

NUTRITIONAL ADHERENCE, BODY SATISFACTION, AND QUALITY OF LIFE IN  
YOUTH WITH CYSTIC FIBROSIS

By

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Abstract of Thesis Presented to the Graduate School  
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Cystic Fibrosis (CF) is a chronic, life-shortening, genetic disorder requiring a complex daily treatment regimen including airway clearance, inhaled and oral medications, nutritional supplements, and a high calorie diet. Adherence to this regimen is problematic, with rates of adherence to dietary aspects of the regimen especially low. Adolescents are particularly at risk, as this developmental stage is a critical period for growth, as well as a time of typically lower adherence compared to other age groups. Furthermore, patient body mass index (BMI) is directly related to lung functioning and health status. Identifying factors that could improve nutritional adherence as well as overall quality of life (QOL) in adolescents has the potential to inform clinical practice such that targeted interventions can be developed to address these factors.

The aims of the current study were twofold: (a) to evaluate nutritional adherence as a mediating variable between the predictor of body satisfaction and the psychosocial outcome of quality of life, as well as (b) to evaluate gender as a moderator in the relationship between body satisfaction and quality of life in youth with CF. Participants included 54 patients (ages 9 to 17) with CF recruited from two pediatric pulmonary centers, one in Florida and the other in Maryland.

When examining data for the overall sample, health status varied, but was on average good for a CF population. Youth reported a high degree of adherence to their dietary regimen, including a high caloric intake with an adequate percentage of calories from fat. Consistent with health care recommendations for many CF patients, most participants desired to gain weight (53.7%), or were content with their current size (29.6%), while only a small percentage wished to lose weight (16.7%).

Correlation analyses showed a negative correlation between body satisfaction and caloric intake, with youth who wished to lose weight taking in fewer calories ( $r = -0.34, p < .05$ ). Youth ratings of QOL were negatively correlated with body satisfaction ( $r = -0.36, p < .01$ ), such that youth who desired a smaller body image endorsed lower scores on the QOL measure. Regression analyses revealed that the hypothesized mediator model was not supported. However, moderator analyses found that the relationship between body satisfaction and quality of life was moderated by youth gender ( $\beta = 0.36, p < .05$ ). Specifically, females who wished to lose weight had lower quality of life than those who wished to gain, while this relationship was not seen in males.

These results have implications for clinical practice such that improving body satisfaction, especially for females, may help to improve adolescent's overall quality of life and potentially impact treatment adherence. Future research is warranted in order to further elucidate gender differences in the relationships of body satisfaction, quality of life, and nutritional adherence, as well as to design interventions specific to youth targeting these factors.

## CHAPTER 1 INTRODUCTION

Cystic Fibrosis (CF) is a genetic disorder transmitted through a recessive trait and affects pulmonary and pancreatic functioning (Beers & Berkow, 2006). Though the disease is progressive and terminal in nature, medical advances have significantly increased the life expectancy of CF patients to a median of approximately 36 years (Cystic Fibrosis Foundation, 2006). With these advances, however, comes a significant treatment burden: a complex and time-consuming daily regimen consisting of airway clearance, inhaled and oral medications, nutritional supplements, and a high calorie diet.

Approximately 85-90% of CF patients have pancreatic insufficiency (PI) that contributes to the malabsorption of nutrients, particularly fat (Borowitz, Baker, & Stallings, 2002). As a result, malnutrition, shortened stature, and delayed puberty may occur. These negative health outcomes may be ameliorated through the use of pancreatic enzyme replacement therapy, as well as consumption of a high fat, high calorie diet. Specifically, enzymes should be taken directly prior to or during all meals and snacks. Guidelines suggest that children with CF should achieve 120-150% of the recommended daily energy intake of healthy children, with 35-40% of those calories coming from fat (Borowitz et al.; Dodge & Turck, 2006).

Adherence to any long-term chronic treatment regimen is challenging, and the CF regimen is no exception. Rates of adherence vary depending on the specific treatment component, but have typically been found to be higher for medications, and lower for airway clearance therapy and vitamins (Abbott & Gee, 1998; Anthony, Paxton, Catto-Smith, & Phelan, 1999).

Compounding the difficulty of an already demanding treatment regimen is the period of adolescence. Studies have shown that adolescents are typically less adherent to their regimen than younger age groups (Anthony et al.; Hobbs et al., 2003). This discrepancy could be due to a

variety of factors, such as youth taking more personal responsibility for their regimen and a subsequent decrease in parental involvement. Non-adherence to a CF regimen has many implications, including more frequent respiratory infections, more rapid disease progression, additional inpatient and outpatient medical visits, and more school absences (Abbott & Gee).

### **Nutritional Adherence**

Of particular concern for adolescents with CF is nutrition. Adolescence is considered a critical period for growth and adequate nutrition. In addition to the extra nutrient and energy required for accelerated growth and pubertal development, the high levels of physical activity and more frequent pulmonary symptoms typical of teens increase their nutritional requirements (Borowitz et al., 2002; Lai et al., 1998). The effects of malnutrition are particularly detrimental and, in addition to delayed growth and onset of puberty, include a diminished immune response thereby increasing propensity to infection and impaired respiratory performance (Anthony et al., 1999). Additionally, there is an established positive association between nutritional status and pulmonary functioning, and in turn, an inverse relation to morbidity and mortality (Bentur, Kalnins, Levison, Corey, & Durie, 1996).

In spite of this, adherence to the nutritional regimen is often low. Dietary adherence is especially problematic, as this treatment component requires significant problem-solving abilities and is more obtrusive to daily life than other aspects of the CF regimen (Anthony et al., 1999). While few studies have examined nutritional adherence in adolescents or adults, several studies have been conducted with younger children. Results show that children with CF typically consume similar nutritional amounts as their healthy peers, thus not achieving the recommended fat and caloric intake (Stark & Powers, 2006). In a study of 75 children with CF age 6 to 9 years-old, 61% did not reach the caloric intake and 72% did not meet the fat intake recommended for patients with CF (Tomezsko, Stallings, & Scanlin, 1992). Additionally, only 29% of these

children had “good” adherence to enzymes (i.e., took enzymes appropriately 80% of the time or more). Similarly, only 16% of 7 to 12-year-olds reached their goal of 120% or more of the recommended caloric intake of healthy same-age peers, with a similar proportion of specific nutrients compared to healthy children, rather than a higher proportion of fat (Anthony, Bines, Phelan, & Paxton, 1998; Anthony et al., 1999).

### **Factors Related to Nutritional Non-Adherence**

Beyond its interference in daily life, there are a variety of potential reasons why the nutritional component of treatment is typically so low. Schools and the media heavily promote a healthy diet (i.e., low fat and low calorie) in direct contrast to the diet appropriate for children with CF (Schall, Bentley, & Stallings, 2006; Stark & Powers, 2006). In fact, interviews with children with CF and their parents found that many caregivers were wary of allowing their child to eat a high fat diet, as it conflicted with their beliefs about “healthy eating,” and these children felt a conflict between the advice of their doctors and what they learned about nutrition at school (Savage & Callery, 2005). Furthermore, because of the potential for adverse physical effects associated with eating high fat foods (i.e., stomachache, nausea), children with CF are prone to develop aversions to these foods (Schall et al.; Stark & Powers), and in fact, many children indicate that they decide what foods to eat based on taste rather than energy or fat content (Savage & Callery). Mealtime behavior problems may promote non-adherence to the dietary regimen as well. Stark and Powers (2006) found that parents often perceive more problem behaviors such as whining and refusing meals than parents of healthy children, and that these parents engage in behaviors aimed at encouraging their child with CF to eat, such as demanding and coaxing. Finally, a lack of nutrition-specific knowledge may influence adherence: mean scores on one CF nutrition knowledge questionnaire were 63% for children age 6 to 11, and 85%

for parents, with specific knowledge deficits for caloric needs, fat content in foods, and salt requirements (Stapleton, Gurrin, Zubrick, Silburn, Sherriff, & Sly, 2000).

Peer and social concerns also have the potential of exacerbating the demands of a CF nutritional regimen in adolescents. Specifically, adolescence is a time when peer acceptance is particularly important, and the dietary aspect of CF regimen particularly may be seen as conflicting with teenage norms. Teens are especially preoccupied with how they appear to others. The idea of an “imaginary audience” evaluating adolescents’ appearance has been described in the literature (Elkind, 1967). In adolescence, body image is beginning to be of increased importance, with teen girls often desiring a slender body shape, and male teenagers wishing to be more muscular (Cohn et al., 1987; Frisen, 2007). This increased awareness of body image has significant implications for youth with CF, as the disease has many physical effects such as short stature, low weight, and clubbing of the fingertips (Wenninger, Weiss, Wahn, & Staab, 2003).

Studies consistently show that adult women with CF tend to underestimate their own body size, while males with CF have a more accurate perception of their current shape (Abbott et al., 2000; 2007). A misperception of one’s own body size is especially concerning for those patients who see themselves as being of normal weight but are in fact significantly underweight, as these patients may not be motivated to gain weight. In fact, one study found that adults with CF who perceived themselves to be overweight were less likely to engage in weight enhancing behaviors (Walters, 2000).

Examining the degree and direction of body satisfaction, a study of 223 teen and adult patients from an adult CF center in the United Kingdom found that males had less body satisfaction than females, which the authors hypothesized may reflect cultural stereotypes, such

that men desire heavier and more muscular bodies, which male patients with CF do not tend to have (Gee, Abbott, Conway, Etherington, & Webb, 2003). In contrast, studies by Abbott and colleagues (2000, 2007) found that British adult females with CF describe poorer body image than males with CF, with females desiring to be thinner, and males wishing to be heavier. It should be noted, however, that these body satisfaction levels were consistent with a healthy comparison group, also suggesting that these patients may be subscribing to cultural norms regarding body size. A study of children age 7 to 12 years found no difference in body size perception between children with CF and healthy children, or between boys and girls (Truby & Paxton, 2001), while another study of adolescents with CF found that females were more likely to accurately perceive their body weight, and teenage males more often underestimated their weight (Bentur, Kalnins, Levison, Corey, & Durie, 1996). However, the children with CF were more likely to desire a larger body size while the healthy children wished for a smaller shape. Additionally, girls were more likely than boys to want a smaller shape than they currently had. Taken together, these studies show that patients with CF tend to be dissatisfied by their bodies, with males wishing to gain weight and females desiring a slimmer shape, though this dissatisfaction may be congruent with the healthy population.

Body satisfaction has the potential to impact eating behaviors in adolescents. Indeed, a relationship has been shown between body image and dieting or disordered eating in the healthy population. A large study of healthy adolescents found that lower body satisfaction in both males and females was tied to more dieting and unhealthy weight control behaviors, such as fasting or skipping meals, abuse of laxatives, and purging (Neumark-Sztainer, Paxton, Hannan, Haines, & Story, 2006). Similarly, for adult female with CF, lower body satisfaction was associated with more self-reported dieting behaviors (Abbott et al., 2000). Especially worrisome is the finding by

Abbott and colleagues (2007) regarding a small group of adult females with CF who were prescribed nutritional interventions, yet still engaged in dysfunctional eating behaviors (e.g., excessive dieting, preoccupation with food). In the single study examining this issue in children, few children with CF reported attempts to lose weight, and most described trying to gain weight; additionally, no children (ages 7-12) with CF had clinically significant scores on a measure of eating attitudes and behaviors (Truby & Paxton, 2001). One study exploring this issue with adolescents with CF found that 5% of participants in their study used compensatory behaviors to avoid weight gain, including excessive exercise and misuse of enzymes (Shearer & Bryon, 2004). Similar findings have been seen in research done with adolescents with Type I diabetes, a population similar to CF as the treatment regimen also includes a significant nutritional component. These studies report that teens have been found to manipulate their treatment regimen in order to control their weight. Specifically, 37% of female adolescents with diabetes reported under-using or omitting insulin for weight control (Fairburn, Peveler, Davies, Mann, & Mayou, 1991), and it is estimated that this behavior may occur in 12-15% of all teenagers with diabetes (Aslander-van Vliet, Smart, & Waldron, 2007).

The relationship between nutritional intake and body satisfaction is different for males and females. Gender may play a pivotal role in the relationship between body dissatisfaction and nutritional behaviors in adolescents with CF. A theory of “gendered embodiment” has been proposed for teens with CF, such that these youth identify first as male or female and second as patients with CF (Willis, Miller, & Wyn, 2001). Because of this, they embrace the cultural norms attributed to their respective gender, and may alter their treatment regimen in order to adhere to these gender roles. As females in general are typically less satisfied with their body than males, and strive for a thinner body shape, females with CF who subscribe to this typical view may be

less adherent to their dietary regimen. In interviews with 40 Australian teenagers with CF, females reported they did not eat as much or as often as males with CF, often skipped meals, and took less enjoyment from food (Willis et al.). The authors hypothesized that female adolescents with CF must go against societal norms about women and food to eat a large quantity of food high in calories and fat. Additionally, males may have an advantage in achieving adequate nutritional status, as the typical male desire to be heavier and have a muscular body shape may enhance their adherence to the CF nutritional regimen (Abbott et al., 2000). This gender difference in nutritional status due to body satisfaction has particular relevance as it has been documented that survival is poorer for females with CF as compared to males (Anthony et al., 1999), though this discrepancy is narrowing as medical advances continue to proliferate (Verma, Bush, & Buchdahl, 2005).

### **Quality of Life as a Related Outcome**

Quality of life is defined as the “psychological functioning...[that] encompasses clinical, social and psychological aspects of a person’s health” (Abbott & Gee, 1998). In healthy populations, body image has been found to be related to quality of life, especially for women, and this has been found to be true in a sample of adults with CF, where body image, along with perception of general health, was the strongest predictor of a patient’s quality of life (Wenninger, Weiss, Wahn, & Staab, 2003). Taken together, the disease itself, its’ treatment, and an individual’s body satisfaction may influence the quality of life in adolescents with CF. As treatment regimens have led to longer life expectancy for patients, it is important to understand the effect that CF and its treatment have on the patient’s life. Previous studies have found that quality of life of CF patients is approximate to that of healthy control participants; however, this finding may be due to a response shift, such that patients with CF have a different definition of “healthy” than healthy peers (Wahl et al., 2005; Britto et al., 2004). Additionally, a consistent

relationship has been found between health status and quality of life, such that CF patients with poorer health report lower quality of life than patients with better lung functioning (Gee, Abbott, Conway, Etherington, & Webb, 2003; Kosciak, Douglas, Zaremba, Rock, Splaingard, Laxova, & Farrell, 2005; Wahl et al.). These findings suggest that it is possible for those living with CF to have a good quality of life, and emphasize the importance of better physical functioning, especially through proper nutritional adherence.

### **Interventions to Improve Nutritional Adherence**

Researchers have proposed several interventions to help increase nutritional intake in patients with CF. Reviews of the literature have found that behavioral interventions for families of young children with CF are successful, and produce results comparable to more invasive medical interventions (Jelalian, Stark, Reynolds, & Seifer, 1998; Mackner, McGrath, & Stark, 2001). These interventions typically involve nutritional education, goal setting, teaching child behavior management strategies to parents, as well as positive reinforcement and differential attention. Studies have shown that these interventions are effective at increasing calories and fat, as well as child weight in children age 4 to 12 (Stark & Powers, 2006). It is noteworthy that the literature, however, consists primarily of intervention studies focused on young children and their parents, with little to no attention given to adolescents.

### **Study Aims**

Because research findings with younger children with CF may not generalize to adolescents with CF, it is important to examine factors that influence nutritional adherence in CF with older youth. For instance, by identifying variables that play a role in dietary adherence in adolescence, researchers could design interventions specific to this age group. Consequently, the principal aim of the current study is to examine a conceptual model hypothesized to explain the role of nutritional adherence in relation to body image satisfaction and quality of life. This

mediation model hypothesizes that body image satisfaction is related to adolescent quality of life through adherence to the dietary regimen. A secondary goal of this study is to evaluate gender as a moderator in the relationship between body image satisfaction and quality of life in adolescents with CF.

## CHAPTER 2 METHOD

### **Procedure**

This multi-site research study utilized an observational cross-sectional design. Families with a child between the ages of 9 to 17 with cystic fibrosis were recruited at their regular clinic appointment from two academic medical centers, one in rural Florida and the other in a metropolitan area of Maryland. After giving informed consent, participating caregivers and youth each completed questionnaires and took part in a joint interview to obtain dietary information for the previous 24-hour time period. After completing study related measures, families received \$20 compensation for their time.

### **Participants**

A total of 38 families were contacted in the Florida clinic, of which 32 agreed to participate. Of the families that declined participation, reasons cited included no interest in research ( $n = 4$ ) and lack of time ( $n = 2$ ). At the site in Maryland, per institutional procedures, a mailing was sent to 124 families informing them of the study. Of these, 58 families were contacted either by telephone or in clinic, and 23 participated in the study. The families that did not participate either were unable to be reached after an initial telephone call by research staff ( $n = 20$ ), cancelled their clinic appointment ( $n = 7$ ), were not able to schedule an appointment prior to the end of the study ( $n = 6$ ), or were not interested in research ( $n = 2$ ). Overall, a total of 55 families (57.23%) agreed to participate. One family was excluded from the study due to incomplete study measures.

Across both sites, the 54 families that completed the study included primarily mothers (77.8%), with a mean patient age of 13.61 years ( $SD = 2.32$ ). Of these children, 46.3% were male, and, as is most common in CF populations, a majority were Caucasian (90.7%). Our

participant sample was primarily of moderate socioeconomic status (median annual income level of \$50k-60k). Independent samples t-tests and Chi-square analyses were performed for continuous and categorical data, respectively, to determine if there were any site differences. Participants did not differ by site significantly ( $p > .05$ ) on any of the above stated demographic variables except with regards to youth gender ( $\chi^2 (1) = 4.05, p < .05$ ), with fewer boys recruited from the site in Maryland.

### **Measures**

**Patient Information Form.** The Patient Information Form was designed specifically for the purpose of this study and was completed by caregivers. The form elicited relevant demographic (e.g., family structure and parent education) and medical information (e.g., presence of liver disease in the patient).

**Cystic Fibrosis Questionnaire Revised (CFQ-R; Quittner, Buu, Messer, Modi, & Watrous, 2005).** This measure consists of questionnaires for parents, adolescents age 14 years and older, and children 12 to 14, as well as an interview form for children 11 years of age and younger. The youth informant versions of the questionnaire were used for the current study. The CFQ-R assesses the impact of CF and its treatment on the child's quality of life and health status along a variety of subscales. This measure has demonstrated reliability with Cronbach's alpha coefficients ranging from .67 to .94 across subscales, as well as satisfactory test-retest stability (Modi & Quittner, 2003; Quittner, Buu, Messer, Modi, & Watrous). For the purpose of the current study, the following subscales were averaged to create a general quality of life measure: physical, emotional and social.

**Figure Rating Scale (FRS; Stunkard, Sorenson, & Schulsinger, 1983).** To assess body satisfaction, the FRS was administered to all patients participating in the study. The FRS is a

two-item self-report measure depicting a series of 9 male or 9 female black-and-white figures ranging from very thin to very heavy in appearance. Participants selected the figure that matched how they currently believed they looked at the time of the assessment, as well as the figure that matched their ideal body image. This measure has demonstrated good test-retest reliability as well as validity for a variety of age ranges (Cohn et al., 1987; Thompson & Altabe, 1990).

Based on these responses, youth were then categorized into one of three groups: those desiring a thinner image (i.e., wish to lose weight), those desiring a heavy image (i.e., wish to gain weight), or those satisfied with their body. For the purpose of this study and consistent with standard weight management advice delivered to CF patients, those youth who wished to gain weight and those who were satisfied with their weight were combined into one group and then compared to those who desired to lose weight.

**24-hour diet recall.** The youth's dietary intake for the previous 24-hour period was obtained through a joint interview with the adolescent and the caregiver. A joint interview was used because it was felt that a more comprehensive evaluation of the patient's food intake would be obtained, given that parents often prepare food for meals at home, but children also eat many foods outside of their parents' presence (e.g., at school). The interview was conducted based on the multiple-pass method developed by the United States Department of Agriculture (described in: Raper, Perloff, Ingwersen, Steinfeldt, & Anand, 2004). The 24-hour diet recall is the most commonly used method of dietary intake in the United States (Buzzard, 1998), and this particular technique has been shown to be accurate in estimating nutrient intake (Blanton, Moshfegh, Baer, & Kretsch, 2006).

Families were informed that the interviewer wished to know about everything the child ate and drank "from the time they woke up yesterday morning, to the time they woke up this

morning” (i.e., the previous 24-hour period). Four “passes” were obtained during the interview: first, a quick listing of all foods and drinks consumed during the period; a review of the foods and drinks listed and obtaining any forgotten items for the second pass; the third pass goes through each meal and snack asking for additions (e.g., condiments) and portion sizes using visual measurement estimation aids (i.e., measuring cups and spoons); finally, the fourth pass reviews and confirms all items. Additionally, families were also asked for information regarding enzymes, vitamins, and nutritional supplements taken throughout the 24-hour period.

Each item from the diet recall was entered into the Food and Nutrient Database for Dietary Studies 1.0 (United States Department of Agriculture, 2004), an online computerized nutrition database to obtain nutrition analysis data (calories and grams of fat). Based on the treatment plans in the participant’s medical record, three adherence scores were then calculated: overall percentage of enzyme adherence, percentage of daily calories consumed from fat, and number of calories consumed per kilogram of the child’s body weight.

**Medical chart review.** The patient’s medical chart was reviewed to obtain information regarding anthropomorphic data and pulmonary function test results from that day’s clinic visit, as well as physician recommendations for treatment regimen from the previous clinic appointment. Specific values obtained include the child’s body mass index (BMI) percentile, which is a measure of body mass based on height, weight, age, and gender, and percent forced expiratory volume (FEV<sub>1</sub>%-predicted), which is a measure of pulmonary functioning indicating the percentage of the volume of air exhaled in one second expected for an individual of a given age, height, ethnicity and sex.

### **Statistical Analyses**

Data were analyzed using SPSS software (Version 14.0, SPSS Inc., Chicago, 2005). Consistent with mediator and moderator analysis instructions in Holmbeck (1997), a series of

linear regression analyses were performed. These analyses employed the following variables of interest: body satisfaction, general quality of life, and nutritional adherence (calories consumed per kilogram of body weight).

The mediation model hypothesized that adherence to the nutritional regimen mediates the relationship between adolescent satisfaction with their body and their quality of life (see Figure 2-1). The model was tested using a series of regression analyses: a) the outcome variable regressed onto the predictor variable, b) the mediator variable regressed onto the predictor variable, c) the outcome variable regressed onto the mediator variable, and lastly, d) the outcome variable regressed onto both the predictor variable and the mediator variable. According to Baron and Kenny (1986), mediation occurs if there is no relationship between the predictor and outcome variables after controlling for the mediating variable (part d above). Partial mediation may occur if this relationship only partly reduces. Subsequently, a Sobel test is performed to determine if the mediation effect is statistically significant.

Secondary analyses were conducted utilizing gender as a moderator between the relationship of body satisfaction and nutritional adherence (see Figure 2-2). First, the variables were centered in order to reduce multi-collinearity. Then, regression analyses were conducted for each model using body satisfaction, child gender, and the interaction of these two variables to predict the outcome of quality of life. Moderation is said to occur when there is a significant effect for the interaction term when controlling for the main effects.

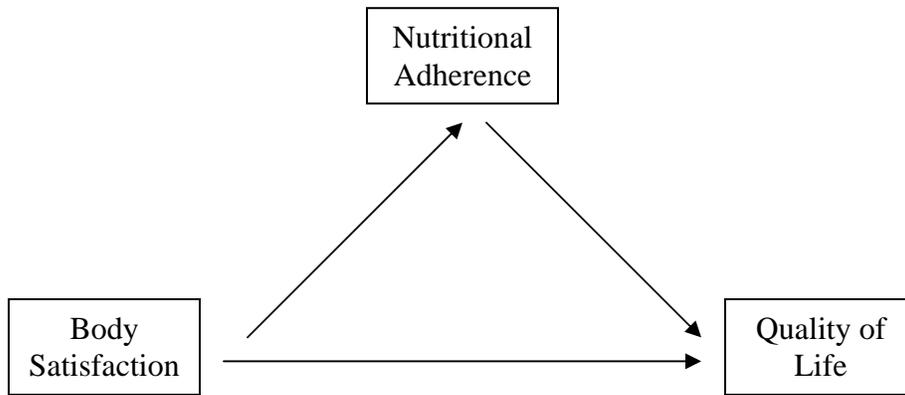


Figure 2-1. Representation of the mediation model: nutritional adherence mediating the relationship between body satisfaction and quality of life.

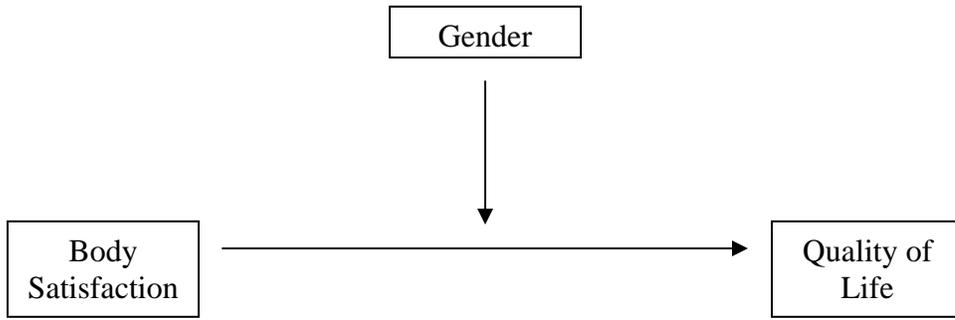


Figure 2-2. Representation of the moderation model: gender moderating the relationship between body satisfaction and quality of life.

## CHAPTER 3 RESULTS

### Descriptive Statistics

The health status of patients in this study varied substantially, but youth, on average, were healthy for a CF population. The average FEV<sub>1</sub> %-predicted was 83.28% ( $SD = 23.62$ ), suggesting a mild to moderate severity of pulmonary disease. Similarly, participant's BMI ranged from the 1<sup>st</sup> to 99<sup>th</sup> percentile, with a mean of 44.67 ( $SD = 29.48$ ). For youth with CF, current guidelines for BMI define below the 10<sup>th</sup> percentile as nutritional failure, with children below the 25<sup>th</sup> percentile at risk for nutritional failure (Dodge & Turck, 2006).

Results from the diet recall suggest that youth ate a large number of calories ( $M = 3951.14$ ,  $SD = 1747.22$ ), with approximately 35% of these calories coming from fat. These results are on par with the recommended intake of 35-40% of calories from fat sources. Percent adherence to enzymes was calculated to be on average 77.10% for all participants ( $SD = 30.96$ ).

Patients generally reported high scores on the quality of life measure: out of a maximum of 100, the mean score for general quality of life was 81.34 ( $SD = 12.26$ ). These scores are congruent with those CFQ scores reported for youth of similar age and disease severity in the extant literature (Modi & Quittner, 2003; Quittner, Buu, Messer, Modi, & Watrous, 2005). On the measure of body satisfaction, most youth described themselves as wishing to gain weight, (53.7%). Only a small percentage reported desiring a smaller body shape (16.7%), with the remainder indicating feeling content with their current size (29.6%).

Exploratory correlation analyses revealed a significant positive correlation between youth BMI percentile and FEV<sub>1</sub> %-predicted ( $r = 0.48$ ,  $p < .01$ ), indicating that youth with a higher BMI percentile had better lung functioning. BMI percentile was also correlated significantly and negatively with the child's rating on the FRS. For those who desired to lose weight, BMI

percentile was higher ( $r = 0.29, p < .05$ ). A negative correlation was found between body satisfaction and caloric intake, such that those youth who wished for a smaller body size took in fewer calories ( $r = -0.34, p < .05$ ). The youth's ratings of QOL were negatively correlated with body satisfaction ( $r = -0.36, p < .01$ ); in particular, youth who wished to lose weight endorsed lower scores on the QOL of measure. Youth age was not significantly related to body satisfaction, QOL, or caloric intake, and thus was not controlled for in subsequent analyses.

### **Regression Analyses**

#### **Mediation**

The regression analyses testing the mediation model that nutritional adherence (kcal/kg) acts as a mediator between the relationship of body satisfaction (FRS) and quality of life (QOL) revealed that a) the predictor variable (FRS) was significantly related to the outcome variable (QOL),  $\beta = -0.36, p < .05$ , b) the mediator variable (kcal/kg) was significantly related to the predictor variable (FRS),  $\beta = -0.34, p < .05$ , c) the mediator variable (kcal/kg) was not significantly related to the outcome variable (QOL),  $\beta = 0.11, p > .05$ , and d) the relationship between the predictor variable (FRS) and the outcome variable (QOL) remained significant ( $\beta = -0.36, p < .05$ ) even while controlling for the mediator (kcal/kg), while the relationship between the mediator (kcal/kg) and the outcome variable (QOL) when controlling for the predictor variable (FRS) remained non-significant. Thus, the results do not support the hypothesis that nutritional adherence mediates the relationship between body satisfaction and quality of life for youth with CF.

#### **Moderation**

The overall regression analysis testing the hypothesis that body satisfaction and quality of life would be moderated by youth gender was found to be statistically significant,  $F(3, 49) = 4.01, p < .05$ . Furthermore, the interaction term (gender x FRS) was found to be statistically

significant,  $\beta = 0.36$ ,  $p < .05$  while controlling for the main effects of body satisfaction (FRS) and gender. A graph of the interaction (Figure 3-1) between body satisfaction and gender showed that girls who wished to lose weight had lower quality of life than those who wished to gain or were happy with their current size, while for boys, those who wanted a larger body or were happy with their current weight had lower quality of life than those who wished to lose weight. Taken together, the results support the hypothesis that gender influences the strength or direction of the relationship between body satisfaction and quality of life for those who desire a smaller body shape compared to those who wish to gain or are content with their current weight.

Table 3-1. Correlational analyses.

	Gender	Child age	FEV <sub>1</sub> - %	BMI %-ile	Kcal/kg	FRS	QOL
Gender	---	0.16	0.14	0.07	0.32*	-0.32*	0.13
Child age	---	---	-0.26	-0.11	-0.19	-0.03	-0.13
FEV <sub>1</sub> - %	---	---	---	0.48**	-0.12	0.03	0.19
BMI %-ile	---	---	---	---	NR	0.29*	-0.03
Kcal/kg	---	---	---	---	---	-0.34*	0.11
FRS	---	---	---	---	---	---	-0.36**
QOL	---	---	---	---	---	---	---

\* $p < .05$ , \*\* $p < .01$ ; NR = Not reported due to the confound of weight in both variables

Table 3-2. Summary of regression analyses for testing the mediation and moderation models.

Outcome Variable	Predictor Variable	<i>F</i>	<i>R</i> <sup>2</sup>	<i>p</i>	$\beta$
<i>Mediation Model</i>					
QOL	Step (a) FRS	7.47	0.11	0.01	-0.36**
Body Satisfaction	Step (b) Kcal/kg	6.67	0.10	0.01	-0.34**
QOL	Step (c) Kcal/kg	0.66	0.01	0.42	0.11
QOL	Step (d) FRS Kcal/kg	3.66	0.10	0.03	-0.36* -0.01
<i>Moderation model</i>					
QOL	FRS Gender FRS x gender	4.01	0.15	0.01	-0.09 0.11 0.36*

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

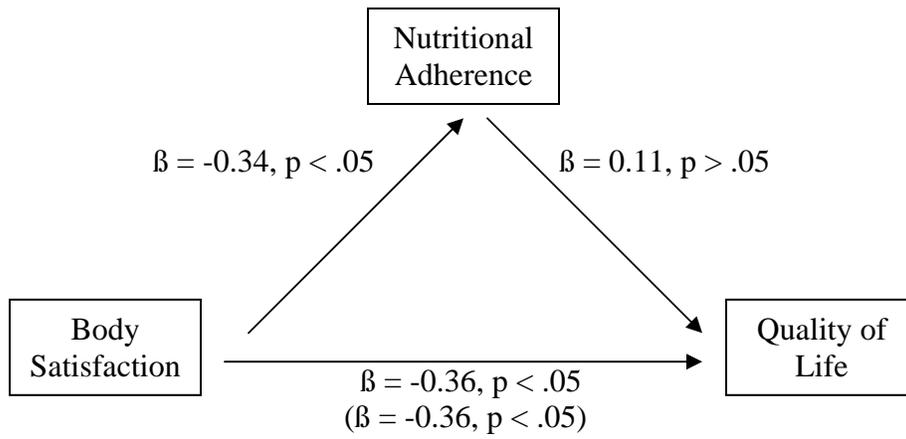


Figure 3-1. Results of the mediation analysis for body satisfaction, quality of life, and nutritional adherence.

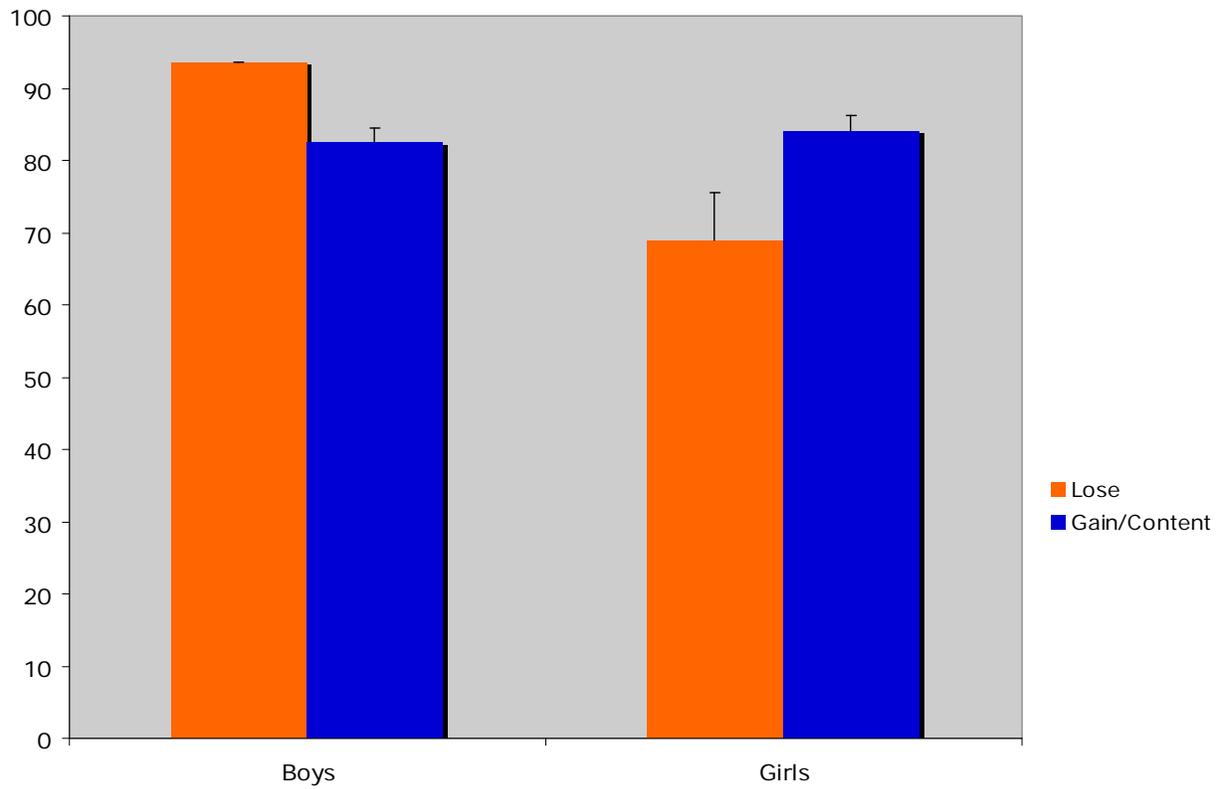


Figure 3-2. Graph of the relationship between body satisfaction and quality of life for males and females.

## CHAPTER 4 DISCUSSION

Treatment for cystic fibrosis involves a significant dietary component including a high caloric intake with a large percentage of fat, as well as pancreatic enzymes taken with all snacks and meals. Adequate intake is especially important for adolescents, as their nutritional requirements are increased due to rapid physical development and worsening pulmonary symptoms. Despite this, adherence to the nutritional regimen has been found to be problematic for youth with CF. With healthy girls typically desiring a smaller figure, and healthy boys wishing to be more muscular, body image becomes more salient in adolescence, which may impact eating behaviors and quality of life. However, few studies have explored the relationships surrounding body satisfaction, nutritional adherence and quality of life in adolescents with CF. Thus, the purpose of the current study was twofold: to test the mediating effects of nutritional adherence on the relationship between body satisfaction and quality of life, and to investigate gender as a moderator in the same relationship.

Correlation results in the current study supported previous research relating lung functioning to BMI. As lung functioning is a significant indicator of disease progression, this relationship underscores the importance of dietary recommendations to increase growth in our youth with CF. Highlighting this relationship, Peterson and colleagues (2003) found that children with CF who weighed more and those who consistently gained weight had better pulmonary function test results. Nonetheless, analysis of the National CF Patient Registry (Lai, 1998) revealed that 33% of children and adolescents were below the 10<sup>th</sup> percentile for height and weight, indicating that proper growth and nutritional status is a significant challenge in many children with CF.

In addition to being associated with health status, our results revealed that BMI was also correlated with body satisfaction. As BMI increased, patients' body satisfaction ratings went down, indicating they preferred a smaller body size and were unhappy with their current shape. This is concerning, as it indicates that the adolescents' desires for their body are contrary to that of their health care providers, and these desires may be damaging to their health. If teens are not accepting of the message that they should desire to gain weight or maintain a healthy weight to improve their CF health status, they may not fully engage in their treatment regimen. This concern could be more salient for females with CF who seem to be subscribing to the cultural ideal of preferring a thin body shape.

In fact, results from this study show that gender does play a role in reported body satisfaction. Analyses supported the moderation hypothesis, finding that gender moderated the relationship between body satisfaction and quality of life. Specifically, lower body satisfaction was associated with lower QOL for females, while this relationship was not found for males. This finding is supported by the extant literature in healthy adolescents, which states that, in Western culture, men typically prefer a larger, muscular body size, while females wish to be slim (Cohn et al., 1987; Frisen, 2007). Additionally, body image has been linked to quality of life in healthy adolescents, such that a negative body image is associated with poorer quality of life (Frisen).

In the CF population, this finding has many potential clinical implications. Encouraging children with CF to gain weight could be in direct conflict of the desire of female patients to be thin. In turn, these patients may be willing to sacrifice their health in order to obtain their desired body image. In fact, body satisfaction was found to be associated significantly with nutritional adherence in the current study. Specifically adolescents with CF who endorsed a smaller body

shape took in significantly fewer calories than those who were happy with their weight or wished to gain weight. This finding is particularly troubling, as CF patients are most susceptible for health complications associated with low BMI; so, it is especially important that they improve their nutritional status. Yet, these patients may be at risk for non-adherence to their nutritional regimen. Indeed, while the current literature shows that patients with CF are no more likely to have eating disorders than their healthy peers, a small percentage do engage in distorted eating practices (Raymond et al., 2000). A study by Shearer and Bryon (2004) found that 16% of the adolescents in their study were currently attempting to lose or maintain their weight, including 5% who were already significantly underweight. Conversely, those patients with better body satisfaction took in more calories, suggesting that a way to improve nutritional adherence may be to improve adolescent contentment with their body.

However, contrary to the stated hypothesis, this study did not find that nutritional adherence had a mediating effect on the relationship between body satisfaction and quality of life. This is surprising, given the expectation that teens may alter their eating behaviors based upon their desired body shape, and that quality of life is so closely tied to body image. Based on the findings of the current study regarding the moderating effect gender has on the relationship between body satisfaction and quality of life, future research conceptualizing a more complex moderated-mediation model (hypothesizing that the mediating relationship of nutritional adherence on body satisfaction and quality of life will only exist for one gender but not the other) may yield more informative results. Moreover, the way this study measured nutritional adherence may have impacted the findings of the current model. For the purposes of this study, only caloric intake was considered for the mediation model. However, nutritional adherence is a multidimensional concept, encompassing caloric intake, fat intake, as well as adherence to

enzyme replacement therapy. Additionally, in our sample, self-reported adherence to the dietary regimen was quite high for all components (calories, fat and enzymes), so ceiling effects may have played a role in limiting the statistical power of our analyses.

Potentially confounding the study results, the dietary recall was obtained at the patient's clinic appointment just subsequent to the physician's and nutritionist's examination of the patient. Thus, youth had just been asked about enzymes and their typical dietary intake, and the message about weight gain was particularly salient. This may have had an effect on their response to the study measures, specifically the diet recall. Furthermore, although interviewing parents and youth together was intended to enhance the accuracy of the recall, this approach also may have led to socially desirable responding, particularly on the part of the youth who may want to please his or her parent. While the diet recall is a simple and common method of obtaining nutritional intake information, studies have shown that both adults (Jonnalagadda et al., 2000) and children (Baxter et al., 2003) tend to underestimate their food consumption. For children with CF, this tendency may be reversed, such that patients over-report their nutrient intake due to both the saliency of the nutritionist's message of increased intake and social desirability.

This study was subject to several other limiting factors. The sample size was relatively small, especially for the analyses performed. While the literature suggests that a large sample size is required for acceptable power in mediation analyses (Fritz & MacKinnon, 2007), the current study is consistent with other research utilizing mediation and moderation analysis in the pediatric psychology literature, where the sample sizes tend to be small (Holmbeck, 1997). While the CF population is generally limited at most sites, future research with a larger, multi-site sample may yield different results. Additionally, our findings may have been limited by the

distribution of males and females across body satisfaction categories (i.e., desire to gain, desire to lose, content). Specifically, the small size of our overall sample coupled with a generally low base rate, the number of males who wished to lose weight was quite small compared to those who wanted to gain or were happy with their weight. Again, a much larger sample is recommended in order to further examine the differences between these groups. Finally, while participants in this study demonstrated a wide range of health status (BMI percentile and lung functioning), it was nonetheless a sample of convenience. The patients who opted to participate were the ones who attended their regularly scheduled clinic appointment, and were in a state of health such that they were able to be seen on an outpatient basis. Home visits may be superior in terms of ensuring unbiased results; however, as many patients live a significant distance away from the clinic, the tertiary care setting was most amenable to study recruitment.

Despite these limitations, this study is one of the first to examine nutritional adherence, body satisfaction, and quality of life in an adolescent CF sample, while measuring these variables through reliable and valid tools and with well-controlled methodology. As such, it offers valuable and possible implications for clinical practice and future research. Regular assessment of body satisfaction as part of routine CF care is recommended in order to detect patients who may have poor body image. Rather than fruitlessly encouraging the adolescent to increase their dietary intake, health care providers can instead focus on increasing body satisfaction. In addition to improving adherence, targeting body image may also improve overall quality of life, which is important for all aspects of a patient's life. More research is needed as to interventions specific to teenagers concentrating on these factors. Additionally, further research to parse out the specific gender differences in these relationships is warranted. Specifically, our study examined those who wanted to lose weight in comparison to those who wished to gain or were

content with their weight. However, males may desire to gain weight, which is consistent with CF treatment goals, yet be highly dissatisfied with their body due to their underweight status. As this consideration was outside the scope of our study, it is an area amenable to further study. Similarly, investigating the specific eating patterns of females with CF who wish to lose weight may identify further areas for intervention.

Overall, this study found that body satisfaction is an important concern for adolescents with CF. The relationship between body satisfaction and quality of life was found to be moderated by gender. Specifically for females, these youth may not be internalizing the nutritional treatment recommendations designed to improve their health status due to their conflicting desire for a smaller body shape. Clinicians should be aware of their patient's body image, as well as the potential for youth with CF to engage in distorted eating practices related to their dissatisfaction with their body. By focusing on improving body satisfaction, especially for females, health care providers and researchers may help to improve youth's overall quality of life and potentially have an impact on treatment adherence and health outcome.

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