

5-3-2007

# Predictors of Treatment Adherence in Adolescents with Inflammatory Bowel Disease: The Role of Age, Body Satisfaction and Prospective Memory in Medication and Diet Behavior.

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PREDICTORS OF TREATMENT ADHERENCE IN ADOLESCENTS WITH  
INFLAMMATORY BOWEL DISEASE: THE ROLE OF AGE, BODY  
SATISFACTION, AND PROSPECTIVE MEMORY  
IN MEDICATION AND DIET BEHAVIOR

by

Christina - Helen Vlahou

Under the Direction of Lindsey L. Cohen, Ph.D.

ABSTRACT

Inflammatory bowel disease (IBD; Crohn's disease & ulcerative colitis) is a chronic illness in which medication and dietary adherence may determine disease natural history and severity of symptoms. We hypothesized that age, prospective memory (PM) and body satisfaction would predict medication and dietary adherence in adolescents with IBD and that gender and age would modify the relation between body satisfaction and adherence, with older girls being less adherent than younger children. Fifty-seven participants aged 10-21 ( $M = 16.5$ ,  $SD = 2.3$ ) with IBD and their caregivers were recruited. Informed consent, demographics and body satisfaction questionnaires were completed. PM was assessed using a naturalistic task. Adherence was measured by the 1-week completion of a medication and dietary log. A questionnaire was administered to evaluate coping strategies used for overcoming obstacles to dietary adherence. Two hierarchical regressions were conducted for medication and diet adherence respectively. As hypothesized, age had a significant effect ( $\beta = -.42$ ,  $p < .01$ ) on dietary adherence, accounting for approximately 17% of the variance ( $R^2$  change = .17;  $F$  change (1,41) = 8.57,  $p = .006$ ), with younger children being more adherent. Body satisfaction had a

greater and more significant effect on dietary adherence than age ( $\beta = -.33, p < .01$ ); i.e. participants more satisfied with their body reported better dietary adherence ( $R^2$  change = .28;  $F$  change (2,35) = 6.97,  $p < .05$ ). Findings remained consistent across multiple measures of body satisfaction and dietary adherence. None of the predictors had a significant effect on medication adherence. Health care providers who treat adolescents with IBD and parents should be made aware of factors affecting adherence in order to improve disease outcomes and patients' quality of life.

INDEX WORDS: PEDIATRICS, INFLAMMATORY Bowel Disease, BODY Satisfaction, MEDICATION Adherence, DIET Adherence

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A Dissertation Presented in Partial Fulfillment of the Requirements for the  
Degree of Doctor of Philosophy  
in the College of Arts and Sciences,  
Georgia State University

2007

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College of Arts and Sciences  
Georgia State University  
August 2007

## Dedication

To Drs. George Kitis and Kyriakos Michaelides, my gastroenterologists, whom I consider great luck in an area in which I stood unlucky; to Drs. John and Christiana Catravas, whose immeasurable kindness I hope to pay forward one day; and to Christos, my *condicio sine qua non*.

## Acknowledgements

This work was supported in part by the Georgia State University Dissertation Grant Program. I would like to warmly thank my Dissertation Chair, Dr. Lindsey Cohen; he has been a precious mentor to me and has made every effort possible to assist and support me in pursuing my research interests. I am deeply grateful to Dr. Mary Morris, my advisor and member of my Dissertation Committee, for initially offering me the opportunity to pursue this degree, and then standing by me and coaching me as a parent every step of the way. I sincerely appreciate the help and advice of Dissertation Committee members Drs. Lisa Armistead and Erin McClure. This project would not have been feasible without the help of Drs. Ben Gold and Jeff Lewis, and the Crohn's and Colitis Foundation of America (CCFA), Georgia Chapter, who offered their interest and cooperation, and allowed me the opportunity to recruit the patients they work with for participation in this study. Special thanks to Amanda Woods who offered her support as a friend, as well as her invaluable assistance with the conceptualization of this project and the statistical analyses. I would also like to kindly thank Don Bearden, Kara Leffingwell, and Latrice Lewis, for their assistance with the data collection process. Throughout this venture, my parents Drs. Loukas and Maria Vlahos and my sister Andriana have been my solid safety net; without their love, support and encouragement I would have either never started or easily quit. Finally, I would like to thank all the patients with IBD and their families who participated in this study; it is my belief that only through working together can we add a positive note to this painfully unfortunate illness.



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## Introduction

### *Adherence to Medical Regimens*

Adherence has been defined as the extent to which individuals take medication, follow diets, or exercise certain life-style changes in accordance with medical advice (Manne, 1998). The issue of pediatric medical treatment adherence has received significant attention in the health psychology scientific literature. Adherence is important because poor adherence can result in decreased quality of life for patients and their families, unnecessary hospitalizations, increased risk for medical complications and chronic illness-related morbidity and mortality, higher medical care costs, and can compromise optimal medical outcome (Riekert & Drotar, 2000).

Despite some variability in the reported rates of adherence in childhood chronic illness, estimates for children and adolescents fall within the range of 50-60% for medication underuse and 10% for medication overuse; indeed, significant numbers of referrals to pediatric hospital mental health providers are related to the evaluation and management of non-adherence (Riekert & Drotar, 2000). Aside from adherence to medication regimens, many pediatric chronic illnesses such as cystic fibrosis, phenylketonuria, juvenile rheumatoid arthritis, insulin-dependent diabetes mellitus, and seizure disorders require strict adherence to dietary recommendations. Dietary restrictions have been associated with the lowest rates of adherence of all pediatric treatment recommendations, but have received little attention in the pediatric adherence literature (Mackner, McGrath, & Stark, 2001; Stark, 2000).

Developmental level appears to be an especially important variable that influences pediatric adherence across chronic illnesses (La Greca & Bearman, 2003; Manne, 1998; Rapoff, 1999). Research across a number of pediatric chronic illnesses suggests that adolescents are less adherent than younger children (for a review, see Rapoff, 1999). For example, social-developmental issues (e.g., peer conformity) and biological changes were found to negatively impact adherence in adolescents between 16 and 19 years old (Manne, 1998). La Greca and Bearman (2003) argue that adolescents have poor ability to manage regimens that require adjustments in major lifestyle, such as dietary restrictions or exercise, have cosmetic side effects, or interfere with their social life. Another factor that plays a significant role in this age group is transition of care, both with regard to the adolescent undertaking the responsibility of the regimen from the parent, as well as with regard to the adolescent transitioning from a pediatric to an adult medical care setting (Desir & Seidman, 2003; Pinzon, Jacobson, & Reiss, 2004; Reiss, Gibson, & Walker, 2005). In light of these findings, it is important that pediatric adherence research closely examines adolescents' adherence and appreciates developmental influences.

A multitude of other factors have been found to affect pediatric adherence to treatment regimens. These variables include regimen and illness characteristics, psychological correlates, personal beliefs, behavioral contingencies, patient/physician relationship characteristics, family stress, parenting skills, general family and marital functioning, family attitudes and support for disease management behaviors, and the parent-child relationship (for reviews, see La Greca & Bearman, 2003; Manne, 1998; Rapoff, 1999). Given the range of variables predictive of adherence, as well as the

different medical regimens across diseases, it is maybe most parsimonious to examine adherence factors tied to specific syndromes and associated treatments.

### *Inflammatory Bowel Disease*

*Overview.* Inflammatory bowel disease (IBD) encompasses a group of disorders where the intestinal system becomes inflamed, resulting in a host of complications. The two most common types of IBD are Crohn's disease and ulcerative colitis. Both Crohn's disease and ulcerative colitis are chronic, incurable, and cause abdominal pain and diarrhea. Whereas ulcerative colitis is limited to the colon (large intestine), evenly distributed, and affects only the superficial layers of the colon, Crohn's disease can affect any area of the GI tract, affects all layers of the intestine, and allows patches of healthy bowel in between the unhealthy areas. Symptoms of Crohn's disease can include persistent diarrhea, crampy abdominal pain, fever, rectal bleeding, loss of appetite and subsequent weight loss, and fatigue; extraintestinal manifestations may also be present including redness and itchiness of the eyes, sores on the mouth, swelling and pain in the joints, bumps and other lesions on the skin, osteoporosis, kidney stones, and liver complications. Symptoms of ulcerative colitis can include pain, cramping, diarrhea, and bloody stool. Abdominal pain and fever can cause loss of appetite and weight loss, and diarrhea and rectal bleeding can also result in body fluid, nutrient, and electrolyte loss (CCFA, 2005a). With both diseases, the inflammation and scar tissue causes temporary and permanent damages to the intestines, respectively. Subsequently, as food nutrients are mainly absorbed in the small intestine, such damages lead to poor absorption of



nutrients from food and thus malnutrition, which can result in delayed growth (CCFA, 2005a).

Up to 1.4 million Americans have either Crohn's disease or ulcerative colitis, and approximately 30,000 new cases are diagnosed in the United States each year. Most individuals diagnosed with IBD are between the ages of 15 and 35, and estimations of those affected under the age of 18 range from 10% of all patients diagnosed (CCFA, 2005a) to 30% (Escher & Taminiau, 2001). IBD is equally distributed across gender with a higher prevalence in the Caucasian population in comparison to other racial groups, and the disease tends to occur more often in people of Jewish heritage (largely of Eastern European ancestry) than in people of non-Jewish descent.

Speculations for the underlying causes of IBD fall along the lines of the diathesis-stress model, implicating interactions between genetic predispositions and environmental factors (CCFA, 2005a). More specifically, three prominent theories have been identified: (1) the autoimmune theory, suggesting that IBD results from inappropriate ongoing activation of the mucosal immune system driven by the presence of normal luminal flora, in a genetically susceptible host; (2) the mycobacterial theory, stating that the pathological response of the immune system is closely linked with the presence of microbes, and specifically mycobacterium tuberculosis or *M. tuberculosis*, a human pathogen that infects almost one-third of the human population but is normally successfully regulated by a healthy immune system; and (3) the immune-deficiency theory, posing that an interplay of genetic factors, environmental factors, or possibly exotoxins associated with subsets of gut flora, result in dysfunctional neutrophils (a type

of white blood cell that plays a major role in the body's defense against bacteria, viruses, and fungi), which then play a central role in the IBD phenotype (Chamberlin & Naser, 2006).

*Treatment.* The effects of IBD on longevity are minimal and the disease is not considered to be terminal (Irvine, 2004). However, IBD is a chronic illness, and the course of the illness is not linear and predictable, but rather is characterized by exacerbations (flare-ups) and remissions. Treatment of Crohn's disease and ulcerative colitis primarily involves management of symptomatology via surgical procedures, long-term parenteral feeding (i.e., intravenous or intratubal feeding), unpleasant, invasive imaging and diagnostic techniques (e.g., colonoscopies), and biological treatments. However, the most typical treatment course for management of Crohn's disease and ulcerative colitis involves taking medications and in some cases also following a dietary plan. Each medication is associated with side effects, which are important to consider when evaluating children's adherence behavior.

Almost all patients with IBD are required to take daily medications, often at mealtimes. Corticosteroids, such as prednisone, are the primary line of treatment for short-term management of flare-ups, but can also be prescribed long-term if the patient is not responding to other types of medication. The purpose of this class of drugs is to reduce the inflammations, thus providing relief of symptoms. Prednisone is most frequently administered orally, but can also be injected, in which case both the therapeutic effect and the side effects are increased and quicker to present. Corticosteroids are known to cause water retention, thus resulting in facial swelling; at

high dosages, the face becomes round or “moon-shaped.” Corticosteroids also cause an increase in appetite, often resulting in weight gain, as well as loss of bone mass, known as osteopenia. Additionally, they can cause an increase in body hair and the appearance of acne. Moodiness and restlessness are other side effects, and impediment of normal growth and development may also occur (CCFA, 2005b).

Treatment with 5-aminosalicylic acid (5-ASA, an aspirin-like compound), such as sulfasalazinem, mesalazine, and mesalamine, are used as alternatives to corticosteroids. These medications have a reduced therapeutic effect, but are also associated with fewer side effects and can thus be used over a longer period of time to prevent recurrences. Some side effects that have been reported, but are rare in comparison to corticosteroid side effects, include nausea, headache, allergic skin rashes and changes in blood count (CCFA, 2005b).

Immunomodulators, such as azathioprine and 6-mercaptopurine (6MP), are used when 5-ASA drugs are not controlling the symptoms (CCFA, 2005b). Both Crohn’s disease and ulcerative colitis have been identified as autoimmune disorders; specifically, they have been associated with dysregulations in the immune system, as inflammations are often the result of excessive immunological activity (Folwaczny, Glas, & Torok, 2003). Therefore, immunosuppressants are administered to lower the effects of the immune system (usually by decreasing the number of white blood cells) and, thus, reduce the symptoms secondary to inflammation. They are considered a long-term treatment and are usually administered orally. Side effects of this treatment are mainly associated with a

weakened immune system, and include proneness to and difficulty in overcoming infections.

Another, more recently developed, family of drugs is that of biological treatments. Biologic therapies represent a new class of drugs, which are genetically engineered from living organisms and their products and which interfere with the body's inflammatory response in IBD by targeting specific molecular players in the process. One example is *cytokines*—specialized proteins that play a role in increasing or decreasing inflammation. Promising targets include tumor necrosis factor (TNF)-alpha, interleukins, adhesion molecules, colony-stimulating factors, and others. The main biological treatment currently used with IBD patients is Infliximab (Remicade®), which is administered over the course of 2-hour intravenous infusions spread apart by several weeks (CCFA, 2005b).

Other medications include antibiotics for the purpose of reducing intestinal bacteria and directly suppressing the intestine's immune system (CCFA, 2005b). In addition, a variety of medications such as antacids, antispasmodics, herbal medicines, and medical supplements are prescribed for patients with IBD in an effort to provide relief from specific symptoms.

Dietary recommendations are a central part of the treatment regimen of IBD. Typically, patients with IBD are encouraged to follow a low-residue diet, avoiding foods that are difficult to digest completely. Some examples of such foods are raw or dried fruits, raw vegetables, nuts, seeds, bran, and whole grains (CCFA, 2005b). Given that nutrients are not fully absorbed and malnutrition and growth delays are common, patients are encouraged to eat small, frequent meals. Additionally, when the disease is active, it is

recommended that patients turn to bland, soft foods and avoid spicy and high-fiber foods (CCFA, 2005a). It is important to note, however, that these general recommendations do not apply to all patients; the ideal diet depends upon the specific diagnosis (i.e. Crohn's disease versus ulcerative colitis), the GI area infected, the type of symptoms the patient presents with (e.g., presence or absence of diarrhea), as well as other contributing factors, such as developmental stage and the presence of complicating factors, for example, lactose intolerance. Therefore, it is critical that patients with IBD cooperate with a physician and/or dietician to form a healthy, balanced diet plan, carefully monitor their diet, and avoid dietary behaviors that can cause exacerbation of symptoms. A dietary supplement such as a multivitamin is also frequently recommended (CCFA, 2005a).

Aside from dietary recommendations, some patients with IBD either have increased nutritional needs due to delayed growth or surgery, or have low tolerance for solid foods due to the severity of their illness. In such cases, nutritional supplements, elemental diet or total parenteral nutrition (TPN) might be recommended or required. Elemental diets comprise liquid supplements that contain predigested foods. Due to their unpleasant taste, they are often administered through a small, flexible nasogastric tube which is passed through the nose into the stomach. TPN comprises providing all nutritional needs intravenously. A catheter is inserted into the subclavian vein near the shoulder and is left in place as long as additional nutritional support is needed (CCFA, 2005b).

*Adherence.* Treatment adherence is critical for the course and symptom management of IBD, the avoidance of complications, and the quality of life of the patient.

Unfortunately, several studies show that poor medication adherence is a significant problem in IBD. Sewitch, Leffondre, and Dobkin (2004) performed a cluster analysis on 158 adult patients with Crohn's disease responding to the Patient-Physician Discordance Scale (PPDS) and identified five patient subgroups. They then compared these groups on their self-reported medication adherence and found nonadherence to vary from 21.9% (in the symptomatic, highly distressed, good communication, and high expectation for medication/testing group) to 66.7% (in the asymptomatic, low distress, good communication and high expectation for medication/testing group). Sewitch and colleagues (2003) report that 33% of their sample was unintentionally nonadherent, 15% was intentionally nonadherent, and 7.2% was both intentionally and unintentionally nonadherent. San Roman and colleagues (2005) examined adherence to mesalazine in a sample of 40 adults using both self-report and urine salicylate levels. Of their total sample, 67% reported involuntary non-adherence, while 35% reported voluntary non-adherence. Finally, Kirchgatterer and colleagues (2002) reported that only 9% of their adult research sample with IBD adhered to critical diet supplements, such as calcium and vitamin D, for the prevention of osteoporosis.

Factors previously found to be associated with poor medication adherence in adults with IBD include a disease presentation of mild severity and longer duration, male gender, single marital status, full-time employment, and frequent dosing (for a review see Kane, 2006; López-Sanromán, & Bermejo, 2006). In addition, Nigro and colleagues (2001) found that adherence was negatively correlated with the presence of psychiatric diagnoses (mainly mild depression, adjustment disorders, and generalized anxiety

disorder). Scheduling another medical appointment, greater certainty that medication would positively affect health, and lower total patient-physician discordance have also been found to increase adherence (Sewitch et al., 2003). Unfortunately, research on adherence in the IBD population has focused heavily on medication adherence, while adherence to dietary recommendations in patients with IBD is largely underrepresented in the literature.

### *Age*

Given that IBD is diagnosed before adulthood 10-30% of the time, it is critical to consider developmental level and treatment adherence. There is considerable research highlighting the relation between age and adherence in other illness populations (for reviews, see La Greca & Bearman, 2003; Manne, 1998; and Rapoff, 1999). In IBD, pediatric adherence rates appear to resemble the low adult rates. Oliva-Hemker and colleagues (2004) examined refill rates of 5-ASA and immunomodulators in 53 children and adolescents who had Crohn's disease. They found overall adherence to be low (39.5% adherence to the 5-ASA and 54% adherence to the immunomodulator), and the refill rate was higher for younger patients. Mackner and Crandall (2005) collected data from 50 children with IBD aged 11 to 17 years old and their parents. Less than half of the children (42%) and their parents (38%) reported perfect adherence to IBD-specific medications (5-ASAs, immunomodulators, and steroids). There is some evidence that dietary adherence decreases in patients with IBD when they are in adolescence (Booth, 1991); however, to our knowledge, there is a paucity of published studies suggesting

factors associated with both adult and pediatric adherence to dietary recommendations in IBD.

In particular, adherence appears to be poor in adolescence, possibly due to the transition from parent to self care and other psychosocial influences (e.g., desire for peer conformity, increased academic demands, development of personal identity, self and body image, distancing from authority figures such as doctors and parents; Booth, 1991). Thus, it might be important to examine relations between age and adherence in pediatric IBD.

#### *Prospective memory*

A factor that has been reported to be important for medication adherence is prospective memory (Ellis, 1998). Prospective memory has been defined as the memory for intentions that are delayed, and has been closely associated with retrospective memory, attention, and planning. In prospective memory research, the dependent variable is the *probability of recall*, in other words, the probability that the intention of the action will be remembered and executed in the future. The content of this intention includes information on the presence of an intent (i.e., that there is something that needs to be done), the action to be recalled (i.e., what to do), the retrieval criteria (i.e., when to do it), and some record of whether this intent has been satisfied (i.e., whether it has been completed) (Ellis, 1998). Two types of prospective memory tasks have been identified in the literature: (1) time-based tasks, which involve remembering to perform an action at a particular time or after a time period has passed, and (2) event-based tasks, requiring remembering to perform an action at the instant an event occurs or following a specific



event (Einstein & McDaniel, 1990). There is also a differentiation between internal and external prospective memory, depending on whether recall is based on internal cues or the use of cues in the environment (e.g., setting an alarm, leaving a reminder note, or marking the calendar).

From a neuropsychological perspective, prospective memory has been associated with the prefrontal systems and the integrity of the executive functions that these systems subserve, rather than temporal lobe systems and retrospective memory. The theoretical assumption that has been proposed is that although frontal brain functions are not directly implicated in the encoding and retention phase of memory, which might be more important to retrospective memory functions, they are intimately involved in the intention formation and the intention execution of the prospective memory action. Martin, Kliegel, and McDaniel (2003) compared young versus elderly adults on a set of prospective memory tasks and also a set of tasks measuring executive functioning. They found that prospective memory was significantly correlated with executive functioning in the elderly population, although this was not the case in the younger adults. In another study, McDaniel and colleagues (1999) compared the importance of frontal versus medial-temporal/hippocampal systems for prospective memory. Using measures of executive functioning and memory, they found a significant main effect of frontal status on prospective memory but no significant effect of hippocampal status. Finally, Kerns and Price (2001) compared children with Attention-Deficit/Hyperactivity Disorder (ADHD) to normal controls on their performance on a computerized measure of prospective memory. They found that children with ADHD had lower prospective memory

performance in comparison to the controls. The authors suggest that executive functioning deficits associated with ADHD might explain the poor prospective memory.

Although much research has focused on the components affecting prospective memory in young adults and the elderly, surprisingly little research has been carried out in children and adolescents. Thus, there is lack of knowledge on what constitutes a normal developmental curve, and how prospective memory might interact with other developing neurological and advanced cognitive systems. Prospective memory skills are important in children's everyday lives (e.g., completing homework assignments, returning books to the library, brushing teeth) (McCauley & Levin, 2004). However, one would imagine that they are especially important for children with chronic illnesses and complicated treatment regimens. As children age and become responsible for managing their medical regimen, prospective memory is likely to become an increasingly essential skill. Thus, examining prospective memory from a developmental perspective might be particularly salient for children with chronic illness and complicated treatment regimens.

Despite the speculation that prospective memory will play a significant role in medication adherence (Ellis, 1998; McCauley & Levin, 2004) and a number of studies that support this link with elderly populations (for review, see Park & Kidder, 1996), there is a paucity of studies linking prospective memory and treatment adherence in pediatric populations. Given that children with IBD are required to remember to take medications and maintain specific diets throughout the day, this population comprises a good candidate for exploring the role of prospective memory in adherent behavior.

### *Body Satisfaction*

The terms body image and body satisfaction have been used interchangeably in the literature, and can be defined as both the personal perception of one's body, and the cognitions and emotions associated with one's body including the degree to which one is satisfied with one's physical appearance (Kelsay, Hazel, & Wamboldt, 2005). The idea that body image can affect the progression of a medical illness is far from new; a study conducted as early as 1968 by Schwab and Harmeling cited several previous studies examining the effect of physical illness on body image and, thus, the emotional well-being of patients. They found that body image scores of medical inpatients were comparable to those of psychiatric patients, and lower than those obtained in healthy populations.

Given that both IBD and treatment for IBD impact a patients' body size, weight, and shape, body satisfaction is a central concern with this population. De Rooy and colleagues (2001) examined the complaints of a clinical sample of 259 individuals with IBD. Their factor analysis yielded three indices: body image and interpersonal concerns, general physical stigma, and disease stigma. Similarly, body image was identified as an area of concern in a review study by Casati and colleagues (2000). In this review, the authors described body image concerns regarding alterations in appearance caused by medication and surgical treatment side effects, such as facial bloating due to prednisone treatment or the presence of an ileostomy (complete removal of the colon). Dunker et al. (1998) evaluated body image, cosmetic results, and quality of life in patients with Crohn's disease. They found that patients who had undergone laparoscopic-assisted

surgery had a higher body image score (i.e., better body image) than those who had undergone open ileocolic resection, a surgical procedure which results in a larger scar.

Although body satisfaction has been identified as an issue for patients with IBD, to our knowledge, no research to date has examined whether body satisfaction impacts IBD medication and/or diet adherence. However, the relation between body satisfaction and medication or diet adherence has been examined in other populations. For example, Walters (2001) found that young women with cystic fibrosis tend to overestimate their weight, which then results in their taking less of the required oral and enteral food supplements. Insulin dosage manipulation and omission has been found to result from disturbed eating attitudes and body dissatisfaction in patients with diabetes mellitus (Colton et al., 1999; Fairburn et al., 1991; Grylli et al., 2005; Schlundt et al., 1999). A comparison of adolescent females/ young women with diabetes mellitus and phenylketonuria that revealed an increased rate of clinical as well as subclinical scores on scales measuring eating attitudes and the presence of eating disorder symptomatology showed that those with pronounced symptoms of eating problems were less adherent to most aspects of their treatment regimen in comparison to those without eating problems (Antisdel & Chrisler, 2000). Similarly, research has revealed that adolescent and young adult patients with cancer (Joyce, 2002) and cystic fibrosis (Abbott et al., 2000) present reduced self-esteem and body physique satisfaction, which can then affect treatment and diet adherence. Thus, although this paradigm has not been studied in IBD, there is evidence in the literature regarding other chronic illnesses that adherence to treatment might relate to poor body image/satisfaction.

However, it is important to note that an association between poor body image and poor adherence might not be present for both genders. It is well established that eating disorders are more prevalent in females in mid to late adolescence (DSM-IV-TR, 2000). Also, females are reported to experience a greater increase in body dissatisfaction secondary to medication and dietary regimens than men, even when they experience less weight gain than men (Antisdel & Chrisler, 2000). Research has also found that females, as compared to males, with cancer (Joyce, 2002) and cystic fibrosis (Walters, 2001) have poorer body image, which is related in turn to poorer adherence. As the traditional and cultural model is for females to maintain thin body figures and males to invest in being physically large and strong (Kostanski et al., 2004), one might expect these differences in ideal body image to result in different levels of adherence behavior. In a study conducted by Abbot et al. (2000), males viewed their BMI as greater than it actually was and expressed desire to be much heavier. Thus one could expect that females might have poor adherence to medications that can result in swelling or increased appetite (e.g., corticosteroids) or may limit their dietary intake in an attempt to lose weight, whereas males might have better medication adherence and pay more attention to nutrition due to their concern with delays in growth.

#### *Summary, Aims, and Hypotheses*

In sum, children with IBD suffer from a broad array of symptoms including intestinal inflammation, poor nutritional absorption, and delays in growth. Treatment regimens are critical for symptom management and avoidance of complications; treatment most often includes medications and dietary guidelines. Unfortunately, IBD

patients have difficulty adhering to their treatment regimens. It is likely that age, especially progressing into adolescence, as well as prospective memory and body satisfaction influence adherence in IBD, but research is scarce in these areas.

The aims of the current study were to identify whether 1) age is related to medication and/or medication adherence, 2) prospective memory is predictive of adherence to medication and/or diet above and beyond age, and 3) body satisfaction influences medication and/or diet adherence above and beyond age and prospective memory, but differs by gender and/or age. It was hypothesized that older adolescents would be less adherent than younger pre-adolescent children. This hypothesis is based on the premise that the psychosocial changes associated with adolescence result in shifts in responsibility of care from the parent to the child. It was also expected that patients with better prospective memory would be more adherent to their diet and medications. Lastly, it was hypothesized that body satisfaction would relate to adherence, demonstrating that those children who were more satisfied with their body would be more adherent to their treatment regimens. Given the importance of body satisfaction to adolescents, especially adolescents with IBD, it was expected that this variable would influence adherence above and beyond the participants' age and prospective memory abilities. However, the relation between body satisfaction and adherence was expected to hold true only for female participants, who are socialized to desire smaller, thinner bodies. Male participants who were dissatisfied with their bodies were not expected to be less adherent given that the medications and diet should serve to increase body size, and males are typically socialized to be larger rather than smaller. Furthermore, given that older adolescents are

more likely to have body satisfaction concerns than the younger pre-adolescents, we predicted a 3-way interaction between age, gender, and body satisfaction in predicting medication/diet adherence. Figure 1 shows a model of expected relations between predictors and dependent variables in the current study, whereas Figure 2 shows the hypothesized nature of the age x gender x body satisfaction interaction.

## Method

### *Participants*

Fifty-seven participants (31 males, 26 females) with a diagnosis of Crohn's disease or ulcerative colitis were recruited for the current study. Their ages ranged from 10 to 21 years ( $M = 16.5$  years,  $SD = 2.3$  years). Forty-six participants identified as Caucasian (80.6%), 10 (17.5%) as Black, and 1 (1.8%) as multiracial. The mean Body Mass Index (BMI) was 22.58 ( $SD = 4.32$ ) for boys, and 23.03 ( $SD = 4.17$ ) for girls, within average range according to the United States BMI population norms for girls and boys aged 2 to 20 years old (National Center for Health Statistics & National Center for Chronic Disease Prevention and Health Promotion., 2000). Their ages at the time of diagnosis ranged from 1 to 18 years old ( $M = 12.12$  years,  $SD = 3.29$  years). Thirty-six participants (70%) reported having been hospitalized for their illness at least once, whereas 22 (42%) reported having undergone surgery for their illness at least once. These did not include outpatient visits and imaging or other diagnostic procedures. The entire sample was taking medication for the purpose of IBD symptom management. Out of the total sample, 43 (75.4%) were taking immunomodulators, 42 (73.7%) were regularly

Figure 1:

Model of predicting and moderating factors of adherence in children with IBD.

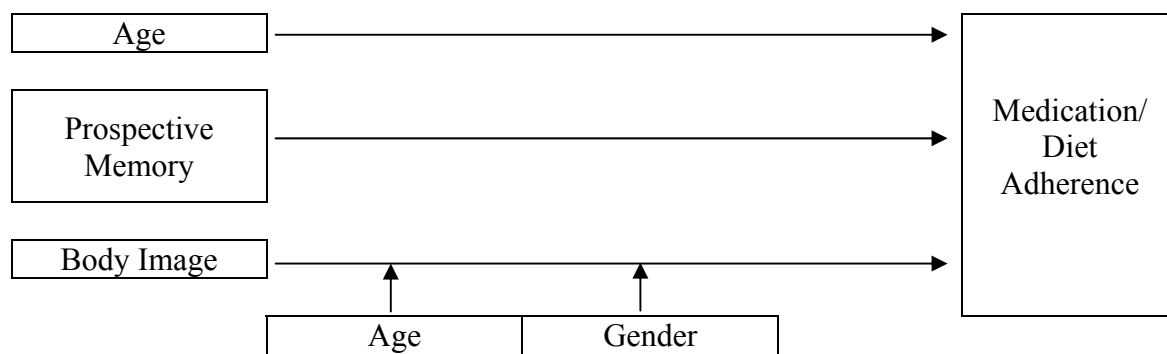
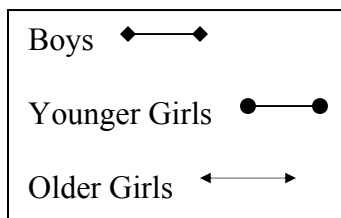
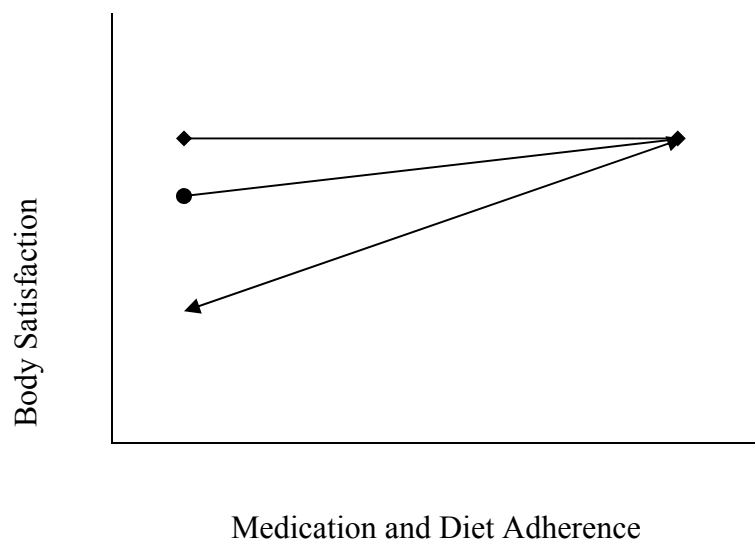




Figure 2.

Hypothesized nature of the age x body satisfaction x gender moderation.



receiving Remicade® infusions, 22 (38.6%) were on 5-aminosalicylic acid, 6 (10.5%) participants were on steroids, 6 (10.6%) were on antibiotics, and 19 (33.4%) participants had been advised by their physician to take one or more dietary supplements. However, 38 (66.7%) reported having forgotten their medicine at least once during the previous 2 weeks, 12 (21.1%) reported having skipped their medicine when feeling better, and 5 (8.8%) reported not taking their medication when experiencing unpleasant side-effects. Within the current sample, 44 (77.2%) participants endorsed having dietary restrictions due to their illness. Additional descriptive information regarding participants is presented in Table 1.

### *Measures*

*Family Information Form.* A family information form (Appendix A) was administered to obtain general background data such as age, gender, age of diagnosis, disease history, and other relevant variables. All items except age and medication adherence questions were used for descriptive purposes or other analyses not relevant to the current aims; age was examined as a predictor of medication and diet adherence. Questions were also included about general impression of adherence, with children responding whether or not in the past two weeks they had: (a) forgotten their medication (yes/no), (b) skipped their medication when feeling good (yes/no), or (c) stop taking their medication when feeling bad after taking it (yes/no). These questions were adapted from Sewitch et al. (2003). Children were also asked to report: (a) their personal perception of their medication and diet adherence (“Overall, how is your adherence to your medications? Do you take them as recommended?” and “Overall, how is your adherence

Table 1.  
Demographic Characteristics of the Total Sample.

	Total Sample ( <i>N</i> =57)
	<i>N</i> (%)
<b>Psychiatric History</b>	
Depression	7(12.3)
Anxiety	1(1.8)
ADHD	1(1.8)
<b>Number of Participants Taking Psychotropic Medication</b>	
	4(7.5)
<b>Number of Underage Participants</b>	
	21(71.9)
<b>Parent Participating</b>	
Mother	35(61.4)
Father	5(8.8)
Grandparent	1(1.8)
<b>Marital Status of Parent</b>	
Married	28(49.1)
Single	5(8.8)
Separated	2(3.5)
Divorced	4(7.0)
	<i>M</i> ( <i>SD</i> )
Parent Total Years of Education	14.25(2.09)
Annual Family Income	\$80,371(\$41,164)

to your diet? Do you eat according to medical recommendations?”), and (b) the personal importance of adherence to their medication and diet adherence (“How important is it to YOU that you take your medications as prescribed?” and “How important is it to YOU that you stick to your dietary recommendations?”), as measured by making a vertical mark on a horizontal 100mm line ranging from “Always” to “Never” and “Not important” to “Very important,” respectively. These questions were used as alternative measures of medication and diet adherence, the two dependent variables of this study.

*Body Satisfaction Questionnaire (BSQ; Appendix B).* To assess body satisfaction, a modified version of the BSQ was administered (Dunker et al., 1998). The original questionnaire was adapted from Dunker and colleagues (1998) who examined body image differences among individuals with IBD post-surgically and yielded two factors: a body image factor and a cosmetic factor. The body image subscale was reported to measure the patients’ perceptions of, and satisfaction with, their own bodies and their attitudes toward their bodily appearance. The cosmetic factor was reported to assess the degree of the patients’ satisfaction with the physical appearance of their surgical scar. Internal consistency for this measure has been shown to be good for the body image (Cronbach’s alpha = .80) and cosmetic (Cronbach’s alpha = .83) scales (Dunker et al., 1998).

For the purpose of this study, some of the items were modified to fit the current sample and only a body image factor score was derived, given that there was no component related to surgery in the present study. The modified questionnaire contained a total of 10 questions. Six questions asked about body satisfaction in direct relation to

the illness (e.g., “Do you think the disease has damaged your body on the outside?” or “Do you feel less attractive as a result of your disease or treatment?”) and were answered on a four-point Likert scale ranging from “No, not at all” to “Yes, extremely.” Three questions asked the respondents to provide general satisfaction ratings for their body (e.g., “On a scale from one to seven, how satisfied are you with your body?” or “Overall, how self-confident do you feel after the disease?”) and were answered on a seven-point Likert scale ranging from “Very unsatisfied/Not at all confident” to “Very satisfied/Very confident.” Finally, one questions inquired about the respondent’s self-confidence prior to his/her diagnosis (“Overall, how self-confident did you feel before the disease?”). This item was not added to the total score, but was separately subtracted from an item included in the total score inquiring about the respondent’s self-confidence *after* the disease (“Overall, how self-confident do you feel after your disease?”) in order to estimate a “before and after” discrepancy score. The total questionnaire score was computed and a higher numerical score was indicative of more body satisfaction. Internal consistency within the current total sample was good ( $\alpha = .85$ ). It was more reliable for girls ( $\alpha = .86$ ) than for boys ( $\alpha = .76$ ).

*Body Image Assessment (BIA)*. The BIA was utilized as an additional measure of body satisfaction. The BIA procedure was originally developed for adults by Williamson and colleagues (1989). However, a preadolescent version (BIA-P) (Veron-Guidry & Williamson, 1996) was later developed and this was used in the current study.

The measure includes four sets of body image silhouettes, mounted on separate 6 in. by 9 in. cards corresponding to male and female preadolescents. Each set of

silhouettes has nine body sizes ranging from very thin to obese. In accordance with the administration guidelines provided by Veron-Guidry & Williamson (1996), the researcher placed the nine cards with the body image silhouettes in random order in front of the participant. As a measure of perception of current body size (CBS), the following verbal instructions were provided: "I want you to look at all these body shapes and point to the one that most looks like you do right now. You can pick only one body shape." The silhouette number of the card the participant selected was then recorded. To measure the participant's perception of his/her ideal body size (IBS), the participant was then provided with the following instructions: "I want you to look at all these body shapes and point to the one that you would most want to look like if you could look like any of these. You can pick only one body shape." Again, the number of the card picked was recorded. A body dysphoria score (BDS) was derived from the difference between the current body size (CBS) and the ideal body size (IBS). The higher the discrepancy between current and ideal body types, the more body dissatisfaction and thus the higher the body dysphoria score (BDS).

Veron-Guidry & Williamson (1996) reported a test-retest reliability of this measure of .94 for the CBS and .93 for the IBS. A one-week reliability check yielded a Pearson  $r$  of .79 ( $p < .01$ ) and .67 ( $p < .01$ ) for the CBS and IBS respectively. Concurrent validity was demonstrated by the significant relation ( $r = .33, p < .01$ ) between the BIA discrepancy score (CBS-IBS) and a measure of eating disorder symptoms. In the current study, concurrent validity was estimated by running correlations between the body dysphoria score (BDS) and the Body Satisfaction Questionnaire (BSQ). Results yielded a

significant negative correlation ( $r = -.420, p < .01$ ), thus suggesting strong concurrent validity.

*Prospective Memory for Medication (Appendix C)*. This measure consisted of a naturalistic task for the evaluation of the participants' internal prospective memory. It followed a traditional paradigm used in research to evaluate prospective memory in which the participant is instructed to remember to perform an action either at a specific time (e.g., in ten minutes) or in relation to a specific event (e.g., whenever a blue letter flashes on the screen), a time-based and event-based task respectively (Ellis, 1998; Guajardo & Best, 2000; McCauley & Levin, 2004; McDaniel, 1999). Participants are asked to conduct a distracting activity in the meantime and are not provided with cues to remember to perform the requested action.

In the current study, the researcher instructed the participant to hypothetically assume that it was time to take their medication and that they had to ask the researcher to provide them with it. The situation was strictly hypothetical, as no real medication was provided to the participant. The participant was instructed to request their hypothetical medication at two times, once in 15 minutes (a clock was positioned so that the participant had clear view of the time) and once right before the examiner left the room following the completion of the testing. The researcher monitored the presence/absence of a correct response on an appropriate form. Participants could obtain a score of 0 (failure to accurately remember both the time-based and the event based task), one (responding to the time-based task but either before or after the target time interval and forgetting the event-based task), two (accurately responding to one of the two tasks but

forgetting the other), three (responding to both tasks, but before or after the target time interval on the time-based task), or four (remembering both tasks accurately). This task was specifically selected in an attempt to simulate a real-life condition and increase the ecological validity of prospective memory for medication adherence.

*Situational Obstacles to Dietary Adherence (SODA; AppendixD)*. The SODA (Schlundt et al., 1996) was used as a proxy for dietary adherence, one of the dependent variables in the current study. The SODA was initially developed for the purpose of evaluating the ability of adolescents with insulin-dependent diabetes mellitus (IDDM) to cope with situational obstacles to their dietary adherence (Schlundt et al., 1996). The original measure was comprised of two scales, a confidence scale, indicating how confident the child feels that he or she could overcome a variety of challenges to dietary adherence, and a behavioral scale measuring use of behavioral strategies to overcome such challenges. Schlundt et al. (1996) reported a Coefficient Alpha of .93 for internal consistency of the confidence scale and .62 for internal consistency across subscales. For the purpose of determining validity, Schlundt et al. (1996) compared the confidence scale to another scale measuring self-efficacy in diabetes and yielded a Coefficient Alpha of .83. The original version of this measure comprised 30 vignettes of hypothetical situations impeding adolescents' adherence to the dietary restrictions necessary for IDDM. Respondents were required to indicate how confident they were that they could solve each problem (confidence scale), and then rate how frequently they were likely to use each of five possible strategies for overcoming this obstacle. All answers were provided on a Likert scale ranging from one ("Not at all confident" or "Never do") to



seven (“Completely confident” or “Always do”). The possible strategies fell under one of the following subscales: “Rigid adherence,” “Complete relapse,” “Cognitive/affective coping,” “Compensate with exercise,” “Compensate with medicine,” “Compensate by adjusting later meals,” “Eat small amounts of forbidden foods,” “Substitute with a permitted food,” “Avoid tempting situations,” “Plan ahead,” and “Behave assertively.”

For the purposes of the current study, in addition to the confidence scale, an ecological validity scale was added indicating how often the adolescent is confronted with similar situations in real life. The confidence scale and the ecological validity scale were examined for descriptive purposes only. Also, the instructions, as well as some of the vignettes and the potential strategies, were either modified from the original version so that they apply to IBD rather than IDDM, or completely excluded if not applicable. Given the extensive length of the original measure, the current study utilized an abbreviated version by removing duplicate vignettes that shared themes and content. The vignettes were evaluated by two separate raters and rated for their degree of similarity. For any two vignettes that both raters considered similar, one was included and the other excluded, resulting in 18 vignettes used in the current study.

Subscale scores were computed by summing up the items that corresponded to each scale. A total score was computed by summing up all behavioral scale items, the total score reflecting the participants’ overall ability to cope with dietary adherence obstacles. Select items were reverse-coded so that a higher numerical score corresponded to better ability to overcome obstacles to adherence. Within the current sample, internal

consistency was excellent, confidence scale ( $\alpha = .92$ ), ecological validity scale ( $\alpha = .92$ ), and behavioral scale ( $\alpha = .94$ ).

*Medication and Diet Adherence Log (Appendix E)*. As a measure of the two dependent variables of the study, medication and diet adherence, participants were asked to record their daily medication intake and perception of dietary adherence daily for a period of 7 days. This is based on research suggesting that patient perception of adherence might be a better measure than actual adherence, and that the shorter the recall periods and the more detailed and objective the questions asked, the more accurate the self-reports (La Greca & Bearman, 2003). Participants were provided with logs that resembled a one-week calendar and asked to complete them at the end of each day by recording (a) the medication they took each hour of each day, and (b) their perceived adherence to dietary restrictions/recommendations, on a three-point scale (1, “I only ate good foods,” 2, “I ate one thing I shouldn’t eat,” 3, “I ate more than one thing I shouldn’t eat”). Participants were also provided with a stamped, self-addressed envelope and asked to mail the logs to the researcher in one week, once completed.

For the medication logs, the researcher compared the medications taken each hour of each day to the prescribed medication regimen reported in the family information form, and made note of whether the participant adhered to their regimen that day or not. Therefore, the total medication adherence score for each participant comprised the number of days that he/she was completely adherent in a period of a week. For the diet logs, participants reported whether they adhered to their diet completely, deviated a little, or deviated a lot and received a corresponding score of 1, 2, or 3 on each day of the week,

with lower scores equaling more adherence. Scores were then reverse coded, so that a higher score was indicative of more dietary adherence. The total scores for medication and diet adherence were used as dependent variables in this study.

### *Procedure*

This study received the approval of the Georgia State University Institutional Review Board (IRB), the Emory University IRB, and the Children's Healthcare of Atlanta IRB. There were two methods of recruitment. First, a letter was sent out by the Crohn's and Colitis Foundation of America (CCFA) addressed to the parents of the 87 children who participate in a summer camp for children with Crohn's disease and ulcerative colitis. The letter (Appendix F) described the current study and requested that the parents call the researcher to volunteer for their child to participate. For those parents who responded, a day was arranged for the researcher to meet with the parent and child at a location of their choice, which in all cases was their home.

Second, participants were recruited in person at two sites, the Emory Children's Center (ECC) and the Children's Center for Digestive Healthcare (CCDHC). Recruitment was conducted somewhat differently at the two sites due to different site policies. At ECC, parents and their children were approached directly by the examiner during their wait for their physician visit or their Remicade® infusion, presented with the study and asked to participate; whereas, at CCDHC, a staff member provided the children and their families with a recruitment letter (Appendix F) during their Remicade® infusion, and only introduced them to the researcher if they were interested in participating.

In all cases, children with IBD and their parents were informed that they were being invited to participate in a study aiming to assist individuals with IBD in taking their medication and sticking to their diet regimens. To protect privacy and prevent external threats to validity such as biased responding, all measures were administered in the form of a self-report questionnaire. For the BIA, which required that the participants physically point to the silhouette of their choice, an effort was made to administer this brief measure in a separate, private room. When this was not possible, parents or children were asked to momentarily leave the room while the other responded, or to look the other way. To compensate the families for the time spent involved in the study, \$10 were paid upon completion of their participation.

All interested families completed parent consent and child assent forms, as well as HIPAA - designated forms providing authorization to release personal health information for research purposes. As the demographic form inquired about factual information, this form was completed with the help of both the parent and child. The parent was then administered the BIA. The remaining measures were completed by the pediatric participant, the prospective memory naturalistic task instructions being provided first, followed by the SODA, BIQ, BIA and other measures not related to the primary aims of the current study, all of which were administered in random order.

Finally, the participant and their parent were provided with the medication and diet adherence log sheet and instructions on how to complete it. Before leaving, the researcher thanked the families for participation and provided the compensation fee. After the researcher left, s/he recorded whether or not the participant remembered the

prospective memory task at the 15 minute time period (time-based) and/or upon completion of the tasks (event-based).

## Results

### *Preliminary Analyses*

The three data collection sites were compared to evaluate whether they were equivalent. Specifically, *t*-tests for interval and ratio data and chi-square tests for all nominal data were performed on all demographic and study measures to compare scores obtained in each site. No differences were found and therefore subsequent analyses were conducted on the entire sample collapsed across data collection sites. Of the 57 participants enrolled in the study, the following participants returned valid 1-week medication and diet logs: 84.2% returned medication logs, and 70.2% returned diet logs. Parent response rate was lower (64.9% of the parents returned medication logs, 45.61% of the parents returned diet logs); however, as 38.6% of our participants were over the age of 18, many of the young adults who participated were not accompanied by or did not live with their parents making it difficult for the parents to participate in the study. The large majority of the adolescents (86% for medication and 89% for diet) and nearly all parents (91% for medication and 100% for diet) reported that adolescents' adherence during the week of the study was equivalent to that of other weeks. Descriptive statistics were computed for each of the predictor measures (age, prospective memory, and body satisfaction) and dependent variables (dietary and medication adherence). These data are summarized in Table 2. For measures of body satisfaction, a one-way analysis of variance (ANOVA) was run to compare males and females. As predicted, females

Table 2.

Descriptive Statistics for BSQ, BIA, Prospective Memory, SODA, Medication Log, and Diet Log for the Total Sample.

Variable	<i>M</i>	<i>SD</i>	<i>MIN</i>	<i>MAX</i>
Predictor Variables				
Age	16.56	2.30	10	21
Prospective Memory	2.60	1.25	0	4
Body Satisfaction				
BSQ				
Boys	37.16	4.61	26	45
Girls	33.32	7.54	10	45
BIA				
Boys	.22	.88	-1	3
Girls	.80	.90	-1	3
Dependent Variables				
Medication Adherence	5.78	1.82	0	7
Diet Adherence				
SODA	417.74	63.20	268	543
Diet Log	18.23	2.33	13	21

reported significantly less body satisfaction than males on both the BSQ ( $F = 5.56$ ,  $p < .05$ ) (Figure 3) and the BIA ( $F = 6.12$ ,  $p < .05$ ) (Figure 4).

*Data reduction.* For the sake of parsimony, a data reduction process was used to identify the optimal measure of dietary adherence (i.e., the total score from the SODA or the diet log) and body satisfaction (i.e., the score derived from the BIQ or BIA). Correlation analyses were run between all predictor and dependent variables, and are presented in Table 3. Both the two body satisfaction measures and the two dietary adherence measures were significantly correlated ( $r = -.420$ ,  $p < 0.01$ , and  $r = .448$ ,  $p < 0.01$ , respectively), but correlations were not considered high enough for them to be combined into a single variable. Therefore, each body satisfaction measure was correlated with the dependent variables (i.e., diet and medication adherence) and each diet adherence measure was correlated with the predictors (i.e., age, prospective memory, and body satisfaction). Of the two body satisfaction measures, the BIA and the BSQ, the BIA was more highly correlated and thus selected to be used in the subsequent analyses. Similarly, of the two diet adherence, the SODA and the diet log, the SODA resulted in the highest correlation and was thus used. In addition, given that the SODA had more items than the diet logs, the SODA displayed a more variable and normal distribution than the dietary logs, and thus was considered a more statistically sound measure of dietary adherence.

*Regression Assumptions.* A series of regression diagnostic tests were performed to ensure that the data met the assumptions of regression. Normality was explored by plotting a histogram and examining skewness statistics. Linearity was examined by

Figure 3.

Male vs. female mean scores on the Body Satisfaction Questionnaire.

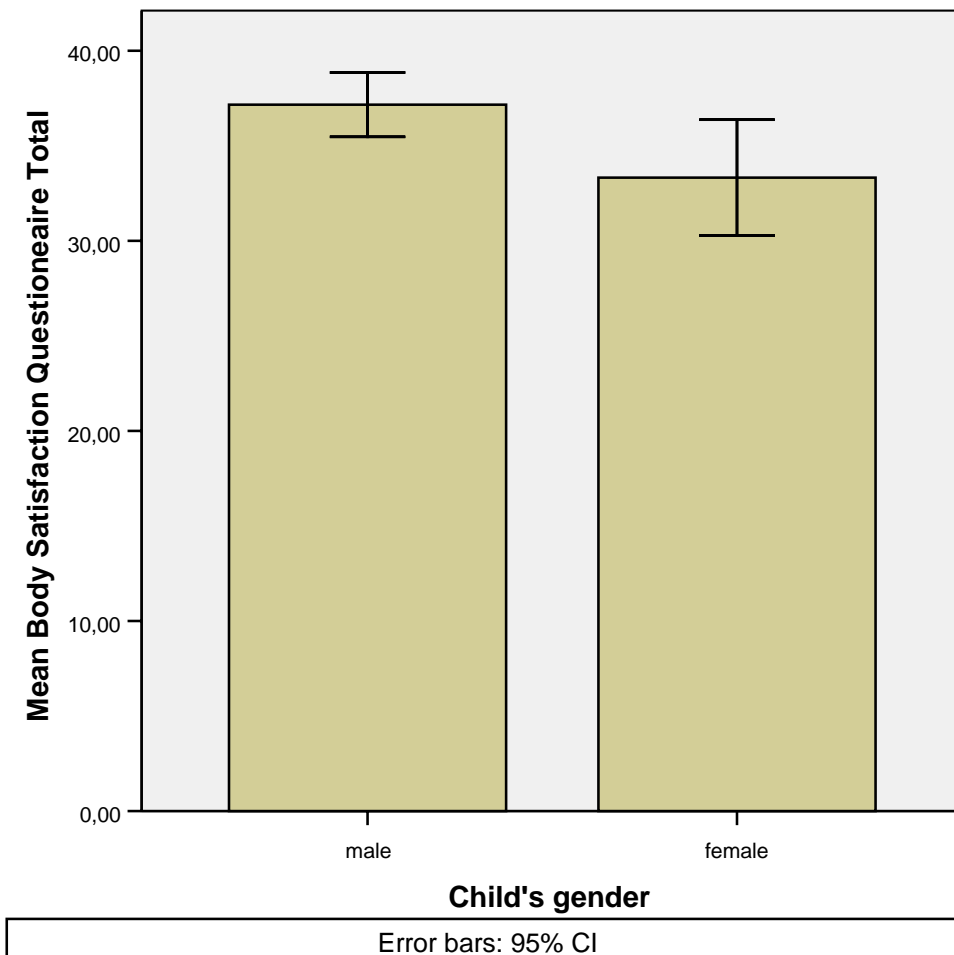




Figure 4.

Male vs. female mean Body Dysphoria Score on the Body Image Assessment.

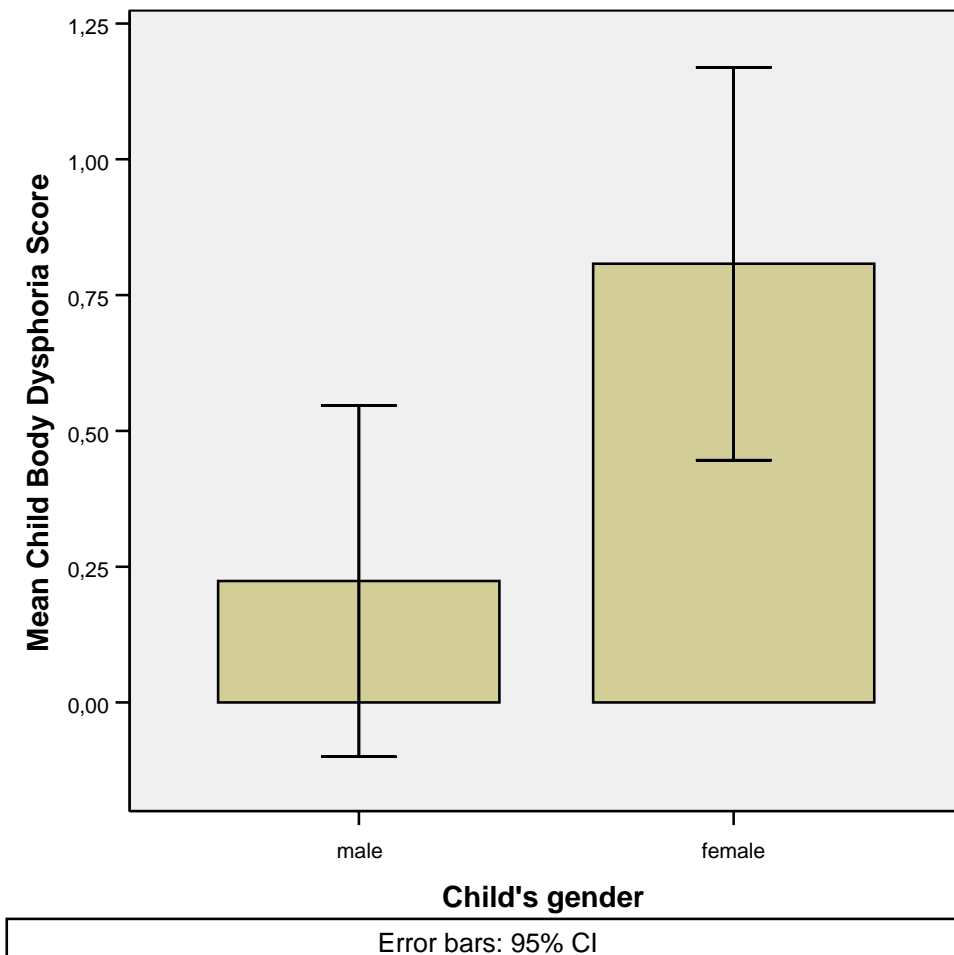


Table 3.

Intercorrelations among BSQ, BIA, Prospective Memory, SODA, Medication Log, and Diet Log for the Total Sample (N=57).

Variable	Age	Prop. Mem.	BSQ	BIA	Med Log	SODA	Diet Log
Age	1	.037	-.22	.02	-.18	-.42**	-.09
Pros. Mem.	.037	1	-.13	-.07	.19	.13	-.13
BSQ	-.22	-.13	1	-.42**	-.12	.40**	.30
BIA	.02	-.07	-.42**	1	.13	-.33**	-.41**
Med. Log	-.18	.19	-.12	.13	1	.28	-.11
SODA	-.42**	.13	.40**	-.33**	.28	1	.45**
Diet Log	-.09	-.13	.30	-.41**	-.11	.45**	1

\* $p < .05$ , \*\* $p < .01$

plotting a scattergram, and homoscedasticity was explored by plotting the standardized predicted residuals for each predictor variable. The results of this analysis revealed that the assumptions of regression were met and no transformations were needed.

### *Primary Analyses*

To examine the main effects of age, prospective memory, and body satisfaction on medication and diet adherence, as well as potential interactions among age, gender, and body satisfaction, two separate hierarchical linear regressions were conducted, one for each dependent variable. Prior to running the analyses and creating the interaction terms, age, gender, and body satisfaction were centered according to recommendations by Aiken and West (1991). Each regression consisted of five steps. Age was entered in the first step, followed by prospective memory in the next step, and body satisfaction in the third step. The two-way body satisfaction by gender interaction was entered into the fourth step, and the three-way age by body satisfaction by gender interaction was entered into the fifth step. The main effects and interaction terms were not interpreted unless the amount of variance accounted for within the corresponding step was above and beyond that of the previous steps (i.e.,  $R^2_{\text{change}}$  was significant).

*Medication adherence.* Results of the regression analysis examining the relation between age, prospective memory, and body dissatisfaction on medication adherence are presented in Table 4. Neither age, prospective memory, nor body satisfaction were found to have a significant main effect on medication adherence. As well, the two-way interaction between body satisfaction and gender did not significantly predict medication adherence and the three-way interaction between body satisfaction, age and gender also

Table 4.

Hierarchical Linear Regression Analysis Examining Main Effects and Interactions among Age, Prospective Memory, Body Satisfaction in Predicting Medication Adherence.

Predictors	$\beta$	$\Delta R^2$
Step 1		.03
Age	-.18	
Step 2		.03
Prospective Memory	.18	
Step 3		.03
Body Satisfaction <sup>1</sup>	.17	
Step 4		.05
Body Satisfaction <sup>1</sup> x Gender	1.42	
Body Satisfaction <sup>1</sup> x Age	.02	
Gender x Age	.12	
Step 5		.05
Body satisfaction <sup>1</sup> x Gender x Age	.29	

<sup>1</sup>Body Image Assessment (Veron-Guidry & Williamson, 1996)

\* $p < .10$ , \*\* $p < .05$ , \*\*\* $p < .01$

was not significant. For exploratory purposes, this regression was also calculated substituting the BSQ as a measure of body satisfaction instead of the BIA, but it did not yield any significant main effects or interactions among the variables of interest. Finally, the interaction between age and prospective memory was also examined for effects on medication adherence and was not found to be significant.

In addition to asking the participants to keep a medication log, they were also directly asked in the family information form to report whether they had forgotten to take their medication during the past two weeks. Responses to this question were also used as an alternative measure of medication adherence. When participants' self-report of whether they had forgotten their medication was substituted as a measure of medication adherence, a two-way interaction between gender and age ( $\beta = .21, p < .01$ ) was observed. The results of this interaction were explicated following the guidelines by Aiken and West (1991), and are represented visually in Figure 5. The nature of this interaction was such that there was no difference between younger (ages 10-16.5 years) boys and girls in their likelihood of forgetting to take their medication; however, older (ages 16.5 - 21 years) boys were more likely on average to forget to take their medication than older girls. A one-way analysis of variance (ANOVA) was used to compare males and females on medication adherence; they were not significantly different ( $F = .40, p = .84$ ).

Finally, when children's self-reported medication adherence measured by the child marking a continuum from "always" to "never" taking medication as recommended was used as the dependent variable, a main effect for prospective memory approached

Figure 5.

Explicated age by gender interaction predicting self-reported number of times children forgot their medication during the previous week.



significance ( $\beta = .25, p = .06$ ), indicating that children with better prospective memory also perceive themselves as more adherent to their medication regimen.

*Dietary adherence.* The regression analysis investigating the main effects and interactions among age, prospective memory, and body satisfaction on dietary adherence are displayed in Table 5. Results of this regression analysis revealed a significant main effect of age ( $\beta = -.42, p < .01$ ) on dietary adherence, accounting for approximately 17% of the variance ( $R^2_{\text{change}} = .17; F_{\text{change}}(1, 41) = 8.57, p = .006$ ). This finding suggests that as hypothesized, older children were less likely to adhere to their dietary regimen. No main effect was found for prospective memory ( $\beta = .10, p = .509$ ) and neither of the two way or three-way interactions were found to be significant. However, body satisfaction yielded a nearly significant main effect on dietary adherence ( $\beta = -.32, p = .09$ ) accounting for 10% of the variance above and beyond baseline levels of age ( $R^2_{\text{change}} = .10; F_{\text{change}}(2, 38) = 2.55, p = .09$ ). It has been suggested that effect sizes may be used as a measure of significance rather than conventional p value cutoffs (Kraemer et al., 1999); given the small sample size and the effect size of body satisfaction, this finding may be considered significant and suggests that as hypothesized, more body dissatisfaction resulted in less dietary adherence. For exploratory purposes, a parallel analysis was conducted using the BSQ as a predictor of body satisfaction (Table 6). A main effect was found for body satisfaction ( $\beta = .36, p < .05$ ), which accounted for 12% of the variance, suggesting that the effect of body satisfaction on dietary adherence remains a constant finding across different measures of body satisfaction ( $R^2_{\text{change}} = .12; F_{\text{change}}(2, 38) = 3.30, p < .05$ ). When the BSQ was entered into the third step of a separate

Table 5.

Hierarchical Linear Regression Analysis Examining Main Effects and Interactions among Age, Prospective Memory, and Body Satisfaction, in Predicting Dietary Adherence (as measured by the SODA).

Predictors	$\beta$	$\Delta R^2$
Step 1		.17***
Age	-.42	
Step 2		.01
Prospective Memory	.10	
Step 3		.10*
Body Satisfaction <sup>1</sup>	-.32	
Step 4		.03
Body Satisfaction <sup>1</sup> x Gender	-.13	
Body Satisfaction <sup>1</sup> x Age	.12	
Gender x Age	-.05	
Step 5		.04
Body satisfaction <sup>1</sup> x Gender x Age	-.24	

<sup>1</sup>Body Image Assessment (Veron-Guidry & Williamson, 1996)

\* $p < .10$ , \*\* $p < .05$ , \*\*\* $p < .01$



Table 6.

Hierarchical Linear Regression Analysis Examining Main Effects and Interactions among Age, Prospective Memory, and Body Satisfaction, in Predicting Dietary Adherence (as measured by the SODA).

Predictors	$\beta$	$\Delta R^2$
Step 1		.17***
Age	-.42	
Step 2		.01
Prospective Memory	.10	
Step 3		.12**
Body Satisfaction <sup>1</sup>	.36	
Step 4		.07
Body Satisfaction <sup>1</sup> x Gender	.28	
Body Satisfaction <sup>1</sup> x Age	.07	
Gender x Age	.04	
Step 5		.05
Body satisfaction <sup>1</sup> x Gender x Age	-.28	

<sup>1</sup>Body Satisfaction Questionnaire (Dunker et al., 1998)

\* $p < .10$ , \*\* $p < .05$ , \*\*\* $p < .01$

analysis after age and the BIA, it was found to account for 5% of the variance in predicting diet adherence above and beyond age and the BIA; although it approached, it did not reach significance ( $R^2_{\text{change}} = .05$ ;  $F_{\text{change}}(1, 38) = 3.06, p = .09$ ).

Another analysis was conducted substituting diet logs as a measure of the dependent variable, dietary adherence (Table 7). A main effect of body satisfaction ( $\beta = -.33, p < .01$ ) was again found, with participants who were more satisfied with their body reporting more dietary adherence ( $R^2_{\text{change}} = .28$ ;  $F_{\text{change}}(2, 35) = 6.97, p < .05$ ). Finally, when children's self-evaluation of dietary adherence as measured by marking a continuum from "always eating according to medical advice" to "never eating according to medical advice" was used as the dependent variable, both age ( $R^2_{\text{change}} = .07$ ;  $F_{\text{change}}(1, 53) = 3.77, p = .06$ ) and body satisfaction ( $R^2_{\text{change}} = .10$ ;  $F_{\text{change}}(2, 50) = 2.98, p = .06$ ) approached significance, suggesting that younger children and participants who were more satisfied with their body perceived themselves as more adherent (Table 8).

Although the body satisfaction by gender interaction was not found to be significant, when regressions were run separately for male and females, body dissatisfaction (as measured by the BIA) accounted for a significant amount of the variance in dietary adherence (as measured by the SODA), but only for the female participants ( $R^2 = .25$ ;  $F(1, 20) = 6.47, p < .05$ ). Genders were compared using a one-way analysis of variance (ANOVA) on diet log and SODA; no differences were found for the SODA ( $F = .03, p = .86$ ), but females reported less adherence than males on the diet log ( $F = 9.22, p < .01$ ). When females were compared to males on their confidence in their ability to overcome obstacles to dietary adherence as reported on the SODA, they were

Table 7.

Hierarchical Linear Regression Analysis Examining Main Effects and Interactions among Age, Prospective Memory, and Body Satisfaction, in Predicting Dietary Adherence (as measured by the Dietary Adherence Log).

Predictors	$\beta$	$\Delta R^2$
Step 1		.01
Age	-.09	
Step 2		.03
Prospective Memory	-.17	
Step 3		.28**
Body Satisfaction <sup>1</sup>	-.33	
Step 4		.04
Body Satisfaction <sup>1</sup> x Gender	-.09	
Body Satisfaction <sup>1</sup> x Age	.05	
Gender x Age	-.19	
Step 5		.00
Body satisfaction <sup>1</sup> x Gender x Age	.00	

<sup>1</sup>Body Image Assessment (Veron-Guidry & Williamson, 1996)

\* $p < .10$ , \*\* $p < .05$ , \*\*\* $p < .01$

Table 8.

Hierarchical Linear Regression Analysis Examining Main Effects and Interactions among Age, Prospective Memory, and Body Satisfaction, in Predicting Dietary Adherence (as measured by the Children's Self-Evaluation of Diet Adherence).

Predictors	$\beta$	$\Delta R^2$
Step 1		.07*
Age	-.26	
Step 2		.00
Prospective Memory	.05	
Step 3		.01**
Body Satisfaction <sup>1</sup>	-.33	
Step 4		.06
Body Satisfaction <sup>1</sup> x Gender	-.14	
Body Satisfaction <sup>1</sup> x Age	-.04	
Gender x Age	-.22	
Step 5		.01
Body satisfaction <sup>1</sup> x Gender x Age	-.14	

<sup>1</sup>Body Image Assessment (Veron-Guidry & Williamson, 1996)

\* $p < .10$ , \*\* $p < .05$ , \*\*\* $p < .01$

found to be significantly less confident ( $F = 4.29, p < .05$ ). No correlation between confidence and age was found ( $r = -.046, p = .77$ ).

An interaction between prospective memory and age was created in order to explore whether age mediated the effect of prospective memory on dietary adherence. However, this interaction was not found to be significant.

### *Exploratory Analyses*

Selected further analyses were conducted in an effort to gain additional information and a better understanding of the current results.

*Body mass index (BMI)*. In an effort to explore the relation between the participant's actual body size (as measured by the BMI) and their body satisfaction, as well as between their BMI and reported medication and dietary adherence, a Pearson  $r$  correlation was run (Table 9). BMI was significantly positively correlated with the Body Satisfaction Questionnaire (BSQ) ( $r = -.389, p < 0.01$ ), suggesting that adolescents with a higher BMI reported less body satisfaction on this measure; it was positively correlated with the total score of the Body Image Assessment (Child Body Dysphoria Score) ( $r = .520, p < 0.01$ ), suggesting that adolescents with a higher BMI reported more discrepancy between their current and ideal body size. There was no correlation however between participants' BMI and their medication and/or dietary adherence, suggesting that although BMI is related to body satisfaction, it does not seem to be directly associated with dietary adherence, and thus other factors besides actual body size might be contributing to the found relation between body satisfaction and dietary adherence.

Table 9.

*Intercorrelations among BMI, BSQ, BIA, SODA, Medication Log, and Diet Log for the Total Sample (N=57).*

Variable	BMI	BSQ	BIA	SODA	Med Log	Diet Log
BMI	1	-.389**	.520**	-.151	-.034	-.160
BSQ	-.389**	1	-.420**	.398**	-.116	.304
BIA	.520**	-.420**	1	.330*	.134	-.412**
SODA	-.151	.398**	.330*	1	.284	.448*
Medication log	-.034	-.116	.134	.284	1	-.105
Diet Log	-.160	.304	-.412**	.448*	-.105	1

\* $p < .05$ , \*\* $p < .01$

*Parent-child agreement.* As the BIA and the medication and diet logs were administered to both the parents and the children, it was considered important to explore their level of agreement on these measures. For this purpose, an interclass correlation coefficient was used estimating absolute agreement. Parent's responses were found to be significantly correlated with the children's responses on all three of the measures that were administered to both the parent and the child, namely the BIA,  $F(39, 0) = .655$ ,  $p < .01$ , the medication adherence log,  $F(36, 0) = .826$ ,  $p < .01$ , and the dietary adherence log,  $F(27, 0) = .366$ ,  $p < .05$ . Parent and child means were compared and were not found to be significantly different (Current Body Size:  $t(94) = 1.718$ ,  $p = .09$ ; Ideal Body Size:  $t(96) = .969$ ,  $p = .34$ ; Body Dysphoria Score:  $t(95) = 1.426$ ,  $p = .16$ ; Medication Log:  $t(83) = .223$ ,  $p = .82$ ; Diet Log:  $t(65) = -1.927$ ,  $p = .06$ ). However, when weighted kappa was calculated for each measure, it was found to be high for the medication adherence log,  $k = .87$ , and average for the dietary adherence log,  $k = .54$ , but low for the BIA (Current Body Size:  $k = .21$ , Ideal Body Size:  $k = .26$ , Body Dysphoria Score:  $k = .28$ ) indicating that on an individual level, there was a discrepancy between the parent and child perspectives of the child's current and ideal body size.

*SODA Subscales.* As age was found to significantly predict SODA total scores, with older children being less adherent, subscales scores of different strategies that could be used to cope with situational obstacles to dietary adherence were correlated with participant age in order to determine whether the age of the participant was related to preference for one strategy over another. Older children were found to be less likely to endorse items falling under the category of "complete relapse" (defined by Schlundt et al.,

1996, as “make no attempt to follow rules or eat healthy and appropriate foods”),  $r = -.452, p < .001$ . They were also less likely to “eat small quantities of the forbidden foods,”  $r = -.465, p < .001$ , and “plan ahead” (or “take steps earlier in order to be ready for a situation when it arises,” Schlundt et al., 1996),  $r = -.479, p < .001$ .

### Discussion

This study is to our knowledge unique, as it is the first to examine both medication and diet adherence in a pediatric population with IBD. Although following a diet plan is critical for many chronic illnesses, and there is evidence that dietary adherence is very low in pediatric populations (Booth, 1991; Mackner, McGrath, & Stark, 2001; Stark, 2000), there has been a lack of research on dietary adherence in IBD. Further, we do not have a solid understanding of the factors that are associated with patients adhering to their diet in this population.

We hypothesized that age, prospective memory, and body satisfaction would predict children's and adolescents' adherence to medication and dietary adherence. More specifically, we expected that younger children would be more adherent to both medication and diet in comparison to adolescents, as adherence is often controlled by the parents when the child is younger, and issues of peer pressure and self image have not yet come into effect as strongly. We also hypothesized that participants with better prospective memory would be more adherent to both their medicine and their diet, as they would be more likely to remember to take their medicine or avoid certain foods. Stretching the argument a bit further, as prospective memory has been associated more strongly with executive skills than memory (Kerns & Price, 2001; Martin, Kliegel, &



McDaniel, 2003; McDaniel et al., 1999), one could hypothesize that participants with better prospective memory would also be better at planning ahead and making better decisions regarding their medicine and diet behaviors. Finally, we hypothesized that body satisfaction would influence medicine taking and diet, with higher body satisfaction being related to better medical regimen adherence. However, we expected this to be true only for females in mid to late adolescence, as they are more likely to be concerned about their body appearance and have a higher incidence of eating disorders (DSM-IV-TR, 2000).

Our hypotheses were not confirmed for medication, as age, prospective memory, and body satisfaction were not found to predict self-reported medication adherence. However, this could be due to a recent shift in the drug of choice for individuals with IBD. In the past, IBD symptoms were largely treated with prednisone, a drug that has many side-effects and significantly impacts appearance by causing facial swelling, increase in appetite, weight gain, acne, and body hair. However, the recently marketed drug Remicade® (Infliximab) has to a large degree taken the place of the corticosteroids for the long-term management of IBD symptomatology. Infliximab, which was administered to 73.7% of our sample in contrast to the 10.5% of the sample that was prescribed corticosteroids, does not affect appearance. Furthermore, although the prednisone is taken orally at home, infliximab is taken at an infusion center on scheduled dates via intravenous infusion. Thus, missing a dose would be more difficult and would have more practical consequences (e.g., billing and scheduling difficulties) with infliximab than prednisone. Indeed, adherence to Infliximab infusions has been found to be very high. Kane and Dixon (2006) reported that out of 1185 infusions scheduled for 274

patients, only 48 (4%) appointments were missed, all of which were accounted for by 6 patients.

It is important to note that an age by gender interaction in the prediction of the child's likelihood to endorse forgetting his or her medication during the week prior to the data collection date was found. Decomposition of this interaction showed that whereas younger boys and girls did not differ in their reports, significantly more of the older boys reported forgetting their medication in comparison to the older girls. As this effect was not observed for medication logs, there is a question regarding whether there is a true difference between adolescent males and females in regard to their medicine taking, or whether other hypotheses need be generated in order to explain this finding. One possibility might be that adolescent males are less accurate in their retrospective reports of medication adherence in comparison to younger males or females. Alternatively, this finding might reflect a real difference in medication adherence, as older males might have been less likely to truthfully keep track of their medication during the week but were able to provide an accurate estimate of their low adherence at the time of the data collection.

In regard to dietary adherence, many of our hypotheses were largely confirmed. First, age was found to be a significant predictor of self-reported adherence; as hypothesized, older children reported being less adherent to their diet on the one-week diet log. In addition, older children reported less ability to overcome obstacles to their dietary adherence. One possible interpretation of this finding is that even though children seek out more independence as they grow into adolescence, they might not simultaneously become more responsible, thus resulting in their not monitoring or

adhering to their diet as would be ideal. Competing factors might also come into play when children reach adolescence, such as need for peer recognition, romantic emotions, puberty, and increased academic pressure and demands. It is important to note however, that this finding could also be the result of older participants having higher standards and more self-demands in regard to their diet, or a better ability to accurately evaluate and report their dietary adherence compared to younger children. Older children are also more likely to have had experience with the disease for a longer period of time, and longer illness duration is one of the factors that have been associated with poorer adherence (for a review see Kane, 2006; López-Sanromán, & Bermejo, 2006). Alternatively, younger children might be more prone to providing socially desirable responses than adolescents.

Secondly, body satisfaction was found to predict diet adherence above and beyond age. As hypothesized, participants who were less satisfied with their body were less likely to report following their diet regimen and vice versa. This finding could suggest that body image and personal satisfaction with body appearance affects the patients' likelihood to choose foods that are healthy and compatible with their chronic illness over foods that will exacerbate their symptoms. On the flipside, this finding could also suggest that participants who are less adherent with their diet are also less likely to be satisfied with their bodily appearance. Other factors could also be affecting this relation, such as an overall negative response style, and although only few ( $N=9$ , 16%) of the participants reported comorbid psychopathology (i.e. depression ( $N=7$ , 12.3%),

anxiety ( $N=1$ , 1.8%), and ADHD ( $N=1$ , 1.8%)), undiagnosed psychopathology should also be taken into consideration.

More specifically, the BSQ was found to predict adherence to diet more strongly than the BIA. This finding might be due to the specificity of the BSQ to changes in, and dissatisfaction with, body appearance that are the result of IBD. In other words, whereas the BIA measured body satisfaction in general, the BSQ targeted body satisfaction *in relation to* IBD. The BSQ was not found to significantly predict diet adherence above and beyond the BIA, although it approached significance.

Female participants were found to be less satisfied with their body than males. This result is consistent with previous findings in healthy populations (Lokken et al., 2003; Pharres, Steinburg, & Thompson, 2004). Although we did not find a body satisfaction by gender interaction, when the analyses were run separately for each gender, a significant effect of body dissatisfaction on dietary adherence was found for females but not for males. This factor is important for healthcare providers to consider when discussing diet regimens, as body satisfaction could potentially influence both boys and girls in their ability to adhere to their diets, but special caution should be exercised in the case of female patients.

Females reported less adherence to diet than the males. As one would expect females to report more adherence for the purpose of social desirability, this finding suggests that responses were likely to be genuine. In consistence, females reported that they were less confident in their ability to overcome obstacles to dietary adherence.

Finally, prospective memory was not found to affect dietary adherence as initially hypothesized. The lack of an effect of prospective memory on dietary adherence could be due to the ecological validity of the measure and its generalizability to dietary adherence. First of all, in the prospective memory task, the participants were asked to hypothesize that the researcher was holding their medicine and to ask for it at a predetermined time or event. However, this paradigm did not directly assess dietary adherence. Conceptually, dietary adherence seems to require more general executive-type skills, such as planning ahead, inhibition, and good decision making. Although prospective memory has been found to relate to both executive skills and medication adherence, it may not be a good indicator of dietary adherence or a skill required for good diet behaviors.

There were some limitations to this study. First, the targeted population was specialized to a certain age group with a diagnosis of IBD living in an urban locale in the Southeastern United States, and the vast majority of the sample (80.6%) was Caucasian and from the same general region. Thus, results of this study might not be generalizable to other regions of the U.S., other cultures/countries, or individuals of other racial or ethnic groups. Furthermore, availability of participants was limited resulting in a small sample size, which might have resulted in inadequate power. Therefore, some of the analyses, such as the interaction analyses, might be considered exploratory in nature and might have been statistically significant with a larger sample. However, when increasing sample size to heighten power, it is important to consider whether statistically significant findings are also clinically significant.

Second, due to the difficulties associated with collecting data in a medical setting, time constraints did not allow for some constructs to be measured comprehensively. Prospective memory was measured by a brief task, and no measures of executive functioning were administered. Future work in this area might focus on exploring the role of prospective memory and other executive measures in medication and dietary adherence, for the purpose of determining whether good executive functions influence children's and adolescents' ability to adhere to a certain medication regimen and/or diet.

Third, even though there was consistency between different measures of the same construct, and between parent and child report on certain measures, the measures used were all self-report and thus factors such as subjectivity, method variance, and response bias need to be taken into account. Future work might use multi-method and multi-informant procedures in an effort to avoid these problems.

Fourth, the difficulties of assessing adherence have been discussed extensively in the literature (La Greca & Bearman, 2003; Manne, 1998; Rapoff, 1999). The use of daily logs for the purpose of recording medication taking and diet is considered more accurate than retrospective reporting due to shorter recall periods (La Greca & Bearman, 2003). In regard to the diet log, for the sake of parsimony and quantification of the data, daily logs were worded so that it was left up to the participants to decide whether or not their daily food intake was consumed according to medical advice. Thus, the assumption was made that the patients and parents had accurate information on what foods are best avoided, an assumption that might be inaccurate, especially in younger children.

Although this study was conducted with a small sample and has limitations, the current findings are provocative and suggest additional exploration of the relations among age, body satisfaction, and diet adherence in children with IBD. Therefore, it is suggested that future efforts are divided between three major areas: (a) further research on the role of diet and body satisfaction in IBD, (b) incorporation of developmental factors into the exploration of predictors of medication and diet adherence, and (c) physician and patient education.

IBD is an illness in which nutrition and diet play a significant role for a number of reasons including the ability of certain foods to exacerbate the symptoms or cause “flare ups,” the presence of reduced oral intake because of abdominal pain, nausea and loss of appetite, malabsorption, and increased caloric requirements because of fever and inflammation (Powers, 1997). This issue is especially a concern in children, due to the increased nutritional needs and potential for growth delays. However, we currently do not have a good understanding of ways to incorporate diet into the treatment regimen and to prevent malnutrition. This factor is complicated by the significant patient variability in terms of food tolerance, as patients frequently have to individually determine their food restrictions through trial and error. Anecdotally, most of the children in our sample reported that the general guidelines they were given by health care providers about what to eat and what to avoid did not correspond with their experience of what was helpful or harmful to them. Modern medicine in general seems to put much faith in drug development and to leave diet unexplored as far as its positive or negative effects.

Beyond IBD, medication and diet adherence are significant for the progress of many chronic illnesses, and can compromise optimal medical outcome. Adherence should not be viewed as a static characteristic of the patient's behavior, as it changes across the lifetime with the influence of various developmental factors. Age and body satisfaction appear to be part of this equation, but others should be explored. Particularly for diet, additional complex issues such as the family's eating habits and culture around food, the children's mood, or understanding of why certain foods can worsen their condition may come into play. Furthermore, cognitive development and maturation of advanced cognitive abilities such as memory and executive functions are likely to individual's ability to adhere. Determining these factors and their relations with one another is suggested as a future research challenge.

Physicians should be informed of these results, both for the purpose of informing their patients, but also for more accurate differential diagnosis. IBD has been reported to be erroneously diagnosed as an eating disorder due to the presence of fear of obesity, weight loss, and body image disturbances, all of which can also be the direct result of IBD. However, physicians must exercise caution for potential co-morbidity for both IBD and eating disorders, in which case one condition complicates the presentation, diagnosis and treatment of the other (for a review, see Powers, 1997).

Finally, it is critical that patients gain a good understanding of the knowledge available on both medical treatments and diet. In IBD, patient education has been found to increase patient satisfaction, whereas a trend for increasing medication adherence has also been found (Waters, Jensen, & Fedorak, 2005). In light of the current findings,



alerting families to the relation of age and body satisfaction, and diet adherence could increase their ability to work towards adherence. Although our findings regarding body satisfaction and diet intuitively make sense, one might expect that the cognitive maturity that comes with adolescence would result in better monitoring of diet and wiser selection of foods, thus the result that younger children are more likely to adhere to diet is to a certain degree counter-intuitive. Therefore, the relation between age and diet adherence potentially warrants the need for preventative measures, such as parents remaining involved in their children's care as they grow into adolescents. Parents should also be encouraged to discuss body satisfaction concerns with their adolescents with IBD, even in the absence of obesity or a diagnosed eating disorder.

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## Appendix A

<b>Family Information Form</b>
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Please take a moment to complete the following forms. If you have any questions, please ask. Thanks!
--

*Questions for Parent*

1. Your Relation to Child: \_\_\_Mother \_\_\_Father \_\_\_Grandparent  
If other, describe: \_\_\_\_\_
2. Your Gender: \_\_\_Male \_\_\_Female
3. Your Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_
4. Your Ethnicity: \_\_\_Hispanic or Latino \_\_\_Not Hispanic or Latino
5. Your Race: \_\_\_White \_\_\_American Indian or Alaska Native \_\_\_Asian \_\_\_Black or African American \_\_\_Native Hawaiian or Other Pacific Islander
6. The highest education level you completed (Please write a number. For example, 8 = completed middle school, 10 = completed sophomore year of high school, 12 = graduated high school, 13 = completed freshman year of college, 16 = graduated college): \_\_\_\_
7. Your Marital Status: \_\_\_Single \_\_\_Married \_\_\_Separated \_\_\_Divorced \_\_\_Widowed
8. The highest education level your husband/wife completed (Please write a number. For example, 10 = completed sophomore year of high school, 12 = graduated high school, 13 = completed freshman year of college, 16 = graduated college): \_\_\_\_
9. Approximate total family income per year \_\_\_\_\_
10. Child's Gender: \_\_\_Male \_\_\_Female
11. Child's Date of Birth: \_\_\_\_/\_\_\_\_/\_\_\_\_

12. Child's Ethnicity: \_\_\_ Hispanic or Latino \_\_\_ Not Hispanic or Latino
13. Child's Race: \_\_\_ White \_\_\_ American Indian or Alaska Native \_\_\_ Asian  
\_\_\_ Black or African American \_\_\_ Native Hawaiian or Other Pacific Islander
14. Child's height: \_\_\_\_\_
15. Child's weight: \_\_\_\_\_
16. Child's diagnosis: \_\_\_\_\_
17. Child's age at diagnosis: \_\_\_\_\_
18. Child's number of hospitalizations: \_\_\_\_\_
19. Child's number of surgeries: \_\_\_\_\_
20. Child's history of psychiatric diagnoses: \_\_\_\_\_
21. Child's medications currently prescribed:

Medication	Quantity/Dose	Frequency

22. Child's dietary recommendations (e.g., foods encouraged/discouraged to eat); please be as specific as possible:
23. Overall, how is your child's adherence to medications? Does he/she take them as recommended?

Never \_\_\_\_\_ Always

24. Overall, how is your child's adherence to diet? Does he/she eat according to medical recommendations?

Never \_\_\_\_\_ Always

25. Please provide your phone number(s) so that we can contact your child in 1 week to inquire about the diet and medication log.

Phone: 1) \_\_\_\_\_ 2) \_\_\_\_\_

*Questions for Child*

26. How important is it to YOU that you take your medications as prescribed? Make a vertical mark on the horizontal line below to answer this.

Not \_\_\_\_\_ Very  
Important \_\_\_\_\_ Important

27. How important is it to YOU that you stick to your dietary recommendations?

Not \_\_\_\_\_ Very  
Important \_\_\_\_\_ Important

28. In the past 2 weeks... (please circle responses)  
Have you forgotten your medication? **Y N**  
When you felt good, did you skip your medication? **Y N**  
When you felt bad after taking your medication, did you stop taking it? **Y N**

29. Overall, how is your adherence to your medications? Do you take them as recommended?

Never \_\_\_\_\_ Always

30. Overall, how is your adherence to your diet? Do you eat according to medical recommendations?

Never \_\_\_\_\_ Always

## Appendix B

**Body Satisfaction Questionnaire****A. Are you less satisfied with your body since your diagnosis?**

1. = no, not at all
2. = a little bit
3. = quite a bit
4. = yes, extremely

**B. Do you feel embarrassed because of how you look?**

1. = no, not at all
2. = a little bit
3. = quite a bit
4. = yes, extremely

**C. Do you think the disease has damaged your body on the outside?**

1. = no, not at all
2. = a little bit
3. = quite a bit
4. = yes, extremely

**D. Do you feel less attractive as a result of your disease or treatment?**

1. = no, not at all
2. = a little bit
3. = quite a bit
4. = yes, extremely

**E. Is it difficult to look at yourself naked?**

1. = no, not at all
2. = a little bit
3. = quite a bit
4. = yes, extremely

**F. Do you think you are less attractive to others because of your disease?**

1. = no, not at all
2. = a little bit
3. = quite a bit
4. = yes, extremely

**G. On a scale from 1 to 7, how satisfied are you with your body?**

<b>1 = very</b>	<b>2 =</b>	<b>3 =</b>	<b>4 =</b>	<b>5 =</b>	<b>6 =</b>	<b>7 = very</b>
<b>unsatisfied</b>	<b>unsatisfied</b>	<b>slightly</b>	<b>neutral</b>	<b>slightly</b>	<b>satisfied</b>	<b>satisfied</b>
		<b>unsatisfied</b>		<b>satisfied</b>		

**H. On a scale from 1 to 7, how would you describe your body?**

<b>1 =</b> <b>ugly/ unattractive</b>	<b>2</b>	<b>3</b>	<b>4 =</b> <b>average</b>	<b>5</b>	<b>6</b>	<b>7 =</b> <b>attractive/ beautiful</b>
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**I. Overall, how self-confident did you feel before the disease?**

<b>1 =</b> <b>not at all confident</b>	<b>2</b>	<b>3</b>	<b>4 =</b> <b>average</b>	<b>5</b>	<b>6</b>	<b>7 = very confident</b>
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**J. Overall, how self-confident do you feel after the disease?**

<b>1 =</b> <b>not at all confident</b>	<b>2</b>	<b>3</b>	<b>4 =</b> <b>average</b>	<b>5</b>	<b>6</b>	<b>7 = very confident</b>
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## Appendix C

**Prospective Memory Naturalistic Task Form**

**Instructions:** *Before we begin today, I would like us to play a game. I would like you to assume that you need to take your medication twice today during the time that we are together: once in exactly 15 minutes, and once before you leave here today, when we are finished. I would also like you to assume that I am the person who is keeping your medication and that in order to take it you need to ask me for it. Keep in mind that this is a game and that I will not be giving you any real medication, however I would like you to assume that it is real.*

*Remember, I will not be reminding you to take your medication; you need to remember on your own. If you forget to ask me for it, then you will end up not taking it just like if you forget in real life. Do you have any questions?*

**Time-based:**

- |  |   |   |
|--|---|---|
| 1. Remembered after 15 minutes           | Y | N |
| 2. Remembered later or before 15 minutes | Y | N |

**Event-based**

- |                              |   |   |
|------------------------------|---|---|
| 1. Remembered before leaving | Y | N |
|------------------------------|---|---|

**Observations:**

Appendix D

Situational Obstacles to Dietary Adherence  
(SODA)

Adolescent Version

Originally adopted from David Schlundt, Ph.D. and adjusted for  
IBD and the purposes of this study



## Instructions

On the following pages there are descriptions of common but hard diet situations that young people with a chronic illness such as Crohn's disease or Ulcerative Colitis sometimes face.

After each situation there is a rating scale on which you will rate from one to seven (1 – 7) how confident you would be about handling that situation. Please read the descriptions carefully. Picture yourself facing that situation or one very similar. First, use the scale to rate how confident you are that you could solve the hard problem. Circle the number that best describes the amount of confidence you would have in that situation. For example, if you would not be at all confident that you could solve the problem, you would circle the number one. If you would be completely confident that you could solve the problem, you would circle number seven.

After rating your confidence, rate how often you encounter an incident similar to the one described. Not necessarily an identical situation, but a situation that is very similar to the one described. If you feel that something like what is described never happens to you, circle the number one. If you feel that this happens to you a lot, circle the number seven.

Finally, look at the following list of solutions. When faced with a problem, we understand that young people don't always act the same way every time. There are five different ways to solve each problem that young people with a chronic illness use a lot. We want to know how you would act. Use the scales provided to rate each choice. Rate how often you would act in the way described. For each choice circle the number that tells us how often you would act that way. For example, if the choice is, "Eat all the cookies," and you would act that way about half the time, you would circle the number four. If you would never eat all the cookies, you would circle the number one. If you would eat all the cookies all the time, you would circle the number seven. Circle a number for all five of the choices. Remember, there are no correct or wrong solutions to these problems. Please ask us any questions you might have.

1. *Your doctor or dietician has given you a meal plan to follow. You do not want to eat the amount that she/he prescribed because you are afraid you might gain or you want to lose weight. You think that you are too fat and you are tempted to cut down on the amount that the dietician told you that you should eat.*

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
---------------------------	---	---	---	---	---	---------------------------

**II. How often does this happen to you?**

Never 1	2	3	4	5	6	Always 7
------------	---	---	---	---	---	-------------

**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Do your best to stick to the meal plan you already have.**

Never 1	2	3	4	5	6	Always do 7
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**B. Talk to your doctor or dietician about changing to a healthy meal plan that would still allow you to lose weight.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**C. Cut back a lot on your meal plan so that you will lose weight fast.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**D. Eat foods you're not supposed to because they are lower in fat and sugar.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**E. Stick to your meal plan and exercise to lose weight.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

2. *You are ready for an afternoon snack. You go into the kitchen and look in the cabinet. There are a lot of snack foods that you are not allowed to eat because other members of your family like to snack on them. You really like these snacks and you are tempted to have some for your snack.*

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
---------------------------	---	---	---	---	---	---------------------------

**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
------------	---	---	---	---	---	-------------

**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Ignore the food and walk away without eating anything.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**B. Eat only what you are allowed to eat.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**C. Talk to your family about keeping only foods you are allowed to eat in the house.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**D. Eat the forbidden snacks but skip dinner.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**E. Eat the forbidden snacks and not tell anyone.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

3. *You are at school and it is time for lunch. You have been having a flare – up the past few days but feel really hungry at the moment. You go to the school cafeteria but nothing is being served that is safe to eat.*

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
------------------------------	---	---	---	---	---	------------------------------

**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
------------	---	---	---	---	---	-------------

**III. How often would you use each of the following solutions? (Circle one number for each solution).**

- A. Try to get the lunch menu ahead of time and bring lunch from home if you know the choices will be bad.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

- B. Not eat anything and remain hungry.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

- C. Eat only small portions of the school lunch.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

- D. Eat the school lunch and not eat any more food that day or take extra medication.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

- E. Eat what's available and just don't worry about it.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

4. *You are at a party and the host is serving yummy foods most of which you are not supposed to eat. You have been having a flare-up but you feel fine today. You are not paying attention to what you are eating because you are having such a good time with your friends. You are dancing and feel great and would rather forget about your illness.*

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
------------------------------	---	---	---	---	---	------------------------------

**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
------------	---	---	---	---	---	-------------

**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Eat only what you are allowed to at the party.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**B. Plan ahead to not eat much that day and bring some snacks you are allowed to eat (or a food supplement) in case you feel hungry.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**C. Ask the host for some snacks that you can eat.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**D. Don't stand near the snacks any pay careful attention to not eat anything you're not supposed to.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**E. Sample everything. It's a party, have fun!**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

5. *You try to do a good job of sticking to foods you are allowed to eat, but you have one weakness, a favorite food that you are not allowed to eat but really like and miss. You try to avoid eating this favorite food but you find it very hard to resist it. You have gotten in trouble before by eating too much of this (or other) favorite food and feeling ill later. You are at the mall and are walking past a food stand when you spot your favorite food. You can smell it, feel hungry and are really tempted to stop and get some.*

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
------------------------------	---	---	---	---	---	------------------------------

**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
------------	---	---	---	---	---	-------------

**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Avoid the food by not walking by the food stand at all.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**B. Get another snack that you are allowed to eat instead.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**C. Have your favorite food this once, and take extra medication.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**D. Get a small order and not eat anything else for the rest of the day.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**E. Go ahead and eat your favorite food, you can't resist.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

6. *It is Saturday afternoon and you are home alone. You don't have anything to do and you are bored. You have finished all your homework and there is not even anything good to watch on TV. You try calling a couple of friends but you are unable to reach them. You go into the kitchen and see your mom prepared some dinner that is dangerous to eat now that you are having a flare-up. You are bored and don't really have anything else to do and you are tempted to eat some of the dinner.*

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
------------------------------	---	---	---	---	---	------------------------------

**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
------------	---	---	---	---	---	-------------

**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Find a snack that is allowed on your meal plan instead of eating the cake.**

Never 1	2	3	4	5	6	Always do 7
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**B. Splurge on a big portion of the dinner. No one is there to catch you anyway.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**C. Go outside and do something fun to keep from eating out of boredom.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**D. Eat a small portion of the dinner and avoid eating for the rest of the day.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**E. Eat a small portion of the dinner and then take extra medication.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

7. *You are getting together with all your relatives for the holidays. Everyone has brought his/her special dish and the food that looks great; however, you are not supposed to eat most of the foods that are there. You feel obligated to try everything because you do not want to hurt anyone's feelings. Besides, several people are urging you to try their "special" dish and you do not want to be rude by refusing.*

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
------------------------------	---	---	---	---	---	------------------------------

**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
------------	---	---	---	---	---	-------------

**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Eat some of everything and take extra medication.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**B. Take only small amounts of food.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**C. Eat some of everything and skip eating for the rest of the day.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**D. Politely refuse the food, and explain to them why you cannot eat everything.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**E. Eat all you want, it is a holiday and you deserve to splurge.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------



8. *You resent all the extra things that you have to do because you have Crohn's disease or Ulcerative Colitis. You wish that you didn't have to eat particular amounts and types of food. You hate being "different." You just want to be like everybody else. You are tempted to "ditch" your meal plan and eat what and when you want.*

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
---------------------------	---	---	---	---	---	---------------------------

**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
------------	---	---	---	---	---	-------------

**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Ignore your feelings and stick to your meal plan no matter what.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**B. Do something fun to get your mind off your feelings.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**C. Forget about what you are supposed to do and eat whatever you want to make you feel better.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**D. Talk to someone about your feelings.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**E. Eat small amounts of forbidden foods to make you feel less different.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

9. *Sometimes you get depressed. When you feel this way you sometimes think, "What's the use, I'm going to suffer these symptoms anyway." During these times you do not follow what you're supposed to eat very well. Sometimes when you feel this way you eat things that do not fit well into your meal plan or eat too little or too much of certain foods. Today you are having these kinds of feelings.*

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
------------------------------	---	---	---	---	---	------------------------------

**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
------------	---	---	---	---	---	-------------

**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Talk to someone you trust about your feelings of depression.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**B. Eat what you're supposed to; you won't feel this way forever.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**C. Ignore what you are supposed to eat and enjoy life.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**D. Pick something you like and is safe to eat and eat it when you feel this way.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**E. Find another activity to get your mind off your feelings.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

10. *You are so stressed out. You are a member of the school soccer team (or some other extra-curricular activity). You must maintain a certain average to keep your position on the team. Lately you have fallen behind in some of your classes. You are worried that your position on the team might be in jeopardy. You try to study but it just seems like you are so far behind that you will never catch up. Grades are to be posted in two weeks. Sometimes when you get stressed out you tend to things you're not supposed to. Sometimes it seems like snacking helps to relieve some of the pressure.*

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
---------------------------	---	---	---	---	---	---------------------------

**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
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**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Quit the team so that you can spend more time studying.**

Never 1	2	3	4	5	6	Always do 7
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**B. Eat only what your are supposed to even though you are stressed.**

Never 1	2	3	4	5	6	Always do 7
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**C. Snack on whatever you like and take extra medication.**

Never 1	2	3	4	5	6	Always do 7
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**D. Eat whatever you like; snacking helps you to study better.**

Never 1	2	3	4	5	6	Always do 7
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**E. Find a way to relax under stress that does not involve eating.**

Never 1	2	3	4	5	6	Always do 7
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11. *You have a big exam tomorrow and you are studying late. You decide to take a break and you go into the kitchen to get a glass of water. You have been having a flare-up and have felt sick all week, thus you are not supposed to eat most foods and feel really hungry. There are some leftovers from your family's dinner out on the counter and you are tempted to snack on them while you study.*

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
------------------------------	---	---	---	---	---	------------------------------

**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
------------	---	---	---	---	---	-------------

**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Find something you are supposed to eat instead.**

Never 1	2	3	4	5	6	Always do 7
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**B. Ignore the dinner and just get some water.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**C. Eat as much of the dinner as you want; you deserve a reward for studying!**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**D. Eat just a little food (and perhaps take some extra medication).**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**E. Ask your mom not to leave tempting foods out on the counter.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

12. *You have been very unhappy with your looks lately. You have lost a lot of weight as a result of a flare-up and/or your face looks puffy because you are taking many steroids. Your peers at school make comments about your looks that hurt you. You want to gain some weight and look normal, but if you get sick again that might mean more steroids and more puffy cheeks.*

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
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**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
------------	---	---	---	---	---	-------------

**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Eat more food anyway in order to gain weight hoping it won't make your illness worse**

Never 1	2	3	4	5	6	Always do 7
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**B. Stick to what you are supposed to eat and be patient; things will get better.**

Never 1	2	3	4	5	6	Always do 7
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**C. Starve yourself in order to feel better and get off the steroids.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**D. Tell someone your trust how you feel.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**E. Make a plan looking at the calendar to see when you might start to look more normal again.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

13. *Today at school the person sitting behind you threw a paper airplane at the teacher when her back was turned and then blamed it on you. You can't believe that she believed the other student instead of you. You are so upset. If that wasn't enough, your parents believed the teacher when she called them and told them what happened. Your parents grounded you for two weeks. You feel like the whole world is plotting against you and you want to get back at both your parents and the teacher. You think of eating foods you are not supposed to so that you get sick and teach them all a lesson.*

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
------------------------------	---	---	---	---	---	------------------------------

**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
------------	---	---	---	---	---	-------------

**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Talk with your parents about this situation.**

Never 1	2	3	4	5	6	Always do 7
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**B. Find another activity to keep your mind off these problems.**

Never 1	2	3	4	5	6	Always do 7
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**C. Give in to your urge for revenge and eat something highly forbidden.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**D. Avoid eating what you are not supposed to but isolate yourself instead.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**E. Starve yourself instead.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

14. Today you have decided to go to a baseball tournament that will last all day. Since you will be at the tournament during lunch time and the concession stand only offers foods you are better to avoid, it will be hard for you to follow your meal plan for lunch.

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
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**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
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**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Eat a small snack you buy at the game but eat lunch when you get home.**

Never 1	2	3	4	5	6	Always do 7
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**B. Plan ahead to bring lunch with you.**

Never 1	2	3	4	5	6	Always do 7
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**C. Leave the ballpark and go to a nearby restaurant for lunch.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**D. Skip that meal entirely.**

Never 1	2	3	4	5	6	Always do 7
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**F. Eat whatever you like – you're at the game to have fun.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

15. *You are having a bad flare-up and are not allowed to eat most foods. The doorbell rings and it is some friends who want you to go to dinner with them. You have already eaten what you were supposed to for the night, but you really want to go with your friends. If you go you feel like you have to get something to eat because you don't want to just sit there and watch your friends eat.*

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
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**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
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**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Go ahead with your friends and eat at the restaurant.**

Never 1	2	3	4	5	6	Always do 7
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**B. Go with your friends and just order a soda.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**C. Bring something from home to eat at the restaurant.**

Never 1	2	3	4	5	6	Always do 7
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**D. Tell your friends to come back after they have eaten.**

Never 1	2	3	4	5	6	Always do 7
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**F. Stay home and let your friends go eat.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------



16. Often when you go out to eat with friends you do not pay much attention to how much you are eating. For example, tonight you are eating pizza with a bunch of friends. Normally you would only eat 3 slices. You do not know how many slices you have had so far tonight because you are not counting, but you think that you have had at least 6. When you are out with friends you do not want to worry about how much you are supposed to be eating.

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
------------------------------	---	---	---	---	---	------------------------------

**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
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**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Don't worry about it now; the damage is done.**

Never 1	2	3	4	5	6	Always do 7
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**B. In the future, don't go out with your friends if you know you'll overeat when around them.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**C. Keep a better count of how many slices you eat next time and eat only what you are supposed to.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**D. Take extra medication that day.**

Never 1	2	3	4	5	6	Always do 7
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**E. Make yourself vomit to avoid side effects before the food reaches your problematic areas.**

Never 1	2	3	4	5	6	Always do 7
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17. *You are at the movies with a couple of friends. Last time you have popcorn it make you feel sick afterwards and you nearly had a flare-up. But when you walk by the concession stand and smell the popcorn, you are really tempted to get some buttered popcorn.*

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
------------------------------	---	---	---	---	---	------------------------------

**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
------------	---	---	---	---	---	-------------

**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Ignore the popcorn and go straight to your seat.**

Never 1	2	3	4	5	6	Always do 7
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**B. Get something else you like instead, like a soda.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**C. Get the popcorn to satisfy your craving hoping it won't hurt you this time.**

Never 1	2	3	4	5	6	Always do 7
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**D. Get the popcorn but do not eat anything else for the rest of the day.**

Never 1	2	3	4	5	6	Always do 7
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**E. Eat a large dinner before you leave home to avoid cravings at the theatre.**

Never 1	2	3	4	5	6	Always do 7
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18. Sometimes your brother (or sister) teases you by offering you foods that they know you try to avoid. You just walked into the house and your brother offered you candy bar with nuts that you know has caused you to feel ill in the past. You know that he just does it to irritate you, but sometimes the candy looks good and you are tempted to have some.

**I. How confident are you that you could solve this problem? (circle one number)**

Not at all confident 1	2	3	4	5	6	Completely confident 7
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**II. How often does something like this happen to you?**

Never 1	2	3	4	5	6	Always 7
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**III. How often would you use each of the following solutions? (Circle one number for each solution).**

**A. Take the candy and not eat anything for the rest of the day.**

Never 1	2	3	4	5	6	Always do 7
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**B. Ignore him so he will stop.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**C. Get something you are allowed to eat instead.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**D. Take the candy bar and eat it to show him you can be like everyone else.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------

**E. Talk to your parents to get them to make him stop teasing you.**

Never 1	2	3	4	5	6	Always do 7
------------	---	---	---	---	---	----------------



## Diet Log

### Child form

For each day, please circle one response about your diet.

<i>Day 1: _____</i>	<i>Day 2: _____</i>	<i>Day 3: _____</i>	<i>Day 4: _____</i>	<i>Day 5: _____</i>	<i>Day 6: _____</i>	<i>Day 7: _____</i>
I only ate good foods	I only ate good foods	I only ate good foods	I only ate good foods	I only ate good foods	I only ate good foods	I only ate good foods
I ate one thing I shouldn't eat	I ate one thing I shouldn't eat	I ate one thing I shouldn't eat	I ate one thing I shouldn't eat	I ate one thing I shouldn't eat	I ate one thing I shouldn't eat	I ate one thing I shouldn't eat
I ate more than one thing I shouldn't eat	I ate more than one thing I shouldn't eat	I ate more than one thing I shouldn't eat	I ate more than one thing I shouldn't eat	I ate more than one thing I shouldn't eat	I ate more than one thing I shouldn't eat	I ate more than one thing I shouldn't eat

Was this week like other weeks?

4. Yes, I ate just like I eat other weeks
5. No, I ate better foods than other weeks
6. No, I did not eat as good as other weeks

## Medication Log

### Parent Form

Please list the medication your child took at different times of the day on each day of the week.

<i>Day 1:</i> _____	<i>Day 2:</i> _____	<i>Day 3:</i> _____	<i>Day 4:</i> _____	<i>Day 5:</i> _____	<i>Day 6:</i> _____	<i>Day 7:</i> _____
Morning (7am-11am)	Morning (7am-11am)	Morning (7am-11am)	Morning (7am-11am)	Morning (7am-11am)	Morning (7am-11am)	Morning (7am-11am)
Afternoon (12pm-5pm)	Afternoon (12pm-5pm)	Afternoon (12pm-5pm)	Afternoon (12pm-5pm)	Afternoon (12pm-5pm)	Afternoon (12pm-5pm)	Afternoon (12pm-5pm)
Evening (6pm-11pm)	Evening (6pm-11pm)	Evening (6pm-11pm)	Evening (6pm-11pm)	Evening (6pm-11pm)	Evening (6pm-11pm)	Evening (6pm-11pm)

Was this week representative of your child's medication-taking behavior?

Yes                      No

Did you help your child in taking his/her medication in any way (e.g. by reminding them to take it, bringing it to them, etc)?

Yes                      No

If yes on what days:

\_\_\_\_\_

## Diet Log

### Parent form

For each day, please circle one response about your child's diet.

<i>Day 1: _____</i>	<i>Day 2: _____</i>	<i>Day 3: _____</i>	<i>Day 4: _____</i>	<i>Day 5: _____</i>	<i>Day 6: _____</i>	<i>Day 7: _____</i>
My child only ate appropriate foods	My child only ate appropriate foods	My child only ate appropriate foods	My child only ate appropriate foods	My child only ate appropriate foods	My child only ate appropriate foods	My child only ate appropriate foods
My child ate one thing he/she shouldn't eat	My child ate one thing he/she shouldn't eat	My child ate one thing he/she shouldn't eat	My child ate one thing he/she shouldn't eat	My child ate one thing he/she shouldn't eat	My child ate one thing he/she shouldn't eat	My child ate one thing he/she shouldn't eat
My child ate more than one thing he/she shouldn't eat	My child ate more than one thing he/she shouldn't eat	My child ate more than one thing he/she shouldn't eat	My child ate more than one thing he/she shouldn't eat	My child ate more than one thing he/she shouldn't eat	My child ate more than one thing he/she shouldn't eat	My child ate more than one thing he/she shouldn't eat

Was this week representative of your child's eating behavior?

Yes                  No

Did you help your child to stick to their best diet in any way (e.g. by reminding them what to eat, monitoring their eating, etc)?

Yes                  No

If yes on what days: \_\_\_\_\_

## Appendix F

Letter to CCFA Parents

Dear Parents,

We enjoyed working with your child at Camp OASIS this past May, and we would like to invite you and your child to participate in a project that is being conducted by the Department of Psychology at Georgia State University, Children's Healthcare of Atlanta, and the Crohn's and Colitis Foundation of America. The purpose of this study is to figure out ways to help children and adolescents take their medication and stick to the recommended diets for Crohn's and Colitis.

To be in this study, we are asking you and your child, age 10-17, to complete questionnaires and take part in an interview with us. This will take approximately 1 hour and can be done on campus at Georgia State University or in your home, whichever you prefer. The questions are primarily about adolescents' body satisfaction, memory, and daily habits. We will also ask your child to keep a 1-week diary of whether or not they followed their diet and took their medications as prescribed. We will provide \$10.00 to thank you and to compensate you for your time and effort in this project.

There are no risks to participating, and participation will help us determine how to best help children with Crohn's and Colitis. We hope that results will serve as a springboard



for ideas and interventions to improve medication taking and diet habits in children with Crohn's and Colitis.

To participate or if you have any questions at all, please contact Christina H. Vlahou, M.A. (404-543-4566; cvlahou@student.gsu.edu). You can also contact the supervising investigator with any questions about this study, Dr. Lindsey Cohen (404-651-1605; llcohen@gsu.edu).

Please do not hesitate to contact us, and we look forward to hearing from you.

Sincerely,

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Christina H. Vlahou, M.A.

Doctoral Candidate

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Lindsey Cohen, Ph.D.

Licensed Clinical Psychologist

### CCDHC Introduction letter

The Department of Psychology at Georgia State University and the Children's Center for Digestive Healthcare are conducting a study to figure out ways to help pre-adolescents and adolescents take their medication and stick to their diets for Crohn's and Colitis.

To be in this project, your child needs to be 10 – 21 years old. We will be asking your child and you to complete questionnaires and take part in an interview with us. The questions are primarily about adolescents' body satisfaction, memory, and daily habits. The total time to complete the questionnaires and interview will be approximately 1 hour. We will also ask your child to keep a 1-week diary of whether or not they stuck to their diet and took their medications as prescribed. We will provide \$10.00 to thank you and to compensate you for your time and effort in this project.

There are no risks to participating, and participation will help us determine how to best help children with Crohn's and Colitis. We hope that results will serve as a springboard for ideas and interventions to improve medication taking and diet habits in children with Crohn's and Colitis.

Contacts for this study are Christina H. Vlahou, M.A. (404-543-4566; [cvlahou@student.gsu.edu](mailto:cvlahou@student.gsu.edu)) and Dr. Lindsey Cohen (404-651-1605; [llcohen@gsu.edu](mailto:llcohen@gsu.edu)).