in for appointments	1	2	3	4	5	N/A
12. Wearing a medical alert ID	1	2	3	4	5	N/A
13. Exercising regularly	1	2	3	4	5	N/A
14. Exercising strenuously	1	2	3	4	5	N/A

Appendix C

Cystic Fibrosis Family Responsibility Questionnaire (CFFRQ)

Cystic Fibrosis Family Responsibility Questionnaire (CFFRQ)

Below are different tasks or situations that relate to cystic fibrosis management in your family. Please check the box by the statement that describes the way each task or situation is handled in your family.

1 = Parent (s) take or initiate responsibility for this almost all of the time

2 = Parent (s) and child share responsibility for this about equally

3 = Child takes or initiates responsibility for this almost all of the time

0 = No one takes responsibility

- 1. Remembering day of clinic appointments
- 2. Telling teachers about cystic fibrosis
- 3. Taking enzymes
- 4. Taking antibiotics (right dose at correct time)
- 5. Taking vitamins
- 6. Telling relatives about cystic fibrosis
- 7. Noticing differences in health such as weight changes or signs of infection
- 8. Telling child's friends about cystic fibrosis
- 9. Taking aresol treatment
- 10. Taking postural drainage treatment
- 11. Deciding what should be eaten at meals
- 12. Explaining absence from school to teachers
- 13. Giving information to the doctor about condition during clinic visits
- 14. Discussing decisions about treatment with the doctor
- 15. Deciding what time of day postural draining treatments should be done
- 16. Deciding what time of day to take antibiotics
- 17. Deciding whether antibiotics need to be taken for symptoms
- 18. Making appointments with doctor

Appendix D

Diabetes Family Responsibility Questionnaire (DFRQ)

Diabetes Family Responsibility Questionnaire (DFRQ)

Below are different tasks or situations that relate to diabetes management in your family. Please check the box by the statement that describes the way each task or situation is handled in your family.

1 = Parent (s) take or initiate responsibility for this almost all of the time

2 = Parent (s) and child share responsibility for this about equally

3 = Child takes or initiates responsibility for this almost all of the time

0 = No one takes responsibility

- 1. Remembering day of clinic appointments
- 2. Telling teachers about diabetes
- 3. Remembering to take morning or evening injections
- 4. Making appointments with doctors, dentists, etc.
- 5. Telling relatives about diabetes
- 6. Taking more or less insulin according to results of blood sugar or urine tests
- 7. Noticing differences in health, such as weight changes or signs of an infection
- 8. Telling child's friends about diabetes
- 9. Noticing the signs of an insulin reaction
- 10. Giving insulin injections
- 11. Deciding what should be eaten when family has meals out (restaurants, friend's home)
- 12. Examining feet and making sure shoes fit properly
- 13. Carrying some form of sugar in case of insulin reaction
- 14. Explaining absence from school to teachers or other school professional
- 15. Rotating injection sights
- 16. Checking expiration dates on medical supplies
- 17. Remembering times when blood or urine should be tested
- 18. Having necessary supplies in the house
- 19. Adjusting insulin dose when the child is sick or has symptoms
- 20. Contacting doctor when the child is sick or has symptoms
- 21. Drawing up insulin
- 22. Doing blood sugar or urine tests
- 23. Keeping record of the tests
- 24. Deciding what should be eaten for snacks at home
- 25. Deciding what should be eaten for meals at home

Appendix E

Conflict Subscale of the Diabetes Responsibility and Conflict Scale
(Conflict Subscale - DRCS - Child)

**Conflict Subscale of the Diabetes Responsibility and Conflict Scale
(Conflict Subscale - DRCS - Child)**

For each of the following parts of your diabetes care, decide how much you argue/hassle with your parents about it.

	Never	Sometimes	½ The Time	Frequently	All The Time
1. Remembering to give shots	<input type="checkbox"/>				
2. Drawing up insulin	<input type="checkbox"/>				
3. Blood Testing	<input type="checkbox"/>				
4. Record Keeping	<input type="checkbox"/>				
5. Urine Testing	<input type="checkbox"/>				
6. Giving Shots	<input type="checkbox"/>				
7. Meals & Snacks	<input type="checkbox"/>				
8. Taking care of low blood sugar	<input type="checkbox"/>				
9. What to eat when eating away from home	<input type="checkbox"/>				
10. Talking with the doctor	<input type="checkbox"/>				
11. Talking with other adults about diabetes (like teacher, nurse, principal)	<input type="checkbox"/>				
12. Telling friends about diabetes	<input type="checkbox"/>				
13. Exercising	<input type="checkbox"/>				
14. Who should know about your diabetes	<input type="checkbox"/>				
15. Supplies	<input type="checkbox"/>				

Appendix F

Conflict Subscale of the Diabetes Responsibility and Conflict Scale (Conflict Subscale - DRCS - Parent)

**Conflict Subscale of the Diabetes Responsibility and Conflict Scale
(Conflict Subscale - DRCS - Parent)**

For each of the following parts of your child's diabetes care, decide how much you argue/hassle with your child about it.

	Never	Sometimes	½ The Time	Frequently	All The Time
1. Remembering to give shots	<input type="checkbox"/>				
2. Drawing up insulin	<input type="checkbox"/>				
3. Blood Testing	<input type="checkbox"/>				
4. Record Keeping	<input type="checkbox"/>				
5. Urine Testing	<input type="checkbox"/>				
6. Giving Shots	<input type="checkbox"/>				
7. Meals & Snacks	<input type="checkbox"/>				
8. Taking care of low blood sugar	<input type="checkbox"/>				
9. What to eat when eating away from home	<input type="checkbox"/>				
10. Talking with the doctor	<input type="checkbox"/>				
11. Talking with other adults about diabetes (like teacher, nurse, principal)	<input type="checkbox"/>				
12. Telling friends about diabetes	<input type="checkbox"/>				
13. Exercising	<input type="checkbox"/>				
14. Who should know about your child's diabetes	<input type="checkbox"/>				
15. Supplies	<input type="checkbox"/>				

Appendix G

Conflict Subscale of the Cystic Fibrosis Responsibility and Conflict Scale
(Conflict Subscale - CFRCS - Child)

**Conflict Subscale of the Cystic Fibrosis Responsibility and Conflict Scale
(Conflict Subscale - CFRCS - Child)**

For each of the following parts of your diabetes care, decide how much you argue/hassle with your parents about it.

	Never	Sometimes	½ The Time	Frequently	All The Time
1. Antibiotics	<input type="checkbox"/>				
2. Enzymes	<input type="checkbox"/>				
3. Vitamins	<input type="checkbox"/>				
4. Tracking weight	<input type="checkbox"/>				
5. Checking for infection	<input type="checkbox"/>				
6. Aerosal treatment	<input type="checkbox"/>				
7. Meals & Snacks	<input type="checkbox"/>				
8. Postural drainage treatment	<input type="checkbox"/>				
9. What to eat when eating away from home	<input type="checkbox"/>				
10. Talking with the doctor	<input type="checkbox"/>				
11. Talking with other adults about cystic fibrosis (like teacher, nurse, principal)	<input type="checkbox"/>				
12. Telling friends about cystic fibrosis	<input type="checkbox"/>				
13. Exercising	<input type="checkbox"/>				
14. Who should know about your cystic fibrosis	<input type="checkbox"/>				
15. Supplies	<input type="checkbox"/>				

Appendix H

Conflict Subscale of the Cystic Fibrosis Responsibility and Conflict Scale
(Conflict Subscale - CFRCS - Parent)

**Conflict Subscale of the Cystic Fibrosis Responsibility and Conflict Scale
(Conflict Subscale - CFRCS - Parent)**

For each of the following parts of your child’s cystic fibrosis care, decide how much you argue/hassle with your child about it.

	Never	Sometimes	½ The Time	Frequently	All The Time
1. Antibiotics	<input type="checkbox"/>				
2. Enzymes	<input type="checkbox"/>				
3. Vitamins	<input type="checkbox"/>				
4. Tracking weight	<input type="checkbox"/>				
5. Checking for infection	<input type="checkbox"/>				
6. Aerosal treatment	<input type="checkbox"/>				
7. Meals & Snacks	<input type="checkbox"/>				
8. Postural drainage treatment	<input type="checkbox"/>				
9. What to eat when eating away from home	<input type="checkbox"/>				
10. Talking with the doctor	<input type="checkbox"/>				
11. Talking with other adults about cystic fibrosis (like teacher, nurse, principal)	<input type="checkbox"/>				
12. Telling friends about cystic fibrosis	<input type="checkbox"/>				
13. Exercising	<input type="checkbox"/>				
14. Who should know about child’s cystic fibrosis	<input type="checkbox"/>				
15. Supplies	<input type="checkbox"/>				

Appendix I

Conflict Behavior Questionnaire (CBQ)

Conflict Behavior Questionnaire (CBQ)

Think back over the last 2 weeks at home. The statements below have to do with you and your mother. Read the statement and then decide if you believe the statement is true. If it is true, then circle true, and if you believe the statement is not true, circle false. You must circle either true or false, but never both for the same item. Please answer all items. Your answers will not be shown to your parents.

- | | | |
|------|-------|----------------------------------------------------------------------------------|
| true | false | 1. My mom doesn't understand me. |
| true | false | 2. My mom and I sometimes end our arguments calmly. |
| true | false | 3. My mom understands me. |
| true | false | 4. We almost never seem to agree. |
| true | false | 5. I enjoy the talks we have. |
| true | false | 6. At least three times a week, we get angry at each other. |
| true | false | 7. My mother listens when I need someone to talk to. |
| true | false | 8. My mom is a good friend of mine. |
| true | false | 9. She says I have no consideration for her. |
| true | false | 10. At east once a day we get angry at each other. |
| true | false | 11. My mother is bossy when we talk. |
| true | false | 12. The talks we have are frustrating. |
| true | false | 13. My mother understands my point of view, even when she doesn't agree with me. |
| true | false | 14. My mom seems to be always complaining about me. |
| true | false | 15. In general, I don't think we get along very well. |
| true | false | 16. My mom screams a lot. |
| true | false | 17. My mom puts me down. |
| true | false | 18. If I run into problems, my mom helps me out. |
| true | false | 19. I enjoy spending time with my mother. |
| true | false | 20. When I state my opinion, she gets upset. |

Appendix J
Demographic Information

Demographic Information

1) **SEX OF CHILD (CHECK ONE):** ___Male ___Female

2) **AGE OF CHILD:** _____

3) **DURATION SINCE DIAGNOSIS (CHECK ONE):**

___1 year ___2 years ___3 years ___4 years ___5 years ___6 years ___7 years or

more 4) **MARITAL STATUS OF BIOLOGICAL PARENTS (CHECK ONE):**

___Continuously Married

___History of Separation /Divorce

___One Parent Deceased

5) **LIVING SITUATION OF CHILD (CHECK ONE):**

___Lives with Mother and Father

___Lives with Mother

___Lives with Father

___Lives with Mother and Stepfather

___Lives with Father and Stepmother

___Other

Appendix K
HSIRB Approval Letter

HSIRB Approval Letter

Date: November 11, 2004

To: Linda LeBlanc, Principal Investigator
Blake Lancaster, Student Investigator for dissertation

From: Amy Naugle, Ph.D., Interim Chair

Re: HSIRB Project Number: 04-07-06

This letter will serve as confirmation that your research project entitled “Examination of the Impact of Age, Family Conflict, and Perceived Parental Involvement on Treatment Adherence for Children and Adolescents with Cystic Fibrosis and Diabetes” has been **approved** under the **full** category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may **only** conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: July 21, 2005