Decision-making Involvement, Social Support for Healthy Behaviors, and Nutritional Adherence in Adolescents with Cystic Fibrosis

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Decision-making Involvement, Social Support for Healthy Behaviors, and Nutritional Adherence in Adolescents with Cystic Fibrosis

Jennifer Kelleher
Decision-making Involvement, Social Support for Healthy Behaviors, and Nutritional Adherence in Adolescents with Cystic Fibrosis

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Thesis submitted
to the Eberly College of Arts and Sciences
at West Virginia University

in partial fulfillment of the requirement for the degree of

Master of Science in
Psychology

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Morgantown, West Virginia
2021

Keywords: Adolescent, Cystic Fibrosis, Calories, Enzymes, Adherence, Decision-making Involvement, Social Support for Healthy Behaviors

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ABSTRACT

Decision-making Involvement, Social Support for Healthy Behaviors, and Nutritional Adherence in Adolescents with Cystic Fibrosis

Jennifer Kelleher

Background: Adolescents with cystic fibrosis (awCF) exhibit suboptimal adherence to dietary and enzyme recommendations despite the fact that eating a high calorie diet with enzymes significantly improves lung functioning. Furthermore, during adolescence teens and their caregivers begin to negotiate treatment responsibility, shifting treatment tasks to the youth. As such, it is important to understand which aspects of the complex decision-making process (e.g., expressing an opinion, asking for information from parents/adults, making joint decisions with parents) relate to better dietary adherence in adolescents with CF and how parents can best support these healthy behaviors. Thus, this study aimed to identify how adolescent decision-making involvement (DMI) relates to both caloric and enzyme adherence in adolescents with CF and how parental social support for healthy behaviors moderates those relations. Method: As part of a larger, ongoing project, 28 adolescents and their caregivers were recruited from five sites in the United States. Adolescents and caregivers completed surveys measuring DMI. Adolescents also completed an online survey on perceived parental support for healthy behaviors, as well as two 24-hour diet recalls by phone or video conferencing. Height, weight, and forced expiratory volume (FEV1) were gathered from medical charts. Self-reported caloric and enzyme adherence were calculated as the percentage of time adolescents followed standard CF calorie or enzyme guidelines. Six moderation models examining the relation between DMI, perceived social support for healthy behaviors, and caloric or enzyme adherence were run in SPSS using PROCESS. Results: It was found that 60% of adolescents reported being 100% adherent to enzyme recommendations. Only 37% of teens met CF dietary guidelines of 120% recommended daily intake (RDI). Nearly 75% of adolescents made a dietary related decision in the past month either with a caregiver or primarily by themselves. Means of caregiver and youth reports of all three DMI subscales (Child Seek, Child Express, and Joint/Options) fell between 1.8-2.3, indicating that most youth asked questions, expressed opinions, and discussed solutions to treatment problems at least “a little bit.” AwCF reported DMI scores were significantly correlated to social support for healthy behaviors ($r=.50-.63$, $p<.05$). Moderation analyses between the DMIS components, social support, and caloric or enzyme adherence were not significant. Discussion: It appears that many awCF report being adherent to their enzymes, but not to CF dietary recommendations. While the primary findings were not significant, these results should be interpreted cautiously due to the study being statistically underpowered. Notwithstanding, the finding that adolescents often discuss enzyme or calorie recommendations with their caregivers, yet still exhibit suboptimal adherence, highlights the need for dietary interventions. Future research will want to expand upon these findings to further understand the role DMI and social support for healthy behaviors play in dietary behaviors in awCF.

Keywords: adolescent, cystic fibrosis, calories, enzymes, adherence, decision-making involvement, social support for healthy behaviors, parent
Acknowledgements

I would like to thank Dr. Christina Duncan for her mentorship and guidance on this project. I am appreciative of all the time she spent advising me and helping me develop my skills as a scientist. Furthermore, I am grateful to my committee, Dr. Nicholas Turiano and Dr. Claire St. Peter, for their contributions to the project.

Also, I would like to thank Kristine Durkin for her leadership and support on my thesis project. The project would not have been possible without her organizational skills and advice. Likewise, I am appreciative of the undergraduate students, Kacie Griffin and Jenna Crouch, for their persistence in recruiting families. A big thanks goes to the site coordinators and study team (Dr. Lori Stark, Dr. Stephanie Filigno, Dr. David Fedele, Dr. Robin Everhart, Dr. Courtney Lynn, and Dr. Kathryn Moffett), for their input and recruitment efforts. Lastly, I want to thank my family and friends for their support and all the participating families for their partnership in our efforts to improve care for cystic fibrosis.

This project was funded by West Virginia University’s Department of Psychology Thesis Award (Jennifer Kelleher). The project was also supported by the Cystic Fibrosis Foundation Student Traineeship Award, National Heart Blood and Lung Institute, Ruth L. Kirschstein National Research Service Award (NRSA) Individual Predoctoral Fellowship (1 F31 HL147491-01A1), and the American Psychological Society Dissertation Award presented to Kristine Durkin.
# DECISIONS AND DIETARY ADHERENCE IN CYSTIC FIBROSIS

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Decision-making Involvement, Social Support for Healthy Behaviors, and Nutritional Adherence in Adolescents with Cystic Fibrosis

Despite recent advances in medicine, cystic fibrosis (CF) continues to be a life-limiting, chronic illness with an average life expectancy of 47.4 years (Cystic Fibrosis Foundation Registry [CF registry], 2018). This congenital lung disease is caused by genetic mutations in Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) proteins, resulting in insufficient water passage across organs and a build-up of mucus in the organs (CF registry, 2018; De Boeck, 2020). CF primarily affects a person’s lungs and pancreas, resulting in pulmonary infections, pancreatic insufficiencies, stunted growth, malnutrition, and sometimes respiratory related death (CF registry, 2018). Preventing pulmonary problems is one of the goals of treating CF, given lung infections increase mortality rates (CF registry, 2018). Commonly prescribed lung treatments include oral antibiotics, nebulizer treatments, and chest physiotherapy (Quittner et al., 2017; Smyth et al., 2014).

Notably, higher body mass indices (BMIs), or BMIs of at least 18.5 (including those who are overweight), are also associated with improved pulmonary functioning (Bonhoure et al., 2020; CF registry, 2018; Harindhanavudhi et al., 2020; Simon et al., 2011). Historically, youth with CF have struggled with low weights as a result of pancreatic insufficiencies and higher daily energy needs (Magoffin et al., 2008) due to the fact their bodies need the extra calories to combat CF symptoms, including infections and proper breathing (Cystic Fibrosis Foundation, n.d.a.). It is reported that about 40% of people with CF have BMIs below the 50th percentile (Cystic Fibrosis Foundation Registry [CF registry], 2020; Simon et al., 2011). Furthermore, about 85% of people with CF are pancreatic insufficient, or have genetic mutations that make it difficult for them to absorb nutrients and fat, impairing the development of normal weight and
growth outcomes (Singh & Schwarenzberg, 2017). Due to these pervasive problems, it is imperative that those with CF who are underweight eat a high fat, high calorie diet in addition to specially formulated vitamins and enzyme supplements that improve nutrient uptake to achieve a healthy BMI (at or above the 50th percentile) and improved lung functioning (CF registry, 2018; Singh & Schwarenzberg, 2017; Smyth et al., 2011).

**Nutrition and Lung Function**

As a person with CF ages, lung functioning progressively decreases (CF registry, 2018; Zemel et al., 2000). As such, people with CF - across all ages - need to build resilience by following dietary recommendations because BMI is associated with improved lung functioning (Zemel et al., 2000; Zindani et al., 2006). BMI serves as a clinical indicator of nutritional status and is associated with better lung functioning because people with CF have higher resting energy expenditures (REE) and therefore, need additional calories to support proper lung functioning and to ward off infection (Collins et al., 2016; Cystic Fibrosis Foundation, n.d.a.; Dorlöchter et al., 2002). For instance, a study of children ages 5-8 years old found that those children who achieved age-appropriate weight-to-height percentiles had higher forced expiratory volumes (FEV1; a percentage of how much air a person breathes out in 1 second), indicating better lung functioning (Healthwise staff, 2019; Zemel et al, 2000). Additionally, older children had worse FEV1 scores, highlighting the need to consistently monitor factors, such as diet and BMI, as children mature (Zemel et al., 2000). The potential for malnutrition and poor lung functioning continues into adulthood. One study even reported that half of the adults with CF experience malnutrition (BMI < 18.5) and that those adults with low BMIs also have lower lung functioning (Godzick et al., 2008). As such, BMI and weight status continue to affect lung functioning throughout the lifespan, making it imperative to intervene and pay attention to caloric intake and
enzyme adherence at pivotal developmental stages where people with CF are most susceptible to non-adherence. Adolescence appears to be one of those pivotal ages. During the time period between childhood and adulthood, youth with chronic conditions begin taking over some of their treatments that their parents used to handle, yet also show signs that they still need support with general treatment management (Lerch & Thrane, 2019). Therefore, it is important to understand what barriers prevent youth with CF from managing their treatments effectively in adolescence.

**Adherence**

Despite the fact that lung treatments, enzymes, and eating a specific diet all improve health outcomes in people with CF, youth often struggle to complete all treatments daily, exhibiting poor adherence. Adherence, or “the extent to which a person’s behavior coincides with medical or health advice” is often difficult for youth with chronic conditions, including those with CF (Bishay & Sawicki, 2016; Modi et al., 2012, p. e474). Among people with CF, adherence rates hover around 50% and vary greatly by treatment type and modality of measuring adherence (Borschuk et al., 2019; Modi et al., 2006). For instance, it is reported that adherence rates to vitamins can be as low as 22% or as high as 94% in children, depending on how adherence is measured (Modi et al., 2006). Parents and children self-reported adherence levels are much higher than adherence rates identified by pharmacy refill data, electronic pill counter, and a 24-hour daily diary logs of all activities including treatment completions (Modi et al., 2006). Similar results are found across nebulizer and airway treatments, with adherence rates as low as 48% and 65%, respectively (Modi et al., 2006). With such a burdensome regimen, it is not surprising that adherence rates are not consistent and less than desirable. Adolescents and young adults report that they often miss some components of their treatment regimen (e.g., enzymes, vitamins, inhaled antibiotics) because they forget or they do not want to complete treatments.
when not in the home (Bregnballe et al., 2011). Youth also find treatments difficult to complete when they are too busy, they think that the treatments will not help them, or they think that the treatments are not needed (Bregnballe et al., 2011; Sawicki et al., 2015). These negative perceptions around treatments and low adherence rates are of clinical concern because they prevent effective health and treatment management. As such, it is important to identify who is most at risk for poor treatment compliance.

While non-adherence is a problem at all ages, it is reported that adherence declines in adolescence (Bishay & Sawicki, 2016; Quittner et al., 2017). For instance, youth 12 years and older have been found to have significantly lower adherence to CF vitamins compared to children younger than 12 when measured by an electronic pill capsule that indicated how many times the bottle was opened to take the vitamin (Zindani et al., 2006). Similarly, youth over the age of 15 have self-reported non-adherence rates as high as 69% for a range of CF treatments, yet their younger peers’ non-adherence rates remained around 24% (Arias Llorente et al., 2008). Furthermore, during adolescence, youth begin taking more responsibility for managing their treatments (Iles & Lowton, 2010). As parents provide adolescents more independence, adherence rates often decrease (Bishay & Sawicki, 2016), making it imperative to understand the barriers and facilitators of adherence in adolescents as they transition to managing their own health.

**Nutritional Adherence**

Notably, adolescents with CF adhere more poorly to dietary guidelines compared to medication and lung treatments (Harrop, 2007). It is estimated that less than 40% of pre-adolescents meet caloric recommendations and even fewer achieve good adherence to enzyme treatments (Schall et al., 2006). One study found that daily diary reports of enzyme adherence rates were as low as 27% (Modi et al., 2006). Although many children with CF eat the same
amount as their disease-free peers, many continue to fail to meet CF dietary guidelines by not consuming at least 40% of their calories from fat and eating fewer calories than recommended for those with CF (Kawchak et al., 1996). The progressive nature of CF makes it important that adolescents take steps to eat a healthy diet with sufficient calories and enzymes to maintain higher FEV1 values and lung functioning (CF registry, 2018; Hollander et al., 2017).

Like lung treatments, many barriers prevent youth from following dietary and enzyme recommendations. These barriers to nutritional adherence in youth include poor body image, diet cultures at school and home, and food avoidance due to aversive symptoms to food (e.g., nausea, bad taste, gastrointestinal problems) as a result of nutrient malabsorption (Savage & Callery, 2005; Simon et al., 2011; Stark & Powers, 2005). The CF dietary recommendations of consuming a diet that is both high energy and high in fat is particularly challenging when families express that low calorie, low fat foods are healthier (Savage & Callery, 2005; Stark & Powers, 2005). Although in recent years Americans have been consuming a greater percentage of their calories from fats (Shan et al., 2019), adhering to the CF diet can still be a challenge when other family members have opposing nutritional needs, such as eating fewer calories or less fat due to issues with obesity or heart conditions (Stark & Powers, 2005).

Adolescents with CF also show signs of negative attitudes towards CF nutritional recommendations. One study found that 44% of adolescent females with CF either wished to be smaller or wanted to maintain their small stature despite being at or below the 50th percentile in BMI, contrary to CF treatment recommendations (Simon et al., 2011). Furthermore, nearly 70% of adolescents with CF perceived their body size to be larger than it actually was (Simon et al., 2019). While rarely meeting diagnostic criteria for an eating disorder, people with CF sometimes take steps to prevent weight gain or lose weight in addition to feeling pressured to eat from
others (Abbott et al., 2007; Bryon et al., 2008). In other words, family culture, self-perceptions, and conversation around food may set expectations contrary to the benefits and importance of following a CF diet, thereby negatively impacting adherence.

**Modulators and Nutrition Variability**

Some may argue that with the introduction of Trikafta®, a new, highly effective, CF modulator medication, that became available in October 2019, some people with CF will no longer need to focus on diet and enzyme adherence to achieve optimal health (Food and Drug Administration, 2019). Trikafta®, also known as the triple combination of Elexacaftor, Texacaftor, and Ivacaftor, aims to improve the functioning of impaired cystic fibrosis transmembrane conductance regulators (CFTR) and is particularly effective for mutations of F508del (Heijerman et al., 2019). CFTR regulators help organs remain hydrated through the proper movement of ions and water across them, preventing the buildup of excess mucus and bacteria (De Boeck et al., 2020). CFTR mutations result in mucus accumulation in the lungs and pancreas leading to suboptimal lung functioning, poor pancreatic functioning, and malnutrition (Cystic Fibrosis Foundation, n.d.b; De Boeck et al., 2020; Sockrider & Ferkol, 2017). People who have started taking Trikafta® have not only seen improvements in lung functioning, but also substantial weight gain (Heijerman et al., 2019). In one study, people with two copies of F508del mutation who took Trikafta® gained an average of 3.5 pounds in four weeks. (Heijerman et al., 2019). Because 90% of people with CF have at least one copy of F508del, Trikafta® is significantly changing the landscape of CF treatments and nutrition (De Boeck, 2020).

Trikafta® is not the first CFTR modulator medication that has led to improvements in lung functioning, BMI, and other clinical outcomes (De Boeck, 2020). Within the past 10-15 years, scientists have developed several CFTR modulators tailored to different classes of
mutations that contribute to the etiology and manifestation of CF (Clancy, 2018; De Boeck, 2020). Yet, unlike Trikafta®, other CFTR modulator medications are either not appropriate for a majority of CF patients or have only improved lung functioning by about 4% (De Boeck, 2020). In contrast, Trikafta® not only has applicability for almost 90% of the CF population, but also is more effective than those previous modulators, highlighting it as a groundbreaking medication paving the way for future CF treatments (De Boeck, 2020; Heijerman et al., 2019). Nevertheless, it is expensive, costing over $300,000 per year (Mahase, 2019). The high cost of Trikafta® could make this medication difficult to obtain (De Boeck, 2020). Furthermore, Trikafta® is not appropriate for about 10% of people with CF (De Boeck, 2020), making it important to understand dietary adherence in this particular population in order to work towards best health outcomes (e.g., improved BMI and lung functioning). When modulator treatments are not available, following dietary guidelines may improve health outcomes as BMI is correlated to FEV1 (Zemel et al., 2000; Zindani et al., 2006).

Furthermore, healthy dietary decision-making is important across all individuals with CF of various weight classes. For example, although people with CF who are overweight or obese have better lung functioning compared to those who are underweight, they may be at higher risk for heart problems (Bonhoure et al., 2020). Consequently, adolescents with CF of various weights must learn to make healthy food choices that coincide with their health needs and dietary recommendations. For many teens with CF, a healthy diet will be higher in calories and fat than their same age peers (Cystic Fibrosis Foundation, n.d.a.; Singh & Schwarzenzberg, 2017; Smyth et al., 2011). Because healthy diet choices are difficult for many adolescents with CF, studying the development of healthy food decision making and enzyme adherence is still relevant and important in the context of recent, breakthrough CF medications.
Parental Involvement and Adherence

As mentioned, non-adherence to treatments is a common problem for teens with CF. However, parental involvement and support can improve adherence rates in these youth. For instance, tangible support (e.g., treatment reminders) from parents may improve disease management in adolescents with CF (Barker et al., 2012). Nevertheless, the perceived helpfulness of the treatment reminders was affected by aspects of familial communication, including the parent’s tone of voice and timing of the reminder (Barker et al., 2012). Adolescents also find it helpful when their parents organize or lay out their medications and treatment materials (Nicolais et al., 2019). Parents not only provide their adolescents with tangible treatment support, but also psychosocial support. Simply having the parent in the same room during treatments demonstrates to adolescents that their parent supports them through treatments (Nicolais et al., 2019).

Despite reports that adolescents with CF find it helpful when their parents assist with medical treatments, it is also reported that adolescents want more autonomy and freedom (Cronly & Savage, 2019; Lerch & Thrane, 2019). Thus, teens enter into a constant tension between needing treatment assistance and support while wanting greater independence. Children’s need for autonomy in relation to meals is even acknowledged by the American Academy of Pediatrics (AAP; AAP Committee on Nutrition, 2013 as cited by Haines et al., 2019). The AAP suggests children should choose the amount of food and which of the available foods they eat while caregivers decide what time meals occur and what food will be offered (AAP Committee on Nutrition, 2013 as cited by Haines et al., 2019). Adolescents with chronic conditions also recognize the need to acquire treatment decision-making skills because eventually they will make medical decisions without their parents’ guidance (Koller, 2016). As the adolescents spend
more time away from home and away from their parents, they are faced with the decision to disclose their illness and follow treatment recommendations, including dietary treatments, in front of their peers or not (Borschuk et al., 2019; Christian & D’Auria, 1997). Consequently, there remains a need for healthcare providers and parents to involve adolescents in health education to promote self-management (Koller, 2016).

Current research on transitioning treatment responsibilities from parents to adolescents with chronic conditions suggests that slowly shifting treatment tasks from the adults to the youth may deter the decline in adherence rates that often occurs during adolescence (Lerch & Thrane, 2019). Other facilitators of successful transition of responsibilities in adolescents with chronic conditions include trust and disease related communication between the adolescents, parents, and other adults (Lerch & Thrane, 2019). However, little research exists on what aspects of parent-adolescent communication and decision-making improve nutritional self-management and adherence in CF. Studies with other disease populations, such as type I diabetes, have found that parental social support and aspects of adolescents’ decision making involvement in treatment decisions improve disease care and/or dietary-related adherence (Drew et al., 2010; La Greca et al., 1995; Miller & Jawad, 2019), illustrating the need to better understand parent-adolescent decision-making in CF in relation to dietary recommendations.

**Family Involvement and Communication at Meals**

Like other parts of the CF treatment regimen, parents play a key role in dietary and enzyme treatments, behaviors, and adherence. For instance, a study of children 6-12.9 years of age found that families with a child with CF have worse meal-time family functioning and communication compared to families with a child without a chronic health condition (Janicke et al., 2005). Also, parents with a child with CF find mealtimes particularly challenging because
younger children often exhibit food refusal behaviors, do not want to sit at the table during meals, and avoid eating foods they do not like, although they do not exhibit more food refusal behaviors than children without CF (Stark & Powers, 2005). Furthermore, the health of the child also influences whether the parent enforces dietary adherence. When children fail to gain weight or are losing weight, parents are more likely to encourage their child to eat the high calorie, high fat diet than when the child is physically well (Savage & Callery, 2005). Some parents have even expressed concerns that the standard CF diet is unhealthy and that they do not think it is necessary for their child to adhere to such treatment recommendations, despite the fact following the dietician’s recommendations is an important part of preventing future health issues (Savage & Callery, 2005; Singh & Schwarenzberg, 2017). Yet, when parents receive either nutrition education or a nutrition/behavioral intervention targeting improved caloric intake, it appears children do achieve and maintain eating the recommended 120% daily caloric intake two years post intervention (Stark et al., 2009). Thus, parents’ knowledge of and involvement in treatment influences dietary related decisions.

Decision-Making Involvement

As the literature shows, families play an important role in either promoting or impairing adherence in youth with CF. Yet, much of the current research on parental social support and communication involving CF nutritional treatments has focused on children rather than adolescents (Janicke et al., 2005; Stark & Powers, 2005). Furthermore, few studies investigate the various roles both parents and adolescents have when making treatment decisions about CF, let alone dietary decisions. Recently, the literature has explored the role of decision-making involvement in increasing adolescents’ autonomy and self-management skills (Miller & Jawad, 2019). Decision-making involvement (DMI), or parent and child engagement in treatment related
discussions and decision-making, differs from problem-solving and family communication in that it examines how engaged the parent and child are in expressing opinions, asking treatment related questions, and making joint decisions (Miller & Harris, 2012; Miller & Jawad, 2019). When parents and youth make treatment related decisions, they exhibit each behavior on a continuum. Children may ask questions or ask for help (Child Seek), state their opinion of what they want to happen or state facts (Child Express), or make decisions with their parent (Joint/Options; Miller & Harris, 2012). Similarly, parents can guide the treatment process by asking for their child’s opinion (Parent Seek) or providing information to their child (Parent Express; Miller & Harris, 2012).

DMI is especially important during adolescence because youth begin to take more responsibility for their treatments and seek more health information, taking an active role in their treatment (Koller, 2016; Miller & Jawad, 2019; Quittner et al., 2017). In a study on adolescents with type I diabetes, it was found that youth who voiced their thoughts more, asked more treatment related questions, and were involved in the decision-making process with their parents also were more adherent to treatments (Miller & Jawad, 2019). Like CF, type I diabetes treatment regimens are complex with both lifestyle (e.g., exercise and diet) and medical (e.g., insulin) recommendations with especially low adherence rates in adolescence (Silverstein et al., 2005). Thus, both CF and diabetes require extensive amounts of behavioral engagement with treatments, including decision-making. Also, a study with multiple chronic illness populations, including CF, found that family communication was positively associated with children expressing their opinion (Child Express DMI scale; Miller & Harris, 2012), yet no study has exclusively examined the relation between DMI and adherence in adolescents with CF, let alone nutritional adherence in CF.
Given adolescents with CF learn to make many dietary-related decisions around nutritional management, such as eating enough calories, eating a balanced diet, and taking enzyme supplements, it is important to study the role of DMI in dietary compliance in this age group. Furthermore, although it is known that parental social support, defined as tangible (e.g., reminders, helping with treatments) and intangible (e.g., encouragement or emotional support) assistance, may improve treatment management in adolescents with CF (Barker et al., 2012; Nicolais et al., 2019), no study has explored the relation between social support for healthy behaviors and DMI or if those families with better social support have higher levels of adolescent DMI. Because adolescents begin taking on more treatment related responsibilities, including deciding to eat enough and to take enzymes when not at home, and given the health importance of adequate caloric intake and enzyme adherence in youth with CF, the primary goal of this study was to investigate the relation between adolescent decision-making involvement, dietary adherence, and parental social support for healthy behaviors in adolescents ages 12-17 with CF. The specific aims of the study are as follows:

Specific Aim 1

Investigate (a) how adolescent report of decision-making involvement (DMI) (e.g., Child Seek, Child Express, Joint/Options) relates to caloric adherence in adolescents with CF and (b) whether parental social support of healthy behaviors moderates the relation between DMI and caloric adherence. Based on previous research on DMI (Miller & Jawad, 2019), it was hypothesized that higher levels of DMI (e.g., Child Seek, Child Express, Joint/Options) would be associated with better caloric adherence and that parental support of healthy behaviors would moderate this relation, where higher levels of support and DMI would be correlated with better adherence rates.
Specific Aim 2

Examine (a) how parent report of adolescent decision-making involvement (DMI) (e.g., Child Seek, Child Express, Joint/Options) relates to caloric intake in adolescents with CF and (b) whether parental social support of healthy behaviors moderates the relation between DMI and caloric adherence. It was hypothesized that the more the adolescent is involved in treatment decisions (e.g., Child Seek, Child Express, Joint/Options), the more adherent the adolescent is to caloric intake recommendations, and that parental support of healthy behaviors moderates this relation.

Specific Aim 3

Investigate how (a) adolescent report of decision-making involvement (DMI) (e.g., Child Seek, Child Express, Joint/Options) relates to enzyme adherence in adolescents with CF and (b) whether parental social support of healthy behaviors moderates the relation between DMI and enzyme adherence. In alignment with previous research on adherence and DMI in other chronic illness populations (Miller & Jawad, 2019), it was hypothesized that improved aspects of DMI (e.g., Child Seek, Child Express, Joint/Options) are associated with better rates of enzyme adherence and that parental support of healthy behaviors moderate this relation.

Specific Aim 4

Examine how (a) parent report of decision-making involvement (DMI) (e.g., Child Seek, Child Express, Joint/Options) relates to enzyme adherence in adolescents with CF and (b) whether parental social support of healthy behaviors moderates the relation between DMI and enzyme adherence. It was hypothesized that greater DMI (e.g., Child Seek, Child Express, Joint/Options) is associated with better rates of enzyme adherence and that parental support of healthy behaviors moderates this relation.
Method

Participants

Twenty-eight adolescents, ages 12-17 years at time of assent, and one parent or legal guardian for each adolescent, were recruited to participate between June 2020 and the end of March/early April 2021. To participate, adolescents must have had a diagnosis of CF for six months or longer and not have another diagnosis that could affect their weight (excluding CFRD). Additionally, the adolescents and the caregivers could not have an intellectual disability and must have been able to speak, read, and write in English.

Procedure

As a part of a larger, mixed-method study, participants were recruited from five pediatric medical centers in the United States (West Virginia University [WVU] Health Sciences; Children’s Hospital of Colorado; Cincinnati Children’s Hospital Medical Center; University of Florida Health-Shands Hospital; and Children’s Hospital of Richmond). Site coordinators screened for eligible participants and approached identified adolescents during both telehealth and in-person clinic visits. The site coordinators briefly explained the purpose of the study and that the family could learn more details from the primary study coordinators at WVU. If both the adolescent and a legal guardian expressed interest in learning more, they completed a consent to contact form or provided verbal consent to contact. The site coordinators then uploaded the consent to contact information to SharePoint® (a HIPAA approved, cloud-based storage platform) for WVU study coordinators to access or sent the information in a secure email to the faculty supervisor.

A research assistant from WVU called the families and provided information about the study. Those families who agreed to be contacted were sent a consent and/or assent form via
email through REDCap®. During phone calls with families, the study coordinators offered to answer any questions about the study and the consent/assent documents. Once the adolescent and caregiver filled out consent/assent forms, they were automatically given access to the study surveys on REDCap®, with separate surveys for the caregiver and adolescent (accessed via two different links). Along with five measures associated with the larger, overarching study, adolescents completed the *Child and Adolescent Social Support Survey for Healthy Behaviors* (CASSS-HB) and the *Decision-Making Involvement Scale* (DMIS). It is estimated that adolescents spent approximately 25-30 minutes completing the surveys. Parents spent about 20 minutes filling out a sociodemographic form, a food security measure, a measure related to the impact of COVID-19 on the family, the DMIS and one other measure for the larger project. Parents and adolescents were paid $20 and $25, respectively, for answering the questionnaires.

Following the completion of the surveys, adolescents completed two, 24-hour diet recalls on the phone or on a video-conferencing platform (ZOOM®) with a research assistant. The goal was to complete both diet recalls within two weeks of survey completion. The exact day the participants completed the 24-hour diet recall depended on the availability of both the participant and research staff. Research assistants followed the *Automated Self-Administered 24-Hour Dietary Assessment Tool* (ASA-24®, Version 2018) website prompts from beginning to end, until all meals, snacks, and drinks were recorded for the selected time period. When participants completed the 24-hour diet recalls over ZOOM®, research assistants shared their screens with the participant so that they could view the ASA-24®'s visual images of food portion sizes and select the amount of food they ate. The calls were audio, but not video recorded. Participants were also asked to report at what meals and snacks they took pancreatic enzymes and whether or not they had gone to school in the past 48 hours. After the 24-hour diet recalls were completed, relevant
information from the ASA-24® was extracted (e.g., calories, enzyme use). Research staff coded the meal data into the *CF Individualized NuTritional Assessment of Kids Eating* (CF INTAKE) to obtain information on how frequently the adolescents missed an opportunity to follow general CF nutritional recommendations. Adolescents were paid $25 for each 24-hour diet recall completed. Finally, site coordinators conducted medical chart reviews to obtain information on the adolescents’ health status (i.e., weight, height, FEV1). The site coordinators uploaded this information to SharePoint® to an individual folder for their site.

**Measures and Variables**

**Sociodemographic Forms**

Parents/caregivers filled out a sociodemographic survey on REDCap®. Parents reported on their and their child’s age, their own marital status, gender of the child, estimated family income, and whether the adolescent is taking Trikafta®, among other information. Caregivers also completed the Food Security (FS) form (Bickel et al., 2000). When caregivers identified their family had not eaten the sorts of foods they wanted or did not have enough to eat in the past year, they answered additional questions on food security (e.g., affordability of food).

A study specific COVID-19 screener was also administered to caregivers. The measure consists of 12 yes-no questions asking families to identify if specific COVID-19 related events have impacted their family (e.g., “Has your child’s time spent at home changed?”). If the caregiver indicated “yes”, then a follow-up multiple choice or check-box question was given about the question that was answered “yes” (e.g., “If yes” the caregiver indicates whether the child has spent “more time spent at home,” “less time spent at home,” or “I choose not to answer”). In total, the caregiver answered 12 yes-no questions and up to 12 follow-up questions.
Decision-Making Involvement Scale (DMIS)

The DMIS (Miller & Harris, 2012) is a measure used to assess attributes of parent and child (ages 8-19 years) treatment related decision-making in youth with chronic health conditions. The measure consists of two sections and two parallel versions (one for the parent and one for the child). The first section is unscored and involves asking a parent and child (in person) to identify a treatment related decision they discussed during the past two weeks (Miller & Harris, 2012). With the permission of the author, this section of the DMIS was adapted to an online format specific to current study procedures. The online format consisted of five questions. The first question listed a menu of treatment-related issues in CF nutrition care (e.g., eating regular meals each day, taking CF enzymes with meals) and asked participants to select all that they discussed in the past month. The last option participants could select was “We did NOT talk about any problems with CF nutrition care,” and if it was the only item marked, the survey discontinued. The next question asked participants to select one nutrition-related discussion they had in the past month to reference for the remainder of the DMIS. For those participants who chose not to answer, the survey discontinued. However, participants who identified a specific CF nutrition care discussion topic then completed the remaining questions. Question 3 asked participants to describe what they talked about (text box format). In a multiple-choice format, questions 4 and 5 inquired if a decision was made (“Yes-Fully”, “Yes-Partly”, “No-Not at All”) and who made the decision (“Parent”, “Child”, “Joint (both of us together)”), respectively.

The second section of the measure consists of 30 Likert-type questions, asking each informant to rate how much each person engaged in specific behaviors during the treatment discussion identified in the first section of the DMIS (Miller & Harris, 2012). The scale ranges from 1 (“Not at all”) to 4 (“A lot”). In total, the DMIS multiple-choice section consists of five
subscales: Parent Seek (n=4), Parent Express (n=5), Child Seek (n=3), Child Express (n=3), and Joint/Options (n=5) (Miller & Harris, 2012). These item totals for the subscales were based on a confirmatory factor analysis on a sample of 226 participants with pediatric chronic illnesses (Miller & Harris, 2012). The measure also includes unscored social desirability items (n=7) and other unscored items (n=3) that are not currently used for data analysis but were a part of the original development of the questionnaire.

Parent Seek and Child Seek subscales indicate whether the parents and/or youth ask for information or advice from the other (Miller & Harris, 2012). An example of a Child Seek item is “I asked my mom/dad for information” or “My child asked me for information,” depending on the informant. Similarly, examples of statements from the Parent Seek subscales include “My mom/dad asked me for my opinion” (adolescent perspective) or “I asked my child for his/her opinion” (parent perspective). Child Express and Parent Express subscales describe the degree to which either party (i.e., parent or child) provided an opinion or information on the matter (Miller & Harris, 2012). Child Express statements ask both the parent and child how much the child “suggested ideas” or “gave…information” (Miller & Harris, 2012). An example of a Parent Express item from the adolescents’ point of view includes “My mom/dad tried to teach me something related to my illness.” The parent is asked to rate similar statements such as “I tried to teach my child about something related to the illness,” (Miller & Harris, 2012, p. 298). Lastly, the Joint/Options subscales asks how much autonomy/choice the parent gave the child in the decision and how much the child and parent worked together to solve the treatment situation being discussed (Miller & Harris, 2012). A statement on the Joint/Options subscale includes “We negotiated (e.g., made a deal)” (Miller & Harris, 2012).
Before calculating subscale scores, items not used in scoring, and items used to decrease social desirability effects are removed across all subscales ($n=10$). A score is calculated for each subscale by averaging its items; higher scores represent greater involvement. In the current study, all items were administered; however, only the Child Express, Child Seek, and Joint/Options subscales were used in the primary analysis in order to maintain power with a smaller sample size and to keep the focus of the analyses on the youth’s decision-making capabilities.

The DMIS has been found to have good psychometric properties in its original format. For example, in a sample of youth with CF ($n=68$), the Cronbach’s alpha reliability estimates were .89, .80, .73, .76, .71, and .89 for parent report and .85, .77, .74, .74, .71, and .91 for child report of Child Seek, Child Express, Parent Seek, Parent Express, Joint/Options, and total, respectively (Miller & Harris, 2012). In the same study, test-retest reliability of 48 parents and 49 children (with CF, type I diabetes or asthma), showed that the DMIS is relatively stable, with intraclass correlation coefficients ranging from .45 to .77 for the subscales and total score (Miller & Harris, 2012). In support of construct validity, family communication (one component of decision-making) scores were significantly correlated with child report of Child Seek, Child Express, and Joint/Options (Miller & Harris, 2012). In other words, better family communication is associated with the child asking more questions, stating his/her opinion more, and participating in decisions with caregivers (Miller & Harris, 2012). Further evidence for construct validity has been found in that as the child’s age increased, so did Child Express scores (Miller & Harris, 2012), illustrating that as youth get older they become more involved in their treatments.

In the current project, internal consistency was examined. The Cronbach’s alphas for the youth-reported Child Seek, Child Express, and Joint/Options were .89, .58, and .88, respectively,
indicating moderate to high reliability. In contrast, parents reported high internal consistency for
the Child Seek (α=.77) and Joint/Options (α=.75) subscales, but not for the Child Express
subscale (α=.35).

**Child and Adolescent Social Support Scale for Healthy Behaviors (CASSS-HB)**

Portions of the CASSS-HB (Menon & Demaray, 2013) were used to measure
adolescents’ perceptions of social support for healthy behaviors provided by their parent or
caregiver. The measure was originally developed with a sample of 121 children in 3rd-5th grade,
examining levels of social support for healthy eating and physical activity in youth, including
those with obesity, across a range of relationships (Menon & Demaray, 2013). The measure
includes 60 items, 12 for each subscale (Parent, Teacher, Classmates, a Close Friend, and
School) (Menon & Demaray, 2013). Each subscale has items representing “emotional,
informational, appraisal, and instrumental” support for healthy behaviors and asks youth to rate
both the frequency and importance of the support (Menon & Demaray, 2013, p. 50). In the larger
project both the Parent and Close Friend frequency subscales were administered. Only the 12-
item, Parent frequency subscale of the CASSS-HB was analyzed due to its relevance to parent-
adolescent communication. On each of the 12 Likert-type questions, adolescents rated how often
their parent(s), presumably the parent participating in the study, provides each type of support
listed. The scale ranges from 1 (“Never”) to 6 (“Always”). A total score, indicating how much
social support for healthy behaviors the parent provides, was calculated by summing the item
responses for each of the 12-items. Higher scores indicated the adolescent perceived more
frequent social support for healthy behaviors from this parent.

Previous research provides some evidence for reliability and validity of the original
measure’s scores in children (Menon & Demaray, 2013). Inter-item correlations for the parent
The CASSS-HB subscale are reported to be in the moderate range (.38 - .70; Menon & Demaray, 2013). The CASSS-HB also has high levels of internal consistency (α = .95; Menon & Demaray, 2013). Also, previous work shows that the parent subscale of the CASSS-HB moderately correlates with other existing measures of social support for healthy eating (r = 0.468, p < .001) and social support for physical activity (r = 0.322, p < .001), providing initial evidence for the validity of the measure (Menon & Demaray, 2013). Notably, the CASSS-HB was not found to significantly correlate with BMI in a sample of children above the fifth percentile in weight, but the authors note that BMI is not always the best predictor of health in children and people of all weights may still receive some sort of social support for healthy behaviors (e.g., to improve health or maintain health; Menon & Demaray, 2013). Although this specific version of the measure has not yet been validated in an adolescent population, the Child and Adolescent Social Support Scale (CASSS), the general social support scale the CASSS-HB was developed from, has been validated in adolescents (Menon & Demaray, 2013; Malecki & Demaray, 2002). The CASSS shows strong psychometric properties in adolescents and correlates with another measure of social support (Malecki & Demaray, 2002). In this project, the internal consistency of the CASSS-HB (α=.95) was the same as the previous literature.

**Automated Self-Administered 24-Hour Dietary Assessment Tool (ASA-24®)**

The ASA-24® (National Cancer Institute [NCI], 2018) diet recall was used to measure daily caloric intake and enzyme use, retrospectively. The ASA-24®, version 2018, developed by the National Cancer Institute, Bethesda, MD, is an online website used to record participants’ 24-hour diet recalls. The ASA-24® system then generates nutritional information for meals from its extensive database of foods and their nutritional values. For each meal, participants were asked to report on a wide array of information including what foods were eaten, the size of the food,
what they had to drink, the amount consumed, and where the food/drink was obtained (e.g.,
grocery, restaurant). Research coordinators also asked the adolescents to report at what meals
they took enzyme supplements and how many enzyme capsules they took. This information was
recorded in the ASA-24®. When the 24-hour diet recall was complete, the website provided
information on each food and drink the person consumed, including calories, macronutrients
(i.e., protein, carbohydrates, fat), and micronutrients (i.e., vitamins and minerals) (NCI, 2018).
Daily totals for outputs were also available (NCI, 2018). For this study, total caloric intake per
day and the total number of meals for which enzymes were taken at were calculated. For calorie
consumption, the number of calories consumed across the two days was averaged.

The ASA-24® obtains dietary information with about the same level of accuracy as the
Automated Multiple-Pass Method for 24-hour diet recalls interviews (AMPM; Thompson et al.,
2015). The AMPM, like the ASA-24®, asks participants to report everything they ate within a
specified time period, yet has typically been done interview style where the participant is asked
multiple questions in regard to food consumption (Conway et al., 2003). Notably, participants
tend to prefer using the ASA-24® over the AMPM (Thompson et al., 2015). Although the ASA-
24® still needs work to improve estimates of portion sizes of foods compared to actual intake, the
ASA-24® provides more accurate portion size estimates than the AMPM (Kirkpatrick et al.,
2016).

**Percent Recommended Dietary Intake (RDI) Achieved.** Using information obtained
from the ASA-24® diet recall across the two days, the ratio of average calories consumed to the
recommended daily calorie needs based on age, gender, height, weight, and activity level was
used to calculate percent dietary intake achieved. Specific daily calorie recommendations were
obtained from the Cystic Fibrosis Foundation dietary guidelines (Leonard et al., 2019). Upon
consultation with the site coordinators, it was decided that using a low-active activity level when calculating RDI was appropriate (S. Filigno, personal communication, March 3, 2021). Furthermore, only about a quarter of children in the United States meet the Centers of Disease Control and Prevention (CDC) physical activity guidelines of exercising for 60 minutes every day, indicating that the “low-active” activity level is likely appropriate for the current study (CDC, 2020; Katzmarzyk et al., 2018). Other studies have also used estimates of activity levels when calculating the calorie needs of youth with CF (Simon et al., 2011). Additionally, the percentage of CF recommended dietary intake consumed was calculated. Traditionally, an index of 120% of age and gender calorie recommendations has been used to estimate recommended calories for children with CF (Borowitz et al., 2002; Schall et al., 2006). Therefore, a ratio of the average daily calories consumed to 120% RDI was calculated.

**CF Individualized Nutritional Assessment of Kids Eating (CF INTAKE).** The CF INTAKE (Powers et al., 2005) is a nutrition tool used to identify when children with CF miss a chance to meet CF dietary recommendations by doing things such as skipping a meal, not adding calorie dense condiments to their food, and not taking enzymes (Powers et al., 2005). The CF INTAKE provides four missed opportunity scores (ratios of the number of times dietary recommendations are not met to the number of times they should be met) and two power scores (indicators that the child “ate high-fat/high-calorie foods;” Powers et al., 2005, p. 118). For this study, the focus was on the calorie and enzyme missed opportunity scores. These scores previously have been used to estimate caloric and enzyme adherence (Powers et al., 2005).

The Enzyme Score provides a ratio of the number of meals/snacks that enzymes would be recommended but not taken, to the total number of “meals and snacks” eaten that require enzymes across the data collection time frame (Powers et al., 2005, p. 117). The number of
meals that the adolescent did not take enzymes when recommended was gathered from the ASA-24® diet recalls and divided by the total number of meals/snacks requiring enzymes that were eaten across the two days. Similarly, the Calorie Missed Opportunity Score takes the ratio of the number of days that 120% RDI was not achieved to the total number of days of data collection (Powers et al., 2005).

When administered to 91 children with CF, ages 7 months to 12 years, the CF INTAKE demonstrated good reliability and validity evidence (Powers et al., 2005). Kappa coefficients for inter-rater reliability for the enzyme and calorie scores were .90 and 1.00, respectively (Powers et al., 2005). Concurrent validity evidence demonstrated the calorie score was negatively correlated with daily calories consumed ($r = -.65, p < .001$), in that those who missed more opportunities to eat the recommended calories, consumed fewer calories throughout the day.

**Determination of Caloric and Enzyme Adherence.** Caloric adherence was estimated three ways (CF-INTAKE Calorie Missed Opportunity Score, % RDI achieved, and % CF RDI achieved). Enzyme adherence was also estimated with the CF-INTAKE Enzyme Missed Opportunity Score and as a percentage of times enzymes were taken when required. Preliminary analyses helped determine which representation of caloric and enzyme adherence to use in the primary analyses.

**Medical Information**

Information on the adolescents’ weight and height was collected via medical chart review for calculations of recommended dietary intake (RDI) and BMI. Forced expiratory volume (FEV1) was also recorded.
Statistical Analysis

To test the primary aims of the study, regression models were run in SPSS using Andrew Hayes PROCESS model one (moderation). Each of the three specified DMIS component standard scores (i.e., Child Seek, Child Express, Joint/Options) were put into the model as predictor variables. The standard score on the CASSS-HB, representing level of perceived parental social support for healthy behaviors, was used as the moderator. Outcome variables were either caloric adherence or enzyme adherence. When identified, covariates were added to the models. Specific moderation models for each aim are listed below. Also, when appropriate parent and youth DMIS subscale scores were assessed together (averaged) and put into the model as one variable. See Figure 1 for an example of one of the models.

Specific Aim 1 and Specific Aim 2 – Caloric Adherence as Outcome

To test if perceived parental social support for healthy behaviors moderates the relation between adolescent and parent reported DMIS components (Child Seek, Child Express, Joint/Options) and caloric adherence, moderation models were run. Child Seek, Child Express, and Joint/Options subscales were run in separate models. Any identified covariates were added to the models.

Specific Aim 3 and Specific Aim 4 – Enzyme Adherence as Outcome

To analyze whether average adolescent and parent report of adolescent decision-making involvement is related to adherence to enzyme intake, moderation analyses were performed. Each of the DMIS subscales (Child Seek, Child Express, Joint/Options) were included as predictor variables in separate models. Social support for healthy behaviors was included as the moderator and enzyme adherence was the outcome variable.
Results

Preliminary Data Analyses

Power Analyses

To determine an appropriate sample size for each primary analyses a priori power analyses were run in GPower 3.1.9.4 with the following parameters: linear multiple regression, fixed model, $R^2$ deviation from zero, three predictors, $R^2 = .25$ (converted to an $f^2$ of .33), $\alpha = .05$, and power = .8. It was decided to use a large effect size ($R^2 = .25$) in the power analysis because similar studies examining factors associated with treatment adherence in adolescents with CF have found $R^2$ values between .17 to .31 (Borschuk et al., 2019; Modi et al., 2008). The power analyses reported that a total of 38 adolescent-caregiver pairs were needed to have enough power for each regression model, suggesting that the current study ($N = 28$) is underpowered.

Data Cleaning and Missingness

All data were added to SPSS and analyzed for missingness. In total, 1 parent and 3 adolescents indicated that they did not talk about any nutrition-related topic on the DMIS screening items, so they did not have DMIS scores. There was more than 5% missing data on the school status (online, in-person, no school; 11%), COVID-19 screener (11%), and family income (11%) variables. Each of these three variables were recoded into different variables where a value of ‘1’ indicated the data was not missing and a value of ‘0’ indicated the variable was missing. When the variables were run through a chi-square test (categorical variables) or an independent samples t-test (continuous variables) it was found that families with missing income data had greater parent-reported DMIS Child Seek scores ($M = 2.33, SD = 0$) compared to families with no missing income data ($M = 1.72, SD=.61$), $t(24) = 5.0, p <.01$. Also, those families with missing income data were found to be significantly different than those with
income data on the following scores: youth reported DMIS scores (Child Seek, Child Express, Joint/Options), average Child Express, enzyme adherence, social support for healthy behaviors and FEV1 (See Table 1). Likewise, those families missing a COVID-19 data score experienced less food insecurity \((M = 0, SD = 0)\) and were more adherent to enzymes \((M = 100, SD = 0)\) than those with COVID-19 total scores \((M_{\text{foodsecurity}} = 1.3, SD = 2.21; M_{\text{enzymeadherence}} = 86.2, SD = 18.9;\) See Table 1). Those missing a school status variable were significantly different from those not missing data on the parent report of Child Express (See Table 1). No differences were found between participants with and without missing data on the listed variables based on gender, race, Trikafta® use, or the caregiver’s education level.

To further analyze missing data, the adolescent and caregiver data were run through an Estimation Maximization Analysis separately to analyze whether the data was Missing Completely at Random (MCAR). Both datasets were MCAR. Estimation Maximization (EM) was not used to impute data because it is known why some of the data is missing (the first 3 participating families did not have access to the COVID-19 screener; screening measures rendered it unnecessary for some participants to complete the DMIS; participants chose not to answer; etc.).

**Univariate Checks**

Univariate tests inspected whether there were issues with skew, kurtosis, and outliers for all primary variables (DMIS average scores & CASSS-HB) and potential covariates. No univariate outliers were found, and a majority of the measures were not skewed or kurtotic. The food security total score was both skewed and kurtotic, with the ratio of the skew value to the standard error of skew (4.88) and the kurtosis value to the standard error of kurtosis (3.88) being greater than 3.3 standard deviations away from the mean. To address these issues, a square root
transformation was performed on the food security total score. After this transformation, the data remained skewed (3.8), but not kurtotic. A logarithmic transformation resulted in the data being both skewed and kurtotic. Due to the fact the square root transformation fixed the issue with kurtosis for the food security total score, when analyzing for covariates this variable was used.

**Bivariate Checks**

Pearson’s correlation coefficients between each of DMI variables (i.e., Child Seek, Child Express, Joint/Options) were correlated with the outcome variables (i.e., CF caloric adherence, enzyme adherence) to test for bivariate linear associations. Only youth reported Child Seek was significantly linearly related to CF caloric adherence. Thus, the remaining DMIS variables and the CASSS-HB cannot be assumed to have a linear relation with this study’s adherence variables. To check for heteroscedasticity, either average DMI components (youth and parent scores combined) or perceived social support for healthy behaviors was plotted on the X axis, while one of the adherence variables (i.e., caloric adherence, enzyme adherence) was plotted on the Y axis. Visual analysis of the plots helped determine if the assumption of homoscedasticity was maintained. It appeared that there were not any major problems with heteroscedasticity, but there was some variability in spread across the graphs. Visual inspection of the scatter plots was difficult due to the non-linear nature of the relationship between the independent and dependent variables. Thus, when interpreting results, these limitations should be considered.

**Multivariate Checks**

To check for independent residuals, simple scatter plots with the studentized residuals on the Y-axis and the standardized predicted values on the X-axis were run for each predictor variable (i.e., average DMIS subscale scores & the CASSS-HB) and outcome variables (i.e., caloric or enzyme adherence). Visual inspection of the graphs revealed slight issues with non-
random residuals for the graph with CASSS-HB with percent CF adherence. However, deviations from heteroskedasticity were minor, so it was decided to proceed with analyses. Multivariate outliers were checked using Mahalanobis distance. No multivariate outliers were found. Additionally, analyses looking at Cook’s D and leverage values assessed if a data point exerted an undue influence on the regression line. All six of the said graphs demonstrated that there were at least some points that may have exerted an undue influence on the regression line. However, due to the small sample size, all data points were kept in the data set. Normality of the residuals were checked using a P-P plot and a histogram. A majority of the residual plots when examining the DMIS and CASSS-HB variables with caloric adherence appeared to be normally distributed or only slightly skewed. In contrast, for all plots run with enzyme adherence, the graphs were skewed left. This may be due to the fact that a majority of participants indicated 100% adherence to their enzymes. Lastly, multicollinearity was assessed using tolerance values, variance-inflation factor (VIF), and condition indices (CI). All of the models had tolerance values greater than .2, VIF values less than 4, and CI values less than 15 indicating no issues with multicollinearity. Any transformations that occurred during the data cleaning phase were saved and used for data analyses.

**Determination of Caloric and Enzyme Adherence**

As mentioned, in this study 120% RDI was used to represent the minimum number of calories that the adolescents needed to be adherent to calorie recommendations. Dietary information was used to calculate adherence three ways: Calorie Missed Opportunity Score (ordinal variable), percent RDI achieved (continuous variable), and percent 120% RDI achieved (continuous variable).
After reviewing the spread of the data, it was decided not to use the Calorie Missed Opportunity Score to represent adherence because 11 or fewer participants fell into each of the following ratio categories: 0 \( (n=7) \), 0.5 \( (n=9) \), and 1 \( (n=11) \). When deciding whether to use the % RDI or % CF RDI (1.2 RDI) to represent caloric adherence, consultation with CF clinical team members was utilized. It was decided to use the percent CF RDI because a CF dietitian informed the study team that when calculating calorie needs, she still multiples RDI by 1-2 to calculate the person’s specific calorie recommendations (R. Juel, personal communication, March 2, 2021). Thus, using the percent CF RDI achieved seemed to be the most clinically relevant measure of caloric adherence.

Enzyme adherence was originally calculated using the procedure from the CF-INTAKE and the information from the ASA-24®. However, a majority of the adolescents reported taking all their necessary enzymes, resulting in incalculable Enzyme Missed Opportunity scores from the CF-INTAKE. Thus, a continuous variable of percent enzyme adherence was calculated by dividing the total number meals with enzymes taken by the total number of meals where enzymes were needed (based on fat content).

**Validation Checks**

As a form of a validation check, correlations were run between the different caloric adherence measures: % CF RDI achieved, % standard RDI achieved, and the Calorie Missed Opportunity Score. It was found that standard adherence percentages and CF adherence percentages were perfectly correlated with each other \( (r=1.0, p<.01) \). The Calorie Missed Opportunity Score was correlated to both continuous measures of adherence \( (r=-.84, p<.01) \), indicating that those who were less adherent to calorie recommendations missed more opportunities to eat the appropriate number of calories.
Descriptive Statistics

In total, 28 adolescents (46.4% male, $M_{age}=15.0$) and their primary caregiver participated in this project (see Table 2). One family withdrew due to disliking study procedures. The sample was relatively homogenous in that 92.9% ($n=26$) of adolescents were White and only 7.1% identified as American Indian/Alaskan ($n=2$; see Table 2). Additionally, half of participating caregivers had a college degree (50.0%) and the majority had yearly incomes equal to or greater than $90,000 (56%). On the food security measure, most families indicated that they do not struggle with food security ($n=24, 86\%$). The remaining families scores indicated they are “food insecure,” but “without hunger” (14%; Bickel et al., 2000, p. 71). Most families with complete data reported at least one change in their lives due to the COVID-19 pandemic (96%). Of note, most of the adolescents (78.6%) in the study were taking Trikafta®, the average FEV1 was 101%, and average BMI was 22.4 (range: 17.7-33.8). Table 2 provides additional demographic and medical information.

On the DMIS, almost 90% of adolescents indicated that they discussed a nutrition-related topic in the past month and so had DMIS subscale scores. Also, 84% of youth reported that they had either partly or fully made a decision related to nutrition in the past month. The most common nutrition topics that adolescents endorsed discussing were “taking enzymes with meals” (71.4%), “eating regular meals each day” (67.9%), and “taking enzymes with snacks” (64.3%). Of those adolescents who discussed a nutrition-related topic, 64% indicated that they had collaborated with their caregiver to make a decision. On the DMIS subscales, youth reported levels of involvement in the middle of the range of possible scores (1-4), with Child Seek, Child Express, and Joint/Options average scores of 2.17 ($SD = .91$), 2.29 ($SD = .72$), and 2.19 ($SD = .89$), respectively. Similarly, parent reported DMIS Child Seek, Child Express, and Joint/Options
subscale scores were 1.77 (SD = .61), 2.15 (SD = .58), and 2.16 (SD = .62). When averaged DMIS subscale scores were as follows: Child Seek (M = 1.94, SD = .63), Child Express (M = 2.23, SD = .55), and Joint/Options (M = 2.20, SD = .58). Adolescents’ scores on the CASSS-HB ranged from 22-72 (M = 54.2, SD = 16.3), with higher scores indicating more social support for healthy behaviors.

A total of 27 participants completed diet recalls, with two adolescents completing the diet recalls by phone and the remaining completing them by videoconferencing (n = 25). Analyses of the ASA-24® indicated that on average, participants reported consuming an average of 2,605 (SD = 1,118) calories a day. Of those adolescents who did not achieve an average RDI of at least 120%, their average calorie consumption was stated to be 1,962 (SD = 486). Additionally, a majority of adolescents (60%) reported being 100% adherent to their enzyme recommendations. The enzyme missed opportunity score is not reported here because of the high number of participants with incalculable scores due to the teens reporting 100% adherent to enzymes. When examining adherence to calorie recommendations, 11 (40.7%) adolescents had a calorie missed opportunity score of one, meaning that these teens did not meet the recommended 120% RDI on either day of the diet recall. Also, 51.9% of adolescents with diet data, on average, ate 100% RDI, but only 37% of teens ate the recommended 120% RDI.

Correlations

Table 3 displays correlation coefficients across study measures. None of the parent-reported or averaged DMIS subscale scores (Child Seek, Child Express, Joint/Options) were significantly correlated to either percent enzyme or caloric adherence. Youth-reported Child Express and Joint/Options were not significantly correlated to enzyme or caloric adherence either. Similarly, the CASSS-HB was not correlated to either measure of adherence. However,
youth-reported Child Seek was correlated with percent CF caloric adherence ($r = .44, p = .03$), indicating that youth who asked more questions or sought out information from their caregivers were more adherent to their calorie recommendations. Also, FEV1 was significantly correlated with caloric adherence ($r = -.40, p = .04$), indicating that those who have worse FEV1 percentages were more adherent to CF calorie recommendations.

**Covariates**

Before running analyses to test the primary outcomes of the study the data set was analyzed for covariates. Specifically, Pearson’s correlations coefficients with the outcome variables (caloric adherence or enzyme adherence) and the following potential covariates were calculated: age, gender, Trikafta® prescription (yes or no), parent informant (mother vs. father), food insecurity status, school status (in person, virtual, no school), FEV1 and impact of COVID-19 on the family. FEV1 was significantly correlated with caloric adherence ($r = -.40, p < .05$) and so it was included as a covariate in the models on caloric adherence. None of the other listed variables were significantly related to enzyme or caloric adherence in this sample. For categorical variables statistically insignificant t-tests and ANOVAs between the variables and adherence confirmed the lack of a relation. Thus, primary analyses were run without additional covariates.

**Reporter (Child-Parent) Agreement**

Correlations were computed to see how similar parent and adolescent report of decision-making involvement were. Also, independent samples t-tests were run to see if there were significant differences in parent and adolescent report of the DMIS components (e.g., Child Seek, Child Express, Joint/Options). Parent and youth reported Child Seek ($r = .48, p < .05$) and Child Express ($r = .47, p < .05$) subscales on the DMIS were significantly correlated with each
other. However, parent and youth reported Joint/Options subscale scores were not significantly correlated. Independent samples t-tests demonstrated that parent and youth report on all three of the DMIS subscales did not significantly differ from each other. Given there were no significant differences between the scores, it was decided to average the youth and parent DMIS scores for primary analyses. Additionally, a previous study analyzed parent- and youth-reported DMIS subscales together to decrease the likelihood of type II error (Turner et al., 2021); thus, this study followed a similar procedure because of its small sample size.

**Primary Data Analyses**

Given, parent and youth report of the DMIS subscales did not significantly differ from each other, before running primary analyses each of the subscale scores were averaged. Only FEV1 was significantly correlated with caloric adherence; therefore, only moderation analyses with caloric adherence included a covariate (FEV1). Also, to avoid any potential issues with multicollinearity (although nothing was flagged in data cleaning), the CASSS-HB and DMIS subscale scores were z-scored before running the primary analyses.

**Specific Aim 1 & Specific Aim 2 – Caloric Adherence as Outcome**

Moderation analyses with the z-scored average parent and child report of the DMIS Child Seek, Child Express, and Joint/Options subscales as predictor variables were run. The z-scored CASSS-HB score was entered as the moderator and the percent CF caloric adherence was the outcome variable. None of the three moderation models were significant (see Table 4). Although the models were not statistically significant, effect size estimates ($R^2$ converted to $f^2$) ranged from .10 to .23. Specifically, when the average Joint/Options subscale and the CASSS-HB (social support for healthy behaviors) score were entered into the regression model, an $f^2$ of .23 was found, indicating a medium effect size (Ferguson, 2009; Wuensch, 2019).
Specific Aim 3 & Specific Aim 4 – Enzyme Adherence as Outcome

To test whether or not various types of adolescent decision-making involvement were associated with social support for healthy behaviors and enzyme adherence, three additional moderation models were conducted. Each of the moderation models were performed with one of the z-scored DMIS subscales (Child Seek, Child Express, and Joint/Options), z-scored CASSS-HB, and percent enzyme adherence. None of these moderation models were significant. Effect size estimates ranged from $f^2 = .04-.25$ (See Table 4). The highest effect size estimate was found in the regression model where enzyme adherence was regressed onto average Child Seek and CASSS-HB (social support for healthy behaviors) scores ($f^2 = .25$).

Discussion

Nutritional adherence in adolescents with CF remains problematic, with adolescents typically exhibiting poorer adherence rates than young children (Arias Llorente et al., 2008; Zindani et al., 2006). Simultaneously, caregivers begin to shift treatment responsibility to their teens (Iles & Lowton, 2010) and adolescents spend more time away from home, allowing for increased treatment autonomy. Thus, adolescents with CF have the opportunity to make nutritional decisions that either correspond to or contradict their CF dietary recommendations. Despite the clinical importance (i.e., long-term health, improved lung functioning) of adolescents learning to follow CF dietary guidelines, few studies have investigated the association of adolescent decision-making involvement (DMI) to caloric or enzyme adherence in adolescents with CF. Treatment decision-making is a complex task that involves many different interactions between the parent and child, including the exchange of information, asking for help, and evaluating options (Miller, 2009). These nuances of the parent-child decision making process in the context of CF care remain understudied. Furthermore, to our knowledge no study has
examined DMI and CF nutritional adherence while accounting for family social support. Thus, the current study adds to the literature in that it evaluated multiple aspects of adolescent nutrition decision-making related to caregiver social support for healthy behaviors, and nutritional (i.e., calorie and enzyme) adherence in adolescents with CF.

In align with the previous research, this study found variable caloric adherence rates, with adolescents eating between 45.4%-208% RDI or 37.8%-173.4% CF RDI. Of the participating adolescents 37% met CF calorie recommendations of 120% RDI. In other words, 63% of adolescents did not meet the CF calorie recommendations. Other studies on nutritional adherence in youth with CF found similar adherence rates, with 61% of adolescents not achieving a RDI of 120% (Schall et al., 2006). Knowing that the caloric adherence rate of adolescents with CF has not improved within the last 15 years highlights the continued need for dietary adherence interventions in this population. Although the low adherence rates in this study may be partially explained by the fact that information on the adolescents’ disease severity and specific activity level were not available for calculating more individualized RDI for each teen, this limitation does not explain why over half of the participants still failed to achieve the standard CF dietary recommendation. Furthermore, having specific information on activity level does not appear to be of great clinical interest given three of the five study sites noted that activity level is not easily accessible in the adolescent’s medical chart.

In contrast, this study found higher enzyme adherence rates compared to previous studies. Sixty percent of adolescents in this study took enzymes at all required meals and snacks, whereas a previous study found that only 4.7% of the participants met the “minimum” enzyme requirements (Borschuk et al., 2019, p. 146). The differences in findings may be explained by the varying methods to measure pancreatic enzyme replacement therapy (PERT) adherence. In the
current study, adolescents self-reported their enzyme intake by recalling which meals and snacks they took an enzyme at across two days. The other study used MEMS® caps, a pill bottle that counts every time the cap is opened, to measure enzyme adherence across a one-month time period (Borschuk et al., 2019). Self-reported adherence measures, although common, tend to inflate actual adherence rates more than objective measures, like electronic monitoring, including in the CF population (Modi et al., 2006; Quittner et al., 2007). Thus, the current study’s estimate of enzyme adherence may be particularly susceptible to social desirability and response biases common in self-report measurements of adherence because the study team asked the adolescents directly if they took enzymes with each reported meal. In other words, repeated questioning about enzymes may have increased the adolescents’ reports of their enzyme adherence. Daily diary reports that ask about all activities, rather than just treatment related activities, tend to reduce recall biases (Modi et al., 2006). In essence, the PERT (enzyme) adherence rate in this study may be inflated by the use of self-report measures and the limited time period of data collection.

However, the high enzyme adherence rates found in this study may also be explained by the quality of information and support adolescents receive from their care teams and parents about the importance of taking enzymes as prescribed. A qualitative study on facilitators of adherence in children with CF reported that both parents and youth found that good communication and relationships with the child’s CF care team supported treatment adherence (Nicolais et al., 2019). Specifically, parents found it helpful for providers to problem-solve ways to improve treatment compliance and discuss the “the value of adherence” (Nicolais et al., 2019, p. 535). This anecdotal hypothesis that parents in the current study value adherence to enzymes is supported by the fact that 71.4% of youth indicated that they discussed taking enzymes at
meals with their caregivers within the past month. Lastly, this sample of participants generally come from well-educated, middle to upper middle-class families which may support enzyme adherence. Financial concerns have been self-reported as barriers to adherence in some families with CF (Dziuban et al., 2010).

Correlations

Unlike previous literature on adherence and decision-making involvement (DMI) in chronic illness populations, this study did not find many significant correlations between the DMIS scales and adherence measures (caloric, enzyme). In the pediatric type I diabetes population, parent- and youth-reported Child Seek, Child Express, and Joint/Options subscales of the DMIS were associated with better treatment adherence, as represented by higher scores on a self-report measure of general diabetes adherence (Miller & Jawad, 2019). This discrepancy between this study and previous literature may be accounted for by the fact that the disease populations were different, the current study was underpowered, there were differences in measurement of adherence, and differences in the types of statistical analyses used. In the study on type I diabetes, adherence to multiple treatment components was measured via a survey (Miller & Jawad, 2019), whereas in this study dietary adherence was measured via 24-hour diet recall codes. Additionally, direct comparison of the results between Miller and Jawad’s (2019) study is not possible because they used linear and quadratic modeling in growth curves to predict adherence rather than correlations. Thus, current insignificant correlations should be interpreted with caution.

In contrast, like Miller & Jawad’s (2019) study, this project found a relation between youth reported Child Seek and adherence. Those adolescents who used their caregivers as a resource for finding out information where more adherent to the CF calorie recommendations.
Developmentally, during adolescence youth begin to take on more of the treatment responsibility (Lerch & Thrane, 2019). It is also known that adolescents who exhibit better adherence sustain some level of parental involvement (Bishay & Sawicki, 2016). Thus, it appears that developing treatment autonomy is a collaborative process between the teen and their caregiver. Our significant correlation between Child Seek and caloric adherence therefore seems to suggest that a key component of this collaborative process may be adolescent engagement through the seeking of information.

Furthermore, in this project youth who reported higher levels of social support for healthy behaviors also reported seeking information ($r = .50$, $p < .05$), expressing their thoughts ($r = .59$, $p < .01$), and being provided decision options/negotiating ($r = .63$, $p < .01$) more frequently than those reporting lower levels of social support. Thus, it appears that adolescents are more involved in nutrition-related decision-making processes when they feel more supported by their caregivers, suggesting the need to further understand the role both social support for healthy behaviors and DMI have in CF treatment outcomes.

**Moderation Analyses**

Of note, neither social support for healthy behaviors nor DMI were significantly associated with adherence in the moderation analyses. Thus, these results seem to suggest that DMI and social support for healthy behaviors play a small role in caloric and enzyme adherence in adolescents with CF. However, there may be methodological and theoretical reasons for the lack of significant relations between the study variables. Methodologically, the null results of the study’s primary aims may be due to the fact that the study was underpowered. Statistically significant results may emerge as the ongoing project continues to recruit additional participants. The fact that some of the models had moderate effect size estimates supports this idea.
Specifically, the moderation model examining the interaction between average Joint/Options and social support for healthy behaviors on caloric adherence had an effect size of \( f^2 = .23, \text{ CI: } -4.00, 27.15 \). Similarly, the moderation model examining the interaction between average Child Seeking behavior (i.e., asking questions; asking for information), social support, and enzyme adherence produced a moderate effect size \( f^2 = .25, \text{ CI: } -16.49, 1.23 \). While these confidence intervals indicate quite a bit of variability, the relation between DMI, social support for healthy behaviors and caloric adherence should not be dismissed until the analyses are re-run with more participants (i.e., greater power).

As mentioned, there also may be theoretical explanations for the lack of significant findings. The Pediatric Self-Management model, a framework used to conceptualize the complex nature of treatment management in pediatric chronic illness, posits that there are many individual, familial, community, and healthcare system factors that interact to influence treatment management behaviors (Modi et al., 2012). Thus, there may be other constructs, as noted in the Pediatric Self-Management model, that better explain dietary adherence in adolescents with CF.

Individual factors on the Pediatric Self-Management Model are particularly relevant to the current study as DMI may influence adherence through other modifiable patient-related factors. For example, one study examining the relation between DMI and adherence in youth with type I diabetes hypothesizes that DMI may relate to feelings of “empowerment”, which may subsequently influence treatment adherence (Miller & Jawad, 2019, p. 69). Other individual level factors previously known to be associated with treatment adherence in youth with CF such as food sensitivity/nausea (Stark et al., 2005), ability to manage one’s time (Bishay & Sawacki, 2016), and motivation to engage in treatments (Nicolais et al., 2019) were also not measured in
this study. It is possible that adolescents’ engagement in nutritional related discussions, as measured by the DMIS, is also associated with one’s motivation and time-management skills, among other factors. Anecdotally, an adolescent in the study noted that they often “forget” to take their enzymes and “often do not want to take them”. Thus, future research should consider accounting for individual factors, such as motivation, in studies on nutritional adherence in adolescents with CF.

Notably, it was surprising that social support for healthy behaviors did not moderate the relation between DMI and adherence and that it was not directly correlated to nutritional adherence. Other research has found that parental social support and additional family factors to be relevant to treatment management in youth with CF. Teens with CF self-reported that receiving tangible (e.g., organizing medications) support from their caregivers is helpful in completing treatments (Nicolais et al., 2019). Furthermore, a study on nutritional adherence in adolescents with CF found that youth experiencing less conflict with their mothers, were more adherent to PERT (Borschuk et al., 2019). Similarly, there appear to be fewer barriers to treatment adherence when families exhibit positive communication (Bregnballe et al., 2011). Given the interconnected nature of familial factors, future studies may want to assess family communication and conflict in addition to social support. It may be that positive familial social support for healthy behaviors facilitates adherence but barriers within the family environment also exist, counteracting the positive familial social support found in this study.

Limitations

The current study is not without limitations. First, both the CASSS-HB and the DMIS were slightly adapted from their original formats. For example, only the CASSS-HB Close Friend and Parent subscales were administered to participants, while the remaining scales
(Teacher, Classmates, and School) were omitted in order to decrease participant burden (Menon & Demaray, 2013). Furthermore, the CASSS-HB has not been validated in a chronic illness population or with adolescents. However, the CASSS-HB still exhibited the same high level of internal consistency as previous work ($\alpha=.95$; Menon & Demaray, 2013).

Likewise, when the DMIS is completed in its original format, a person on the research team assists the caregiver and child identify a treatment related discussion they had within the past two weeks by asking the family a series of questions (Miller & Harris, 2011). This procedure ensures the caregiver and child are referring to the same treatment related discussion when completing the survey questions. While it would have been ideal to administer the first part of the DMIS via an interview, it was not feasible to hire a staff member for each of the five sites to administer the DMIS given limited time and funding. As such, with Dr. Miller’s permission, the DMIS was adapted to an online format. Despite this limitation the DMIS still showed relatively high levels of internal consistency for the Child Seek ($\alpha_{\text{child}}=.89; \alpha_{\text{caregiver}}=.77$) and Joint/Options ($\alpha_{\text{child}}=.88; \alpha_{\text{caregiver}}=.75$) subscales and these alpha levels are similar to what has been found in a previous study (Child Seek $\alpha_{\text{child}}=.89; \alpha_{\text{caregiver}}=.85$; Joint/Options $\alpha_{\text{child}}=.89; \alpha_{\text{caregiver}}=.91$; Miller & Harris, 2011). Only the scores on the Child Express subscale appear to be different from previous work (Current project $\alpha_{\text{child}}=.58; \alpha_{\text{caregiver}}=.35$; Previous work $\alpha_{\text{child}}=.80; \alpha_{\text{caregiver}}=.74$; Miller & Harris, 2011).

More generally, the results of the study, especially adolescents’ decision-making involvement, need to be interpreted within the context of the adolescents’ food environments. During adolescence parents still make certain food decisions (e.g., what to buy at the grocery) without their adolescent’s input. Yet many adolescents eat meals in a variety of settings (school, home, social events), and it appears that their food preferences change based on which
environment they are in, with a preference for less nutritionally dense food when away from home (Brown et al., 2000). Thus, although some parents continue to control what food is provided at home by conducting the grocery shopping, adolescents actively make efforts to increase their autonomy related to food decision-making (e.g., food refusal; Bassett et al., 2008; Brown et al., 2000). Furthermore, youth with CF must grapple with and consider additional nutrition factors (e.g., taking enzymes/taking vitamins; Singh & Schwarenzberg, 2017; Smyth et al., 2011), when not under their parents’ supervision underscoring the importance of examining adolescent meal decision-making. Thus, future research may want to gather additional data about the adolescents’ attitudes around eating at school, at home, and at a variety of activities.

Other contextual factors not accounted for in this study include whether or not the adolescents have any food allergies or food sensitivities and specific activity levels. Food sensitivities may play a role in the adolescents’ desire to eat and consume CF dietary recommendations. Moreover, exceptionally active adolescents may require more calories than was assumed in this study with a low-active activity level. However, clinical care team members and researchers noted that specific activity levels are not of great clinical concern given that activity levels are not readily available in many of the medical charts (Teens Talk Study Site Coordinators, personal communication, April 15, 2021)

Furthermore, the study was conducted in the unprecedented time of the COVID-19 pandemic. When the study was conceptualized and designed in the fall of 2019, COVID-19 had not yet become a widespread concern in the United States. Right around the time the study launched, the United States implemented stay-at-home orders. Thus, the study did not account for the impact of COVID-19 when originally designed. Also, the pandemic brought many changes to daily living including school closings, and restrictions to access to healthcare
(Plevinsky et al., 2020). These changes can make adhering to complex treatments, such as those required for appropriate CF care, even more challenging (Plevinsky et al., 2020). For instance, some children who received access to healthy foods at school no longer had that support (Plevinsky et al, 2020). In contrast, some families during the pandemic may have found it easier to eat healthy meals and complete all aspects of the child’s treatment regimen, given they were spending more time at home and had fewer places to be (Plevinsky et al., 2020). Furthermore, in some families the COVID-19 pandemic has limited the opportunities that youth have had to learn to take responsibility and make decisions related to their treatment given parents are spending more time at home and have more time to take a hands-on approach to their child’s care (Plevinsky et al., 2020). Regardless of the circumstances, the COVID-19 pandemic has affected many aspects of adherence, including nutritional adherence, in adolescents with chronic illnesses. Thus, these results may not generalize to times when youth have more demands from school and extracurricular activities outside the home. To address this limitation the study team developed and administered a COVID-19 screener to account for factors that may have impacted the results, although the measure was not a part of the original study design. However, with the current sample, COVID-19 impact is not a covariate in primary study outcomes.

Likewise, the original study had to be adapted when Trikafta®, the newest CF modulator medication, was introduced. In October 2019, right around the time the study was developed, the Food and Drug Administration (FDA) approved Trikafta® (FDA, 2019). Studies noted that people on Trikafta® started to achieve higher weight statuses (Heijerman et al., 2019). In the current project, 78.6% of participants are taking Trikafta®, and thus may have also experienced increases in weight. Although no official changes to dietary guidelines were made throughout the course of the project, it is important to consider that CF nutrition care may be changing in the
near future and that this study does not incorporate any future changes in dietary recommendations despite being conducted in the era of new modulator medications.

**Strengths**

Although results of the study should be interpreted within the context of the COVID-19 pandemic, modulator therapies, and measurement limitations, the study has some key strengths. First, the fact that the study was conducted across five sites in the United States, enabled data collection from a geographically, and potentially medically diverse, CF population. Additionally, efforts were made to conduct the diet recalls by ZOOM® or phone. Having two ways to complete the diet recalls, allowed participants with limited access to the internet or with a strong preference for phone communication to participate in the study. Another strength of the study is that it captures information about nutritional adherence across the teen years (ages 12-17). Changes in adherence with age was not of interest in this particular study, but the wide age range makes future investigation of such variables possible. Furthermore, the age span of 12-17 aligns with previous literature on nutritional adherence in adolescents with CF (Borschuk et al., 2019), making it feasible to compare across studies (e.g., systematic review, meta-analyses) in the future.

Methodologically, the study has some key strengths as well. First, most of the variables used in the study had less than 5% missing data. Electronic administration of the surveys allowed for some surveys to be set up with a forced choice. Participants had to pick one of the responses or “I choose not to answer”. Furthermore, it is a strength of the study that the DMIS was administered to both children and parents. Their responses did not significantly differ from each other, suggesting that adolescents with CF and their parents may evaluate the adolescent’s role in the decision-making process similarly. Parent- and youth-report of how frequently youth
were given choices or allowed to provide input during decision-making did not correlate, but again were not significantly different from one another. This nuance may indicate that despite the fact parents and adolescents generally concur on the teen’s role in DMI, there still is variability. These lack of differences between informant (adolescent, caregiver) ratings can be seen as an additional form of construct validity for each of the DMI subscales and their related concepts. In essence, this study provides many descriptive details about the decision-making processes adolescents and parents engage in, strengthening the overall clinical utility of the study.

Furthermore, the study’s methodology was strengthened by the use of the ASA-24®. This system is known to provide more accurate portion size estimates than the Automated Multiple-Pass Method (AMPM; Kirkpatrick et al., 2016), about overall equal levels of accuracy as the AMPM (Thompson et al., 2015), and is preferred by participants over the AMPM (Thompson et al., 2015). Overall, this study’s rigorous data collection methods strengthen its scientific contribution to the literature on nutritional adherence in adolescents with CF.

**Implications and Future Directions**

As laid out by the Pediatric Self-Management Model, many psychosocial factors impact adolescents’ adherence to CF enzyme and calorie recommendations. While the primary analyses in this study were not significant, previous research emphasizes the importance of adolescents’ DMI (Miller & Jawad, 2019) and familial social support (Nicolais et al., 2019) to adherence. Given adherence rates in adolescents with CF often decline (Bishay & Sawicki et al., 2016), further exploring these individual (DMI) and familial (social support) factors as related to nutritional adherence in adolescents with CF is necessary to inform future interventions.
Future intervention work will want to explore whether social support for healthy behaviors and decision-making involvement relate to nutritional adherence above and beyond other familial factors such as family communication and trust. In other studies, family communication (Bregnballe et al., 2011) and lower conflict with one’s mother (Borschuk et al., 2019) were reported to be related to measures of treatment adherence in adolescents with CF. Separating the effects of these different factors from one another is important so that the underlying mechanisms of poor adherence can be targeted in nutritional interventions.

Furthermore, additional studies with larger sample sizes may want to separately analyze adherence rates in adolescents with and without rare gene mutations. Although people with rare mutations only make up about 15% of the CF population (CF registry, 2020) they may be the ones with the greatest need for adherence interventions, given that more people with rare mutations do not have as many CF modulator treatments available to them (Harutyunyan et al., 2018; Joshi et al., 2019). To capture the nuances of nutritional adherence across mutation groups in adolescents with CF, researchers may want to consider supplementing quantitative data with qualitative data. Lastly, additional research is necessary to verify that the results found in this study represent dietary behaviors in adolescents with CF outside of a global pandemic.

**Conclusions**

In summary, this study investigated the relation between adolescents’ decision-making involvement, parental support for healthy behaviors, and adolescents’ calorie and enzyme adherence. Although DMI and social support were found to be significantly correlated with each other, only youth-reported Child Seek was associated with caloric adherence. None of the other DMI scores or the CASSS-HB were related to enzyme or caloric adherence. Similarly, the interactions between the DMI components and social support for healthy behaviors were not
related to either caloric or enzyme adherence. Despite these null results, this study provides important insight into dietary behaviors of teens with CF. Specifically, almost 90% of adolescents indicated that they had talked about a nutrition topic in the past month with caregivers and many had been involved in a joint decision. Thus, studying nutritional adherence in adolescents with CF is of high importance given the prevalence of dietary discussions within families. Additionally, researchers will want to consider other individual and family factors not accounted for in this study that may influence dietary outcomes. In sum, this study provides initial information on the complex processes of dietary decisions and how they are related to social support for healthy behaviors and dietary adherence in adolescents with CF. The groundwork laid out in this study may be used to inform future clinical research and clinical care of adolescents with CF.
References


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Wuensch, K. (2019). Cohen’s conventions for small, medium, and large effects [Handout]. East Carolina University, Greenville, NC.


Table 1

Independent T-Tests Comparing Families with and without Missing Data

<table>
<thead>
<tr>
<th>Variable</th>
<th>Missing</th>
<th>Not Missing</th>
<th>t(df)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td><strong>Comparing Families with and without Income Information</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child Seek (caregiver)</td>
<td>2.33</td>
<td>0</td>
<td>1.72</td>
<td>.61</td>
</tr>
<tr>
<td>Joint/Options (youth)</td>
<td>3.4</td>
<td>0</td>
<td>2.09</td>
<td>.85</td>
</tr>
<tr>
<td>Child Seek (youth)</td>
<td>3.67</td>
<td>.47</td>
<td>2.04</td>
<td>.82</td>
</tr>
<tr>
<td>Child Express (youth)</td>
<td>3.33</td>
<td>.47</td>
<td>2.20</td>
<td>.66</td>
</tr>
<tr>
<td>Child Express (average)</td>
<td>3.33</td>
<td>-</td>
<td>2.18</td>
<td>.51</td>
</tr>
<tr>
<td>% Enzyme Adherence</td>
<td>100</td>
<td>0</td>
<td>86.2</td>
<td>18.91</td>
</tr>
<tr>
<td>Social Support</td>
<td>72</td>
<td>0</td>
<td>52.1</td>
<td>16.0</td>
</tr>
<tr>
<td>FEV1 (%)</td>
<td>80.2</td>
<td>29.0</td>
<td>103.59</td>
<td>14.88</td>
</tr>
<tr>
<td><strong>Comparing Families with and without COVID-19 Scores</strong></td>
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</tr>
<tr>
<td>Food Security</td>
<td>0</td>
<td>0</td>
<td>1.3</td>
<td>2.21</td>
</tr>
<tr>
<td>% Enzyme Adherence</td>
<td>100</td>
<td>0</td>
<td>86.2</td>
<td>18.91</td>
</tr>
<tr>
<td><strong>Comparing Families with and without School Status Information</strong></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child Express (caregiver)</td>
<td>2.77</td>
<td>.38</td>
<td>2.10</td>
<td>.56</td>
</tr>
</tbody>
</table>
# Table 2

## Demographics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean(SD) / %</th>
<th>Child (N=28)</th>
<th>Parent (N=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12-14</td>
<td>15.0 (1.59)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15-17</td>
<td></td>
<td>42.9% (n=12)</td>
<td>47.1% (n=16)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>46.4% male (n=13)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>American Indian/Alaskan</td>
<td>7.1% (n=2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>92.9% (n=26)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hispanic/Latino</strong></td>
<td>3.6% (n=1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking Trikafta</td>
<td>78.6% (n=22)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Comorbidities?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes (e.g., cancer, CFRD)</td>
<td>17.9% (n=5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>82.5% (n=23)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>FEV1</strong></td>
<td>101% (17.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Height (meters)</strong></td>
<td>1.61 (.09)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Weight (kg)</strong></td>
<td>58.6 (13.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>BMI</strong></td>
<td>22.4 (3.5)</td>
<td></td>
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</tr>
<tr>
<td><strong>Caregiver Relation to Child</strong></td>
<td></td>
<td>81.5% (n=22)</td>
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</tr>
<tr>
<td>Mother</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Father</td>
<td>14.8% (n=4)</td>
<td></td>
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</tr>
<tr>
<td>Other (i.e., step-parent, adopted parent)</td>
<td>3.7% (n=1)</td>
<td></td>
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<tr>
<td><strong>Caregiver Education Level</strong></td>
<td></td>
<td>3.6% (n=1)</td>
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<tr>
<td>Some High School</td>
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<tr>
<td>High School Graduate/GED</td>
<td>10.7% (n=3)</td>
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<tr>
<td>Some College</td>
<td>17.9% (n=5)</td>
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<tr>
<td>Associate’s Degree</td>
<td>17.9% (n=5)</td>
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<tr>
<td>Bachelor’s Degree</td>
<td>25.0% (n=7)</td>
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<tr>
<td>Master’s/Professional Degree</td>
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<tr>
<td><strong>Family Income (n=25)</strong></td>
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<td>$10,000-19,999</td>
<td>4.0% (n=1)</td>
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<td>8.0% (n=2)</td>
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<td>$30,000-39,999</td>
<td>12.0% (n=3)</td>
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<td>$40,000-49,999</td>
<td>4.0% (n=1)</td>
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<td>$50,000-59,999</td>
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<td>$60,000-69,999</td>
<td>8.0% (n=2)</td>
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<td>$100,000 or greater</td>
<td>40.0% (n=10)</td>
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<tr>
<td>Other/unclear</td>
<td>4.0% (n=1)</td>
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<tr>
<td><strong>Marital Status</strong></td>
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</tr>
<tr>
<td>Marital Status</td>
<td>Percentage</td>
<td>Number</td>
<td></td>
</tr>
<tr>
<td>-------------------------------</td>
<td>------------</td>
<td>--------</td>
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</tr>
<tr>
<td>Never been married</td>
<td>7.1%</td>
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<tr>
<td>Married to other biological parent</td>
<td>71.4%</td>
<td>20</td>
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<td>Divorced/separated</td>
<td>10.7%</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Remarried to step-parent</td>
<td>7.1%</td>
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<tr>
<td>Widowed</td>
<td>3.6%</td>
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</table>

*Note.* Medical data reflects the information available closest to date of enrollment.
Table 3

Correlation Table of Covariates and Primary Variables of Interest

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<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>M(SD)</th>
<th>Range</th>
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<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
<th>16</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age</td>
<td>28</td>
<td>15 (1.6)</td>
<td>12-17</td>
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<td>-</td>
<td>-</td>
<td>-</td>
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<td>-</td>
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</tr>
<tr>
<td>2. Height (m)</td>
<td>28</td>
<td>1.6 (1)</td>
<td>1.4-1.8</td>
<td>.55**</td>
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<td>-</td>
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</tr>
<tr>
<td>3. Weight (kg)</td>
<td>28</td>
<td>58.6</td>
<td>40.4- 95.4</td>
<td>.59**</td>
<td>.76**</td>
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<tr>
<td>4. FEV1 (%)</td>
<td>28</td>
<td>101</td>
<td>46.8- 134</td>
<td>.14</td>
<td>.23</td>
<td>.33</td>
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<tr>
<td>5. Child Seek (Youth)</td>
<td>25</td>
<td>2.2(9)</td>
<td>1-4</td>
<td>.13</td>
<td>.06</td>
<td>.07</td>
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<tr>
<td>6. Child Seek (Caregiver)</td>
<td>27</td>
<td>1.8(6)</td>
<td>1-3</td>
<td>.38</td>
<td>.15</td>
<td>.33</td>
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<tr>
<td>7. Child Seek (Average)</td>
<td>24</td>
<td>1.9(6)</td>
<td>1-3.2</td>
<td>.32</td>
<td>.28</td>
<td>.30</td>
<td>.11</td>
<td>.90**</td>
<td>.81**</td>
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<tr>
<td>8. Child Express (Youth)</td>
<td>25</td>
<td>2.3(7)</td>
<td>1.3-3.7</td>
<td>.03</td>
<td>-.12</td>
<td>-.14</td>
<td>-.35</td>
<td>.60**</td>
<td>.35</td>
<td>.56**</td>
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<tr>
<td>9. Child Express (Caregiver)</td>
<td>27</td>
<td>2.1(6)</td>
<td>1-3</td>
<td>.06</td>
<td>-.22</td>
<td>-.14</td>
<td>.29</td>
<td>.47*</td>
<td>.58**</td>
<td>.63**</td>
<td>.47*</td>
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</tr>
<tr>
<td>10. Child Express (Average)</td>
<td>24</td>
<td>2.2(5)</td>
<td>1.2-3.3</td>
<td>.11</td>
<td>-.11</td>
<td>-.13</td>
<td>-.06</td>
<td>.62**</td>
<td>.56**</td>
<td>.69**</td>
<td>.89**</td>
<td>.82**</td>
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<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>11. Joint/Options (Youth)</td>
<td>25</td>
<td>2.2(9)</td>
<td>1-3.6</td>
<td>.08</td>
<td>.03</td>
<td>-.09</td>
<td>-.26</td>
<td>.77**</td>
<td>.25</td>
<td>.63**</td>
<td>.62**</td>
<td>.26</td>
<td>.52**</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>12. Joint/Options (Caregiver)</td>
<td>27</td>
<td>2.2(6)</td>
<td>1.2-3.2</td>
<td>.11</td>
<td>-.05</td>
<td>-.16</td>
<td>-.36</td>
<td>.19</td>
<td>.34</td>
<td>.27</td>
<td>.20</td>
<td>.27</td>
<td>.23</td>
<td>.22</td>
<td>-</td>
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<tr>
<td>13. Joint/Options (Average)</td>
<td>24</td>
<td>2.2(6)</td>
<td>1.2-3.2</td>
<td>.14</td>
<td>.10</td>
<td>-.10</td>
<td>-.30</td>
<td>.66**</td>
<td>.33</td>
<td>.61**</td>
<td>.55**</td>
<td>.29</td>
<td>.51*</td>
<td>.86**</td>
<td>.69**</td>
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<tr>
<td>14. Social Support</td>
<td>28</td>
<td>54.2 (16.3)</td>
<td>22-72</td>
<td>-.26</td>
<td>.05</td>
<td>-.06</td>
<td>-.31</td>
<td>.50*</td>
<td>.03</td>
<td>.32</td>
<td>.59**</td>
<td>-.02</td>
<td>.42*</td>
<td>.63**</td>
<td>-.11</td>
<td>.40</td>
<td>-</td>
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<td>-</td>
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<tr>
<td>15. Enzyme Adherence</td>
<td>25</td>
<td>87.9 (18.3)</td>
<td>46.2- 100</td>
<td>-.12</td>
<td>.22</td>
<td>.23</td>
<td>.26</td>
<td>.11</td>
<td>.28</td>
<td>.17</td>
<td>-.01</td>
<td>.40</td>
<td>.16</td>
<td>.10</td>
<td>.06</td>
<td>.02</td>
<td>.15</td>
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<tr>
<td>16. Calorie Adherence (of 120% EER)</td>
<td>27</td>
<td>92.1 (34.4)</td>
<td>37.8- 173.4</td>
<td>-.28</td>
<td>-.38</td>
<td>-.15</td>
<td>-.40*</td>
<td>.44*</td>
<td>.13</td>
<td>.21</td>
<td>.11</td>
<td>.02</td>
<td>.02</td>
<td>.34</td>
<td>.21</td>
<td>.27</td>
<td>.25</td>
<td>.04</td>
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</table>

*p<.05, **p<.01
### Table 4

*Moderation Models of DMIS Subscales, Social Support, and Dietary Adherence*

<table>
<thead>
<tr>
<th>Variable</th>
<th>$\beta$(SE)</th>
<th>CI (95%)</th>
<th>p value</th>
<th>Model Indices</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Moderation model 1:</strong> Caloric adherence from social support and average child seek, FEV1 (covariate)</td>
<td></td>
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</tr>
<tr>
<td>FEV1</td>
<td>-.32(.52)</td>
<td>-1.42, .78</td>
<td>.55</td>
<td>$F$-statistic</td>
</tr>
<tr>
<td>Avg. Child Seek</td>
<td>5.64(7.50)</td>
<td>-10.12, 21.41</td>
<td>.46</td>
<td>Df</td>
</tr>
<tr>
<td>Social Support</td>
<td>2.63(7.91)</td>
<td>-14.0, 19.26</td>
<td>.74</td>
<td>$R^2$</td>
</tr>
<tr>
<td>Avg. Child Seek x Social Support</td>
<td>-4.61(7.98)</td>
<td>-21.38, 12.14</td>
<td>.57</td>
<td>$f^2$</td>
</tr>
<tr>
<td><strong>Moderation model 2:</strong> Caloric adherence from social support and average child express, FEV1 (covariate)</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>FEV1</td>
<td>-.16(.48)</td>
<td>-1.16, .84</td>
<td>.74</td>
<td>$F$-statistic</td>
</tr>
<tr>
<td>Avg. Child Express</td>
<td>-3.76(7.66)</td>
<td>-19.85, 12.32</td>
<td>.63</td>
<td>Df</td>
</tr>
<tr>
<td>Social Support</td>
<td>6.33(7.78)</td>
<td>-10.01, 22.68</td>
<td>.43</td>
<td>$R^2$</td>
</tr>
<tr>
<td>Avg. Child Express x Social Support</td>
<td>-4.92(6.25)</td>
<td>-18.05, 8.22</td>
<td>.44</td>
<td>$f^2$</td>
</tr>
<tr>
<td><strong>Moderation model 3:</strong> Caloric adherence from social support and joint/options, FEV1 (covariate)</td>
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<td>FEV1</td>
<td>-.03(.46)</td>
<td>-1.00, .93</td>
<td>.94</td>
<td>$F$-statistic</td>
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<tr>
<td>Avg. Joint/Options</td>
<td>4.33(7.46)</td>
<td>-11.35, 20.01</td>
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<td>Df</td>
</tr>
<tr>
<td>Social Support</td>
<td>6.93(7.48)</td>
<td>-8.78, 22.6</td>
<td>.37</td>
<td>$R^2$</td>
</tr>
<tr>
<td>Avg. Joint/Options x Social Support</td>
<td>11.58 (7.41)</td>
<td>-4.00, 27.15</td>
<td>.14</td>
<td>$f^2$</td>
</tr>
<tr>
<td><strong>Moderation model 4:</strong> Enzyme adherence from social support and average child seek</td>
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<td></td>
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</tr>
<tr>
<td>Avg. Child Seek</td>
<td>2.56(4.34)</td>
<td>-6.60, 11.73</td>
<td>.56</td>
<td>$F$-statistic</td>
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<tr>
<td>Social Support</td>
<td>.49(4.24)</td>
<td>-8.45, 9.43</td>
<td>.91</td>
<td>df</td>
</tr>
<tr>
<td>Avg. Child Seek x Social Support</td>
<td>-7.63(4.20)</td>
<td>-16.49, 1.23</td>
<td>.09</td>
<td>$R^2$</td>
</tr>
</tbody>
</table>

| Model Indices | $f^2$ | .25 |
### Moderation model 5: Enzyme adherence from social support and average child express

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD)</th>
<th>95% CI</th>
<th>F-statistic</th>
<th>df</th>
<th>R²</th>
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</thead>
<tbody>
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<td>Avg. Child Express</td>
<td>1.91 (4.79)</td>
<td>-8.21, 12.02</td>
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<td>Social Support</td>
<td>1.91 (4.69)</td>
<td>-7.98, 11.81</td>
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<td>3, 17</td>
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<tr>
<td>Avg. Child Express x Social Support</td>
<td>-.38 (3.85)</td>
<td>-8.51, 7.75</td>
<td>.92</td>
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<td>.04</td>
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</tbody>
</table>

Note. The table displays the outcome of 6 moderation models examining the effect of DMI on caloric or enzyme adherence, as moderated by parental social support for healthy behaviors. None of the models were significant, yet the study was underpowered.
Figure 1

*Example Moderation Model*

Note. The figure shows a moderation model of the relation between adolescents' treatment decision making involvement (Child Seek) to their caloric adherence as moderated by social support for healthy behaviors. FEV1 is included as a covariate.