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The Relationship between Body Mass Index, Lung Function, and Nutrition Knowledge in Adolescents with Cystic Fibrosis

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THE RELATIONSHIP BETWEEN BODY MASS INDEX, LUNG FUNCTION, AND NUTRITION KNOWLEDGE IN ADOLESCENTS WITH CYSTIC FIBROSIS

by

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ABSTRACT

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Objective To determine the relationship between body mass index, lung function, and nutrition knowledge in adolescents with Cystic Fibrosis.

Design Baseline data were examined for participants who were given 20 minutes to complete a nutrition knowledge questionnaire.

Participants Twenty-five participants ages 13-19 with Cystic Fibrosis from the University of Tennessee Cystic Fibrosis Care and Research Center consented to enroll in the study.

Results Average age was 15.52 (SD = 2.0) and average body mass index percentile was 31 (22.81). Forty-eight percent of participants had lung function between 50-90% of the predicted forced expiratory value. There was not a statistically significant relationship between body mass index and total nutrition knowledge ($r = 0.16$; $p = 0.44$). There were statistically significant relationships involving specific nutrition knowledge questions.

Conclusion It was determined that there was no relationship between body mass index, lung function, and total nutrition knowledge, although certain questions did positively correlate.

TABLE OF CONTENTS

CHAPTER I

REVIEW OF LITERATURE

Introduction

Cystic fibrosis (CF) is a common, severe autosomal recessive disorder characterized by respiratory complications, weight loss, pancreatic insufficiency, and biliary obstruction (1). Poor weight maintenance and lung complications such as chronic cough, wheezing, and lung infections are common symptoms of cystic fibrosis. Typically, as people with CF age, weight and lung function (FEV_1 percent predicted or forced expiratory volume in one second expressed as a percent of predicted) decrease leading to more complications including malnutrition, and ultimately death from respiratory complications (2,3).

Data from the CF Foundation Patient Registry show that in 2008 adolescents with CF, ages 13 to 19, fall between the 30^{th} to 50^{th} body mass index (BMI) percentile, which when compared to same aged children without the disease is below average (4). The average BMI percentile for children without CF is the 50^{th} percentile (4). The goal of treatment is to have children and adolescents grow at the same rate as children without the disease (4).

According to studies, better nutritional status and increased weight of a cystic fibrosis patient lead to better lung function and a longer, healthier life (3,4,5). According to the 2008 CF Patient Registry, children and adolescents with a BMI greater than the 50^{th} percentile had an FEV_1 percent predicted of 90 or greater (4). Pancreatic enzyme therapy is usually necessary along with a high calorie, high fat, and high salt diet to allow

absorption of nutrients from food into the intestines, which facilitate weight gain in CF patients (2). The majority of CF patients are pancreatic insufficient (about 90%) requiring the use of oral pancreatic enzyme supplements (2).

Even though research supports the importance of nutrition intervention for CF patients, it is often hard to have nutritional and enzymatic compliance and weight gain in children with CF (2). Adherence depends on the parents and patients having maximum amounts of knowledge on proper food choices and the appropriate time to administer enzymes (2). The purpose of this study is to explore the relationship between BMI, lung function, and nutrition knowledge in adolescents with cystic fibrosis.

Nutritional Knowledge

In patients with cystic fibrosis, nutritional knowledge is crucial in the management of the disease, although pediatric patients and parents do not necessarily understand the role of nutrition. In a study published in 2000, 42 CF children ages 6 to 11 years and 55 caregivers of CF children ages 2 to 11 years were given nutritional knowledge questionnaires (1). The researchers found that a high proportion of pediatric patients and caregivers (34 out of 42 and 50 out of 55, respectively) knew the accurate amount of pancreatic enzymes needed and when the enzymes were to be administered (1). However, when it came to knowledge about fat content of food the subjects could not differentiate between two meals containing considerably different amounts of fat (1). Using the results of this study, nutrition education interventions may be useful in providing patients and caregivers more detailed nutritional knowledge for the appropriate care of CF.

A 2001 study examined nutritional knowledge of children ages 2 to 11 years who had CF. The children were randomly assigned to participate in a nutrition intervention group or control group to determine if nutritional and enzyme knowledge was increased (2). There were six steps implemented each week to help the children use their nutritional knowledge (2). Validated questionnaires evaluating nutritional knowledge and self-management were used three times during the trials (2). The self-management questions were mostly open ended questions asking "What would you do if this happened?" (2). In both the intervention ($p=.02$) and control ($p=.03$) groups, the children's knowledge was better when the child had an appropriate self-management score (2). The study also found that immediately after the intervention there was an improvement in the children's knowledge ($p=.001$) (2). The study concluded that long-term education may be important to retain knowledge (2). These two studies show that it is important to consistently provide nutrition education interventions to children with CF over long periods of time to encourage the retention of nutritional knowledge.

Nutritional Status and Behavior

Behavioral and nutritional interventions have been shown to improve weight in CF children ages 18 to 48 months (6). According to a pilot study published in 2005, with 10 CF participants between the ages of 18 to 48 months, the nutrition and behavior intervention group reported a significantly higher mean of energy intake per day compared with the control group ($p=.011$) (6).

Powers et al. examined the eating behavior and caloric intake of infants and toddlers with CF (7). Calorie intake was measured by a video taping of the meals and

behavior was measured by a questionnaire for the caregiver (7). In regard to the amount of food eaten, the CF children ate 103% of the Recommended Daily Allowance (RDA) calories per kilogram (kg) compared to the control children who ate an average of 88% of the RDA calories per kg (7). However, the amount the CF children consumed was still not an adequate amount for the increased energy requirements of their disease state (7). The duration of selected meals was found to be longer for CF children versus the healthy age-related control children ($p=.03$; CF: $M=20.2$ minutes, $SD=7.3$ and Control: $M=16.4$ minutes, $SD=6.2$) (7). The CF caregivers reported having more problematic mealtime behaviors than the control caregivers and there was a positive correlation (0.29; $p=.03$) between number of problems and meal length (7). The study shows that behavior of CF children compared to control children is different regarding meal length and behaviors (7). This population may benefit from nutritional education; however, that may be challenging as a result of the children's young age.

Despite the similarities between eating behaviors in adults and children with CF, the children and adults face different issues. Children tend to have more meal time eating behavior problems and adults have more body image related issues (7,8). A 2006 study evaluated the relationship between nutritional status and body image in an adult CF population (8). The CF subjects in the study felt significantly more pressure from others to eat ($p<.006$ to $p<.001$) (8). The research found that nutritional status of adults with CF was related to eating attitudes, body satisfaction, and quality of life along with the age, lung function, BMI, and height (8). The researchers felt that this study may benefit a younger population in order to maximize growth potential (8). Intervening in a younger population may allow the CF patients to reach their peak height and weight.

Weight and Lung Function

In cystic fibrosis, increased weight is shown to improve and increase lung function. Severity of lung disease in CF is determined by FEV_1 percent predicted (4). The FEV_1 percent predicted is derived from healthy, non-smoking people of the same age and gender (4). Normal lung function is an FEV_1 percent predicted of 90 or greater (4). The 2008 CF Patient Registry found that children and adolescents with a BMI greater than the 50^{th} percentile had an FEV_1 percent predicted of 90 or greater (4). The positive relationship between BMI and lung function shows the importance of having a BMI greater than the 50^{th} percentile, and BMI may be increased with appropriate amounts of nutrition knowledge.

In a 2000 study evaluating the CF Foundation National CF Patient Registry data of children aged 5 to 8, found that early diagnosis and nutrition related interventions result in greater weight gain and length through age ten (3). The study supports finding a relationship between nutrition knowledge and BMI, which could potentially show that having more nutrition knowledge could play a beneficial role in keeping CF children healthy. The analysis of the data also supports that with increased nutritional status (BMI) better lung function results (3). The higher weights also decrease pulmonary infection and slow deterioration in lung function (3).

Nutrition Care Practices

The recent standards set by the Cystic Fibrosis Foundation (CFF) are intended to improve the quality of life in CF patients. The new standards of practice set by CFF include using BMI to assess nutritional status (9). A study conducted in 2008 examined

the use of the new standards in CF clinics around the United States (9). The study found it to be unclear if changing to BMI from percent ideal body weight (%IBW) in CF clinics could actually reduce malnutrition rates (9). According to the collected data, the CFF change from using %IBW to the BMI goal of above the 50th percentile on the Centers for Disease Control and Prevention (CDC) Growth Charts caused an increase in reported malnutrition (9,10,11). The change from %IBW to BMI was necessary since %IBW misclassifies tall people as being underweight (9). The CFF recommendations are found in an article published in 2008, which also state that people with CF are underweight with a BMI of 18.5 or less (10). The study found that malnutrition should be evaluated by other means in addition to using BMI including abnormal status of fat-soluble vitamins and essential fatty acids (9). The research shows that greater nutritional knowledge could possibly benefit patients and clinics by decreasing the number of patients with malnutrition when nutritional status is assessed with BMI.

Correlates of BMI, Lung Function, and Nutrition Knowledge

According to a study evaluating health profile scores and physiology in adults with cystic fibrosis, no correlation was found between the health profile scores and BMI or FEV_1 percent predicted (12). Although there were no correlations found in this study, it shows the need to determine if there is a relationship in adolescents with CF between BMI, lung function, and nutrition knowledge.

An additional study, by van Dillen et al., comparing nutrition awareness and nutrition behaviors in 603 Dutch participants ages 18-80, found that people with higher nutrition knowledge tended to eat more healthy food (26% vs. 11%), where people with

lower nutrition knowledge tended to eat more of foods that tasted good (52% vs. 42%) (13).

The van Dillen study is similar to a study by Campbell et al., which gave 558 adult participants a tailored nutrition intervention or a non tailored nutrition intervention, and found that with the new knowledge received from the intervention produced a greater weight loss than the participants who did not receive an intervention (23% vs. 9%) (14). Although, the Campbell study deals with weight loss, it does support finding a positive relationship between BMI and nutrition knowledge whether it is for weight loss or weight gain.

In the van Dillen study, people with high nutrition awareness were found to be more involved with nutrition ($F = 187.3$, $P = 0.00$) and sought more information about nutrition ($F = 8.1$, $P = 0.01$) (13). This also supports the idea that adolescents with CF should have an increased BMI and lung function with increased nutrition knowledge, since with the increased nutrition knowledge they would care about having a healthy weight above the 50^{th} percentile and achieving better lung function (10).

Conclusion

In summary, the literature suggests that in order to successfully live with CF, patients and their parents need to have high levels of nutritional knowledge (2). Determining if there is a relationship between nutritional knowledge, BMI, and lung function could improve therapy compliance and knowledge of CF (2). Due to the importance of having increased BMI and lung function in CF patients, it is necessary to examine if nutritional knowledge plays a role in BMI and lung function. Nutrition

education may be needed at some point to promote knowledge in the adolescents with CF, since the person is in a transitional period of gaining more independence from the parents.

There are minimal studies relating BMI and lung function to nutritional knowledge in people with CF, and none with adolescents. Most studies conducted in CF use young children or adults as subjects. Adolescence is an important time in people with CF because it is the transition from the parents managing the disease to the child. This stage of life is a prime time to intervene because it can be tracked into adulthood. The overall finding of the current research is that having increased knowledge about nutrition from education may help to improve nutrition status, knowledge and weight at least while the nutrition education programs are in place (1, 2, 5, 6, 13). Therefore, the purpose of this study is to explore the relationship between BMI, lung function and nutrition knowledge in adolescents with cystic fibrosis.

CHAPTER II

METHODOLOGY

Research Design

This study examined baseline data for 13-19-year-old participants with CF who attended a nutrition education program. Prior to the start of the program, relationships were examined among BMI, lung function, and nutrition knowledge.

Participant Selection

Participants were recruited from the University of Tennessee (UT) CF Care and Research Center, which follows approximately 110 children. The goal was to recruit 25-30 study participants. Inclusion criteria included adolescent patients between the ages 13 to 19 years old seen in the CF clinic, who gave consent (including parent if under 18 or participant only if over 18).

Procedures

The study was approved by the Institutional Review Boards at The University of Memphis and The University of Tennessee/LeBonheur Children's Hospital. Participant recruitment started on the first Thursday of March, 2010. After consent was received, the participants completed a CF questionnaire.

On Study Visit 1, after consent was obtained, participants were asked by a qualified Graduate Student (GS) and/or Registered Dietitian (RD) to complete a previously verified CF Questionnaire in their exam room without assistance. The GS and/or RD read a previously scripted paragraph explaining the questionnaire to the

participant. The participants had 20 minutes, timed by a GS and/or RD, to complete the questionnaire.

Nurses and respiratory therapists collected the participant's weight, height, BMI, and lung function (FEV_1 percent predicted) during clinic visits. The participant's age, gender, race, insurance, and residence were determined from the participant's records. BMI percentile was found using the CDC growth charts with the participants' calculated BMI from height and weight measurements.

There were no known risks to participants who participated in the study.

Measurements

Measurements used in this study consisted of participant demographics, a CF knowledge questionnaire, weight, height, BMI/BMI percentile, and lung function. These data were used to better evaluate the participants.

Demographics

Demographic information included gender, age, race, type of insurance, and residence. Nurses and nurse assistants collected this data during each participant's first visit to the LeBonheur/UT CF clinic, and entered into a computer database. The demographic information was updated in the computer database when changes occurred. This study obtained demographic information from the participant's records in the computer database.

CF Questionnaire

The CF questionnaire used to assess nutrition knowledge was originally created and verified by Kristen K. Marciel, PhD and Alexandra Quittner, PhD of the University of Miami. The questionnaire was later reviewed and adjusted by the CF team at the LeBonheur/UT clinic. After adjustments from the LeBonheur/UT CF team, the questionnaire was given to a few patients in the clinic to test accuracy. The questionnaire contained 14 nutrition-related questions and 46 total questions regarding CF care. Other sections of the questionnaires included lung health, general cystic fibrosis health, and treatments. Only the nutrition-related questions were used for evaluation and data collection.

Height

Height was collected at the beginning of each clinic visit by a nursing assistant. The height was measured with a calibrated wall measure. The height was then entered into the computer database.

Weight

Weight was also collected at the beginning of each clinic visit by a nursing assistant using a calibrated scale. The weight was then entered into the computer database.

BMI/BMI Percentile

BMI was calculated by the computer database where the weight and height were stored. BMI was then recalculated by the graduate student to verify the number. The calculation is as follows: kilograms/meters^2. Once BMI was calculated and verified, the online CDC growth chart percentile calculator was used to determine the participant's specific BMI percentile.

Lung Function

Lung function tests were performed by the respiratory therapists during each clinic to determine the forced expiratory volume of the lungs versus the predicted. Results were then recorded and saved in the computer database. Lung function results for this study were collected from the participant's computer database records.

Statistical Analysis

Analyses were conducted using SPSS version 15.0 for Windows ("SPSS for Windows, Rel. 15.0.1.," 2006). Cross-sectional baseline data were analyzed from 25 13- to 19-year-old cystic fibrosis patients being recruited for a nutrition education program. Descriptive statistics conducted included frequencies, percentages, means, and standard deviations on gender, race, age, residence, insurance, BMI, BMI percentile, lung function, and 14 nutrition-related questions from the CF questionnaire. Of the 14 questions from the nutrition section of the CF questionnaire, the questions that contained multiple answers were broken into individual questions for analysis creating a total of 18

correct answers. The relationship between BMI, BMI percentile, lung function, and nutrition knowledge were examined using Pearson correlations.

CHAPTER III

RESULTS

Descriptive Results

Out of 29 adolescents approached to participate in the study, only 25 consented to participate. Among the 25 participants, 52% (n = 13) were female, 48% (n = 12) were male, 88% (n = 22) Caucasian, and 12% (n = 3) African Amercian. Sixty percent (n = 15) of subjects lived in TN, while 40% (n = 10) were from MS. Sixty-four percent (n = 16) of subjects had private insurance and 36% (n = 9) had public. Out of the 25 subjects 12% (n = 3) had lung function (FEV_1 percent predicted) greater than 100%, 20% (n = 5) had lung function (FEV_1 percent predicted) between 90 and 100%, 48% (n = 12) had lung function (FEV_1 percent predicted) between 50 and 90%, and another 20% (n = 5) had lung function less than 50%.

Mean BMI was 19.1 (SD = 1.64), while the mean BMI percentile was 31 (SD = 22.81) on the Center for Disease Control Growth Charts. The average age was 15.52 (SD = 2.002), and nutritional knowledge scores had a mean of 12.56 (SD =2.599). Table 1 shows the demographics of the study participants.

Table 1. Participant's Demographics

Variable	Data
Demographic (continuous); mean, (std. dev)	
Age	15.52 years (2.0)
BMI	19.1 kg/m^2 (1.64)
BMI percentile	31(22.81)
Total Nutritional Knowledge	12.56 out of 18 (2.6)
Demographic (categorical); *n*, (%)	
Lung Function FEV_1% predicted)	
>100%	3(12)
90-100%	5(20)
50-90%	12(48)
<50%	5(20)
Gender	
Male	12 (48)
Female	13 (52)
Ethnicity	
Caucasian	22 (88)
African American	3 (12)
Insurance	
Private	16 (64)
Public	9 (36)
Residence	
Tennessee	15 (60)
Mississippi	10 (40)

Correlations

There was not a statistically significant relationship between BMI percentile and nutrition knowledge based on the total score from the knowledge survey ($r = 0.16$; $p = 0.44$). Lung function and total nutrition knowledge also did not show a statistically significant association ($r = 0.08$; $p = 0.72$). However, there was a significant positive relationship between BMI percentile and whether the participants knew that teens with

CF eat more because their metabolism is faster ($r = 0.41$; $p = 0.04$). In other words, as BMI percentile increased the participants increased knowledge of metabolism in CF patients. In addition, lung function was positively associated with whether the participant knew calories provided energy for growth ($r = 0.4$, $p = 0.05$), and if the participant knew extra calories for teens with CF could come from tube feedings ($r = 0.4$, $p = 0.05$). Moreover, as lung function increased the participants had greater knowledge of energy needed for growth in the CF population. Another statistically significant correlation was as lung function decreased so did the BMI percentile ($r = 0.52$, $p = 0.001$). See Table 2 for results.

Table 2. Correlations

	BMI %	FEV_1%	Age	NKQ 5	NKQ 9b	NKQ 14b	Total Nutrition Knowledge
BMI Percentile							
Lung Function (FEV_1% predicted)	-0.52**						
Age	-0.49*	0.41*					
NKQ 5	-0.13	0.40*	0.26				
NKQ 9b	0.41*	-0.19	-0.05	0.2			
NKQ 14b	0.01	0.40*	-0.08	0.17	0.03		
Total Nutrition Knowledge	0.16	0.08	0.08	-0.12	0.29	0.40*	

* sig. at the 0.05 level (2-tailed)
**sig. at the 0.001 level (2-tailed)
NKQ = Nutrition Knowledge Question

CHAPTER IV

DISCUSSION

The purpose of this study was to determine if there were any relationships between BMI, lung function, and disease specific nutrition knowledge. Until this investigation there was no research on adolescents with CF and knowledge of nutrition.

Characteristics of the Sample

The demographics show findings similar to known facts about CF. The sample was split almost evenly between males and females (48% vs. 52%). CF is known to affect more Caucasian people than any other ethnicity, which was shown in this study's sample (88% Caucasian). More people had private (64%) insurance than public (36%), and more participants were from Tennessee (60%) than Mississippi (40%). The mean BMI percentile of 31 was considerably lower than the CF guidelines of greater than the 50^{th} percentile to promote better lung function (10). Lung function and the BMI percentile were negatively correlated ($r = 0.52$, $p = 0.001$), which matches previous research (3).

Relationship between BMI, Lung Function, and Total Nutrition Knowledge

Comparable to the article published in 1998 relating a health score to the overall health of adult participants with CF (10), there was no significant relationship found. The finding of no relationship between BMI, BMI percentile, or lung function and nutritional knowledge differs from the findings of the 2006 article by Abbott et al. In the Abbott article a relationship between BMI, lung function, and nutritional status was found (8).

This shows a need for further intervention possibly including some type of nutrition education intervention to prevent poor nutrition status found in the Abbott article.

Previous studies, including the one by Stapleton et al. in the Journal of the American Dietetic Association, have shown that nutritional knowledge is important for children and parents with CF (1). However, data found in the present study is dissimilar to Stapleton's data in that there is no relationship between the amount of nutrition knowledge in adolescents and their BMI or lung function due to BMI and lung function not being examined and the subjects were ages 2-11.

Relationship between BMI, Lung Function, and Specific Nutrition Knowledge

Although there was no relationship between total knowledge of nutrition and BMI, a positive correlation was found when the BMI percentile was related to whether the participant knew that people with CF have a faster metabolism ($r = 0.41$; $p = 0.04$). This indicates that the more the patients know about having an increased metabolism, the higher the BMI percentile. The above relationship is consistent with the findings from the van Dillen, et al. study since it found that the people with greater nutrition knowledge were more concerned and involved with nutrition (13).

Additionally, there also were no relationships found between total nutrition knowledge and lung function, but there were two specific questions that showed positive correlations. If the participants knew that calories were needed for growth ($r = 0.4$, $p = 0.05$) and that tube feedings ($r = 0.4$, $p = 0.05$) could provide extra calories for growth, the participants had better lung function. These findings are also supported by the van Dillen and Campbell studies, since if the participant had a greater understanding of

nutrition they were more likely to be concerned about nutrition and take action towards their health (13, 14).

Due to the fact that there were relationships with specific, more challenging questions versus all the questions as a whole indicates that more challenging questions may be needed in order to a link between BMI, lung function, and nutrition knowledge.

Limitations

There were limitations that could have affected the results. The greatest limitations of the study were the small sample size (n = 25) and the short amount of time to recruit participants (three months). The small sample size was unable to obtain a significant relationship with total nutrition knowledge in this study, which may not fully represent the wider CF population. Increasing participants may have more power, and therefore show a statistical significance. Recruiting participants from only one CF clinic may have had an impact on the results as well. The participants from the clinic all received the same education from the same CF clinic team, which may also skew the results. Also, controlling for the prognosis of the disease could be examined because decreased prognosis could indicate a decreased BMI.

To better determine the factors that play a role in BMI and lung function other areas besides nutrition knowledge need to be examined. The study being of a cross-sectional design in limited in the fact it only shows a snapshot of the sample. Cross-sectional studies are for the most part generalized and do not focus on specifics. This leads the study to have multiple factors that could potentially alter the results. In order to create a better study, each factor needed to be analyzed in more depth to determine other

if there could be other relationships. A specific intervention, for example nutrition education, in this population may decrease the extraneous factors that could have lead to the minimal statistically significant results.

Conclusion

Overall, this study determined there were no relationship among BMI, lung function, and total nutrition knowledge. Although no relationship was found with total nutrition knowledge, certain questions did positively relate to BMI percentile and lung function, which may show that more advanced nutrition questions could produce a different outcome. If the adolescents could answer the more advanced nutrition questions correctly, it could show a greater understanding of the disease, possibly promoting increased nutritional management in adolescents with CF. Studies in the past have shown that people with more nutritional knowledge care more about their nutritional status (13). This also relates to the sample in that most of the participants are in high school or have graduated from high school, which means the questions need to be more challenging to promoting thinking. It would be interesting to examine other scenarios using this questionnaire or another more advanced questionnaire with nutrition education as an intervention. Further research is needed in the area of nutrition knowledge and education in adolescents with CF to better determine if there is a link with total health.

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APPENDIX A

Paragraph to be read after consent is obtained:

This questionnaire is about cystic fibrosis. It contains four sections including general cystic fibrosis health, nutrition, lung health, and treatments. Please circle the best possible answer. You will have 20 minutes to complete the survey. Survey results will remain confidential after this study. Thank you for your participation in this research study.

APPENDIX B

Nutrition Knowledge Questionnaire

I. Nutrition

1. Most of the food you eat is absorbed in the:
    a. intestines
    b. stomach
    c. liver

2. Stomach cramps and gas are signs :
    a. that your body was not able to absorb the nutrients from food
    b. of hunger
    c. of lack of vitamins

3. If you are not digesting fat from the foods you eat, your stools/bowel movement may:
    a. sink
    b. not change
    c. float

4. If you notice that you are going to the bathroom more often and have stomach aches nearly everyday:
    a. you may need to eat less food
    b. you should discuss this with the CF Team because you may need to change your enzymes
    c. you will just have to learn to live with it

5. The energy we need for growth and activities comes from:
    a. water
    b. sun
    c. calories
    d. hanging out with your friends

6. The foods that contain the most energy/calories come from:
    a. fats
    b. carbohydrates
    c. proteins
7. Meat, beans, and eggs are good sources of:
    a. carbohydrates
    b. proteins
    c. fats

8. Teens with CF should eat about:
    a. 125-150% of the recommended amount of food for teens without CF
    b. the same amount of food as teens without CF
    c. three times the amount of food as teens with CF

9. Teens with CF may eat more because: (circle all that apply)
    a. some energy is lost through problems absorbing foods
    b. their metabolism (process of turning food into energy) is faster
    c. they have to fight off infections
    d. their appetites are naturally bigger

10. People with CF should eat _____ snack(s) per day:
    a. none
    b. one
    c. 2-3
    d. More than 10

11. People with CF take vitamins A, D, E, and K because:
    a. these vitamins need extra water to be absorbed
    b. these vitamins are not found in foods that people normally eat
    c. these vitamins are often poorly absorbed

12. One way to add calories to scrambled eggs is:
    a. mix them with 2% milk instead of whole milk
    b. add salt and pepper
    c. add grated cheese
    d. cook them longer

13. Your CF Team is always talking about your BMI (Body Mass Index): (Circle all that apply)
    a. Your BMI should be the same as your age
    b. Your BMI should be between 10-25%
    c. Your BMI should be more than 50%
    d. Your BMI comes from measuring your height and weight

14. Teens with CF need extra calories so their bodies can mature and develop. Where do extra calories come from? (Circle all that apply)
    a. vegetables
    b. high calorie shakes
    c. tube feedings
    d. soda/pop

II. Pulmonary Health

1. You have lots of organs in your body. The one organ CF affects the most is your:
    a. lungs
    b. brain
    c. heart
    d. liver

2. CF causes:
    a. dry, thin mucus
    b. less mucus to form in the lungs
    c. thick, sticky mucus

3. Changes in your mucus, cough, or energy level:
    a. should be watched, but not reported to the CF nurse
    b. suggest that you should exercise more
    c. may indicate the start of an infection

4. What are the <u>early</u> signs of a pulmonary exacerbation (lung infection)?
    a. fever, cough, fast breathing
    b. chest pain, shortness of breath
    c. blue color around your nails and lips
    d. cough, increased sputum (mucus)

5. What is the best way to treat a pulmonary exacerbation (lung infection)?
    a. antibiotics
    b. airway clearance
    c. aerosols
    d. all of the above

6. How soon should one start antibiotics for a pulmonary exacerbation (lung infection)?
    a. when you lose lots of weight
    b. after two weeks of cough, shortness of breath, poor appetite and wheezing
    c. with several early signs of a pulmonary exacerbation

7. If you cough up a small amount of new blood on a Friday night, which should you do?
    a. do your aerosol and airway clearance
    b. call the CF nurse on Monday morning
    c. call the CF doctor on-call at your hospital
    d. call your pediatrician

8. The CF bacteria in your lungs will always be killed with antibiotics:
    a. True
    b. False

9. The key to slowing/preventing lung damage in CF is to be aware of and treat lung infections early.
    a. True
    b. False

10. Which of the following are things you can do to decrease the number of lung infections you get? (Circle all that apply)
    a. Stay away from people who are sick
    b. Make sure you keep up with your airway clearance
    c. Stay away from tobacco smoke
    d. Wash your hands
    e. Get a flu shot

11. Your CF Team can find out if you have a lung infection by:
    a. doing a PFT (pulmonary function test)
    b. listening to your lungs
    c. asking questions
    d. getting a sputum/mucus sample
    e. all of the above

III. CF Health

1. Exercise, especially in the summer, can cause a decrease in the salt and water in your body. What should you do?
    a. take extra salt
    b. drink more water
    c. take extra salt and water

2. You are having trouble with frequent bowel movements, gas and weight loss. Who would be the best person to discuss this with? (Circle all that apply)
    a. the social worker
    b. the doctor
    c. the dietitian
    d. the nurse

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3. Exercise builds strength in the muscles used for breathing.
    a. True
    b. False
    c.

4. Stress (lots of homework, problems with a friend or family member) affects your: (Circle all that apply)
    a. sleep
    b. eating
    c. hearing
    d. mood
    e. health

5. Stress affects your:
    a. stomach
    b. head
    c. kidneys

6. When you feel stress, it helps to: (Circle all that apply)
    a. listen to music
    b. ignore it
    c. talk to someone who cares about you
    d. act out (yelling, hitting)

7. Being open and talkative with your CF Team is important because: (Circle all that apply):
    a. the team needs information from you
    b. they are nosey about your life
    c. you know the most about your body
    d. it helps your clinic visits go faster
    e. you have a better relationship with them

8. To avoid missing things at your clinic visit, you could: (Circle all that apply)
    a. ask your CF Team to write down what you need to know
    b. ask questions if you don't understand something
    c. write down your questions before going to your clinic visit
    d. keep a journal or write down changes in your health or treatments

9. To keep you from getting new CF bacteria in your lungs, you should:
    a. not hang out with other people with CF
    b. cough into tissues and throw away
    c. wash your hands a lot
    d. all of the above

10. Your CF Team will check your blood sugar (glucose) because people with CF have a higher chance of having diabetes.
    a. True
    b. False
    c.

IV. Treatments

1. Airway clearance:
    a. makes your body produce more mucus
    b. removes mucus from your lungs
    c. should be done only when you feel sick
    d. should only be done in the morning

2. Exercise can always be done instead of airway clearance.
    a. True
    b. False

3. Pulmonary Function Tests (PFTs) are a fancy name for tests that:
    a. show the CF Team that you are taking your enzymes
    b. show how your lungs are working
    c. only need to be done once in a while

4. Timing is everything, especially when it comes to taking inhaled antibiotics. They generally work best if done.
    a. before airway clearance
    b. after airway clearance
    c. in the morning

5. Bronchodilators (albuterol) are used to:
    a. remove mucus
    b. control bacteria
    c. open your airways
    d. clear up a stuffy nose

6. With CF, coughing
    a. is important to clear mucus from your lungs
    b. gives CF to other people
    c. is OK to control with cough medicines
    d. tires you and you should not do it

7. What is true about cleaning your nebulizer?
    a. clean it once a week
    b. have your Mom do it
    c. put it in the dishwasher or boil for 5 minutes
    d. wash with vinegar and water

8. It is best to take enzymes:
    a. as soon as you remember
    b. at the beginning of a snack or meal
    c. once a day
    d. after eating

9. Enzymes should be kept in a cool, dark place.
    a. True
    b. False

10. Large amounts of undigested food will pass through your digestive system if you have:
    a. too many enzymes
    b. too few enzymes
    c. the right amount of enzymes

11. It is OK to skip your everyday medicines when you are feeling good.
    a. True
    b. False.

APPENDIX C

Answers to Nutrition Knowledge Questionnaire

I. Nutrition

1. Most of the food you eat is absorbed in the:
   a. **Intestines –**
   Food is broken down in the stomach, but it is absorbed in the intestine. The small intestine is where the most of absorption and digestion take place. The small intestine is where the enzymes are activated and work to help your body absorb nutrients.
   b. stomach
   c. liver

2. Stomach cramps and gas are signs of:
   a. that your body was not able to absorb the nutrients from food - Stomach cramps, gas, frequent bowel movements, and oil in the bowel movements are all signs that you are not adequately absorbing the nutrients in food.
   b. hunger
   c. lack of vitamins

3. If you are not digesting fat from the foods you eat, your stools/bowel movement may:
   a. sink
   b. not changes
   c. float –
   Not absorbing adequate amounts of fat from food causes stool to float due to the excess gas in the stool.

4. If you notice that you are going to the bathroom more often and have stomach aches nearly everyday:
   a. you may need to eat less food
   b. you should discuss this with the CF Team because you may need to change your enzymes –
   Stomach pain and increased bowel movements may indicate that the dose or type of enzyme may need to be adjusted. Do not decrease or increase your enzyme dose without talking with the CF office or CF dietitian.
   c. you will just have to learn to live with it

5. The energy we need for growth and activities comes from:
    a. water
    b. sun
    c. <u>calories</u> – The calorie is the standard measurement for the energy that is contained in food. Almost all foods contain calories. Exceptions are water, tea without sugar, coffee without sugar or cream, sugar-free gelatin, and other sugar-free flavored beverages. Fat, carbohydrates, and protein all contain calories.
    d. hanging out with your friends

6. The foods that contain the most energy/calories come from:
    a. <u>Fats</u> – Fat, carbohydrates, and protein all contain calories. Fat is the highest in calories, and therefore, has the most energy. A diet high in fat causes weight gain.
    b. carbohydrates
    c. proteins

7. Meat, beans, and eggs are good sources of:
    a. carbohydrates
    b. <u>protein</u> – Protein is used to build muscle and repair tissue. The body needs adequate protein to grow.
    c. fat

8. Teens with CF should eat about:
    a. <u>125-150% of the recommended amount of food for teens without CF</u> – Research has shown that boys and girls with CF need at least 125 – 150% of people without CF. This means that you will need to eat 25 – 50% more that someone else you size and age to meet your energy/calorie needs.
    b. the same amount of food as teens without CF
    c. three times the amount of food as teens with CF

9. Teens with CF may eat more because: (circle all that apply)
    a. <u>some energy is lost through problems absorbing foods</u>
    b. <u>their metabolism (process of turning food into energy) is faster</u>
    c. <u>they have to fight off infections</u>
    Even though you may be taking enzymes, they are not perfect and there will always be a small amount of nutrients that are not absorbed by the intestine.
    Your lungs are working harder to breathe, which means that your body needs more calories to meet the body's energy needs.
    The body to uses energy to fight off infection and fever. This energy comes from the food you eat.
    d. their appetites are naturally bigger

10. People with CF should eat _____ snack(s) per day:
    a. none
    b. one
    c. <u>2-3</u> – In order to meet the energy/calorie needs for CF, you should eat 2 to 3 snacks per day in addition to 3 meals per day. Boys and girls with CF who's body mass index (BMI) is at the 50th percentile or above eat 3 meals and 2 – 3 snacks per day in order to achieve this weight gain.
    d. More than 10

11. People with CF take vitamins A, D, E, and K because:
    a. These vitamins need extra water to be absorbed
    b. These vitamins are not found in foods that people normally eat
    c. <u>These vitamins are often poorly absorbed</u> – Even though you may eat foods that contain vitamins A, D, E, and K, they are not well absorbed in the body. As previously mentioned, nutrients, which include these vitamins, need digestive enzymes in order to be absorbed in the intestine. Even though you take enzymes, they are not perfect and will result in low vitamin levels if you do not take a CF vitamin.

12. One way to add calories to scrambled eggs is:
    a. mix them with 2% milk instead of whole milk
    b. add salt and pepper
    c. <u>add grated cheese</u> – Cheese is not only delicious, but it is also high in calories and fat. Adding cheese to eggs, sandwiches, crackers, macaroni, and other foods increases the energy and fat of those foods.
    d. cook them longer

13. Your CF Team is always talking about your BMI (Body Mass Index): (Circle all that apply)
    a. It should be the same as your age
    b. Should be between 10-25%
    c. <u>Should be more than 50%</u> - Research shows that a body mass index (BMI) at the 50th percentile or above is associated with better lung health. In fact, a higher BMI = better lung function!

    d. <u>Comes from measuring your height and weight</u> – Body Mass Index (BMI) is when we compare your weight to your height. The taller you are, the more you should weigh.

14. Teens with CF need extra calories so their bodies can mature and develop. Where do extra calories come from? (Circle all that apply)
    a. vegetables
    b. <u>high calorie shakes</u> (store-bought or homemade – Milkshakes, Blizzards (Dairy Queen), Boost, Ensure, and protein shakes are all high in calories and will help maintain or increase weight gain.
    c. <u>tube feedings</u> – Tube feedings are a great alternative for people who do not enjoy high fat foods or high calorie beverages. The tube feeding is started at bed time and is stopped in the morning.
    d. soda/pop

V. Pulmonary Health

1. You have lots of organs in your body. But the one organ CF affects the most is your:
    a. **<u>Lungs</u>**
    b. brain
    c. heart
    d. liver

2. CF causes:
    a. dry, thin mucus
    b. less mucus to form in the lungs
    c. **<u>thick, sticky mucus</u>: The main problem with cystic fibrosis is the thick, sticky mucus in the body and especially the lungs.**

3. Changes in your mucus, cough, or energy level:
    a. should be watched, but not reported to the CF nurse
    b. suggest that you should exercise more
    c. **<u>may indicate the start of an infection</u>: Some symptoms of lung infections are increased cough, increase in amount or change in color of mucus (phlegm/sputum), decreased energy level, decreased appetite, decreased lung function, or loss of appetite.**

4. What are the <u>early</u> signs of a pulmonary exacerbation (lung infection)?
    a. fever, cough, fast breathing
    b. chest pain, shortness of breath
    c. blue color around your nails and lips
    d. **<u>cough, increased sputum (mucus)</u>: Fever, fast breathing, chest pain, shortness of breath, blue color around your nails and lips are all later signs of a serious lung infection.**

5. What is the best way to treat a pulmonary exacerbation (lung infection)?
    a. antibiotics
    b. airway clearance
    c. aerosols
    d. **all of the above: Antibiotics kill bacteria in the lungs, airway clearance clears the mucus from the lungs, and aerosols (like hypertonic saline and albuterol) to open the airways and help clear the mucus.**

6. How soon should one start antibiotics for a pulmonary exacerbation (lung infection)?
    a. when you lose lots of weight
    b. after two weeks of cough, shortness of breath, poor appetite and wheezing
    c. **with several early signs of a pulmonary exacerbation (cough, increase sputum, decreased PFTs): The earlier the treatment for lung infection, the better the response and the quicker the recovery of lung function.**

7. If you cough up a small amount of new blood on a Friday night, which should you do?
    a. Do your aerosol and airway clearance
    b. Call the CF nurse on Monday morning
    c. **Call the CF doctor on-call at your hospital: New blood in the mucus/sputum needs urgent medical attention. Your CF doctor would be the best person to contact.**
    d. Call your pediatrician

8. The CF bacteria in your lungs will always be killed with antibiotics:
    a. True
    b. **False: Antibiotics do not completely rid the lungs of bacteria, but they do decrease their numbers.**

9. The key to slowing/preventing lung damage in CF is to be aware of and treat lung infections early.
    a. **True**
    b. False

10. Which of the following are things you can do to decrease the number of lung infections you get? (Circle all that apply)
    a. **<u>Stay away from people who are sick</u>: Even normal colds and viruses can affect the lung function of people with CF.**
    b. **<u>Make sure you keep up with your airway clearance</u>: Airway clearance is one of the most important ways to keep your lungs clear and it has to be done regularly in order to be effective.**
    c. **<u>Stay away from tobacco smoke</u>: Both active and secondhand smoking has been shown to damage lungs in CF.**
    d. **<u>Wash your hands</u>: Germs are spread by most commonly by hand contact.**
    e. **<u>Get a flu shot</u>: The flu shot does not give you the flu. The flu is a serious infection in patients with CF that can effectively prevented by the flu shot.**

11. Your CF Team can find out if you have a lung infection by:
    a. doing a PFT (pulmonary function test)
    b. listening to your lungs
    c. asking questions
    d. getting a sputum/mucus sample
    e. **<u>all of the above</u>: When you have a lung infection, your pulmonary function worsens, lung sounds may change, and we may find a new bacterial infection in your lungs.**

VI. CF Health

1. Exercise, especially in the summer, can cause a decrease in the salt and water in your body. What should you do?
    a. take extra salt
    b. drink more water
    c. **<u>take extra salt and water</u> – People with CF excrete more salt than people without CF. Although we see it everywhere and don't really think about it, but salt is actually an important nutrient and is needed for hydration. Water and salt are *both* important for hydration.**

2. You are having trouble with frequent bowel movements, gas and weight loss. Who would be the best person to discuss this with? (Circle all that apply)
    a. the social worker
    b. **<u>the doctor</u>**
    c. **<u>the dietitian</u>**
    d. **<u>the nurse</u>**

    The doctor, dietitian, or nurse can help you if you have symptoms of weight loss, frequent bowel movements, or gas.

3. Exercise builds strength in the muscles used for breathing.
    a. True
    b. **False: When you exercise, your breathing muscles are not necessarily strengthened, but you breathe deeper, improve your ability to exercise, and improve your mucus clearance.**

4. Stress (lots of homework, problems with a friend or family member) affects your: (Circle all that apply)
    a. **sleep**
    b. **eating**
    c. hearing
    d. **mood**
    e. **health**

5. Stress affects your:
    a. **Stomach: You might experience stomach pain when you are stressed.**
    b. **Head: You might have a headache if you are stressed.**
    c. kidneys

6. When you feel stress, it helps to: (Circle all that apply)
    a. **Listen to music**
    b. Ignore it
    c. **Talk to someone who cares about you**
    d. Act out (yelling, hitting)

7. Being open and talkative with your CF Team is important because: (Circle all that apply):
    a. **the team needs information from you**
    b. they are nosey about your life
    c. **you know the most about your body**
    d. it helps your clinic visits go faster
    e. **you have a better relationship with them**

8. To avoid missing things at your clinic visit, you could: (Circle all that apply)
    a. **ask your CF Team to write down what you need to know**
    b. **ask questions if you don't understand something**
    c. **write down your questions before going to your clinic visit**
    d. **keep a journal or write down changes in your health or treatments**

9. To keep you from getting new CF bacteria in your lungs, you should:
    a. not hang out with other people with CF
    b. cough into tissues and throw away
    c. wash your hands a lot
    d. **all of the above**

10. Your CF Team will check your blood sugar (glucose) because people with CF have a higher chance of having diabetes.
    a. **True – The older you are with CF the higher your chances are of having diabetes. This is why we check for diabetes starting at age 13.**
    b. False

VII. Treatments

1. Airway clearance:
    a. makes your body produce more mucus
    b. **Removes mucus from your lungs: Airway clearance helps to loosen and move mucus from the lungs and should be done 2 – 3 times per day.**
    c. should be done only when you feel sick
    d. Should only been done in the morning

2. Exercise can always be done instead of airway clearance.
    a. True
    b. **False - Regular exercise is important for CF lung health, but should not substitute for routine airway clearance.**

3. Pulmonary Function Tests (PFTs) are a fancy name for tests that:
    a. show the CF Team that you are taking your enzymes
    b. **Show how your lungs are working: The pulmonary function tests measures how much air that you can inhale and exhale. It gives the doctor an idea of the health of your lungs at each clinic visit.**
    c. only need to be done once in a while

4. Timing is everything, especially when it comes to taking inhaled antibiotics. They generally work best if done.
    a. before airway clearance
    b. **After airway clearance: If antibiotics are taken *before* airway clearance, then the antibiotic is coughed out. The antibiotics need to stay in the lungs in order to work better.**
    c. in the morning

5. Bronchodilators (albuterol) are used to:
    a. remove mucus
    b. control bacteria
    c. **<u>Open your airways</u>: Bronchodilators are a type of inhaled medicine that relax your airway muscle.**
    d. clear up a stuffy nose

6. With CF, coughing is:
    a. **<u>Is important to clear mucus from your lungs</u>: Mucus clogs the airway and traps bacteria. Coughing is the best way to remove mucus from your lungs.**
    b. gives CF to other people
    c. is OK to control with cough medicines
    d. tires you and you should not do it

7. What is true about cleaning your nebulizer?
    a. clean it once a week
    b. have your Mom do it
    c. **<u>Put in the dishwasher or boil for 5 minutes</u>: A hot dishwasher or boiling will kill bacteria.**
    d. wash with vinegar and water

8. It is best to take enzymes:
    a. as soon as you remember
    b. **<u>at the beginning of a snack or meal</u> – Enzymes work the best when they are taken at the beginning of meals.**
    c. once a day
    d. after eating

9. Enzymes should be kept in cool, dark place.
    a. **<u>True</u> – The potency of enzymes may be damaged by extreme temperatures, moisture, light, or air (leaving the enzyme bottle open).**
    b. False

10. Large amounts of undigested food will pass through your digestive system if you have:
    a. too many enzymes
    b. **<u>too few enzymes</u> – Not taking enough enzymes will cause there to be undigested food in the intestine. Signs of undigested food in the intestine include loose, frequent and/or large bowel movements, poor weight gain even though you have a large appetite, oil or mucus in the bowel movement, excessive gas, stomach pain, or bloating.**
    c. the right amount of enzymes

11. It is OK to skip your everyday medicines when you are feeling good.
    a. True
    b. **<u>False</u> – you need to keep taking your medicines every day to keep feeling good.**