

ADOLESCENT-MOTHER DISCREPANCY IN PERCEPTIONS OF FAMILY RELATIONS
AS A PREDICTOR OF DEPRESSION AMONG CHRONICALLY ILL ADOLESCENTS

By

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Para mi querida Mami. Eres mi inspiración.

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TABLE OF CONTENTS

	<u>page</u>
ACKNOWLEDGMENTS	4
LIST OF TABLES	7
ABSTRACT	8
CHAPTER	
1 INTRODUCTION	10
2 REVIEW OF THE LITERATURE	14
Adolescents with a Chronic Illness.....	14
Psychosocial Impact of Chronic Illness on Adolescents	15
Psychosocial Impact of Adolescent Chronic Illness on the Family	18
Factors that Influence Adjustment of Chronically Ill Adolescents	20
Family Cohesion and Family Conflict and Their Influence on the Adjustment of Chronically Ill Adolescents.....	21
Depressive Symptoms and Chronic Illness in Adolescence.....	25
Adolescent Depressive Symptoms	25
Chronic Illness and Depressive Symptoms	27
The Association of Chronically Ill Adolescents' Depressive Symptoms with Perceived Level of Family Cohesion and Family Conflict.....	30
The Association of Adolescents' Depressive Symptoms with Discrepancies in Perceived Level of Family Cohesion and Family Conflict.....	33
Purpose of the Proposed Study	35
3 METHODOLOGY	36
Participants	36
Instruments	37
Procedure	40
Recruitment of Participants	40
Procedure	42
4 RESULTS	45
Descriptive and Normative Data for all Major Variables.....	46
Correlations Between Variables of Interest and the Marlowe-Crowne Social Desirability Scale-Short Form	46
Results of Analyses to Test Hypothesis 1.....	47
Results of Analyses to Test Hypothesis 2.....	47
Results of Analyses to Test Hypothesis 3.....	48
Results of Analyses to Test Hypothesis 4.....	49

Results of Research Question Analyses	50
5 DISCUSSION.....	58
Results Regarding Hypotheses 1 and Hypothesis 2	58
Results Regarding Hypothesis 3 and Hypothesis 4	62
Results of Analyses to Examine a Research Question	65
Limitations of the Research.....	67
Implications for Future Research.....	68
Implications for the Field of Counseling Psychology	69
APPENDIX	
A YOUTH INFORMATION QUESTIONNAIRE	72
B ADULT INFORMATION QUESTIONNAIRE.....	75
C FRI.....	77
D CES-D.....	79
E M-C SDS-SF.....	81
F INFORMED CONSENT ADULTS	83
G ADOLESCENT ASSENT FORM.....	94
H INVITATION LETTER	99
I COVER LETTER (ADOLESCENT).....	101
J COVER LETTER (PRIMARY PARENT/CAREGIVER)	102
LIST OF REFERENCES.....	103
BIOGRAPHICAL SKETCH	118

LIST OF TABLES

<u>Table</u>	<u>page</u>
3-1 Demographic Description of African American and White American Participant	44
4-1 Descriptive and Normative Data for the FRI, CES-D, and M-C SD-SF Inventories	52
4-2 Relationship Between Social Desirability Scores and Variables of Interest	53
4-3 Pearson Correlations Among Study Variables for Adolescents and Mothers by Ethnic Group.....	54
4-4 Multiple Regression Predicting Adolescent Depressive Symptoms Scores from Adolescent Family Cohesion, Mother Family Cohesion, and Cohesion Difference Scores.....	55
4-5 Stepwise Regression Predicting Adolescent Depressive Symptoms Scores from Adolescent Family Conflict, Mother Family Conflict, and Conflict Difference Scores Using African American Participants' Data	56
4-6 Multiple Regression Predicting Adolescent Depressive Symptoms Scores from Adolescent Family Conflict, Mother Family Conflict, and Conflict Difference Scores Using White American Participants' Data.....	56
4-7 Summary of MANOVA Models to Test Research Question.....	57

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This study examined the association of perceived family relations (family cohesion, family conflict) and adolescent depressive symptoms among lower-income African American adolescents with a chronic illness and their mothers (n = 64) and among lower-income White American adolescents with a chronic illness and their mothers (n = 98). Secondly, this study examined whether adolescent-mother discrepancies in perceived level of family relations were stronger predictors of adolescents' reported depressive symptoms, as compared to their individual and their mothers' perceived level of family relations. Participants in the study completed inventories assessing their perceptions of family cohesion and family conflict; adolescents also rated their own depressive affect.

Pearson correlation analyses, conducted separately by racial group, revealed that perceived levels of family cohesion were negatively associated with adolescent depressive symptoms and perceived levels of family conflict were positively associated with adolescent depressive symptoms among African American adolescents, White American adolescents, and White American mothers. The present study did not find evidence that discrepancies in family members' perceptions of family relations are related to adolescent depressive symptoms among

chronically ill adolescents. However, multiple regression analyses, conducted separately by racial group, revealed that adolescent perception of family cohesion was the only significant predictor of adolescent depressive symptoms for both groups. Additionally, adolescent perception of family conflict was the only significant predictor of White American adolescent depressive symptoms.

These findings suggest that adolescent perception of family cohesion may be an important factor in adolescent adjustment among African American and White American adolescents living with a chronic illness and that perceptions of family conflict may be an important factor in the occurrence of adolescent depressive symptoms among White American adolescents. These findings provide support for examining family relations and adolescent depressive symptoms separately by race as suggested by the Difference Model research approach.

CHAPTER 1 INTRODUCTION

A chronic illness is a long-term condition that is either incurable or that requires special assistance or adaptation in function (Eiser, 1993; Hayes, 1997; Jessop & Stein, 1985). Such conditions have various degrees of severity – some may be permanent and require intensive care while others are transitory and treated without difficulty. Moreover, a diagnosis does not always suggest the severity of a chronic condition; for instance, asthma, which is considered a chronic illness, may either impair one's functioning on a daily basis or only occasionally cause disability. Epidemiological studies have revealed that 20-30% of teenagers have a chronic illness and that 10-13% of those adolescents require extensive care and have substantial limits in their daily functioning (Yeo, & Sawyer, 2003). Although there is a diverse range of illnesses, adolescents with a chronic illness have great similarities in their life experiences.

Chronic illness in adolescents, such as asthma or diabetes, affects all of the members of the family system (Kazak, 1989). For example, challenges brought by the chronic illness usually increase adolescents' reliance upon the immediate family, particularly the mother or mother figure. Traditionally, the mothers' role in the family system is to assist their offspring to meet developmental, emotional, and social needs. In addition to these roles, studies have indicated that mothers of an adolescent with a chronic illness are more likely to also coordinate and provide medical care to that adolescent. Mothers are also typically more responsible for the daily maintenance of illness-related care than are fathers. Moreover, mothers, as compared to fathers, report significantly greater emotional strain in managing their illness-related care-giving role (Quittner, DiGirolamo, Michel, & Eigan, 1992). Additionally, mothers of chronically ill children are more likely to feel responsible for their child's happiness, and become depressed themselves (Mastroyannopoulou, & Stallard, 2001).

An important feature of all adolescents' family environment is the relationships that they have with their mothers. Adolescent-mother relationships, specifically those perceived as positive, may serve as a valuable source of support for a youth with a chronic illness whereas the absence of such support has been linked to the onset of depressive symptoms (Moos, Cronkite, & Moos, 1998). Yet, there is evidence that conflict is more frequent among adolescent-mother relationships than among adolescent-father dyads (Hill, 1988; Montemayor, 1983; Smetana, 1988).

As the result of the onset of a chronic illness, some families come together and enhance their relationships by being supportive and cohesive. These families can be as supportive and cohesive as families with healthy adolescents. However, some families respond to the chronic condition negatively, suffering noticeable signs of despair and dysfunction (Hostler, 1991; Moos, 2002). Reacting negatively to a chronic health condition could place stress on family relationships which, in turn affect adolescent adjustment to the chronic illness.

Maternal support has a significant influence on the psychological adjustment of an adolescent with a chronic illness. Adolescents look toward their mother for comfort and support, especially when challenges arise. Without support, particularly from their mothers, adolescents with a chronic illness will likely have difficulties coping with the stressors of managing their chronic illness (Bobrow, AvRuskin, & Siller, 1985; Perrin, Ayoub, & Willet, 1993).

Moos and Moos (1994) reported that the quality of adolescent relationships with their mother moderated or reduced the potential negative affect of acute and chronic stressors. Specifically, Moos found that when adolescents with juvenile rheumatic disease experienced low or moderate level of acute or chronic stressors, those who reported a better relationship with their mother had more social competence and fewer behavioral problems.

The literature concerning the effect of family relations on the adaptation of a child or an adolescent diagnosed with a chronic illness suggests that family cohesion is positively associated with better adaptation of the child and adolescent (Davis, Tucker, & Fennel, 1996; Meijer & Oppenheimer, 1995; Moos & Moos, 1994; Reichenberg & Broberg, 2005), whereas a high level of family conflict is associated with increased signs of psychological dysfunction (Anderson et al., 2002; Hamlet, Pellegrini, & Katz, 1992; Mahoney, O'Sullivan, & Robinson, 1992) and increases behavioral problems (Miller-Johnson et al., 1994; Varni et al., 1996) among adolescents with a chronic illness. It is likely that families characterized by high family cohesion and low family conflict function as an integrated unit that promotes the mental and physical well-being of adolescents (Pender, 1996).

Recent studies have indicated that the early onset of physical illnesses such as diabetes or asthma increases the risk of psychosocial adjustment problems such as depression in adolescents (Anderson, 2004; Canning, Canning, & Boyce, 1992; Klinnert, McQuiad, McCormick, Adinoff, & Bryant, 2000). However, previous research studies have not investigated perceived level of family relations among adolescents with a chronic illness and their mothers and how the level of discrepancies in these perceptions might be related to depressive symptoms in the adolescents.

Researchers have found that adolescents and parents often differ in their views of family relations (e.g., Henggeler, Borduin, & Mann, 1987; Pelton & Forehand, 2001; Tein, Roosa, & Michaels, 1994). Discrepancies in perceived family relations may be attributed to home environments where there are changes in family members' roles, lack of communication, and trust issues. The discrepant ways in which a mother and her adolescent view their relationship may contribute to adolescent adjustment difficulties, which may, in turn, contribute to adolescent depressive symptoms. For example, Tein, Roosa, and Michaels (1994) proposed that such

discrepancies may partially contribute to an adolescents' externalizing and internalizing symptomatology (e.g., conduct disorder, depression).

Examining the differences in perceived level of family relations between adolescents with a chronic illness and their mothers is important given that found discrepancies may obstruct the provision of support that such adolescents need to adjust psychologically and socially to their illness. Thus, the present study examined adolescents' and their mothers' perceptions of family cohesion and family conflict and discrepancies in these perceptions as predictors of adolescents' reported level of depressive symptoms.

CHAPTER 2 REVIEW OF THE LITERATURE

Adolescents with a Chronic Illness

Living with a chronic illness involves unique and complex challenges for adolescents. One such challenge is having to deal with treatment regimens that can be time consuming and monotonous. For example, on average it takes an hour a day for adolescents with diabetes to manage their illness, which includes giving themselves or receiving insulin injections and monitoring or having their blood glucose level monitored (Sawyer, Reynolds, Couper, et al. 2005). For adolescents with cystic fibrosis, treatment regimen tasks such as physiotherapy, overnight feeding, and use of inhalers take 1.5 hours a day (Sawyer, Reynolds, Couper, et al. 2005). Many adolescents living with a chronic illness face the challenges of managing their illness with resilience and adjust well to their condition (Olsson, Boyce, Toumbourou, & Sawyer, 2005). However, some epidemiological studies have reported that adolescents with a chronic illness have twice the rate of mental health disorders as their healthy peers (Mrazek, 1994).

The diagnosis of a chronic illness is typically a stressful life event that is undesirable and usually beyond the control of the afflicted individual. Because of the cognitive development of adolescents, they may have a greater understanding of the impact of disease than children, and therefore suffer from higher stress level than children in association with having a chronic illness. Stress among adolescents may result in the experiencing of depressive symptoms (Cole, Nolen-Hoeksema, Girgus, Paul, 2006). Moreover, adolescents with more severe chronic illness and those who have additional life stressors (e.g., poverty) are at risk of developing behavioral and psychosocial adjustment problems (Moos, 2000).

The family has been recognized as an important factor in the process and outcome of medical care (Hayman, Mahon, Turner, 2002). Treatment requirements, medical interventions such as surgery, and symptom management are some of the challenges which adolescents and their family face together. Those adolescents who perceive their families to be supportive and caring during an illness are better equipped to cope emotionally and adapt to their condition (Perrin, Ayoub, Willet, 1993)

Mother-adolescent relationships have a significant influence on the emotional and physical well-being of adolescents with a chronic illness. For example, relationships with mothers that are perceived as supportive can serve as a buffer for adolescent illness-related stress. Relationships perceived as high in family cohesion and low in family conflict maximize the use of family resources and strengthen the mental and physical health of adolescents (Pender, 1996).

In a study of 187 children (ages 7 –18) and their mothers, Perrin, Ayoub, & Willet (1993) found that the social and environmental characteristics of the family were important to the psychological adjustment of these children, including those that were healthy and those with various chronic illnesses, independent of age and socioeconomic status. According to report accounts by the children in the study, family environment and their health status directly influenced their psychosocial adjustment. When children’s adjustment was reported by their mother, the reported adjustment level was also positively related to the children’s health status and family environment. Additionally, mothers’ perception of their children’s adjustment varied with disease severity. Overall, mothers of children with a chronic illness rated their children as less adjusted than did parents of healthy children.

Psychosocial Impact of Chronic Illness on Adolescents

Adolescence is a stressful developmental process that is further complicated by a diagnosed chronic illness. Illness related disruptions in daily and age-appropriate activities may

indeed threaten normal psychosocial adjustment including social adjustment, school performance, and autonomy from parents (Bauman, Drotar, Leventhal, Perrin & Pleass, 1997). The psychological and social complications that may accompany a chronic illness can potentially affect normal developmental processes experienced during adolescence.

Establishing of peer relationships and experiencing social adjustment are major developmental tasks of adolescence (Hartup, 1989). However, adolescents with a chronic illness may have difficulty with these developmental tasks due to their physical condition. For example, altered physical appearance related to their illness may make it difficult for adolescents to make friends and be accepted by their peers. Diminished physical ability and stamina may interfere with playing team sports and participating in extracurricular activities (Snethen, Broome, Kelber, & Warady, 2004). Being absent from social activities because of illness-related factors may limit opportunities for social interactions, making it difficult to develop friendships (La Greca, 1990).

Attending school is important to an adolescent's academic development. Yet, due to illness-related factors, adolescents with a chronic illness may miss many days from school. This absenteeism can lead to academic difficulty, having to repeat a grade, and withdrawal from school. Epidemiological studies have found differences in school problems among children with chronic illnesses in comparison to their healthy peers. For example, the U.S. National Health Interview Survey on Child Health (1988) reported that children with asthma had higher rates of grade failure than did healthy children and were twice as likely to have a learning disability as reported by their parents. Children with cancer have rates of absenteeism that are four times higher than their healthy peers (Stehbens, Kisker, & Wilson, 1983). Moreover, children with cystic fibrosis and sickle-cell disease miss 23 to 25 days from school per year (Fowler, Johnson,

Atkinson, 1985). An adolescent's inability to engage in the academic process could have deleterious effects on their pursuit of higher education and future careers.

When adolescents have a chronic illness, they are inclined to be dependant on their parents and are not as inclined to seek independence from their parents. Additionally, parents are more resistant to their adolescent children's efforts towards autonomy. Therefore, the normative task of gaining independence from their parents toward individuation may become more taxing for teenagers with a chronic illness and may threaten their normal developmental processes.

Individuation has been defined as an individual having achieved a level of differentiation that allows him or her to function within relationships as autonomous and self-directed without being controlled, impaired, or feeling overly responsible for significant others, particularly the nuclear family (Harvey & Bray, 1991). According to transgenerational family theory, family systems that allow differentiation among family members, encourage cohesion and adaptability, and are openly receptive to the expression of individual thoughts and ideas, keep harmony in the system. When a family system resists individual growth and change, the process of self-identity as well as decision-making can be compromised (Meeus, Iedema, Maassen, & Engels, 2005).

Shulman, Seiffge-Krenke, and Samet (1987) believe that family types supportive of change foster in adolescents more adaptive, self-confident attitudes for dealing with the demands of the outside world, whereas overprotective and highly controlled family climates are more likely to interfere with the adolescents' development of competent methods for dealing with stressful situations. Shulman et al. (1987) surveyed 186 healthy twelfth grade students to examine the relationship between coping ability and family environment, which was assessed using the Family Environment Scale (Moos & Moos, 1986). They found that family cohesion and respect for individual development were positively related to functional coping, and that lack

of family support and an over-controlling family climate were associated with dysfunctional coping.

Psychosocial Impact of Adolescent Chronic Illness on the Family

For the parents of an adolescent, receiving the news that their adolescent has a chronic illness is a traumatic experience that often involves a period of mourning, grieving, and adjustment (Blacher, 1984). Research on trauma to the care-giving system suggest that unresolved trauma can impact the care-giving system and lead to relationship problems between the parent and offspring (Main & Hesse, 1990).

In a study of mothers' resolution or nonresolution of their child's chronic illness diagnosis, Sheeran, Marvin, and Pianta (1997) found that mothers' ability to accept their child's illness and adjust to the diagnosis was strongly correlated with secure child-mother relationships, less parenting stress, and marital satisfaction. Those mothers who experienced ongoing distress and/or denial regarding their child's illness reported more parenting difficulties, higher level of stress, and insecure child-mother relationships. Even though this study was of families who have young children diagnosed with a chronic disorder, the results of this research study can likely be extended to adolescent-mother relationships.

When an adolescent has a chronic illness, the management of this illness nearly always involves the parents or other primary caregivers. However, the mother or mother figure is usually responsible for the daily care of an adolescent and management of his or her illness (Gallo & Knafel, 1998; Glazer, 1990; Jessop, Reissman, & Stein, 1988; Kazak, 1989). Some mothers give up employment or choose to not work in order to meet the medical care demands of their teenager (Mastroyannopoulou, Stallard, Lewis, Lenton, 1997; Rearsan, Urban, Baker, McBride, Tuttle, & Jaward, 2000). For these mothers, treatment and management of their adolescents' chronic illness becomes a main focus of their role as caregiver.

Having an adolescent with a chronic illness is emotionally demanding on the mother or mother figure who is the adolescent's primary caregiver. The feelings of powerlessness, isolation, and fear that often come with having an adolescent with a chronic illness can be overwhelming to the primary caregiver of the adolescent. Often, mothers of an adolescent with a chronic illness compare themselves to their peers who are not burdened by an illness, and ask "why me?" However, the majority of mothers develop coping strategies to deal with illness related stressors and are resilient to the associated negative life events (Eiser, 1990). In a longitudinal study of adolescents with juvenile rheumatic disease, it was found that when mothers felt better able to manage the stress associated with their adolescent's chronic illness, the adolescents reported experiencing less distress, participated in more activities with friends, and were more socially integrated at school (Moos, 2002). This suggests that there is a link between the psychological adjustment of the mother and that of their chronically ill adolescent.

Research has suggested that mothers' psychosocial functioning may impact the medical outcome of their adolescents' chronic illness. For example, in a study by Chen, Bloomberg, Fisher, and Strunk (2003), the relationship between children with asthma (ages 4-18) and their mothers' characteristics (psychosocial adjustment) were examined. They found that high level of family conflict and mother characteristics (e.g, being emotionally bothered by asthma, lower sense of mastery) were associated with higher level of adolescent hospitalization due to asthma complications. Furthermore, those mothers who felt less confidence in their ability to provide adequate asthma-related treatment to their adolescent experienced greater personal strain. These findings are consistent with previous studies that demonstrated the relationship of mother characteristics and asthma prevalence (Wade et al., 1997) as well as other childhood chronic illnesses (Zahr, Khoury, & Saoud, 1994).

Factors that Influence Adjustment of Chronically Ill Adolescents

Adolescents with a chronic illness have to cope with the demands of illness-related stressors, everyday stressors, and developmental tasks. Stress increases when the adolescent with a chronic illness is not able to cope with, or does not believe that they can cope with, their life altering medical condition. To cope with stressful life events, adolescents with a chronic illness need to rely on their own resources and social support (e.g., support from their family, friends, and health care providers) to manage the demands of their illness and their illness related stress (Folkman & Lazarus, 1988).

Adjustment of an adolescent with a chronic illness is influenced by characteristics of the adolescent, the illness, and the family. Parents or parental figures are an important source of support for coping and adjusting to a chronic physical illness. In a study of adolescents with juvenile rheumatic disease, Timko, Stovel, Moos, & Miller (1992) found that the quality of relationship with their mother moderated or reduced the potential negative affect of acute and chronic stressors. Their results indicated that those adolescents who reported experiencing close and supportive relationships with their mothers were more socially competent and had fewer behavioral problems while experiencing low or a moderate level of acute or chronic stressors.

A stress adaptation model, proposed by Pollack (1993), posits a framework of adolescent adjustment to chronic illness. In this framework, adaptation is an active process in which the chronically ill adolescent adjusts to her/his environment. The stress adaptation model proposes that an individual's level of adjustment to physical illness is associated with the psychological response to the condition (e.g., depressive symptoms), individual differences that may influence the response and adaptation (e.g., family relations, coping responses), and characteristics such as age and gender. Difficulty in adjusting to a chronic illness could stem from psychological and individual characteristics as well as from complications of medical factors such as chronic pain.

The degree to which chronic illness affects an adolescent's psychological adjustment is debated within the literature. Inconsistent findings may be due to methodological differences among research studies. Wallander and Thompson (1995) propose that there is no direct relation between psychosocial adjustment and chronic illness among adolescents. Rather, adolescents have a wide range of psychosocial responses to the stress associated with a chronic illness. Some studies indicate that major illness related psychological disturbance is not common among these youth (Capelli et al., 1989; Kellerman, Zeltzer, Ellenberg, Dash, & Zigler, 1980; Key, Brown, Marsh, Spratt, Recknor, 2001). However, clinical and epidemiological studies generally indicate that adolescents with a chronic illness are at increased risk for psychosocial problems (e.g., depression, anxiety) (Bennett, 1994; MacLean, Perrin, Gortmaker, & Pierre, 1992; Seigel, Golden, Gough, Lashley, & Sacker, 1990).

Family Cohesion and Family Conflict and Their Influence on the Adjustment of Chronically Ill Adolescents

Family relationship dimensions, such as family conflict and family cohesion, are part of the nuclear family climate that sets the stage for adolescent development and affects adolescents' reactions to life transitions and crises (Moos, 2002). Family conflict refers to level of verbal and aggressive behaviors and attitudes between and among adolescents and their parents. Family cohesion is characterized by the level of closeness, support, and caring relations between and among adolescents and their parents. Family relations has the potential to reduce the effects of stressors of chronic illness or to contribute to the stressors and disruption caused by such illness.

It is widely accepted that during adolescence, adolescent-mother conflict increases (Richardson, Galmbos, Schulenberg, & Peterson, 1984). Additionally, family conflicts arise due to issues such as disagreement on family management, differences in values between the adolescent and her/his parents, and the adolescent's pursuit of autonomy. Negative emotions

accompanying adolescent-mother conflict can directly influence an adolescent's management of a chronic illness. For instance, as the level of adolescent-mother conflict increases, the adolescent's energy may be diverged from self-care due to increases in arousal and negative emotions. Such negative emotions can also weaken the adolescent-mother relationship and the mother's motivation to engage in stressful and time consuming medical treatment regimens (Orem, 2001). Furthermore, family conflict in general can have a negative effect on the management of a chronic illness (e.g., diabetes, asthma, sickle cell disease); if treatment is compromised, negative medical consequences may occur for the adolescent.

There have been few studies that examined the impact of family cohesion, family conflict, the adolescent-mother relationship, and the adjustment of adolescents with a chronic illness. The few studies investigating family relations have focused on the adjustment of children with a chronic illness and on medical treatment compliance. However, a review of current empirical studies reveal that family relations play a significant role in the psychological adjustment and physical wellbeing of children and adolescents with a chronic illness, regardless of age and disease type.

In a cross-sectional study of children and adolescents with diabetes and their parents, Anderson et al. (2002) found that diabetes-related conflict significantly predicted glycemic control. Families characterized as high in family cohesion and low in family conflict tend to have adolescents who exhibited good glycemic control and psychological adjustment. It was also found that tension caused by family conflict can make it more difficult for adolescents to perform diabetes self-care and obtain adequate treatment for their diabetes (Miller-Johnson et al., 1994). Miller-Johnson et al. suggest that positive family interaction and involvement around diabetes-related tasks is important for diabetes management among children and adolescents.

Research studies have emphasized that family relationships are more important than family rules and structure when it comes to the metabolic status of adolescents with diabetes (Moos, 2002). For example, high level of family support and family cohesion are associated with better adjustment among children with diabetes. Diabetic adolescents who perceive their families as supportive and cohesive are more likely to follow their prescribed diet and adhere to their treatment regimen. Those who perceive their family as having a high level of conflict are more likely to have poor metabolic control and to not follow glucose testing procedures (Moos, 2002).

Several studies have reported that family cohesion and family conflict are associated with adjustment among children with cancer. For example, in a study which investigated the influence of family relations on the psychological adjustment of pediatric cancer patients, Varni, Katz, Colegrove, and Dolgin (1996) found that family cohesion was a predictor of lower psychological distress among the children. Moreover, family conflict was a predictor of child behavior problems among their sample of pediatric cancer patients. Likewise, Rait, Ostroff, and Smith (1992) found that a high level of perceived family cohesion was associated with the psychological adjustment of adolescent cancer survivors after cancer treatment.

Studies have indicated that specific aspects of family relations are associated with the experience of pain among pediatric patients. Among adolescents who underwent orthopedic surgery, those who reported a high level of family conflict reported more physical pain after surgery (Gil, Ginsberg, Muir, Sullivan, & Williams, 1992). Similarly, among children with arthritis, those who reported a high level of family cohesion reported less pain (Thompson, Varni, & Hanson, 1987). These findings are comparable to findings on adult pain management and family relations (Moos, 2002).

Asthma is one of the most widely investigated chronic illness among children, however, there are few published studies that have investigated the impact of family relations on the adjustment of adolescents with asthma. In general, research studies suggest that positive family interactions are favorable to the adjustment of children with asthma. Moreover, high level of family conflict and reduced family cohesion have been related to poorer psychological adjustment among children with asthma (Hamlett, Pellegrini, & Katz, 1992).

In a cross-sectional study of children with asthma and their parents, Reichenberg and Broberg (2005) found that family cohesion has a direct linear relationship to positive family outcomes. In other words, high level of reported cohesion are related to optimal family functioning. Moreover, children's psychological adjustment (e.g., few emotional and behavioral problems) was positively associated with family cohesion and negatively associated with family conflict.

In a study of families with children who have uncontrolled or controlled asthma, Meijer and Oppenheimer (1995) found that families characterized as high in cohesion tended to have children with controlled asthma and psychological adjustment. The authors suggest that the way mothers or mother figures and children deal with disease-related medical treatment as well as factors that influence compliance to medical treatment by children are associated with family cohesion and can predict child adjustment to asthma.

Gender is an important factor that influences family relations and adolescent adjustment of chronic illness. In a study of child and family adjustment to chronic childhood illness, differences based on child gender were evident (Holden, Chmielewski, Nelson, Kager, & Foltz, 1997). Mothers of girls who have a chronic illness reported experiencing higher level of family cohesion than mothers of boys who have a chronic illness. In a qualitative study of mother-

daughter interactions and adolescent diabetes care, Bobrow, Avuskin, and Siller (1985) reported that when conflict between the dyad was more emotionally charged, coupled with less capacity between members to negotiate matters, the daughter reported less self-care management skills and less adherence to medical treatment regimen. Likewise, Jacobson et al (1994) reported that adolescent boys were more sensitive to conflict in the family in comparison to adolescent girls. These researchers also reported that longitudinally, measures of family cohesion and family conflict were related to glycemic control with boys being especially sensitive to conflict level. Those boys who reported experiencing high level of conflict were found to have deterioration in glycemic control four years later.

In conclusion, empirical studies have revealed that perceived quality of family relations, including family cohesion and family conflict, are associated with adolescent adjustment to a chronic illness, regardless of disease type. Most of these studies have focused on adjustment with regard to disease management and compliance to medical treatment (e.g., glycemic control, asthma hospitalization) rather than on psychological adjustment. Furthermore, existing studies are limited to certain illnesses that are more common among adolescents (e.g. asthma, diabetes) and are exclusive to illnesses that are not as prevalent.

Depressive Symptoms and Chronic Illness in Adolescence

Adolescent Depressive Symptoms

A combination of biological, genetic, and psychosocial factors are involved in the development of depressive symptoms among adolescents (U.S. Department of Health and Human Services, 1999). Currently, several epidemiological and clinical studies have evidenced an early onset of depressive symptoms in adolescence (e.g., Harrington, 1992; Cicchetti & Toth, 1998; Chrisman, Egger, Compton, Curry, & Goldston, 2006). Such studies have found that depressive symptom patterns in adolescence are similar to those of adults including anhedonia,

low self-esteem, sadness, social withdrawal, weight changes, vegetative signs, and suicidal behavior (Wight, Sepulveda, & Aneshensel, 2003). Additionally, adolescents have unique symptoms which include the following symptoms: irritability, somatic complaints, familial aggression, and school withdrawal (Crowe, Ward, Dunnachie, & Roberts, 2006; Chrisman et al., 2006). However, disturbed mood is the core-defining characteristic of depression among adolescents (Chrisman et al., 2006). The symptoms of depression that begin in childhood often increase in early adolescence (Rutter, 1986) and may persist or reoccur in adulthood, often with increased symptom severity (Weissman et al. 1999).

It is common to find discordant reports of depressive symptoms from parents and adolescents (Chrisman et al., 2006). Research has found that parents are even less likely to identify depressive symptoms in their adolescents than are the adolescents themselves (Fleming, & Offord, 1990). Parents often mistake depressive symptoms as rebellion or “acting out” behavior. Further complicating this problem is that the psychological condition of the parent can affect the perception of adolescent depressive symptoms. For example, depressed mothers have been found to over report the depressive symptoms of their adolescent (Renouf & Kovacs, 1994). Such varying reports on adolescent adjustment are influenced by interpretations of adolescent behavior and are dependent on the parent as an observer as well as the relationship between the parent and the adolescent.

In comparison to normal or nondepressed teenagers, clinically depressed adolescents report family relations as less cohesive and express less secure attachment style with their parents (Armsden, McCauley, Greenberg, Burke, & Mitchell, 1990). Insecure attachment organization have been found to contribute to adolescent depressive symptoms (e.g., low self-esteem, helplessness, hopelessness, negative attributional biases) and to interpersonal difficulties during

adulthood (Kobak, Sudler, & Gamble, 1991). Moreover, studies have found that quality of family relations contributes to adolescents' internal representation of self and affect regulation (Cicchetti & Toth, 1998). Thus, it is notable that depressive symptomatology has been found to be related to family relations.

Chronic Illness and Depressive Symptoms

Considerable disagreement exists as to whether chronic medical problems increase the risk of depressive symptoms among adolescents. Published studies have reported conflictive and inconclusive evidence of higher depression rates among this clinical population with some studies citing more emotional problems among chronically ill adolescents (Anderson, 2004; Canning, Canning, & Boyce, 1992; Klinnert, McQuiad, McCormick, Adinoff, & Bryant, 2000) and others reporting no difference in these rates between healthy adolescents and those with a chronic illness (Capelli et al., 1989; Kellerman, Zeltzer, Ellenberg, Dash, & Rigler, 1980; Key, Brown, March, Spratt & Recknor, 2001). For example, Canning, Canning, and Boyce (1992) found more depressive symptoms among adolescents with a chronic illness, while Capelli et al. (1989) and Kellerman, Zeltzer, Ellenberg, Dash, and Rigler (1980) reported finding no difference in the amount of reported depressive symptoms between healthy adolescents and those with a chronic illness.

Researchers have found links between asthma and internalizing behavior among children and adolescents (Klinnert, McQuiad, McCormick, Adinoff, & Bryant, 2000; Wambolt, Fritz, Mansell, McQuaid, & Klein, 1998). Moreover, Seigel, Golden, Gough, Lahley, and Sacker (1990) reported finding that adolescents with asthma have more depressive symptoms than their healthy peers. Similar research studies have found evidence that children and adolescents who have asthma experience psychosocial problems that place them at risk for depressive symptoms (McNelis, et al., 2000; Shasha, Lavigne, Lyons, Pongracic, & Martini, 1999). Other studies,

however, reported that depressive symptoms of adolescents with asthma were within the normal range (Bender, Lerner, & Poland, 1991; Koinis, Murdock, & Berz, 2004; Roder, Kroonenberg, & Boekarerts, 2003; Sandler, Reynolds, Kliewer, & Ramirez, 1992).

Several studies have found high levels of depressive symptoms among adolescents with cancer as reported by their parents (Armstrong, Wirt, Nesbit, & Martinson, 1982; Sanger, Copeland, & Davidson, 1991). However, some studies have found no differences between adolescents with or without cancer in their level of depressive symptoms (Greenberg, Kazak, & Meadows, 1989; Kaplan, Busner, Weinhold, & Lenon, 1987; Radcliffe, Bennett, Kazak, Foley, Phillips, 1996).

Several studies of the prevalence rates of major depressive disorder among adolescents with cystic fibrosis using diagnostic interviews have found prevalence rates among these adolescents for this disorder to be within the normal range (2 – 4%) (Burke et al, 1989; Thompson, Hodges, & Hamlett, 1990), while others have reported a higher prevalence rate (9%) of a major depressive disorder among adolescents with cystic fibrosis than among children without a chronic illness (Thompson, Gustafson, Hamlett, & Spock, 1992). In addition, Simmons et al. (1985) reported more depressive symptoms among girls with cystic fibrosis compared to a normalized sample.

Although most studies of adolescents with diabetes mellitus have reported rates of depressive symptoms similar to those of healthy adolescents, several exceptions exist. For example, Hood (2006) found that adolescents with diabetes reported more depressive symptoms than their healthy peers with depressive symptoms. Moreover, their sample of adolescents with type 1 diabetes nearly doubled the highest estimated depression rate in community adolescents.

Seigal et al (1990) found that the rates of depressive symptoms among adolescents with diabetes were similar to those with asthma and sickle cell disease and higher than a healthy control group.

In a study of adolescents with Crohn's disease and ulcerative colitis, the investigators found that those with a chronic condition were more depressed than their healthy peers (Raymer, Weininger, & Hamilton, 1984). Burke et al. (1989) found that adolescents with Crohn's disease have a higher prevalence rate of depressive symptoms than a normal control group. Additionally, Engstrom (1992) found that adolescents with inflammatory bowel disease had higher reported level of depressive symptoms than healthy controls, with 25% of the adolescents meeting the criteria for a major depressive disorder.

Several studies have reported that adolescents with recurrent abdominal pain are at higher risk for depressive symptoms than their healthy peers. For example, Garber, Zeman, and Walker (1990) reported a prevalence rate of major depression to be 38% among children and adolescents with recurrent abdominal pain. Similarly, Walker et al. (1993) also reported more depressive symptoms among adolescents with recurrent abdominal symptoms than their healthy peers.

There are similar findings for studies on adolescents with sickle cell anemia. For example, in a study of 327 children and adolescents with sickle cell disease, Barbarin, Whitten, and Bonds (1994) found that 25 percent of their sample had significantly high level of depressive symptoms and higher level of depressive symptoms than healthy controls.

Key, Brown, Marsh, Spratt, and Recknor (2001) compared adolescents with various chronic illnesses to healthy comparison controls on reports of depressive symptoms. They hypothesized that the prevalence of depressive symptoms among the chronically ill group would be higher than those in the healthy adolescent group. They found few differences between these groups. However, their findings indicate that adolescents with asthma and sickle cell disease had

higher level of depressive symptoms relative to other groups with a chronic illness. Adolescents who perceived their illness as severe reported more depressive symptoms than those who rated their illness as mild. The authors suggest that distorted or inaccurate perceptions of disease severity are likely to result in the learned helplessness phenomenon and high level of depressive symptoms. Likewise, Frank, Blount, and Brown (1997) found that depressive attitudes, such as helplessness and distortions, predicted depression in children with cancer.

The inconclusive and conflictive evidence regarding the association of chronic illness with depression among adolescents may be due to variations in research methodology and a lack of an empirically based taxonomic classification system in which research findings could be integrated. However, general conclusions regarding the emotional adjustment of adolescents with a chronic illness indicate that these adolescents are at risk of having depressive symptoms (Thompson & Gustafson, 1996).

The Association of Chronically Ill Adolescents' Depressive Symptoms with Perceived Level of Family Cohesion and Family Conflict

It is notable that the relationship between depressive symptomatology and family relations has been extensively examined among physically healthy adolescents; however, there has been very limited attention to examining this relationship among adolescents with a chronic illness. Much of the prior research on the psychosocial adjustment of adolescents with a chronic illness has focused solely on the individual, without considering the family's role in patient adjustment. Furthermore, most studies of adolescent adjustment that include a focus on family relations have investigated adherence to treatment regimen, disease management, and family functioning at the time of diagnosis. Only a small number of studies have focused on family relations and the psychosocial adjustment of chronically ill adolescents.

In a study of adolescents with juvenile rheumatic disease, important associations between life stressors, family relations, and adaptation were identified. Timko, Stovel, Moos, and Miller (1992) found that those adolescents who experienced more negative life events reported more depression. After negative life events were controlled, chronic stressors among parents (e.g., conflict) were associated with depressive symptoms among the adolescents. Overall, chronic and acute stressors and lack of support from parents were associated with depressive symptoms among adolescents with juvenile rheumatic disease. In a similar study that included adolescents with juvenile rheumatic disease and healthy adolescents, support from family members was associated with more self-confidence and less depressive symptoms (Moos & Moos, 1994). Likewise, among studies of children with asthma, researchers have found a positive relationship between family cohesion and child psychological adjustment (Reichenberg & Broberg, 2005; Donnelly, 1994).

In a study on families with children who have epilepsy, the children with epilepsy who reported high level of depressive symptoms scored lower on family support and cohesion than did children with epilepsy who had low or no depressive symptoms. (Rodenburg, Meijer, Dekovic, & Aldenkamp, 2005). Similarly, Dunn, Austin, and Huster (1999) reported that children with epilepsy who experienced high level of family conflict had high level of depression.

Depressive symptomatology has also been found to be related to adolescents' and mothers' reports of conflictual family relations in physically healthy adolescents (Fendrich, Warner, & Weissman, 1990; Stark, Humphrey, Crook, & Lewis, 1990, Cole & McPherson, 1993; Forehand et al., 1988; Hops, 1990). Conflict may be a source of stress in the relationship and could result in a stressful family environment. Studies have indicated that perceptions of high level of

adolescent-mother conflict among adolescents are correlated with high level of adolescent depressive symptoms (Marmorstein, & Iacono, 2004). Moreover, adolescents who report high level of depressive symptoms also report less warmth, closeness, support, and intimacy in their relations with their mothers (Greenberger, Chen, Tally, & Dong, 2000).

In a study using a community sample of healthy adolescents and their mothers, Sheeber, Hops, Alpert, Davis, Davis, and Andrews (1997) reported that the quality of family relationships is associated to depressive symptomatology among adolescents. Specifically, low level of family cohesion and high level of family conflict were associated with greater depressive symptomatology at baseline and prospectively over a 1-year period. These results are similar to clinical studies which have shown that parent-adolescent interactions predict the course of adolescent depressive disorders (Asarnow, Tompson, & Woo, 2001; Sanford et al., 1995). Similarly, Sheeber, Hops, Alpert, Davis, and Andrews (1997) demonstrated that adolescent perceptions of negative family relations (high level of conflict and low level of cohesion) were a stable characteristic of those adolescents with depressive symptomatology. Consequently, a conflictive, stressful family environment could be associated with depressive symptoms among chronically ill adolescents (Ge, Lorenz, Conger, Elder, & Simons, 1994).

It has also become evident that the associations between family relations and depressive symptomatology may vary according to the gender of the adolescent (Kavanagh & Hops, 1994). Several studies have indicated that a lack of cohesive and supportive family relations has a stronger association with depressive symptomatology among girls than boys (Avison & McAlpine, 1992; Rubin et al., 1992; Slavin & Rainer, 1990; Windle, 1992). Similarly, Windle (1992) found that low level of family cohesion was a predictor of depressive symptomatology among adolescent girls. A reason for this may be because girls gain individuation more slowly

than boys (Huston & Alvarez, 1990). Girls often have more conflictive relationships with their mothers and are monitored more closely on their activities than boys (Huston & Alvarez, 1990). Furthermore, girls are more oriented toward interpersonal relationships and place greater value on interpersonal concerns than boys, making girls more susceptible to experiencing depressive symptoms when they are in conflictive and unfulfilling family relations (Jones & Costin, 1995; Wong & Csikszentmihalyi, 1991, Hops, 1995; Leadbeater, Blatt, & Quinlan, 1995).

Cultural and ethnic differences among family relations and adolescent depressive symptoms have not been thoroughly investigated. In a study by Cuffe, McKeown, Addy, and Garrison (2005), undesirable life events and low family cohesion were associated with adolescent depression among African American and White American participants. The authors reported that African-American adolescent females were at significantly lower risk of depressive symptoms than African-American adolescent males, whereas white adolescent females showed a higher risk than white males, but not at a significant level.

The Association of Adolescents' Depressive Symptoms with Discrepancies in Perceived Level of Family Cohesion and Family Conflict

Disagreement between mother and adolescent perceptions of the quality of their family relations is not uncommon (Henggeler, Borduin, & Mann, 1987; Pelton and Forehand, 2001; Noller & Callan, 1986). Reported differences on views of the family environment often reflect unique perspectives, different experiences, and biases among different family members (Achenback, McConaughy, & Howell, 1987; Offord, Boyle, & Racine, 1989). Therefore, each family member may perceive family interactions differently.

To date, research has shown that there is considerable disagreement between mothers and adolescents perceptions of family relations (Henggeler, Bourduin, & Mann, 1987; Pelton & Forehand, 2001; Noller & Callan, 1986). However, few published studies have examined the

association of depressive symptoms with discrepant views of family relations among healthy adolescents, and there are no such published studies examine these associations that involve chronically ill adolescents.

Paikoff, Calton-Ford, and Brooks-Gunn's (1993) studied divergent perceptions (or "discrepant" perceptions) within the mother-daughter relationship and the association of such divergence with the daughter's emotional and behavioral adjustment. Specifically, they investigated how much of a discrepancy exists between groups of mother versus groups of daughters on their perceived family relations and whether the level of discrepancy was associated with depressive symptomatology and dieting behavior among the daughters. These researchers found that high level of discrepancies between mothers and daughters on perceived family conflict and family cohesion was related to depressive symptoms and dieting behavior of the daughters. Moreover, the authors reported a significant association between the level of discrepancy between mothers and daughters reports of family conflict and adolescent depressive symptoms, with higher level of depressive symptoms related to higher level of discrepancy between mother-daughter perceptions of family conflict.

Given the research findings indicating that discrepancies in perception between adolescents and their mothers may be negatively related to adolescent adjustment, it is important to study how such discrepancies may be linked to depressive symptoms among chronically ill adolescents. Yet, studies to investigate such links have not been published. This study will address this gap in the adolescent health research.

Purpose of the Proposed Study

The present exploratory study examined chronically ill adolescents' and their mothers' perceptions of family cohesion and family conflict and discrepancies in these perceptions as predictors of the adolescents' reported level of depressive symptoms. The four hypotheses and one research question that were investigated are presented in the following section.

Hypothesis #1: Family cohesion, as perceived by the chronically ill adolescents and their mothers, would have a significant negative association with the level of depressive symptoms reported by the adolescents such that higher perceived family cohesion level would be associated with lower reported level of depressive symptoms by the adolescents.

Hypothesis #2: Family conflict, as perceived by chronically ill adolescents and their mothers, would have a significant positive association with the level of depressive symptoms reported by the adolescents such that higher perceived family conflict level would be associated with higher reported level of depressive symptoms.

Hypothesis #3: Discrepancies in perceived level of family cohesion between chronically ill adolescents and their mothers would be a stronger predictor of the level of depressive symptoms reported by the adolescents, as compared to their individual and their mothers' perceived level of family cohesion.

Hypothesis #4: Discrepancies in perceived level of family conflict between chronically ill adolescents and their mothers would be a stronger predictor of the level of depressive symptoms reported by the adolescents, as compared to their individual and their mothers' perceived level of family conflict.

Research question: Will there be significant differences in adolescents' perceived level of family cohesion and family conflict, or reported level of depressive symptoms in association with their gender and age?

CHAPTER 3 METHODOLOGY

Participants

This study is a secondary study from a larger study of health promoting behaviors and health risk behaviors among African American and White American adolescents diagnosed with a chronic illness (i.e., asthma, diabetes, hypertension) who receive health care through Children's Medical Services (CMS) in Gainesville, Florida. CMS is a healthcare agency that primarily provides and coordinates health care services for children and adolescents in low-income families.

The present study approaches the investigation of adjustment among adolescents with a chronic illness by including different types of chronic illnesses rather than researching a specific illness. Lavigne and Faier-Routman (1990) presented a framework for organizing approaches towards researching adjustment of children and adolescents living with a chronic illness. This framework emphasized the importance of investigating generic factors that extend across different types of chronic illness that may influence adjustment difficulties as well as factors that are specific to individual illnesses. The authors recommend that both types of research approaches are important and should serve as guides for subsequent research.

A total of 145 eligible CMS patients agreed to participate in this study. From those 145 adolescent-mother pair participants, 87 pairs (64% return rate) returned their assessments to the principal investigator. Of those who did not return their assessments, 10 indicated that they changed their mind about participating in this study and the remaining 38 either could not be contacted or did not return our follow-up calls. It is not known whether those who participated are a representative sample of all eligible CMS patients because the CMS data management

system was not capable of identifying demographic distributions (e.g., ethnicity, race, gender) regarding their patient population.

The participants for the present study are the same as those who participated in the larger study. These participants consisted of 32 African American adolescents (23 females and 9 males) and their mothers (32 females) and 49 White American adolescents (28 females and 21 males) and their mothers (49 females). The adolescent participants ranged in age from 12 to 17 years old, with a mean age of 13.3 for the African American adolescents ($SD = 1.5$) and 13.8 for the White American adolescents ($SD = 1.3$). The adult participants ranged in age from 30 to 67 years old, with a mean age of 44.1 for the African American mothers and 41.1 for the White American mothers. The demographic characteristics of the participants in this study are presented in more detail in Table 1-3.

The criteria for inclusion in this study were as follows: (a) is between the ages of 12 and 17 years old; (b) has attended CMS at least once in the year prior to the start of planned research; (c) identifies as African American not of Hispanic origin or White American not of Hispanic origin (d) has had a diagnosis of a chronic medical illness (i.e., asthma, diabetes, hypertension) for at least one year prior to the planned research, (e) reports as being able to communicate effectively verbally or in writing in her or his native language, (f) gives written assent or consent to be a research participant. The criteria for exclusion from this study were as follows: (a) children younger than 12 and adolescents older than 18, (b) identifies her or his race or ethnicity as being other than African American and White American, (c) is part of an adolescent-male primary caregiver pair.

Instruments

All participants (adolescents and their mothers) were asked to complete an assessment battery that consisted of several research instruments. The adolescents were asked to complete

the Family Relations Index, the Center for Epidemiologic Studies-Depression Scale, the Marlowe-Crowne Social Desirability Scale-Short Form, and the Youth Information Questionnaire. Their mothers were asked to complete the Family Relations Index, the Marlowe-Crowne Social Desirability Scale-Short Form, and the Adult Information Questionnaire. These instruments are described in the following section.

The Family Relations Index (FRI; Moos & Moos, 1994). The conceptualization of family relations used in the present study is based on Moos and Moos's (1986) empirical approach which measures family characteristics, specifically those that are important in the psychological adaptation of family members. Moos and Moos's model describes the family environment in terms of three dimensions: a) relationship dimension, which measures the overall quality of family support, b) personal growth dimension, which describes the family's goal orientation and activity, and c) system maintenance dimension, which describes the family's control and structure.

The Family Relations Index (Moos & Moos, 1986) assesses the quality of a family's social relationships by measuring family cohesion, family expressiveness, and family conflict. The FRI consists of three subscales, Cohesion, Expressiveness, and Conflict, with each subscale comprised of nine true or false items. The cohesion subscale measures the general degree to which family members' display receptivity and emotional support of one another. It is the degree of commitment, help, and support family members provide for one another. An item example is "Family members really back each other up". The conflict subscale measures the level of openly expressed anger, aggression, and conflict among family members. Therefore, the conflict subscale is the negative direction variable on which healthier families score lower. An item example is "We fight a lot in our family." The Expressiveness subscale measures the level to

which family members are encouraged to express their feelings and act openly towards each other. An item example is “We tell each other about our personal problems”. For the purpose of this study, only Family Cohesion data and Family Conflict data were considered for statistical purposes.

For the Cohesion subscale, high scores indicate very connected, supportive family relationships. For the Conflict subscale, low scores indicate low level of conflict and high scores indicating high level of conflict among family members. The FRI subscales have moderate to high internal consistencies, with Cronbach’s alphas ranging from .61 to .78. Two-month test re-test reliabilities for two of the subscales are .86 for cohesion, and .85 for conflict. The authors of the instrument report the FRI as having high internal consistency (Cronbach’s alpha = 0.89). Additionally, the FRI was found to significantly correlate with other social support inventories and outcome measures.

The Center for Epidemiologic Studies-Depression Scale (CES-D; Radloff, 1977). The CES-D scale is a short report scale designed to measure 20 depressive symptoms in the general population. Each item is rated on a Likert-type scale with the following four response categories: “Rarely or None of the time”, “Some or a little of the time,” “Occasionally or a moderate amount of the time,” and “Most or all of the time.” An item example is “I felt depressed”. Scores range from 0 to 60, with higher scores indicating higher level of depressive symptoms. The CES-D has high internal consistency with Cronbach’s alphas ranging from .85 to .90. Correlations of the CES-D with other report depression scales give reasonable evidence of discriminant validity (i.e., Bradburn Balance Scale .62; Bradburn Negative Affect Scale .63; Lubin Affect Scale .70).

The Marlowe-Crowne Social Desirability Scale-Short Form (M-C SDS-SF: Crowne & Marlowe, 1960). The M-C SD-SF scale is used to measure the degree to which those who

completed it tend to present themselves in a socially desirable manner. It is based on a 33-item instrument originally developed by Crowne and Marlowe (1960). The M-C SD-SF scale consist of 20 questions to be responded to using a true or false format. An item example is “I like to gossip at time.” Scores on the M-C SD-SF range from 0 to 20, with high scores indicating high need for approval.

Research studies have reported high Pearson correlations of .98 between the original version and the short version of the M-C SD-SF indicating adequate construct validity for the short version (Fraboni & Copper, 1989; Strahan & Gerbasi, 1972). The authors of the measure report M-C SD-SF test-retest reliabilities range from .80 to .84.

The Youth Information Questionnaire (YIQ; developed by the researchers who conducted the larger study). The Youth Information Questionnaires was designed to elicit personal information about the adolescent participants that may be relevant to the analysis and results of the study. The YIQ has questions that ask for: (a) demographic data (e.g., age, ethnicity, level of education), (b) reported chronic health conditions (e.g., diabetes, obesity, and/or hypertension), and (c) leisure activities.

Adult Information Questionnaires (AIQ; developed by the researchers who conducted the larger study). The Adult Information Questionnaires was designed to elicit personal information about the adult research participants that may be relevant to the analysis and results of the study. The AIQ has questions that ask for: (a) demographic data (e.g., age, ethnicity, work information, level of education), (b) information about family size, and (c) information about their adolescent.

Procedure

Recruitment of Participants

Permission to conduct research using adolescents and their primary parent/caregiver who utilize the health care services of Children’s Medical Services (CMS) was obtained from CMS.

Approval of the research protocol was obtained from the Institutional Review Board-01 of the University of Florida and from Florida's Department of Health. Once the sought permission and approvals were obtained, participants were recruited using two methods –letters of invitation and recruitment posters.

The letters of invitation method involved having CMS staff members identify potential CMS adolescents and their primary parents/caregivers for participation in the larger study of which the present study is a part using the specified inclusion and exclusion criteria. Each potential adolescent and primary parent/caregiver pair identified using this method was mailed an invitation packet which included: (a) an invitation letter, (b) two copies of the Adult Consent Form, (c) two copies of the Adolescent Assent Form, (d) the Youth Information Questionnaire, (e) the Adult Information Questionnaire, and (f) postage-paid, pre-addressed envelopes –one for the mother's completed packet and the other for the adolescent's completed packet. The invitation letter included a brief summary of the study and specified the participation criteria. Additionally, it stated that (a) each adolescent-mother pair would be paid \$20 for their participation, (b) the duration of participation would be approximately 45 minutes, (c) not all volunteer patient-parent pairs would be selected for participation in the study, (d) neither participation nor nonparticipation would affect the adolescents' healthcare in any way, (f) selected adolescent-mother pairs would be assigned (by researcher) to one of three parts of the larger research project, (g) invited interested parents should read and sign the Adult Consent Forms, (h) invited interested adolescents should read and sign the Adolescent Assent Forms, (i) interested parents should return the signed Adult Consent Form and the Adult Information Questionnaire in an enclosed postage-paid, pre-addressed envelope, (j) interested adolescents should return the signed Adolescent Assent Form and the Youth Information Questionnaire in an

enclosed postage-paid, pre-addressed envelope, (k) a copy of the Adult Consent Form and the Youth Assent Forms should be kept as records of their participation agreement.

The recruitment poster method involved displaying recruitment posters with an attached drop-box and contact information requests at Children's Medical Services offices. The posters: (a) briefly described the study and specified the participation criteria, (b) had attached cards with blanks for the parent(s)' name(s), address, ethnicity/race, and phone number, (c) gave instructions to place completed cards in the attached drop-box, and (d) indicated that if a card was filled out and put in the drop-box, someone would call the primary parent/caregiver within five days to explain the study more fully. During this telephone call, primary parents/caregivers were told (a) what would be expected of her/him as a research participant, (b) that each adolescent-parent pair would be paid \$20 for their participation, (c) that the duration of participation would be approximately 45 minutes, (d) that not all volunteer adolescent-parent pairs would be selected for participation in the study, (e) that neither participation nor nonparticipation would affect the adolescents' healthcare in any way, and (f) that selected adolescent-parent pairs would be assigned (by researcher) to one of three parts of the larger research project. Once a adolescent-parent pair verbally agreed to participate in the research, the pair was sent an invitation packet which included (a) an invitation letter (b) two copies of the Adult Consent Form, (c) two copies of the Adolescent Assent Form, (d) the Youth Information Questionnaire, (e) the Adult Information Questionnaire, and (f) postage-paid, pre-addressed envelopes –one for the mother's completed packet and the other for the adolescent's completed packet.

Procedure

Regardless of the technique used to recruit participants, after all interested participants returned the Adult Consent Form or the Adolescent Assent Form, they were then sent an

individual assessment packet containing: (a) a cover letter, (b) The Family Relations Index, (c) The Center for Epidemiologic Studies-Depression Scale, (d) The Marlowe-Crowne Social Desirability Scale-Short Form, and (e) a postage-paid, pre-addressed envelope.

The cover letter described the content of the packet, gave brief instructions on how to complete the assessments, and included that it would take approximately 45 minutes to complete. It also included the instruction to (a) read and carefully follow the instructions at the top of each instrument/questionnaire, (b) respond to the questions as honestly as possible, and (c) choose the responses that best fit how they feel, think, and behave. It was also stated in the cover letter that all information provided would be used exclusively for research purposes and would remain completely confidential and anonymous.

To ensure anonymity, researchers pre-assigned codes (instead of names) to all instruments in the assessment packet. Participants were asked not to write any identifiers (e.g., names, addresses) on their inventories or on their postage-paid, pre-addressed envelopes. Adolescent-mother pairs were asked to separately complete and return all assessment packets in the postage-paid, pre-addressed envelopes within two weeks of receiving them.

Each of the adolescent-mother pairs were given a monetary compensation of \$20.00 for participation within two weeks of receiving their completed packet. To ensure confidentiality, all Adult Consent Forms and Adolescent Assent Forms were kept in a locked file cabinet separate from participant's research data.

Table 3-1: Demographic Description of African American and White American Participant

Variable	African American		White American	
	Adolescent	Mother	Adolescent	Mother
	N = 32	N = 32	N = 49	N = 49
Age				
Range	12 -17	30 – 67	12 – 17	30 – 67
Mean	13.3	44.1	13.8	41.1
Gender	<u>N</u>	<u>N</u>	<u>N</u>	<u>N</u>
Female	23	32	28	49
Male	9		21	
Diagnosis	<u>N</u>		<u>N</u>	
Asthma	6		15	
Diabetes	5		3	
Other	21		31	
Income Level		<u>N</u>		<u>N</u>
Below \$10,000		7		6
\$10,000-\$19,000		11		19
\$20,000-\$29,000		6		20
\$30,000-\$39,000		2		3
\$40,000 or above		3		1
Missing		3		0

N = 162

CHAPTER 4 RESULTS

This chapter presents the descriptive data and the results of the data analyses conducted to test the hypotheses and examine the research question set forth in this study. All data analyses were conducted separately on the African American adolescent-mother group and the White American adolescent-mother group consistent with the culturally sensitive Difference Model research approach (Oyemade & Rosser, 1980). This approach stresses the importance of recognizing within-group differences by identifying culture-specific factors when investigating academic, cognitive, or social behavior of diverse cultural groups. This is important because differences found between these groups could be the result of cultural differences rather than deficits or deficiencies in one culture as opposed to the other.

The results are presented in five major parts. First, descriptive and normative data on all of the measures are presented. Second, Pearson correlation analyses to assess the degree of relationship between the Marlowe-Crowne Social Desirability Scale-Short Form and each of the independent and dependent variables are reviewed. Third, the results of a series of Pearson correlation analyses to test Hypotheses 1 and 2 are discussed. Fourth, the results of multiple regression analyses used to determine the amount of variance that each predictor variable accounted for in each of the criterion variables are discussed. Lastly, the results of two MANOVAs used to test the research question are discussed. All statistical analyses were performed using the Statistical Package for Social Science 15.0 for Windows.

With respect to the third and fourth hypothesis, the present study approached disagreement in perception of family functioning as the discrepancy in reported level of family conflict and family cohesion between adolescent and mother pairs. To examine the level of discrepancy, standardized difference scores were computed for statistical analyses (Carlton-Ford, Paikoff, &

Brooks-Gunn, 1991; Reyes, & Kazdin, 2004). These scores were derived in two steps: (1) raw discrepancy scores were created by subtracting adolescent and mother pair reports of level of family cohesion and level family conflict; and (2) absolute difference scores were created by taking the absolute value of the raw discrepancy scores. The absolute difference score tests the possibility that discrepancy in either direction (adolescent over mother, or vice versa) would play a role in adolescent adjustment (Paikoff, Carlton-Ford, & Brooks-Gunn, 1993).

Descriptive and Normative Data for all Major Variables

Table 1-4 presents the means, standard deviations, and range for each variable under investigation in this study. Additionally, normative data for all available measures are presented in Table 1-4. It should be noted that the Marlowe-Crowne Social Desirability Scale-Short Form does not have norms available for adults and adolescents.

Correlations Between Variables of Interest and the Marlowe-Crowne Social Desirability Scale-Short Form

A preliminary Pearson Correlation analysis was performed to examine the relationships between social desirability as measured by the Marlowe-Crowne Social Desirability Scale-Short Form (M-C SDS-SF) and scores on the Family Relations Index (family conflict and family cohesion scores) and the Center for Epidemiologic Studies-Depression Scale (CES-D) (adolescent depressive symptoms scores). This procedure was conducted to determine if any of the ratings of the variables of interest were influenced by the tendency to give socially desirable responses by the adolescent and mother participants. The results indicated that only one of the family relation variables correlated significantly with social desirability: the African American mothers' scores on the M-C SDS-SF had a low but significant negative relationship ($r = -.357$, $p < .05$) with mothers' level of perceived family conflict. Thus, social desirability was controlled in data analyses involving African American mothers' perception of family conflict. Scores on

the M-C SDS-SF were not significantly associated with any of the other variables of interest among the African American or the White American groups. Table 2-4 contains the results of this analysis.

Results of Analyses to Test Hypothesis 1

A series of Pearson correlation analyses were performed in order to test Hypothesis 1, which stated that family cohesion (as perceived by adolescents and their mothers) would have a significant negative association with the level of depressive symptoms reported by the adolescents. The result of the correlation analysis involving African American adolescents revealed that the adolescents' perceived level of family cohesion had a significant negative association with their reported level of depressive symptoms ($r = -.534, p < .01$), thus supporting Hypothesis 1. The result of the correlation analysis involving African American mothers indicated that the mothers' perceived level of cohesion was not significantly associated with adolescents' reported level of depressive symptoms ($r = -.279, p > .05$) and does not support Hypothesis 1. The result of the correlation analysis involving the White American adolescents revealed that the adolescents' perceived level of family cohesion had a moderate, significant negative association with their reported level of depressive symptoms ($r = -.415, p < .01$), which provides support for Hypothesis 1. The result of the correlation analysis involving the White American mothers revealed that the mothers' perceived level of cohesion had a moderate but significant negative association with adolescents' reported level of depressive symptoms ($r = -.382, p < .01$), thus providing support for Hypothesis 1. Table 3-4 presents the results of these analyses.

Results of Analyses to Test Hypothesis 2

A series of Pearson correlation analyses were performed in order to test Hypothesis 2, which stated that family conflict, as perceived by adolescents and their mothers, would have a

significant positive association with the level of depressive symptoms reported by the adolescents. The result of the correlation analysis involving the African American adolescent revealed that the adolescents' perceived level of family conflict had a significant positive association ($r = .575, p < .001$) with their reported level of depressive symptoms, thus providing support for Hypothesis 2. The result of the correlation analysis involving African American mothers' perceived level of family conflict was not significantly associated with adolescents' reported level of depressive symptoms and does not support Hypothesis 2, ($r = .215, p > .05$). The result of the correlation analysis involving the White American adolescents revealed that the adolescents' perceived level of family conflict had a significant positive association ($r = .577, p < .001$) with their reported level of depressive symptoms, which provides support for Hypothesis 2. The result of the correlation involving the White American mothers revealed that mothers' perceived level of family conflict had a moderate but significant positive association ($r = .353, p < .01$) with adolescents' reported level of depressive symptoms, thus providing support for Hypothesis 2. Table 3-4 presents the results of these analyses.

Results of Analyses to Test Hypothesis 3

Hypothesis 3 stated that discrepancies in perceived level of family cohesion between chronically ill adolescents' and their mothers' (cohesion difference score) would be a stronger predictor of the level of depressive symptoms reported by the adolescents, as compared to their individual and their mothers' perceived level of family cohesion. Two forced entry multiple regression analyses were conducted to test Hypothesis 3—one with the data of the African American participants and one with the data of the White American participants, in accordance with the Difference Model research approach (Oyemade & Rosser, 1980). The criterion variable for these analyses was adolescents' reported level of depressive symptoms and the predictor variables were the adolescents' level of perceived family cohesion, the mothers' level of

perceived family cohesion, and level of adolescent-mother pair perceived differences in family cohesion (as represented by cohesion difference scores). The predictor variables were entered simultaneously in the multiple regression analyses. These findings are summarized in Table 4-4.

The model for the group of African American adolescent-mother pairs was tested first. Variance inflation factors (VIF) and tolerance statistics were examined. There was no evidence of multicollinearity; VIF values were between 1.30 and 1.03 and all tolerance values were between .96 and .76. This model was significant $F(3,23) = 5.09, p < .01$ and accounted for 32.1% of the variance in adolescent depressive symptoms. However, adolescent perception of family cohesion was the only significant predictor of adolescent depressive symptoms ($t = -3.41, p < .01$). The results of this analysis do not provide support for Hypothesis 3.

Lastly, the model for the group of White American adolescent-mother pairs was tested. There was no evidence of multicollinearity; VIF values were between 2.02 and 1.16 and all tolerance values were between .86 and .49. This model was significant $F(3,43) = 4.68, p < .01$, and accounted for 24.6% of the variance in adolescent depressive symptoms. However, adolescent perception of family cohesion was the only significant predictor of adolescent depressive symptoms ($t = -2.53, p < .05$). The results of this analysis do not provide support for Hypothesis 3. These findings are summarized in Table 4-4.

Results of Analyses to Test Hypothesis 4

Two separate multiple regression analyses were conducted to test Hypothesis 4, which stated that discrepancies in perceived level of family conflict between chronically ill adolescents' and their mothers' would be a stronger predictor of the level of depressive symptoms reported by the adolescents, as compared to their individual and their mothers' perceived level of family conflict. The criterion variable for these analyses was adolescents' level of depressive symptoms, and the predictor variables were the adolescents' level of perceived family conflict, the mothers'

perceived level of family conflict, and levels of adolescent-mother pair perceived differences in family conflict (as represented by conflict difference scores). These findings are summarized in Tables 5-4. and 6-4.

A stepwise multiple regression analysis was performed to test Hypothesis 4 using the data from the African American participants. The Marlowe-Crowne Social Desirability Scale-Short Form scores for the African American mothers was entered in the first step in order to control for social desirability, given that these scores were significantly correlated with their scores on the perceived family conflict measure. There was no evidence of collinearity; VIF values were between 1.01 and 1.12 and tolerance values were between .89 and .99. This model was not significant $F(3,21) = 2.53, p > .05$. The results of this analysis do not provide support for Hypothesis 4. These findings are summarized in Table 5-4.

A forced entry multiple regression analysis was performed to test Hypothesis 4 using the data from the White American participants. There was no evidence of multicollinearity; VIF values were between 1.09 and 1.45 and tolerance values were between .68 and .91. This model was significant $F(3,44) = 7.50, p < .001$, and accounted for 33.8% of the variance in adolescent depressive symptoms. However, adolescent perception of family conflict was the only significant predictor of adolescent depressive symptoms ($t = 3.57, p < .001$). The results of this analysis do not provide support for Hypothesis 4. These findings are summarized in Table 6-4.

Results of Research Question Analyses

To examine the research question, which asked whether there are significant differences in adolescents' perceived level of family cohesion and family conflict or in their reported level of depressive symptoms in association with their gender and age, two Multivariate Analyses of Variance (MANOVA) were performed-one using the data of the African American adolescents and one using the data of the White American adolescent participants. The independent variables

in the MANOVAs were age and gender, and the dependent variables were the adolescents' perceived level of family cohesion, family conflict, and their own depressive symptoms. The data of adolescent age was entered as a categorical variable and was distributed into one of two groups: early adolescence or late adolescence.

Results of the MANOVA for the group of African American adolescents, using Wilks's criterion, did not reveal significant effects for age $F(18, 563) = .76, p > .05, \eta = .64$, or gender $F(18, 563) = 2.25, p > .05, \eta = .74$. No significant interaction effects emerged.

The results of the second MANOVA for the group of White American adolescents, using Wilks's criterion, indicated a significant effect for gender, $F(36, 1014) = 2.83, p < .05, \eta = .80$, but not for age, $F(36, 1014) = .62, p > .05, \eta = .77$. However, the results of the tests of between-subjects effect for gender did not reveal significant effects for cohesion $F(1, 45) = 2.76, p > .05$, conflict, $F(1, 45) = 2.09, p > .05$, or adolescent depressive symptoms, $F(1, 45) = .633, p > .05$. Additionally, the interaction between age and gender was not significant, $F(36, 1014) = 1.15, p > .05, \eta = .68$. These findings are summarized in Table 7-4.

Table 4-1: Descriptive and Normative Data for the FRI, CES-D, and M-C SD-SF Inventories

Variables	Present Study			Norms	
	Mean	SD	Range	Mean	SD
Adolescent					
FRI Cohesion				6.09	2.11
African American	6.23	1.87	2 - 9		
White American	5.97	2.04	1 - 9		
FRI Conflict				4.30	2.27
African American	3.10	1.99	0 - 7		
White American	3.62	2.33	0 - 9		
Social Desirability				N/A	N/A
African American	12.09	4.12	4 - 20		
White American	13.71	3.77	5 - 20		
CES-D				13.8	9.09
African American	16.18	15.31	0 - 51		
White American	11.92	12.47	0 - 46		
Adult					
FRI Cohesion				6.80	2.02
African American	6.30	2.07	1 - 9		
White American	6.26	2.49	0 - 9		
FRI Conflict				3.76	2.32
African American	2.89	2.37	0 - 9		
White American	3.24	2.00	0 - 8		
Social Desirability				N/A	N/A
African American	14.58	3.93	3 - 20		
White American	11.98	3.59	4 - 18		
Cohesion Difference Score				N/A	N/A
African American	1.56	1.88	0 - 8		
White American	1.82	1.62	0 - 6		
Conflict Difference Score				N/A	N/A
African American	1.80	1.32	0 - 5		
White American	1.70	1.42	0 - 5		

N = 162

N/A = Norm data is not available

Table 4-2: Relationship Between Social Desirability Scores and Variables of Interest

	Adolescent M-C SD-SF	Mother M-C SD-SF
Adolescent Depressive Symptoms		
African American	-.054	
White American	.111	
Adolescent Family Cohesion		
African American	.288	
White American	-.134	
Adolescent Family Conflict		
African American	.045	
White American	-.015	
Mother Family Cohesion		
African American		-.032
White American		.149
Mother Family Conflict		
African American		-.357*
White American		-.224

* Correlation is significant at the 0.05 level (1-tailed)

Table 4-3: Pearson Correlations Among Study Variables for Adolescents and Mothers by Ethnic Group

	1	2	3	4	5	6	7
1. Adolescent Cohesion							
African American	--	.00	-.12	-.42*	-.02	.02	-.53**
White American	--	.37**	-.68**	-.53**	-.31*	-.33*	-.42**
2. Mother Cohesion							
African American		--	-.24	-.43**	-.55**	.46**	-.28
White American		--	-.10	-.44**	-.73**	-.20	-.38**
3. Cohesion Difference Score							
African American			--	.38*	.30	-.17	.23
White American			--	.22	.01	.35**	.13
4. Adolescent Conflict							
African American				--	.48**	-.01	.57**
White American				--	.50**	.22	.58**
5. Mother Conflict							
African American					--	.07	.22
White American					--	-.06	.35**
6. Conflict Difference Score							
African American						--	-.04
White American						--	.13
7. Adolescent Depression							
African American							--
White American							--

Note: * $p < .05$, ** $p < .01$

Table 4-4: Multiple Regression Predicting Adolescent Depressive Symptoms Scores from Adolescent Family Cohesion, Mother Family Cohesion, and Cohesion Difference Scores

Variable	Standardized Beta	t
African American (n = 32 pairs)		
Adolescent Cohesion	-.562	-3.41**
Mother Cohesion	-.071	-.389
Cohesion Difference Score	.179	.971
White American (n = 49 pairs)		
Adolescent Cohesion	-.477	-2.53*
Mother Cohesion	-.234	-1.64
Cohesion Difference Score	-.217	-1.21

Note: * $p < .05$, ** $p < .01$

Table 4-5: Stepwise Regression Predicting Adolescent Depressive Symptoms Scores from Adolescent Family Conflict, Mother Family Conflict, and Conflict Difference Scores Using African American Participants' Data

Variable	Standardized Beta	t
African American (n = 32 pairs)		
Step 1		
Mother M-C SDS-SF		.439
Step 2		
Adolescent Conflict	.536	2.72*
Mother Conflict	-.112	-.567
Conflict Difference Score	-.032	-1.68

Note: * $p < .05$, ** $p < .01$

Table 4-6: Multiple Regression Predicting Adolescent Depressive Symptoms Scores from Adolescent Family Conflict, Mother Family Conflict, and Conflict Difference Scores Using White American Participants' Data

Variable	Standardized Beta	t
White American (n = 49 pairs)		
Adolescent Conflict	.528	3.56**
Mother Conflict	.090	.619
Conflict Difference Score	.018	.140

Note: * $p < .05$, ** $p < .01$

Table 4-7: Summary of MANOVA Models to Test Research Question

Variable	F	η
African American Model		
Age	.762	.644
Gender	2.25	.738
Age x Gender	.546	.921
White American Model		
Age	.620	.765
Gender	2.83	.795*
Age x Gender	1.15	.679

Note: * $p < .05$, ** $p < .01$

CHAPTER 5 DISCUSSION

The purpose of this chapter is to summarize and interpret the results of the performed data analyses. This chapter is organized in four parts. First, results regarding Hypotheses 1 and 2 are reviewed and discussed. Second, the results regarding Hypothesis 3 and 4 are reviewed and discussed. Next, the results of a research question concerning gender and age differences in the variables of study are discussed. Lastly, limitations of the present study and implications for future research and for the field of counseling psychology are presented.

Results Regarding Hypotheses 1 and Hypothesis 2

Hypothesis 1 proposed that family cohesion, as perceived by adolescents with a chronic illness and their mothers, would have a significant negative association with the level of depressive symptoms reported by the adolescents such that higher perceived level of family cohesion by the adolescents and their mothers would be associated with lower reported level of depressive symptoms by the adolescents. To address Hypothesis 1 two Pearson correlations were conducted for each ethnic group—one that included the cohesion and depressive symptoms data of the adolescents and one that included the cohesion data of the mothers and the depressive symptoms data of the adolescents. Findings included that among the African American adolescents perceived level of family cohesion was significantly associated with their reported depressive symptoms. Those adolescents with high scores on family cohesion had low scores on depressive symptoms, providing support for Hypothesis 1. Additionally, it was found that among the African American mothers, perceived level of family cohesion was not significantly correlated with level of adolescent depressive symptoms.

For the group of White American adolescents, it was found that perceived level of family cohesion was significantly associated with their reported level of depressive symptoms. Those

adolescents with high scores on family cohesion had low scores on depressive symptoms, providing support for Hypothesis 1. Additionally, it was found that White American mothers' perceived level of family cohesion was significantly associated with their adolescents' reported level of depressive symptoms, providing support for Hypothesis 1.

Hypothesis 2 proposed that perceived level of family conflict, as experienced by adolescents with a chronic illness and their mothers, would have a significant positive association with the level of depressive symptoms reported by the adolescents such that higher level of family conflict by the adolescents and their mothers would be associated with higher reported level of depressive symptoms by the adolescents. To address Hypothesis 2 two Pearson correlations were conducted for each ethnic group –one that included the conflict and depressive symptoms data of the adolescents and one that included the conflict data of the mothers and the depressive symptoms data of the adolescents. Findings included that among the African American adolescents perceived level of family conflict was significantly associated with their reported level of depressive symptoms such that those adolescents with high scores on family conflict had high scores on depressive symptoms, providing support for Hypothesis 2. Additionally, it was found that among the African American mothers, perceived level of family conflict was not significantly correlated with level of adolescent depressive symptoms.

For the White American adolescents, it was found that perceived level of family conflict was positively associated with their reported level of depressive symptoms. Additionally, it was found that White American mothers' perceived level of family conflict was positively associated with their adolescents' reported level of depressive symptoms, providing support for Hypothesis 2.

The findings for Hypothesis 1 and 2 in the present study are consistent with earlier studies on family relations among adolescents with a chronic illness. Previous studies have indicated that there are protective factors associated with high level of family cohesion (Donnelly, 1994; Moos & Moos, 1994; Reichenberg & Broberg, 2005; Timko, Stovel, Moos, & Miller, 1992) and maladaptive factors associated with high level of family conflict (Cuffe, McKeown, Addy, & Garrison, 2005; Dunn, Austin, & Huster, 1999) among adolescents with a chronic illness. This suggests that family relations, such as those perceived as cohesive by adolescents, serve as a buffer that reduces stressful life events and disease-related stressors. On the other hand, family relations perceived as high in conflict by adolescents are associated with added stressors and increased depressive symptoms among adolescents with a chronic illness.

It should be noted that perceived level of family relations (family conflict and family cohesion) by African American mothers was not associated with adolescent reports of depressive symptoms. This finding is similar to a longitudinal study by Sagrestano, Paikoff, Hombeck and Fendrich (2003) which found that African American parents' reports of family conflict were not associated with child and adolescent depressive symptoms whereas child and adolescent reports of family conflict were positively associated with their depressive symptoms. A reason for this could be that reports of family relations as perceived by family members are subjective. Moreover, subjective reports are subject to report bias. As such, adolescent perceptions are stronger predictors of adolescent outcomes and mother perceptions are stronger predictors of mother outcomes.

A second factor which may have influenced the findings in relation to African American mother participants in this study may be due to variation in parenting behaviors among different ethnic groups (Dearing, 2004). It is likely that effective parenting behavior may depend on

cultural and environmental differences as well as individual family characteristics. For example, African American mothers value obedience, conformity, and respect for authority as child-rearing goals. They tend to use restrictive monitoring and parental control as effective parenting behaviors more than White American parents who have similar socio-economic status (Elder, Eccles, Ardel, & Lord, 1995; Furstenberg, Cook, Eccles, Elder, & Sameroff, 1999). Recent studies have found benefits of restrictive parenting styles for African American children and not for White American children living in similar settings (Dearing, 2004). The measures used in this study may not have been sensitive to cultural differences in parenting styles and values among African American mothers.

Another possible reason for the insignificant findings in relation to African American mothers' report of family cohesion and family conflict, and adolescent report of depressive symptoms is the questionable validity of data in the current study. It is possible that the wording of items could have been misinterpreted. It may be that participants were confused or did not understand some items but completed them without clarification. Thus, scores on the Family Relations Index could have failed to reliably reflect level of family cohesion and family conflict as perceived by African American mothers. Moreover, since the Family Relations Index was normed on a mostly white, middle S.E.S. sample from mid-western states, it is possible that the communication, actions, customs, beliefs, and values of low income African American families were not taken into consideration in the development of the instrument.

Another reason could be that response bias may have threatened the validity of the data acquired by African American mothers' completed questionnaires. Some respondents may have completed the questionnaires with the intention of portraying socially desirable family

interactions. Although efforts were made to control for socially desirable responses, it is possible that social desirability systematically biased the family relations variables investigated.

Results Regarding Hypothesis 3 and Hypothesis 4

Hypothesis 3 proposed that discrepancies in perception of family cohesion between chronically ill adolescents and their mothers would be a stronger predictor of the level of depressive symptoms reported by the adolescents, as compared to their individual and their mothers' perceived level of family cohesion. Results of two forced entry multiple regression analyses yielded significant models for the group of African American adolescent-mother pairs and for the group of White American adolescent-mother pairs. However, discrepancies in perceived level of family cohesion between adolescents and their mothers did not predict adolescent depressive symptoms. In contrast, for both ethnic groups, adolescent perception of family cohesion predicted adolescent depression. The results of these analyses did not provide support for Hypothesis 3.

Hypothesis 4 proposed that discrepancies in perception of family conflict between chronically ill adolescents and their mothers would be a stronger predictor of the level of depressive symptoms reported by the adolescents, as compared to their individual and their mothers' perceived level of family conflict. Results of a step-wise regression analysis yielded an insignificant model for the group of African American adolescent-mother pairs. Therefore, discrepancies in perceived level of family conflict between African American adolescents and their mothers perceived level of family conflict, as well as their individual and their mothers perception of family conflict, did not predict adolescent depressive symptoms.

For the group of White American adolescent-mother pairs, a forced-entry multiple regression analysis yielded a significant model. However, adolescent perception of family conflict was the only predictor of adolescent depression. Discrepancies in perceived level of

family conflict between adolescents and their mothers did not predict adolescent depressive symptoms. Hypothesis 4 was not supported.

The findings from the present study did not support the view held by some family theorist and clinicians (e.g., Moos & Moos, 1986; Tein, Roosa, & Michaels, 1994) that discrepancies in family members perception of family relations are related to adolescent internalizing behaviors (Ohannessian, Lerner, Lerner, & von Eye, 1995) and problems in family relationships (Moos & Moos, 1986). A study by Carlson, Cooper, and Spradling (1991) yielded some interesting results which are relevant to the present study. They examined adolescent-mother perceptions of family cohesion and family conflict and reported that discrepancies in adolescents' and their mothers' perception of family conflict was related to lower level of adolescents' self-esteem and self-competence. However, the reverse was found when they examined discrepancies between the level of family cohesion between boys and their mothers with high level of discrepancy positively associated with adolescent self-competence and self-esteem. According to the authors, their findings suggest that there may be an adaptive component to discrepancies in adolescent-mother perception of family relations.

Moreover, according to some developmentalists (e.g., Montemayor & Flannery, 1991; Steinberg, 1990, 1991) discrepancies in adolescent-mother perceptions of family relations may be adaptive in some respects. Minor disagreements in perceptions of family cohesion and family conflict may be necessary for mastery of specific developmental tasks such as the development of identity and autonomy. For example, Holmbeck and O'Donnell (1991) found that conflicts related to adolescent issues (e.g., chores, appearance) may result in discrepancies in perceptions of family conflict and cohesion. In that study, the authors note that changes in family relations convey changes in the adolescent and their role in the family and provide support for successful

individuation. This is consistent with models of individuation (e.g, Grotevant & Cooper, 1986) which state that in order for adolescents to successfully develop their identity they need to individuate from their family. Even though discrepancies in perceptions of family cohesion and family conflict are associated with increased level of conflict and stress among family members, discrepancies in perceptions of family relations may be adaptive for adolescents.

A factor which may have influenced the nonsignificant findings on the relation between discrepancies of family relations and adolescent depressive symptoms was the low levels of discrepancy of family relations reported by participants in the present study. For the African American adolescent-mother pair group, the mean for the conflict difference score was 1.8 and the mean for the cohesion difference score was 1.6. For the White American adolescent-mother pair group, the mean for the conflict difference score was 1.7 and the mean for the cohesion difference score was 1.8. This indicates that overall there was a small degree of variation in perception of family conflict and family cohesion between adolescents and mother participants in this study. It should be noted that including a larger sample of adolescent-mother pair participants who have higher level of discrepancies in their view of family relations may yield significant findings.

Interestingly, low level of family cohesion predicted depressive symptoms for African American adolescents and White American adolescents whereas high level of family conflict predicted adolescent depressive symptoms uniquely for White American adolescents. This finding is consistent with previous studies which indicate that family cohesion is the most critical family relations variable that predicts adolescent depressive symptoms among low-income African American families (Carlton-Ford, Paikoff, Oakley, Brooks-Gunn, 1996; Herman, Ostrander, & Tucker, in press). The importance of family cohesion among African American

families could be due to traditional values of family connectedness which includes a broader network of relationships and extended family members. Hill (1998) described several strengths of contemporary African American families which includes formation of strong kinship bonds and flexible family roles. One strategy to help prevent or treat African American adolescent depressive symptoms is to build on these cultural values and strengthen family connectedness and cohesion.

White American families are generally less inclusive, with limited number of family members, and an emphasis on the nuclear family structure. The traditional family is generally defined in terms of autonomy, individual responsibility, and individual happiness (Stone, 1994). The importance of individual happiness and autonomy allows children and adolescents to disagree and argue with their parents. Generally, people from other cultures would consider such “disagreements” as signs of disrespect and lack of family connectedness however; it is considered part of developing individuality. Seen in this context, some degree of conflict is common amongst family members. However, increasing communication and support among family members and decreasing family conflict would be effective interventions to prevent or treat adolescent depressive symptoms.

Results of Analyses to Examine a Research Question

The research question asked whether there were significant differences in adolescents’ perceived level of family cohesion and family conflict and their reported level of depressive symptoms in association with their gender and age. The results of a Multivariate Analysis of Variance (MANOVA) analyses for the African American adolescent group revealed that there were no differences among the dependent variables in association with gender and age.

The results of a second MANOVA analyses for the White American adolescent group revealed that there was a significant effect for gender but not for age. However, test of between-

subjects effects did not find a significant effect for gender in relation to family cohesion, family conflict, or adolescent depressive symptoms. Considering that the mean age of participants in present study was 13, the insignificant findings of the age and gender variables in both MANOVAs are consistent with the literature in the area, which suggests that depressive symptoms are more prominent during late adolescence. Prior research has indicated that gender differences associated with depression begin at age 13 but are most detectable at age 16 (Angold & Rutter, 1992). After puberty, the ratio of depression is approximately two females to one male, reaching the prevalence rate found in adults (Allgood-Merten, Lewinsohn, & Hops, 1990; Hankin et al., 1998; Petersen et al., 1993).

Similarly, in a longitudinal study of family relations, parenting style, and depression among low-income African American adolescents (ages 9 – 15), Sagrestano, Paikoff, Holmbeck, and Fendrich (2003) did not find gender or age differences in association with adolescent symptomatology across 2 waves of data collection. Further, in a study of depressive symptoms among adolescents with a chronic illness, Key, Brown, March, Spratt & Recknor (2001) did not find differences among gender, race, and socio-economic status in predicting depressive symptoms among adolescents.

A factor that could have affected this study's nonsignificant results is the small number of adolescent subjects ($n = 32$ African American; $n = 49$ White American) participating in the present study. The small amount of adolescent participants may have resulted in inadequate power in the statistical analyses to detect any significant differences between family conflict, family cohesion, and adolescent depressive symptoms in relation to gender and age. Moreover, a sample with greater variation in adolescent age could have yielded different findings.

Limitations of the Research

Although the current study contributes to the body of literature in a number of ways, it is worthy to note limitations. It should be noted that the present study had a sample of adolescent–mother pair participants who reported low levels of discrepancy in perception of family relations which may have in turn reduced that possibility of important variation. The next step in the study of discrepancy of family relations among adolescents with a chronic illness and their mothers should involve the use of adolescent-mother pairs who have higher level of discrepancy in perception of family relations.

Another limitation of this study was that the sample size was relatively small and restricted to a particular geographic area (North Central Florida). Moreover, the sample only included African American and White American adolescent-mother pairs. Therefore, the present study has limited generalizability, and interpretations should be viewed with caution. Longitudinal studies with a larger group of ethnically and culturally diverse participants are needed to confirm the proposed relationships and causal sequence. Furthermore, a larger sample size may reveal stronger findings than those found in the present study.

This study relied on self-report measures of family relations and adolescent depressive symptoms, which might represent another limitation. Even though the present study included use of a social desirability scale to control for source bias, there is a common method variance that arises from purely self-report measures. Moreover, including self-report depressive symptoms scores gathered during one time point might not have given an exact assessment of adolescent depressive symptoms which might have changed over time. Lastly, as with any study an unexplained “third” variable may influence the association of perception of family relations and adolescent depressive symptoms. Therefore, the findings of the present research study cannot be

assumed to be causal. Even given these limitations, the present research study has implications for future research.

Implications for Future Research

While there has been previous research studies conducted on the association of family relations and the adjustment of adolescents with a chronic illness, the study of the discrepancies in the perceptions of family cohesion and family conflict among adolescents with a chronic illness and their mother as predictors of adolescents' depressive symptoms is novel. Published studies have yielded inconclusive and conflictive evidence regarding the association of discrepancies of family relations and the adjustment of physically healthy adolescents, with some studies reporting adolescent adjustment problems and others reporting positive adolescent outcomes. The present study did not find evidence that discrepancies in family members' perceptions of family relations are related to adolescent depressive symptoms among chronically ill adolescents. Further examination of adolescent-mother discrepancies in perceptions of family relations as adaptive or maladaptive among adolescents with a chronic illness are warranted and should address the limitations of the present study.

Future studies of discrepancies in family member's perceptions of family relations and adolescent adjustment should include families who report high levels of discrepancies in perception of family relations as well as include more representative samples (e.g., age, race/culture, and socio-economic diversity). Inclusion of both parents or primary caregivers, siblings, and extended family members may provide further insight on the relationship between family relations and adjustment of adolescents with a chronic illness. Additionally, longitudinal research designs that incorporate culturally sensitive inventories, measures of observation and behavioral analysis, and diagnostic measures of adolescent depression should be a next step in

research studies aimed at understanding the implications of family member discrepancies in perceptions of family relations among adolescents living with a chronic illness.

Implications for the Field of Counseling Psychology

One implication of the findings of this study is that that family cohesion and family conflict may be useful indicators of psychosocial functioning among adolescents with a chronic illness. Assessment of African American adolescent perceptions of family cohesion and White American adolescent perceptions of family cohesion and family conflict are important because they are linked to adolescent depressive symptoms. Moreover, assessment of family cohesion and family conflict facilitates the identification of family strengths and weaknesses on which to build on through counseling interventions.

Considering that the findings of the present study suggest that adolescent perceptions of family relations are better predictors of adolescent depressive symptoms, individual therapy may better facilitate treatment and prevention of adolescent depressive symptoms. Clinical intervention and prevention programs should evaluate perception of family relations and depressive symptoms among adolescents with a chronic illness and incorporate improving family communication, mutual respect, and family support as targets for individual and family interventions. Ideally, interventions would be adaptable to the particular aspects of the individual and the family's cultural background as well as broadly applicable to various cultures. As a result, studying the factors that contribute to adolescent adjustment can help improve positive health outcomes and adolescent adjustment.

Conclusions

The present study was conducted for two major purposes. First, this study was conducted to examine the association of family relations (family cohesion, family conflict) and adolescent depressive symptoms among African American adolescents with a chronic illness and their

mothers and among White American adolescents with a chronic illness and their mothers. Second, this study was conducted to examine among chronically ill African American adolescents and their mothers and among chronically ill White American adolescents and their mothers whether discrepancies in perceived levels of family relations (family cohesion, family conflict) were stronger predictors of adolescents' reported depressive symptoms than their individual or their mothers' perception of family relations. Statistical analyses were performed to test four hypotheses related to the above stated major purposes of this study and one research question. These analyses were performed separately by race according to the Difference Model research approach (Oyemade, & Rosser, 1980).

Findings from this study did not support the view that discrepancies in family relations among adolescents with a chronic illness and their mother predicts adolescent depression. However, it should be noted that African American adolescents' perception of family cohesion and White American adolescent perception of family cohesion and family conflict did predict adolescent depressive symptoms. Thus, the present study could be interpreted as suggestive of patterns of family relations and adjustment of African American adolescents and White American adolescents with a chronic illness. According to the results, it is possible that family cohesion may serve as a buffer against depressive symptoms for African American and White American adolescents with a chronic illness regardless of discrepancies of perception of family cohesion among family members. These findings suggest that improving family cohesion (or positive family relations) may help prevent or alleviate depressive symptoms among African American and White American adolescents with a chronic illness. Moreover, reducing family conflict, for White American families, may help prevent or alleviate adolescent depressive symptoms.

Rather than using universal explanations for the results of the present study, separately examining predictors of adolescent outcomes within specific racial and ethnic groups yielded unique relationships between family cohesion, family conflict and adolescent depressive symptoms. Findings such as these support the Difference Model research approach (Oyemad & Rosser, 1908) and the understanding that the socio-contextual factors associated with adolescent adjustment may vary among different ethnic groups.

APPENDIX A
YOUTH INFORMATION QUESTIONNAIRE

Directions: Please give all of your answers by completely filling in the circle beside your answer. It should look like this: ●. Remember, your answers to all questions in this packet will be kept completely private.

Are you female or male?

- Female
- Male

How old are you?

- 12
- 13
- 14
- 15
- 16
- 17

How do you describe yourself?

- African-American/Black-American (not of Hispanic origin)
- Caucasian/White/European-American (not of Hispanic origin)
- Hispanic/Latino
- Multi-Racial (please describe: _____)

What grade are you in?

- 5th
- 6th
- 7th
- 8th
- 9th
- 10th
- 11th
- 12th
- I do not go to school

How many hours per week do you usually take part in sports and athletics at school or in your community (such as soccer, football, cheerleading, swimming, running, walking, or weightlifting)?

- None
- 1-5 hours each week
- 6-10 hours each week
- 11 or more hours each week

When we mail you things would you like them to be written in:

- English
- Spanish

Have you felt any of these things? (Fill in all that you have felt.)

- blurry vision
- dizzy
- shortness of breath
- thirsty a lot of the time

- headaches
- tired a lot of the time
- none

Which of the following, if any, has your doctor or someone else at your doctor's office asked you to do to treat your health condition or illness? (Fill in all that you have been told to do.)

- take medication
- change the kinds of things you eat
- exercise
- lose weight
- OTHER: _____

Do you think your doctor or someone else at your doctor's office has taught you how to take care of your health condition or illness? (Fill in one answer only.)

- Agree a lot
- Agree a little
- Not Sure
- Disagree a little
- Disagree a lot

Do you have (Fill in all that you have):

- high blood pressure
- diabetes (sugar)
- asthma
- allergies
- other: _____
- ADHD
- cardiac (heart) disease

Do you think you are overweight?

- No
- Yes

In school, which of these grades do you mostly make?

- A
- B
- C
- D
- F

This year, what is your overall Grade Point Average (GPA)? _____

This year, what grade have you mostly made in English/Language Arts/Reading?

- A
- B
- C
- D

F

This year, what grade have you mostly made in Math?

A

B

C

D

F

This year, what grade have you mostly made in Social Studies/History?

A

B

C

D

F

This year, what grade have you mostly made in Science?

A

B

C

D

F

APPENDIX B
ADULT INFORMATION QUESTIONNAIRE

Directions: Please give all of your answers by completely filling in the circle beside your answer. It should look like this: • Remember, your answers to all questions in this packet will be kept completely private.

What is your sex?

- Female
- Male

How do you describe yourself?

- African-American/Black-American (not of Hispanic origin)
- Caucasian/White/European-American (not of Hispanic origin)
- Hispanic/Latino
- Multi-Racial (Please describe: _____)

What is your current relationship status?

- Divorced or separated
- Married, living with partner
- Married, not living with partner
- Single, living with partner
- Single, living without partner
- Widow/Widower

What is your employment status?

- Work Full Time (30-40 hrs)
- Work Part Time (10-30 hrs)
- Do not work

What is the highest level of education that you have completed?

- Elementary School
- Middle/Junior High School
- High School
- Some College/Technical School
- College
- Professional/Graduate School

What is your annual household income level?

- Below \$10,000
- \$10,000 to \$19,999
- \$20,000 to \$29,999
- \$30,000 to \$39,999
- \$40,000 or above

How many children currently live with you in your home?

- none
- one
- two
- three
- four
- five
- six
- seven
- eight
- other: _____

How many adults currently live with you in your home?

- none
- one
- two
- three
- four
- five
- six
- seven
- eight
- other: _____

Do you believe your child is overweight?

- Yes
- No

When we mail you things would you like them to be written in:

- English
- Spanish

Which county do you live in?

- Alachua
- Bradford
- Columbia
- Dixie
- Gilchrist
- Other (Please specify: _____)
- Hernando
- Levy
- Marion
- Putnam

Please write your answers to the following questions in the blanks provided:

In the last year, how many times have you visited the medical clinic you usually attend: _____

How many years have you lived in this community: _____

Your age: _____

PLEASE RETURN BOTH PAGES OF THIS QUESTIONNAIRE

Thank you for helping us with this research!

APPENDIX C
FRI

Directions: There are 27 statements on these pages. They are statements about families. You are to decide which of these statements are true of your family and which are false.

True – Fill in the circle under the “True” column when you think the statement is True or mostly True of your family.

False – Fill in the circle under the “False” column when you think the statement is False or mostly False of your family.

You may feel that some of the statements are true for some members and false for others. Fill in the circle under the “True” column if the statement is true for most members. Fill in the circle under the “False” column if the statement is false for most members. If the members are evenly divided, decide what is the stronger overall impression and answer accordingly.

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

- | <u>True</u> | <u>False</u> | |
|-----------------------|-----------------------|---|
| <input type="radio"/> | <input type="radio"/> | Members really help and support one another. |
| <input type="radio"/> | <input type="radio"/> | Members often keep their feelings to themselves. |
| <input type="radio"/> | <input type="radio"/> | There is a lot in our family. |
| <input type="radio"/> | <input type="radio"/> | Arguments seem to be killing time at home. |
| <input type="radio"/> | <input type="radio"/> | Nothing we want to do around home. |
| <input type="radio"/> | <input type="radio"/> | Members rarely become openly angry. |
| <input type="radio"/> | <input type="radio"/> | Members put a lot of energy into what we do at home. |
| <input type="radio"/> | <input type="radio"/> | Members do not “blow off steam” at home without upsetting somebody. |
| <input type="radio"/> | <input type="radio"/> | Members sometimes get so angry they throw things. |
| <input type="radio"/> | <input type="radio"/> | There is a strong feeling of unity and cohesion in our family. |
| <input type="radio"/> | <input type="radio"/> | Members talk to each other about our personal problems. |
| <input type="radio"/> | <input type="radio"/> | Members hardly ever lose their tempers. |
| <input type="radio"/> | <input type="radio"/> | Members do not volunteer when something has to be done at home. |
| <input type="radio"/> | <input type="radio"/> | Members do not like doing something on the spur of the moment we often just pick up and go. |
| <input type="radio"/> | <input type="radio"/> | Members often criticize each other. |
| <input type="radio"/> | <input type="radio"/> | |
| <input type="radio"/> | <input type="radio"/> | |

16. Family members really back each other up.
17. Someone usually gets upset if you complain in our family.
18. Family members sometimes hit each other.
19. There is very little group spirit in our family.
20. Financial matters are openly discussed in our family.
21. If there's a disagreement in our family, we try hard to smooth things over and keep the peace.
22. We really get along well with each other.
23. We are usually careful about what we say to each other.
24. Family members often try to one-up or out-do each other.
25. There is plenty of time and attention for everyone in our family.
26. There are a lot of spontaneous discussions in our family.
27. In our family, we believe you don't ever get anywhere by raising your voice.

APPENDIX D
CES-D

Directions: For the 20 items listed below, please fill in the answer that best describes how you have felt over the last week. It should look like this: ●

	Rarely or none (<1 day)	Some or a little (1-2 days)	Occasionally (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I did not feel like eating; my appetite was very poor.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I felt that I could not shake off the blues even with the help from my family and friends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I felt that I was not as good as other people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I had trouble keeping my mind on what I was doing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I felt depressed.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I felt that everything I did was an effort.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I felt hopeless about the future.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I thought my life had been a failure.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I felt fearful.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. My sleep was restless.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. I was unhappy.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. I talked less than usual.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. I felt lonely.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. People were unfriendly.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. I did not enjoy life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- | | | | | |
|-------------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 17. I had crying spells. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 18. I felt sad. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 19. I felt that people disliked me. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 20. I could not get “going”. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

APPENDIX E
M-C SDS-SF

Directions: For each of the following statements, please completely fill in the answer you consider to be True (T) or False (F). It should like this: ●

- | | True | False |
|---|------|-------|
| 1. I never hesitate to go out of my way to help someone in trouble. | O | O |
| 2. I have never intensely disliked anyone. | O | O |
| 3. I sometimes feel resentful when I don't get my way. | O | O |
| 4. I like to gossip at times. | O | O |
| 5. There have been times when I felt like rebelling against people in authority even though I knew they were right. | O | O |
| 6. I can remember "playing sick" to get out of something. | O | O |
| 7. There have been occasions when I took advantage of someone. | O | O |
| 8. I'm always willing to admit it when I make a mistake. | O | O |
| 9. I always try to practice what I preach. | O | O |
| 10. I sometimes try to get even, rather than forgive and forget. | O | O |
| 11. When I don't know something I don't at all mind admitting it. | O | O |
| 12. I am always courteous, even to people who are disagreeable. | O | O |
| 13. At times I have really insisted on having things my way. | O | O |
| 14. There have been occasions when I felt like smashing things. | O | O |
| 15. I would never think of letting someone else be punished for my wrong-doings. | O | O |
| 16. I never resent being asked to return a favor. | O | O |
| 17. I have never been irked when people expressed ideas very different from my own. | O | O |
| 18. There have been times when I was quite jealous of the good | | |

fortune of others.

19. I am sometimes irritated by people who ask favors of me.

20. I have never deliberately said something to hurt someone's feelings.

APPENDIX F
INFORMED CONSENT ADULTS

UF-IRB01 194-2003, RCHS 1266

Informed Consent to Take Part in Research
and Authorization for Collection, Use, and
Disclosure of Protected Health Information
(Parents/Caregivers - CMS)

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You are being asked to take part in a research study. This form provides you with information about the study and seeks your authorization for the collection, use and disclosure of your protected health information necessary for the study. The Principal Investigator (the person in charge of this research) or a representative of the Principal Investigator will also describe this study to you and answer all of your questions. Before you decide whether or not to take part, read the information below and ask questions about anything you do not understand. Your participation is entirely voluntary.

1. Name of Parent/Caregiver Participant (please print):

Last name	First name	Middle name

2. Title of Research Study
The Children's Health Self-Empowerment Project

3a. Principal Investigator and Telephone Number(s):
Carolyn M. Tucker, Ph.D.
University of Florida
Distinguished Alumni Professor
Professor of Psychology and Director of Training
Professor of Pediatrics
Professor of Community Health and Family Medicine
352-392-0601 Ext. 256

3b. Co-Investigator
Sharon Surrency, RN, MPH
Children's Medical Services

Executive Nursing Director, Gainesville/Ocala/Daytona/Jacksonville

4. Source of Funding or Other Material Support

The State of Florida Department of Health, Division of Children's Medical Services, is funding this research.

5. What is the purpose of this research study?

The goal of this project is to teach young people ways to live more healthy lives. The project will involve both teenagers and their parents or guardians. The people who take part in the project will be African American, Hispanic/Latino(a) American and Caucasian American. Teenagers who take part in the study will be patients at Children's Medical Services (CMS). There will be about 270 teenagers who will take part in this project. One parent or guardian will take part with each teenager, so there will be about 270 adults taking part in this project.

Another goal of this project is to teach ways to live more healthy lives to a group of African American teenagers who took part in a neighborhood after school program. The teenagers' parent or guardian will also take part. If these teenagers want to take part, they must tell us that they are overweight and/or have high blood pressure. They might also say that their parent or guardian is overweight and/or has high blood pressure. There will be 25 teenagers and 25 adults in this group.

The project will use 3 workshops to teach:

1. ways to eat healthier, exercise, and worry less.
2. ways to not fight, not use drugs and alcohol, and not have protected or unprotected sex.
3. ways to lose weight if they are overweight.
4. ways to lower their blood pressure if they have high blood pressure.
5. ways to lower their blood sugar levels if they have diabetes.

The project will also ask teenagers who have CMS health care providers and their parents or guardians:

1. What behaviors and attitudes of their CMS Nurse Care

Coordinators, doctors, nurses, and clinic staff can make them feel:

- a) more comfortable
- b) more respected
- c) more trusting

2. how the waiting room and doctors exam room of the clinic can make them feel:

- a) more comfortable
- b) more respected
- c) more trusting

6. What will be done if you take part in this research study?

You are being invited to take part in this project because your child:

1. Is 12 to 17 years old.
2. Is a patient of Children's Medical Services (CMS).

This project has two parts: Part I and Part II. If you want to take part in this project, you will be chosen for only one of the two parts. Here is what will happen in each of the two parts:

Part I. If you are chosen to be in this part of the project, you will be asked to:

1. answer questions about your child's Nurse Care Coordinator, doctors, nurses, and clinic staff. The questions will ask what these persons can do to make you feel:
 - a) more comfortable
 - b) more respected
 - c) more trusting of them
2. rate how important some behaviors and attitudes are to make you feel:
 - a) more comfortable
 - b) more respected
 - c) more trusting of them
3. answer some true or false questions about yourself

It should take about one hour to answer all of these questions. Your name and your child's name will not be put on any of your answers to the questions that you are asked to fill out. Instead of using your name we will give you a code. We will write this code on all of the research forms to protect your privacy. None of your child's CMS Nurse Care Coordinators, doctors, nurses, or clinic staff will see your answers. These persons will also not be told if your family is taking part in the project.

If you are chosen to take part in Part I, you will get a packet in about 3 weeks. You will be asked to fill out the forms and send them back to us in about 2 weeks. We will send the packet after we get your completed and signed Informed Consent Form. Once you finish the packet and send it to the CHSE research team you should get paid in about 3 weeks (go to item number 10 on page 8 to learn about getting paid for taking part in this research). The total time you could be asked to take part in this research is about 3 months.

A person from the CHSE research team may call you if the packet is not completed and sent back to us in about 2 weeks. This call will be made to make sure that you got the packet. You may also be called after you send your packet to us. A person from the CHSE research team may call you if some of the information is missing. When we call, if you do not want to answer the questions you do not have to.

All information about you will be kept private. All information about you will be given a code to make this information private. Your name will be kept in a locked file cabinet in the Psychology building at the University of Florida. None of your child's CMS Nurse Care Coordinators, doctors, nurses, or clinic staff will be told if you are in this project.

Part II: If you are chosen for this part of the project, you will be asked to:

1. take part in 3 health workshops. Each workshop will be about 4 hours long. The health workshops will teach you things like:
 - how to have less family worry and sadness

- how to make and eat healthier food
- how to exercise more and worry less
- the risks of having unprotected and protected sex, and so on.

You will be asked to take part in all of the workshop activities. You can choose not to take part in any activity that makes you feel uncomfortable. You can also choose not to finish any activity that you may have started.

2. answer some questions about things like:

- your health behaviors and beliefs
- how your family deals with worry and sadness
- if you have unprotected sex
- smoking
- drug use
- alcohol use
- violent behaviors
- if you have tried to kill yourself
- if you exercise
- what kinds of foods you eat
- how motivated you are
- whether some questions about you are true or false

If you have problems or need help with these things, please talk to your doctor. We will not be able to help you. Your answers to these questions will be kept private.

It should take you about two hours to answer all of the questions. You should take breaks when filling out the forms so that you do not get tired. Please try to work on the forms for only 45 minutes at a time. Then take at least a 2-hour break before working some more on finishing the forms.

Your name will not be put on any of the questions or forms you fill out. Instead of using your name we will give you a code. We will write this code on all of the forms that you fill out to protect you and your child's privacy. None of your child's CMS Nurse Care Coordinators, doctors, nurses, or clinic staff, will see your answers. They will not be told if your family is taking part in the project.

There will be 2 different groups in Part II. If you are chosen to take part in Part II, you will be put in only one of the groups.

- Part II Intervention Group
 - About 3 weeks after we get your completed Informed Consent Form you will get your first packet of questionnaires and forms.
 - Once you finish the packet and send it to the CHSE research team you should get paid in about 3 weeks (go to item number 10 on page 8 to learn about getting paid for taking part in this research).
 - About 2 months later you will be asked to take part in the 3 workshops.

- The 3 workshops will be about 3 weeks apart. Each workshop will be about 4 hours long. You should get paid about 3 weeks after you go to the 3rd workshop (go to item number 10 on page 8 to learn about getting paid for taking part in this research). You will need to go to all 3 workshops to get paid.
- About 6 months after the 3rd workshop you will get your 2nd packet of questionnaires and forms.
- Once you finish the packet and send it to the CHSE research team you should get paid in about 3 weeks (go to item number 10 on page 8 to learn about getting paid for taking part in this research).

This means that if you are chosen to be in the Part II Intervention Group you would take part for about 9 months.

- Part II Control Group
 - About 3 weeks after we get your completed Informed Consent Form you will get your first packet of question forms.
 - Once you finish the packet and send it to the CHSE research team you should get paid in about 3 weeks (go to item number 10 on page 8 to learn about getting paid for taking part in this research).
 - About 9 months later you will get your 2nd packet of questionnaires and forms.
 - About 3 weeks later you will be asked to take part in the 3 workshops.
 - The 3 workshops will be about 3 weeks apart. Each workshop will be about 4 hours long. You should get paid about 3 weeks after you go to the 3rd workshop (go to item number 10 on page 8 to learn about getting paid for taking part in this research). You will need to go to all 3 workshops to get paid.
 - About 6 months after the 3rd workshop you will get your 3rd packet of questionnaires and forms.
 - Once you finish the packet and send it to the CHSE research team you should get paid in about 3 weeks (go to item number 10 on page 8 to learn about getting paid for taking part in this research).

This means that if you are chosen to be in the Part II Control Group you would take part for about 18 months.

A person from the CHSE research team may call you if a packet is not sent back in about 2 weeks. This call will be made to make sure that you got the packet. You may also be called after you send a packet to us. A person from the CHSE research team may call you if some of the information is missing. When we call, if you do not want to answer the questions you do not have to. Lastly, a person from the CHSE research team may call to remind you about upcoming project activities.

All information about you will be kept private. All information about you will be given a code. Your name will be kept in a locked file cabinet in the Psychology building at the University of Florida. None of your child's CMS Nurse Care Coordinators, doctors, nurses, or clinic staff will be told if you are in this project.

7. What are the possible discomforts and risks?

If you want to take part in this research, there should be no physical or psychological risks to you.

Some of the questions that will be asked may make you feel uncomfortable. If you do feel uncomfortable, please feel free to skip the questions that caused this feeling. During the study we will tell you of any changes in the risk of you taking part in the research. We will also tell you about any information that may change your wanting to take part in the study.

If you want to talk about the information above or any worries you may have, please call the Principal Investigator of the research, Dr. Carolyn M. Tucker. Dr. Tucker's phone number is (352) 392-0601 Ext. 256.

- 8a. What are the possible benefits to you?
If you are chosen for Part I, there is no instant or direct benefit to you.
If you are chosen for Part II, you may gain helpful ways to make healthy life choices. Your family may gain from learning how to deal with worries and disputes better in the health workshops.
- 8b. What are the possible benefits to others?
Your answers to the questions during the study will be joined with the answers of the other people in the study. When put together, your answers may help other people. They may help teach teenagers and their parents or guardians ways to live healthier lives. Your answers may also help teach CMS Nurse Care Coordinators, doctors, nurses, and clinic staff helpful ways to give better health care to all of their patients. These results may also raise patients' liking of the health care that they get.
9. If you choose to take part in this research study, will it cost you anything?
No, this research will not cost your family any money.
10. Will you receive compensation for taking part in this research study?
Yes. How much you will get paid depends on the part of the study you take part in. You cannot choose the part of the study that you will take part in. The amount of money that will be paid to you (and your child) for taking part in the research study is explained below:
- 1) Each family (you and your child together) in Part I who fill out and send back the question form packet will get a total of \$20.
 - 2) Each family (you and your child together) in Part II who is asked to take part in the intervention group and who fill out and send back the question form packet will get \$20. Each family is asked to do this 2 times for a total of \$40. You will get another \$40 for going to all 3 workshops. So, each family in the intervention group will get a total of \$80.
 - 3) Each family (you and your child together) in Part II who is asked to take part in the control group and who fill out and send back the question form packet will get \$20. Each family is asked to do this 2 times for a total of \$40. You will get another \$40 for going to all 3 workshops. After the 3 workshops you will be asked to fill out and send back the question form packet a 3rd time. You will get an

extra \$10 for doing this. So, each family in the control group will get a total of \$90.

Please Note: You will not get paid for sending us back this Informed Consent Form and the Adult Information Questionnaire. The question forms you will get paid for filling out will be sent to you after you agree to take part in the project.

In order to pay you, we will have to give your name and social security number to the people at the University of Florida who write the checks. They will also write down that you have been paid. You will get paid about 3 weeks after we get each of your packets. You will also get paid about 3 weeks after you go to all 3 workshops. If you stop taking part during the research study, you will only be paid for the parts that you took part in.

11. What if you are injured because of the study?
If you get hurt as a direct result of this study, you can be seen by a professional consultant at the University of Florida Health Science Center free of charge. But, hospital bills will have to be paid by you or your insurance provider. No other payment for being injured is offered.
12. What other options or treatments are available if you do not want to be in this study?
We do not know of any other options or treatments that are available to you if you do not want to be in this study.
- 13a. Can you withdraw from this research study?
Yes, you may stop taking part in or decide not to take part in this study at any time. If you do choose to stop taking part in the middle of the study,
- you will not be punished
 - your child will not be punished
 - you will still be paid for the parts that you took part in
- If you decide to stop taking part in the middle of the study for any reason, you should contact Dr. Tucker, the Principal Investigator, at (352) 392-0601 ext. 256.
- If you have any questions regarding your rights as a research subject, you may phone the Institutional Review Board (IRB) office at (352) 846-1494 or the Florida Department of Health Review Council for Human Subjects at (850) 245-4585, or toll free in Florida at (866) 433-2775.
- 13b. If you withdraw, can information about you still be used and/or collected?
Yes.
- Any information collected about you can be used for further research purposes.
 - Any information given directly to us by you can be used for further research purposes.
 - Only information collected before your decision to no longer take part in this research study will be used.
 - No further information will be collected after you decide to stop taking part in this research study.

- 13c. Can the Principal Investigator withdraw you from this research study?
 Yes, we may not allow you to stay in the study if:
- 1) You do not return this Informed Consent Form (or contact the principal investigator) within two weeks of getting it.
 - 2) You do not send us the question sheets we send you to fill out within two weeks of getting them.
 - 3) You are sent to jail or prison for more than one month while you are in the study.
 - 4) The Principal Investigator (Dr. Tucker) gives you a job while you are in the study.
 - 5) You do not meet the rules for taking part in the study. If you are not sure about these rules, please call the Principal Investigator (Dr. Tucker) at (352) 392-0601 Ext. 256.
 - 6) The Principal Investigator (Dr. Tucker) or Co-Investigator (Ms. Surrency) think that you might be hurt if you stay in the study.
 - 7) The study is stopped by the State of Florida Department of Health and/or is stopped for other administrative reasons.
14. How will your privacy and the confidentiality of your protected health information be protected?
 To keep your privacy:
- your Informed Consent Forms which identify you will be separated from your Adult Information Questionnaire
 - both will be locked in separate filing cabinets in the Psychology Building at the University of Florida.
 - a 3-digit number code followed by a “P” for parent will be placed on your questionnaires in place of your name.
 - the master-list that identifies you will be kept in a separate key-locked filing cabinet in Dr. Tucker’s office in the Psychology Department at the University of Florida.
- If you take part in this research, your private health information will be collected, used, and shared under the terms specified in sections 15–24 below.
15. If you agree to participate in this research study, what protected health information about you may be collected, used and disclosed to others?
 To find out if you can be in the study, the following information may be collected, used, and shared with other
- Your name, address, and phone number (which will not be shared with others)
 - Your age and ethnicity
 - Your answers to the questions that you will be asked to complete
16. For what study-related purposes will your protected health information be collected, used and disclosed to others?
 No personal protected health information will be given out. All of your information will be joined with other people’s information. Your protected health information will be collected to make a general report. Your protected health information will be used to find out if you are eligible for our study. Your information added to information

from others to report how useful the workshops are for helping people (teenagers and parents or guardians) with:

- lowering blood pressure
- lowering body weight
- lowering blood sugar level
- lowering drug use, violence, and unprotected sex in teenagers
- helping people to exercise, eat healthy foods, and worry less.

17. Who will be authorized to collect, use and disclose to others your protected health information?

Your private health information may be collected, used, and shared with others by:

- Dr. Carolyn M. Tucker, Ms. Sharon Surrency, and Dr. Tucker's research staff (Dr. Frederic Desmond, Dr. Keith Herman, Christopher Mack, Kellie Hyde, Phyllis Ivery, Rachelle Studer, and Cynthia Karlson)
- Other professionals at the University of Florida or Shands Hospital that provide study-related treatment or procedures
- The University of Florida Institutional Review Board
- The Florida Department of Health Review Council for Human Subjects

18. Once collected or used, whom may your protected health information be disclosed to?

Your protected health information may be given to:

- a. The Florida Department of Health Review Council for Human Subjects
- b. US and foreign governmental agencies who are responsible for overseeing research, such as the Food and Drug Administration, the Department of Health and Human Services, and the Office of Human Research Protections
- c. Government agencies who are responsible for overseeing public health concerns such as the Centers for Disease Control and Federal, State and local health departments

19. If you agree to participate in this research, how long will your protected health information be collected, used and disclosed?

Your private health information may be collected, used, and shared until the end of our study. The subject identifiers will be removed at the end of the study and the information will be maintained in a secure database forever.

20. Why are you being asked to authorize the collection, use and disclosure to others of your protected health information?

Under a new Federal Law, researchers cannot collect, use or share any of your private health information. Researchers must get you to allow them to do so by having you sign this consent form.

21. Are you required to sign this consent and authorization and allow the researchers to collect, use and disclose (give) to others of your protected health information?

No. If you do not want them to get your private health information, do not sign this consent form. It will not change anything of yours outside of this research study. If you do not sign this consent, you cannot take part in the research study. If you do not send this consent form back to us, you will not be contacted again.

22. Can you review or copy your protected health information collected, used or disclosed under this authorization?
Yes. You have the right to look at and copy your private health information. But, you will not be allowed to do so until after the study is done.
23. Is there a risk that your protected health information could be given to others beyond your authorization?
Yes. There is a small risk that information given to the researchers could be given to others. It would be outside of your control and not covered by the law.
24. Can you revoke (cancel) your authorization for collection, use and disclosure of your protected health information?
Yes. You can stop allowing the collection, use, and sharing of your private health information at any time. It could be before, during or after you take part in the research. No new information will be collected about you after you tell us to stop. If information was already collected it may still be used and shared with others. You can tell the researchers to stop collecting information by writing to us and signing your name.
25. How will the researcher(s) benefit from your being in this study?
In general, doing research helps the career of a scientist. So, Dr. Carolyn M. Tucker and her research team may benefit. They will benefit if the results of the study are shown at scientific meetings or in scientific journals.
26. Signatures
As the Principal Investigator of this study, I have shared with you:
- the goals
 - the things that you will have to do if you want to take part
 - the possible benefits
 - the risks of this research study
 - the other options to being in the study
 - how your private health information will be collected, used, and shared.

Carolyn M. Tucker, Ph.D. (Principal Investigator)

Date

As the person who wants to take part in this study, you agree that you have been told about:

- the goals
- the things that you will have to do if you want to take part
- the possible benefits
- the risks of this research study
- the other options to being in the study
- how your private health information will be collected, used, and shared.

You have been given the chance to ask questions before you sign. You have also been told that you can ask other questions at any time.

You voluntarily agree to take part in this study. By signing this Form, you are allowing the collection, use, and sharing of your private health information. This is described in sections 15-24 above. By signing this Form, you are not giving up any of your legal rights.

Parent/Guardian Signature

Date

APPENDIX G
ADOLESCENT ASSENT FORM

You are being asked to take part in a research study. The goal of the project is to teach young people ways to live more healthy lives. The project will involve both teenagers and their parents (or guardians). There will be about 270 teenagers who will take part in this project. One parent or guardian must take part with each teenager. Most of the teenagers who take part in this project will be patients at Children's Medical Services. To take part in this project you will need to be African American, Caucasian American, or Hispanic/Latino(a) American.

Your parent must give permission for you to be in this study, but you can make up your own mind whether or not you want to take part in it.

1. What is the name of the research project?

The name of the project is the Children's Health Self-Empowerment Project (CHSE).

2. Who is in charge of the project?

Dr. Carolyn M. Tucker is in charge of the project. Dr. Tucker works at the University of Florida. A group of university students help Dr. Tucker with the project.

3. Why are you being invited to take part in this project?

You are being invited to take part in this project because you:

1. are 12 to 17 years old
2. are a patient of Children's Medical Services

4. What will you be asked to do if you want to take part in this project?

There are two parts of the project, Part I and Part II. You will be asked to take part in only one of the two parts of the project. You cannot choose which part you want to be in.

Part I. If you are chosen to be in this part I of the project, you will be asked to:

1. answer questions about your Nurse Care Coordinator, doctors, nurses, and clinic staff. The questions will ask what they can do to make you feel:
 - d) more comfortable
 - e) more respected
 - f) more trusting of them
2. rate how important some behaviors and attitudes are to make you feel:
 - d) more comfortable
 - e) more respected
 - f) more trusting of them
3. answer some true or false questions about yourself

If you are chosen to take part in Part I, you will get a packet of question forms in about 3 weeks. We will send the question forms after we get your completed and signed Assent Form. You will be asked to fill out the forms and send them back to us in about 2 weeks. If you are chosen to be in Part I, you will be in the project for about 3 months.

Part II: If you are chosen for this part of the project:

1. You will be asked to take part in 3 health workshops. Each workshop will be about 4 hours long. The health workshops will teach you things like:

- to have less family worry and sadness
- how to make and eat healthier food
- how to exercise more and worry less
- the risks of having unprotected sex and protected sex, and so on.

You will be asked to take part in all of the workshop activities. You can choose not to take part in any activity that makes you feel uncomfortable. You can also choose not to finish any activity that you may have started.

2. You will be asked to answer some questions about things like:

- your health behaviors and beliefs
- how your family deals with worry and sadness
- if you have unprotected sex
- smoking
- drug use
- alcohol use
- violent behaviors
- if you have tried to kill yourself
- if you exercise
- what kinds of foods you eat
- how motivated you are
- whether or not some questions about you are true or false

If you have problems or need help with these things, please talk to your doctor. We will not be able to help you. Your answers to these questions will be kept private.

There will be 2 different groups in Part II. If you are chosen to take part in Part II, you will be put in only one of the groups.

- Part II Intervention Group
 - About 3 weeks after we get your completed Assent Form you will get your first packet of question forms.
 - About 2 months later you will be asked to take part in the 3 workshops. At the workshops, trained nursing students will collect your height, weight, and blood pressure.
 - Each workshop will be about 4 hours long.
 - About 6 months after the 3rd workshop you will get your 2nd packet of question forms.
 - At this time you may be asked to go to your local Health Department or to a central location to have your height, weight, and blood pressure taken.

This means that if you are chosen to be in the Part II Intervention Group you would take part in the project for about 9 months.

- Part II Control Group
 - About 3 weeks after we get your completed Assent Form you will get your first packet of question forms.

- At this time you may be asked to go to your local Health Department or to a central location to have your height, weight, and blood pressure taken.
- About 9 months later you will get your 2nd packet of question forms.
- About three weeks later you will be asked to take part in the 3 workshops. At the workshops, trained nursing students will collect your height, weight, and blood pressure.
- Each workshop will be about 4 hours long.
- About 6 months after the 3rd workshop you will get your 3rd packet of question forms.
- At this time you may again be asked to go to your local Health Department or to a central location to have your height, weight, and blood pressure taken.

This means that if you are chosen to be in the Part II Control Group you would take part in the project for about 18 months.

5. Will you get paid for taking part in this project?

Yes. How much you will get paid depends on the part of the study you take part in. You cannot choose the part of the study that you will take part in. The amount of money that will be paid to you and your parent or guardian for taking part in the research study is stated below:

- 1) Each family (your child and you together) in Part I that fills out and sends back the question forms we send you will get a total of \$20.
- 2) Each family (you and your child together) in the Part II intervention group that fills out and sends back the question forms we send you will get \$20. Each family is asked to fill out questions forms two times for a total of \$40. Each family will get another \$40 for going to all 3 workshops. So, each family in the Part II intervention group will get a total of \$80.
- 3) Each family (you and your child together) in the Part II control group that fills out and sends back the question forms we send you will get \$20. Each family is asked to fill out question forms two times for a total of \$40. Each family will get another \$40 for going to all 3 workshops. After the 3 workshops each family will be asked to fill out question forms a third time. Each family will get an extra \$10 for doing this. So, each family in the Part II control group will get a total of \$90.
- 4) Each child that goes to her or his local Health Department or a central location to have her or his height, weight, and blood pressure taken will be given a gift certificate to a local business

Please Note: You will not get paid for sending us back this Informed Consent Form and the Adult Information Questionnaire. The question forms you will get paid for filling out will be sent to you after you agree to take part in the project. You will get paid about 3 weeks after we get each of your packets of question forms. You will also get paid about 3 weeks after you go to all 3 workshops. If you stop taking part during the research study, you will only be paid for the parts that you finished.

6. What information will we ask about you?

If you are chosen to be in the project, we will need to get your grade point average (GPA). We will get it from the school board where you go to school. By signing this form, you are telling us that it is okay to get your GPA. We will also ask Children's Medical Services Nurse Care Coordinators to give us the following medical information from your Children's Medical Services medical chart:

- medical diagnosis
- body weight
- height
- blood pressure
- blood sugar level
- only medications that you are taking for your medical diagnosis
- your social security number (to check your grades)
- the name of your Nurse Care Coordinator.
- the name of your regular doctor's clinic

This is the only information about you that our research team will get from Children's Medical Services. This information will be used for research reasons only. We will only get this information during the time the research study is going on. By signing this form, you are telling us that it is okay for us to get your medical information.

7. How long will it take to answer the questions in the packets we send to you?

Part I: It should take you about one hour to answer all of these questions.

Part II: It should take you about two hours to answer all of the questions.

You should take breaks when filling out the forms so that you do not get tired. Please try to work on the forms for only 45 minutes at a time. Then take at least a 2-hour break before working some more on finishing the forms. You should work on the question forms in a quiet place, away from other people. This is so that no one else will see your answers. That way you will be able to answer the questions honestly.

8. Will we call you during the project?

A person from the research team may call you if you do not send a packet back to us within 2 weeks of getting it. This call will be made to make sure that you got the packet. You may also be called after you send a packet to us. A person from the CHSE research team may call you if some of the information is missing. When we call, if you do not want to answer the questions, you do not have to. Lastly, a person from the CHSE research team may call to remind you about upcoming project activities.

9. Will all of your information be kept private?

Yes. All information about you and your parent or guardian will be kept private. All information about you will be given a code to make this information private. Your name will be kept in a locked file cabinet in the Psychology Building at the University of Florida. None of your CMS Nurse Care Coordinators, doctors, nurses, or clinic staff will be told if you are in this project.

10. Tell us what you would like to do by putting an "X" in only one of the boxes below :

I agree to take part in this study.

I do not want to take part in this study.

Print your name here

Date

Sign your name here

Date

APPENDIX H INVITATION LETTER

Date:

Dear Parent/Caregiver:

Children's Medical Services is supporting a new health improvement research project in which children and parents are being invited to participate. Dr. Carolyn M. Tucker, who works at the University of Florida, is leading the project. Because our records show that one of your children has attended Children's Medical Services within the past 3 months, we are inviting both you and your child to take part in the project. One of the major reasons for this project is to teach children who have health problems (are overweight, have diabetes—also called “sugar,” and/or have high blood pressure) how to live healthier lives. Another reason for this project is to find out what you think your healthcare providers (doctors, nurses, clinic staff, etc.) and Nurse Care Coordinators can do to make you feel more comfortable, feel more respected by them, and also feel more trusting of them. This information may help healthcare professionals give healthcare that is more satisfactory to you and your family.

Please carefully read the Adult Informed Consent Form and the Adolescent Informed Consent that was included in this mailing. Also have your child read the Adolescent Assent Form. These forms explain the project and what you and your child will be asked to do, if you choose to participate. Basically, if you and your child agree to participate, both of you will complete some questionnaires during the next 12 months. Some parents and children will also be asked to attend three health improvement workshops. If you decide to participate in the project, you will be paid for completing the questionnaires and/or for attending the workshops. The amount of pay is explained in the Informed Consent Forms.

A parent or primary caregiver must participate with each child. Also, only one parent (or primary caregiver) and one child from each family can take part in the project.

If you do not wish to participate, do not return the forms sent along with this letter. If you do not participate, the healthcare your child receives at Children's Medical Services will not change in any way. In fact, the doctors, nurses, and office staff at Children's Medical Services and at the clinics will not know if you and your child do or do not take part in this project. If you and your child would like to participate, you should do the following:

1. Read the Adult Informed Consent Form and the Adolescent Informed Consent Form.
2. Print your full name on the first page of the Adult Informed Consent Form and the Adolescent Informed Consent Form (item number 1).
3. Sign BOTH of the Adult Informed Consent Forms and BOTH of the Adolescent Informed Consent Forms.
4. Complete the Payment Release Form (the last page of the Adult Informed Consent Form) and sign your name at the bottom of the page.
5. Keep one of the Adult Informed Consent Forms and one of the Adolescent Informed Consent Forms for your records and information.
6. Complete the Adult Information Questionnaire.
7. Put the Adult Information Questionnaire, one copy of the signed Adult Informed Consent Form (please do not tear off the Payment Release Form), and one copy of the signed Adolescent Informed Consent Form in one of the pre-stamped, pre-addressed envelopes.
8. Put this envelope in the mail.

Now,

1. Have your child read and sign his/her name on BOTH of the Adolescent Assent Forms.
2. Have your child complete the Youth Information Questionnaire.
3. Your child should keep one of the Adolescent Assent Forms for her or his records and information.
4. Have your child put the Youth Information Questionnaire and ONE copy of the signed Adolescent Assent Form in the second pre-stamped, pre-addressed return envelope.
5. Put this envelope in the mail.

NOTE: Please do not put your forms and your child's forms in the same envelope. Also, if you want to participate please make sure that you return these materials within 2 weeks.

Within two months of sending us these materials, we will send your first packet of questionnaires (if you and your child are selected to take part in the project). If you move before you receive this first packet, or at any time during the project, please call the researchers at (352) 392-0601, Ext. 260 to give them your new address.

During the whole project, we will make sure that your confidentiality is protected as much as possible. Also, no one at Children's Medical Services will see what you or your child writes on any of the questionnaires.

If you have any questions about taking part in this research project, or would like the materials we have sent you in Spanish, call the Principal Investigator of the research, Dr. Carolyn M. Tucker, at (352) 392-0601, Ext. 260.

Thank you for your time. We hope you will think about participating in this project.

Sincerely,

Arlan Rosenbloom, M.D.
Gainesville/Ocala Medical Director,
Children's Medical Services

APPENDIX I
COVER LETTER (ADOLESCENT)

Dear Adolescent Participant:

This is your first packet of question forms for the Children's Health Self-Empowerment Project. These question forms ask you and your primary parent/caregiver about things like health behaviors and beliefs, your family, stress (worry), sadness, and so on.

It should take you about 45 minutes to finish these question forms. Please finish the question forms in a quiet place, away from others in your household.

All information about you will be kept completely private. Your name will not be used on the question forms.

In order to finish your part in this research project please:

- Finish the enclosed question forms
- Finish the Payment Release Form
- Return all of the forms by mail in the envelope provided
- Return all of the finished question forms within three weeks

When you finish and return these question forms, your family (you and your primary parent/caregiver together) will get a payment of \$20.

If you have any questions about this research project, please call a member of my research team at (352) 392-0601 ext. 256, or toll free at 1-866-290-5770 ext. 256. Thank you for taking part in the research project.

Sincerely,

Dr. Carolyn M. Tucker
Distinguished Alumni Professor
Professor of Psychology
Professor of Pediatrics
Professor of Community Health and Family Medicine

APPENDIX J
COVER LETTER (PRIMARY PARENT/CAREGIVER)

Dear Primary Parent/Caregiver:

This is your first packet of question forms for the Children's Health Self-Empowerment Project. These question forms ask you and your child about things like health behaviors and beliefs, your family, stress (worry), sadness, and so on.

It should take you and your child about 45 minutes to fill out these question forms. Please finish the question forms in a quiet place, away from others in your household.

All information about you and your child will be kept completely private. Your name and your child's name will not be placed on the question forms.

In order to finish your part in this research project please:

- Finish the enclosed question forms
- Finish the Payment Release Form
- Return all of the forms by mail in the envelope provided
- Return all of the finished question forms within three weeks

When you finish and return these question forms, your family (you and your child together) will get a payment of \$20.

If you have any questions about this research project, please call a member of my research team at (352) 392-0601 ext. 256, or toll free at 1-866-290-5770 ext. 256. Thank you for taking part in this research project.

Sincerely,

Dr. Carolyn M. Tucker
Distinguished Alumni Professor
Professor of Psychology
Professor of Pediatrics
Professor of Community Health and Family Medicine

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BIOGRAPHICAL SKETCH

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