# THE USE OF SINGING AND PLAYING WIND INSTRUMENTS TO ENHANCE PULMONARY FUNCTION AND QUALITY OF LIFE IN CHILDREN AND ADOLESCENTS WITH CYSTIC FIBROSIS

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#### **Abstract**

# THE USE OF SINGING AND PLAYING WIND INSTRUMENTS TO ENHANCE PULMONARY FUNCTION AND QUALITY OF LIFE IN CHILDREN AND ADOLESCENTS WITH CYSTIC FIBROSIS

Although Cystic Fibrosis (CF) is one of the most fatal and devastating lung diseases in the world, treatments to enhance lung capacity and Quality of Life (QOL) are still in their infancy. The purpose of this study was to investigate the effects of music therapy, specifically singing or playing a wind instrument, on pulmonary function and QOL in children and adolescents with CF. Three participants with CF participated in this two week study, which consisted of two, thirty minute sessions a day, for a total of twenty sessions per person. The sessions for one week of the study included singing, playing the recorder or kazoo, and the other week included just talking, playing board games or playing video games. The Pulmonary Function Test (PFT) results and the Cystic Fibrosis Questionnaire (CFQ) results were used in this descriptive study as outcome variables. These data were collected three times throughout the study: pre-study, mid-study and post-study. For two participants, PFT results showed a higher increase during the music week than during the non-music week. For the third participant, he did not complete the study and only participated in the full non-music week and two days of the music week. His PFT results increased more during the non-music week. No significant trends were found when comparing the CFQ results. Suggestions for future research are discussed.

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## Chapter One

#### Introduction

#### Problem/Need

Seventy years ago, children diagnosed with Cystic Fibrosis (CF) typically did not survive past their first year (Bush, Alton, Davies, Griesenbach, & Jeffe, 2006). CF is a devastating illness that affects an individual's pancreatic and pulmonary function through an excess of sticky, bacteria ridden mucus secretions. This mucus clogs the lungs, making it hard to breathe and causing lung infections, as well as blocks the pancreas, diminishing the body's ability to process and absorb food and, thus, making it difficult to maintain and gain weight (Cystic Fibrosis Foundation, About Cystic Fibrosis, 2010; Glasscoe & Quittner, 2008; Nissim-Rafinia, Linde, & Kerem, 2006). Although individuals with CF still have a shortened lifespan, it has drastically increased from one year to an average of 40 years due to advances in diagnostic tests, treatments and a better understanding of the illness (Bush, Alton, Davies, Griesenbach, & Jeffe, 2006; Glasscoe & Quittner, 2008).

Since CF was first identified, research has continued to expand on appropriate diagnostic tests and treatments. The main diagnostic test is the sweat test, which tests for an elevated level of chloride content. Babies who have recurrent pneumonia and/or a difficult time gaining weight (indicating a pancreatic insufficiency) are tested for CF in order to begin treatment as soon as possible. Early treatment has been shown to enhance weight gain, prolong lifespan, decrease hospital visits and enhance babies' overall health (Bush, Alton, Davies, Griesenbach, & Jeffe [Eds.] 2006; Cystic Fibrosis Foundation, About Cystic Fibrosis, 2010; Karczeski & Cutting, 2006; Nissim-Rafinia, Linde, & Kerem, 2006).

Treatments consist of Airway Clearance Techniques (ACT), nebulizer treatments or antibiotics, physical exercise, pancreatic enzymes, as well as nutritional supplements (Cystic Fibrosis Foundation, Therapies for Cystic Fibrosis, 2010; Griggs-Drane, 2009; Pryor, Main, Agent, & Bradley, 2006). Although there are several different ACT's, the main goal for each of them is to loosen up mucus, making it easier for the individual to cough it out of his or her body (Cystic Fibrosis Foundation, Airway Clearance Techniques, 2010; Cystic Fibrosis Foundation, Therapies for Cystic Fibrosis, 2010; Griggs-Drane, 2009). ACT's are often paired with the nebulizer treatment, which is usually used approximately 30 minutes before attempting airway clearance. Nebulizer treatment is a device that mixes medication with air, which the individual then breathes in through a plastic tube. This medication can help fight against disease, decrease respiratory symptoms and help loosen up mucus in the lungs. Individuals with CF can also take oral antibiotics to help kill bacteria and decrease mucus (Cystic Fibrosis Foundation, Therapies for Cystic Fibrosis, 2010; Pryor, Main, Agent, & Bradley, 2006).

Individuals with CF are also encouraged to exercise, in an effort to enhance the bodies immune system, and take enzymes and nutritional supplements (Cystic Fibrosis Foundation, Therapies for Cystic Fibrosis, 2010; Griggs-Drane, 2009; Pryor, Main, Agent, & Bradley, 2006). Enzymes enable our bodies to absorb nutrients and combined with nutritional supplements, can help the body to gain and maintain a healthy weight (Cystic Fibrosis Foundation, Therapies for Cystic Fibrosis, 2010; Griggs-Drane, 2009). Even though great strides have been made to improve treatments over the years, they are still complex and time consuming. Recent research has shown that because of this, individuals with CF often have a lower quality of life (QOL) and do not adhere to treatments as much as recommended (Abbot & Gee, 1998; Foster, Eiser, Oades, Sheldon, Tripp, Goldman, Rice, & Trott, 2002; White, Miller, Smith, & McMahon, 2009).

Complicated and time-consuming treatments can be discouraging and can cause a decrease in QOL. QOL is defined as a person's general well-being and is mainly concerned with how a person *feels* about his or her life (Abbot & Gee, 1998). Although a low QOL is not always a direct result of a chronic illness, there is a strong, positive correlation. In addition to this, a low QOL is associated with low adherence to treatments. Thus, along with the constant research to enhance treatments to address physical symptoms found in CF, there has been a recent push to develop treatments to address QOL as well (Abbot & Gee, 1998; Anabar & Murthy, 2010; Bosley, Fosbury, & Cochrane, 1995; Glasscoe & Quittner, 2008; Hegarty, MacDonald, Watter, & Wilson, 2008; Nabors, Hoffman, & Ritchey, 2011).

#### Rationale

Treatments for CF have vastly improved since it was first identified 70 years ago. Since then, treatments have been developed and have extended the average life expectancy to 40 years (Bush, Alton, Davies, Griesenbach, & Jeffe, 2006). However, while treatments are developing and improving, they are also becoming more complex and time consuming (White, Miller, Smith, & McMahon, 2009). Thus, an illness that by definition is already difficult to live with, becomes more life altering and disruptive just in order to combat symptoms and enhance lifespan. Professionals have recently been searching for treatments to address QOL as well as methods to decrease or slow down pulmonary and pancreatic damage (White, Miller, Smith, & McMahon, 2009).

Music therapy has been shown to enhance QOL in a variety of patients and can enhance a person's affect, optimism and coping skills. It can reduce anxiety (Oliva, Hunter, Jane, Gaisser, & Salipante, 2009; Thornby, Haas, & Axen, 1995) promote socialization (Silverman, 2011), encourage expression (Grocke, Bloch, & Castle, 2009; Lindenfelser, Grocke, & McFerran, 2008;

Silverman, 2011), provide an emotional outlet (Choi, 2010; Grocke, Bloch, & Castle, 2009), enhance creativity (Grocke, Bloch, & Castle, 2009), and allow for decision-making opportunities (Azoulay, 2009), all of which can enhance a person's QOL (Choi, 2010; Grocke, Bloch, & Castle, 2009; Silverman, 2011).

A study run by Choi demonstrated how music therapy can enhance QOL (2010). Choi studied the effects of music therapy on caregivers of terminally ill children. She found that music therapy significantly enhanced QOL as well as reduced anxiety and fatigue, which are associated with low QOL.

Another study run by Grocke, Bloch, and Castle (2009) studied music therapy's effect on the QOL of individuals living with mental illnesses. They found significant results and allowed the participants to comment on how they felt music therapy helped improve their QOL.

Participants said that music therapy was enjoyable, promoted socialization, enhanced creativity and gave them something to be proud of. In addition to enhancing QOL, music therapy has also been shown to enhance pulmonary function (Eley & Gorman, 2010; Griggs-Drane, 1989; Griggs-Drane, 2009; Lord, Cave, Hume, Flude, Evans, Kelly, et al., 2010; Lucia, 1994; Marks, 1974; Wade, 2002).

There are several studies supporting the use of singing and playing wind instruments to enhance pulmonary function. In order to successfully play a wind instrument or sing, individuals need to use diaphragmatic breathing, also known as abdominal or deep breathing. Through learning how to breathe correctly, respiratory muscles are exercised and strengthened and enhanced control over the breathing process is learned. There have been several studies demonstrating that instrumentalists and singers have higher vital capacities, total lung volume,

lung clearance index, and forced expiratory volume than non-musicians (Bouhuys, 1964; Collyer, 2009; Formby, 1987; Huttlin, 1982; Loewy, Azoulay, Harris, & Rondina, 2009).

In addition to studies determining the differences between musicians and non-musicians, there have also been studies on the effect of playing wind instruments or singing on individuals with lung diseases (Eley & Gorman, 2010; Griggs-Drane, 1989; Griggs-Drane, 1998; Griggs-Drane, 2009; Lord, Cave, Hume, Flude, Evans, Kelly, et al., 2010; Lucia, 1994; Marks, 1974; Wade, 2002). Marks (1974) taught children with lung diseases how to play wind instruments and found that participation decreased symptoms and progression of their diseases as well as enhanced lung capacity.

Similarly, Wade (2002) compared the use of singing and relaxation techniques on respiratory symptoms for children with asthma. She found a significant increase in lung function for the singing condition, but results were not as consistent for the relaxation condition. Wade commented that this may be in part from the participant's ability to choose which songs they would sing in the singing condition, allowing for more control and, thus, enhanced QOL. This may also be a result of learning and practicing diaphragmatic breathing in the singing condition, and not the relaxation condition.

As research has indicated, music therapy has the potential to enhance QOL and pulmonary function. Although QOL and physical symptoms of CF last from childhood into adulthood, children often have a harder time understanding the detriments of not adhering to treatments. In addition, adolescents have the additional stress of trying to fit in with peers (Angelo & Lask, 2003). However, despite the research supporting the use of music therapy to enhance QOL and pulmonary function in children and adolescents, there has been little research

on the effect of music therapy on QOL and pulmonary function in children and adolescents with CF.

# Purpose

The purpose of this study was to examine the effects of singing and playing wind instruments on pulmonary function of children and adolescents with Cystic Fibrosis (CF).

Analysis will be descriptive and will compare pre-study, mid-study and post-study scores of the Pulmonary Function Test (PFT) and Cystic Fibrosis Questionnaire (CFQ) measurements.

### **Chapter Two**

#### **Review of Literature**

This chapter has 5 aims; first, to define and describe Cystic Fibrosis and current treatments; second, to define the needs in this population, as related to Quality of Life and pulmonary function; third, to review existing literature on the use of music to enhance pulmonary function; forth, to review existing literature on the use of music therapy to enhance Pulmonary Function and Quality of Life of individuals with pulmonary diseases, and; fifth, to define the purpose of this study and state research questions.

Cystic Fibrosis: An Overview

Cystic Fibrosis affects 1 in 2,500 individuals and is the most fatal, hereditary disease for Caucasians in the world (Glasscoe & Quittner, 2008; Hegarty, MacDonald, Watter, & Wilson, 2008; Nissim-Rafinia, Linde, & Kerem, 2006; White, Miller, Smith, & McMahon, 2009). The disease is defined as a dysfunction of the exocrine glands, which produce an excessive amount of harmful, sticky and bacteria ridden mucus secretions. This mucus clogs the lungs, making it difficult to breath, as well as leads to lung infections. The mucus also effects the pancreas by blocking it, diminishing the bodies ability to breakdown and absorb food (Cystic Fibrosis Foundation, About Cystic Fibrosis, 2010; Glasscoe & Quittner, 2008; Nissim-Rafinia, Linde, & Kerem, 2006).

Symptoms of the disease are wheezing, coughing, recurrent pneumonia, difficulty in gaining weight, irregular bowel movements, and nasal polyps (Cystic Fibrosis Foundation, About Cystic Fibrosis, 2010). The disease is also progressive, so symptoms worsen over time, diminishing physical ability (Hegarty, MacDonald, Watter, & Wilson, 2008). Other organs, such as the sweat glands, salivary glands, mammary glands, stomach and liver can be affected as well;

however, the symptoms of the lungs and pancreas are most detrimental and most often lead to mortality (Cystic Fibrosis Foundation, About Cystic Fibrosis, 2010; Glasscoe & Quittner, 2008; Nissim-Rafinia, Linde, & Kerem, 2006).

When the disease was first identified, the lifespan of a person with CF was no more than one year. Now, 70 years later, due to a more comprehensive understanding of the disease, the creation of diagnostic tests and progressive treatments, the average survival rate is 40 years (Bush, Alton, Davies, Griesenbach, & Jeffe, 2006; Glasscoe & Quittner, 2008).

In 1953, it was discovered that patients with CF have an elevated level of chloride concentration in their sweat. Since then, when a baby exhibits typical signs of CF (e.g., pancreatic insufficiency, recurrent pneumonia) a sweat test is given in order to rule out or diagnose CF early in life. Early diagnosis allows treatment to commence sooner and has been shown to promote growth, keep babies' lungs healthier, decrease hospital visits, and enhance lifespan (Bush, Alton, Davies, Griesenbach, & Jeffe, 2006; Cystic Fibrosis Foundation, About Cystic Fibrosis, 2010; Karczeski & Cutting, 2006; Nissim-Rafinia, Linde, & Kerem, 2006). *Cystic Fibrosis Treatments* 

The main goal in CF treatment is to slow down or prevent pancreatic and pulmonary damage. Some of the most common daily treatments can include Airway Clearance Techniques (ACT), nebulizer treatments and antibiotics, physical exercise, pancreatic enzymes and other medications, and nutritional supplements (Cystic Fibrosis Foundation, Therapies for Cystic Fibrosis, 2010; Griggs-Drane, 2009; Pryor, Main, Agent, & Bradley, 2006). There are several different ACT's; however, Chest Physiotherapy (CPT) is the most common one. CPT consists of the patient wearing a vibrating vest for a specific amount of time, several times a day. This vest helps to loosen up the mucus in the lungs, which the patient is then encouraged to cough up.

Other ACT's include Postural Drainage, Oscillating Positive Expiratory Pressure, High-frequency Chest Wall Oscillation, Positive Expiratory Pressure Therapy, Active Cycle of Breathing Technique and Autogenic Drainage. Each of these techniques has the same basic goal of loosening up the mucus in order to allow the patient to cough the mucus out of his or her body. Patients may use a combination of these techniques based on the progression and symptoms each individual experiences (Cystic Fibrosis Foundation, Airway Clearance Techniques, 2010; Cystic Fibrosis Foundation, Therapies for Cystic Fibrosis, 2010; Griggs-Drane, 2009). Although CPT is one of the most important components of CF treatments for slowing down pulmonary damage, it has been shown to typically adhere only 40% of the time (Glasscoe & Quittner, 2008). CPT is usually done for about thirty minutes after a nebulizer treatment has been given (Griggs-Drane, 2009).

The nebulizer is a device that medicates air for the patient to breathe in through a tube. This medication helps to thin mucus, fight against infections, decrease respiratory symptoms, and bring water into the lungs to make it easier to cough out mucus. Patients can also take antibiotics for similar benefits. In the case of CF exacerbations, patients are usually prescribed both of these treatments (Cystic Fibrosis Foundation, Therapies for Cystic Fibrosis, 2010; Ferkol, Rosenfeld, & Milla, 2006; Pryor, Main, Agent, & Bradley, 2006).

Physical exercise can be anything the patient is comfortable doing, including walking, running, swimming and playing sports. Physical exercise should be an activity preferred by the patient in order to increase adherence, and has been shown to strengthen lung function and improve Quality of Life (QOL) (Cystic Fibrosis Foundation, Therapies for Cystic Fibrosis, 2010; Pryor, Main, Agent, & Bradley, 2006).

Pancreatic enzyme supplements are needed for patients with CF to promote weight gain through enhanced nutrient absorption. Nutrition supplements, such as weight gain shakes, like Ensure, are also needed for patients with CF to get the high amount of calories needed to maintain and/or gain weight (Cystic Fibrosis Foundation, Therapies for Cystic Fibrosis, 2010; Griggs-Drane, 2009). In order for children with CF to gain weight, they need to consume 120% to 200% of the recommended allowance for healthy children. However, it has been show that children with CF usually consume only 80% of the recommended caloric intake (Glasscoe & Quittner, 2008).

Although advances in treatment have lengthened the survival rate, these treatments are often time consuming, invasive and often not fully adhered to. Because there have been so many advances in treatment, the amount of treatments used on a daily basis for patients with CF has also increased. Treatment depends on the severity and progression of the disease; however, treatments almost always interfere with normal daily activities (Foster, Eiser, Oades, Sheldon, Tripp, Goldman, Rice & Trott, 2002; White, Miller, Smith, & McMahon, 2009). Treatments are time consuming, they diminish the patients' feelings of control and freedom, children and adolescents can get teased at school for having to leave class for treatments or sit out during gym activities, and individuals are required to cough up sticky green mucus, which can make a child feel embarrassed in front of peers (Abbot & Gee, 1998; Angelo & Lask, 2003; Madge, 2006). Adherence, defined as "the degree to which a patient actively participates in the prescribed medical recommendations and treatment regimen provided by the CF team" (White, Miller, Smith, & McMahon, 2009, p. 97) can enhance QOL by decreasing symptoms and the progression of CF; however, it has also been shown that the complex and time consuming

treatment requirements can also decrease QOL (Abbot & Gee, 1998; White, Miller, Smith, & McMahon, 2009).

# *Quality of Life*

QOL is a term used to describe general well being. Some factors that can influence QOL include wealth, environment, physical and mental health, education, social belonging, leisure activities and leisure time. It is important to evaluate and treat QOL when working with children and adolescents with CF (Abbot & Gee, 1998). Due to the time-consuming, daily treatments and emotional stress from physical symptoms, children and adolescents with CF have a higher likelihood of having a lower QOL (Anabar & Murthy, 2010; Bosley, Fosbury, & Cochrane, 1995; Glasscoe & Quittner, 2008; Hegarty, MacDonald, Watter, & Wilson, 2008). It is important for the CF team to continually evaluate QOL in order to evaluate the effectiveness of treatment. Regardless of how effective a treatment is, if a person's QOL is low and they *feel* as though it is not effective, they may decide to not adhere to treatment. Treatment is essential for a positive prognosis of children and adolescents with CF, thus, there has been a recent push to develop treatments to address QOL (Abbot & Gee, 1998; Nabors, Hoffman, & Ritchey, 2011).

There have been several studies on effective interventions to address attitudes toward treatment and QOL. Anbar and Murthy (2010) describe a case study of a 9-year-old that, as he waited for a lung transplant, lost all hope. This hopelessness was due to the child feeling as though his life only consisted of treatments and that he had nothing to look forward to; the child told his physician that he wanted to stop all treatments and give up. His physician responded by encouraging the patient to think of things that he would like to do. The child decided to go on a trip with his family, which enhanced his QOL and coping skills. After returning, he said he was ready to keep fighting, continue with his treatments and was able to wait long enough to receive

a lung transplant. Learning to use coping skills as well as increasing optimism may enhance a child's likelihood to adhere to treatment, as well as enhance QOL (Abbot & Gee, 1998).

Similar to the 9 year-old's physician, Bauldoff, Hoffman, Zullo, and Sciurba (2002) demonstrated the importance of allowing the patient some control in treatment in order to enhance adherence and QOL. This study tested the effectiveness of distractive auditory stimuli (DAS) in the form of music on maintaining an exercise regimen for patients with Chronic Obstructive Pulmonary Disease (COPD). Each participant was allowed to choose music, as well as a walking location. Patient preferred materials enhanced participation, which in turn enhanced the effects of the treatment.

Bosley, Fosbury, and Cochrane (1995) also pointed out the importance of tailoring each treatment regimen to each individual based on their interests, needs and circumstances. This study defined psychological factors that contribute to poor compliance of patients with Asthma. The authors concluded that, in addition to good communication skills and listening to the patient's needs, tailoring treatments to each individual would enhance adherence. Thus, as research suggests, in order to enhance adherence and clinical outcomes, QOL and coping skills must be addressed.

Music Therapy and Quality of Life

One of the main issues found with children and adolescents with CF has been decreased QOL. Music therapy has been shown to enhance QOL in several different populations. Music therapy provides a unique opportunity to enhance affect and optimism, as well as educate patients on coping skills (Lindenfelser, Grocke, & McFerran, 2008). Music can induce a state of relaxation and, biochemically, can reduce cortisol levels and increase immunoglobulin A,

allowing an individual to stay healthier by enhancing the immune system (Eley & Gorman, 2010; McKinney, Antoni, Kumar, Tims, & McCabe, 2007; McCraty, Atkinson, & Rein, 1996).

Oliva, Hunter, Sayler, Gaisser, and Salipante (2009) found that the use of music therapy with patients being weaned from mechanical ventilation decreased anxiety, improved their ability to cope with the increasing amount of time off ventilation, and decreased heart rate and respiratory rate, indicating enhanced relaxation. Data on number of days to wean from mechanical ventilation, heart rate, respiratory rate, and patient and nursing satisfaction were collected. Satisfaction questionnaires consisted of a short, five-question survey asking if music therapy effectively decreased anxiety and stress, if the intervention was perceived as helpful and if the patient would participate in music therapy again. Results found that 98% felt less anxious, 80% felt less stressed, 96% felt that music therapy was helpful and 100% would participate in music therapy again. In addition, because music therapy allowed treatment – or decreased mechanical ventilation use – to be more tolerable, the patients could decrease the amount of time hospitalized, as well as decrease stress and anxiety and enhance coping skills.

Silverman (2011) studied music therapy's ability to affect knowledge of coping skills with psychiatric patients as compared with a control psychoeducational group, which also taught coping skills. Silverman used the brief COPE Inventory, which has 28 items and aimed to determine an individual's use of coping skills. In order to test, instead, the knowledge of coping skills rather than the use of coping skills, Silverman changed the format of the inventory to true/false and tested its validity and reliability on music therapy students. Silverman did not find any statistical difference between groups; however, there was a higher attendance rate in the experimental group when compared to the control group. This indicated that, although both

groups successfully promoted knowledge of coping skills, music therapy may encourage participation more and, thus, can have a higher success rate.

Grocke, Bloch, and Castle (2009) also studied music therapy's effect on participants living with mental illnesses, only on its ability to enhance QOL rather than coping skills. The authors used the WHOQOLBREF questionnaire and found that music therapy showed statistically significant improvements on general QOL, health, support from friends, pain and opportunities for leisure. Participants also commented on their experiences, saying that music therapy was enjoyable, enabled them to successfully work as a team, supported creativity and they took pride in the songs each participant wrote.

In a similar study, Choi (2010) studied the use of music therapy on anxiety, fatigue, and QOL for family caregivers of hospice patients. In order to test anxiety, the Spielberger State Train Anxiety Inventory was used. Fatigue was measured using the Fatigue Visual Analogue Scale, which is a 12 cm horizontal line with the words "no fatigue" on the left side and "extreme fatigue" on the right. Caregivers were asked to mark an "x" on the line to indicate their current level of fatigue.

In order to measure QOL, the Caregiver Quality of Life Index-Cancer was used. It was initially created for caregivers of cancer patients, but has also been shown to be valid and reliable with caregivers of hospice patients. Choi also found that music therapy significantly improved QOL measures, as well as decreased anxiety and fatigue.

Lindenfelser, Grocke, and McFerran (2008) did not collect data on QOL or related measurements, but studied parents' perceptions of music therapy with their terminally ill children. Data was collected using a semi-structured, quantitative interview protocol with the parents at the end of the study. Interviews found that the parents felt that music therapy altered

perceptions of their situation in a positive way, allowed for remembrance, enhanced communication and expression, and allowed the entire family to cope with the situation.

As described earlier, Bauldoff, Hoffman, Zullo, and Sciruba (2002) examined the effects of Distractive Auditory Stimuli (DAS) on exercise tolerance, as measured by breathlessness and fatigue, and compared this group to a control group that received no DAS. In addition to measuring physical improvements, the study also examined improvements in anxiety, depression, health-related QOL (HRQOL) and global QOL. Tests used were the Spielberger State-Trait Anxiety Inventory to measure anxiety, Center for Epidemiologic Studies Depression Questionnaire to measure depression, St. George's Respiratory Questionnaire (SGRQ) to measure HRQOL and a visual analog scale to measure global QOL. The SGRQ 76-item questionnaire was specifically tailored to measure QOL in patients with COPD. Results demonstrated that the DAS group reported improved HRQOL scores as compared to baseline, while the control group had a gradual reduction in this score.

Grasso, Button, Allison, and Sawyer (2000) also described the ability of music therapy to enhance treatment regimens for patients with lung diseases. This study measured the effects of recorded music on children's and parent's enjoyment of Chest Physiotherapy (CPT). Enjoyment was measured using a seven-point bipolar Likert-type scale. They found that adding music to CPT significantly increased enjoyment, and thus adherence, when a positive routine had not been previously established. In addition to enhancing QOL and coping skills, music has been shown to enhance pulmonary function in healthy individuals.

### Music and Pulmonary Function

Music, specifically singing and playing wind instruments, can strengthen respiratory muscles, thus increasing lung function (Loewy, Azoulay, Harris, & Rondina, 2009). Bouhuys

(1964) studied vital capacity, total lung volume, lung clearance index and forced expiratory volume in 42 professional wind players on 15 different wind instruments compared with a control group. Bouhuys found that vital capacity, total lung volume and forced expiratory volume were significantly higher in younger subjects. He also found that wind instrumentalists had higher vital capacities than subjects who did not play a wind instrument. Huttlin (1982) found similar results supporting the fact that wind instrumentalists had larger vital capacities than non-musicians. Collyer (2009) and Formby (1987) both found that trained singers who learned how to use their diaphragm correctly when breathing demonstrated a larger lung capacity than non-singers.

In summary, wind instruments and singing require an enhanced awareness of the breathing process. In order to sing or play a wind instrument, an individual must learn and successfully apply diaphragmatic breathing (or abdominal/deep breathing), as well as control breath and exercise the muscles controlling the lungs. In addition to enhancing pulmonary function in healthy individuals, there has been research demonstrating music therapy's effectiveness in enhancing pulmonary function in individuals with lung diseases (Harris & Rondina, 2009).

## Music Therapy and Lung Diseases

Not only have there been studies on pulmonary differences between musicians and non-musicians, but there has also been research on how music can enhance pulmonary function in individuals with lung diseases. Marks (1974) found that teaching children wind instruments, encouraging them to hold out long notes and enhancing breathing techniques, can reduce the progression of pulmonary disease, improve vital capacity and total lung volume, as well as decrease residual volume and residual capacity.

Griggs-Drane (2009) also found several physiological benefits for patients with lung diseases. Benefits included an increased physical endurance, increased expiratory pressure, respiratory endurance, as well as enhanced airway clearance (Griggs-Drane, 1989). The author also pointed out that playing a wind instrument mimics traditional therapies to treat lung diseases by blowing against a resistive force; however, it can be enjoyable, individualized, engaging and social in nature, which can enhance QOL. The author outlines several non-musical considerations for all patients with lung diseases. It is imperative for patients to use maximum effort in order to gain the most benefits with most treatments. However, when using devices like the nebulizer treatment, there is no immediate feedback on whether maximum effort is being used. When learning to play a musical instrument, patients receive immediate auditory feedback, which teaches them when they are using correct diaphragmatic breathing techniques. This better understanding of how maximum effort feels on an instrument may be transferred to maximum effort during treatments. In addition, just as musicians need to consistently practice their instrument in order to improve, patients with lung diseases need to consistently complete their treatments. Adding a musical instrument in their routine can enhance the routine or can be a reward for treatments. The author recommended allowing each patient to choose his or her preferred instrument in order to encourage continued use and enjoyment, to instruct the patient on correct body posture and diaphragmatic breathing, to encourage airway clearance when needed, and to encourage each patient to join a choir or band in order to add a social aspect to the instrument. If the patient joins a band or choir, the author suggested collaborating with the director in order to enhance their expectations of the patient.

Lord, Cave, Hume, Flude, Evans, Kelly, et al. (2010) studied the effects of singing to enhance pulmonary function, only with patients with COPD. The authors found that singing did

not improve breathing measures or exercise capacity, but did enhance QOL and decreased anxiety. The authors concluded that they might have found enhanced physical changes if the singing groups were held more often than twice a week. The authors recommended further research to gain a better understanding on the benefits of singing for patients with COPD.

Azoulay (2009) also demonstrated the effect of music therapy with adults with COPD. The author described a program called Music for Advances in Respiration (AIR), which incorporated instrument playing, singing and music visualization for groups with COPD. Using each group's preferred music, AIR taught patients how to play preferred instruments or sing, which also provided opportunities for expression and anxiety reduction. The program began with a warm-up, followed by the main therapeutic work, then closure. The main work and closure were fluid and determined by the therapist according to the needs and interests of the group. The author also discussed the importance of assessing and working on tone, vibrato, note length and physical movements involved in instrument playing and singing, as they may indicate the level of respiratory function, stress, or tension. Paying attention to the process of playing an instrument or singing can enhance pulmonary function and improve education on respiration. Azoulay also pointed out that music therapy allows a patient to use his or her own creativity, which can enhance motivation to continue participating in treatment, while positively influencing breathing.

Raskin and Azoulay (2009) also outlined the benefits of singing and playing a wind instrument on respiratory functions, but expanded the population to patients with asthma as well. They supported the use of music to enhance oxygen saturation, heart rate, respiration rate, anxiety, depression and QOL. However, the authors also explained that there is a need for more

research to support the positive outcomes of music therapy on pulmonary function of patients with lung diseases.

Wade (2002) conducted a study comparing the use of singing and relaxation techniques to enhance pulmonary function in children with asthma. The author measured pulmonary function using a peak flow meter, which measures all peak expiratory flow rates (PEFR). Each patient in the study received both the singing and relaxation variables, one following the other, the order of which was random. Several sessions were held and during each session, the PEFR was recorded 3 times: once at the beginning of session, once between variables, and once at the end of the session. The author found that patients maintained or increased lung function after singing, but results were not as consistent for the relaxation condition. This may have been partially due to the added choice of which songs the patients sang during the singing condition, which allowed them more control over treatment.

Lucia (1994) studied teenagers with asthma, comparing wind-instrumentalists with non-instrumentalists. Lucia's study found that the instrumentalists were better able to cope with having asthma, as well as perceived less asthmatic symptoms. The instrumentalists also reported that their asthma impeded their regular daily activities less than the non-wind players, demonstrating that the instrumentalists QOL may have been higher than the non-wind players

Similarly, Eley and Gorman (2010) tested didgeridoo and singing with aboriginal Australians to enhance asthma management. They recognized the problem of non-adherence in this population and the need for treatment to be enjoyable and individualized. Thus, they chose culture appropriate instruments to enhance adherence and pulmonary function. Similar to Wade (2002), lung capacity was also gauged using a PEFR. They found music was very engaging,

enhanced adherence to treatment for asthma, as well as significantly enhanced respiratory function.

In summary, music therapy, specifically the use of singing or playing wind instruments, can combine creative musical expression, to enhance QOL, with breathing exercises, to enhance pulmonary function. There have been several studies demonstrating the positive effects music has both on QOL, lung function in healthy individuals, as well as lung function in patients with lung diseases. However, there has been little research on music therapy for children and adolescents with CF (Irons, Kenny, & Chang, 2010). Thus, the purpose of this study was to investigate the effects of singing and playing wind instruments on pulmonary function and QOL for children and adolescents with CF. The following research questions were addressed:

- Does engagement in music therapy applications that require the use of the lungs enhance
   Pulmonary Function Test results for children and adolescents with Cystic Fibrosis?
- 2. Does engagement in music therapy enhance quality of life for children and adolescents with Cystic Fibrosis?

## **Chapter Three**

# Methodology

#### **Participants**

Participants (N=3) for this descriptive study were recruited from a local Midwestern hospital who were in the hospital due to a Cystic Fibrosis (CF) exacerbation, as determined by the each participants Primary Care Physician. Participants were included in the study if they met the following criteria: 1) had a diagnosis of Cystic Fibrosis (CF), as determined by a sweat test, 2) were between the ages of six and 18, 3) were currently in the hospital due to a CF exacerbation, 4) had a signed parental informed consent, and 5) were willing to participate and comply with the study as indicated by minor assent.

# Design and Data Analysis

The data were defined by casual comparative analysis, as defined by Madsen and Madsen (1997). The casual comparative analysis involved assessing "causative factors by comparisons of difference stimuli, subjects or events" (p. 16). Specifically relating this definition to the current study, PFT and CFQ results will be compared between weeks on an individual basis afor all three participants.

#### Materials

At the beginning of the study, the researcher verbally assessed each participant's preferred songs, instruments and non-musical activities. Choices during the music week were to sing, play the recorder or play the kazoo with the researcher for each session throughout the week. If a participant chose an instrument, he or she was provided with his or her preferred instrument to keep, in order to insure infection control. The researcher always used a guitar and the same songbook, which was put together by the researcher and included preferred songs of

each participant. Options during the non-music week were to talk, to play board games, or to play video games.

#### Measuring Instruments

The outcome variables were the level of Quality of Life (QOL) and pulmonary function. In order to test each participant's QOL, the Cystic Fibrosis Questionnaire (Appendix) was used. In order to test each participant's pulmonary function, the results of the Pulmonary Function Test were used.

Two forms of the Cystic Fibrosis Questionnaire were used for this study: the Cystic Fibrosis Questionnaire - Child Version and the Cystic Fibrosis Questionnaire - Revised. The child version (CFQ-CV) is for ages 6-13 and the teen/adult version (CFQ-R) is for ages 14 and older. Following evidenced-based protocol, when using the CFQ-CV, the researcher will assist the child with filling it out. However, for adolescents' ages 12 or older the questionnaire will be filled out independently (Modi & Quittner, 2003; Quittner, Buu, Messer, Modi, & Watrous, 2005) (see Appendix). Internal reliability for the CFQ-R was tested using Cronbach  $\alpha$ , with the majority of the coefficients > 0.70. Similarly, internal consistency coefficients for the CFQ-CV ranged from r = 0.60-0.76, except for treatment burden (Cronbach's  $\alpha = 0.44$ ). In order to demonstrate validity, relationships between the CFQ-R, age, pulmonary function, and body mass index were tested. Results demonstrated the CFQ to be significantly correlated with other generic QOL measurements, including Short Form-36 Health Questionnaire, on differences between age, disease progression and nutritional status (Quittner, Buu, Messer, Modi, & Watrous, 2005). For the CFQ-CV, correlations between health status and the CFQ-CV were tested. Correlations were found to be low; however, it was hypothesized that this was due to the restricted range of disease severity. Correlations between CFQ-Child and CFQ-Parent were also

calculated and found to significantly correlate. Results show that both the CFQ-R and CFQ-CV are reliable and valid.

The CFQ is a closed format in which each participant checks a box that represents his or her answer most accurately. The CFQ-R measures functioning in 12 different domains, including physical function, vitality, emotional functioning, treatment burden, health perceptions, social functioning, body image, role functioning, weight, respiratory functioning and digestion. The CFQ-CV measures functioning in 8 different domains, including physical, emotion, social, eating, body image, treatment burden, respiratory functioning and digestion. This questionnaire does not provide a global QOL measurement, only measurements for each domain. The score for each domain is a number between zero and 100; zero being the lowest level of functioning in that domain and 100 the highest.

There are 3 sections in each version: Demographics, QOL, and Symptom Difficulty. The Demographics section gathers the patients' age, gender, race, and grade level data, as well as determines whether or not the child was recently on vacation or out of school for reasons other than his or her health. This section simply asks the participant to check the box that is appropriate. The next section gathers information on the participants current QOL. An example statement assessing QOL is, "During the past two weeks you felt tired." Each participant checked a box under one of the following statements: always, often, sometimes, or never. The last section of the CFQ inquires about current symptoms each participant is currently experiencing. One example assessing symptoms is "In the last 2 weeks have you had trouble gaining weight?" which will be answered by checking a box indicating, "A great deal," "Somewhat," "A little," or "Not at all." Versions for children 13 and younger have 35 questions each and the CFQ-R has 50 questions.

The Pulmonary Function Test (PFT) is a well-known test used to assess lung function. The PFT is a part of standard care when patients are admitted to the hospital for a CF exacerbation, and are taken regularly throughout hospitalization, as determined by the physician. It tests the volume of gas expired, as well as the rate at which it is expired using a spirometer. For each test, each participant took a deep breath in order to maximally fill the lungs and then completely emptied the lungs as fast as possible, while blowing into the spirometer via a mouthpiece. The resulting measurement is known as the Pulmonary Function Test (PFT) score (Castile, 1998).

The PFT results are calculated by a computer and are a percentage based on the expected average PFT for that age group. The lower the PFT, the more difficult it is for the individual to breath; however, the number representing the PFT could be unlimited because it is a percentage. Each individual's goal PFT score was different because it is also based on his or her baseline number and was determined by the physician (Castile, 1998).

#### Procedure

Participants were asked to volunteer after they and their guardian(s) were verbally informed of the purpose of the study and were given an opportunity to ask questions. At this time, one guardian of each participant signed an informed consent form and each child responded to a minor assent, as regulated by the Institutional Review Board. Participants all received both independent variables with the same researcher on the pediatric unit, but the order of the weeks was randomly assigned. At the beginning of the study, each participant had the choice of where on the unit he or she wanted to hold the sessions.

Regardless of which week each participant received first, the researcher began the study by having each participant fill out the CFQ-R or CFQ-CV and recording the PFT result for baseline data. These tests were given and/or recorded three times throughout the study: once at the beginning of the study, once between conditions, and once at the end of the study.

Participants during the music week received two music therapy sessions for 30 minutes each, everyday (for a total of 5 days), which mimics the protocol for standard of care treatments during an exacerbation (Ferkol, Rosenfeld, & Milla, 2006). The sessions consisted of their choice of singing, playing the recorder or playing the kazoo to preferred songs with the researcher. The researcher also educated participants on more efficient ways to play their instruments and breathe during these sessions. All participants were instructed that they can choose any instrument or sing, but once they made a decision they needed to continue with that same instrument or singing for the rest of the week.

During each treatment session, the researcher engaged each participant in 5 minutes of warm-ups to enhance deep breathing and education on correct ways to breathe. This warm-up consisted of simple exercises using their instrument of choice, as well as education and practice on how to effectively use diaphragmatic breathing. During this education, the researcher focused on the expansion of the belly, rather than raising the shoulders when taking a deep breath. Then for the remainder of the session, the participant chose different songs to play his or her instrument to or sing while the researcher played along with her guitar and/or sings. If the participant was learning a new song, then the researcher taught the song by splitting the song into short sections and teaching them one by one, until the participant could play through the whole song. Throughout this portion of the session, the researcher continued to remind and encourage the participant to practice healthy ways of breathing.

Individuals during the non-music week also participated in two, 30-minute sessions of individual activity with the researcher each day for one week. These sessions consisted of their

choice of talking, playing video games or playing board games. These sessions were held in the same area on the unit as the music-week. All participants were instructed that they can choose any activity, but once an activity was chosen they had to continue with that same activity for the remainder of the week.

### **Chapter Four**

#### Results

The purpose of this study was to investigate the effects of singing or playing wind instruments on pulmonary function and quality of life (QOL) in children and adolescents with Cystic Fibrosis (CF). The purpose of this chapter is to present the findings as they relate to the three participants. The chapter will first outline demographics and choices each participant made within the study. This is followed by the data collected from the Pulmonary Function Tests (PFT's) and Cystic Fibrosis Questionnaires. The following research questions will be answered:

- 1. Does engagement in music therapy applications that require the use of the lungs enhance Pulmonary Function Test results for children and adolescents with Cystic Fibrosis?
- 2. Does engagement in music therapy enhance quality of life for children and adolescents with Cystic Fibrosis?

#### Participant Case Study Information

This study had three participants: A who was a 16-year-old male, B who was an 18-year-old male and C who was a 13-year-old female. A was a 16-year-old, Caucasian male who chose to hold sessions in his private hospital room. He received the music week first, during which he chose to play the recorder. This week was followed by the non-music week, during which he chose to talk. He was previously known to the researcher and had participated in music therapy sessions before; however, he had never played the recorder with the researcher. During the previous 2 weeks his schedule was normal (no vacation), which included taking online, high school level courses at home. A's preferred activities were video games, creating websites, creating applications for the iPhone, iTouch and iPad, and soccer.

During the music week, it was often difficult to get him to focus and take an active role within sessions; however, he was also heard playing on his own in his room without the researcher and his paternal grandfather reported to the researcher that he sometimes practiced right before a session. His posture was not supportive of proper diaphragmatic breathing throughout the sessions and he would not follow the researcher's advice on how to improve breathing and posture. He learned several preferred songs on the recorder though, and began to memorize the names of the notes and actively learned and corrected his playing from his mistakes to improve his sound.

During the non-music week, he initially said, "I want to talk during this week, because that way I can still play video games while we talk." His engagement in the activity was sporadic and random, but the researcher and participant still discussed a wide-variety of topics. Topics of conversation throughout the week included:

- websites he has designed
- the video game he is in the process of designing
- his reason to continue with school online due to his amount of hospitalization and "the school's lack of working with me and my family"
- how "stupid kids my age are"
- how he dislikes iPhones
- his disinterest in going to Colorado for his lobectomy at the end of the month
- how he misses being able to playing soccer (he was not able to anymore due to his illness)
   and had not found a sport alternative
- the game Minecraft
- the game Ace of Spades

- Lego's
- · his mother
- classes
- bad teachers
- playing "hooky"

Despite requests from the researcher to keep sessions consistent, several of the sessions included his friend, who A was able to converse with through an online video game the two of them were playing at the time.

B was an 18-year-old, Caucasian male who chose to hold sessions in his private hospital room. He received the non-music week first, during which he chose to play board games. This was followed by the music week, during which he chose to play the recorder. The researcher did not previously know B and he had been out of school and out of his normal schedule for at least 2 weeks before being admitted to the hospital. He completed high school and was currently not in college due to his health and possible symptoms of depression. His preferred activities were running and writing stories. He did not play an instrument or sing, and did not consider himself a musical person. While hospitalized, Behavioral Pediatrics was consulted to assess for depression and to make recommendations. He was not able to complete the study due to being discharged from the hospital before the study was complete, but he completed seven out of ten days (fourteen sessions) of the study.

During the non-music week, B chose several different preferred board games to play, including Chess, Checkers, Chinese Checkers, Mancala and Connect Four. He seemed to have strong problem-solving skills that he was able to exercise while playing board games. He was

quiet and had a flat affect for most of the sessions; however, he was polite and appropriately participated in conversations while playing board games. Topics included:

- his family
- his passion for running and that he used to qualify for a college scholarship for running but
   he hurt his knees, lost the scholarship and now cannot run competitively anymore
- that he will still run but misses the competition
- that he has not started college due to his health, as well as not knowing what to do
- that his Make-A-Wish wish was a 2-year gym membership
- his job as a referee
- politics
- religion

His affect slowly improved and he became more actively engaged in conversations as the week progressed. His interest drastically increased on the last day of the non-music week (session eight) when the researcher and B discussed the importance of pursuing a vocation. He began talking about politics and religion, as well as his strong beliefs toward both topics and became very actively engaged in the sessions.

B was only able to participate in 2 days of the music week, due to being discharged from the hospital after less than 2 weeks. He stated several times that he felt very uncomfortable playing an instrument, but actively worked on learning notes, as evidenced by asking many appropriate questions and demonstrating focused attention throughout sessions. He also responded appropriately to instructions on how to play the recorder, practiced correct diaphragmatic breathing and seemed proud whenever he mastered a new song. His main difficulty was to not breath out too much air and to control the airflow. On the second day of

this week, the first thing he said to the researcher was, "The recorder worked! My PFT's were at 82 (previously at 75), which is a higher jump between 2 days than I've had so far!" He continued to work hard at learning songs, and also stated in his final session that he was surprised at how difficult it was to control his breath in order to play the recorder.

C was a 13-year-old, African American female who held sessions in her private hospital room. This was not her choice, but was due to her being febrile when she was first admitted to the hospital. According to the unit policy, patients are not allowed to go to the common room until they have been afebrile for at least 24 hours. Thus, C did not have a choice of where to hold the sessions at the beginning of the study, and in order to keep the study consistent, she had to hold all of her sessions in her room, even after becoming afebrile.

She received the music week first, during which she chose to play the recorder. This was followed by the non-music week, during which she chose to play board games. She was previously known to the researcher and had participated in music therapy sessions before this study, which included singing, playing the recorder, and writing and performing songs, in both individual and group sessions. During the previous 2 weeks her schedule was normal, which included attending seventh grade, public school classes and practicing and performing with her praise dance group.

C had a high interest in music and actively worked at perfecting songs, notes, and diaphragmatic breathing accurately. She sang periodically throughout the sessions, due to her own enjoyment of singing and elevated mood, but she primarily played the recorder.

During the non-music week, she was very disappointed that she could not hold her sessions in the common room and she mentioned this several times throughout the week. Topics discussed while playing board games included that she enjoyed school better than the hospital

because "I learn what I need to learn" and because she has to take more medications while in the hospital.

She also vocally improvised several short songs and was usually in a very fun and energetic mood throughout the sessions, thus the theme of these sessions usually included laughing with C about the lighthearted things she was doing.

Throughout the entire study, her mother, grandmother, and/or sister were usually in the room during sessions. Periodically staff members were present as well; however, only C and the researcher participated in the music or board games.

Does engagement in music therapy applications that require the use of the lungs enhance Pulmonary Function Test results for children and adolescents with Cystic Fibrosis?

Each participant's PFT scores taken throughout the study are documented and shown in the Figures below. A received the music week first, followed by the non-music week. His PFT score increased 5 points during the music week, and stayed the same during the non-music week. See Figure 1 for each PFT score taken while A was in the hospital.

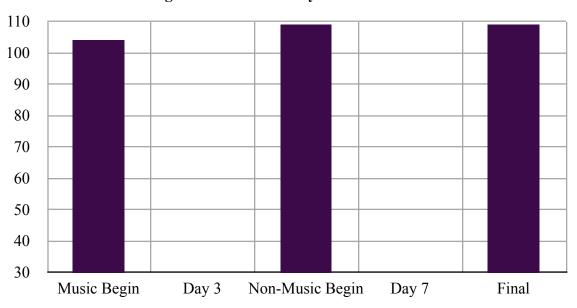


Figure 1. A's Pulmonary Function Test Scores

B received the non-music week first, followed by the music week. B's PFT score increased 15 points during the non-music week, and increased by 7 points during the music week. See Figure 2 for each PFT score taken while C was in the hospital. His music week only lasted 2 of the 5 days. No final score could be taken because he was discharged from the hospital on day 7 of 10 needed for the study.

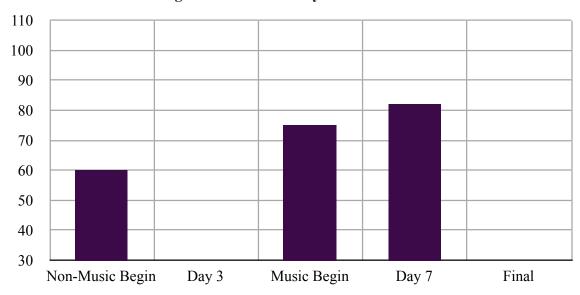


Figure 2. B's Pulmonary Function Test Scores

C received the music week first, followed by the non-music week. C's PFT score increased 9 points during the music week, and decreased 2 points during the non-music week. See Figure 3 for each PFT score taken while C was in the hospital.

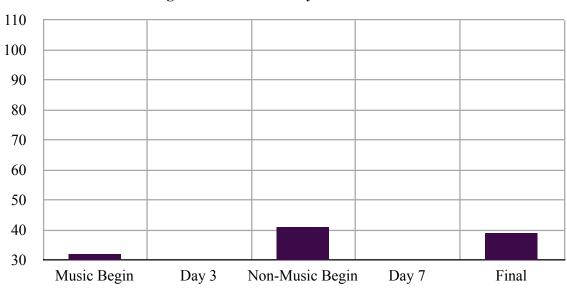


Figure 3. C's Pulmonary Function Test Scores

Does engagement in music therapy enhance quality of life for children and adolescents with Cystic Fibrosis?

Quality of Life (QOL) was calculated using the Cystic Fibrosis Questionnaire (CFQ). Within the CFQ-R, the QOL was rated across 12 different domains: physical, vitality, emotion, eating, treatment burden, health perceptions, social, body image, role, weight, respiratory, and digestion. Following evidence-based protocol, this version was given to A and B due to their age. Within the CFQ-CV, the QOL was rated across 8 different domains: physical, emotion, social, eating, body image, treatment burden, respiratory, and digestion. This version was given to C because she was under the age of 14. Also following evidenced-based protocol, each participant filled out the questionnaires independently.

Within each domain, scores could range from 0 to 100. The higher the number, the higher the level of functioning within that domain is. The results within each domain for each participant are seen in Figures 4 through 6. Results varied and few trends were noted between participants within any of the domains.

Figure 4. A's Cystic Fibrosis Questionnaire Results

Domain	Baseline	After Music	After Non- Music
Physical	58.3	76.2	75.0
Vitality	75.0	58.3	66.7
Emotion	93.3	93.3	93.3
Eating	100.0	100.0	100.0
Treatment Burden	77.8	77.8	66.7
Health Perceptions	55.6	66.7	88.9
Social	77.8	94.4	66.7
Body Image	88.9	66.7	100.0
Role	83.3	83.3	83.3
Weight	100.0	100.0	100.0
Respiratory	50.0	61.1	77.8
Digestion	100.0	100.0	100.0

Figure 5. B's Cystic Fibrosis Questionnaire Results

Domain	Baseline	After Non- Music	After Music
Physical	100.0	95.8	87.5
Vitality	33.3	58.3	58.3
Emotion	66.7	80.0	80.0
Eating	100.0	88.9	88.9
Treatment Burden	44.4	55.6	55.6
Health Perceptions	44.4	66.7	77.8
Social	55.6	77.8	77.8
Body Image	44.4	55.6	55.6
Role	83.3	83.3	83.3
Weight	0.0	0.0	0.0
Respiratory	55.6	77.8	61.1
Digestion	100.0	77.8	88.9

Figure 5. C's Cystic Fibrosis Questionnaire Results

Domain	Baseline	After Music	After Non- Music
Physical	61.1	72.2	83.3
Emotion	87.5	79.2	87.5
Social	95.2	90.5	90.5
Eating	55.6	77.8	100.0
Body Image	77.8	88.9	100.0
Treatment Burden	66.7	55.6	77.8
Respiratory	41.7	33.3	58.3
Digestion	100.0	100.0	100.0

#### **Chapter Five**

#### Discussion

The purpose of the present study was to explore the effect of music therapy on pulmonary function and Quality of Life (QOL) in children and adolescents with Cystic Fibrosis (CF). The following discussion is based on the descriptive statistics available from the three participants and, thus, no assumptions can be made about trends, variance or other observations concerning the data collected. However, ideas for protocol development and future studies can be considered from this study.

Does engagement in music therapy applications that require the use of the lungs enhance Pulmonary Function Test results for children and adolescents with Cystic Fibrosis?

One trend found was that participants A and C had a larger increase in PFT results during the music week than during the non-music week. A increased by 5 points more during the music week than the non-music week. C increased by 11 more points during the music week than the non-music week. And B did not complete the study, so the data gathered from his hospitalization ended on day 7 out of 10 needed. Because his music week was only 2 days long, his data demonstrates a larger increase in PFT results during the non-music week. However, there was still an increase in 7 points during the 2 days that he was able to participate in the music week. Although these data do not allow for causation assumptions to be made, the higher increase in PFT results during the music week does support the idea that engaging in music therapy, specifically playing a wind instrument or singing, may enhance pulmonary function in children and adolescents with CF.

Does engagement in music therapy enhance quality of life (QOL) for children and adolescents with Cystic Fibrosis?

The results of the CFQ's varied across all participants and domains, thus, trends were difficult to find. One trend found was in the health perception domain across the study. Health perception was not tested using the CFQ-CV, which was the version C filled out. However, it was tested in the CFQ-R, which A and B filled out. In both of their questionnaires their health perception increased throughout the entire study. The increase did not seem to be dependent on either treatment condition. This result may have been due to feeling healthier from the increase in therapies provided while in the hospital.

Two other trends that were tested in the CFQ-R and, thus, only assessed for A and B, were found within the role functioning and weight domains. Across the study, for both A and B their scores stayed the same in both those domains. Many factors influence role functioning; however, one consideration for these data is that patients are not in their normal environment when hospitalized. Thus, neither A nor B were in their normal roles and no change in their perception of their roles could be made within this study.

When considering the lack of fluctuation for feelings toward weight, A did not have a weight problem and felt very good about his ability to keep at a healthy weight. Thus, A consistently scored 100 in this domain. B, on the other hand, according to his charts, was not happy with his weight and felt frustrated with his inability to keep weight on. B was also discharged home earlier than his doctor recommended, due to transportation issues. Thus, B did not fully complete the study or his medical treatment. If B had spent at least 2 full weeks in the hospital, his weight may have increased and his feelings toward his weight may have enhanced.

One final trend noted was that body image increased for all participants during the non-

music week. No relationship between the events of the week and this trend were found.

Despite the difficulty in finding consistent trends across all domains and the inability of the questionnaire to provide a global QOL score, several thoughts concerning QOL can still be made. One is that QOL may be higher when a patient is about to go home, especially after having been in the hospital for a week and a half to 2 weeks. The first two questionnaires were given while the participants were still not sure when they would get to go home. As stated in earlier chapters, having a low level of control may decrease QOL. Participants may have felt a higher level of control and more optimism about the effectiveness of treatments toward the end of the study, when they knew how much longer they would be in the hospital. This may have enhanced various QOL domains at the end of the study.

Another consideration to be made is that participants may perceive physical health as lower at the end of the study due to being in the hospital and having less mobility opportunities for the previous week and a half to 2 weeks. Participant B scored progressively lower in the physical domain as the study progressed. He may have defined himself more as a patient, rather than as an individual. This possible shift in perception may have decreased his QOL due to a decrease in autonomy and a decrease in preferred activities over the previous weeks.

For participants A and B, music was not a preferred activity. Thus, during the music week they engaged in an activity that was not preferred, while the non-music week allowed them to engage in an activity that was preferred. Therefore, the non-music week may have enhanced QOL more than the music week. As research has demonstrated, music therapy can enhance QOL through enhanced expression opportunities (Choi, 2012; Grocke, Bloch, & Castle, 2009). However, if playing an instrument is not a preferred activity, while it may enhance pulmonary function, it will most likely not enhance QOL or adherence to treatments. Thus, for both A and

B, because playing wind instruments was not their preferred activities, their QOL would most likely not increase during the music week.

#### Limitations

The first and most obvious limitation to this study was the low enrollment of participants, which decreased the reliability of the results, as well as effected the methodology of comparing results. This low enrollment was due to several factors. First, the pediatric unit at the hospital where this study was run was a small unit (19 beds), and the unit was not often full. Thus, the low census decreased the number of patients that were screened as possible participants.

Another reason for the low enrollment was that within the low census of pediatric patients, there was an even smaller number of patients that fit the criteria at the hospital. Within the time allowed for enrollment into this study (approximately three and a half months) there were only 7 patients with CF admitted to the hospital. When admitted, two were told they would only be in the hospital for a few days and two were under the minimum age requirement, and thus were not considered to be in the study. The remaining three participated in the study. Thus, if the data collection period had been extended and if the hospital had a higher census that fit the criteria for the study, the enrollment might have been higher.

In addition to the above reasons for low enrollment, the study required a long hospital stay (2 weeks), which also decreased the number of available participants. As stated above, there were two patients who fit the criteria; however, they were hospitalized with the knowledge that they would only be in the hospital for a few days. Thus, they were not enrolled into the study. If the study had been designed in a way to allow for a shorter hospital stay, a larger number of participants could have enrolled in the study.

Another limitation to this study was that the instrument options did not require a great

amount of lung capacity to produce sound. According to studies, there are other wind instruments (such as the trumpet, trombone, etc.) that require a greater amount of breath and control (Bouhuys, 1964; Harris & Rondina, 2009; Huttlin, 1992; Loewy, Azoulay, Harris, & Rondina, 2009). Instruments that require more breath and control may exercise and strengthen those muscles more, which may enhance lung capacity and PFT results.

#### Future Recommendations

Conclusions

Several future recommendations can be made from this study. The most obvious and perhaps the most important will be to expand the sample size in future studies. A larger enrollment number will increase the power behind the data collected.

Once the sample size is increased, each participant could then randomly receive the music (treatment) or the non-music (control) condition, rather than receiving both. This would allow the length of the study to decrease from 2 weeks to 1 week, which will increase the number of patients who can be screened to be in the study. With a larger number of participants, then option for statistical analyses using comparison groups will be available.

Another recommendation for futures studies is based off of the observation that the three participants in this study all chose to play the recorder during the music week. Therefore, no data were collected on the effect that singing or playing the kazoo could have on pulmonary function or QOL. Thus, no variance concerning the PFT results could be noted between the recorder, kazoo or singing. Future studies may want to explore which music therapy treatment is more effective on enhancing pulmonary function or QOL and the possible reasons behind why one treatment may be more effective than another. Future studies may also want to explore whether one instrument is more appropriate for a specific age group or population than another.

In conclusion, no significant results were generated by this study. Very little is known about the effects of playing a wind instrument or singing on pulmonary function and QOL in children and adolescents with CF. However, people with CF continue to struggle with low QOL's due to the large number of treatments required to sustain their health. Music therapy may enhance pulmonary function and QOL, but it is up to future research studies to make conclusions about effectiveness.

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# Appendix



#### Children Ages 6 to 11 (Interviewer Format)

CYSTIC FIBROSIS QUESTIONNAIRE-REVISED

This questionnaire is formatted for use by an interviewer. Please use this format for younger children. For older children who seem able to read and answer the questions on their own, such as 12 and 13 year olds, use this questionnaire in its self-report format.

There are directions for the interviewer for each section of the questionnaire. Directions that you should read to the child are indicated by quotation marks. Directions that you are to follow are underlined and set in italics.

**Interviewer:** *Please ask the following questions.* 

A.	What is your date of birth?
	Date
	Mo Day Year
В.	Are you? ☐ Male ☐ Female
C.	During the <b>past two weeks</b> , have you been on vacation or out of school for reasons <b>NOT</b> related to your health?
	☐ Yes ☐ No
D.	Which of the following best describes your racial background?  Caucasian  African American  Hispanic  Asian/Oriental or Pacific Islander  Native American or Native Alaskan  Other (please describe)
	Prefer not to answer this question
	Smile

Ε.	What grade are you in now?
	(If summer, grade just finished)
	☐ Kindergarten
	☐ 1 <sup>st</sup> grade
	$\square$ 2 <sup>nd</sup> grade
	$\square$ 3 <sup>rd</sup> grade
	4 <sup>th</sup> grade
	☐ 1 <sup>st</sup> grade ☐ 2 <sup>nd</sup> grade ☐ 3 <sup>rd</sup> grade ☐ 4 <sup>th</sup> grade ☐ 5 <sup>th</sup> grade ☐ 6 <sup>th</sup> grade ☐ 7 <sup>th</sup> grade
	☐ 6 <sup>th</sup> grade
	7 <sup>th</sup> grade
	☐ Not in school
	— Trot in sensor



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#### Children Ages 6 to 11 (Interviewer Format)

#### CYSTIC FIBROSIS QUESTIONNAIRE-REVISED

**Interviewer:** *Please read the following to the child:* 

"These questions are for children like you who have cystic fibrosis. Your answers will help us understand what this disease is like and how your treatments help you. So, answering these questions will help you and others like you in the future."

"For each question that I ask, choose one of the answers on the cards I'm about to show you." Present the orange card to the child.

"Look at this card and read with me what it says: very true, mostly true, somewhat true, not at all true."

"Here's an example: If I asked you if it is very true, mostly true, somewhat true, not at all true that elephants can fly, which one of the four answers on the card would you choose?"

Present the blue card to the child.

"Now, look at this card and read with me what it says: always / often / sometimes / never."

"Here's another example: If I asked you if you go to the moon always, often, sometimes, or never, which answer on the card would you choose?"

Present the orange card to the child.

"Now, I will ask you some questions about your everyday life."

"Tell me if you find the statements I read to you to be very true, mostly true, somewhat true, or not at all true."

#### Please check the box indicating the child's response.

"During the past two weeks":	Very True	Mostly True	Somewhat True	Not at all True
1. You were able to walk as fast as others				
2. You were able to climb stairs as fast as others				
3. You were able to run, jump, and climb as you wanted				
<b>4.</b> You were able to run as quickly and as long as others				
<b>5.</b> You were able to participate in sports that you enjoy (e.g., swimming, soccer, dancing or others)				
<b>6.</b> You had difficulty carrying or lifting heavy things such as books, your school bag, or a backpack				





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# Children Ages 6 to 11 (Interviewer Format)

#### CYSTIC FIBROSIS QUESTIONNAIRE-REVISED

**Interviewer:** *Present the blue card to the child.* 

Please check the box indicating the child's response.

"And during these past <b>two weeks</b> , tell me how often": 7. You felt tired	Always	Often	Sometimes	Never
8. You felt mad				
9. You felt grouchy				
10. You felt worried				
11. You felt sad				
12. You had trouble falling asleep				
13. You had bad dreams or nightmares				
14. You felt good about yourself				
15. You had trouble eating				
16. You had to stop fun activities to do your treatments				
17. You were pushed to eat				
Interviewer: <u>Present the orange card to the child.</u>				
"Now tell me if you find the statements I read to you to true, or not at all true."	be very t	rue, most	ly true, some	ewhat
Please check the box indicating the child's response.				
"During the past <b>two weeks</b> ":	Very True	Mostly True	Somewhat True	Not at all True
18. You were able to do all of your treatments				
19. You enjoyed eating				
20. You got together with friends a lot				
21. You stayed at home more than you wanted to				
22. You felt comfortable sleeping away from home (at a friend or family member's house or elsewhere)				
23. You felt left out				



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# Children Ages 6 to 11 (Interviewer Format)

CYSTIC FIBROSIS QUESTIONNAIRE-REVISED

"During the past <b>two weeks</b> ": <b>24.</b> You often invited friends to your house	Very True	Mostly True	Somewhat True	Not at all True
25. You were teased by other children				
26. You felt comfortable discussing your illness with others (friends, teachers				
27. You thought you were too short				
28. You thought you were too thin				
29. You thought you were physically different from others your age.				
30. Doing your treatments bothered you				
Interviewer: Present the blue card to the child again				
Please check the box indicating the child's response.				
"Tell me how often in the past <b>two weeks</b> ":	Alw	ays Often	Sometimes	Never
31. You coughed during the day	[			
32. You woke up during the night because you were coughing	[			
33. You had to cough up mucus	[			
34. You had trouble breathing	[			
35. Your stomach hurt	[			

Please be sure all the questions have been answered.

# THANK YOU FOR YOUR COOPERATION!





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#### CYSTIC FIBROSIS QUESTIONNAIRE-REVISED

These questions are for children like you who have cystic fibrosis. Your answers will help us understand what this disease is like and how your treatments help you. So, answering these questions will help you and others like you in the future.

Please answer all the questions. There are no right or wrong answers! If you are not sure how to answer, choose the response that seems closest to your situation.

#### Please fill in the answer or check the box that matches your response to these questions.

Ā.	What is your date of birth?  Date Mo Day Year	E. What grade are you in now?  (If summer, grade you just finished)  □ 5 <sup>th</sup> grade
	Are you?  Male Female  During the past two weeks, have you been on vacation or out of school for reasons NOT related to your health?	☐ 6 <sup>th</sup> grade ☐ 7 <sup>th</sup> grade ☐ 8 <sup>th</sup> grade ☐ 9 <sup>th</sup> grade ☐ 10 grade ☐ Not in school
D.	☐ Yes ☐ No  Which of the following best describes your racial background? ☐ Caucasian ☐ African American ☐ Hispanic ☐ Asian (Oriental or Posific Islander)	
	□ Asian/Oriental or Pacific Islander □ Native American or Native Alaskan □ Other (please describe) □ Prefer not to answer this question	



**Smile** 

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# CYSTIC FIBROSIS QUESTIONNAIRE-REVISED

Please check the box matching your response.				
In the past <b>two weeks</b> :	Very True	Mostly True	Somewhat True	Not at all True
1. You were able to walk as fast as others				
2. You were able to climb stairs as fast as others				
3. You were able to run, jump, and climb as you wanted				
4. You were able to run as quickly and as long as others				
<b>5.</b> You were able to participate in sports that you enjoy (e.g., swimming, soccer, dancing or others)				
<b>6.</b> You had difficulty carrying or lifting heavy things such as books, your school bag, or a backpack				
Please check the box matching your response.				
And during these past two weeks, indicate how often:	Always	Often	Sometimes	Never
7. You felt tired				
8. You felt mad				
9. You felt grouchy				
10. You felt worried				
11. You felt sad				
12. You had trouble falling asleep				
13. You had bad dreams or nightmares				
14. You felt good about yourself				
15. You had trouble eating				





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CYSTIC FIBROSIS QUESTIONNAIRE-REVISED

# Please check the box matching your response.

And during these past two weeks, indicate how often:

	Always	Often	Sometimes	Never
16. You had to stop fun activities to do your treatments				
17. You were pushed to eat				
Please check the box matching your response.				
During the past two weeks:	Very True	Mostly True	Somewhat True	Not at all True
<b>18.</b> You were able to do all of your treatments				
19. You enjoyed eating				
20. You got together with friends a lot				
21. You stayed at home more than you wanted to				
22. You felt comfortable sleeping away from home (at a friend or family member's house or elsewhere)				
23. You felt left out				
24. You often invited friends to your house				
25. You were teased by other children				
<b>26.</b> You felt comfortable discussing your illness with others (friends, teachers)				
27. You thought you were too short				
28. You thought you were too thin				
29. You thought you were physically different from others your age.				
30. Doing your treatments bothered you				



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CYSTIC FIBROSIS QUESTIONNAIRE-REVISED

#### Please check the box matching your response.

Let us know how often in the past two weeks:	Always	Often	Sometimes	Never
31. You coughed during the day				
32. You woke up during the night because you were coughing				
33. You had to cough up mucus				
<b>34</b> . You had trouble breathing				
35. Your stomach hurt				

Please be sure all the questions have been answered.

# THANK YOU FOR YOUR COOPERATION!





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# CFQ-R

# Adolescents and Adults (Patients 14 Years Old and Older)

CYSTIC FIBROSIS QUESTIONNAIRE - REVISED

Understanding the impact of your illness and treatments on your everyday life can help your healthcare team keep track of your health and adjust your treatments. For this reason, this questionnaire was specifically developed for people who have cystic fibrosis. Thank you for your willingness to complete this form.

**Instructions:** The following questions are about the current state of your health, as you perceive it. This information will allow us to better understand how you feel in your everyday life.

Please answer all the questions. There are **no** right or wrong answers! If you are not sure how to answer, choose the response that seems closest to your situation.

5	Section I. Demographics  Please fill-in the info	rmo	tion or check the box indicating your answer.
В.	What is your date of birth?  Date	F.	What is the highest grade of school you have completed?  Some high school or less  High school diploma/GED  Vocational school  Some college  College degree  Professional or graduate degree
D.	☐ Yes ☐ No  What is your current marital status? ☐ Single/never married ☐ Married ☐ Widowed ☐ Divorced ☐ Separated ☐ Remarried ☐ With a partner	G.	Which of the following best describes your current work or school status?  Attending school outside the home Taking educational courses at home Seeking work Working full or part time (either outside the home or at a home-based business) Full time homemaker Not attending school or working due to my health Not working for other reasons
E.	Which of the following best describes your racial background?  Caucasian  African American  Hispanic  Asian/Oriental or Pacific Islander  Native American or Native Alaskan  Other (please describe)  Prefer not to answer this question		



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#### Adolescents and Adults (Patients 14 Years Old and Older)

CYSTIC FIBROSIS QUESTIONNAIRE - REVISED

#### Section II. Quality of Life

Please check the box indicating your answer.

				2 02 0	22
Dı	ring the past <b>two weeks</b> , to what extent have you had difficulty:	A lot of difficulty	Some difficulty	A little difficulty	No difficulty
1.	Performing vigorous activities such as running or playing sports				
2.	Walking as fast as others				
3.	Carrying or lifting heavy things such as books, groceries, or school bags				
4.	Climbing one flight of stairs				
5.	Climbing stairs as fast as others				
During the past two weeks, indicate how often:		Always	Often	Sometimes	Never
6.	You felt well	. 🔲			
7.	You felt worried	. 🗆			
8.	You felt useless	. 🗆			
9.	You felt tired	. 🔲			
10.	You felt energetic	. 🗆			
11.	You felt exhausted				
12.	You felt sad				П

Please circle the number indicating your answer. Please choose only one answer for each question.

Thinking about the state of your health over the last two weeks:

- 13. To what extent do you have difficulty walking?
  - 1. You can walk a long time without getting tired
  - You can walk a long time but you get tired
  - You cannot walk a long time because you get tired quickly
  - You avoid walking whenever possible because it's too tiring for you
- 14. How do you feel about eating?
  - Just thinking about food makes you feel sick
  - You never enjoy eating
  - You are sometimes able to enjoy eating
  - You are always able to enjoy eating
- 15. To what extent do your treatments make your daily life more difficult?
  - 1. Not at all
  - A little
  - 3. Moderately
  - A lot





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# CFQ-R

# Adolescents and Adults (Patients 14 Years Old and Older)

# CYSTIC FIBROSIS QUESTIONNAIRE - REVISED

16.	How much time do you currently spend each day on your treatments?  Some A little Not very much				
17.	<ul> <li>How difficult is it for you to do your treatments (including medications) each day?</li> <li>Not at all</li> <li>A little</li> <li>Moderately</li> <li>Very</li> </ul>				
18.	<ol> <li>How do you think your health is now?</li> <li>Excellent</li> <li>Good</li> <li>Fair</li> <li>Poor</li> </ol>				
Ple	ease select a box indicating your answer.				
	ninking about your health during the past <b>two weeks</b> , indicate the tent to which each sentence is true or false for you.	Very true	Somewhat true	Somewhat false	Very false
19.	. I have trouble recovering after physical effort				
20.	. I have to limit vigorous activities such as running or playing sports				
21.	. I have to force myself to eat				
22.	I have to stay at home more than I want to				
23.	I feel comfortable discussing my illness with others				
24.	. I think I am too thin				
25.	. I think I look different from others my age				
26.	. I feel bad about my physical appearance				
27.	. People are afraid that I may be contagious				
28.	. I get together with my friends a lot				
29.	. I think my coughing bothers others				
30.	. I feel comfortable going out at night				
31.	. I often feel lonely				
32.	. I feel healthy				
33.	. It is difficult to make plans for the future (for example, going to college, getting married, advancing in a job, etc.)				
34.	I lead a normal life				
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# Adolescents and Adults (Patients 14 Years Old and Older)

CYSTIC FIBROSIS QUESTIONNAIRE - REVISED

# Section III. School, Work, or Daily Activities

Questions 35 through 38 are	e about school,	work, or other daily	tasks.				
<ul> <li>35. To what extent did you have to two weeks?</li> <li>1. You have had no trouble</li> <li>2. You have managed to kee</li> <li>3. You have been behind</li> <li>4. You have not been able to</li> </ul>	keeping up ep up but it's been	difficult	ofessional wo	rk, or other d	aily activities	during the pas	
36. How often were you absent from school, work, or unable to complete daily activities during the last two weeks because of your illness or treatments?							
☐ Always	☐ Often	☐ Sometimes	□ No	ever			
37. How often does CF get in the □ Always	way of meeting you  Often	ur school, work, or person  Sometimes	nal goals	ever			
38. How often does CF interfere w	ith getting out of the	he house to run errands so	uch as shoppin	ng or going to	the bank?		
☐ Always	☐ Often	☐ Sometimes	□ No	ever			
Section IV. Symptom Difficulties  Please select a box indicating your answer.							
Indicate how you have been	feeling during th	he past <b>two weeks</b> .	A great deal	Somewhat	A little	Not at all	
39. Have you had trouble gaining	weight?						
40. Have you been congested?							
41. Have you been coughing during	ng the day?						
42. Have you had to cough up mu	eus?					Go to Question 44	
43. Has your mucus been mostly:	□ Clear □ Clea	ar to yellow   Yellowis	h-green 🗆 G	reen with trac	es of blood	Don't know	
How often during the past tw 44. Have you been wheezing?			Always	Often	Sometimes	Never	
45. Have you had trouble breathin	ıg?						
46. Have you woken up during th	e night because you	u were coughing?					
47. Have you had problems with g	gas?						
48. Have you had diarrhea?	<u> </u>						
49. Have you had abdominal pain	?						
50. Have you had eating problems	s?g						
Please be sure you have answered all the questions.							
THANK YOU FOR YOUR COOPERATION!							
CCiCystic							

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